



Patient-Reported and Patient-Recorded Outcomes in Interstitial Lung Diseases and Pulmonary Hypertension

1. The objective of adapting a patient-reported outcome measure in an additional language is to ensure that all items are understood in the same way in all participating countries and that conceptual equivalence rather than linguistic equivalence is achieved (this thesis).
2. It is important to continuously evaluate the benefit-risk ratio of prednisone treatment in consultation with each individual patient with sarcoidosis (this thesis).
3. A home monitoring program including wireless home spirometry, is highly feasible and appreciated in an elderly population of patients with IPF (this thesis).
4. Lung function laboratories should use uniform reference values to ensure equal chances for patients to participate in clinical trials (this thesis).
5. Every PH patient should be offered a pulmonary rehabilitation program considering the existing evidence of the beneficial effects of pulmonary rehabilitation (this thesis).
6. Patient-reported outcome measures have great potential in better understanding patient's acceptability and tolerability when it comes to therapies (Russell AM et al., BMC Med 2015).
7. 'Knowledge of rare diseases, or at least learning how to suspect them in a timely fashion, may reduce the usual diagnostic delay that is common to all of them and has very negative impacts on the prognosis of affected patients' (Harari S, Humbert M, ERJ 2016).
8. Next to clinical trials, to improve understanding and management of rare lung diseases, it is essential to collect data from real-life cohorts and international global registries. (Cottin V, Wuyts W, ERJ 2015)
9. 'Clean air shouldn't be a privilege, dictated by where you can afford to live, but a right to which we are all entitled' (Kevin de León).
10. Using wearable devices which measure daily physical activities will provide better insight in the effect of therapeutic interventions in future studies (Sehgal S et al., Respir Med 2019).
11. To ensure optimal quality of pulmonary function measurements and data acquisition for multicentre research, dedicated pulmonary function technologists are essential.