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The role of e-registries in advancing Interstitial Lung Disease research; insights from the AccessILD registry in the UK.

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Objectives

ILD is a group of rare, heterogeneous conditions causing lung fibrosis and inflammation. Different trajectories across the ILD spectrum call for better disease characterization. The rarity of ILD and other, physical, geographical or financial constraints are key barriers in studying cohorts or registries which are representative of the true spectrum of the ILD population.

We established a fully remote registry that allows in-depth ILD stratification by combining Electronic Health Records (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 web-link.

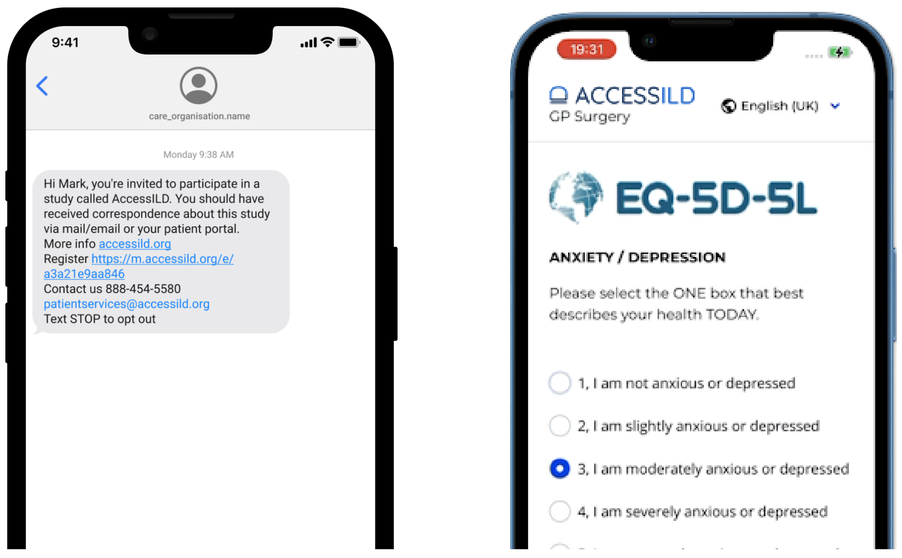

Figure 1. SMS invitation to join AccessILD (left), example of ePRO (EQ-5D-5L) sent to AccessILD participants (right)

Enrolled patients are sent further ePRO surveys to collect additional data which are then integrated with their existing EHR.

Table 1. Data routinely collected from participants in AccessILD.

Patient profile	
EHR & ePROs	• Demographics (incl. ethnicity) • Date of Diagnosis • Current symptoms • Vital signs • Caregiver arrangements • Family, social, occupational history
Treatment journey	
EHR & ePROs	• ILD and other medication codes • Current and previous medications • Medication duration & funding
Quality of life	
ePROs	• HRQoL (EQ-5D-5L) • Leicester Cough Questionnaire (LCQ) • Living with Pulmonary Fibrosis (L-PF) • Hospital Anxiety Depression Scale (HADS)

Results, structure & timeline

1968 patients from 144 UK primary care practices were invited. 355 patients joined AILD, with a current ePRO completion rate of 70% (n=249).

Average patient age is 69.2 years with ±7.6 years since diagnosis. 48% of participants are female and 52% male. 62% of patients are treated at a non-specialist hospital.

AccessILD has enrolled a wide spectrum of patients with ILD, including 36% of patients with Idiopathic Pulmonary Fibrosis (IPF) and 64% with non-IPF ILD, including systemic disease with lung involvement (21%), occupational/ environmental ILD (6%), drug-induced ILD (3%) and other (34%) ILD types.

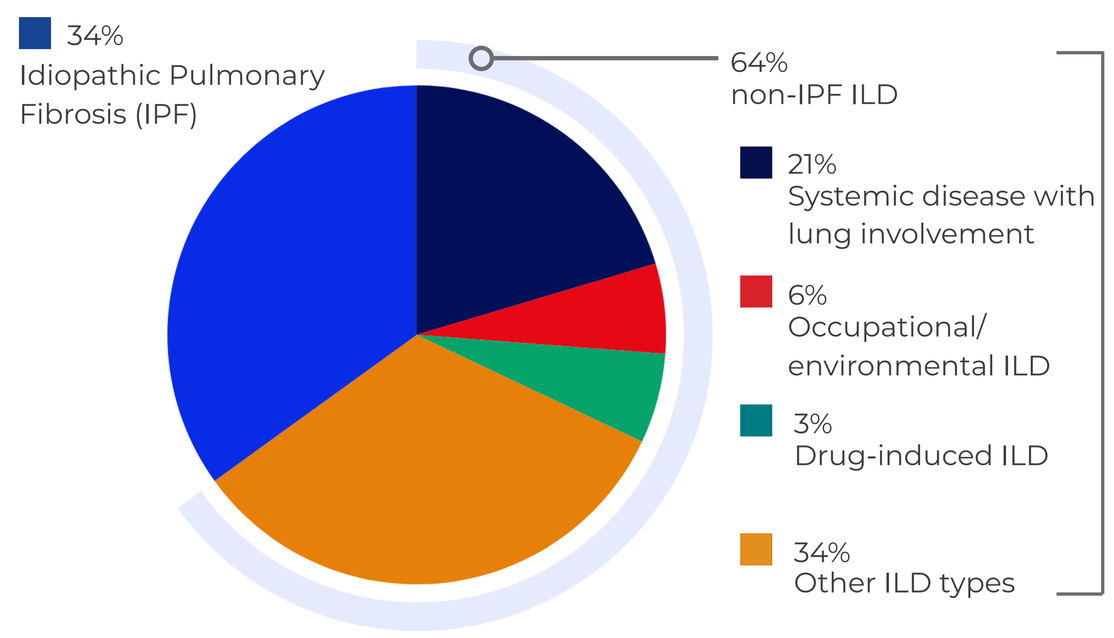

Figure 2. Aggregate data collected from participants within AccessILD showing breakdown by disease-type.

Conclusions

Remote participation was well received by patients with ILD, even at advanced age and was key to developing a broadly inclusive ILD registry.

This is particularly useful in allowing us to compare clinical and patient reported outcomes across a greatly diverse ILD population and better understand the pathways that differentiate disease progression between different types of ILD.

More work is needed to understand how remote data collection in ILD affects the quality of patient-centered outcomes measured by ePRO and home-testing tools.

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