



WORKING GROUP MEETING MINUTES: ILD/IPF Working Group

15th October 2024
ICLAF Athens

Meeting details			
Meeting location	"THEATRON" Cultural Center "Hellenic Cosmos" (room TBC), Athens / MS Teams		
Meeting date	Tuesday 15 th October 2024		
Meeting time	14.15-15.15 local time		
Chair(s)	Pilar Rivera-Ortega		
Attendees	<table border="0"> <tr> <td>Gina Amanda Katerina Antoniou Arata Azuma Harshana Bandara Jack Callum Tamera Corte Juan Enzghelmayer Graham Lough George Margaritopoulos</td> <td>Pilar Rivera-Ortega Laurence Pearmain Claudia Ravaglia Abdullah Sakkat Stefan Stanel Gabriela Tabaj Erini Vasarmidi Bavi Vijayakumar</td> </tr> </table>	Gina Amanda Katerina Antoniou Arata Azuma Harshana Bandara Jack Callum Tamera Corte Juan Enzghelmayer Graham Lough George Margaritopoulos	Pilar Rivera-Ortega Laurence Pearmain Claudia Ravaglia Abdullah Sakkat Stefan Stanel Gabriela Tabaj Erini Vasarmidi Bavi Vijayakumar
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Objectives			
1	Outline of steps in the 'Towards Standardisation in IPF / PPF Registry Data' flagship project		
2	Discussion of individual projects		
Items			
Outline of steps in the 'Towards Standardisation in IPF / PPF Registry Data' flagship project	<p>The Working Group were thanked for their participation for the previous vMDT project, which was published in ERJ Open Research.</p> <p>A brief outline was provided on the process involved in the 3 research projects within the flagship project: Towards Standardisation in IPF / PPF Registry Data:</p> <ol style="list-style-type: none"> 1. Identifying Key Variables through a Global Prioritisation Task 2. Identifying Data Elements for Disease Management 3. Development of a Global Composite Staging System for IPF / PPF Disease Progression 		



Discussion of individual projects

As Project 3 was an example of an ideal end-goal project utilising the dataset created in Projects 1 and 2, the focus was on the first 2 projects in the stream.

Project 1: Identifying Key Variables

The group expressed support for the research design of Project 1, including the decision to involve patients. Proposed methods for engaging patients were discussed, including:

- Reaching out to patient organisations such as the European Lung Federation and PF Warriors.

Project 2: Identifying Data Elements for Disease Management

The main concern raised was the challenge of standardising diagnostic procedures across regions. Key points discussed:

- **Regional Comparison:** Procedures can be compared across regional cohorts, even in cases where certain procedures are unavailable.
- **Correlations Between Procedures:** The project aims to assess correlations between different procedures to determine which variables are essential, with proxies identified as alternatives where applicable. The goal is to standardise processes where feasible.

Additional Variables:

- Pulmonary Hypertension parameters will be included in the data collection.

Challenges and Solutions

The group acknowledged difficulties in involving many sites with relatively few patients, touching on issues like budget constraints, contracting, ethics approval, and data quality.

Several suggestions were made to address these concerns:

- **Minimum Patient Numbers:** It was suggested that a minimum number of patients per site (e.g., 30 with complete data) could be set to ensure site authorship.
- **Variation in Disease Subgroups:** There is a need to ensure sufficient variation in disease subgroups, such as age and sex.
- **Data Collection Platform:** REDCAP was proposed as the preferred platform for data collection across all sites.
- **Timeline Considerations:** The group discussed the need to define how frequently measurements should be taken and the overall project timeline.

New Approaches to Data Collection

- A novel idea was proposed to gather QoL data directly from patients through patient organisations, running parallel to data collection from clinical sites.
- The INBUILT app was suggested as a useful tool for this purpose.



Action Points

- Revision of research proposals based on feedback from Working Group
- Finalise proposals with steering committee and send to potential funders.