ERS 2019
WORKING GROUP MEETING MINUTES: ILD/IPF Working Group

29th September 2019
Novotel Madrid, Campo de las Naciones

Meeting details		
Meeting location	Novotel Madrid, Campo de las Naciones	
Meeting date	Sunday 29th September 2019	
Meeting time	12.00-13.00	
Chair(s)	Luca Richeldi (Naomi Launders)	
Attendees	Michael Walker Naomi Launders Sarah Lucas Graham Lough Kevin Flaherty Paul Reynolds Bertrand Verwee	Klaus-uwe Kirchgässler Paola Pattal Tony Durzo Nazia Chaudhuri Pilar Rivera Ortega Stefaiy Stamel
Objectives		
1	Updates from previous meetings	
2	Finalise the ILD-MDT phase II study	

Items	
1	• **The 1st phase of the ILD project was briefly described.** The paper from the first phase of the ILD has just been published. Details were given of the recruitment, methodology and findings.
2	• **Phase 2 of the ILD project was outlined.** It was mentioned that 97% of participating centres from phase 1 were interested in participating in phase 2. Each centre will be presented with electronic ILD dummy cases and asked to provide a diagnosis. Purpose of study: explore the diagnostic agreement between centres and between MDTs; and to identify the best practice MDT, and best practice given resources. • **The Veracyte study was described as a potential option to aid phase 2.** The digital platform through which MDTs could access dummy cases and make notes on diagnoses has not yet been decided. REG met with Veracyte at ATS and discussed the project with them. They need to validate their analysis tool by asking two separate MDTs in one centre to diagnose a dummy case, where one MDT has the tool and one does not. They

have completed a study in one setting but want to expand and have 96 digitized dummy cases. They don't need 457 centres, nor lower-middle income countries. They are interested in the list of centres gathered through phase 1.
There's an opportunity to work with Veracyte where the ILD project can utilise some of Veracyte's dummy cases; and Veracyte can access REGs list of centres from the phase 1. Additionally, the ILD project can advertise the Veracyte study to its centres. This would make the study easier to coordinate. They've spent 3-4 months already assessing platforms and choosing their digital supplier. Even just giving us a list of suppliers and what they thought of each supplier would help, but ideally using their supplier and cases is easiest. It was agreed that if Veracyte were willing to share and let us use their cases, it would be the route to take.

- **The logistics of the project were discussed**

The concern was raised that sending multiple cases out to MDTs was resource-consuming, as the whole MDT would need to meet to discuss a dummy case. The questions revolved around time needed to complete the task and the number of cases acceptable to give each centre. It needs to be clarified how many cases would be given to each centre, and how we would incentivise participation. A workload of 30-40 cases was suggested as a manageable amount. It was decided that there was a need to find the balance between easy and hard cases.
In terms of resources, it was questioned *how long the study would run* for, and *how much time would we give the centres to respond*. Each dummy case would need 1.5 to 2 hours to discuss, rather than discuss the normal process of 10 in an hour. The MDTs can organize discussion of the cases in their schedule. This would allow inclusion of 1-2 extra cases per month. A quarterly newsletter would be a good way of ascertaining feedback and progress.

- **The best ways to incentivize participation was discussed.**

It was acknowledged that MDTs may worry that they are being examined, i.e. whether they get the diagnosis right or wrong. The need to provide an incentive that they are being offered an *educational opportunity* was established.
A role of critical appraisal was suggested as a good incentive: the opportunity for a centre to submit their cases as a virtual MDT, e.g. 5 cases per year sent to another centre. This allows the opportunity to verify their diagnosis. A peer review by an international collaborative of an MDT is an excellent incentive. Thus, providing the centres with constructive feedback and answers to improve practice. There is an opportunity for networking and connecting with other centres. This is an excellent way for building up resource-challenged centres.

- **The aims of the study were discussed**

The hypothesis and aims of the study were not clear to most of the group. It was highlighted that an interesting part of the research could be whether a centre with limited resources is able to operate as well as high-resource centres with certain amount of accuracy, but it was felt that the bigger picture was lacking.
The advice for the project was to see the *end point*. The selling point is not just a result, but continuous *learning*. MDTs want to know where their strengths are, and where can they develop? The ultimate goal of the project, then, is to ***create a gold standard of MDT.*** We need to *assess* that gold standard. Thus, the platform would be opened up to all MDTs; so

	gold standard is used in practice. This would create incentive to participate as MDTs would help develop registry which is going to help them. It was suggested an ***opinion piece*** may be beneficial at some point – what should you be looking for in a referral (in patient pathway through healthcare setting)? But it was decided it may be too ambitious for a small company. • **Action points** We need to get in touch with Veracyte, and need to **fix the platform**, decide on **source of dummy cases** and **assess cost**. We need to know now from a funding perspective if there is concrete interest before commencing with project. Next steps: **revisit and develop protocol, identify research question**, then **share with industry**, get comments.