

Consultation Guide:

Proposed changes to specialised severe intestinal failure services for adults

Consultation guide on proposed changes to specialised severe intestinal failure services for adults

Version number: 1

First published: August 2018

Prepared by: Specialised Commissioning

Classification: OFFICIAL

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Medical	Operations and Information	Specialised Commissioning
Nursing	Trans. & Corp. Ops.	Strategy & Innovation
Finance		

Publications Gateway Reference: 08388

Document Purpose	Consultations
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Document Name	Proposed changes to specialised severe intestinal failure services for adults – consultation guide
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Author	Specialised Commissioning
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Publication Date	17 August 2018
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Target Audience	CCG Clinical Leaders, CCG Accountable Officers, Foundation Trust CEs , Medical Directors, Directors of Nursing, NHS Trust Board Chairs, NHS England Regional Directors, NHS England Directors of Commissioning Operations, Directors of Finance, Allied Health Professionals, NHS Trust CEs, Patients, carers, HPN providers
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Additional Circulation List	
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Description	
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Cross Reference	
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Superseded Docs (if applicable)	
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Action Required	
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Timing / Deadlines (if applicable)	
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Contact Details for further information	Internal Medicine Programme of care Specialised Commissioning NHS England 3B Skipton House 80 London Road London SE1 6LH
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1 Executive summary

Severe intestinal failure (SIF) is a rare condition which affects the ability to digest food and drink, and usually requires complex surgical procedures and lifelong medical care. NHS England has been reviewing specialised services for SIF for adults over the past year, to make sure that patients have access to consistently high quality care. Last year we consulted on a new service specification that introduces two types of SIF centre – Integrated IF Centres that offer medical and surgical support to patients, and centres to support Home Parenteral Nutrition (HPN) that offer medical support only in hospital and to people at home. The new proposals would mean that all centres need to work more closely together in local networks, to ensure patients are getting the right care, including access to specialist care and advice when required.

As SIF is a rare condition and is caused by different medical problems it requires an expert team of people including doctors, nurses and dieticians. SIF surgery procedures are often highly complex, so we believe only hospitals with teams that perform this surgery regularly should be providing these interventions to patients. This will mean that fewer hospitals can undertake SIF surgery, and could mean some patients need to travel further. Equally we believe only hospitals that have a complete team and ability to offer support 24/7 will be able to meet the national standards for medical care to people living with permanent SIF, and therefore there will be fewer hospitals providing support to patients living with SIF.

2 Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

An equalities impact assessment has been completed in regard of this service review, and can be found alongside the other documents relating to this consultation.

3 What is Severe Intestinal Failure?

Severe Intestinal failure (SIF) is a severe condition with inability to absorb sufficient nutrients and/or water required to maintain health. Patients are given nutrients and/or fluids called parenteral nutrition via their blood stream. There are 3 types of intestinal failure:

- **Type 1** IF is a more temporary condition where a patient loses intestinal function for less than a month, as the result of illness or while recovering from surgery. Type1 IF is not commissioned by NHS England and is not under consideration in this review.
- **Type 2** IF is an acute condition and is managed through medical and surgical treatments. This can be a lengthy process with frequent hospital stays and periods at home on Home Parenteral Nutrition (HPN). A small number of type 2 patients can be cured and no longer require feeding by parenteral nutrition; however, the majority of these patients will require feeding with parenteral nutrition for the rest of their lives.
- **Type 3** patients have chronic (long term) IF and are reliant on parenteral nutrition. This is delivered to them at home and can be self-administered in the majority of cases.

IF affects both adults and children. These two services are managed separately and this consultation is related to the adult service only.

In England around 1600 adults are living with type 3 IF, and nearly 120 new adult patients a year are diagnosed with type 2 IF. Currently, there are 45 hospitals that are providing some support to people living with both type 2 and 3 IF varying from a very small service to a comprehensive service.

4 Why is NHS England reviewing severe intestinal failure services?

NHS England Specialised Services has carried out a national service review supported by an expert Clinical Working Group, made up of surgeons, physicians, specialist nurses, pharmacists, commissioners and a dietician.

IF services were first set up at two hospitals in the 1990s and following the success of these services a National Framework was published in 2008.

It is recognised that patients need 3 main elements of care:

- Timely and accurate diagnosis and treatment planning by a specialist team.
- Medical and surgical interventions.
- Long term care at home.

In addition, patients who receive HPN will have this prescribed by their hospital but usually it will be made and delivered by an independent sector company. The role of hospitals in overseeing the patient's care and the quality of the outsourced service needs to be recognised in the service model.

For a number of different reasons a clear national plan for the service was not implemented and hence services have developed in an unplanned way over the last decade. At present there is no national designation of the services delivered by most hospitals.

This has led to variation in the quality of services and a lack of information on outcomes in most services. The Clinical Working Group believe some cases of IF could be avoided if patients are seen by more experienced teams.

In addition, there is significant variation in how long patients stay in hospital in different hospitals which suggests clinical practice may not be evidence based. There is also variable staffing of teams and some services are too small to ensure 24/7 support to patients.

Furthermore, there is variable access to services for patients. This is sometimes because no services are available in an area or because a local hospital may have a relationship with a centre in a different area and for historical reasons do not link up with a SIF service closer to the patient's home locality.

5 Why do we need a different service model for specialised severe intestinal failure services?

SIF can be due to a range of causes. SIF may be something people are born with, or is caused as a result of other diseases over a short or long time, or can result as a consequence of planned surgery or can result from accidental injury. This means the team of people looking after SIF patients need to have a broad understanding of all these different factors and have specialist skills in IF, in order to manage each patient in the best way.

IF surgical procedures are a small number of specified colorectal procedures aimed at restoring and/or stabilising intestinal function, which are particularly complex and require a very high level of expertise. These are described in detail in the revised service specification that can be found on the NHS England website here:

<https://www.england.nhs.uk/wp-content/uploads/2018/08/Intestinal-Failure-Service-Spec.pdf>

The nature of the surgery means that complication rates are high, which can result in severe infection (sepsis) or leave the patient with permanent type 3 IF. Over 40% of SIF cases are caused by surgical interventions¹; however, the Clinical Working Group believe around 10% of operations would have better outcomes if performed in

¹ Soop M and Carlson G. Intestinal failure. In: European Manual of Coloproctology, 2nd. Edition. Eds. Herold A, Lehur P-A, Matzel KE, O'Connell PR. Springer, Berlin 2017:418-430

more experienced centres. So ensuring teams have the opportunity to further develop and maintain surgical competence is essential.

The Association of Surgeons of Great Britain and Ireland Surgical Management of Patients with Acute Intestinal Failure September 2010 Issues in Professional Practice state that:

‘The Lead Surgeon must have spent at least six months of dedicated specialist training in intestinal failure surgery in a unit with expertise in managing acute intestinal failure (undertaking >10 cases per year)’.

Currently, 8 out of 33 hospitals providing treatment to type 2 patients do not meet this minimum and a further 3 hospitals only complete 20 operations a year which is also considered low. NHS England believe that only the most experienced specialist centres should be undertaking complex SIF surgery. This is consistent with the advice from the Clinical Working Group.

Whilst the improvement in quality of care for patients undergoing complex surgery is a key aim of this review, the revised service specification also introduces enhanced quality standards to ensure all centres have the adequate resources and staffing levels.

6 What changes are NHS England proposing?

In August 2017, we conducted a consultation on the revised service specification for adult SIF services and the proposed changes have been approved by NHS England Specialised Services.

The revised model sets out a specification to commission:

- **Integrated IF Centres:** These centres will manage patients who need complex surgery and medical treatment and will provide a clinical service to patients discharged on HPN. Centres will liaise with (usually) independent sector companies who manufacture and deliver the home parenteral nutrition (HPN) for patients.
- **IF Home PN Centres:** These centres will not offer complex surgery services but will provide a clinical service to patients discharged from Integrated IF Centres on HPN. Centres will liaise with (usually) independent sector providers who manufacture and deliver the HPN for patients.
- **A networked model of centres,** to ensure that hospitals in each region work together so that patients are managed in the right setting to ensure optimal outcomes for patients.

In addition, the revised service specification outlines an education and training function for Integrated IF Centres who will offer support and expert oversight to the IF Home PN Centres in their regional network. It is intended that this will drive up

standards across each region, allowing a more formal route for sharing knowledge and expertise to less experienced centres.

The service review has identified that the national provision of IF services is currently characterised by a large number of low volume hospitals. This means too many hospitals are performing complex SIF surgery and managing patients on HPN. The new model of care as set out in the revised service specification is based around a model of a reduced number of Integrated IF Centres and Home PN Centres and generally requires Integrated IF Centres to carry out at least 10 IF operations per year, and both Integrated IF Centres and Home PN Centres to have at least 30 active HPN patients.

This means there is an overall reduction in the number of hospitals caring for people living with IF so that each team can provide 24/7 cover and have a full range of medical expertise.

The consultation on the service specification is now closed. However NHS England has subsequently undertaken further engagement with patients, clinicians and providers of SIF services and modelling of future demand for SIF services and how this can be met whilst achieving the standards of the revised service specification.

NHS England has selected a proposal for implementation of the service specification and is now consulting on this proposal, before proceeding with a procurement process. NHS England has a legal duty to involve patients and the public where we are proposing that services will be delivered differently in a way which impacts on patients. NHS England will also be consulting with hospital and industry providers of these services, including homecare companies providing HPN, as part of this exercise.

7 What impact will these changes have on patients?

The main impact on patients is that there will be fewer hospitals undertaking complex surgery for SIF and fewer hospitals nationally managing patients on HPN.

This is to ensure that surgery and the management of complex patients on HPN are only available at hospitals which have SIF teams with the full range of different disciplines and with the experience of regularly caring for a wide range of patients with SIF. Such SIF teams will have the expertise to deliver high quality clinical care and the experience to help patients understand all the treatment options available to them.

In accordance with the revised service specification, the Integrated IF Centres will be large enough to provide 24/7 support and cover and will have access to specialist support from services such as interventional radiology and critical care. This will mean only the most experienced and capable hospitals (Integrated IF Centres) can perform complex SIF surgical procedures and deliver SIF care (Integrated and Home PN centres).

This will reduce the choice of hospitals where patients can go as new patients to undergo SIF surgical procedures and be managed for HPN. It may mean that some patients need to go to a different hospital or travel further when they need complex surgery. This may not be the case for many patients as they will either still be cared for at the same hospital or they may still be able to go to another service that is reasonably close to where they live. However, importantly this will ensure patients have access to specialist teams able to offer the highest quality care and the best outcomes for recovery.

During the service review, some patients told us that they currently pass a centre close to their home to travel to a different centre that they believe is better. Consequently, after implementation of the new model of care some patients may transfer their care to a hospital closer to home as the quality of service improves.

7.1 What have patients said about these proposals so far?

NHS England has worked with patient groups in developing the new service model.

Patient engagement carried out over the past year has demonstrated support for this new service specification, as a majority of patients have indicated that they are willing to travel further in order to receive safe, high quality care from an experienced team when they have complex needs.

Equally some patients could be receiving care closer to home if they had more confidence in their local hospital having the right experience and resources to support them. Where people feel that they have had a poor experience, they are choosing to travel long distances, sometimes when feeling unwell, in order to be treated where they feel most comfortable.

Patients have also asked for a more joined up system, where hospitals work in partnership so that patients can be more easily referred for specialist support when required and that hospitals help co-ordinate care and not leave this to patients to do.

7.2 How will the new service work?

- **Patients with type 2 IF** will only be seen in an **Integrated IF Centre**, as these centres will be the only ones with specialist teams able to offer a comprehensive assessment, treatment planning and able to consider all treatment options as well as having regular IF surgical expertise.
- **Patients with type 3 IF** can be seen at either an **Integrated IF Centre or an IF Home PN Centre** as both will have specialist team members such as dieticians and pharmacists with an interest in IF as well as doctors and nurses.

Generally type 3 IF is a permanent condition, which cannot usually be corrected by further surgery. People living with type 3 IF need ongoing monitoring. This is to ensure they're receiving the right levels of fluids and & nutrition from the HPN.

Having a permanent central venous catheter line going into their blood stream puts people at a much higher risk of infection, which can quickly become serious and patients need speedy access to appropriate care.

HPN is supplied by a range of homecare companies, which hospitals are able to choose from through the HPN Framework. The Framework Agreement is managed on behalf of hospitals by NHS England; however, it is out of scope for this consultation, which is only concerned with hospital services. [More information is available in the HPN Patients Charter.](#)

8 What will the reduction in hospitals to deliver the new service model for specialised severe intestinal failure services look like?

8.1 Current Provision

The table below sets out the number of hospitals that are providing services to type 2 and type 3 patients or are contracted to:

Region	Current Hospitals: type 2 and 3 IF services
North	11
Midlands and East	12
London	8
South	14
Total all	45

Of these services, 8 of them performed less than the absolute minimum of 10 IF operations on type 2 patients in 2016/17 and 26 of them currently look after less than 30 patients on HPN as stipulated in Annex A2 – Centre Specification of the revised Service Specification. Of the 26 centres, 6 no longer look after any patients on HPN.

8.2 Proposed Provision

At this stage we do not know which centres will be chosen, as this will be subject to a procurement process. We can confirm the factors we considered and share the modelling we have done to reach the proposed numbers of centres. We believe the numbers outlined in the table below will help deliver improved quality of care and meet the capacity required for England and provide reasonable access to centres

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across the country: NHS England divides the country into four health regions so the proposal refers to North, Midlands and East, London and South regions.

Region	Integrated IF Centres including HPN (Type 2 and Type 3 patients)	Home PN centres (Type 3 only)	Total centres
North	4	2	6
Midlands and East	2	4	6
London	2	2	4
South	3	3	6
Total	11	11	22

We looked at the delivery of the service and considered that specialist teams and centres needed to be of sufficient size to meet the needs of patients and to be able to deliver hospital based services that are available 7 days a week in both surgical and medical specialties and the oversight of long term specialist care to patients in their home. In addition, the centres need to work as a network to reduce variation in standards of care and to share best practice.

The factors we considered were:

Patient Feedback - we identified from patient feedback that:

- The provision of a quality service was important, with a number of patients currently by passing a service closer to them to attend a service that they believe is better.
- Better co-ordination of care between teams and services through good network arrangements.
- The ability to support patients 24/7 and access some team members with particular skills.
- Geographic coverage to give reasonable access for patients needing both hospital delivered care and long term care.

Quality of Service - the modelling was based on:

- Centres completing a minimum of 20 complex SIF operations based on Clinical Working Group advice, the future population needs described in the service specification and above the absolute minimum set out by the Association of Surgeons of Great Britain and Ireland – The Surgical Management of Patients with Acute Intestinal Failure published in September 2010 is greater than 10 for the lead surgeon with the expectation that there will

be at least 2 surgeons in line with Annex A2 – Centre Specification of the Service Specification.

- Centres looking after a minimum of 50 patients on HPN, which is above the minimum of 30 stated in the service specification. This higher threshold is to ensure financial viability for centres to deliver the service to the service specification and the Association of Surgeons of Great Britain and Ireland guidance with adequate resources and staffing levels across the multi-disciplinary team. In addition, it takes into account the future population needs described in the service specification. Ensuring hospitals work more collaboratively together in networks is also expected to greatly improve patient experience and outcomes. Integrated IF Centres will lead local networks which will ensure hospitals who may need to refer patients into the Centre or are looking after patients with Type 3 IF know how to make referrals or access advice and support for their patients.

We also took into account the number of patients in each region, including expected growth over 10 years.

The factors we considered were:

Capacity – the modelling was based on:

- Analysis of:
 - The volumes currently undertaken by the centres and required based upon future patient modelling out to 5 and 10 years.
 - The bed requirements based upon future patient modelling out to 5 and 10 years.
- Travelling times for 90% of patients to travel up to 2 hours to an Integrated Centre and up to 1 hour to a Home Parenteral Nutrition centre.

The net result of this implementation will be that there will be fewer hospitals undertaking complex IF surgery. Instead Integrated IF centres will generally be carrying out both medical and surgical interventions for more patients.

NHS England believe that this reduction is necessary in order to ensure Integrated Centres have the specialist teams and expertise required to undertake complex surgery at adequate volumes to remain competence, improving outcomes and reducing the number of patients who go on to develop type 3 IF.

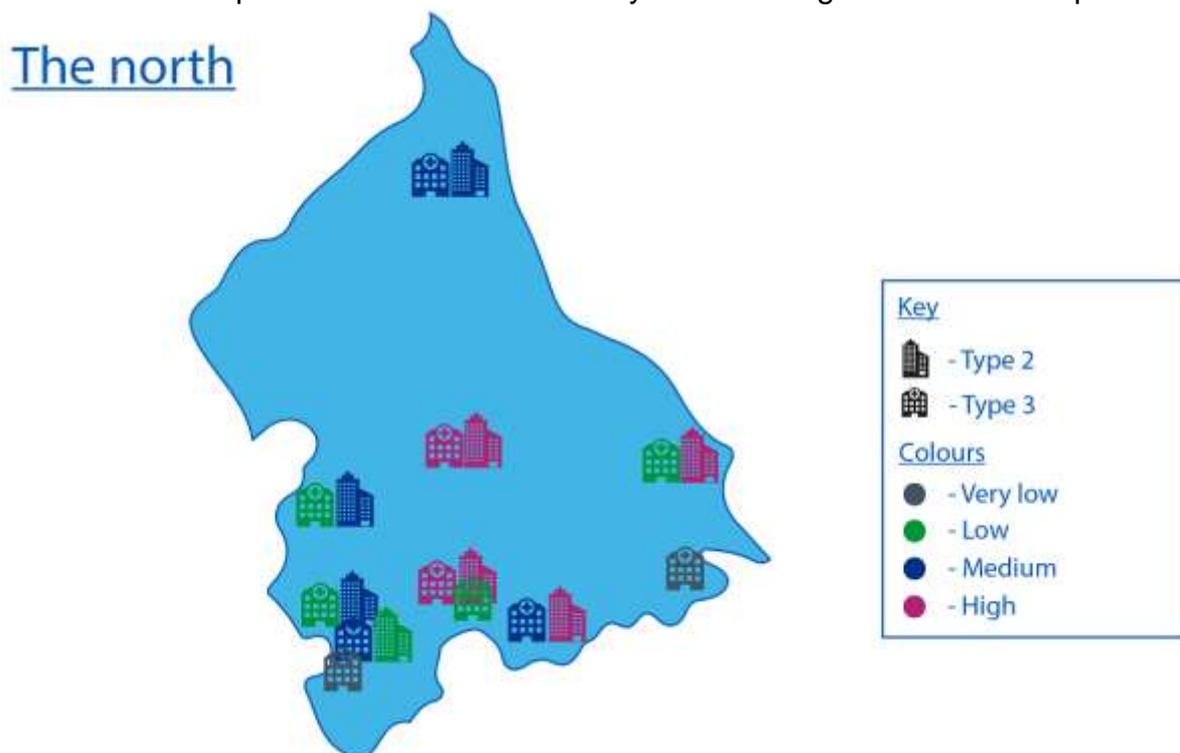
Similarly, there will be fewer centres providing care to patients on HPN. Currently, 26 (58%) of providers do not meet the minimum number of 30 HPN patients stated in the Service Specification and a further 6 do not meet the 50 patient threshold. Long-term HPN management is challenging and complicated and has considerable potential for complications that can foreshorten a patient's life expectancy. It is NHS England's belief, supported by expert clinical advice, that HPN should be managed only by centres with proven expertise and experience in managing such patients. Therefore, it is proposed that the number of centres providing such care is reduced in order to have teams with the right expertise, with a view to improve outcomes and

reducing the number of visits to hospital and HPN catheter related infections and other complications. The new model will not affect patients' ability to receive parenteral nutrition at home. The changes are expected to make it easier for the hospitals to liaise with home care companies as this will be a more regular part of their IF service and it will be clear to home care companies who they need to liaise with at each hospital.

9 What will the reduction in hospitals to deliver the new service model for specialised severe intestinal failure services look like where I live?

9.1 North Region

The North region currently has 11 hospital services that provide some care to type 2 or 3 patients. Nine of these provide surgical services for type 2 patients and all 11 look after patients on HPN. Two of the centres performed less than 10 complex IF procedures in 2016/17 and 5 centres look after less than 30 patients on HPN. The map below indicates where current services exist – please note adjoining icons indicate one hospital and the levels of activity for both surgical and medical patients.



In 2016, 297 adult patients were treated for Type 2 IF and 506 patients on HPN were cared for within the region. Based on the area where patients live, there were a very small number of patients who were treated who came from another region. We have based our modelling of the proposed centres on the number of patients living in the region in 5 years' time.

Outlined below are the current and future numbers of hospitals where IF care will be available is outlined below:

Current	Proposed Number of Centres	
All Centres	Integrated IF Centres	Home PN Centres
11	4	2

Consequences

As we are looking to reduce the number of centres to provide quality services, there will be a transition period for services to move to the successful providers which may mean that some patients may need to transfer to another centre during their treatment. Patients who are travelling into the region for treatment may continue to be treated this way or may choose to relocate their care to a hospital with a SIF service closer to them as the standard of care improves following the implementation of the new model of care. The new model will not affect patients' ability to receive parenteral nutrition at home.

9.2 Midlands and East

The Midlands and East region currently has 12 hospital services that provide some care to type 2 or type 3 patients. Eight of these provide surgical services for type 2 patients and all 12 look after patients on HPN. Three of the centres performed less than 10 complex SIF procedures in 2016/17 and a further centre under took 20 complex SIF procedures in the same period. In addition, eight centres look after less than 30 patients on HPN.

The map below indicates where current services exist – please note adjoining icons indicate one hospital and the levels of activity for both surgical and medical patients.

The midlands



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In 2016, 126 patients were treated for Type 2 IF and 360 patients on HPN were managed within the region. Based on the area where patients live, there was a number of patients who travelled to another region to receive treatment, 21 type 2 patients and 134 patients on HPN. The majority of these patients travelled into London. We have based our modelling on the number of centres required on the number of patients living in the region in 5 years' time and assuming they will choose to be treated at a hospital within their home region in the future.

Outlined below are the current and future numbers of hospitals where SIF care will be available is outlined below:

Current	Proposed Number of Centres	
All Centres	Integrated IF Centres	Home PN Centres
12	2	4

Consequences

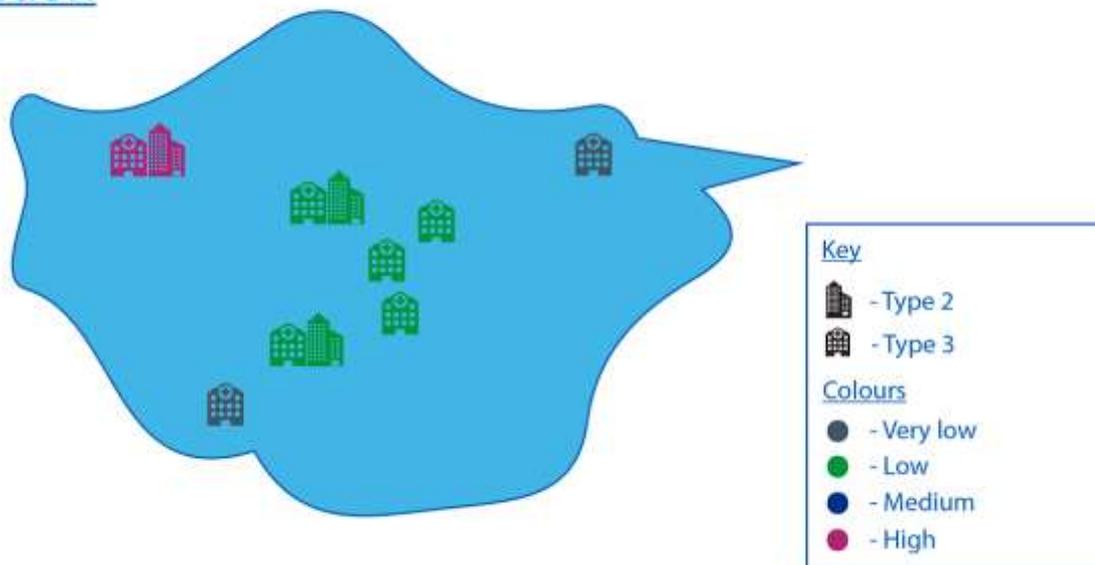
As we are looking to reduce the number of centres to provide quality services, there will be a transition period for services to move to the successful providers which may mean that some patients may need to transfer to another centre during their treatment. Patients who are travelling out of the region for treatment may continue to be treated this way or may choose to relocate their care to a hospital closer to them as the standard of care improves following the implementation of the new model of care. The new model will not affect patients' ability to receive HPN at home.

9.3 London

The London region currently has eight hospital services that provide some care to type 2 or 3 patients. Five of these provide surgical services for type 2 patients and all of them look after patients on HPN. One of the centres performed less than 10 complex SIF procedures in 2016/17. In addition, 3 centres look after less than 30 patients on HPN.

The map below indicates where current services exist – please note adjoining icons indicate one hospital and the levels of activity for both surgical and medical patients.

London



In 2016, 88 adult patients were treated for Type 2 IF and 574 patients on HPN were managed within the region. Based on the area where patients live, there were a number of patients who travelled to London from others regions to receive treatment: 23 type 2 patients and 319 patients on HPN. The majority of these patients travelled from the South Region followed by those from the Midlands and East Region. We have based our modelling of the centres on the number of patients living in the region in 5 years' time and those from outside of London choosing to be treated within their own region following the implementation of the new service specification and centre configuration.

Outlined below are the current and future number of hospitals where IF care will be available is outlined below:

Current	Proposed Number of Centres	
All Centres	Integrated IF Centres	IF Home PN Centres
8	2	2

Consequences

As we are looking to reduce the number of centres to provide quality services, there will be a transition period for services to move to the successful providers which may mean that some patients may need to transfer to another centre during their treatment. Patients who are travelling into the London region for treatment may continue to be treated this way or may choose to relocate their care to a hospital closer to them as the standard of care improves following the implementation of the new model of care. The new model will not affect patients' ability to receive parenteral nutrition at home.

9.4 South

The South region currently has 14 hospital services that provide some care to type 2 or type 3 patients. Eleven of these provide surgical services for patients with type 2 IF and all 14 look after patients on HPN. Four of the centres performed less than 10 complex IF procedures in 2016/17 and a further centre undertook 20 complex IF procedures in the same period. In addition, 10 centres look after less than 30 patients on HPN.

The map below indicates where current services exist – please note adjoining icons indicate one hospital and the levels of activity for both surgical and medical patients.



In 2016, 112 adult patients were treated for Type 2 IF and 216 patients on HPN were cared for within the region. Based on the area where people live, there was a number of patients who travelled to another region to receive treatment, 13 type 2 patients and 179 patients on HPN. The majority of these patients travelled into London. We have based our modelling of the centres on the number of patients living in the region in 5 years' time choosing to be treated within the region following the implementation of the new service specification and centre configuration.

Outlined below are the current and future numbers of hospitals where SIF care will be available is outlined below:

Current	Proposed	
All Centres	Integrated IF Centres	IF Home PN Centres
14	3	3

Consequences

As we are looking to reduce the number of centres to provide quality services, there will be a transition period for services to move to the successful providers which may mean that some patients may need to transfer to another centre during their treatment. Patients who are travelling out of the region for treatment may continue to be treated this way or may choose to relocate their care to a provider closer to them as the standard of care improves following the implementation of the new model of care.

Note: Current population is based on number of patients treated in hospital. Future population is based on patient CCG registrations at year 5.

10 Consultation questions

Respondents can share their feedback to this consultation on the NHS England website. **The closing date for this consultation is Friday 26 October 2018.**

- In what capacity are you responding to this consultation?
- In what region / hub are you located?
- To what extent do you agree with the plan to have fewer larger specialist teams delivering IF care so they have a greater experience, broad range of skills and can offer 24/7 cover?
- Do you have comments about our proposal for a reduced number of Integrated IF centres commissioned to undertake complex surgery and expert oversight?
- If so, is there anything that you think should be changed?
- Do you have any comments about our proposal for reducing the number of Home Parenteral Nutrition centres to look after the long term care of patients living with type 3 IF?
- If so is there anything that you think should be changed?
- Do you think networks of hospitals supporting patients with IF will improve co-ordination of care and communications about such care?
- How do you think these plans could promote equality and address health inequalities? Can you state any particular impacts on specific groups that these plans could cause?
- Please describe any other comments or concerns you have about our proposed model for specialised intestinal failure services for adults?
- Please declare any financial or other interests in any specialised services. For example, if you are responding on behalf of a voluntary organisation and your

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organisation received any funding within the last two years (including sponsorship or grants) from companies that manufacture drugs or treatments used in the treatment of specialised services, you must declare this. If you are a commercial supplier to the NHS of specialised services this should also be specified.