

IFR - FAQs

Area	Question	Answer
Account	I'm having trouble accessing my account, or require a new password.	Please contact the support team on england.support.outcomeregistries@nhs.net
Account	I do not have access to the correct IF centre, or have moved locations	Please contact the support team on england.support.outcomeregistries@nhs.net
Account	All account, log in queries should be directed to the support team.	england.support.outcomeregistries@nhs.net
Application	What happens if we do not know when last DEXA was done could be done at another hospital?	Data is being migrated from the legacy system. There is the concept of a home location in the new IFR registry. A home location can share a record on a temporary basis with another BAPEN provider that requires access to clinical data. This will be available from go live. There will also be an additional permanent transfer function coming in September. This transfers a patient record on a permanent basis from the old to new home location with access to the key summary clinical data.
Application	Can you run a report to list incomplete records across your patient cohort so you can update these as the information comes in?	The Patient Record shows the statuses of all records associated with the patient and the record status, Incomplete, Complete or Submitted.
Application	Is there a function to record patient patients who DNA appointments and a function where it can record when some patients are unable to have bone scans performed?	That was not part of the current specification, but we maintain a product backlog where we can add new ideas and requirements. NEC then presents these ideas to NHSE for approval and prioritisation.
Application	Will users be able to use trust specific addresses to log in in absence of nhs.net addresses	Any approved hospital email domain can be added to the application
Application	When sharing a patient record with another centre, can they record events even if they occurred before the share?	This is explained in the User Guide which may be viewed via the Resources tile
Application	We sometimes share care with another centre, with both centres needing to be active and able to make additions, is that possible?	This is explained in the User Guide which may be viewed via the Resources tile

IFR - FAQs

Area	Question	Answer
Application	Would it be possible for the registry managers to distribute a contact list of primary contacts in each trust?	An IF Registry Working Group user list can be found in the Resources section of the platform
Application	Can the system recognise that someone has been dc from IF care but then 18months later becomes IF patient again?	Once a patient record is added to the platform it will stay for the life of the registry, you can always find your patient and add new records at any time. An end user can always search to see if a patient has been discharged from the Registry. If this were at a different BAPEN centre the end user would need to request access from that organisation
Application	Does the register tell you which trust the patient is registered under if it is not your own?	Yes, once you have found your patient it will tell you where their home location is.
Application/ Programme	What is the patient data conversation and what is the patient declines for their data to be used?	Consent is not required for England, Scotland, and Wales- at present NI needs consent- Data conversation is a courtesy – Patient Leaflets will be available
Clinical	For the teduglutide GLP2 clinic visit and outcomes, this was very limited and did not fit what we do on the old registry. Is this the same as before or has it been adjusted?	Some fields have been adjusted in the new system
Clinical	For vascular access can we go back in time to the date of insertion e.g. 2020?	Yes, I believe so
Clinical	Are type 2s classed as anyone on PN >28days? We have a lot of pancreatic long stay inpatients	To be recorded on the IF Registry patients are under an IF/HPN unit - not just NST - We appreciate in many trusts the personnel are similar - but should be accepted by IF/HPN unit

IFR - FAQs

Area	Question	Answer
Clinical	SSQD - is the assumption that IF surgery is not happening at medical HPN centres and therefore 90-day mortality etc not applicable?	Correct
Clinical	Does data held in Ebans transfer across from 1.7.26?	Yes, E-Bans is the Streets Heaven System.
	Will data from Ebans pull across for launch 1.8.26?	Yes from 1.7.26
Data/ Reporting	Will the data reports be patient level and what level of data can be extracted?	The initial data reports will focus on high-level metrics based on volume and counts rather than analysis or any patient data. The reports will be issued quarterly.
Data/ Reporting	Will IF data be visible to NHSE or will providers be required to submit data to NHSE separately similar to request in March?	Historic data have been transferred and have been uploaded behind the scenes. Interim data submissions will also be stitched into the registry. Some centres have chosen to backfill their interim collections once the registry goes live, however.
Data/ Reporting	just to clarify do we still need to submit the SSQD quarterly data in addition to the registry (or will the registry do this if properly completed?)	SSQD returns will be taken from the registry directly, so you will no longer need to duplicate effort by submitting the same data twice.
Data/ Reporting	just to clarify do we still need to submit the SSQD quarterly data in addition to the registry (or will the registry do this if properly completed?)	SSQD returns will be taken from the registry directly, so you will no longer need to duplicate effort by submitting the same data twice.
Data/ Reporting	Is there any way NEC can back date data submission to 01/03/2026?	We have already clarified that data can be backdated to 01/03/2026. There is no limit on retrospective dates.
Data/ Reporting	We currently do not get feedback from SSQD data e.g. surgical outcomes - would we be able to get national or local feedback on all the SSQD outcomes?	Yes. All outputs, reports and dashboard developments will be overseen by BAPEN. We will certainly fulfil this requirement if directed by BAPEN.
Data/ Reporting	SSQD returns will be taken from the registry directly, so you will no longer need to duplicate effort by submitting the same data twice.	Yes
Data/ Reporting	I appreciate we need to try and keep this as contemporaneous as possible, but if we are a bit behind due to workload but the registry auto submits SSQD can we submit our own SSQD from the trust until we are up to date?	To be clarified with Yasmin Stammers and NHSE commissioning but we would prefer that IF Registry were used to collect data and not other sources.

IFR - FAQs

Area	Question	Answer
Data/ Reporting	We will have a major gap in our activity as we have not had admin support to fill in the interim data collection tool, are we able to add the records in once the IFR is live?	Appreciating this administrative task requires capacity, activity can be entered retrospectively, and you can add it yourself from when the new IFR goes live if you prefer
Programme	Is the Registry exempt from National Data Opt-out obligations?	It is, with the exception of Northern Ireland where consent is required.
Programme	Is a data sharing agreement necessary (or are these already in place) for sharing a patient record with another trust?	These are not necessary. The registry remains under Data Services for Commissioners Directions, 2015. Data Processing Agreements are managed by NHSE.
Programme	Will this include paediatric patients and if so, when?	The roll out of the Paediatric IFR is scheduled for September 2026. Paediatric users will be contacted in due course to confirm the go live data and training sessions.
Programme	is it the email that has been used for the meeting today, or the one previously used for the streets heaver system	Application/ technical support - england.support.outcomeregistries@nhs.net / clinical support - ifregistry@bapen.org.uk
Programme	Also, our CNS who is the contact for IFR is off medium-term sick - how do we get access for other team members please? Thanks	Requests need to be preapproved by the IF working group Lead for Trust, once approved requests can be submitted to england.support.outcomeregistries@nhs.net .
Programme	Who submits for patients living in and funded by Wales, but clinical team based in England? Clinical trust or trust supplying funding?	It is the clinical team at present
Programme	Can we only have one lead per centre?	The Registry supports any number of users in the defined roles. Limiting each centre to one lead was the decision of the BAPEN Clinical Steering Group but this will be reviewed.