Registry for Better Understanding of ILD (RE-BUILD) mobile application

L.M. Glenn[1,2,3], D. Jackson[2], B. Tefay[4], A.E. Holland[3,5,6,7], N.S.L. Goh[6,8,9], L.K. Troy[1,2], M. Brooke[10], I.N. Glaspole[3,11,12], T.J. Corte[1,2,3] *on behalf of the AILDR Steering Committee*

[1]Department of Respiratory and Sleep Medicine, Royal Prince Alfred Hospital, NSW, Australia
[2]The University of Sydney School of Medicine (Central Clinical School), Sydney, NSW, Australia
[3]NHMRC Centre of Research Excellence in Pulmonary Fibrosis, Australia
[4]Stacktrace Pty Ltd., Brisbane, Queensland, Australia
[5]Department of Physiotherapy, Alfred Health, Victoria, Australia
[6]Institute for Breathing and Sleep, Melbourne, Victoria, Australia
[7]Department of Allergy, Clinical Immunology and Respiratory Medicine, Monash University, Victoria, Australia
[8]Department of Respiratory and Sleep Medicine, Austin Health, Heidelberg, Victoria, Australia
[9]Faculty of Medicine, University of Melbourne, Melbourne, Victoria, Australia
[10]Lung Foundation Australia
[11]Department of Respiratory and Sleep Medicine, Alfred Health, Melbourne, Victoria, Australia
[12]Central Clinical School, Monash University, Melbourne, Australia

Background:

Interstitial lung diseases (ILD) are a heterogeneous group of >200 disorders which cause inflammation and/or fibrosis of the lung interstitium, resulting in ventilatory restriction. They exhibit variable natural history and treatment response. Disease progression is associated with breathlessness, exercise intolerance, respiratory failure and ultimately, death. The most common ILD diagnoses in Australia are idiopathic pulmonary fibrosis (IPF), connective tissue disease-associated ILD and hypersensitivity pneumonitis.

Figure 1: Axial high resolution computed tomography (HRCT) image from patient with IPF, showing extensive lung fibrosis with characteristic "honeycomb" cyst formation

Figure 2: IPF lung – demonstrating replacement of normal alveolar architecture with dense fibrotic tissue

Recent Australian data have shown that patients with interstitial lung disease identify "understanding the causes of ILD and disease progression" among their top research priorities. Additionally, patient-reported outcome measures (PROMs), including validated health-related quality of life questionnaire scores, correlate with disease progression and survival. Hence, PROM data collection must be prioritised.

Introduction:

Digital solutions for patient engagement, education, and research data collection are desirable. The Australasian Interstitial Lung Disease Registry (AILDR) is a binational clinical registry with >2000 participants across 21 sites. We propose a smartphone application, RE-BUILD (Registry for Better Understanding of ILD), to integrate with the AILDR. This ePoster reports the **development stage** of this project.

Aims:

The concurrent aims of the study were to a) develop, and b) assess usability and feasibility of the RE-BUILD smartphone application. Secondary endpoints include:

- Participant satisfaction
- Usage of the application
- Completeness and accuracy of participant-entered data

Methods:

The RE-BUILD smartphone application was designed by a collaborative team of ILD clinicians from the AILDR and Centre of Research Excellence (CRE-PF) who identified a core set of functionalities including self-monitoring and educational functions. Preliminary testing by developers, health professionals and consumers has been conducted.

In a pilot study testing usability, fifty ILD patients ≥18 years old from three Australian centres will be enrolled. Participants will download the RE-BUILD application and use it for a 6-month period. They will be sent a link to the mHealth App Usability Questionnaire at 1,3, and 6 months; telephone interviews will be performed in a subset of 20 participants at 3-6 months.

Results:

- The RE-BUILD mobile application has now been developed in accordance with Australian Communications Consumer Action Network guidelines, to integrate with data from the AILDR.
- Patients create a "profile": age, gender, ethnicity, height & weight, smoking, diagnosis, past medical history.
- RE-BUILD will also include patient-reported pulmonary function tests, medication and supplemental oxygen use data, and PROM scores.
- Local air quality measurements and physical activity are also displayed, and patients can access educational material through the application.
- Patients receive monthly prompts to update and/or enter new data.
- Qualitative feedback has been provided by health professionals and consumers.
  - Overall positive, with specific feedback and suggestions for improvement provided.
    - ***"It is an exciting initiative that could really change the way that patients retain information and interact with their medical teams in the future."***
    - ***"From a patient perspective, this project represents an opportunity for increased participation in treatment, results and potentially a feeling of increased control of your situation."***

Application Design and Functions

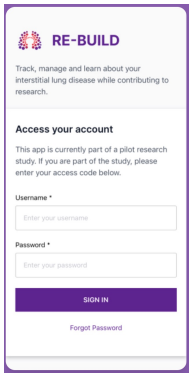


Figure 3: Log-in page

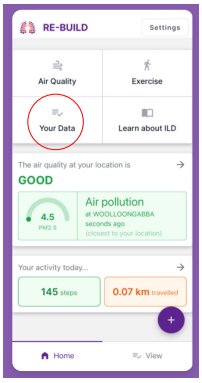


Figure 4: Home page

Figure 5: Lung function test results

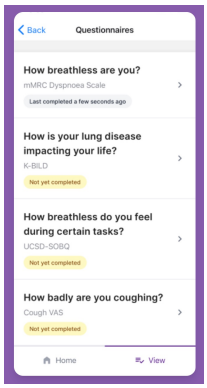


Figure 6: Questionnaires

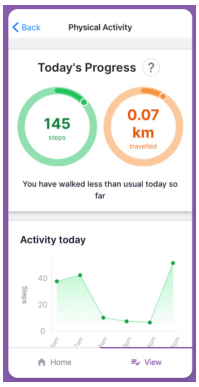


Figure 7: Physical activity monitor

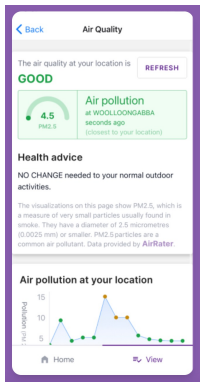


Figure 8: Air Quality

- Specific to patient location

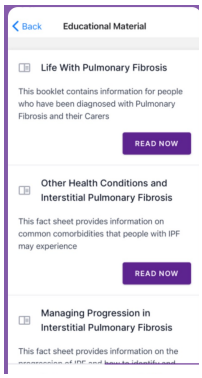
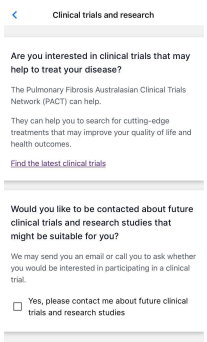


Figure 9: Educational material

- Videos
- PDFs
- Websites

Figure 10 – Additional features:

- Notifications regarding clinical trials and research studies
- Message inbox – receive messages from investigators
- Support – contacts for investigators



Moving forward:

- Pilot study commenced – 6 patients recruited thus far.
- The primary endpoint (App usability) will be assessed by the mHealth App Usability Questionnaire (MAUQ) for Standalone mHealth Apps Used by Patients score – a validated usability questionnaire for mobile health apps.
- Future potential for more widespread use by all ILD patients in Australia (and overseas).

Conclusion:

The RE-BUILD mobile application has now been developed and preliminarily tested. Its feasibility and usability will be tested in a pilot study. We anticipate that it will be a usable platform for participant data self-collection in ILD.

Grant support:

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