BRITISH THORACIC SOCIETY

Lung Disease Registry Programme

NHSE ILD Quality Dashboard Completion and the BTS ILD Registry

Virtual Event Follow-Up Information Pack
September 2021

On 15th September BTS ran a virtual event detailing the upcoming changes to the NHSE ILD Quality Dashboard items which English specialist centres are required to submit to the NHS.

BTS and NHSE had been in ongoing discussions regarding the Quality Dashboard items, and BTS proposed the pre-existing Dashboard items be replaced with items which were easier to collate, used IPF as a surrogate marker for ILD, and incorporated the five Quality Statements from the 2015 NICE Quality Standard for IPF. These items were agreed at the BTS ILD Registry Steering Group, with feedback sought from the BTS Interstitial and Rare Lung Disease Specialist Advisory Group (IRLD SAG) and leads from specialist centres across England.

Although the Quality Dashboard is only mandated for specialist centres in England it is anticipated that the resources created to support the process for these centres will be able to be used by district general hospitals and hospitals in the devolved nations to support benchmarking.

There are a few key points to note:

- NHSE previously requested quarterly dashboard returns. The updated dashboard will require **six monthly returns** only (biannual).
- Patient consent to the Registry can be achieved by a face-to-face interaction with wet ink signature **and also remotely**. Further details are in the Q&A section of this pack.
- Each specialist centre should have a **minimum of 70% Registry uptake**, to ensure that submitted data represent the cases seen as realistically as possible.

This information pack is available on the BTS ILD Registry website and the main BTS website, and the recording of the event and the slide set used on the day are also available. Please do circulate this to any of your colleagues who would be interested.

This document covers four areas:

The New NHSE ILD Quality Dashboard Items

This is a brief description of each item. For full definitions please click here (this redirects you to another part of this document).

Items listed in black are those which are collated directly through the UK IPF Registry.

Items listed in red are those which are collated outside the UK IPF Registry.

Item	Measure	Brief definition
1	**IPF referrals discussed at ILD MDT**	Percentage of new IPF referrals discussed at ILD MDT within 2 months of first assessment in the specialised service.
2	**IPF patients offered or received ILD Specialist Nurse input**	Percentage of new IPF referrals who were offered or received ILD Specialist Nurse input within 2 weeks of their first attendance in the service.
3	**IPF patients assessed for pulmonary rehabilitation needs**	Percentage of new patients with IPF assessed for pulmonary rehabilitation needs.
4	**IPF patients assessed for their palliative care needs**	Percentage of new patients with IPF assessed for palliative care needs.
5	**IPF Referral Waiting Times**	Average wait, in weeks, for new IPF referrals to be seen in the specialist ILD clinic from the date the referral letter was received at the centre.
6	**IPF patients assessed for their oxygen needs.**	Percentage of new patients with IPF who have had their oxygen needs assessed (both long term and ambulatory oxygen).
7	**UK IPF Registry completion**	Of those in the denominator, the number of patients whose clinical information dataset has been included in the UK IPF Registry.
8	**New incident IPF cases**	The number of new IPF cases which came to clinic in the reporting period.
9	**Clinical trial activity**	Have you actively recruited patients to an ILD clinical trial in the last 6 months? Yes/No (answered once per site, not per patient).

Collating items 1 to 6 through the UK IPF Registry

Each of the first six Quality Dashboard items relate directly to six specific questions in the UK IPF Registry dataset. These questions will be indicated clearly in the Registry site (labelled as *NHSE Quality Dashboard Item 1*, etc.) and will eventually be marked as such on the downloadable data collection sheets (available in the Document Library section of the Registry website).

The Registry site contains a section called *Statistics/Reports*, directly accessible from the front page of the UK IPF Registry. Within this section are a number of reports that all Registry users may access. Each user would only see reports relating to their own site.

One of these reports is the *NHSE ILD Quality Dashboard Data Report*. This report is a simple text report (with no charts included) which clearly states the items the user's site would include in their Quality Dashboard submission to NHSE (or in local reporting, which would be useful for English DGHs and for centres in devolved nations).

Important information about the report:

- The report includes data from all relevant patient demographic records, but only includes data from **committed clinical information records**. When a clinical information record is completed users are able to 'lock' the record by committing it – details of this are included in the Registry user guide documents.
- To open the report users must select the first and last dates they want the report to cover. Users may select any dates, making the report versatile for any local management/ benchmarking. Each downloaded report clearly indicates these 'dates from and to'.
- The cases included in the report are those where the recorded date of first clinic visit – as entered by the Registry user – falls within the dates from and to (inclusive). It is not based on the dates records are entered or committed on the site.
- Users may enter data both prospectively and retrospectively. This means that the exact figures included in a report will change slightly if more records are entered covering the period chosen. To prevent confusion, every report includes the date the report was run/downloaded in the footer.

Specialist centres in England can enter the figures included in this report into their NHSE ILD Quality Dashboard return. The figures will be entered exactly as they appear in the report; no calculations are required.

NHSE ILD Quality Dashboard items – Full Descriptions and Definitions

These are the full listed definitions for each Dashboard item. Please do let us know if you would like anything clarified, we want to make sure sites have all the information they need. Please contact us at registry@brit-thoracic.org.uk

Item 1 – IPF referrals discussed at ILD MDT
Percentage of new IPF referrals discussed at ILD MDT within 2 months of first assessment in the specialised service. **Numerator** Number of new IPF referrals discussed at ILD MDT within 2 months of first assessment and on the Registry **Denominator** Total number of new IPF referrals seen and on the Registry.
A definition of what constitutes an MDT*:* *In this context an MDT is a structured interaction incorporating the input of a number of different ILD specialists with the aim of making the most accurate ILD diagnosis possible. As a minimum it should include respiratory ILD physicians and a thoracic radiologist. It should also include a thoracic pathologist if tissue biopsies are available for review. The MDT panel could also include an ILD nurse, a physiotherapist, palliative care team members, etc.* ***New IPF referrals means**: a case of ILD, referred to a specialist service, where that service makes or confirms a diagnosis of IPF. That patient may already have had a diagnosis of IPF made by the referring/local/non prescribing centre but they are new to specialist centre, within reporting period, and it is expected that their case will go through an ILD MDT process at the specialist centre as this is a NICE standard of care item. The diagnosis of IPF itself does not need to be' new' to the patient - it is that they are new to the specialist service.* **Note:** To remind all data for all items will be affected by the number that consent to inclusion in the Registry but with a minimum of 70% Registry uptake expected will give a reasonable representation of overall standards.

Item 2 – IPF patients offered or received ILD Specialist Nurse input
Percentage of new IPF referrals who were offered or received ILD Specialist Nurse input within 2 weeks of their first attendance in the service. **Numerator** The number of new patients with IPF who have interacted with or been offered interaction with an ILD Specialist Nurse within 2 weeks of their first attendance in the service and on the Registry. **Denominator** Total number of new IPF referrals seen and on the Registry.
The definition of ILD specialist nurse: People with idiopathic pulmonary fibrosis should have an interstitial lung disease specialist nurse available to them. This nurse can ensure that people with idiopathic pulmonary fibrosis, and their families and carers, receive the information and support they need throughout the care pathway. This includes information about investigations, diagnosis, treatment, management of symptoms and support groups that may be available. Staff should also provide information and signpost patients to relevant lung charities. These organisations can

provide peer support, further useful information and details of wider support networks/groups for patients and carers. This specialist nurse should also be able to sensitively discuss prognosis, disease severity and progression and life expectancy. Some people with idiopathic pulmonary fibrosis may have an interstitial lung disease specialist nurse who is located a considerable distance from them, because of the specialist nature of these nurses' role. To ensure equality of access to care, measures should be put in place to support access to interstitial lung disease specialist nurses, for example by providing telephone and email contact details if needed. It should be noted that the ILD specialist nurse will also provide care as outlined above for patients with any form of ILD (not just patients with IPF) in the care of their service.

A definition of interacted with or been offered interaction with:
In short this means either a face to face interaction or other communication (telephone, video call, etc.) is offered within two weeks of the first clinic visit.

Ideally all patients with IPF should be offered a face to face interaction with an ILD specialist nurse usually in an outpatient setting. This interaction should be made available to patients as soon as possible after an IPF diagnosis has been given or confirmed by the specialist centre so support is available as early as possible in the patient's journey. However this may not always be possible for various reasons including patient choice and/or busy services or service structure e.g. ILD specialist nurses are not available to work alongside medical staff giving diagnosis information in clinics with 'open' or 'as needed' clinic slots. Where the offer of a same day interaction with an ILD specialist nurse is not possible contact by an appropriate means agreed between nurse and patient should be offered.

This first contact should be offered to occur within 2 weeks of diagnosis to reduce patient anxiety as much as possible. Planned nurse contact agreed with the patient must be booked into an appointment system for this standard to be achieved. If the appointment subsequently does not occur within 2 weeks for e.g. because patient cancels and re books after the 2-week period has expired the original standard was still met for the purposes of data collection. The issue here is that the specialist service has systems and staffing in place to achieve a 2 week specialist nurse review where the patient wishes for that to occur. This achieves the intended standard.

Item 3 – IPF patients assessed for pulmonary rehabilitation needs

Percentage of new patients with IPF assessed for pulmonary rehabilitation (PR) needs.

Numerator
The number of new patients with IPF who have been assessed for PR needs and on the Registry.

Denominator
Total number of new IPF referrals seen and on the Registry.

The definition for 'an assessment for pulmonary rehabilitation (PR) needs':
On the UK IPF Registry the question around PR is shown below:

At this clinic visit have you assessed if this patient is suitable to be referred to a pulmonary rehabilitation programme and referred them if appropriate? Answer options include:

1) Yes assessed and referred
2) Yes assessed – patient declined
3) Yes assessed but patient completed in last 12 months
4) Yes assessed patient not suitable
5) No – not assessed
6) Not known

If 1, 2, 3 or 4 has been answered as 'YES' appropriate PR assessment has occurred. The sum of points 1,2,3

and 4 is called "Percentage of new IPF patients assessed for pulmonary rehabilitation needs" and will be provided to centres in their data summaries.

Guidance on how a pulmonary rehabilitation programme should be delivered can be found in the BTS Pulmonary Rehabilitation Guideline available at https://www.brit-thoracic.org.uk/quality-improvement/guidelines/

Item 4 – IPF patients assessed for their palliative care needs

Percentage of new patients with IPF assessed for palliative care needs.

Numerator
The number of new patients with IPF who have been assessed for palliative care needs and on the Registry.

Denominator
Total number of new IPF referrals seen and on the Registry.

The definition for 'assessment for palliative care needs':
Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness by prevention and relief of suffering by means of early identification and impeccable assessment and treatment of breathlessness, pain and other problems, physical, psychosocial and spiritual. It is applicable at any stage of a patient's illness (even early on) and can include investigations needed to better understand and manage distressing clinical complications.

If a palliative care needs assessment as outlined above has been conducted by the team at the specialist centre then an answer 'yes' to the UK IPF Registry palliative care question can be selected. This assessment may be conducted by the medical team or the ILD specialist nurse. Selecting a 'yes' after the assessment has been carried out does not mean that any new treatments or onward referrals e.g. to palliative care or to other services have been made. A patient may be found to have no new needs after assessment. However, if 'yes' is selected after the assessment and new treatments e.g. drugs for breathlessness, palliative care referrals, or provision of palliative oxygen are required it is expected that whatever is needed for future care will be organised at that point. So 'yes' means nil new needed or input needed and has been arranged.

Further information can be found at: https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/

Item 5 – Referral Waiting Times

Average wait, in weeks, for new IPF referrals to be seen in the specialist ILD clinic from the date the referral letter was received at the centre.

This number is calculated automatically from the UK IPF Registry dataset and can be submitted to the NHSE dashboard.

Due to the cancer-like outcomes of IPF, **patients should be seen within 8 weeks of referral**. Centres not achieving this standard should assess their service to establish why the wait is longer than this standard. ILD services should work with their Trusts to move towards achieving the standard. It is known that many centres will not initially reach this standard often due to staffing resource. However, other factors of service efficiency may also play a part.

Item 6 – IPF patients assessed for their oxygen needs.

Percentage of new patients with IPF who have had their oxygen needs assessed (both long term and ambulatory oxygen)

Numerator
The number of new patients with IPF who have had their oxygen needs assessed and managed and on the Registry.

Denominator
Total number of new IPF referrals seen and on the Registry.

The definition for 'an assessment of oxygen needs ':
All new patients with IPF when first seen by a specialist ILD service should have an assessment of both their long term and ambulatory oxygen needs. Any oxygen interventions required should be arranged from that first appointment. This may include referring the patient back to their local teams to deliver further oxygen assessments and set ups. Ideally oxygen needs should also be assessed at any subsequent follow up visits. Further information on how to conduct these assessments can be found in the BTS Guidelines for Home Oxygen Use in Adults (https://www.brit-thoracic.org.uk/quality-improvement/guidelines/home-oxygen/).

In the UK IPF Registry the question around oxygen assessment and onward management is:

Have you assessed the oxygen needs of this patient at this clinic visit?
1. Yes – assessed and referred (or already on oxygen)
2. Yes – assessed but patient DOES NOT REQUIRE oxygen therapy at this time
3. Yes – assessed but PATIENT DECLINED (does not wish it, etc.)
4. Yes – assessed but NOT SUITABLE (e.g. home environment unsafe for oxygen use)
5. No – not assessed
6. Not known

If you have ticked 1, 2, 3 or 4 you have achieved the standard of assessing oxygen needs and arranging onward referral where needed. The sum of points 1,2,3 & 4 is called "Percentage of new patients with IPF assessed for oxygen needs" and is provided to centres in their data summaries.

Item 7 – UK IPF Registry completion (collected outside the Registry)

Of those in the denominator, the percentage of patients whose clinical information dataset has been included in the UK IPF Registry.

Numerator
Number of new IPF referrals with the clinical information dataset included in the UK IPF Registry.

Denominator
The number of new IPF cases which came to clinic in the reporting period.

Centres would be asked to calculate the percentage using the following figures:

1. Number of all new patients with IPF **seen** at centre for reporting period of 6 months.
2. Number of new patients with IPF with the clinical information dataset **entered** to the Registry for reporting period of 6 months.

Example: Centre sees 100 new patients with IPF in the 6 month period.
85 of the 100 seen have clinical information dataset entered onto the Registry.
Therefore 85% is the UK IPF Registry completion rate

A minimum of 70% of all new patients in the IPF caseload over a 6 month period should have their clinical information entered into the UK IPF Registry to hit the minimum standard.

The definition for 'clinical information dataset included in the UK IPF Registry':
For a patient to be considered as included in the UK IPF Registry the following steps must have been taken:

1. Patient consent must have been obtained (either wet ink or typed/scanned).
2. The short patient demographic dataset must have been completed online (to create a Registry record for that patient).
3. The clinical information dataset must have been completed online, and the record must have been **committed** (by this we mean the extra step taken through the site to confirm/lock the clinical information record).

Item 8 – New incident IPF cases (collected outside the Registry)

The number of new IPF referrals seen at centre for the reporting period of 6 months.

Item 9 – Clinical trial activity (collected outside the Registry)

Have you recruited patients to an ILD clinical trial in the last 6 months? Yes/No.

Simple yes/no question to assess if the specialist centre has actively recruited patients into clinical trials in field of ILD in the 12 month reporting period It is important that ILD Specialist centres strive towards offering access to clinical trials in the field of ILD to patients. Clinical trials offer patients access to a wider landscape of potential therapies in a field which is rapidly evolving.

Questions and Answers

The questions listed here were asked during the virtual event held on 15th September 2021. We anticipate more questions will be submitted over the coming months, and we want to make sure any extra information/clarifications are clearly made and available to all.

If you have any questions which are not currently covered in this document please email us at registry@brit-thoracic.org.uk

Questions related to the NHSE ILD Quality Dashboard

Q. I appreciate the NICE guidance suggests review with CNS as soon as possible. At our centre, patients see CNS and pharmacist. Could we/should we include pharmacy review?

For the purpose of Item 2 – IPF patients offered or received ILD Specialist Nurse input *and the dataset question relating to it we would only be considering Specialist Nurse input. However, we fully recognise the importance of pharmacy input and are very grateful for you highlighting this.*

When the Registry was started back in 2013 there were no ILD specialist pharmacists, and now we still only have a handful of these. We completely take on board your point, however. We fully recognise the importance of the pharmacist in the ILD services.

The NICE Quality Standard document does not specify pharmacy input either; again due to the history of the field. You have raised a very relevant point, and the BTS ILD Registry Steering Group going forward can consider if any amendments should be made in the future either to any Registry questions or the information supporting them. We cannot substitute a pharmacy visit for an ILD nurse visit because the two roles are slightly different – not that you had asked for that but just to note. At your centre I think you say patients see both. There has been no intent to leave our pharmacists out in any way here, and we welcome you raising this very important point.

Q. Is there a way of making the centres aware of ongoing clinical trials to help them improve enrolling onto trials?

Yes. It's something the Registry can do but has only rarely done, so we need to promote this actively to maximise the benefit to patients.

BTS does not hold a list of active trials; however, researchers running trials may contact BTS to request their information be passed on to all Registry users. This could either be in the form of a general message sent to all Registry users or, more specifically, a message sent to Registry users whose site includes patients who may be suitable for participation in the trial concerned.

For example, if a trial was focused on patients with IPF under the age of 40 who had received a specific drug and whose lung function fell within a specific range, BTS would be able to pass a message onto sites with suitable patients (and could even highlight which patients may be suitable, using their anonymous Patient IDs).

Through this process the only contact would be from BTS to Registry users/Registry Leads. BTS would not pass the list of Registry users to any third parties. In addition, patients would never be

directly contacted by BTS or researchers. The treating clinicians are the only ones who are able to identify and contact patients.

Additionally, in every region ideally the ILD network regional meetings should be taking place, where hubs running trials could share clinical trials information across regions though this network as well.

Q. What pressures will NHSE apply on trusts for outliers?

The intention is for any response from NHSE to be supportive rather than punitive. If a site is underperforming then there will be one or more causes contributing to that, and the role of NHSE is to support the service to improve performance.

Local teams would initially have a role in investigating the causes of low recorded performance. If local review does not improve performance then more formal peer review/flying visits can be initiated.

The intention of these reviews would be to identify why the service is not able to deliver and what additional support is required. Therefore we would expect that the Trust in question might be asked, for example, why staff had not been recruited to specific roles, etc. (if staffing was suspected to be an issue). The importance of appropriate resourcing for the service may be highlighted where appropriate..

Q. How does the IPF referrals discussed at ILD MDT 'to occur within 2 months from first assessment' fit with new IPF referrals seen in 8 weeks? Does the IPF referral waiting time actually mean suspected IPF, as presumably MDT required to confirm?

*Practically speaking, yes. Referrals would typically be for suspected IPF, with initial tests, a clinic visit and full ILD MDT expected to take place at the specialist centre. The inclusion criteria for the UK IPF Registry state a '*definite or strongly suspected diagnosis of IPF' *as a requirement, so we would expect patients suspected to have IPF but found not to have it not to be included in the Registry.*

The target of eight weeks for referral is to recognise the cancer-like outcomes of IPF and to make sure patients suspected to have IPF are seen and assessed at specialist centres rapidly.

We are also aware that different specialist centres take different approaches to managing referrals, and that while some centres hold the MDT before the first clinic visit there are also centres which routinely hold the MDT shortly after the first clinic visit.

We want both the first clinic visit and the full MDT to be held rapidly, and we don't want to discriminate against centres that hold the MDT after the first clinic visit. That's why the MDT timeframe includes all MDTs held within two months of the first assessment.

If we did not set a time frame around the MDT date, centres could see patients quickly then delay their MDT. This could mean treatment would be delayed, defeating the object of getting them seem in a timely manner. We understand it does seem odd, but it is to allow for the way different centres operate regarding the timing of their MDT.

*You will have seen in the section about the NHSE ILD Quality Dashboard report that the report includes MDT data from committed (i.e. locked) clinical information records only. When a report is committed it can be unlocked by BTS staff so that centres can update information about the MDT status – all the Registry user needs to do is open the clinical information/diagnosis page for the patient and select '*Send request to site administrators to uncommit this submission'* *at the top of the page.*

Q. How would we determine whether 'offered nurse input, O2 assessment, palliative care, PR' was considered to be adequate? For example, for a patient with very mild disease some of these may not be relevant. How would/should we record 'palliative needs assessed' in a letter about a patient with very mild IPF?

The detailed definitions for these items are included here, and the simple answer is that it would vary on a case-by-case basis.

For example, if a patient is experiencing breathlessness a full assessment to identify what kind of oxygen they may require and when would be appropriate.

However, for patients with very mild disease a much less formal assessment would be more than adequate. For example, if a patient walks briskly across the hospital to attend the clinic and neither exhibits nor reports breathlessness, then the clinician would be able to use that information (along with any other information available) to make an informed professional assessment that additional oxygen therapy would not be required at that time.

If the clinician has done the relevant assessments and any onward referrals that are required (or decided nil is needed) then the assessment has been done. It is not what is received that is being measured here it is that the appropriate assessments have been done. We cannot measure the outcomes easily as some patients for example will decline PR, but that doesn't mean it was not offered. We rely on the honesty and integrity of medical teams to tick right answers to questions on the forms.

Q. Will the item relating to palliative care needs only apply to certain patients with end of life care, rather than all patients with IPF on initial visits?

The item relating to palliative care needs will relate to all patients, regardless of disease severity or how recently they have presented to the service. The purpose of this dashboard item is not simply to record palliative care assessments, but also to ensure that palliative care as a holistic approach is considered as soon as the patient is diagnosed.

We define the palliative care item in the full definitions section. In short, by palliative care we mean symptom management to improve quality of life. So a patient's needs relating to breathlessness, pain, depression/anxiety or spiritual considerations should all be part of the conversation from the first clinic visit.

Palliative care needs or symptom control should ideally be part of the review of every IPF and indeed every ILD patient going through ILD services, whether new or follow up patients. The Registry also has an annual follow up form that is available, and palliative assessments are included in a recurring question there too.

Other questions related to the BTS ILD Registry

Q. How can we access raw national data (from the whole of the UK) for the purpose of research?

Through the BTS Data Access Request Process.

Researchers considering using BTS data for the use of research (from our Lung Disease Registry, Clinical Audit Programme or MDR-TB Clinical Advice Service) may apply to access anonymised data items by completing a Data Access Request Form. Applications are reviewed by the BTS Information Governance Committee.

There is a fee for successful applications only, which is £2,000 +VAT for non-commercial organisations, reduced to £1,000 +VAT if the organisation has entered information into the dataset.

This fee is per dataset, so successful applicants would pay the fee once to access UK IPF Registry dataset data, but would pay the fee twice if they were access both UK IPF Registry and UK Sarcoidosis Registry data.

More information is included in our Data Access Policy (available at the link above). If you have any further questions please do email either registry@brit-thoracic.org.uk or bts@brit-thoracic.org.uk

Q. Is there funding attached for engagement with the Registry? Many of our centres are stretched even before COVID and this is difficult to prioritise for our managers if engagement is voluntary.

There is currently no funding attached to engagement with the Registry. This is something we're very conscious of, because we know how tight resources are.

The Registry is, in itself, not eligible for inclusion in the NIHR portfolio. However, if an eligible study were to take place using all Registry data then it would be possible to obtain extra resource through this route (if you or your colleagues would like to use Registry data in this way please consider our Data Access Request Process, outlined in the answer to the question above).

Some sites in the Registry will have financial support for completing the Registry over the next few years; those involved in a randomised clinical trial called 'Treating idiopathic Pulmonary Fibrosis with the Addition of Lansoprazole (TIPAL)'. This study is being run by the Norwich Clinical Trials Unit and is financed by the National Institute of Health Research (NIHR). It involves directly capturing lung function and other relevant data from the UK IPF Registry for patients participating in the trial. This study is open for recruitment from all sites working with the registry. More information is available from tipal@uea.ac.uk

We anticipate that the necessity of submitting NHSE ILD Quality Dashboard Data will at least provide English specialist centres with a strong case for requesting additional support from their trust.

Should any additional funding become available in the future we would contact all participating sites immediately to make the aware of this.

Additionally, the Registry does offer useful outputs for users. Data for service management and benchmarking can be shared with your trust management or completed as supervised projects, for trainees for example.

Q. Will there be linkage to GP data (CPRD) or HES data?

Not at this time. However, approvals and consents are in place specifically regarding the use of ONS data (or similar) whereby this option is open to being explored when time, resource and technology allow. We recognise the increasing importance of data linkage, and we hope to address this in the future.

Q. Can the consent form be completed electronically?

Yes. In October 2020 we receive approval to modify the consent process to allow for remote consent in line with the 2018 MHRA/HRA Guidance on the Use of Electronic Consent.

Using the standard consent forms, patients may return their form to your clinic electronically. Consent will therefore be considered valid if patients:

- *Email the clinic an electronic copy of a signed form (scanned, photographed, etc.)*
- *Email the clinic a form with a their signature typed in*

We have prepared a template letter which you can use when sending forms to patients either by post or by email. This template is available at:

www.brit-thoracic.org.uk/media/455289/cover-letter-template-for-participating-sites-v1-280920.docx

Q. Is there a central facility to record if a patient has declined to consent to the UK IPF Registry? We don't have many but there are a few.

There is no central facility for recording this, but sites could keep their own record locally (both to have a good idea of what proportion of patients decline and also to prevent repeatedly asking a patient who has already declined to take part).

Anecdotal evidence from participating sites is that very few patients decline involvement, although it would be useful to have a national perspective on this.