

## **Supplementary file 1: Global ILD characterisation study questionnaire – English Language**

Dear Colleague,

This survey is part of an academic, global research initiative to understand how patients with Interstitial Lung Disease (ILD) are being diagnosed in your centre, your country and around the world. It is the first of a two-part project, the second of which will explore how diagnostic practices affect the diagnosis of idiopathic pulmonary fibrosis (IPF).

Your participation and contribution is of great value to help build a more complete picture of current diagnostic practice around the world. The survey findings will be published in a peer review respiratory journal for the benefit of the ILD community.

The survey has been reviewed and approved by the University of Southampton Faculty of Medicine Ethics Committee in the United Kingdom. It asks a little about you and about your centre – its case load, diagnostic practice case load, access to licensed IPF therapies. Finally you will be asked to indicate if you would like to take part in the second phase of this study. In total, it should take no more than 30 minutes to complete. All the information you provide will be securely handled during and after the study (see confidentiality details below).

Please note, the survey has been developed for completion by someone directly involved in the diagnosis of ILDs.

Please answer every question as completely as you can and provide contact details at the end if you wish to participate in the second phase of this work. Should you

have any questions or queries, please direct these to:

ILD@effectivenessevaluation.org

Our sincere thanks.

Luca Richeldi, Fernando Martinez, Kevin Flaherty, Simon Walsh, Jeffery Myers on behalf of the Respiratory Effectiveness ILD Working Group

### **Purpose of Research**

You are being asked to participate in a research study designed as a survey to collect data on the diagnosis of Interstitial Lung Disease (ILD). You are being asked to participate in this research study because you have been identified by an ILD expert in your country as working at centre that diagnoses ILD. Your participation will involve answering an on-line survey and will take about 15 minutes to complete. By completing this survey, you are giving your consent to participate in this research study.

**Confidentiality:** All information gathered from the study will remain confidential.

Your individual identity as a participant will not be disclosed. Your responses will be aggregated with other data and curated within a research database that will be analysed for the a priori purposes of the study. Site-specific data will only be available to the Principal Investigators (PI) on the REG ILD research team. During the study, data will be held securely within the Qualtrics e-survey system, governed by this data security statement. On completion of data capture phase, data will be deleted from Qualtrics and transferred to by REG's password protected cloud-based management systems Smartsheet, working to this security statement. Only authorized members of the REG Research team (i.e. Assigned REG Researchers, Study PIs, REG's Chief Scientific Officer and members of the study Steering

Committee) will be provided with the login details to access the study dataset via Smartsheet. Only the Respiratory Effectiveness Group (REG) ILD research team will have access to the research materials and data. Requests to view the data from outside the REG ILD research team will be considered on a case-by-case basis via an application to the REG.

**Voluntary Participation / Withdrawal Without Prejudice:** Participation in this research study is voluntary; refusal to participate will involve no penalty. Each participant is free to discontinue participation in this research study at any time without prejudice from this institution.

**Risks and Discomforts:** You will not be at physical or psychological risk and should experience no discomfort resulting from the research study methods. If you are uncomfortable with any questions in the survey you can stop taking at any time without penalty.

**Costs and/or Payments to Subject Participation in Research:** You will not be given remuneration for participation in the research study.

## QUESTION BANK

### ‘ABOUT YOU’

Q2.1 Which of the following best describes your medical specialty?

- ☐ Family Practice
- ☐ Internal Medicine / General Physician
- ☐ Pulmonology
- ☐ Critical Care
- ☐ Other \_\_\_\_\_

Q2.2 Are you personally involved in the diagnosis of ILDs at your centre?

- ☐ Yes
- ☐ No

If No Is Selected, Then Skip To End of Block

Q2.3 How many years have you been in clinical practice post specialization?

- ☐ ≤5 years
- ☐ 6-10 years
- ☐ 11-20 years
- ☐ 21-30 years
- ☐ 31-40 years
- ☐ ≥40 years

Q2.4 Indicate how much of your time at work is spent on each of the following activities:

	None of my time	A little of my time	A moderate amount of my time	A lot of my time	All of my time
Pre-clinical research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical research / clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Administrative activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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### **‘ABOUT YOUR CENTRE’**

Q3.1 In which country is your medical centre/practice located?

Q3.2 In which city / town is your medical centre/practice located?

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Q3.3 What is the name of your medical centre/practice?

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Q3.4 Do you work at an Academic or University Medical Centre?

☐ Yes

☐ No

Q3.5 Do you work at an ILD Centre?

☐ Yes

☐ No

☐

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### **‘ABOUT THE ILD CASE LOAD AT YOUR CENTRE’**

Q4.1 Approximately how many new cases/referrals of IPF does your centre diagnose in an average month?

\_\_\_\_\_ IPF (new cases/referrals)

Q4.2 Approximately how many new cases/referrals of Non-IPF ILD does your centre diagnose in an average month?

\_\_\_\_\_ Non-IPF ILD (new cases/referrals)

Q4.3 Of these newly diagnosed patients, what percentage are managed (treated and followed up) at your centre?

\_\_\_\_\_ IPF

\_\_\_\_\_ Non-IPF ILD

Q4.4 Please think about all of your new cases/referrals for ILD. Approximately what percentage are:

\_\_\_\_\_ Self-referred / not Physician referred

\_\_\_\_\_ Referred by another Pulmonologist

\_\_\_\_\_ Referred by a Rheumatologist

\_\_\_\_\_ Referred by a General Practitioner / Primary Care Physician

\_\_\_\_\_ Other

Q4.5 Which of the following tests do the majority of your suspected ILD patients receive:

- Prior to arriving at your centre (first column)?
- At your medical centre/practice (second column)? Both columns should be selected for tests that are conducted before the patient arrives at your centre and then repeated at your centre.

	Prior to arriving at your centre	At your centre
Lung Function: Spirometry	<input type="checkbox"/>	<input type="checkbox"/>
Lung Function: Diffusing Capacity of the Lungs for Carbon Monoxide (DLCO)	<input type="checkbox"/>	<input type="checkbox"/>
Chest X-ray	<input type="checkbox"/>	<input type="checkbox"/>
Chest High-Resolution Computed Tomography (HRCT)	<input type="checkbox"/>	<input type="checkbox"/>
Electrocardiogram (ECG)	<input type="checkbox"/>	<input type="checkbox"/>
Echocardiogram	<input type="checkbox"/>	<input type="checkbox"/>
Polysomnograph	<input type="checkbox"/>	<input type="checkbox"/>
Helicobacter pylori Serology	<input type="checkbox"/>	<input type="checkbox"/>
Rheumatologic Serology	<input type="checkbox"/>	<input type="checkbox"/>
Type III Antibodies	<input type="checkbox"/>	<input type="checkbox"/>
B-type Natriuretic Peptide (BNP) Blood Test	<input type="checkbox"/>	<input type="checkbox"/>

Six Minute Walk Testing	<input type="checkbox"/>	<input type="checkbox"/>
Cardiopulmonary Exercise Testing	<input type="checkbox"/>	<input type="checkbox"/>

Q4.6 What percentage of your new ILD cases/referrals receive each of the following tests PRIOR to arriving at your centre?

- \_\_\_\_\_ Surgical Lung Biopsy
- \_\_\_\_\_ Transbronchial Biopsy
- \_\_\_\_\_ Endoscopic Lung Cryobiopsy
- \_\_\_\_\_ Broncho-Alveolar Lavage

Q4.7 What percentage of your new ILD cases/referrals receive each of the following tests AT your centre?

- \_\_\_\_\_ Surgical Lung Biopsy
- \_\_\_\_\_ Transbronchial Biopsy
- \_\_\_\_\_ Endoscopic Lung Cryobiopsy
- \_\_\_\_\_ Broncho-Alveolar Lavage

Q4.8 Please indicate the approximate distribution of diagnoses assigned to ILD cases/referrals at your centre:

- \_\_\_\_\_ Idiopathic Pulmonary Fibrosis (IPF)
- \_\_\_\_\_ Idiopathic Non-Specific Interstitial Pneumonia (NSIP)

\_\_\_\_\_ Other Idiopathic Interstitial Pneumonias (e.g., Desquamative interstitial pneumonia (DIP); Acute interstitial pneumonia (AIP); Respiratory bronchiolitis interstitial lung disease (RB-ILD); Cryptogenic organizing pneumonia (COP); Lymphocytic interstitial pneumonia (LIP))

\_\_\_\_\_ Sarcoidosis

\_\_\_\_\_ Hypersensitivity Pneumonitis (HP)

\_\_\_\_\_ Connective Tissue Disease related ILD

\_\_\_\_\_ Exposure-related ILD (drug or environmental)

\_\_\_\_\_ Unclassifiable ILD

\_\_\_\_\_ Other (please specify)

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#### ‘ABOUT YOUR DIAGNOSTIC PRACTICE’

Q5.1 Do you have meetings at your centre/practice to discuss new ILD cases/referrals?

☐ Yes

☐ No

If No Is Selected, Then Skip To 5.2.b

Q5.2 Approximately what percentage of the meetings you attend to discuss new ILD cases/referrals at your centre/practice are "formal" meetings and what percentage are more "informal" meetings?

(Must total 100%)

Please consider:

- Formal meetings to be those that are scheduled / pre-planned.
- Informal meetings to be those that are more spontaneous / unplanned.

\_\_\_\_\_ Formal Meetings

\_\_\_\_\_ Informal Meetings

Q5.3 What percentage of new ILD cases/referrals are typically presented at:

(Must total 100%)

\_\_\_\_\_ Formal Meetings ONLY

\_\_\_\_\_ Informal Meetings ONLY

\_\_\_\_\_ BOTH Formal and Informal Meetings

\_\_\_\_\_ Not Presented

The following questions refer only to your FORMAL meetings.

Q5.4 How frequently do these formal meetings take place at your centre/practice?

- ☐ More than once a week
- ☐ Once a week
- ☐ Once every 2 weeks
- ☐ Once every 4 weeks
- ☐ Less than once every 4 weeks

Q5.5 Are Non-ILD patient cases also discussed at these formal meetings?

- ☐ Yes
- ☐ No

Q5.6 Approximately how many ILD cases/referrals are discussed at each formal meeting?

- ☐ 1–5 cases
- ☐ 6–10 cases
- ☐ 11–15 cases
- ☐ 16–20 cases
- ☐ >20 cases

Q5.7 How long does each formal meeting generally last?

- ☐ 30 minutes
- ☐ 31-60 minutes

- ☐ 61-90 minutes
- ☐ 91-120 minutes
- ☐ >120 minutes

Q5.8 What is the USUAL format of your formal meetings? (Select all that apply)

- ☐ Face-to-face
- ☐ Telephone or teleconference
- ☐ Videoconference (e.g. Skype, WebEx, etc.)
- ☐ Multi-Media Messaging, e.g. WhatsApp

Q5.9 Which of the following disciplines REGULARLY attend these formal meetings?

(Select all that apply)

- ☐ Pulmonology
- ☐ Radiology
- ☐ Histopathology
- ☐ Rheumatology
- ☐ Clinical Immunology
- ☐ Thoracic surgery
- ☐ Lung Transplant
- ☐ Palliative care
- ☐ Respiratory Nursing
- ☐ Physiotherapy
- ☐ Fellows/registrars
- ☐ Junior trainees

- ☐ Medical students
- ☐ Pharmacy
- ☐ Care coordinators

Q5.10 What other information is specifically discussed and/or documented during the formal meeting?

	Discussed	Documented
Available diagnostic evidence	<input type="checkbox"/>	<input type="checkbox"/>
Recommended diagnostic tests	<input type="checkbox"/>	<input type="checkbox"/>
Diagnosis	<input type="checkbox"/>	<input type="checkbox"/>
Prognosis	<input type="checkbox"/>	<input type="checkbox"/>
Predictive markers of progression	<input type="checkbox"/>	<input type="checkbox"/>
Therapeutic treatment - currently available drugs	<input type="checkbox"/>	<input type="checkbox"/>
Clinical trials	<input type="checkbox"/>	<input type="checkbox"/>
Supportive care	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care	<input type="checkbox"/>	<input type="checkbox"/>

Suitability for transplant	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

If answered 'No' to Q5.1

Q5.2b What are your typical next steps when you cannot confidently diagnose a case of ILD?

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Q5.3b Which of the following specialties do you consult with when you cannot confidently diagnose the ILD?

- ☐ Pulmonology
- ☐ Radiology
- ☐ Histopathology
- ☐ Rheumatology
- ☐ Clinical Immunology
- ☐ Thoracic surgery
- ☐ Lung transplant
- ☐ Palliative care
- ☐ Respiratory nursing
- ☐ Physiotherapy
- ☐ Fellows / registrars
- ☐ Juniors / trainees
- ☐ Medical students

- ☐ Pharmacy
- ☐ Care coordinators

#### **'ABOUT IPF DRUG ACCESS'**

Q6.1 Do you have access to the anti-fibrotic agents nintedanib and/or pirfenidone at your centre?

- ☐ Yes
- ☐ No

Q6.2 Is Multi-Disciplinary Team (MDT) permission required to access nintedanib and/or pirfenidone?

- ☐ Yes
  - ☐ No
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#### **'FURTHER RESEARCH OPPORTUNITIES'**

Q7.1 Would you be interested in participating in a linked IPF diagnostic agreement study? About the study: the study will explore the implications of diagnostic practice variation across different centres on IPF diagnosis. If you are interested in participating, you will be sent a number of selected study cases to review and diagnose. The agreement study is expected to commence in early 2017.

- ☐ Yes
- ☐ No

Q7.2 For future study information, please provide the name of the centre in which you work and a principal point of contact and contact email address:

(a) Name of Centre

(b) Surname of Contact

(c) Email Address of Contact