NHS England's response to the public consultation on proposed changes to specialised severe intestinal failure services for adults

Contents

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1. Introduction

Intestinal Failure (IF) comprises a group of disorders characterised by an inability to maintain adequate nutrition and/or fluid balance via the intestines. The disorders are described in the types of 1, 2 and 3. Type 1 IF is short term and is not specialised. Type 2 occurs in patients who are usually in hospital and frequently metabolically unstable. Type 2 patients usually require prolonged (> 28 days) parenteral nutrition, enteroclycis or fistuloclycis, often over periods of many weeks or months. Type 3 Intestinal Failure is a chronic condition, requiring long term parenteral feeding. Types 2 and 3 are classed as Severe Intestinal Failure (SIF).

IF may result from chronic illness, acute illness and trauma or as a consequence of multiple surgical interventions or occur as a result of a congenital defect or disease-associated loss of absorption. The condition is characterised not only by the inability of an individual to maintain protein-energy nutritional status, but also by difficulty in maintaining water, electrolyte or micronutrient balance. This can particularly arise when there has been a significant reduction in the length of a patient's small intestine. If intestinal failure persists for more than a few days, treatment with intravenous delivery of nutrients and water then parenteral nutrition (PN) is usually required. Patients with severe Intestinal Failure (SIF) may require extended spells in hospital to stabilise their condition. They usually require complex surgery and will usually be dependent on lifelong intravenous feeding at home once they have been discharged from hospital.

The provision of SIF services in England has developed over time without a formal national service configuration strategy being agreed. This has led to variation in the quality of services and a lack of information on outcomes in most services. Clinical experts have advised that 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 services 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 which is a key issue for patients.

Access to services for patients is variable. 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 an IF service closer to the patient's home locality.

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. There are currently 45 hospitals known to provide some support to people living with type 2 and 3.

A National Strategic Framework document for SIF services was published in 2008 followed by a Peer Review process. After NHS England was established a compliance based approach to the selection of centres was undertaken in 2014. NHS England then took the decision that it would not award contracts through this

process and that a more significant planned service reconfiguration change was required to ensure appropriate expertise and capacity be built into the system.

NHS England Specialised Services subsequently carried out a national service review of SIF supported by an expert Clinical Working Group.

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.

A revised service specification for adult SIF services was drafted following this review. In August 2017, a public consultation was undertaken on the revised service specification and the proposed changes were subsequently approved by NHS England Specialised Services and published in August 2018.

The revised model of care for adult IF services set out a specification to commission:

- **Integrated SIF Centres**: These centres will manage patients who need complex surgery and medical treatment and will provide a clinical service to patients discharged on Home Parenteral Nutrition (HPN). Centres will liaise with (usually) independent sector companies who manufacture and deliver the HPN for patients.

- **SIF Home PN Centres**: These centres will not offer complex surgery services but will provide a clinical service to patients discharged from Integrated SIF 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 integrated SIF centres and SIF home PN centres in each region work together to ensure that patients are managed in the right setting according to their needs to ensure optimal outcomes for patients.

The service review identified that the national provision of SIF services is characterised by a large number of hospitals seeing small numbers of patients. Also that 2 hospitals were still seeing significantly more patients than most services which was one of the factors making it harder for patients to access support close to home once discharged. Too many hospitals are performing complex IF surgery and managing patients on HPN without having teams skilled in this area or able to offer 24/7 care.

The new model of care as set out in the revised service specification describes service provision based around a model of a reduced number of Integrated SIF Centres and Home PN Centres.

This latest public consultation by NHS England is to inform how this new service specification will be implemented. 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 has also consulted with hospital and industry providers of these services as part of this exercise.

The purpose of the public consultation was to obtain feedback on the proposal to reduce the number of centres nationally from 45. An assessment was made of the centres treating patients with IF. Of these services, 8 performed fewer than the absolute minimum of 10 IF operations/annum on type 2 patients in 2016/17 and 26 centres have a caseload less than the minimum standard of 30 patients on HPN [as stipulated in Annex A2 – Centre Specification of the revised Service Specification]. Of the 26 centres designated to look after patients on HPN, 6 no longer look after any patients on HPN but still have the service in their contract.

The preferred option consulted on was a proposal to reduce the number of centres to 22 in total, composed of 11 Integrated SIF centres for type 2 and type 3 IF patients and 11 centres for Home PN that look after type 3 IF patients on HPN. This is to ensure that surgery and the management of complex patients on HPN are only available at hospitals which have IF teams, who can provide 24/7 cover, with the full range of different disciplines and with the experience of regularly caring for a wide range of patients with IF.

2. The engagement and consultation process

The service review proposals were published and sign-posted on NHS England's website and were open to consultation feedback for a period of 60 days from 24 August 2018 to 29 October 2018. In addition, 4 webinars were held for patients, providers and clinicians to explain and answer questions on the proposals. Comments from those who responded to the consultation were shared with the Clinical Advisory Group to allow members to consider the feedback and review the proposals.

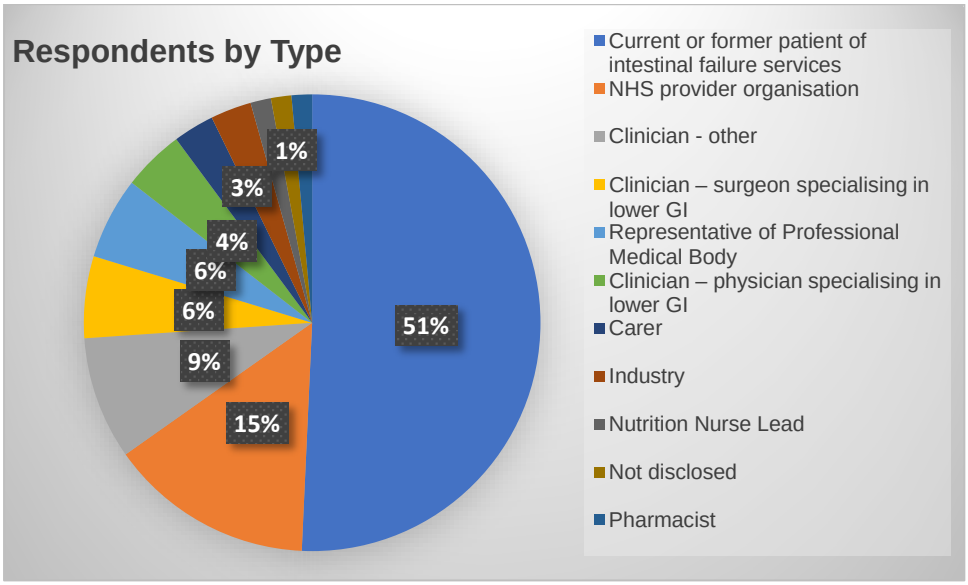
The following questions were asked as part of the consultation process:

- In what capacity are you responding to this consultation?
- In which region are you based?
- To what extent do you agree with the plan to have fewer Integrated IF Centres delivering severe intestinal failure 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?
- To what extent do you agree with the plan to have fewer Home PN Centres, offering long term care to people living with Type 3 IF?
- Do you have any comments about our proposal for reducing the number of Home PN 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 severe intestinal failure services for adults?
- Please declare any financial or other interests in any specialised services

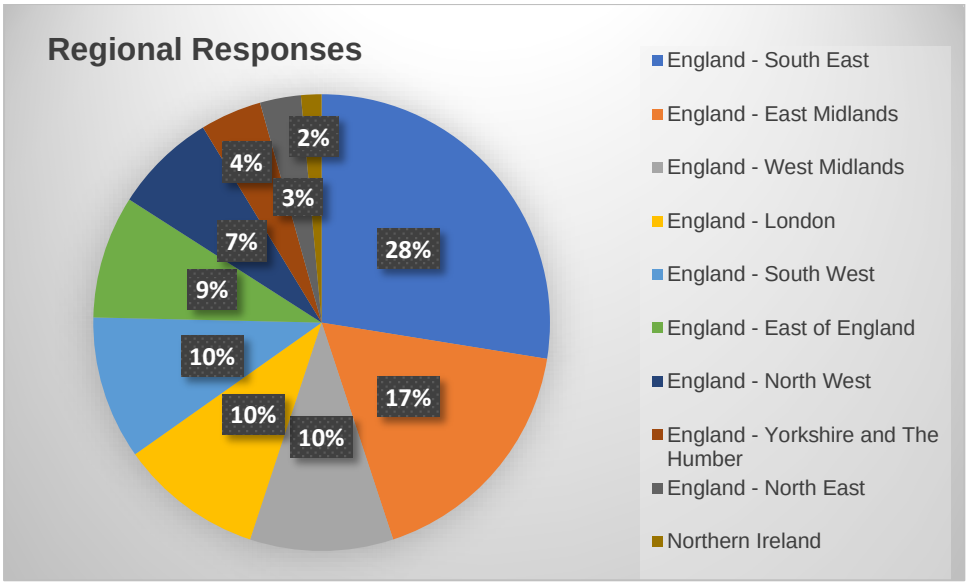
3. Summary findings and NHS England response

This section sets out a summary of key themes arising from the consultation responses.

There were 69 responses to the consultation. The majority (51%) were from current or former patients of intestinal failure services.



There were more responses from people living in the South East (28%) and East Midlands (17%) than elsewhere in the country, the distribution across the North West, West Midlands, East of England, London and the South West was fairly even with only 3 responses from Yorkshire and the Humber and 2 responses from the North East. One response was received from a person living in Northern Ireland which is outside the scope of the review.



More respondents agreed with the proposal for fewer integrated and Home PN centres and for networked working than disagreed. However, there were 2 recurring concerns that emerged across both the questions relating to fewer centres from all groups whether they agreed or not and these were:

- Increased travelling time for patients and families leading to increased costs and also difficulties for families to visit patients.
- Concern over capacity in the centres ranging from resources (eg beds and staff) to increasing waiting and transfer times that are already an issue.

Travelling Times

Respondents concerns over potential increased travelling times are understandable and have been considered by the service review and taken account of in the revised proposal.

In order to ensure reasonable access the proposal has been amended to allow greater flexibility to better meet the need for local care for people with Type 3 SIF. There will continue to be 11 Integrated Centres which will also provide Type 3 services to the local population, however in addition there will be up to 15, rather than 11 Type 3 HPN Centres. The exact configuration for Type 3 services will be confirmed after the Integrated centres have been confirmed in order to determine and then address where significant issues of access remain a concern.

The complex nature of the clinical problems involved in treating IF requires highly specialised treatment and high quality highly specialised treatment cannot be delivered in multiple low volume centres. Most patient groups now recognise the need for specialist treatment to be concentrated in larger centres. This is one of the factors for the proposal to have fewer centres than are currently delivering SIF services.

In addition, there are a large number of patients who already travel outside of their region to be treated e.g. 45% of HPN patients currently travel out of the South Region for specialist care. One of the objectives of the implementation of the new model of care and the fewer centres is to improve access by ensuring that sufficiently large and experienced centres in each Region will be able to offer care for patients currently treated a distance away from home.

We recognise that some patients may need to travel further following the reconfiguration of services; however, the improvements in outcomes and reducing the number of visits to hospital and HPN catheter related infections and other complications should reduce the frequency of travel for appointments and the length of stay that patients remain in hospital.

As highlighted above the service has developed in an unplanned way and thus the location of centres does not support equitable access across England. The procurement lotting strategy, which identifies the type and number of centres in each region, has been developed to address this and the number of centres required has been based on assessment of the likely volume of activity which needs to be commissioned. Location will be determined by geography, available expertise and the quality of the bid.

Capacity

Concern over capacity in the centres and thus increasing waiting and transfer times that are already an issue has also been taken into account during the service review and the implementation proposal.

As part of the procurement process, bidders to provide the service will need to demonstrate how they will deliver the surgical, medical and bed capacity to meet the expected number of patients within their catchment area. Furthermore, one of the objectives of the model is of the proposal is to ensure that complex IF care is only commissioned at specialised centres, where the required resources and expertise are available, and the relevant professional standards can be met.

The length of time taken for transferring patients to a centre was recognised during the revision of the Service Specification. Consequently, the service specification includes a maximum target wait of 14 working days from acceptance for transfer from a referring hospital to a receiving SIF (or Home PN) centre. As part of the procurement process each bidder will need to demonstrate how they will meet capacity requirements to meet quality targets including waiting times. In addition, once commissioned, the service will need to report on this metric on a quarterly basis which will be monitored by the commissioning hub.

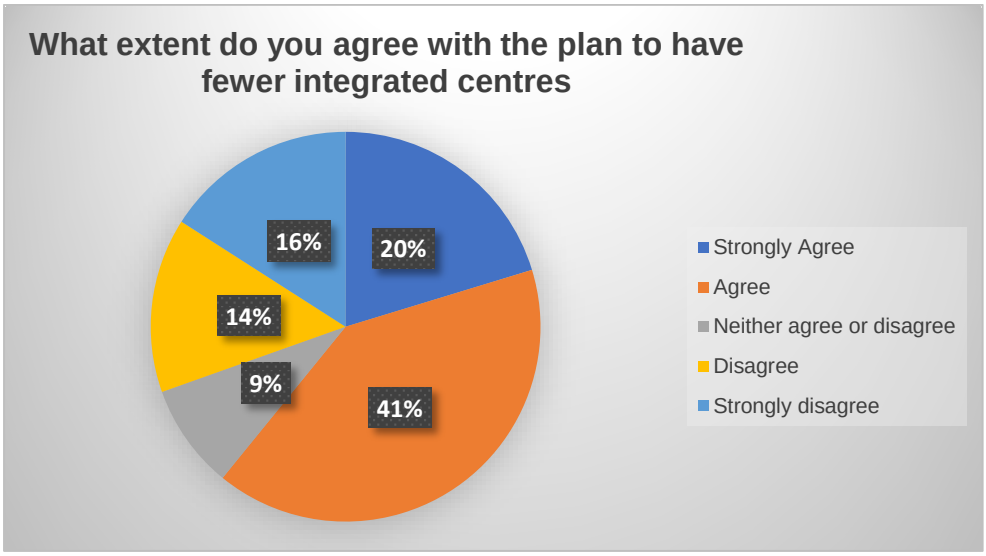
Integration with other specialised services

In addition, there was a view expressed by one respondent that centres that undertake small bowel transplants and cytoreductive surgery for cancer (CRS) with hyperthermic intraperitoneal chemotherapy (HIPEC) should automatically be a SIF service. Clinical advice from the CRG/ Clinical Working Group is that the centres that deliver CRS with HIPEC do not need to be collocated with a SIF centre. This is underpinned in that 2 centres currently commissioned to deliver Highly Specialised CRS with HIPEC do not currently provide other SIF services but report good outcomes for patients.

The number of patients undergoing small bowel transplants in England is small, these patients require complex and expert management. All of the patients have SIF at referral and the required competencies are present in the 4 bowel transplant centres. The requirements of a small bowel transplant service are described in a separate service specification and do not need to be collocated with SIF services but should be linked into the SIF Network. Providers will be able to bid to provide SIF services as part of the procurement process.

3.1 Establishing SIF Integrated Centres

Forty-two respondents (61%) strongly agreed or agreed with the plan to have fewer Integrated Centres delivering SIF care so they have a greater experience, broad range of skills and can offer 24/7 cover. There were twenty-one respondents (30%) strongly disagreeing or disagreeing with the proposal.



Patients supportive of the Integrated Centre model described current difficulties with accessing MDTs with the right skills and reported variation in practice and care between hospitals and poor communication within hospitals and between hospitals.

Health staff supportive of the Integrated Centre model recognised current issues with lack of clear referral pathways, variation in practice and the need for a 7 day a week service model.

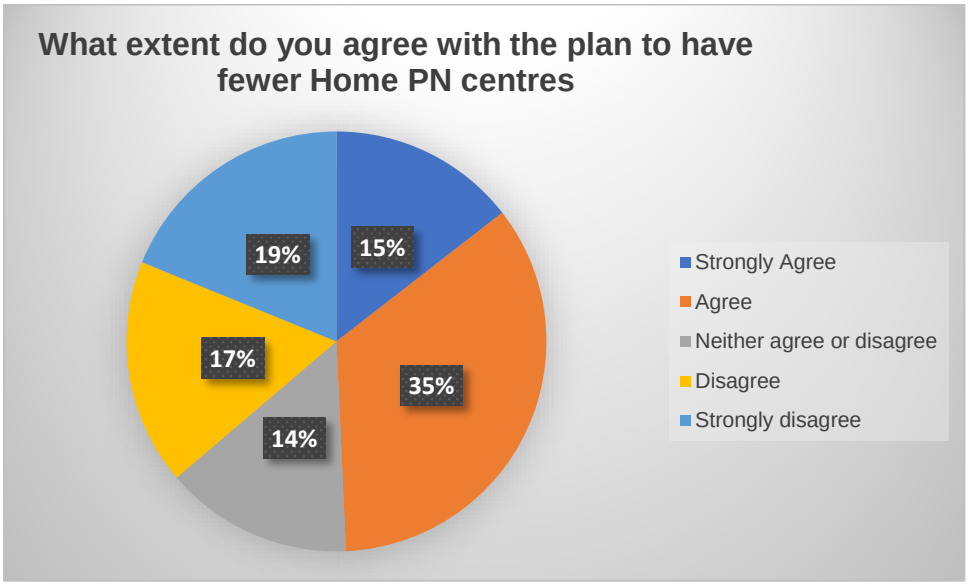
There was a concern about patients with particularly complex needs, but commissioners would expect the Integrated Centre to decide if a patient should continue to be managed at an SIF centre or not depending on the primary needs of the patient and taking account of other medical conditions they may have.

Where respondents did not support the proposal they were still very aware of problems with current services and reported examples of the problems they had experienced but were mainly concerned about the impact on the service they use or about capacity or staffing of the new model rather than a concern about the clinical model itself. They often wanted strengthening of teams and networks overall.

There was only one specific comment about Option 3 which proposed less Integrated and HPN Centres than in Option 2. The comment noted they were unclear on the difference in impact between the two and wanted this explained more fully. Option 3 was based on modelling using patient numbers as the key criteria rather than access, whereas Option 2 aimed to balance sustainable sized services and access.

3.2 Sustainable Home PN Centres

Thirty-four respondents (49%) strongly agreed or agreed with the proposal for reducing the number of Home PN centres to look after the long-term care of patients living with type 3 IF with twenty-five respondents (36%) strongly disagreeing or disagreeing with the proposal.



Patients often described difficulty with accessing care in local hospitals and that local hospitals did not have the skills to recognise problems or inadvertently caused problems, with poor knowledge about management of feeding lines being mentioned most often.

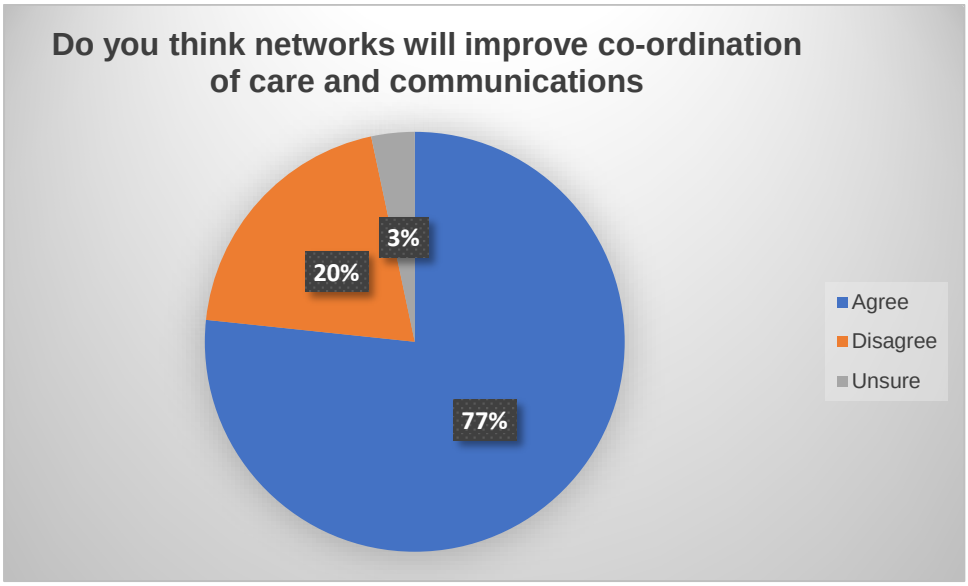
Where respondents did not support the proposal this was usually because of concerns about the potential impact on the service they use or a concern about increased delays in being admitted if there are fewer services.

The main concern was about increased travel times and costs for patients and carers.

3.3 Networks

Do you think networks of hospitals supporting patients with IF will improve co-ordination of care and communications about such care?

Forty-six respondents (77%) agreed that networks of hospitals supporting patients with SIF will improve co-ordination of care and communications about such care with twelve not agreeing.



Those that supported networks saw this as a means of improving poor communications and those that did not were concerned about lack of expertise in local hospitals. However the network model is about Integrated Centres and HPN Centres working together including clear roles and referral pathways across the whole network.

3.4 Equality

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?

There was recognition that there was a lack of equity now both in terms of quality and physical access. There was support for the new model as a means of raising quality across SIF services. A concern was also raised that there could be differential referral rates of patients for long term home parenteral nutrition.

The concerns about equity mainly related to travelling times and geographical equity of access.

3.5 Other Points raised

Please describe any other comments or concerns you have about our proposed model for specialised severe intestinal failure services for adults?

Respondents also mentioned the need for better support for carers, and that patients can also be a source of support to other patients with particular examples given.

Given it can be difficult for patients to travel it was requested that the new services consider new ways of supporting patients remotely, this could be by using technology.

Centres will be asked to consider these points as part of their bid.

Appropriate training of staff was raised. It is recognised that training is an important area and NHS England will review with clinical advisors where gaps in skills or training exist to ensure these are raised with relevant bodies.

It was requested that paediatric services and transition from paediatric services to adult services were important areas for future work which NHS England will facilitate, once the new model is implemented.

4. NHS England's consideration of the responses on the Options

Option 1: To do Nothing – 45 providers offering care of SIF Type 2 and Type 3.

There were no direct comments about Option 1. However, the responses received clearly demonstrated that both patient and clinical respondents recognised the significant problems with the current service and the need for change to improve outcomes. Where respondents did not want any changes, these were usually in the context that they were concerned about the potential impact on the service they used now rather than in support of unchanged service provision nationally.

Option 3: To reduce the number of centres to 20 in total, composed of 10 Integrated SIF centres for type 2 and type 3 IF patients and 10 centres for Home PN.

There was only one specific comment about Option 3. The respondent noted they were unclear on the difference in impact between this and Option 2 and wanted this explained more fully. Option 3 was based on modelling using patient numbers as the key criteria rather than access, whereas Option 2 aimed to balance sustainable sized services and reasonable access.

Option 2: The preferred option: - To reduce the number of centres to 22 in total, composed of 11 Integrated SIF centres for type 2 and type 3 IF patients and 11 centres for Home PN. Overall more respondents supported the change than did not support it and were concerned that the agreed model should now be implemented, noting the previous problems with implementing change nationally for this service.

The concerns raised could be divided into 2 categories;

Category 1. Concerns where respondents perceived problems could arise which commissioners did not consider were related to the preferred option and may have reflected a misunderstanding about how the changes would be implemented. For example, a number of respondents were concerned about the preferred option increasing delays in referrals and a lack of capacity to take additional referrals within current bed allocations. The aim of the new model is to streamline referral pathways and explicitly set out roles and responsibilities of the different services within each SIF network. Commissioners recognise services in the new model will need to be sized in line with the expected cohort of patients they will look after. The procurement process will make it clear the expected capacity required so that providers can submit bids on this basis and will be expected to address how they will meet increased demand where that applies.

Category 2. Concerns where respondents perceived problems could arise which commissioners did consider related to the preferred Option. The key concern raised was about patients having to travel further, particularly if unwell and the impact on carers. It is noted that in the current service configuration patients do not always go to the closest hospital but often travel long distances to an “expert” centre. Therefore, the new model does not necessarily mean patients will travel further, however this could be the case. There was stronger recognition of the case for fewer Integrated Centres for surgical care and more concern about the impact on patients needing ongoing or more urgent support for Type 3 care.

The responses relating to clinical concerns were specifically discussed by commissioners with the SIF Clinical Working Group. It strongly endorsed the need for Integrated Centres to be seeing a sufficiently large cohort of patients for the team to maintain the necessary expertise and skills to manage the variety of clinical presentations that are inherent within SIF as a condition and to address sub-optimal decision making that currently creates potentially avoidable SIF within the NHS.

They considered that improvement of outcomes in England was dependent on a fundamental change to the current model as described in Option 2.

Commissioners noted that the Clinical Working Group also supported the proposal for 11 HPN Centres in addition to those with Integrated Centres. However, given that distance from the new HPN Centres was the issue most consistently raised by respondents Commissioners have reconsidered if more allowance can be made for access whilst still maintaining sufficiently skilled HPN teams. Therefore, it is now proposed that in addition to the HPN service provided within Integrated Centres there could be up to 15 standalone centres. This will offer more flexibility within the procurement to Commissioners to ensure patients will have reasonable access to the service they would expect to be supported by over their lifetime.

5. Conclusion

NHS England welcomes the valuable feedback received through this consultation process. More respondents agreed or strongly agreed with the proposal to reduce the number of centres. Having carefully considered all comments received, in particular those relating to capacity and travel times, the concerns raised are noted, the view of NHS England is that the positive impact on patient care that will be achieved by centralising expertise in larger centres and addressing the current variability in care offered to patients by reducing the number of SIF Centres in England will overall offer great advantages to this complex group of patients.

NHS England, supported by the majority of responses to this consultation and by expert clinical advice, is of the view that SIF should be managed only by skilled team at centres with proven expertise and experience in managing such patients and that the procurement of centres based on the revised SIF service specification should now proceed. The issues raised during the consultation will be taken into account during the procurement process to ensure the best possible service configuration is achieved and that services in England are established to achieve the best possible clinical outcomes for this patient group.

Specifically, the concern raised about travel has prompted reconsideration of the model for HPN Centres and the revised model allows for additional sites to be considered once the Integrated Centres are procured to ensure where feasible access within 1 hour can be met.

Annex A

Detailed Consultation Comments and Responses for the Internal Medicine PoC Board

3.1 Establishing comprehensive SIF Integrated Centres for people requiring surgical and medical care

Key themes in feedback	NHS England Response
Consolidating services in fewer centres will ensure that SIF teams have the expertise to deliver high quality clinical care and the experience to help patients understand all the treatment options available to them.	This is the intention of the new model of care and will provide 24/7 access in line with the service specification.
Centres need to be resourced to deliver the service such as funding, staff and beds.	NHS England is investing an additional £18.5m over 5 years (£3.7m per year) in the service. In addition, bigger centres will have an increase in activity thus increasing income and viability of the service
Reduction in the number of centres will increase waiting times and delay transfers.	Based on data submitted 8 out of 33 hospitals providing treatment to type 2 patients do not meet the minimum number of operations. This will have an impact on bed availability. Under the new model, the commissioned centres will have to undergo a minimum of 20 operations per year and manage a minimum of 50 patients on HPN. As part of the procurement a centre will need to demonstrate their capacity (including beds) and how they will manage waiting times and transfers.
Reduction in the number of centres will result in fewer beds available to SIF patients.	The proposal does not mean there will be fewer beds as beds will be redistributed in line with projected demand.

Reduction in the number of centres will increase the travel time for patients and families	There may be an increase in travel time for some patients as the overall number of centres will reduce. However, the reduction has been balanced against the need to deliver improved quality of care and meet the capacity. The 2015 National Sarcoma UK Survey showed that nine in ten patients didn't mind travelling further to receive the best care. In addition, some patients may travel less as we are aware that some patients currently bypass a service closer to home to attend one further away that they believe offers a better quality service.
Increased travel time will mean patients and families incur increased travel costs	It is NHS England's belief, supported by expert clinical advice, that SIF surgery and medical treatment should be managed only by centres with proven expertise and experience in managing such patients. Whilst some patients may need to travel further the improvements in outcomes and reducing the number of visits to hospital and HPN catheter related infections and other complications should reduce the frequency of travel and the and length of stay that patients remain in hospital.
NHS England should consider a maximum time or distance for patients to travel especially in large geographic areas like the South West	The travelling times for 90% of patients to travel up to 2 hours to an Integrated Centre and up to 1 hour to a Home PN Centre were considered as part of the modelling. The geographic location of centres is being considered as part of the procurement.
Will accommodation be available for visiting relatives	The service specification states that the Service will ensure fluidity of patient

	movement between integrated SIF centres and HPN centres, in order to support both the clinical needs of the patient and also the social needs of their family / carers. The provision of family accommodation will be determined by the centres.
Centres should be expanded not reduced delivering care closer to home for patients	It is NHS England's belief, supported by expert clinical advice, that SIF surgery and medical treatment should be managed only by centres with proven expertise and experience in managing such patients. Currently, 8 out of 33 hospitals providing treatment to type 2 patients do not meet the minimum number of operations performed per year. In addition, the patient numbers nationwide do not support increasing the number of centres and maintaining and delivering a high-quality service.
How do other centres gain the skills to have opportunity to tender	NHS England recognise that some centres may need to develop the service to meet all requirements. Centres who do not meet the service specification and minimum volumes will outline within their bid in the procurement on how they will gain the skills and be able to deliver the service against the service specification by the end of the 3 year transition period. The tender includes provision for 2 reference centres for a 3 year period to assist other centres whilst they are in transition.
NHS England should site SIF centres with Bowel transplant centres	It is recognised bowel transplant centres require SIF skills to manage patients and their role will need to be described as part of the wider SIF Network. There is no requirement within the Severe Intestinal Failure in the service

	specifications for colocation of the 2 services. The procurement will be an open competition and bowel transplant centres are welcome to apply for specific recognition as SIF centres.
Reducing the number of centres could impact on the ability of clinicians to maintain their clinical skills.	Given the low numbers of patients seen at some units, it can be difficult for clinicians and teams to practice enough in order to develop their skills. Consolidating the centres and increasing the minimum patient numbers will enable clinicians to maintain and improve their skills.
Patients may want to stay with their current provider for excellent care and not forced to move to a local centre	The aim of the new model of care is for the service to improve outcomes and for each centre to deliver the service to a minimum standard. The procurement will be an open competition, so we are unable to confirm if a current provider will be selected and commissioned for the service as this will be determined through evaluation of all the bids and needs within that locality. Should the provider that you are being treated at now be successful then you will not be forced to transfer; however, the aim is for all centres to deliver high quality clinical care and you may wish to transfer to a centre closer to home once implemented. Clearly where a service is not selected then any patients will need to transfer to a new hospital team.

3.2 Establishing sustainable Home Parenteral Nutrition Centres for people requiring medical care and home care

Key themes in feedback	NHS England Response
Consolidating services in fewer centres will ensure that SIF teams have the expertise to deliver high quality clinical care and the experience to help patients understand all the treatment options available to them.	This is the intention of the new model of care.
Centres need to be resourced to deliver the service such as funding, staff and beds.	NHS England is investing an additional £18.5m over 5 years (£3.7m per year) in the service. In addition, bigger centres will have an increase in activity thus increasing income and viability of the service.
Reduction in the number of centres will increase waiting times and delay transfers.	The commissioned centres will have a minimum capacity of managing 50 patients on HPN increasing their capacity. As part of the procurement a centre will need to confirm they can manage the patient caseload, demonstrate their bed capacity and how they will manage waiting times and transfers.
Reduction in the number of centres will result in fewer beds available to SIF patients.	The model is not designed to reduce the number of beds but to better match demand and capacity across England
Reduction in the number of centres will increase the travel time for patients and families	There may be an increase in travel time for some patients as the overall number of centres will reduce. However, the reduction has been balanced against the need to deliver improved quality of care and meet the capacity. Some patients may travel less as we are aware that some patients currently bypass a service closer to home to

	attend one further away that they believe offers a better-quality service.
Increased travel time will mean patients and families incur increased travel costs	NHS England has concluded, supported by expert clinical advice, that HPN should be managed only by centres with proven expertise and experience in managing such patients. Whilst some patients may need to travel further the improvements in outcomes and reducing the number of visits to hospital and HPN catheter related infections and other complications should reduce the frequency of travel and the time that patients remain in hospital.
NHS England should consider a maximum time or distance for patients to travel especially in large geographic areas like the South West	The travelling times for 90% of patients to travel up to 1 hour to a Home PN Centre were considered as part of the modelling. In addition, the geographic location of centres is being considered as part of the procurement.
Reducing the numbers of IF centres offering PN will be detrimental to patient care and thus patient experience	NHS England has concluded, supported by expert clinical advice, that HPN should be managed only by centres with proven expertise and experience in managing such patients leading to improved outcomes with a minimum of 50 patients on HPN, where feasable. Sarcoma UK highlight on their website https://sarcoma.org.uk/news/2018/10/nhs-are-asking-how-sarcoma-can-be-better-treated-tell-them-today that: 'Being treated at a sarcoma specialist centre means knowing the right people, with the right expertise and experience are the ones caring for you. It makes sense therefore that GIST or RPS patients are treated at centres that see a high number of these operations and have the necessary infrastructure to support patients. Our 2015 National

	Sarcoma Survey showed that nine in ten patients didn't mind travelling further to receive the best care.' NHS England considers that this is relevant to SIF.
We feel that there is a need for more Home PN centres in the South than the 6 proposed. This area is large and a decrease to 6 centres will require patients to travel a long way for review. The current set up with 14 centres already requires patients to be managed remotely which has been unsatisfactory with patients receiving a lower standard of care.	Of the 14 centres in the South, 10 look after less than 30 patients. In addition, 45% of HPN patients travel out of the region for specialist care. 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 leading to improved outcomes with a minimum of 50 patients on HPN. Consequently, those patients currently travelling long distances and out of region should be able to access one of these centres closer to home and receive high quality care should they wish to.
How do other centres gain the skills to have opportunity to tender	NHS England envisage that it may take up to 3 years for centres to deliver a service in line with the service specification. Thus, we are also tendering for 2 reference centres for a 3-year period to assist other centres to meet the minimum standard of care. Centres who currently don't meet the service specification and minimum volumes will outline within their bid in the procurement on how they will gain the skills and be able to deliver the service against the service specification by the end of the 3-year transition period.
NHS England should take into account paediatric transitioning patients in to the capacity calculations	The growth used in the modelling is based on the number of patients on HPN in the last few years which

	includes paediatrics transitioning to adults.
NHS England should site SIF centres with Bowel transplant centres	There is no requirement within the Severe Intestinal Failure or Small Bowel Transplant adult service specifications for colocation of the 2 services but should be described in network arrangements. The procurement will be an open competition and bowel transplant centres are welcome to apply.
Reducing the number of centres could impact on the ability of clinicians to maintain their clinical skills.	Given the low numbers of patients seen at some units, it can be difficult for clinicians to practice enough in order to develop their skills. Consolidating the centres and increasing the minimum patient numbers will enable clinicians to maintain and improve their skills.

3.3 Severe Intestinal Failure Networks

The detailed comments and responses relating to networks are as follows:

Key themes in feedback	**NHS England Response**
The differing protocols makes travelling difficult. If we get sick in another area, we have to contend with a local hospital either not understanding our care needs and line care or trying to override current care plans to suit themselves and not the patient. There need to be central access to IF patient info for hospitals to ensure the right level of care is given.	The Service Specification covers these requirements: Robust local networks of care will be developed between integrated SIF centres, and HPN centres. 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 / discussions.
I think networks are a good idea but these would have to include all hospitals, particularly those with little/no experience in HPN or IF patients	The role of hospitals in the pathway who are not Integrated IF Centres or HPN Centres will also need to be defined and included in information about the service
Patients will usually require multidisciplinary care and will have to travel to different centres for management, such as haematology, oncology and vascular to name a few.	This is covered in the service specification. In most cases these services are likely to be onsite, if services are not available on site, there should be transparent, robust and formal contractual arrangements for timely access to these services by the specialised IF service.
Will clinical reference centres be appointed at the same time during the procurement? If yes how will NHSE ensure the new CRC have the resilience and sustainability to formalise the network whilst delivering their contractual obligations?	Yes. The requirement to be able to deliver a SIF Integrated centre service in line with the service specification will be part of the requirement to be a reference centre.
Need to be resourced appropriately	NHS England is investing an additional £18.5m over 5 years (£3.7m per year) in the service. In addition, bigger centres will have an increase in activity thus increasing income and viability of the service.

3.4 Equality

Key themes in feedback	NHS England Response
Reducing the number of centres could mean longer travelling times which could particularly impact on people on lower incomes and those with other long-term conditions or disabilities.	NHS England has concluded, supported by expert clinical advice, that SIF should be managed only by centres with teams with proven expertise and experience in managing such patients. Whilst some patients may need to travel further the improvements in outcomes and reducing the number of visits to hospital and HPN catheter related infections and other complications should reduce the frequency of travel and the length of time that patients remain in hospital.
There is an inequity of access for patients waiting to be transferred from their local hospital to the SIF service opposed to those that live near the centre and are directly admitted.	NHS England concluded that more even provision of larger Integrated Centres and HPN Centres will have create the ability to manage demand over a 24/7 period as they will have larger teams and greater depth and breadth of experience to support patients in the most appropriate way.
How will centres consider that some patients will be travelling long distances to attend clinics and need appropriately appointment times	The SIF Adult Service Specification includes a metric for services to collect information on patient experience. Both good and bad experiences should be fed back into the service. In addition, patient access will be included in the procurement process. Patients have flagged they would be interested in using technology as part of their care so providers will be asked to consider how they can support this over the next 3 years
The proposal should address the current geographical inequity of access	Demand modelling has considered unmet need and geography has been taken into account and will be taken into account during the procurement.

How will centres address local translation and cultural services for patients who are not from the immediate area around the centre?	The SIF Adult Service Specification covers the requirement for commissioned integrated SIF centres and HPN centres to develop patient information and literature. In addition, there is a quality metric related to patient information that a provider needs to report against and is reviewed by commissioners.