

Severe Intestinal Failure Consultation: Frequently Asked Questions

As part of our engagement with patients, we have already received some questions as people try to understand what the impact that our plans could mean for individuals. These are some of the questions received to date and the NHS England response.

We will update these FAQ later in the consultation to reflect the questions that we receive from stakeholder feedback

Will this resolve any of the current capacity issues in terms of getting a bed in my own centre? If my centre becomes an Integrated IF Centre, won't it have even more patients to look after?

When hospitals bid to be an IF centre they will need to say how many patients they expect to care for and explain how they will deliver the service, including the inpatient facilities. Some hospitals may need to alter how they organise the new service so this may take a while to be up and running. In our modelling of the number of centres we have taken account of future patient numbers and thus expect when fully implemented beds will be available.

Will Home PN Centres be able to manage central line and port-a-cath repairs, or will I need to go to an Integrated IF Centre for that?

Yes, all Type 3 Centres supporting patients on Home PN will be able to support patients with these issues.

If admitted into another hospital, will they have access to expert advice from the Integrated IF centres about IF?

Yes, once implemented the service specification identified the requirement for centres to have 24 hour on call staff and to have clear processes for patient help and advice by appropriately trained and experienced staff 24 hours a day, 7 days a week

What guarantee do we have that centres will have appropriately trained and safe staffing levels in these centres?

NHS England have a number of ways of monitoring the performance of centres and compliance with the service specification. Each centre will need to submit data into a dashboard on their performance and complete an annual self-assessment of their compliance against the service that are reviewed at both Regional and National level. In addition, in the first 3 years of implementation, we will be appointing 2 reference centres to ensure all centres have get access to advice whilst networks and services are getting established.

Will the two national reference centres be able to carry out their own role and oversee others? Will this affect patient care if they are busy supporting other centres instead of their own patients?

The role of the 2 national reference centres will be to provide advice and offer training to other services. Those that apply will need to show how they can do this in addition to their normal service. This should not have a detrimental effect on patient

care and in fact we hope this will have a positive impact as the other centres meet the service specification standards and the networks are developed,

Who will ensure that there is equity for the provision of the IF services?

NHS England will consider a number of factors when selecting centres, one of these will consider access to services. In terms of access to services of the same standard the national team sets the national quality standards and the local commissioning hubs monitor compliance with achieving these standards..

Do people have a choice if they do not wish to transfer to another centre?

This will depend on the outcome of the procurement and your treatment requirements.

If your current centre is commissioned then you can continue to be treated there.

If you are currently at a centre that is not successful in the procurement and subsequently not commissioned then you will need to transfer to another Centre that should be reasonably accessible to you. The aim of the new model of care is that each centre will provide standardised care so over time the centre closer to where you live should be providing the same service that you are currently receiving but you will have a reduced travel time if you transfer.

How and when will people be informed about changes directly related to their own care?

This consultation is to advise you what the new service model will look like and how this may affect services you use but it cannot address the impact on individuals at this stage.

Once the new centres are selected the network and those sites will be expected to develop an implementation plan so there will be a formal process to engage with patients who may be individually affected.

Will I need to travel further for HPN monitoring? Will all hospitals be accessible by public transport (as travelling time only useful for people who have cars)

This will depend on the outcome of the procurement and where you are currently treated. We believe some patients will have to travel less as the aim of the model of care is to deliver standardised care closer to home. However, not all of the centres currently delivering the service will continue to do so after the procurement and so some patients will have to travel further for their HPN monitoring. Patient access is one of the criteria considered within the procurement process, so hospitals should be easily accessible by public transport or other access arrangements.

What does 24/7 cover actually mean? For example, does this mean that there would be stoma nurse cover over the weekend?

IF services will need to state what they will offer by way of 24 hour support. Stoma nurses support a range of services not only patients with IF.

Will less centres mean an overall reduction in staff with IF expertise?

We do not expect that the change of service model will reduce the number of staff with IF expertise. It is actually intended to increase the number of IF patients seen by each team to increase skills and experience.

I'm happy to continue travelling further to the hospital I have a long term relationship with. Could I be told that I need to go to a hospital closer to home?

We recognise that patients already being looked after may be anxious about these changes. If the hospital you currently go to is not selected as either an Integrated centre or a centre for HPN then you would need to go to another hospital. However if the hospital you go to continues as a centre and that is the centre closest for you then we would expect your care to remain with that centre. If you are attending a centre for HPN support but that is not close to where you live you will be made aware of where services closer to your home will be so you have the option to transfer your care.