WORKING GROUP MEETING AGENDA: ILD/IPF Working Group

19th March 2026
REG Summit Palma de Mallorca

Meeting details	
Meeting location	Meliá Palma Marina hotel, Palma de Mallorca/ MS Teams
Meeting date	Thursday19th March 2026
Meeting time	13.00 -14.00 CET
Chair(s)	Pilar Rivera-Ortega
Objectives	
1	Update of steps in the 'Towards Standardisation in IPF / PPF Registry Data' flagship project
2	Discussion of FATE-PF 'Fibrotic ILDs Acute Exacerbations Trajectory'
3	Update of 'Genomic Testing for ILD' project
4	Discussion of 'Genetic determinants of pulmonary hypertension in ILD' project
5	New project ideas

Items	
Update of steps in the 'Towards Standardisation in IPF / PPF Registry Data' flagship project	Project aims: • Identify essential and desirable clinical registry variables. • Create a registry standardization framework. • Create a global standardized and refined dataset. • Develop a global composite staging system for disease progression.
Discussion of FATE-PF 'Fibrotic ILDs Acute Exacerbations Trajectory'	Project aims: 1. To develop and externally validate time-specific prognostic models predicting mortality following acute exacerbations of pulmonary fibrosis at clinically meaningful horizons (<5, <30, and <90 days). 2. To identify and characterise distinct exacerbation phenotypes, distinguishing frailty-dominant trajectories from potentially modifiable presentations. 3. To create CT-agnostic prognostic tools and quantify the impact of CT availability on risk stratification, trial eligibility, and equity of care.

	4. To evaluate the health-economic impact of acute exacerbations of pulmonary fibrosis, linking prognostic strata to healthcare utilisation, costs, and value-based decision-making.
Update of 'Genomic Testing for ILD' Delphi project	Project aims: • Identify centres around the world where genomic testing is offered for ILD cases and characterize the existing practice (mapping). • Identify the core features for establishing a Genetics-ILD service, taking into account current practices and disparities in access to genomic testing and genetic counselling. • Reach consensus on the utility of genomic testing and screening of relatives for early ILD diagnosis.
Discussion of 'Genetic determinants of pulmonary hypertension in interstitial lung disease' project	Project aims: • Investigate the overlap and distinction of genes associated with Group 3 pulmonary hypertension (PH) in Interstitial Lung Disease (ILD) patients to highlight unique genetic markers for targeted screening and therapeutic interventions. • Identify genetic variants linked to the development of PH in ILD patients. • Compare genetic profiles between ILD patients with and without PH, as well as with other respiratory patients, to highlight unique genetic signatures associated with PH development in ILD.
New project ideas	New project ideas will be discussed • Dr Asmita Mahta - New multicentre ILD registry in India

MS Teams Link:
Join:
https://teams.microsoft.com/meet/33841572755011?p=YAgaCtcypc1oai3nMi

Meeting ID:
338 415 727 550 11
Passcode:
DH9HL2AH