Fit for the future: Future-proofing care for patients with IPF

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Future-proofing care for patients with IPF: Executive summary

• Idiopathic pulmonary fibrosis (IPF) is a devastating, terminal lung condition which is known to affect at least 15,000 patients in the UK\(^1\). Recent estimates have suggested that the true scale of IPF in the UK may be more than double this figure\(^2\).

• IPF patients require access to a complex variety of services to provide the best treatment and supportive care across primary, secondary and specialist care settings\(^3\).

• Patients tell us that there are variations in the standard of IPF care that they receive, such as diagnosis from a multi-disciplinary team\(^4\). As a condition that cuts across many NHS priorities, the experience of IPF patients is a measurement of broader NHS success.

Report findings

This report finds a number of challenges to delivering better care for patients with IPF, now and in the future:

• **The rising number of patients with IPF**
  – Incidence of IPF is rising rapidly, with a 35 per cent increase in diagnosed cases between 2000 and 2008\(^1\).

• **An increasingly ageing population**
  – One in five people are expected to be over the age of 65 by 2035\(^5\). Pressure on IPF services, as a condition which predominantly affects the older adult population, is likely to grow alongside the rate of ageing.

• **Challenges in delivering sustainable specialised services for uncommon conditions**
  – Whilst some patients already receive excellent IPF care, variations in access to high-quality care, such as diagnosis from a multi-disciplinary team, persist\(^4\).

• **Difficulties in delivering effective preventative strategies without essential, accurate and definitive data**
  – Now a new approach to data gathering is required so that the real number of patients with IPF may be better understood, to plan the strategies needed to slow and minimise the impact of IPF on patients and their families.
Future-proofing care for patients with IPF: Executive summary continued

These findings have exposed substantial uncertainty about the true number of patients living with IPF in the UK, and raise questions about the ability of the NHS to provide care for these patients now and in the future without improvements in the quality of available data.

In this report, Action for Pulmonary Fibrosis detail the challenges associated with ensuring there is provision of consistent, high-quality care and support for people living with IPF and propose an immediate intervention to address this data and knowledge gap.

Action for Pulmonary Fibrosis call to action

In order to plan the optimum services for patients with IPF, we need to have more accurate information about the incidence and prevalence of this terminal lung disease.

It is vital that the NHS knows the number of patients suffering from IPF. We ask NHS England to introduce the mandatory collection of data relating to the number of people diagnosed with IPF by a multi-disciplinary team (MDT). Through a better understanding of the true scale of IPF, the NHS can ensure that it makes best use of its resources to provide high-quality care both now and in the future.
Future-proofing care for patients with IPF

Idiopathic pulmonary fibrosis (IPF) is a devastating, terminal lung condition. Published research estimates that there are 15,000 people living with the disease in the UK, but it is possible that the true number is more than double this figure.

This relatively uncommon condition is complex, and difficult to diagnose. As such, patients rely on swift identification in primary care, rapid referral to a specialist multidisciplinary team who can confirm diagnosis, early access to treatments, and support that can slow the progression of the disease or help patients better manage their symptoms.

What is IPF?

- In IPF, scar tissue builds up around the small air sacs (alveoli) in the lungs, which impairs the function of the lungs to transfer oxygen into the body. This leads to shortness of breath that worsens as the disease progresses, and ultimately ends in respiratory failure.
- Each year 5,000 people die from the disease in the UK, and the average life expectancy after diagnosis is around three years. Just one in five patients with IPF survive more than five years from diagnosis.
- IPF patients have a poor prognosis, and the number of people living with the disease is rising.

While patients with IPF need ongoing coordination of care by a specialist nurse and access to expert assessments in a specialised centre, much of their care takes place in the community, with pulmonary rehabilitation, oxygen therapy and palliative and supportive care provided by local services. IPF patients therefore need access to a complex breadth and depth of services: requiring access to treatment, care and support across primary, secondary and specialist care settings. Despite drives to establish more effective, networked pathways, within this complicated environment there is a risk that variations in access to quality care will persist.

With current pressures on the entire health service building, including budget constraints, an ageing population, and an increasing need for a preventative approach, several challenges could further affect the ability of the NHS to provide high-quality care to IPF patients.

In order to plan services for patients with IPF, we need to have more accurate information about the incidence and prevalence of this terminal lung disease, taking best practice from other complex conditions to ensure we understand and address the needs of these patients.
This report highlights:

**Current variations** in the standard of IPF care, demonstrating the impact discrepancies can have on patients.

**IPF as a 'litmus test' for the NHS**, as it is a condition that cuts across many NHS priorities, with the experience of IPF patients a measurement of broader NHS success.

**Lessons can also be learned** from successes in the way IPF care is delivered to reduce variation not only in IPF patient outcomes, but also for patients with other similar conditions.

**The importance of implementing the NICE Quality Standard on IPF care**, and maintaining momentum for implementing the updated ILD service specification.

**The need for improved data collection to establish the true number of IPF patients**, calling for the mandatory collection of data relating to the number of people diagnosed with IPF by a multi-disciplinary team (MDT).

This report provides recommendations for local, regional and national services to address these issues now, to ensure that IPF care is fit for the future, and that no IPF patient suffers as a result of being denied life-enhancing support. We will encourage every parliamentarian and policymaker with an interest in IPF care to help us implement these recommendations as quickly and effectively as possible.

**Action for Pulmonary Fibrosis:**
**The voice of the patient since 2013**

Action for Pulmonary Fibrosis is driven by the interests of IPF patients and we are proud of our reputation as the ‘voice of the patient’. Our objectives are set as a direct result of what we learn from our expanding support group network and the daily contact we have with patients.

APF continues to work with IPF patients, the NHS, policy makers and parliamentarians to ensure that the voice of IPF patients is heard in the planning and delivery of IPF care. This report is our latest nationwide initiative in listening, learning and taking action from what patients tell us. In this way we aim to ensure that everyone living with IPF has a better future.
The ideal IPF patient journey

Several guidelines exist which outline the care which patients with IPF in England should receive:

- The NICE quality standard on IPF\(^1\)
- NICE Technical Appraisals for anti-fibrotic treatments\(^{13,14}\)
- NICE IPF diagnosis and management clinical guideline\(^8\)
- The interstitial lung disease (ILD) service specification\(^3\)

Many IPF patients receive excellent care from dedicated staff in specialist and non-specialist hospitals in line with these guidelines. Action for Pulmonary Fibrosis’ 2015 patient survey captured many of these positive experiences of the care and support\(^\text{15}\). All qualitative quotations in this report are taken verbatim from the results of this survey\(^\text{16}\).
NICE guidelines and the NHS England service specification for ILD services set out the stages and standard of care that patients with IPF can expect, to live as long and active a life as possible. The British Thoracic Society Registry collects data on how closely these standards are being met\(^7\).

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<tr>
<th>What is needed?(^8)</th>
<th>Why is this important to patients?</th>
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<tr>
<td><strong>Accurate diagnosis</strong></td>
<td>• As IPF is a terminal condition, it is vital that patients have access to treatment and support as early as possible to slow the progression of the disease.</td>
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<td>• As IPF is difficult to diagnose, a specialist multidisciplinary team must confirm diagnosis</td>
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<td>• Where IPF is suspected, primary care and secondary care professionals should refer a patient they suspect of having IPF to a specialist centre as quickly as possible</td>
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<td>• Specialist centres should lead a network of the teams to educate teams in primary and secondary care how to identify IPF early and how to refer as quickly as possible</td>
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<td><strong>Access to a specialist nurse</strong></td>
<td>• Accurate and early diagnosis can reduce the emotional burden of uncertainty(^3)</td>
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<td>• Patients should have access to a specialist nurse, to provide the information and support that patients and their families need</td>
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<td>• Specialist nurses act as a central point of contact for the coordination of care – whether provided locally or in a specialist centre</td>
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<td><strong>Access to information about treatment</strong></td>
<td>• Patients need to make informed decisions about the treatment and management of their condition</td>
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<td>• As a terminal condition, and with only 3 per cent of patients globally receiving a lung transplant(^17), it is vital that patients are supported to consider the right treatment options available as early as possible to slow disease progression</td>
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<td>• Patients should be assessed as early as possible to evaluate their suitability for anti-fibrotic treatment (based upon their lung function tests)</td>
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<td><strong>Assessment for pulmonary rehabilitation</strong></td>
<td>• Anti-fibrotic treatments have the potential to slow disease progression so can offer patients hope following a diagnosis of IPF(^17)</td>
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<td>• Following diagnosis, IPF patients should be assessed for pulmonary rehabilitation (PR), a training programme that provides education, physical training and breathlessness management</td>
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<td>• This programme should be tailored to the specific needs of patients with IPF</td>
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<tr>
<td><strong>Assessment for oxygen therapy</strong></td>
<td>• With time precious for IPF patients it is vital they have access to the information they need to understand the treatment options available to them</td>
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<td>• Patients with IPF should be assessed regularly for oxygen therapy, which can relieve symptoms of breathlessness and help to improve their mobility</td>
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<td>• This should happen at diagnosis and each time a patient with IPF attends follow-up appointment</td>
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<td>• Oxygen therapy can help patients feel they are living a ‘normal life’(^1)</td>
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<td>• For patients who are usually too unwell to take part in PR, oxygen therapy can make them well enough to complete a course(^2)</td>
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<td>• Oxygen therapy can help with symptom control(^2)</td>
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<td><strong>Access to palliative support</strong></td>
<td>• PR is likely to contribute to an improved quality of life for IPF patients(^12)</td>
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<td>• Patients with IPF should have their palliative and supportive care needs assessed throughout their care</td>
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<td>• There should be collaboration between all of the healthcare professionals involved in the person’s care, in line with best practice</td>
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<td>• Regrettably, the average life expectancy after an IPF diagnosis is around three years(^1)</td>
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<td>• Patients with IPF, their carers and their families should be supported through difficult times to ensure that patients with IPF receive the life-enhancing support they need</td>
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The challenges facing IPF patients – now and in the future

Whilst many IPF patients experience excellent care, there are challenges associated with each stage of the ideal patient pathway, and barriers to all IPF patients receiving good care. Patients tell us that this has a significant impact on their experience of care, and access to the support they need.

- **Diagnosis**: A lack of awareness of IPF, or knowledge about the symptoms, can lead to delayed identification in primary or secondary care, and confirmed diagnosis by an expert multidisciplinary team.

- **Access to a specialist nurse**: Patients may not be able to access their nurse when they need them, and the nurse may not be able to coordinate their care effectively. Half of the hospitals asked may not have enough staff to support all IPF patients.

- **Access to information about treatment**: Patients without access to a specialist nurse may not have access to information to make informed decisions about their treatment.

- **Assessment for pulmonary rehabilitation**: PR programmes are not always tailored to IPF and patients may not have access to local programmes.

- **Assessment for oxygen therapy**: IPF patients are not always assessed for oxygen therapy at diagnosis and subsequent follow-up appointments. This can prevent patients from being more mobile and accessing PR.

- **Access to palliative support**: Patients with IPF, and their carers, may be reaching the end stages of the disease with no support from professionals. There are variations in the closeness of relationships between centres and palliative services.

47% of IPF patients experience breathlessness for at least two years before being diagnosed, and many don’t receive their initial diagnosis from an expert MDT.

Almost 1/3 patients don’t have access to specialist nurse.

Around 50% of eligible patients receive anti-fibrotic treatment.

Just four in ten patients who have taken a course of PR have their course tailored to their IPF. Less than half have taken part in a PR programme at all.

Oxygen assessment takes place in less than three quarters of follow-up.

95% of IPF patients were not referred to palliative care services.

“When I was first diagnosed I was told to look [IPF] up on the internet”

“Nobody has taken ownership of my condition”

“The treatment that I am on has helped me tremendously in keeping my condition on a level playing field”

“I had to fight to get pulmonary rehab”

“Sadly, I had to miss some lung rehabilitation sessions because of being unwell.”

“I am left with a death sentence”

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Patients tell us that variations in care currently exist – both in the quality of care they receive and in access to the services and support outlined in the NICE Quality Standard. However, we do also know that excellence exists – patients have told us of the impact that rapid, early access to expert care and ongoing information and support can have on their lives\textsuperscript{16}. The reasons for these discrepancies could be varied including patient demand exceeding service capacity and insufficient workforce capacity and training.

However, whatever the reasons, what we do know is that there is a risk these variations will only worsen.

**At present**

There are 15,000 people in the UK with IPF\textsuperscript{1} with other estimates placing this figure far higher.

There are over 5,000 IPF patients are diagnosed every year\textsuperscript{1}.

There are over 15,000 hospital admissions for IPF each year in England alone\textsuperscript{18}.

There are over £16.2m in hospital admissions for IPF in England each year\textsuperscript{18}.

While the causes remain unknown, the incidence of IPF is rising rapidly, with a 35 per cent increase in diagnosed cases between 2000 and 2008\textsuperscript{8}. If the incidence continues to rise in this way, so too will the pressures on the system. Recent estimates suggest that there may be twice as many people living with IPF in the UK as previously thought\textsuperscript{2}.

**The potential future burden of IPF**

By the same measure, if length of survival remains the same, almost double the number of people could be living with IPF by 2020 – over 27,000 patients\textsuperscript{*}.

If cases of IPF continue to rise by the rate observed in previous studies, by 2020 we can expect around double the number of people to have IPF – an estimated annual figure of 9,000 patients\textsuperscript{†}.

It is estimated that by 2020, there will be 20,000 hospital admissions each year in England alone\textsuperscript{19}.

IPF admissions are expected to cost the NHS England over £20m by 2020\textsuperscript{19}.

\* Current prevalence is 5,000 patients diagnosed each year, multiplied by the duration of the disease (three years). Assumes that if duration of the disease remains the same and incidence is 9,113 by 2035, the prevalence in 2035 will be 27,338 (9,113 multiplied by three years).

\† Assumes that incidence will continue to rise by 35 per cent every eight years from 2011, as observed at: [http://thorax.bmj.com/content/66/6/462.full.pdf+html](http://thorax.bmj.com/content/66/6/462.full.pdf+html)
Why is this important for IPF patients?

This potential steep rise in the number of patients living with IPF makes it ever more important that current variations are reduced to ensure each patient with IPF receives the support they need and to maintain sustainable services. In the last four years, emergency hospital admissions for IPF related diagnoses have been steadily rising\(^1\) suggesting that numbers of patients are indeed rising and that people are not receiving the appropriate support, care and treatment they need to manage their conditions effectively in the community. Estimates suggest that this burden is already increasing and that previous patient number calculations have drastically underestimated the scale of the challenge\(^3\). The NHS has the responsibility to ensure that best practice is spread now, before pressures rise further and it becomes increasingly challenging to deliver effective patient-centred IPF care within the resources available.

What needs to happen to ensure all patients with IPF benefit?

- NHS England should work with NHS Digital to review current inpatient and outpatient coding for IPF patients to ensure that accurate patient numbers are recorded and used to plan services effectively

- Specialist centres should review their staffing and training levels in line with the most recent data relating to IPF patient numbers and admissions, to prevent future capacity gaps that impact on the quality of IPF care

Our call to action

In order to plan the appropriate care for IPF, we need to know the number of new diagnoses as well as the number of people living with IPF. NHS England should introduce the mandatory collection of data relating to the number of people diagnosed with IPF by a multi-disciplinary team (MDT)
The NHS is facing a number of different challenges that directly relate to IPF care, treatment and support. While steps must be taken to prevent a negative impact on the experience of IPF patients, the NHS also has an opportunity to take positive action, spreading the best practice that exists across all IPF care settings and championing these ‘new models of care’ to ensure every patient with IPF benefits, both now and in the future. In the process, the NHS can learn from excellence in IPF care, and disseminate these learnings across other similar services that are facing the same challenges.

AN INCREASINGLY AGEING POPULATION

Ongoing service pressures in the NHS are being acutely felt in 2016, due to a lack of trained staff, an increasing demand for efficiency initiatives and ongoing financial resource limitations, matched with a seemingly exponential growing patient demand. Yet these problems are only going to get worse with the NHS’s biggest crisis yet to come.

Since its inception, the NHS has had to face a range of challenges, but none more threatening than the rise in the ageing population. In 1945, almost 50 per cent of the population died before they were 65, now this has dropped to as low as 14 per cent. The demographic of the entire population, and the needs of patients, is expected to transform by 2035, when as many as one in five people are expected to be over 65. Estimates suggest that, due to the complex needs of an older population, this could raise the cost of the NHS by £106 billion a year – the equivalent of paying for a second NHS.

NHS England’s Five Year Forward View was grounded in the premise that “we live longer, with complex health issues”, with 70 per cent of the NHS budget already spent on long term conditions. As NHS England acknowledges, the service needs to shift from one of providing a “one-off cure” to one where patients are “informed and involved […] offering opportunities for better health through increased prevention and supported self-care” for the remainder their lives. This will involve transforming our system to one where barriers are broken down between hospital and primary care and between specialist and generalist support, ensuring that care is truly coordinated around the needs of the patient.
Why is this important for IPF patients?

IPF care should be closely monitored in the context of an ageing population as it is a condition which mostly affects the older adult population, with the average age of diagnosis 74 years¹ and the majority of inpatient care provided to older patients. With a growing ageing population and an increase in the prevalence of IPF more broadly, pressures on IPF services will grow, including needing to deal with the complications of supporting older people with multiple co-morbidities.

Services will also need to ensure patient-centred care is delivered given the additional risks associated with treating older patients including falls, pressure ulcers, and healthcare-acquired infections. The need to support patients to stay well for as long as possible, without the need for hospital admissions, will be even more urgent.

Many IPF services are already tackling these issues to deliver high quality care in line with the NICE Quality Standard. For example, virtual MDTs are recommended as an innovative way to diagnose IPF, and to deliver care closer to home, reducing the travel burden on patients and ensuring a timely diagnosis – regardless of the location of healthcare professionals. Many patients are already benefiting from such effective approaches, but these practices will need to become more widespread to ensure services are sustainable and able to meet the complex needs of an ageing population.

What needs to happen to ensure all patients with IPF benefit?

- Specialist centres should continue to drive the implementation of the NICE guidelines on IPF care to ensure consistent, patient-centred care is provided to all IPF patients despite their complex needs

- IPF best practice in terms of care models should be sourced by NHS England’s Clinical Reference Group for Specialised Respiratory in line with their service specification, and promoted through networks to reduce variations in care and improve sustainable models of delivery
DELIVERING HIGH QUALITY, SUSTAINABLE SPECIALISED SERVICES

NHS England is responsible for commissioning specialised services and reducing variation in the care of people with specialised conditions. This responsibility includes establishing a uniform, expert process for diagnosing, treating and managing rarer conditions which require specialist expertise for diagnosis and management. Specialised services are designated according to the following four principles:

- The number of individuals who require the service
- The cost of providing the service or facility
- The number of people able to provide the service or facility
- The financial implications for Clinical Commissioning Groups (CCGs) if they were required to arrange for provision of the service or facility themselves

Currently, specialised services account for approximately 14 per cent of total NHS spending, with an annual budget of £13.8 billion. Since its advent, controversy has surrounded these services after a £450 million overspend highlighted tensions between increasing financial pressures in the system and the continued imperative of developing accessible, centralised services that meet the needs of patients with less common conditions. NHS England continues to evolve this process, with the inclusion of new principles for decision making.

Why is this important for IPF patients?

IPF is a typical specialised service due to the comparatively rare and complex nature of the condition, and the small number of specialist healthcare professionals able to care for the condition appropriately. There are at least 15,000 IPF patients in the UK, and around 18 centres which specialise in IPF and other interstitial lung diseases. All of these specialist centres have MDTs which diagnose and offer treatment plans to patients with IPF, while ongoing support to manage the condition is offered locally by CCGs.

While we know that some patients are already receiving excellent IPF care, we also know that variations in access to quality care persist. For example, 30 per cent of IPF patients have to wait six months or more before referral to a specialist centre. Such discrepancies are seen in the expert care that IPF patients need, for which NHS England is responsible through specialised commissioning; including accurate and timely diagnosis, access to a nurse specialist, access to information about treatment and access to appropriate and frequent assessments for ongoing critical aspects of care. However, the quality of and access to care provided in local community settings such as oxygen therapy, pulmonary rehabilitation and palliative support are also varied.

To ensure that patient care becomes more consistent, NHS England needs to educate and communicate effectively with local service providers to support them to improve the co-ordination of IPF patients’ care. This will not only improve the future for patients with IPF, but will also ensure that the specialised commissioning model is a success, and that its success is measured in meaningful patient outcomes.
What should be done?

• The Department of Health should continue to drive the effective implementation of specialised commissioning to reduce variations in IPF care, and support NHS England to deliver against the new service specification for IPF, which is now in line with the NICE Quality Standard for IPF and informed by two years of learning.

• NHS England should establish processes within the Clinical Reference Group to evaluate services against the newly introduced NHS Outcomes Indicators outlined in the service specification to continue to drive improvements in IPF patient outcomes:
  – Preventing people from dying prematurely
  – Enhancing quality of life for people with long-term conditions
  – Helping people to recover from episodes of ill health or following injury
  – Ensuring people have a positive experience of care
  – Treating and caring for people in a safe environment and protecting them from avoidable harm

• Specialist centres should continue to spread best practice amongst their regional networks, educating their peers in primary and secondary care to ensure rapid and accurate referral and improve patient access to ongoing, coordinated care and support.
A PREVENTATIVE APPROACH USING DATA-DRIVEN STRATEGIES

Prevention is increasingly becoming a key weapon in the NHS’s fight to deliver improved outcomes and more efficient care\(^1\). However, for many conditions where the cause is unknown, focus on prevention must shift from stopping a condition’s occurrence to slowing and minimising the impact on the individual patient, their family and friends, NHS services and the NHS budget. This is a strategy being adopted by NHS England at scale within the *Five Year Forward View*\(^1\).

To achieve this shift in the context of increasing demand, and ongoing service pressures, we need to understand what works now, and how this can be applied to broader patient populations in the future. To deliver positive outcomes, there is an increasing call for measuring real world evidence to track what works in preventing rapid declines in patient outcomes, and the subsequent healthcare resources used to address poorer outcomes, and understanding the outcomes that are important to patients\(^1\).

**Why is this important for IPF patients?**

IPF is a condition for which there is no cure, so all efforts focus on the prevention of the disease worsening, and the rate at which it does, in order to to limit the impact on patients, their carers and the broader NHS. Treatment focuses on keeping patients out of hospital to help them live as long and active a life as possible. In 2014-15 there were over 5,000 emergency admissions for idiopathic pulmonary fibrosis related conditions that could perhaps have been prevented if patients had the treatment, care and support they need to effectively manage their condition in the community\(^1\).

The British Thoracic Society (BTS) Registry tracks and monitors patient care for 660 IPF patient records\(^1\) and presents a range of data that can be used to implement effective prevention strategies:

- 47 per cent of patients recorded had chest symptoms as long as 24 months before presenting at the clinic for diagnosis. This indicates that more can be done to identify the disease earlier in primary care to improve swift diagnosis and start treatment earlier before the IPF progresses

- Fewer than 55 per cent of eligible patients received a NICE-approved treatment for IPF, despite the clinical guidelines
The data collection methods included in the service specification have the opportunity to track outcomes that are meaningful for patients, in a way that identifies best practice preventative strategies:

- Data on disease progression via Forced Vital Capacity readings annually
- Health related quality of life data annually under specialist centre follow up
- Data on the proportion of patients enrolled in pulmonary rehabilitation 12 months following diagnosis
- Data on the proportion of patients assigned a diagnosis and management plan at their first visit to a specialist centre
- Evidence of shared protocols and the development of remote access MDTs

**What should be done?**

APF proposes a new approach to data gathering so that the real number of patients with IPF may be better understood. In this way we will be more accurately informed to plan the appropriate IPF care with equitable access for anti-fibrotic therapies, assessment of oxygen and pulmonary rehabilitation, and palliative and supportive care.

To achieve this we recommend:

- The Department of Health mandates the collection of IPF patient data
- NHS England instructs specialist ILD multi-disciplinary teams (MDTs) to complete an audit of all new IPF cases diagnosed and establish a database for ongoing consistent collection
- This data collection will involve MDTs recording the date of diagnosis and details of each patient’s condition; methods should be established to ensure data collection is efficient and does not place a significant resource burden on IPF teams

This will provide accurate incidence data, which in time will inform the true prevalence of IPF in England. Without these data, we will not be able to ensure that there is the appropriate future-proofing for the NHS services for IPF care on every level including primary care support through to estimation of palliative care resources required.

- The CRG needs to ensure all available IPF data is analysed at a national and level to identify best practice, address variations in patient outcomes, and plan services effectively
Future-proofing IPF care

IPF patients risk being affected by a number of challenges, both now and in the coming years, unless steps are taken to address discrepancies not only in access to but also the quality of care as outlined in the NICE Quality Standard. The challenges we face are:

- Rising number of patients with IPF
- Increase in the ageing population
- Challenges of delivering sustainable specialised services for uncommon conditions
- Difficulties of delivering effective preventative strategies without accurate, useful data

What needs to be done?

Every person involved in the commissioning and provision of IPF care has a role to play in addressing these challenges. Each should ensure that IPF services are considered leaders in the field in their work to help patients live with hope for a better future, rather than IPF care descending into fragmented, variable services that fail to provide patients with the life-enhancing support they need. The excellence which exists across many IPF care providers should be spread and lessons should be learned about what works for delivering effective IPF care, based on patient-centred, data-driven strategies.

Spread best practice

Monitor the situation
Nationally:
**Education and sharing of best practice** – NHS England’s CRG should actively work with regions to promote the implementation of the new service specification, share information about the best models of care that improve IPF patient outcomes efficiently, and use this information to inform service planning and ongoing IPF research.

**Monitor the situation** – NHS England’s CRG should establish uniform coding criteria for the new indicators outlined in the service specification and across inpatient and outpatient care. It should regularly track the amount and quality of data collected across the CRG, BTS ILD Registry and NHS Digital, and use the information to inform future-proofing strategies that reduce variations in care, and commission services based on accurate patient numbers.

Regionally:
**Spread best practice** – Specialist centres should take the lead in delivering the updated service specification across their region, focusing on improving education and pathways at a local level amongst non-specialist providers, to ensure rapid and accurate referral and coordinated, patient-centred ongoing support. They should continue to identify innovative models of care, and keep NHS England informed of their impact on patient outcomes.

**Monitor the situation** – Specialist centres should be required to collect data including for the BTS ILD Registry and NHS Digital, leading their region in coding data effectively and efficiently in line with national criteria, and use these data to plan services effectively.

Locally:
**Education and sharing** – Local providers across primary, secondary and community care should continue to foster excellence in service delivery, seeking closer relationships with regional specialist centres in order to accurately identify and support IPF patients in the community setting.

**Monitor the situation** – Local services should work with regional and national bodies to support the accurate coding of data on the front-line of care, to ensure services are planned in a way that truly benefits IPF patients, based on the latest outcomes data.
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