Innovation approaches: An ILD service fit for the future

ILD Interdisciplinary Network Conference

Mel Wickremasinghe

October 8th 2017

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Disclosures

- Roche Pharmaceuticals
- Boehringer Ingleheim
- Action for Pulmonary fibrosis

Innovation approaches in ILD

- Patient pathways
- Communication systems
- Non-pharmacological approaches
- Benchmarking patient experience

NHS

NHS Patient Experience Framework

In October 2011 the **NHS National Quality Board (NQB)** agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. This framework outlines those elements which are critical to the patients' experience of NHS Services.

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DH Department of Health

Quality of care
Safety,
Clinical effectiveness
Patent Experience

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Picker Institute Europe

Fast access to reliable healthcare advice

Effective treatment delivered by trusted professionals

Continuity of care and smooth transitions

Involvement of, and support for, family and carers

Clear, comprehensible information and support for self-care

Involvement in decisions and respect for patient's preferences

Emotional support, empathy and respect

Attention to physical and environmental needs

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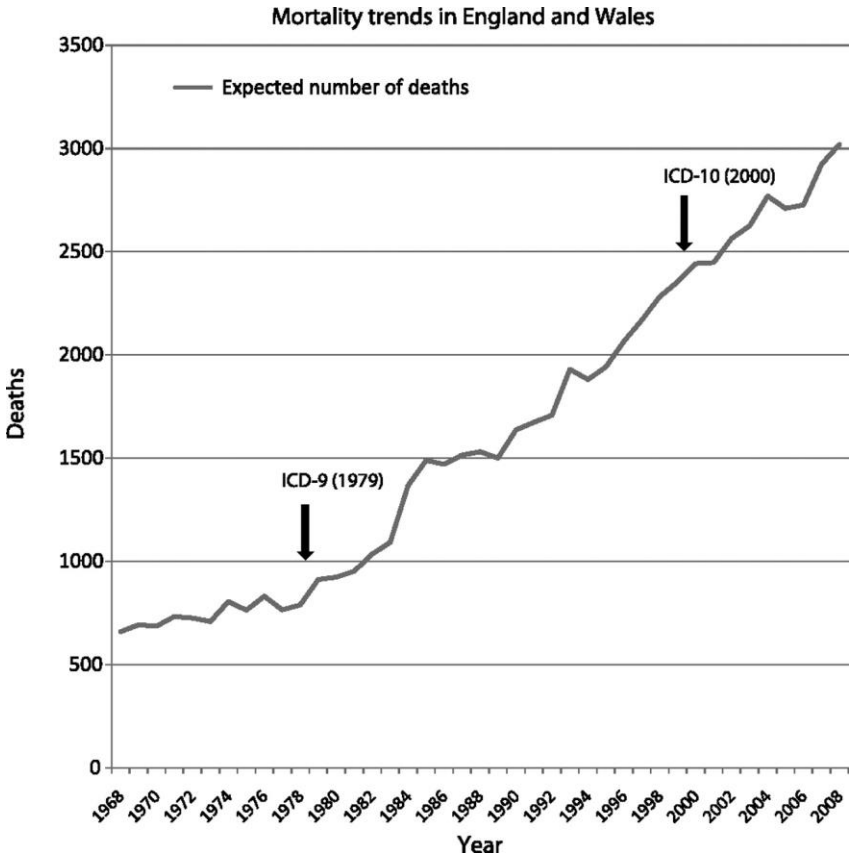
IPF 32500 estimated
6000 new cases/yr

The rising incidence of idiopathic pulmonary fibrosis in the UK

V Navaratnam,[1] K M Fleming,[2] J West,[2,3] C J P Smith,[2] R G Jenkins,[1] A Fogarty,[1] R B Hubbard[1]

- April 2011 Thorax
- The incidence of IPF-CS in primary care increased by 35% from 2000 to 2008,
- Overall incidence rate of 7.44 per 100 000 person-years (95% CI 7.12 to 7.77)
- Average GP surgery of 10,000 patients will have two new cases every 3 years

Estimated number of deaths from idiopathic pulmonary fibrosis clinical syndrome, age standardised to the 2008 population of England and Wales.



V Navaratnam et al. Thorax 2011;66:462-467

THORAX

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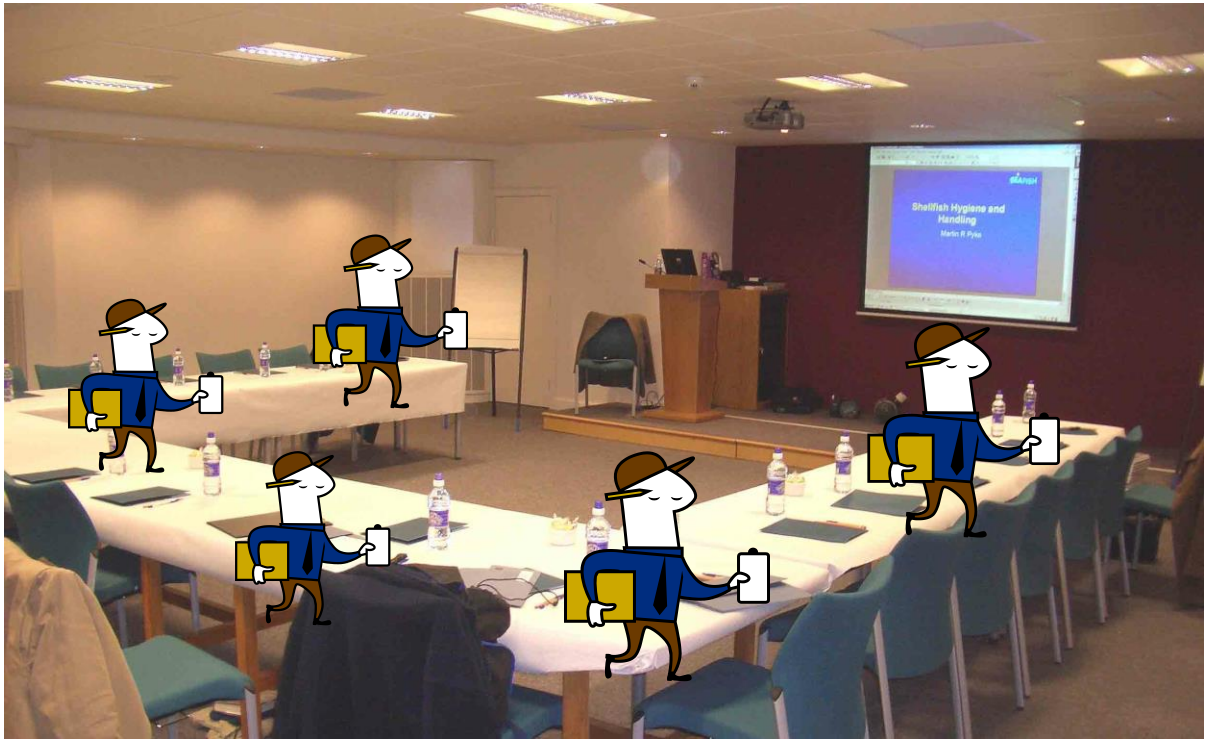
Multi-Disciplinary Discussion



NHSE

Dedicated ILD radiologist
Pathologist
Respiratory Physician
ILD Nurse
MDT coordinator
(Cardiothoracic Surgeon)

NICE guidance

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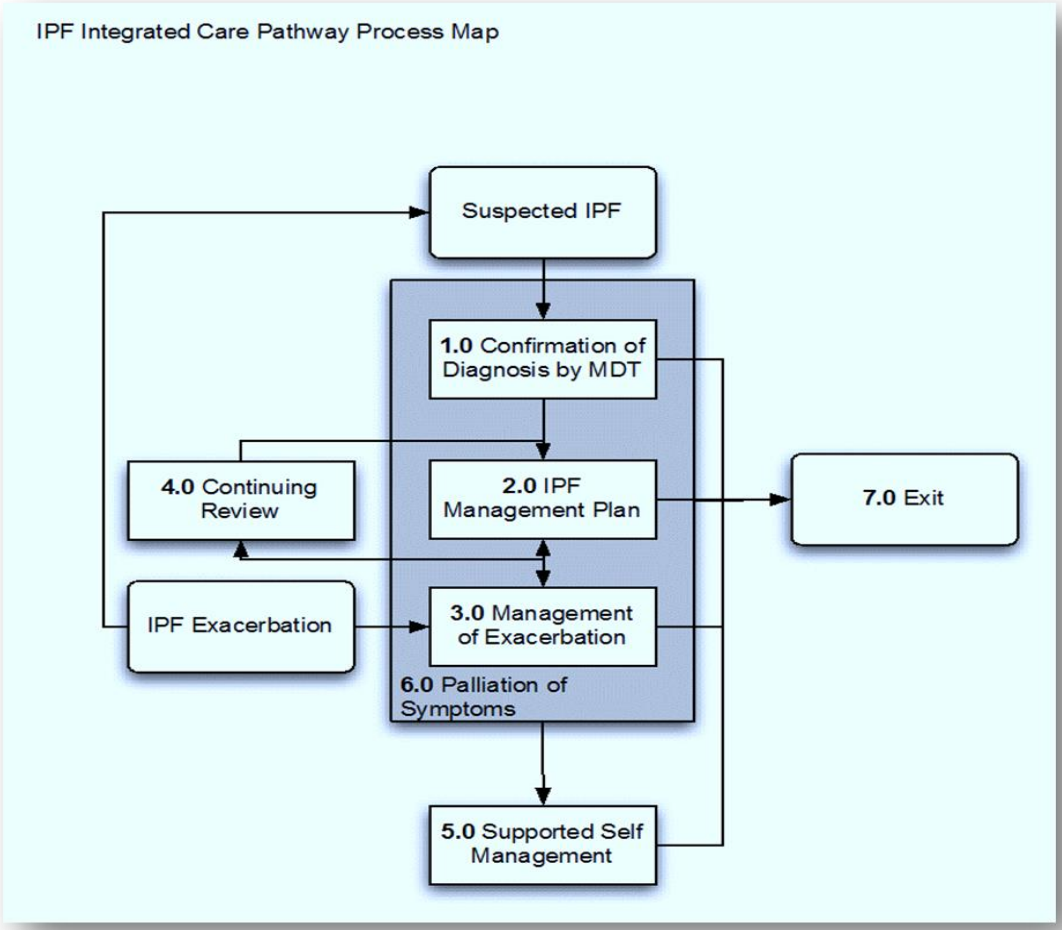

IPF Integrated Care Pathway Process Map
Suspected IPF
1.0 Confirmation of Diagnosis by MDT
2.0 IPF Management Plan
3.0 Management of Exacerbation
4.0 Continuing Review
IPF Exacerbation
6.0 Palliation of Symptoms
5.0 Supported Self Management
7.0 Exit

Key periods in disease

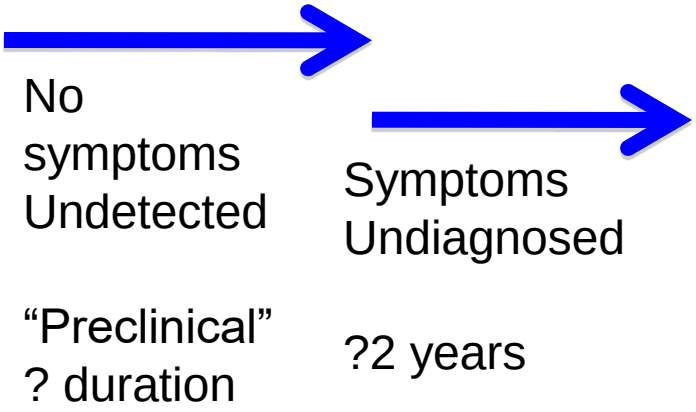
No
symptoms
Undetected

“Preclinical”
? duration

Suspecting the diagnosis: how can we diagnose earlier?

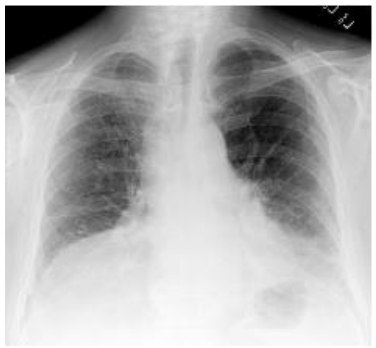
- Period before symptoms
  - Unknown duration
  - Incidental pick up on CT abdomen, CT coronary angiograms, CT chest, Screening for lung cancer (Jin 2013, Tushima 2010)
- Examination chest
  - Velcro crackles early sign (Cottin 2012)
- Familial disease

Key periods in disease



Symptomatic but not diagnosed

- Unexplained breathlessness
- Non productive cough
- GP
- “COPD” Emphysema
- Delay 1-2y symptoms to diagnosis



Imperial College Healthcare NHS Trust

Click here to print

Mail Online

It's a new killer baffling doctors. And the only warning sign is feeling out of breath...

By Lucy Elkins

Last updated at 10:58 PM on 9th May 2011

Like 544

- As it is only just becoming more common, not all GPs are used to spotting the condition either.
- ‘For a GP to diagnose IPF is hard,’ says Dr Kevin Gruffydd-Jones, the Royal College of GPs spokesman on respiratory issues.
- “Asthma” diagnosis
- Referred to Cardiologist,

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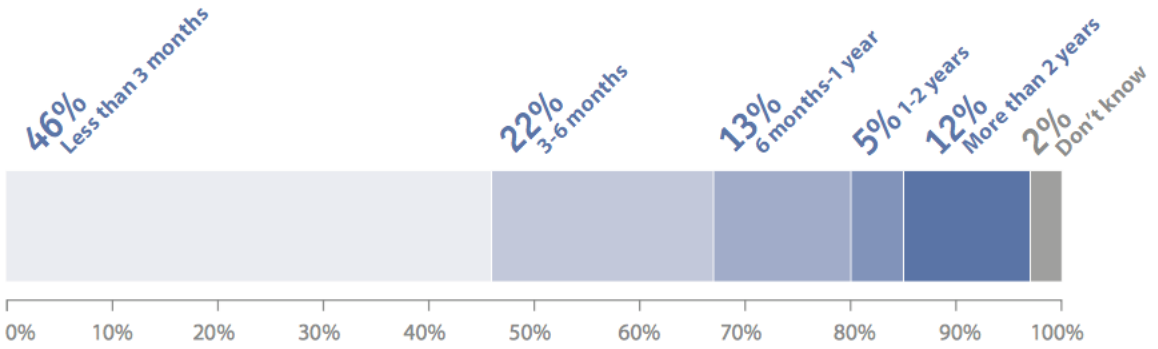
Referral waiting times to specialist



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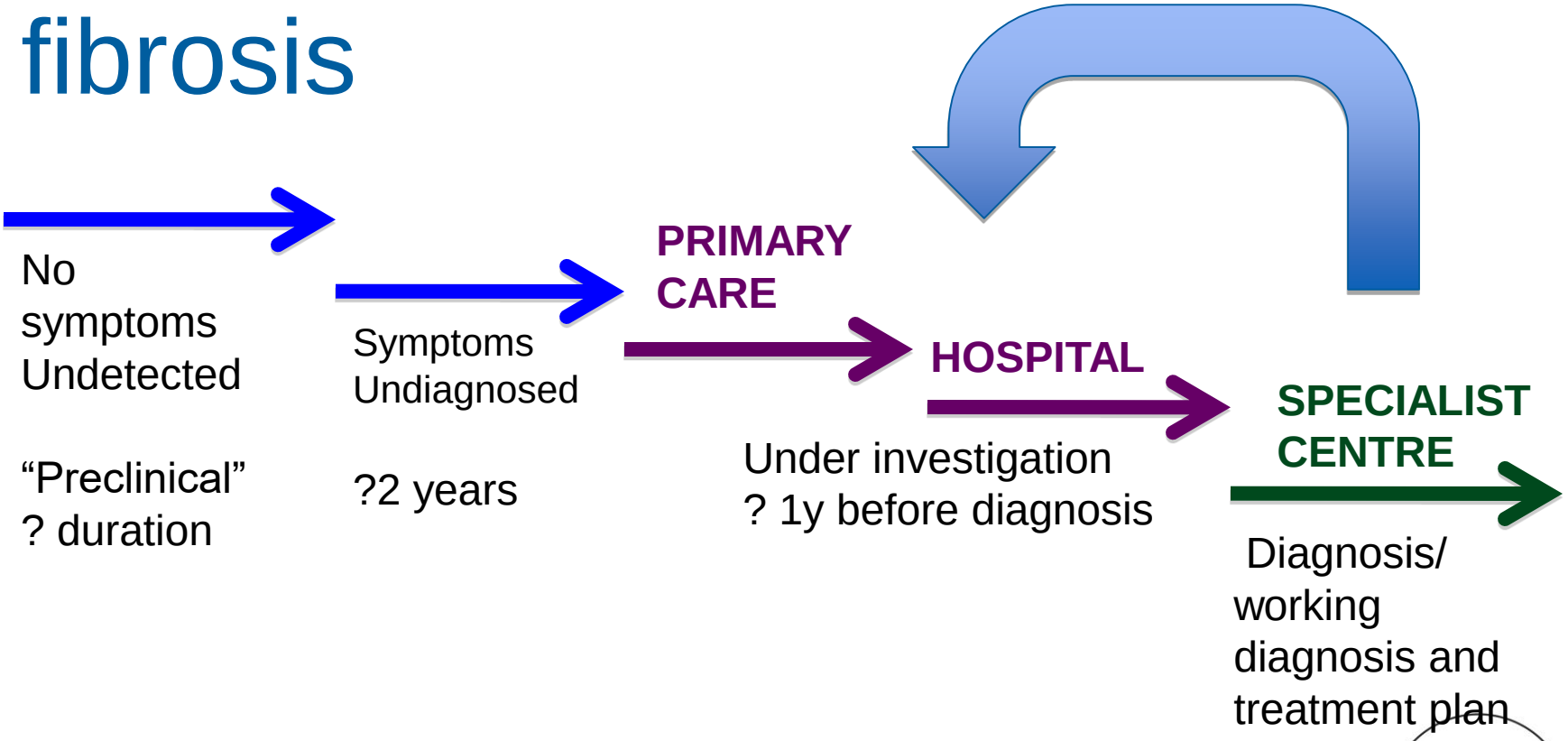
Map of key periods in lung fibrosis



Delays:worse outcomes, mean FVC75% Δ

Lamas 2011, Noth 2014, Collard 2007

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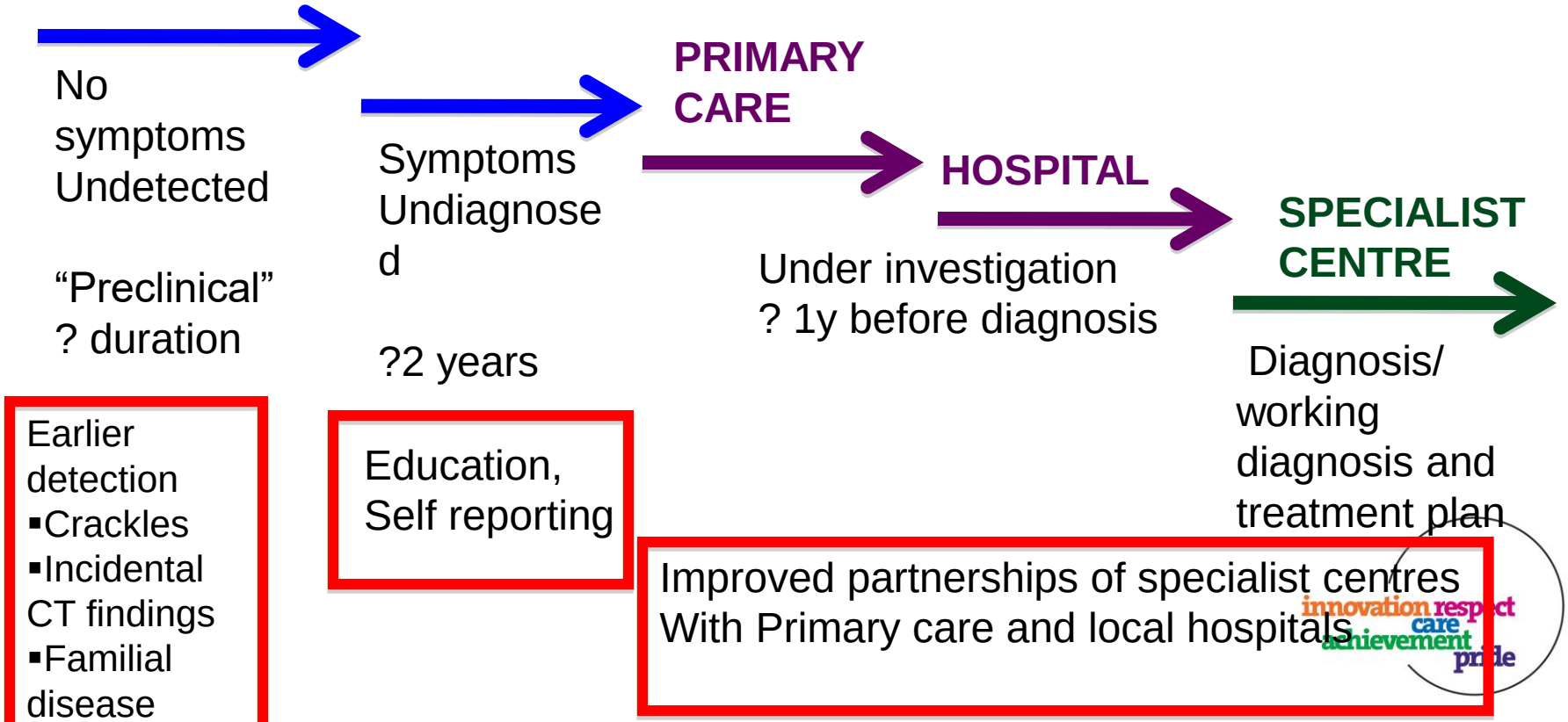
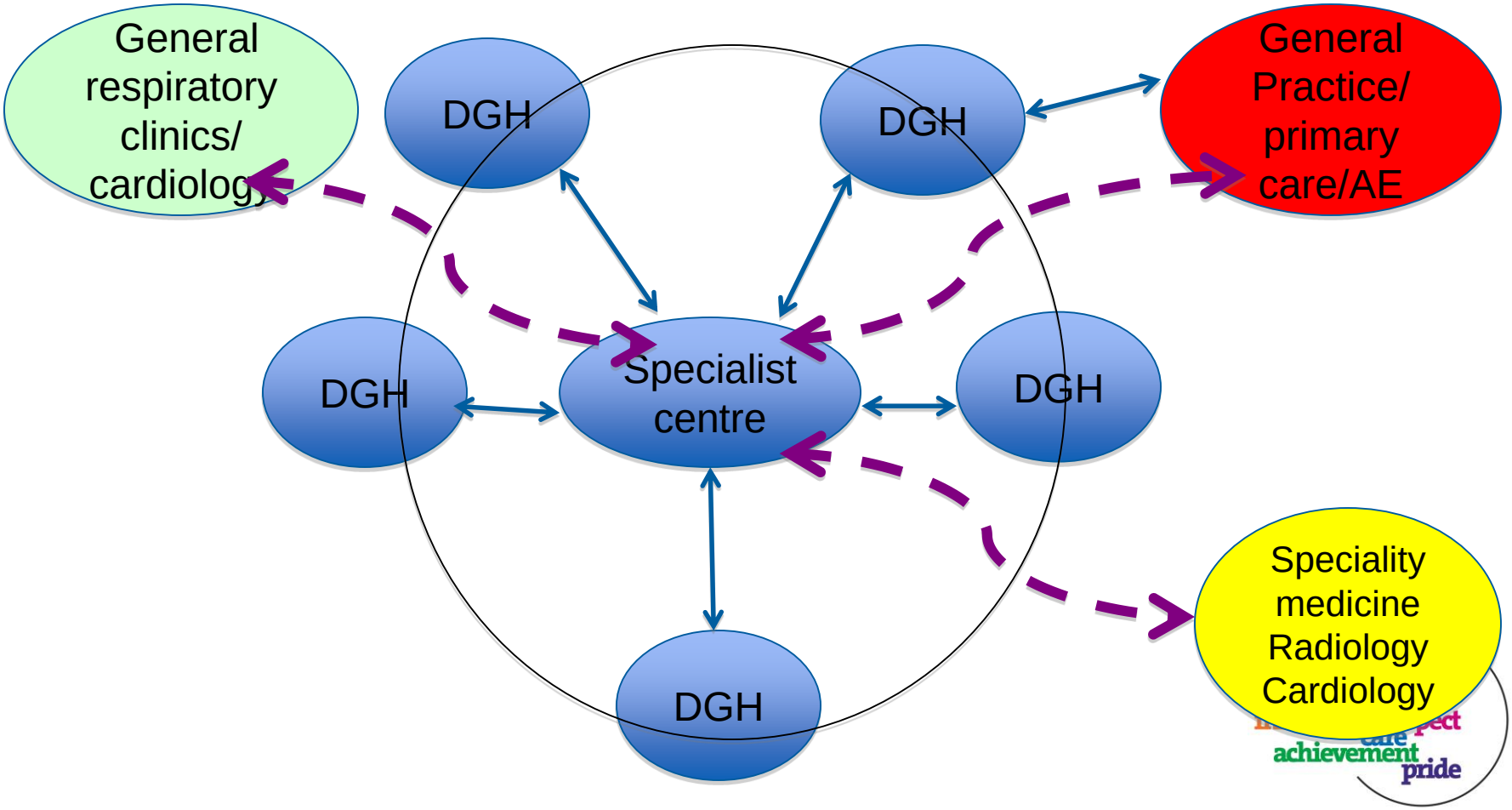
Lung fibrosis pathways



Hub and spoke model



Community Integrated Cardio-Respiratory Servcies ICHNT

- Community clinics : symptom based
  - cough , breathlessness clinics
- Access to
  - Spirometry
  - Oxygen information and diagnosis
  - Cardio investigations
  - HRCT
  - bloods

Community Integrated Servcies ICHNT

- Set up first Community ILD clinical meeting
- Fast pathway for triage, pulls patients into the service
  - More likely to arrange CT than GP, info from GP SystmOne
  - Will arrange tests after meeting
- Education
  - to community team by ILD Physician/ILD CNS
- Documentation
    - Into Cerner system
- Integration
  - Real-time information
  - Systm One

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Communication: digital innovations

Distance balance of shared care but maintaining involvement

End of life, “sense of abandonement”

Co-ordination of professionals, relatives

Technological Approach	What is known
Email consultations	proof of concept; uncertainty on 'rules of engagement' for online interaction
Text messaging	convey tests results or sending health promotion messages
Online portals: Patient access to online MR	proof of concept - Prescription ordering & Booking appointments
Telephone	Various models: assessment and triage of acute problems, + /- clinical advice; telephone consultations: linear format; focus on narrow range of pre-planned themes; less opportunity for the patient to raise issues spontaneously
Telemedicine	Sustainability of telemedicine services complex including cost, logistics and subtle adverse impacts on professional roles and work routines
Telehealth 'telecare'	Proof of concept. Small trials Possibly being replaced by apps?
Video consultations	The addition of high-quality visual medium emulates the face-to-face environment

Greenhalgh T, Vijayaraghavan S, Wherton J, et al Virtual online consultations: advantages and limitations (VOCAL) study BMJ Open 2016;6:e009388. doi: 10.1136/bmjopen-2015-009388

- '*New technologies that support alternatives to face-to-face consulting are seen by policymakers as potentially improving the financial efficiency as well as the clinical effectiveness of services.'*

DH. Innovation health and wealth: accelerating adoption and diffusion in the NHS. London: Stationery Office, 2011.

NHSE CQUIN Telemedicine 2016

ICHNT
Global digital exemplars (GDE)
Partner with fast followers
Self management –apps
Access

NEXT STEPS ON THE
NHS FIVE YEAR FORWARD VIEW

New Ways of working

Care Information Exchange

Imperial College Healthcare NHS
NHS Trust

What will the Care Information Exchange do?

Support person-centred, integrated health and social care in North West London by:

- giving individuals access to information about their care held by different health and social care providers
- allowing individuals to share that information with health and social care professionals
- providing secure messaging, shared care planning, and symptom tracking for individuals and professionals

Funded by
Imperial College Healthcare Charity
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IMPERIAL COLLEGE HEALTH PARTNERS

- North West London Boroughs of
- Brent, Ealing, Hillingdon, Harrow,
- Hounslow, Hammersmith & Fulham,
- The Royal Borough of Kensington and Chelsea & Westminster City Council.
- Partner organisations include:
- Six hospital trusts
- Two mental health trusts
- One community health trust
- Eight clinical commissioning groups
- Three universities

2,300,000 people

£3.4 billion annual health spend

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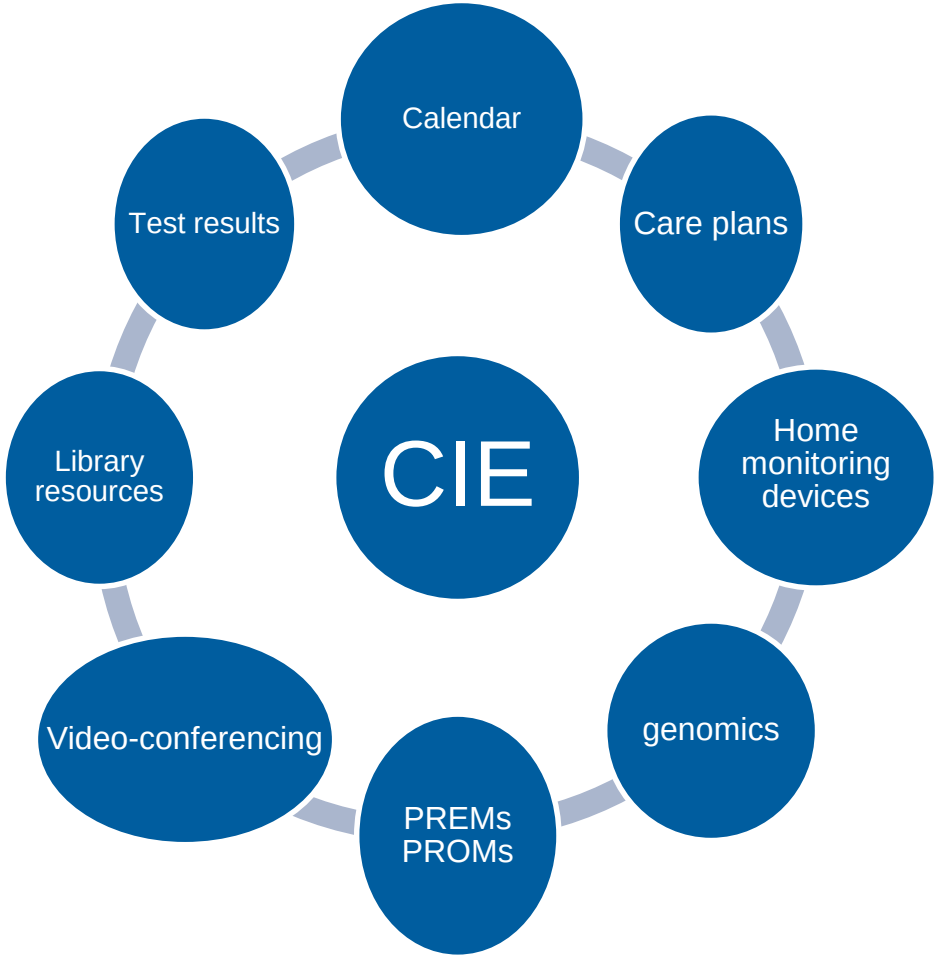

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ORIGINAL ARTICLE

Daily Home Spirometry: An Effective Tool for Detecting Progression in Idiopathic Pulmonary Fibrosis

Anne-Marie Russell[1,2], Huzaifa Adamali[3], Philip L. Molyneaux[1,2], Pauline T. Lukey[4], Richard P. Marshall[4], Elisabetta A. Renzoni[1,2], Athol U. Wells[1,2], and Toby M. Maher[1,2]

[1]National Institute for Health Research Biomedical Research Unit, Royal Brompton Hospital, London, United Kingdom; [2]Fibrosis Research Group, National Heart and Lung Institute, Imperial College London, London, United Kingdom; [3]Bristol Interstitial Lung Disease Service, North Bristol Lung Centre, Southmead Hospital, Westbury-on-Trym, United Kingdom; and [4]Fibrosis and Lung Injury DPU, GlaxoSmithKline R&D, Stevenage, Herts, United Kingdom

ORCID ID: 0000-0001-7192-9149 (T.M.M.).

Abstract

Rationale: Recent clinical trial successes have created an urgent need for earlier and more sensitive endpoints of disease progression in idiopathic pulmonary fibrosis (IPF). Domiciliary spirometry permits more frequent measurement of FVC than does hospital-based assessment, which therefore affords the opportunity for a more granular insight into changes in IPF progression.

Objectives: To determine the feasibility and reliability of measuring daily FVC in individuals with IPF.

Methods: Subjects with IPF were given handheld spirometers and instruction on how to self-administer spirometry. Subjects recorded daily FEV_1 and FVC for up to 490 days. Clinical assessment and hospital-based spirometry was undertaken at 6 and 12 months, and outcome data were collected for 3 years.

Measurements and Main Results: Daily spirometry was recorded by 50 subjects for a median period of 279 days (range, 13–490 d). There were 18 deaths during the active study period. Home spirometry showed excellent correlation with hospital-obtained readings. The rate of decline in FVC was highly predictive of outcome and subsequent mortality when measured at 3 months (hazard ratio [HR], 1.040; 95% confidence interval [CI], 1.021–1.062; $P \leq 0.001$), 6 months (HR, 1.024; 95% CI, 1.014–1.033; $P < 0.001$), and 12 months (HR, 1.012; 95% CI, 1.007–1.016; $P = 0.001$).

Conclusions: Measurement of daily home spirometry in patients with IPF is highly clinically informative and is feasible to perform for most of these patients. The relationship between mortality and rate of change of FVC at 3 months suggests that daily FVC may be of value as a primary endpoint in short proof-of-concept IPF studies.

Keywords: interstitial lung disease; clinical trials; biomarker; personalized medicine

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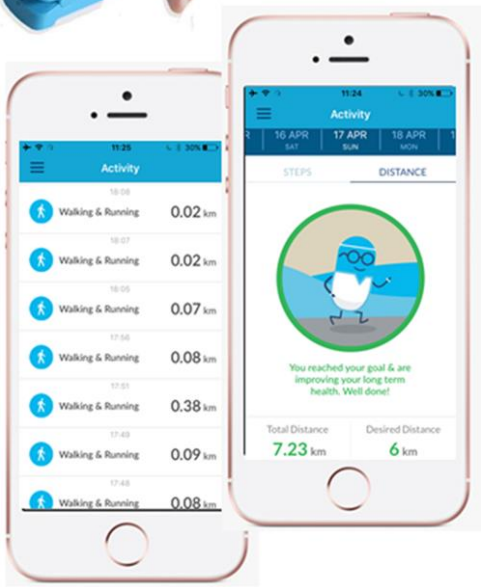

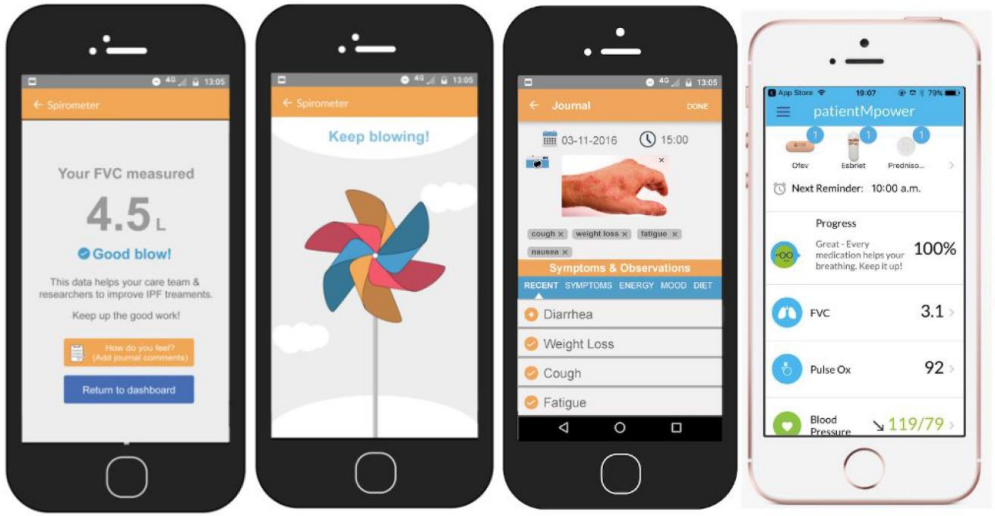

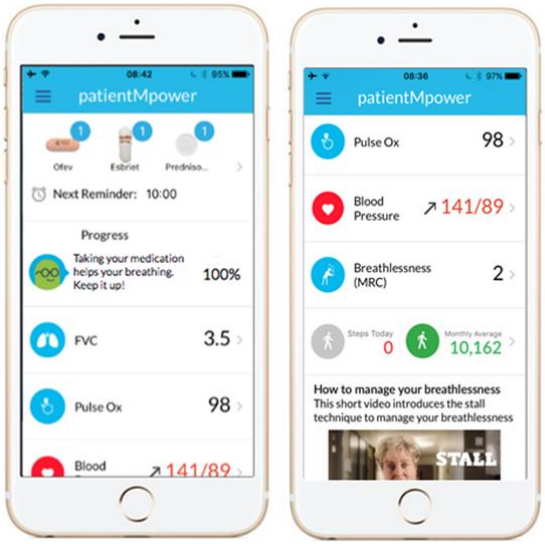

patientMpower

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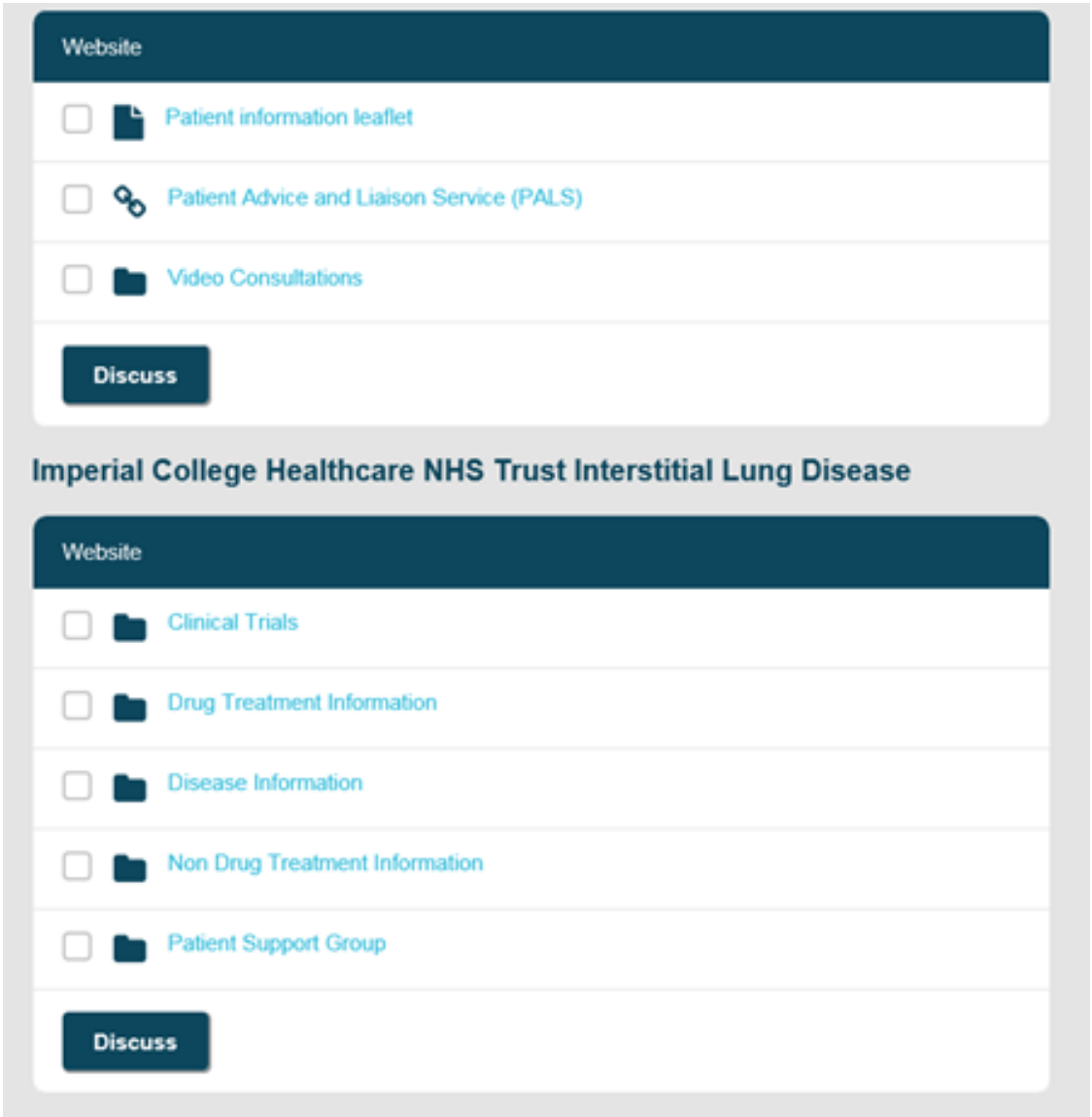
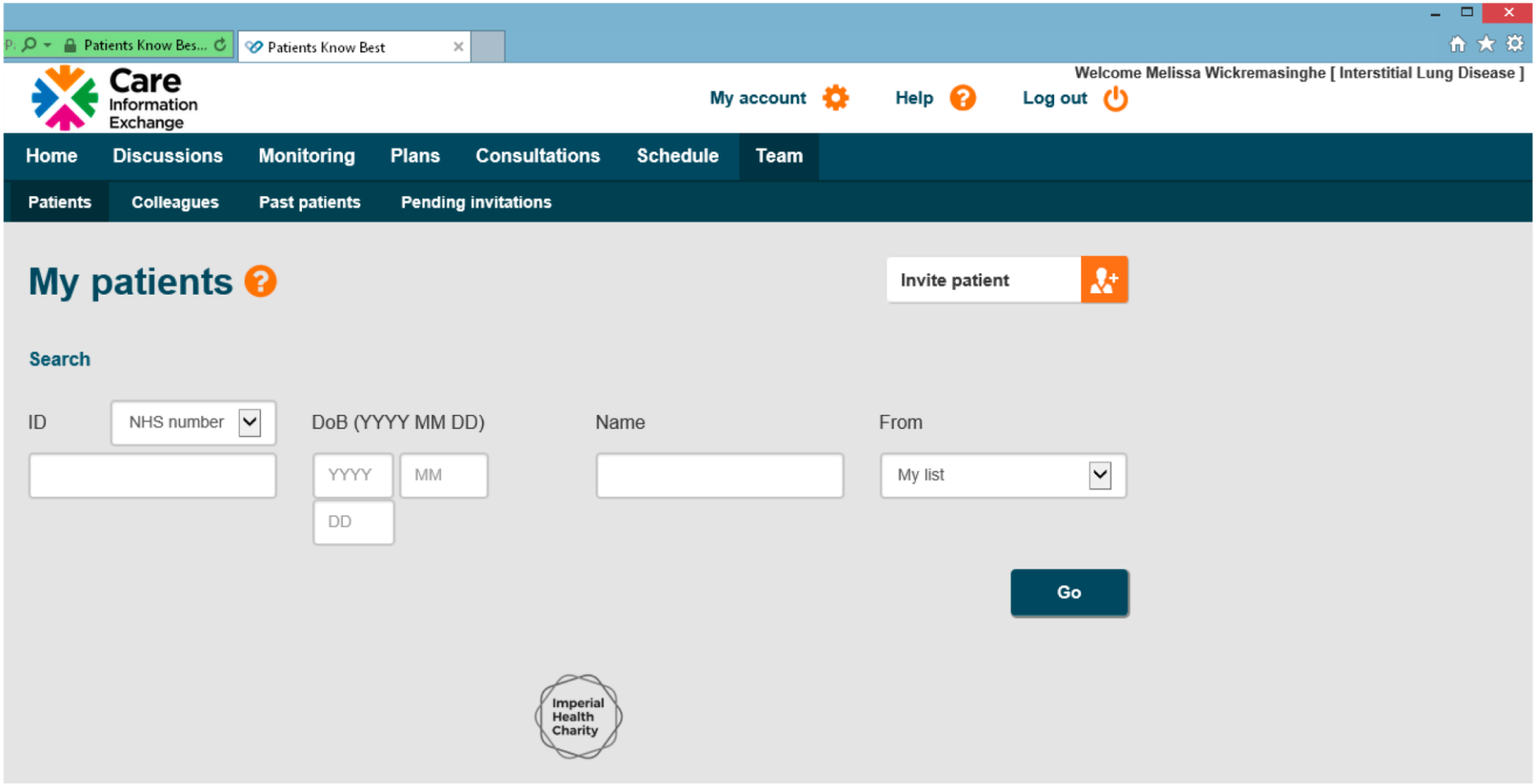
Library Resources



Care Information Exchange



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Care Information Exchange

Welcome Melissa Wickremasinghe [Interstitial Lung Disease
Help Log out

Edit

Back to my patients | Summary | Discussions | Health | Treatments | Diary | Files | Apps | Sharing

Journal | Appointments

appointments

Add appointment

Overview

Oct 2017						
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

Nov 2017						
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

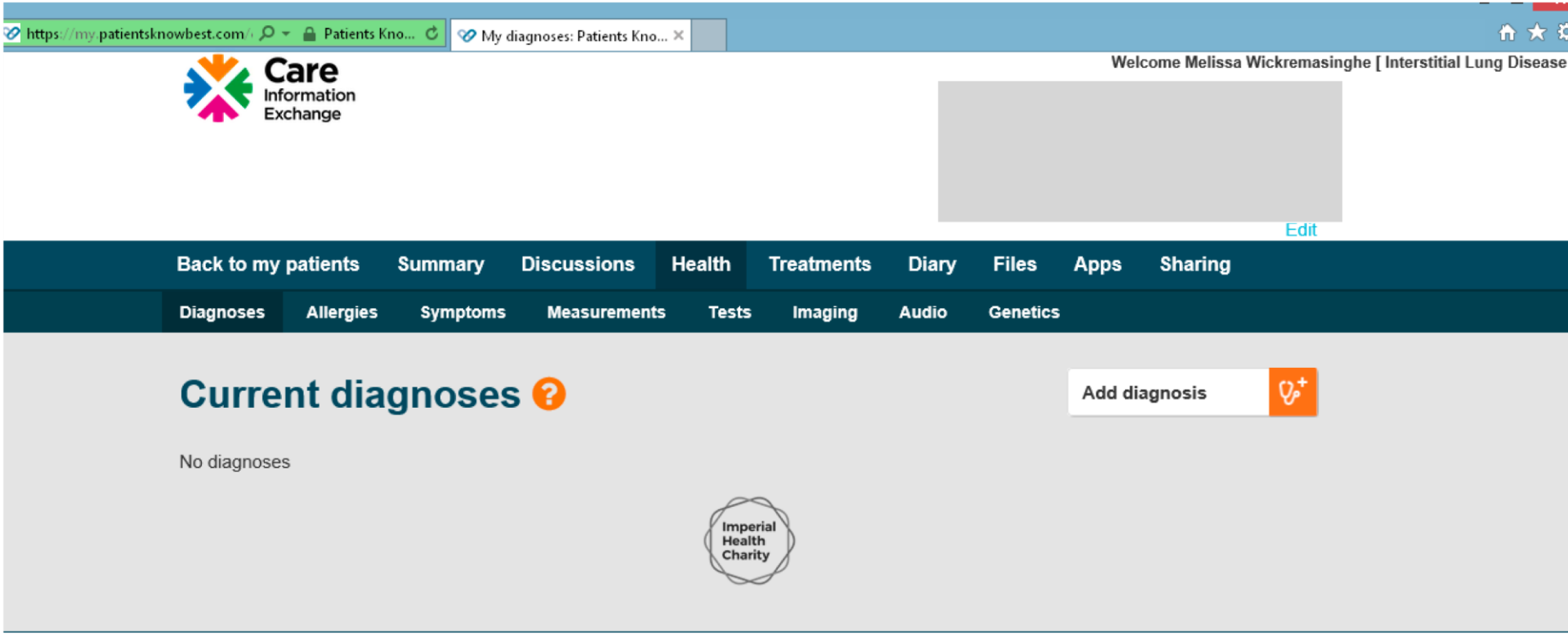
Dec 2017						
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

Jan 2018						
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Feb 2018						
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28				

Mar 2018						
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

4 appointments in this range



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Care Information Exchange

Help Log out

Edit

Back to my patients | Summary | Discussions | Health | Treatments | Diary | Files | Apps | Sharing

Diagnoses | Allergies | Symptoms | Measurements | Tests | Imaging | Audio | Genetics

Add measurements

Measurement date * 07/10/2017

Measurement time * 18:14 Europe/London

Measurement values

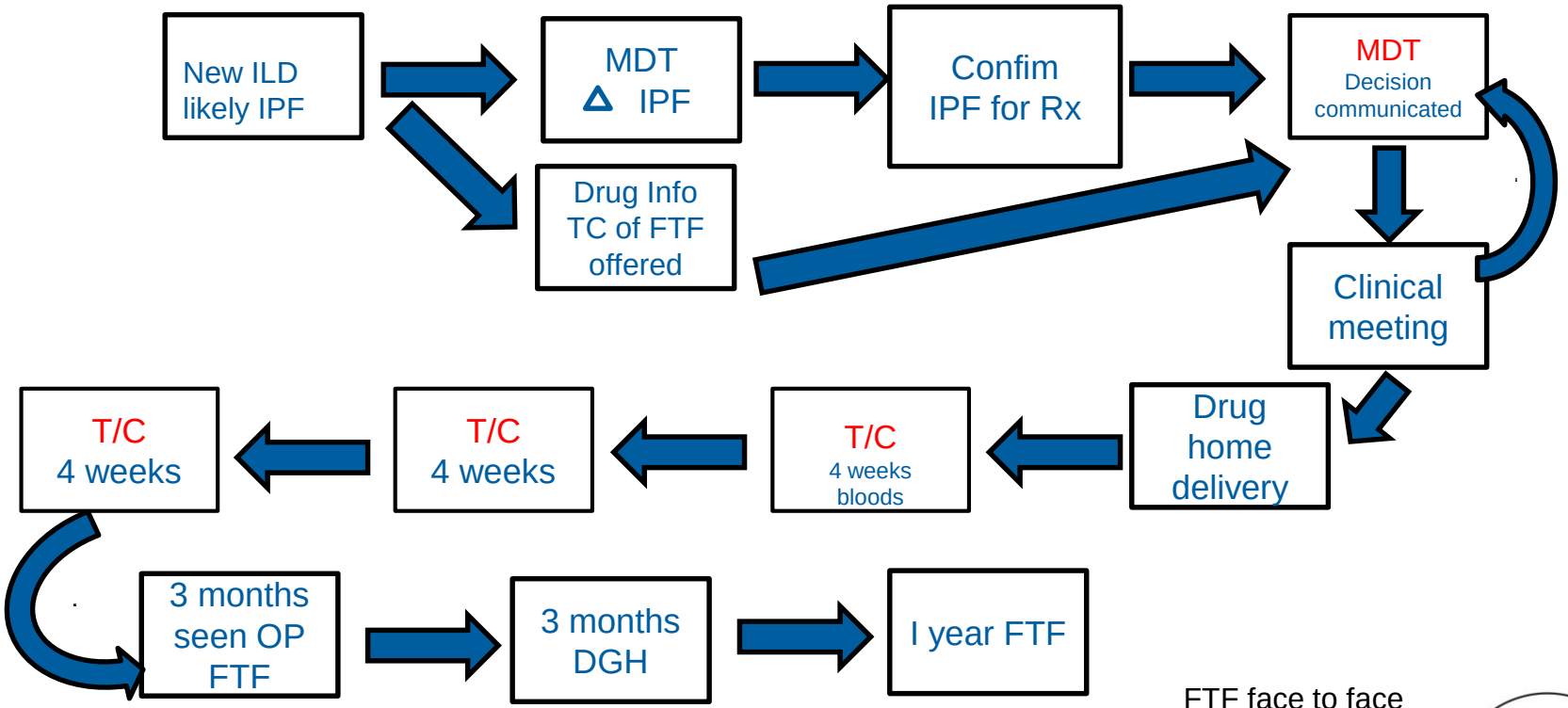
Weight kg

Weight pounds

Measurement date
The date on which the measurements were taken

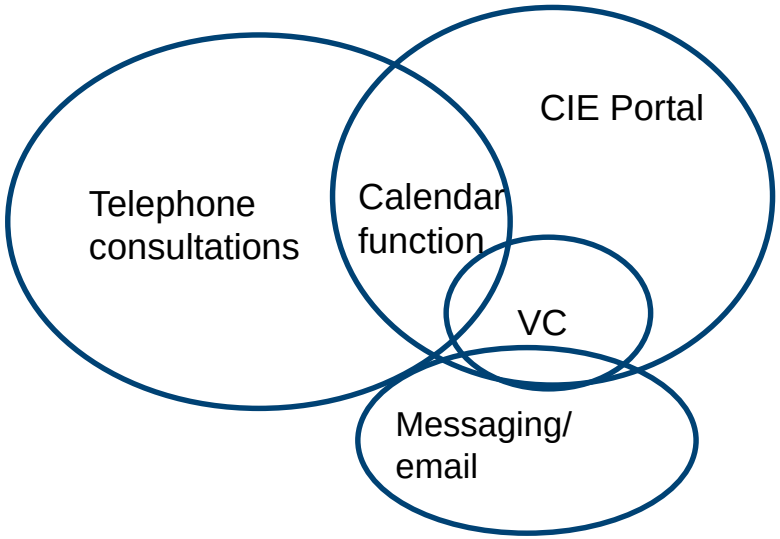
Values
Enter list of results for this test

IPF telemedicine pathway



FTF face to face
IPF idiopathic Pulmonary Fibrosis

Digital technology :Lung Fibrosis service ICHNT



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discussions

Send message

Start consultation

Call patient

May | June | July | August | September | October

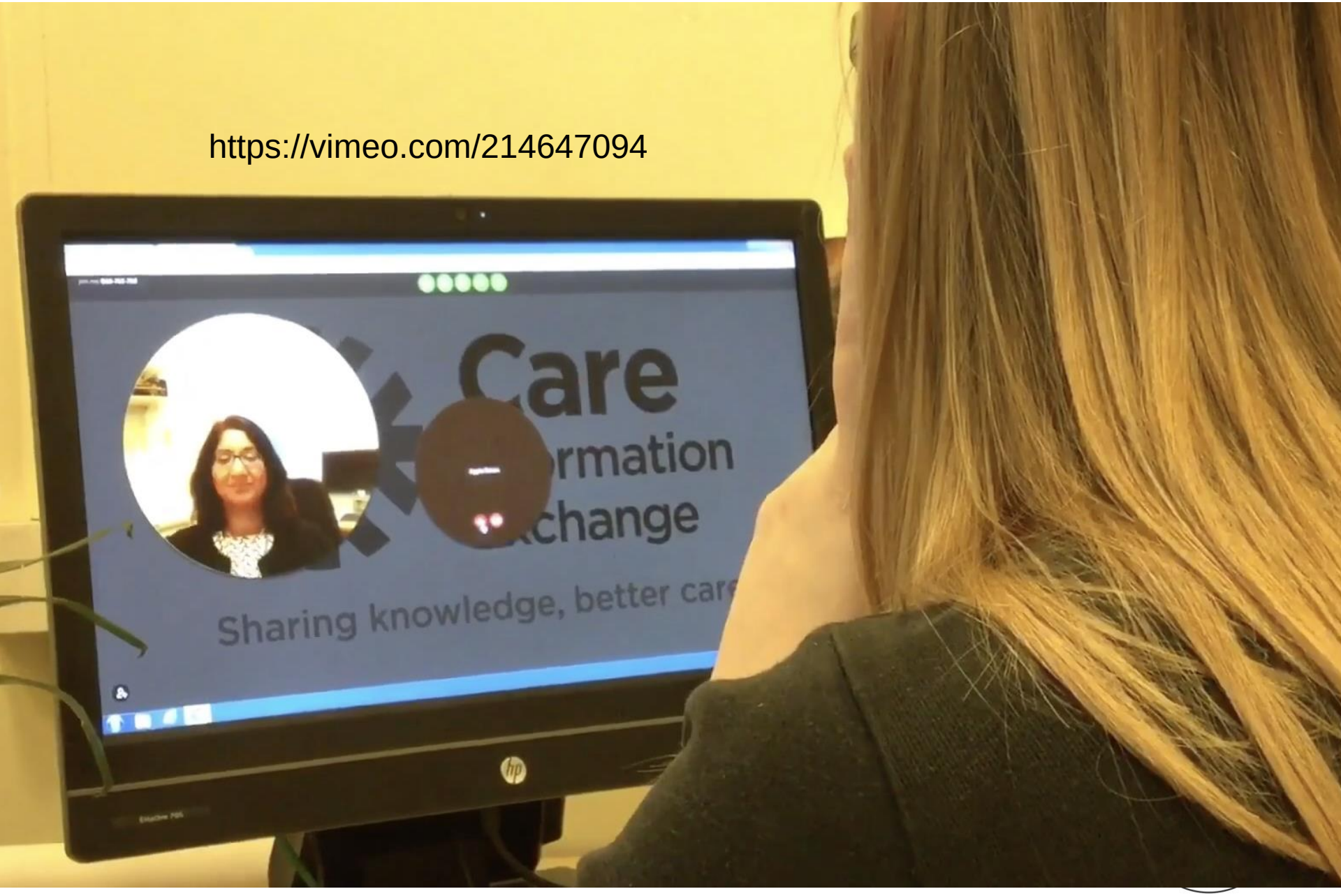
Last Thursday

join.me appointment - Online communication
Started By: Melissa Wickremasinghe [consultant in Interstitial Lung Disease Imperial College Healthcare NHS Trust]

General health

1

https://vimeo.com/214647094



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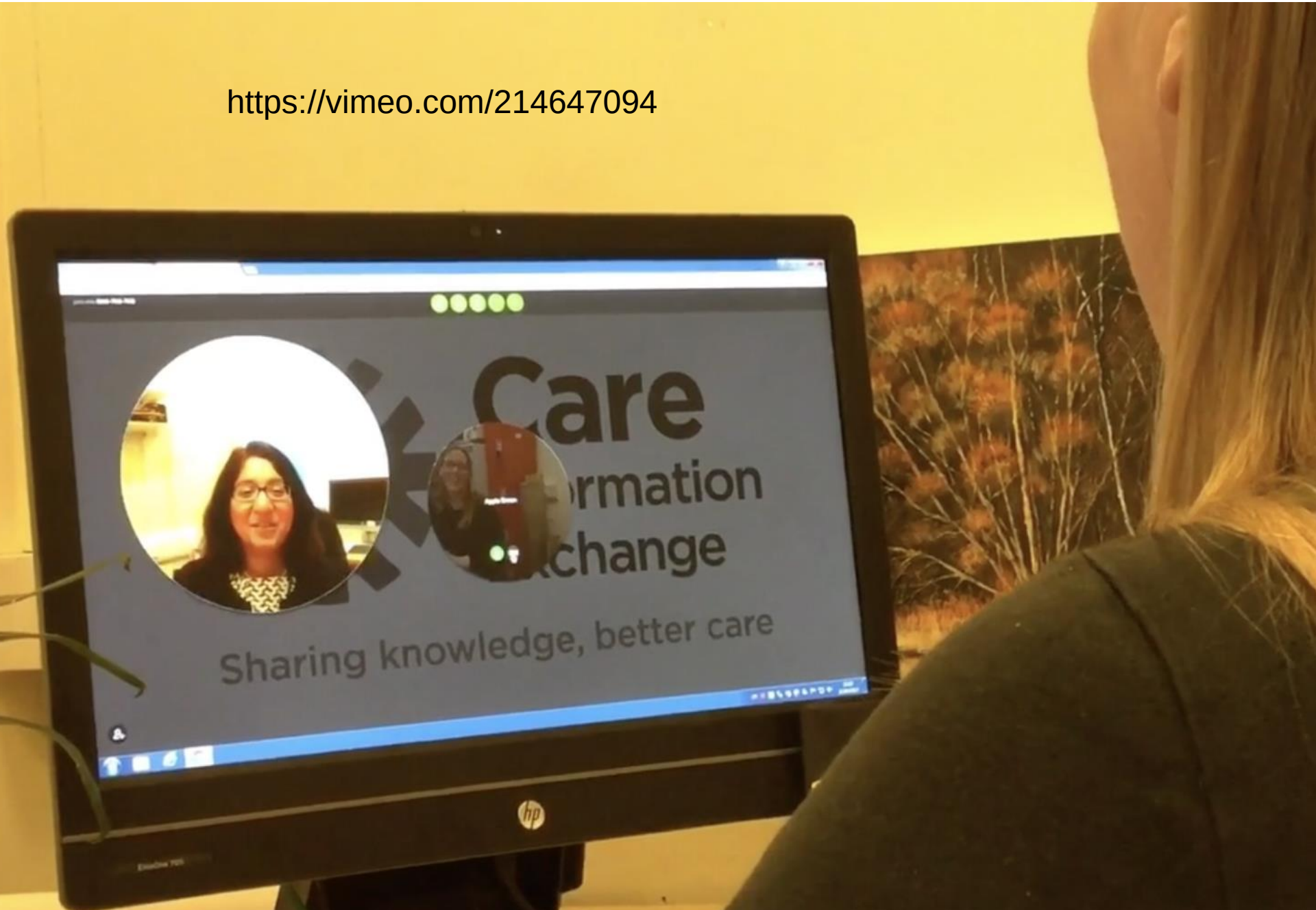


Benefits of Telemedicine and the CIE for ILD patients at ICHCT

- Better access to education and information
- Improved coordination of care:
  - access to investigation results in a timely manner
  - access to clinic letters due
  - streamlined hospital visits
  - less duplication in clinical care
- Maintenance of link with National centre for advice and care
- Better physician – patient relationship
- Better clinician –physician partnerships
- Development of network of care
- Enabling practical self-management

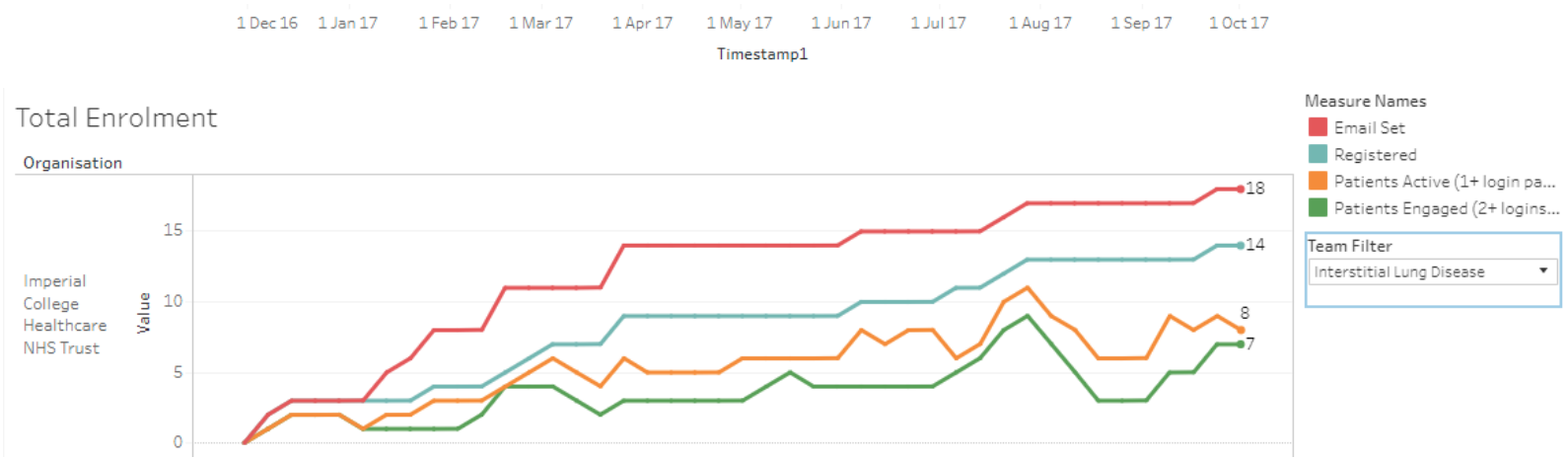
Potential Barriers

- Visual examination but not physical examination (SOP/escalation policy)
- Changes in prescribing
- Impact FTF activity

- Technological/logistic challenges
- Training
- Cost
  - NHSE Tariff
  - VC-License for software

Benefits of Digital technology:

- Encourages concept of supported self management
- Travel avoided
- Maintain specialist center relationship/better engagement
  - Potential in Palliative care pathways at end of life
- Relatives involvement
- Empowering patients
- Improved patient experience
- Clinical networks for health professional


1 Dec 16
1 Jan 17
1 Feb 17
1 Mar 17
1 Apr 17
1 May 17
1 Jun 17
1 Jul 17
1 Aug 17
1 Sep 17
1 Oct 17
Timestamp1
Total Enrolment
Organisation
Imperial College Healthcare NHS Trust
Value
0
5
10
15
18
14
8
7
Measure Names
Email Set
Registered
Patients Active (1+ login pa...
Patients Engaged (2+ logins...
Team Filter
Interstitial Lung Disease

Non-Pharmacological measures

From high tech to ancient practices..

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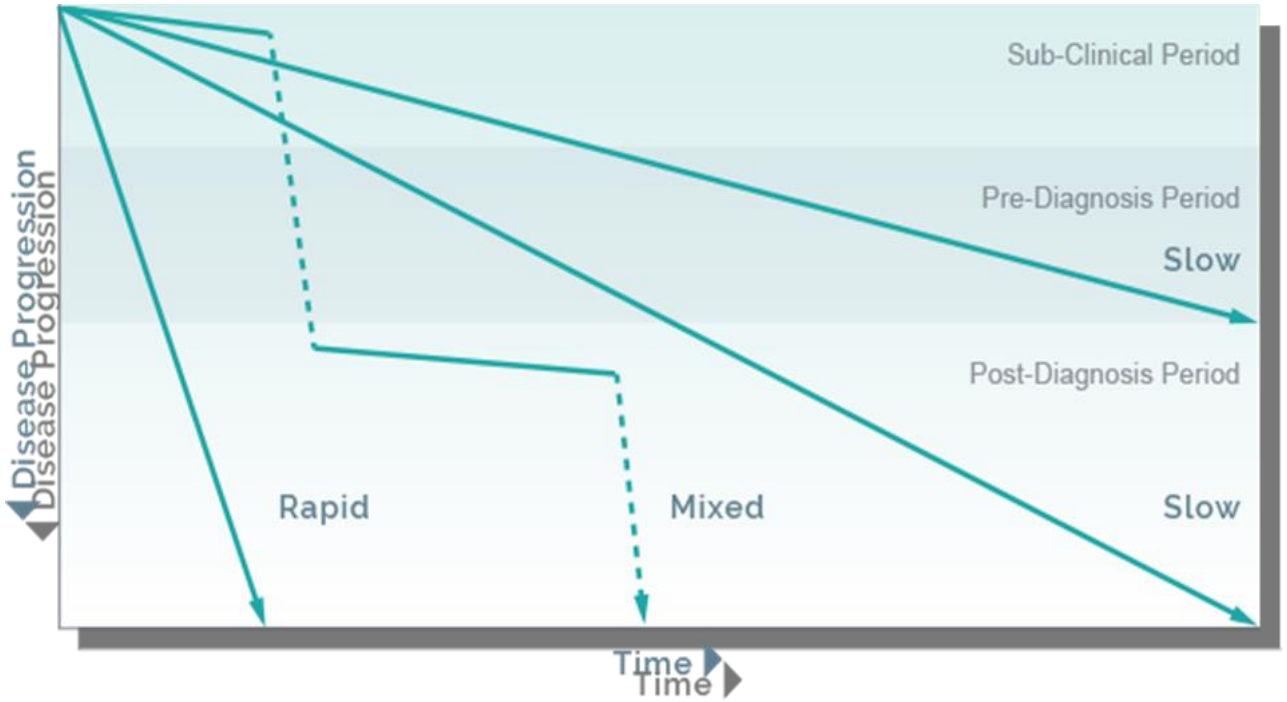
Disease Trajectory



Ley B, Collard HR, King TE Jr et al Clinical course & prediction of survival in idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med* 2011; **183**:431–40

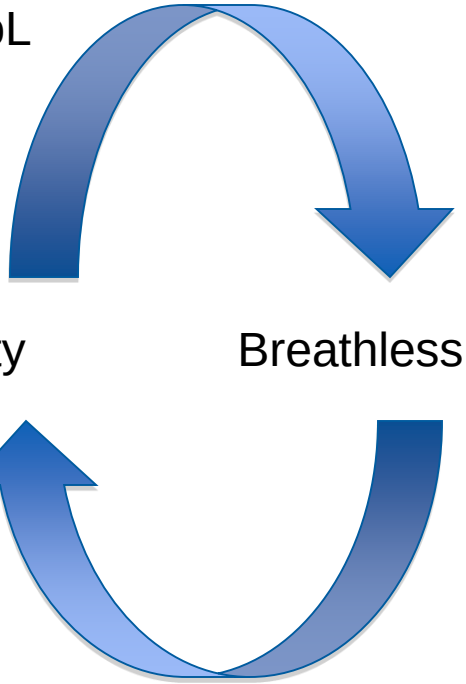
NICE CG 163 on the diagnosis and management of suspected IPF 2013

Anxiety for other reasons

Due to impact on QoL and family

Due to diagnosis itself

Due to the symptom



Disease causes low oxygen

Disease causes symptom
“stiff lung” feels different

Deconditioning

Perception of breathlessness, altered by disease and anxiety

Catherine Jaschinski

Yoga and Mindfulness Practitioner

Mindful Breathing for Lung Fibrosis Patients

- **Pilot program aims to teach patients**
  - To regulate their breath in a way that can ease their symptoms and improve breathing function
  - How to manage their breath in a way that can address the emotional and mental wellbeing (anxiety, frustration, stress, low mood) associated with the symptoms
- **Tailor-made course which includes**
  - Mindful Breathing
  - Chair-based exercises to strengthen / stretch respiratory muscles
  - Specific breathing techniques to regulate and manage the breath
- **Developing tools to assess the physical and wellbeing impact**


Palliative Care

Patient questionnaire pre and post Yoga/Mindfulness class

I am aware of my breathing (breathing patterns, rhythm, the quality of my breath)
I often experience breathlessness
I feel anxious about my breathing
I feel in control of my breathing
I do less physical activity because of my breathing problems
I feel that my breathing negatively affects my general energy levels
I feel I am not able to do the things I want to do because of my breathing problems
I feel that my breathing affects my quality of life
I feel that I have techniques / exercises that I can do to help me manage my breathing

Initial patient feedback

‘Despite the fact the course is still in its initial phase (3 sessions), this constitutes a rather important discover for me…’

‘There was nothing to help a patient to fully take on board the anxiety and depression which are recognised to accompany the symptoms of certain lung diseases’

‘ Too often, the emphasis has been solely on the muscular system with corrective exercises…In this instance, the starting point is the breath and how to give it space, the environment, the calm it needs to optimise itself within the boundaries imposed by the incurable lung disease.’

Initial patient feedback

Mr JN

‘I have found the psychological and intellectual effects of the meetings extremely helpful and supportive…invaluable insight and sense of wellbeing and belonging gained from meeting with my co-patients’

‘…it seemed like a great club to which (we) have been granted a membership, the shared load is, truly…the lightened load’

Mr MS

‘When you suggested a course of yoga I was surprised but very willing to try...and now in week 4 I am beginning to feel the benefits.

I try to practice the exercises daily and I am happy to say that at the latest control, yesterday, there was an improvement in my lung function.’

Preliminary results

Increase in Nos aware of their breathing pattern

Increase in Nos who felt in control of their breathing

Increase in Nos who felt they had techniques/exercise to manage their breathing

Very high satisfaction with the course

Very likely to continue using the techniques learnt on the course

Felt more able to undertake physical activity

Better understanding of how to manage breathlessness

npj | Primary Care Respiratory Medicine
www.nature.com/npjpcrm

PERSPECTIVE OPEN

The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease

Anna Spathis[1,2], Sara Booth[2], Catherine Moffat[1], Rhys Hurst[1], Richella Ryan[2], Chloe Chin[1] and Julie Burkin[1]

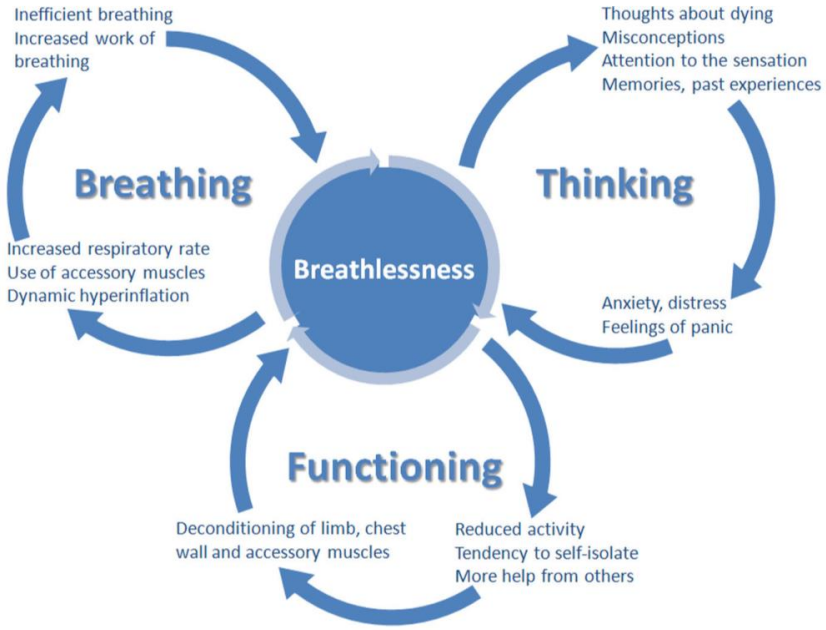


Fig. 1 The Breathing, Thinking, Functioning clinical model

Table 2. Categorisation of symptom management approaches according to Breathing, Thinking, Functioning domain

Breathing	Thinking	Functioning
Breathing techniques	Cognitive behavioural therapy	Pulmonary rehabilitation
Handheld fan	Relaxation techniques	Activity promotion
Airway clearance techniques	Mindfulness	Walking aids
Inspiratory muscle training	Acupuncture	Pacing
Chest wall vibration		Neuromuscular electrical stimulation
Non-invasive ventilation		

NHS

NHS Patient Experience Framework

In October 2011 the **NHS National Quality Board (NQB)** agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. This framework outlines those elements which are critical to the patients' experience of NHS Services.

- **Respect for patient-centred values, preferences, and expressed needs,** including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;
- **Coordination and integration of care** across the health and social care system;
- **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings;
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Picker Institute Europe

Fast access to reliable healthcare advice

Effective treatment delivered by trusted professionals

Continuity of care and smooth transitions

Involvement of, and support for, family and carers

Clear, comprehensible information and support for self-care

Involvement in decisions and respect for patient's preferences

Emotional support, empathy and respect

Attention to physical and environmental needs

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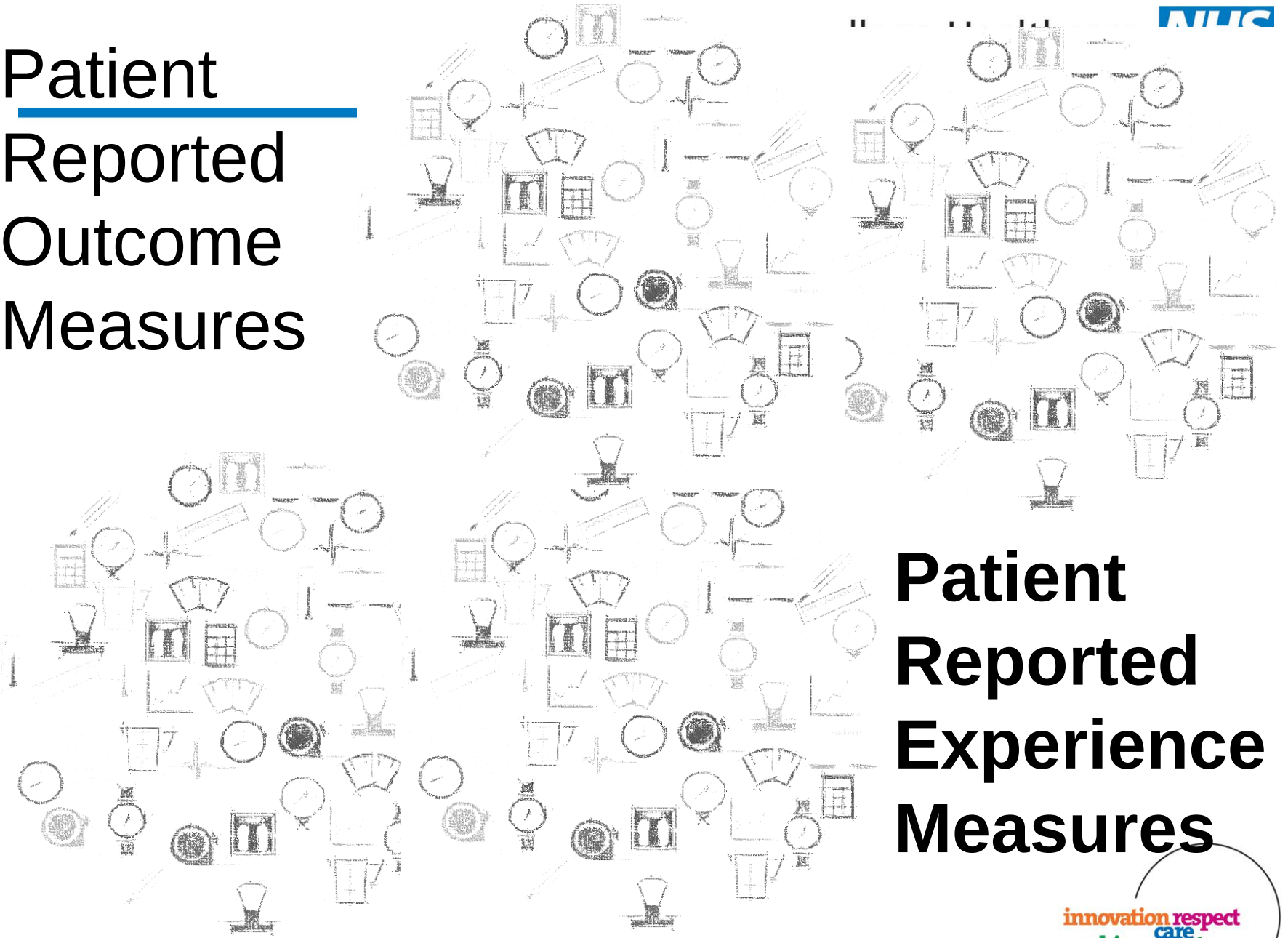
Patient Reported Outcome Measures



Patient Reported Experience Measures

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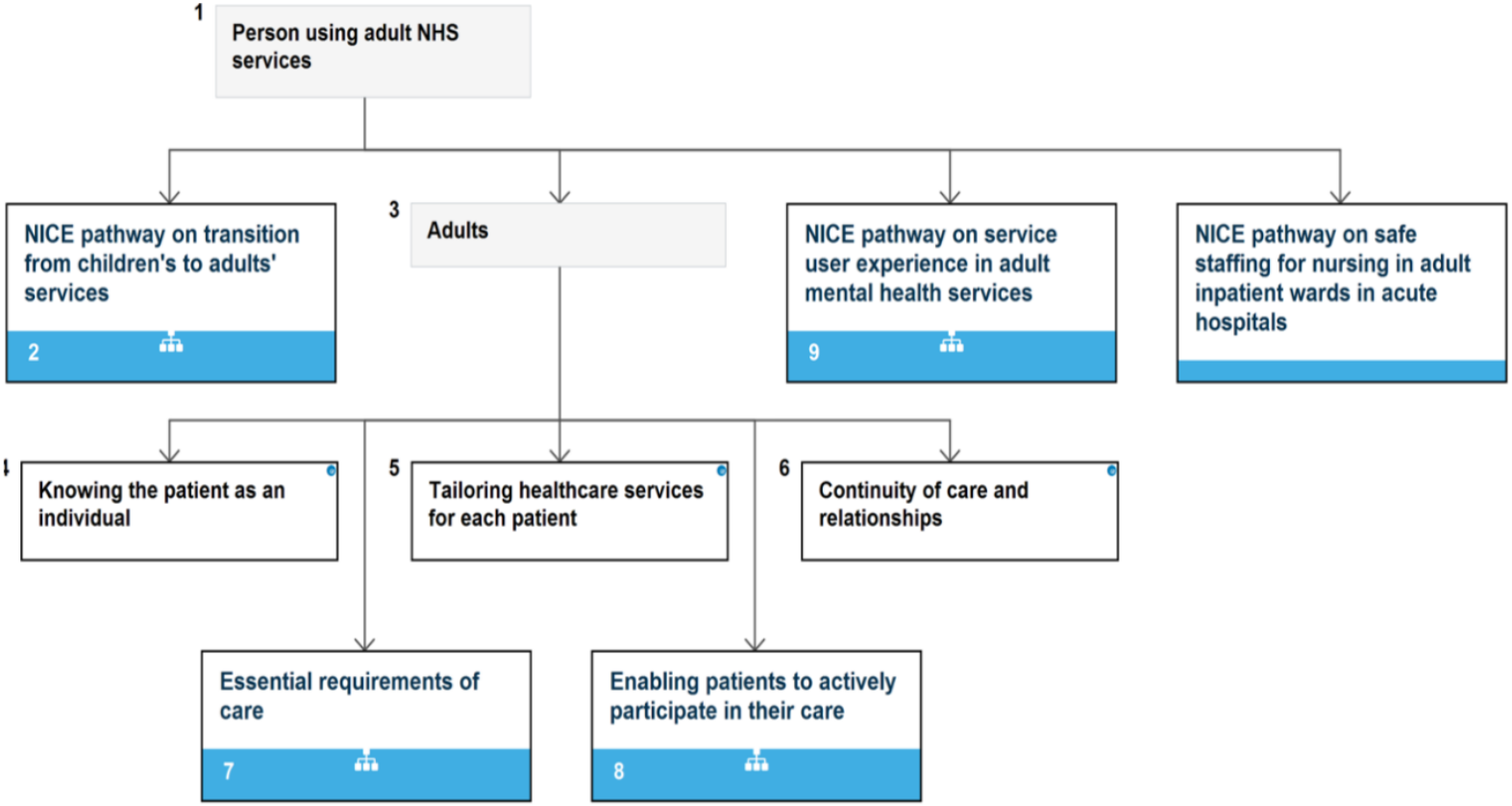
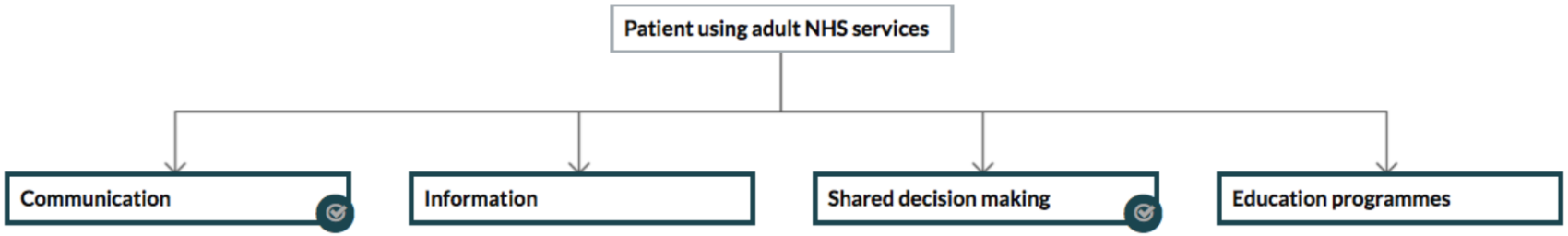
Patient experience in adult NHS services overview

NICE Pathways




Patient using adult NHS services
Communication
Information
Shared decision making
Education programmes

Imperial College Healthcare NHS
NHS Trust

Patient Reported Experience Measure (PReM) For IPF

Context

- Commitment to patient-centeredness
- Patient-reported experience metrics to standardise comparative information
- Monitor and measure service performance

To influence provider behaviours to become more patient-centered

To increase patient adherenc concordance and engagemen

To improve communication, patients' health experience, satisfaction with care, and fficient use of health resources

Approach

Patients and caregivers – discussion aligned to NHS Patient Experience Framework (NPEF) principles

Respect for patient-centred values & preferences	Welcome the involvement of family and friends
Coordination and integration of care	Information, communication , and education
Emotional support	Transition and continuity
Physical comfort	Access to care

Outcomes and next steps

- Patient centered IPF-PREM
- a valuable quality indicator for IPF service delivery at all stages of the disease trajectory, complementing existing IPF Patient Reported Outcome Measures (PROMs)
- PREM data will enable commissioners and providers to improve quality of the services and patients' experience of care

"Having choice reinforces the patient-practitioner partnership interaction and allows you to take responsibility for your own health"

Focus group patient

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Anne –Marie Russell 2017

JWP initiative with Roche

Shared Pathways of Care

- Understanding the patient experience of a service is becoming increasingly important
- The stakeholder voice is essential
- There is evidence that links good patient experience to good outcomes of care
- Initiatives that contribute to an improvement of the patient experience of the pathway of care in Lung fibrosis are needed

NHS England Domain 4 Ensuring that people have a positive experience of care

British Lung Foundation The battle for breath the impact of lung disease in the UK BLF 2016

Innovations: Summary

- Integrated care pathways
- Communications and digital health technologies
- Supporting self care management
- Instruments to measure Patient experience

Thank you

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- Anne Marie Russell ILD Nurse Consultant
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- Elizabeth Leung ILD CNS ICHNT
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- Arnie Dattab ILD Consultant ICHNT
- Raminder Aul ILD Consultant ICHNT
- Helen Crawford PA ILD

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END

- Fast access to reliable healthcare advice
- Effective treatment delivered by trusted professionals
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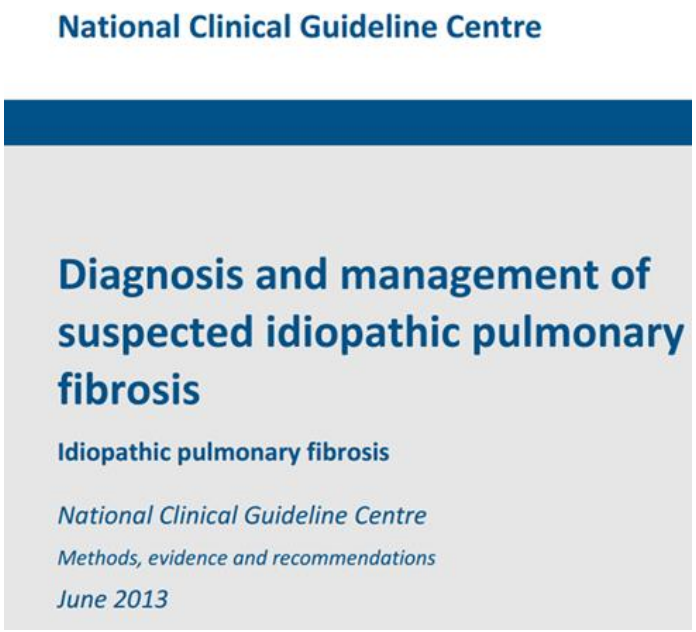
- Clear, comprehensible information and support for self-care
- Involvement in decisions and respect for patient's preferences
- Emotional support, empathy and respect
- Attention to physical and environmental needs

Patient-centred care



- 1.1 Awareness of clinical features of idiopathic pulmonary fibrosis
- 1.2 Diagnosis
- 1.3 Information and support
- 1.4 Prognosis
- 1.5 Management
- 1.6 Review and follow-up

Anti-fibrotic therapy

Pirfenidone for treating idiopathic pulmonary fibrosis

Technology appraisal guidance
Published: 24 April 2013
nice.org.uk/guidance/ta282

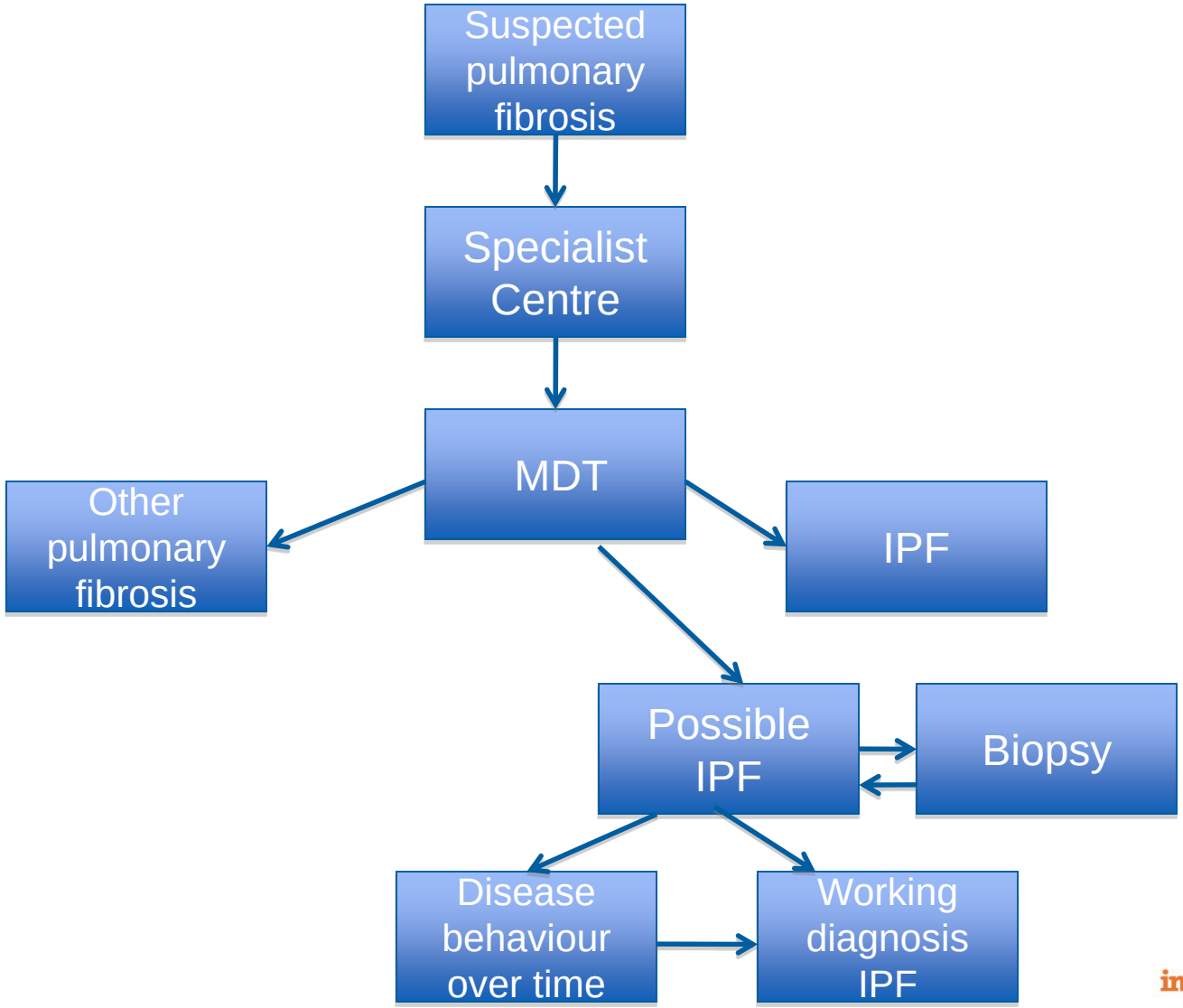
NICE guidance

Nintedanib for treating idiopathic pulmonary fibrosis

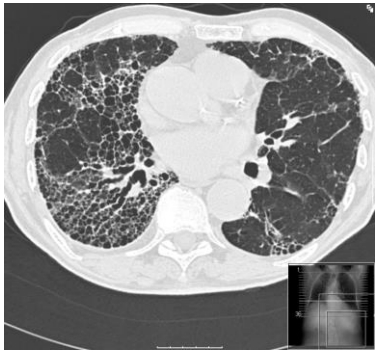
Technology appraisal guidance
Published: 27 January 2016
nice.org.uk/guidance/ta379

AMERICAN THORACIC SOCIETY DOCUMENTS

An Official ATS/ERS/JRS/ALAT Clinical Practice Guideline: Treatment of Idiopathic Pulmonary Fibrosis
An Update of the 2011 Clinical Practice Guideline



Management approach



Do nothing- monitor

AIM :to slow the disease, reduce Progression, unable to reverse honeycomb change.

AIM :reverse some of the inflammation

Lung Inflammation and fibrosis

Steroids
Immunosuppressants
Rituximab

IPF

Antifibrotic agents
Pirfenidone
Nintedanib

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Close communication with local hospital/GP

Treatment

- When to treat
- Predictors of progression, biomarkers
- Variable progression in IPF- heterogenous