



## Minutes: Working Group Meeting: IPF/ILD

3<sup>rd</sup> February 2026  
Microsoft Teams

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Meeting details	
Meeting location	Microsoft Teams
Meeting date	3 <sup>rd</sup> February
Meeting time	13:00 – 14:00 GMT
Chair(s)	Pilar Rivera Ortega
Agenda	
1	Brief Introductions
2	Update on ILD/IPF Registry standardisation proposal
3	Update on ILD-PH Genomics proposal
4	Update on Fibrotic ILD Acute Exacerbation Trajectory
5	Update on ILD Genomics Delphi
6	Future Project ideas
7	Any other business

Attendees: Pilar Rivera Ortega (PRO), Helena Emery (HE), Laurence Pearmain (LP), Graham Lough (GL), Jessica Shore (JS), Fernando Martinez (FM), Nazia Chaudhuri (NC), Gina Amanda (GA), Katerina, Claudia (KC), Eirini Vasarmidi (EV), Deborah Assayag (DA) and Azuma Arata (AA)

Minutes	
1. Brief Introductions	
2. Update on ILD/IPF Registry standardisation proposal	<p>HE provided project summary and status update: (proposal attached) BMS 50% funded, Waiting to hear from BI regarded remaining 50%</p> <p>GL – If BI don't come through can REG fund the remaining 50%?</p>



	<p>HE – We will wait to hear from BI before further consideration.</p> <p>PRO – It is a good idea to have a Plan B for funding so REG is a possibility</p> <p>GL – is the funding for the whole project or just part one?</p> <p>HE – Just part one</p>
<p><b>3. Update on ILD-PH Genomics proposal</b></p>	<p>HE provided project summary and status update: (proposal attached, requires updating) United Therapeutics is interested after a long wait. Need to revise the budget, proposal and biobanks. Looking at using UK Biobank and USA “ All of Us Research Program” which contains 613,000 bio samples. 350,000 with hypertension (all hypertension). Require external expertise for genetic analysis work.</p> <p>NC – Are you planning on using UK Biobank?</p> <p>HE – Yes planning on using UK Biobank and a second one, likely to be the larger US one.</p> <p>GL – When I started looking into this, I did consider including other respiratory conditions, but this wouldn’t improve the sampling. Also looked at PH and decided on strict group 3 PH and associated ICD10 codes. Also looked at difference in telomere length, PH have short length, ILD and PH-ILD had the same. Looked into the UK Biobank sample size, and we will need more than just what is there. I am working with “Our Future Health”, so I will also look into their samples.</p> <p>LP – How well is PH characterised? And if using biobanks from different countries, we need to consider whether they characterise PH the same way. In the UK we primarily use Echocardiography. May differ elsewhere.</p> <p>PRO – Lucilla and I worked on this project, it will now need some input from a PH specialist and Genetics’ specialist. We also need to review and update the proposal. Can discuss further in March.</p> <p>HE to share Proposal to PRO/SC</p>
<p><b>4. Update on Fibrotic ILDs Acute Exacerbations Trajectory</b></p>	<p>LP provided summary and update: (outline attached) Developing a proposal, in early discussions with a possible funder.</p> <p>Planning on this being in three phases with one and two being funded as one project and phase 3 funded separately. BI is the funder approached as they have already funded the data collected which we would use in this study.</p>



	<p>GL – What prognostic modelling have you decided to use?</p> <p>LP – Multi-variant regression GL – What date horizons have been chosen? LP – 30 and 90 days post AE are clinically relevant and fairly well accepted. The earlier date (5 days post AE) will need to be looked at in the modelling to determine what is the best to look at, 5 days is just a guess at the moment. We would need to do a trajectory analysis to determine this.</p> <p>FP – Could you borrow data from ARDS literature?</p> <p>LP – May be possible but setting the event horizons based on our data may be better.</p> <p>GL – You could do a competing risk/multistate model which includes time but defines cumulative risk over time, would include risks for example, going for a transplant. GL to send textbook/paper to HE and PL on the model</p> <p>PRO – Competing risk analysis isn't too hard, have done this before</p> <p>LP – Also need to pin down the group phenotype, need to describe the biology of the different outcomes/groups, building in age etc to ensure it is useful and informative.</p>
<p><b>5. Update on ILD Genomics Delphi</b></p>	<p>PRO give summary and update: First round of Delphi is complete, we received over 300 responses, Abstract submitted to ATS and we have been accepted to present a poster on this first round data. shortlisting for round 2 of Delphi is underway with the aim of identifying the best practice for genetic testing in ILD.</p> <p>Looking for funding for the next step and thank you for those who have collaborated on this project.</p>
<p><b>6. Future Project ideas</b></p>	<p>NC – Longitudinal follow-up of Interstitial lung abnormality (ILA). In the UK we have ILARK</p> <p>PRO – Intend on doing a longitudinal follow-up, could do a prospective study</p> <p>KC – ILA, we will have results from our study at the end of February and could possibly discuss this in March ILAS could be part of a future project. PRO- would need to think of a funding strategy for ILAS, good to discuss in March</p>



**7. Any other business**

HE - Reminder of REG Summit on March 19<sup>th</sup> -21<sup>st</sup>  
ILD WG meeting: 19th March 13:00 - 14:00 CET.

PRO – summarised and closed meeting.