Practice gaps and variations in the pharmacological management of Interstitial Lung Disease (ILD); real-world insights from the AccessILD registry in the UK

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Objectives

Electronic Health Record (EHR) data on the pharmacological management of different ILD types is not routinely available. Difficulty in distinguishing between different ILD types introduces further discrepancies in EHR coded data.

We established a fully remote registry to address EHR data limitations in studying clinical practice variations in ILD, by allowing real-time data sharing through integration of EHR and electronic Patient Reported Outcomes (ePRO) data.

Methods

Potential participants are identified using primary care provider EHR and invited by text to join the AccessILD (AILD) registry via a study portal weblink.

Enrolled patients were sent an ePRO survey to trace their pharmacological treatment pathways since diagnosis and responses were integrated with patients' existing EHRs.

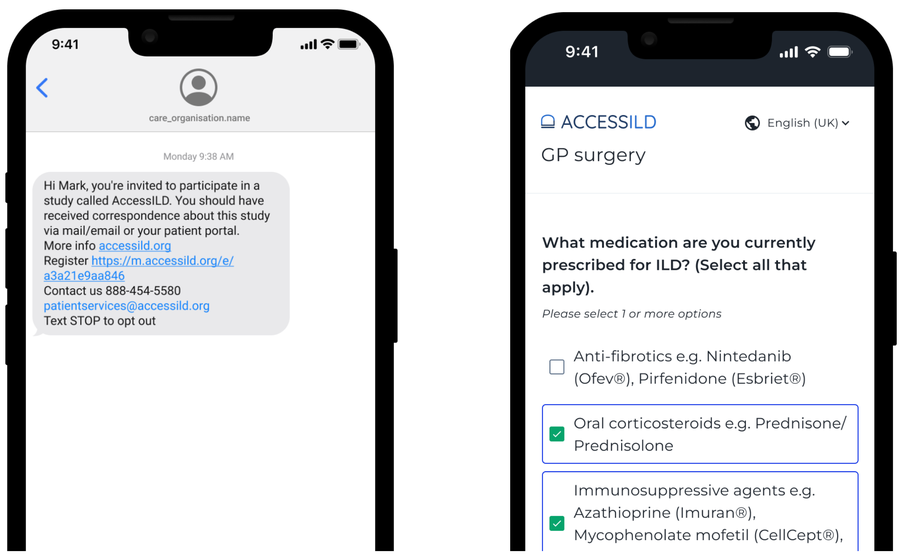

Figure 1. SMS invitation to join AccessILD (left), example of ePRO sent to AccessILD participants (right)

Results

355 patients from 144 UK primary care practices joined AILD and 249 completed the ePRO survey.

36% have Idiopathic Pulmonary Fibrosis (IPF) and 64% have non-IPF ILD, including "systemic disease with lung involvement" (21%), "occupational/environmental" (6%), "drug-induced ILD" (3%) and "other ILD types" (34%).

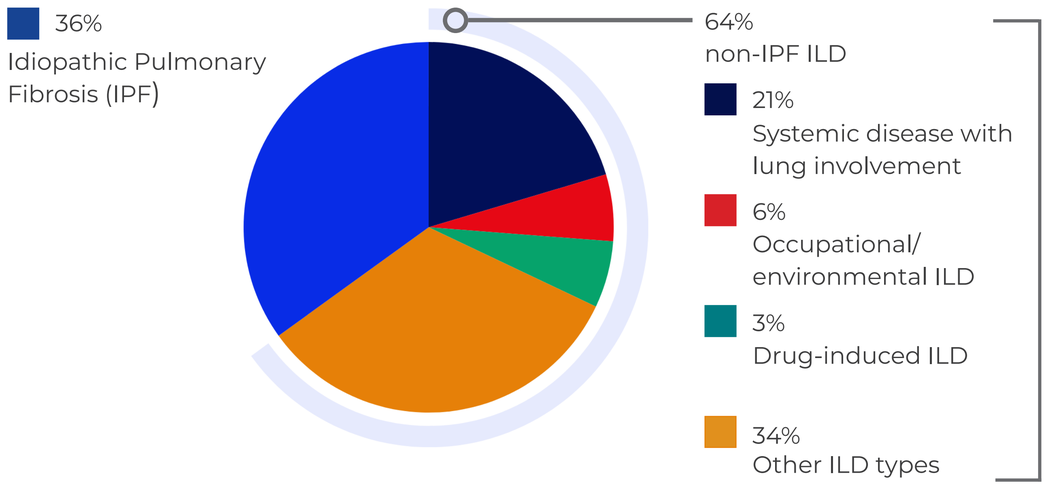

Figure 2. Aggregate data collected from participants within AccessILD showing breakdown by disease-type.

Average patient age is 69.2 years and average time since diagnosis is ±7.8 years.

62% of patients are treated at a "non-specialist hospital", 15% at a "specialist center" and 8% at a "GP".

61% don't take any medication for ILD, 15% take immunosuppressants, 13% antifibrotics and 21% oral corticosteroids, while 7% of IPF patients reported concomitant use of corticosteroid and antifibrotic therapy.

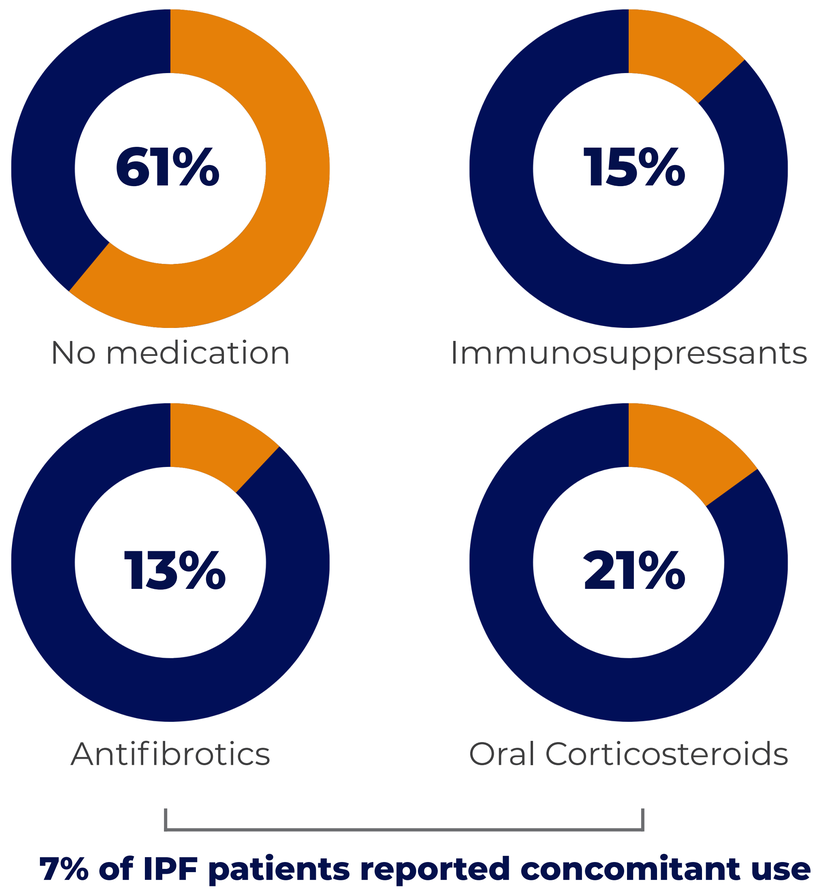

Figure 3. Breakdown of pharmacological treatment data collected from participants within AccessILD.

Antifibrotics were primarily used by IPF patients (88%), although use in "drug-induced ILD" (3%) and "other ILD types" (9%) was also reported.

Conclusions

Discrepancies exist between different care settings in the pharmacological management pathways for ILD.

As antifibrotics are being deployed among an increasingly broader ILD patient population, remote, interactive registries in ILD can be particularly useful in capturing and bridging evidence-practice gaps at the population-level and improving our understanding of treatment pathways within ILD patient populations.

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