WORKING GROUP MEETING MINUTES: 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

Attendees

Online: Linda Brown (LB), Baptiste Coxam (BC), Arata Azuma (AA), Vishnu Nair (VN), Nazia Chaudhuri (NC), Diego Federico Funes (DFF), Zoran Arsovski (ZA), Joan Soriano (JS), Alan Kaplan (AK), Silvia Correlgé Conte (SCC), Andrew Li (AL), Laurence Pearmain (LP), Asmitha Mehta (AM)

In-person: Pilar Rivera-Ortega (PRO), Helena Emery (HE), Katerina Antoniou (KA), Athena Gogali (AG), Emmanouil Symvoulakis (ES), Gabriela Ispas (GI), Aditi Desai (AD), Graham Lough (GL), Ronald Dandurand (RD), Ceri Banks (CB), Shahid A Syed (SAS).

Items	
PRO – Welcomed all to the summit and started meeting	
Update of steps in the 'Towards Standardisation in IPF / PPF Registry Data' flagship project	HE – Introduced project briefly; this is a project created by the work group members noticing the need for more consistency across the various IPF registries and for future registries to make the data collected more easily combined globally, allowing research to be cheaper, faster and with a larger cohort, using data across multiple registries. This project aims to create a standardisation tool to allow for consistent data collection, to enable larger studies to be conducted more easily, leading to the creation of a disease staging system similar to that in cancer. The project is

	separated into 3 more manageable projects with the aims for project one being: • 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. We have secured 50% of the funding for this project and are awaiting the decision on the remaining 50%, with further talks in early April. KA – is this study for a registry protocol? Are we going to be recording patients? PRO – No, this is to define the features of registries across the globe. We want to be able to compare data between registries but this is currently difficult as they collect data differently. The first part of this project is that we need a consensus of what are the essential variables to collect, how to collect them and then test on a data set that tool or guideline works.
Discussion of FATE-PF 'Fibrotic ILDs Acute Exacerbations Trajectory'	HE gave a quick introduction to the study – This project aims to: 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. This proposal is still in development and we are looking for funding. GI – What is the timeline and budget for this project? PRO – This is still in development, we are looking for funding, this could be a hybrid funding situation or shared with multiple supporters. Laurence Pearmain, Laura White and I are participating in the project, and we currently have ~ 800 ILD/PF patients who have experienced an acute exacerbation in the UK. We used a retrospective method with a database that includes clinical characteristics, lung function, radiological

	patterns and other data from all stages of the patient care. This work was part of a previous project, and the data will be used in the first phase of the proposed project, so the information is already available. For the second phase, the data will be global, and we will need more patients, but first we should complete phase 1. GL – A data question. Have you got 500 patients with acute exacerbation or patients with PF but no exacerbation? PRO – All patients had a clinical diagnosis of acute exacerbation of ILD/PF. However, this does not mean that all of them had a reliable diagnosis of it. Some did not undergo CT scans, which could be because the patients were very ill upon admission (on high-flow nasal cannula) or because this test was not considered necessary at the time of admission. In that case, how do we establish the acute exacerbation diagnosis? By extrapolating existing knowledge? We need to provide guidance to the respiratory community in general. GL – Do you have data on mortality or transplant? PRO – In general, 50% of patients with acute exacerbation of PF passed away in the hospital. Of the 50% who are discharged, approximately 50% of them die within the following six months. We should bear this in mind; a true diagnosis of acute exacerbation of PF has a high mortality rate. While some patients may be candidates for a lung transplant (if they were already on the active transplant list), only a small number actually receive one. KA – Committee of guidelines – IPF and fibrotic lung disease. There are different treatments approved with the use of anti-fibrotics' and ILDs. It would be nice if we could differentiate ILD by exacerbation, differentiate worsening of exacerbation and see if there is a difference in mortality. We could account for the worsening of the condition, need to recognise how we think about acute exacerbation with high mortality vs worsening when it could be due to an infection where the outcomes can be better. ES – This is a goof observation. Care needs to be considered as if we would like to look at optimising treatment. We would look at the whole history after the exacerbation as failure of another organ later after the exacerbation could be linked to the initial exacerbation. PRO – We will take this into consideration. Thank you for your suggestion.
Update of 'Genomic Testing for ILD' Delphi project	PRO summarised the project, the aims for this are: • 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, considering 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. We have completed the first phase of this study and will circulate the second phase of the Delphi soon. The publication/manuscript from phase one will be out later this year and create a map for patients and clinicians to see. AD - Would the population for genetic tests be opened up to relatives? PRO – Currently in the UK, genetic testing is only offered to relatives if a likely pathogenic / pathogenic variant (formerly called 'mutation') has been found in the patient with PF (called proband). Genetic tests for relatives are generally offered by geneticists, prior genetic counselling. We do not currently perform lung screening tests on relatives as part of routine clinical practice in the UK. However, screening programmes exist as part of non-commercial research; and there is currently an exploratory phase 3 clinical trial offering the possibility of screening first-degree relatives of patients with PF for interstitial lung abnormalities (ILAs). Globally, there are diverse clinical practices regarding the recommendations and tests that should be offered to first-degree relatives of patients with PF, so a consensus is needed on this matter.
Discussion of 'Genetic determinants of pulmonary hypertension in interstitial lung disease' project	HE introduced the 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. We have had some initial interest from funders and we are currently updating the proposal to include an additional registry, had previously planned to just use the UK Biobank but will need to use another one such as Our Future Health to have a large enough study population. We are also outsourcing the genomics to someone with experience of conducing GWAS to ensure a reliable study. GL – The Biobank doesn't have enough patients with PH with ILD so need to bulk up the sample elsewhere. We can do analysis in separate banks then combine outputs

	PRO – Lucilla, one of the leads / main driving forces behind this project, who sadly passed away, dedicated a lot of time to this idea and we want to continue the work. AG – The data from the UK biobank, does it have echo GL - the biobank uses hospital data ES – Some patients might not be sure if it is with PH or not, need to look for common genomic pathways. PH-ILD and other respiratory conditions to look for similarities. This will strengthen the sample. AG – This will be an interesting study AA – Can you measure PVR to model risk? PRO – Thank you the initial idea came from PH focus, anyone interested in PH, as well as genetics experts, is welcome to join. This is a genome-wide association study (GWAS), and our goal is to identify genes that could/may be related to PH and ILD. While risk factors could also be identified, this is not the purpose of this study. RD – How are you going to identify PH? GL – Based on using the hospital diagnosis of group 3 pH RD – If you pull 100 CT scans and do a PAH to predict you can then check the coding against the database. If the database isn't good then you can use the CT to check. PRO – This is a biobank database, we need to rely on the coding as a first step, GWAS; then we could do prospective comparison of CT scans and diagnosis. This is possibly a future project.
New project ideas	Dr Asmita Mahta (AM) gave summary of project - New multicentre ILD registry in India. We are creating an Indian ILD registry, India has a large and underrepresented ILD population and has the potential to strengthen ILD global evidence. We already have 38 centres signed up across 22 cities. The database will have CT scan images, PFT data and allow for follow up. We are reaching out to you at REG as an opportunity to collaborate and advise in the creating of the registry. We have funding for this so we are not looking for funding, just collaboration to help advise on creation. PRO – The current ILD registry standardisation project and biobank project are highly relevant to your work,

	REG carries out projects worldwide, how would you like REG to support yours? How is it funded? AM – This is funded and supported through the collaborating University and hospital where I work, so it is fully funded. PRO – We are trying to have as global a presence as possible, is there a possibility of expanding your registry to other Asian countries? Any ideas? AM - Is there a way we could be part of the REG registry project? PRO – You are now part of the ILD working group and will have the opportunity to meet with other members and offer suggestions on the registry project and other aspects, especially in defining the variables we should include. Let's keep in touch and we will help you in any way we can. LP – Feel free to drop me an email about samples and I can help out how I can. RD – Do you know Sandeep? Speak to him. Oscillometry might be the missing link in the ILD space. It gives a clear signature, different from COPD and would provide you with unique data. AM – Thank you, we have oscillometry. RD – Link up with Sandeep about it. HE – Any other project or ideas you want to discuss here? AA –I would like to propose another ILD biomarker, that is good responsible to treatment with anti-fibrotic agents in real world management. I would like to look at incidence of lung or systemic cancer and ILD antifibrotic treatment, Which might be association with survival benefit. RD – There is a CT scan metric in COPD and ILD it can be done on historic scans to look at diagnosis and

	disease progression. Could it be a new project and validated more widely?