

Keeping you up-to-date with AccessILD & research opportunities.



Welcome to the first edition of the AccessILD update!

In these quarterly newsletters, you can expect updates on new sub-studies, real-life experiences shared by participants living with ILD, interesting insights gathered from aggregated anonymous participant data, and a roundup of noteworthy ILD research that's been hitting the headlines.

We are excited to share that there are now **267 patients** participating within AccessILD, and **122 healthcare providers** from across the UK have now signed-up to provide their patients access to the study. This is amazing news for the research community!

We'd like to thank you again for taking part in AccessILD. Your involvement is vital in advancing our understanding of this group of diseases, and will play a huge role in the development of new treatments.

We hope you enjoy this update and as always if you have any questions about the content of this newsletter or about your participation in AccessILD please don't hesitate to get in touch.

Meet the helpdesk

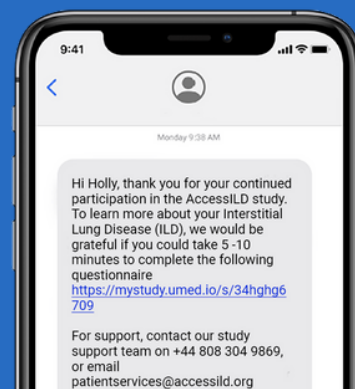
If you have questions about AccessILD, please contact our study support team at: patientservices@accessild.org.

Alternatively you can contact our helpdesk number on **+44 (0) 808 304 9869**



Reminder to complete the Baseline Questionnaire

Just a gentle reminder to complete the baseline questionnaire if you haven't done so already. You will have received a text message and an email with a link to the questionnaire. The information you provide within this questionnaire will be combined with data from other participants in the study and will be anonymised, meaning you will not be identifiable from this information.



If you have any questions or require support with the completion of the questionnaire, please contact our study support team.

Welcome from the AccessILD Investigators

We'd like to introduce you to the Study Investigators for AccessILD in the UK and the US. As the lead researchers they are responsible for the overall design and conduct of the study.

Timothy Michael Dempsey, MD

AccessILD Chief Investigator (US)



Timothy Michael Dempsey is a health care provider primarily located in Travis AFB, California in the United States. He specialises in Pulmonology, Critical Care Medicine, and Internal Medicine.

“ I am honoured to be the Chief Investigator on the AccessILD research project. Having worked as a pulmonologist, I have seen the impact that this group of diseases has on the lives of my patients, and how the development of new therapies has the ability to transform lives.

Many patients living with these diseases are eager to assist with research and to help with the development of new treatments, but they are often faced with the barrier of having to travel to participate. By enabling patient participation from home, I believe AccessILD has the capacity to completely transform research within this field and I am excited to see the impact of these research outcomes within my clinical practice in the near future.



Professor Philip Molyneux

AccessILD Principal Investigator (UK)



Professor Philip Molyneux is a professor of Interstitial Lung disease at Imperial College London. He is the Asthma and Lung UK Chair of Respiratory Research. He is a consultant in Interstitial lung disease and the director of the NIHR Cardiorespiratory Clinical research facility at the Royal Brompton Hospital.

“ I'd like to say a big thank you to all the patients that have so far signed-up to AccessILD, your involvement will be invaluable to advance research within this field.

To be able to develop better treatments and hopefully cures for these diseases, we need the data and insights that only you as patients can provide.

As a practising respiratory consultant I see how Interstitial Lung Disease affects my patients everyday, so I am excited to see the outcomes of the research that is being made possible by AccessILD.



Baseline data roundup



149

completions of the
baseline questionnaire



69.2

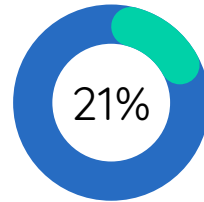
average age at
enrollment



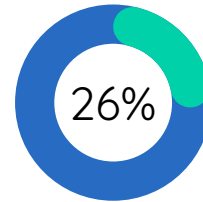
23%

report a family
history of ILD

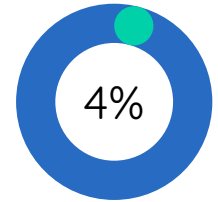
Breakdown of ILD type



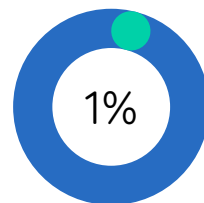
Systemic disease
with lung
involvement



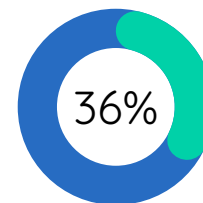
Other



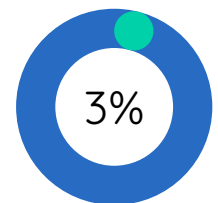
Occupational or
environmental
exposures



Fibrosis of lung due
to radiation



IPF



Drug-induced ILD

A huge thank you to all the participants who have already completed our baseline questionnaire. Your insights are shaping our path forward. To those who haven't had a chance yet, we'd love to include your voice too. Filling out the questionnaire only takes a few minutes, but your feedback can make a lasting impact. Join us in reaching our goal of 100% participation!

In the news...

In each update we'll be sharing recent research developments, external to AccessILD, that are supporting the advancement of better treatments and outcomes for patients with ILD.



Shared from: [Healio](#)

Palliative telecare team improves quality of life in COPD, ILD

A recent study has found that patients who received telecare from a nurse and social worker reported better quality of life vs. usual care, and disease-specific health status, depression and anxiety also improved with this intervention.

[Read more +](#)