Australasian Interstitial Lung Disease Registry

Data Dictionary

Coordinating Principal Investigator	A/Prof Tamera Corte
Principal Investigators	• Dr Shalini Bastiampillai • A/Prof Ben Kwan • Prof Dan Chambers • Prof Fiona Lake • Dr Jason D'Costa • Dr Kuan Pin Lim • Dr Adrienne Edwards • Dr Chong Weng Ong • Dr Odette Erskine • Dr Jyotika Prasad • Dr Harry Gallagher • Prof Paul Reynolds • A/Prof Ian Glaspole • Prof Frank Thien • A/Prof Nicole Goh • Dr Elizabeth Veitch • A/Prof Chris Grainge • Dr Jeremy Wrobel • Dr Greg Keir • Prof Margaret Wilsher

PATIENT DEMOGRAPHICS

Field Heading	Field	Type of Data	Data ranges	Where to Locate Data	Important to note
Patient Details	First Name	text			
	Middle Name	text			
	Last Name	text			
	Former Names	text			
	Gender	dropdown	M/F		
	Date of Birth	date	00/00/0000		
	Ethnicity	dropdown	Caucasian, Black/African American, Aboriginal/Torres Strait Islander, Asian, Inidan Subcontinental, Maori, Pacific Islander, Other	Documented on lung function test	It is important to fill this field in as it affects how lung function % predicted is calculated. If left blank, will default to "Caucasian". Lung Function Test results can also be entered manually
	Address	text			
	Suburb/Locality	text			
	Postcode	number			
	State or Territory	text			
	Telephone Number	Text			
	Personal email address	Text			
	Medicare eligibility status	Text			
	Medicare Number	Text			
	NZ NHI Number	Text			New Zealand Use Only
	Notes	free text			
Misc. Info	MRN	text/number			
	Lung Transplant	dropdown	Yes/No		To document whether patient has had a lung transplant, for patients referred and on wait list, tick "Wait Listed"
	Wait Listed	check box			
Vital Status	Mortality Status	dropdown	Alive, Dead, UNK		
	Date Deceased	date	00/00/0000		

Study Name: Australasian Interstitial Lung Disease Registry

	As of Date	date	00/00/0000		If date deceased unknown, date that data manager aware of death
	Vitality Comment	dropdown/free text			customisable per site
Physicians	Referring Specialist				
	Physician	Asterix to search/add physicians			
	Specialty				
	Suburb				
	Phone				
	General Practioner (GP)				
	Name	Asterix to search/add physicians			
	Specialty				
	Suburb				
	Phone				
	ILD Treating Physician				
	Name	Asterix to search/add physicians			
	Specialty				
	Suburb				
	Phone				
Consents	Registry	dropdown	Yes/No/Withdrawn		If "Yes" or "Withdrawn" entered, date will be requested
	Blood Sub-study	dropdown	Yes/No/Withdrawn		
	Blood Collected	dropdown	Yes/No/Withdrawn		
	BAL	dropdown	Yes/No/Withdrawn		
	Lung Tissue	dropdown	Yes/No/Withdrawn		
	DNA	dropdown	Yes/No/Withdrawn		
Smoking	Smoking Status	dropdown	Current/Ex/Non	This information should be documented on initial consultation form	If "Current" or "Ex" entered, pack years will be requested
Family History	Pulmonary Fibrosis	dropdown	Y/N		

Study Name: Australasian Interstitial Lung Disease Registry

	Autoimmune Disease	dropdown	Y/N		
Environmental Exposures		check boxes	Asbestos, Metals, Moulds/Damp, Chemicals/gases, Birds, Mineral dusts/silica, Compost/potting mix, Farm, TB, Drugs within last 5 years, Other (freetext)	"none" needs to be an option	
Drug Trial Details	**'+' to add drug trial details**	free text to enter consent date, drug trial name and notes specific to site			Sites can enter any trials (not just drug trials)

CLINICAL DATA

Field heading	Field	Type of Data	Data Ranges	Where to find Data	Important to Note
History and Examination					
Symptoms	Initial Symptoms	check boxes	Dyspnea, Lethargy, Decreased Exercise Tolerance, Cough, Weight Loss, None	This information should be documented on initial consulation form	
	Symptom Onset Date	date	00/00/0000	Should be documented during initial consultation and/or on referral letter. If just a month is documented, record 01/XX/XXXX, if just the year is documented, record 01/01/XXXX	
	Dyspnea (WHO Class)	dropdown	1, 2, 3, 4		
	Cough Severity	dropdown	Mild, Moderate, Severe		
	Cough Quality	dropdown	Dry, Productive		
	Respiratory Symptoms	check boxes	Dyspnea, Lethargy, Haemoptysis, Orthopnea, Cough, Weight Loss, Fever, Oedema, Sputum, Chest pain, Night Sweats		

Study Name: Australasian Interstitial Lung Disease Registry

	CTD Symptoms	Check boxes	Raynaud's, Sicca, Other (free text), Inflammatory Arthritis, Uveitis, Morning Stiffness, Proximal Weakness, Rash/skin changes, Telangiectasia, GORD/Dysphagia, Digital ulcer/fissuring/oedema		
Medical History at Presentation	Cardiac	dropdown	Y/N		
	Liver	dropdown	Y/N		
	TB	dropdown	Y/N		
	Asthma/COPD	dropdown	Y/N		
	Lung Cancer	dropdown	Y/N		
	Diabetes	dropdown	Y/N		
	Thromboembolism	dropdown	Y/N		
	Autoimmune Disease	dropdown	Y/N		
	OSA	dropdown	Y/N		
	Surgery	dropdown	Y/N		
	Other Medical Problems	free text			
Visit Details	**'+' to add each visit**				
	Examination Date	*date*	*00/00/0000*	*This information is documented per clinic visit. If a patient has had many visits, the minimum data to be entered should be from the first visit and most recent visit*	
	ILD Physician	*Asterix to search/add physicians*			
Oxygen Saturation	*Resting O2 Saturation %*	*number*	*50-100*		
	on	*dropdown*	*R/A, L/min (prompt for numerical value once entered)*		
	WHO Functional Class	*dropdown*	*1, 2, 3, 4*	*Only record if documented per visit. Do not continue to record value from initial consultation.*	

Chest	Crackles on Examination	dropdown	Y/N		
	Wheezes on Auscaltation	dropdown	Y/N		
Cardiovascular	Right Heart Failure	dropdown	Y/N	Documented raised Jugular Venous Pressure (JVP) or swelling in the legs (oedema) indicates right heart failure (if not specifically documented)	
Extremities/Joints/Skin/Lymphatics	Clubbing	dropdown	Y/N		
	Joint Deformities	dropdown	Y/N		
	Sclerodactyly	dropdown	Y/N		
	Telangiectasia	dropdown	Y/N		
	Cyanosis	dropdown	Peripheral, Central, Both		
	Weakness	dropdown	Y/N		
	Rash	dropdown	Y/N		
	Referral	check boxes	Palliative care, Transplant, Rheumatology, Cardiology, Pulmonary Rehab		
	Notes	free text			

MEDICATIONS

Field Heading	Field	Type of Data	Data ranges	Where to find Data	Important to Note
Oxygen Usage	Use of Oxygen at Home?	dropdown	Yes/No		
	Date commenced 02	date	00/00/0000		*When 'yes' is selected dropdown will prompt for date commenced, frequency and flow rate. This information can be updated as oxygen requirements change by pressing log change - 02 History log will be generated below*

	When	dropdown	Continuous (24hrs, most of the day (16hrs), Some of the day (as needed), Only at night, Only exercise, During exercise and at night		
	Flow rate	number			
Medication History	see notes on final tab				Medications can be added individually using '+' or click '+ Batch Add' to add commonly used medications for ILD patients. Medications added via batch add can then be clicked on individually to fill in further medication details.
Medication Details	Base Medication	dropdown/free text			Most medications should be on dropdown menu and will appear when the word is typed. If not on dropdown menu, medications can be added by typing directly into the box. **Please ensure that medication is typed correctly and is definitely not already entered before entering new medication**
	Category	Automatic		Auto-populates based on 'base medication' field.	
	Dose	free text			Enter free text instead of dropdown

	Times per day	dropdown/ free text	Mane, Midi, Nocte, BD, TDS, q6hr, q6hr PRN, q8hr, q8hr PRN, q4hr, Weekly x 1, Weekly x 2, Weekly x 3, Daily on Mon's & Frid's only, Daily on Sat's & Sun's only, Daily on Mon's & Wed's & Frid's		*Ensure frequency required is not available before adding new frequency*
	Current	Check box			
	Started	date	00/00/0000		
	Stopped	date	00/00/0000		
	Notes	free text			

INVESTIGATIONS

Field Heading	Field	Type of Data	Data Ranges	Where to find data	Important to note
Blood Tests & Serology				EMR or referring doctor	Blood tests can be added individually using '+' or click '+ Batch Add' to add all baseline blood attended for new patients. All bloods are negative unless changed to positive (via dropdown). The value or characteristics of results can be entered into 'Results/Notes'. Try to standardise terms used at each site so they can be searched for more easily. Generally only baseline bloods need to be entered but sites may record more results as desired.
HRCT Results					HRCT results can be added using '+' in top right hand corner.
HRCT Results	*HRCT date*	*date*	*00/00/0000*		
	Scan Available	dropdown	*No/Digital/Film*	*Used to indicate if scans are available on site either in digital or film format*	*Sites can add their own fields as desired*
	HRCT Results	*free text*			*Sites to determine what data to be entered i.e. summary - UIP, NSIP etc OR copy and paste whole report. This data is captured in ILD Diagnosis tab so not clear whether this field has utility*
6MWT					

6 Minute Walk Tests					6MWT can be added using '+' in top right hand corner. Minimum data entered should be initial and most recent 6MWT
	Test date	*date*	*00/00/0000*		
see notes	*Sp02 (start)*	*number*	*0-100*		
	Sp02 (finish)	*number*	*0-100*		
	HR (start)	*number*	*0-250*		
	HR (finish)	*number*	*0-250*		
	Borg Dyspnea Score (start)	*number*	*0-10*		
	Borg Dyspnea Score (finish)	*number*	*0-10*		
	Min. SpO2	*number*	*0-100*		
	O2	*number*	*0-15*		
	Distance	*number*	*0-1000*		
	Limiting Symptoms	*free text*			
	Comments	*free text*			
PFT					There will be an option for sites to import PFT data from their local labs. More information to be sent out once this becomes available.
Pulmonary Function Tests					PFTs can be added using '+' in top right hand corner. Minimum data entered should be initial and most recent PFTs.
	Test date	*date*	*00/00/0000*		
see notes	Height at test	*number*	*0 - 250*		
	Weight at test	*number*	*0 - 250*		
	BMI			*auto-populatesfrom height and weight*	
	Age at Test			*auto-populates from DOB*	
	Outside Lab	*check box*			

Study Name: Australasian Interstitial Lung Disease Registry

				Predict and % Predicted auto-populates based on height, weight and ethnicity (entered in patient demographics)	Manual % Predicted - Can be entered if auto-populated field is incorrect
	FVC - Forced Vital Capacity (L)	numbers			
	FEV1 - Forced Expiry Volume (L)	numbers			
	FEV1/FVC Ratio % Predicted	numbers			
	Total Lung Capacity (L)	numbers			
	Residual Volume (L)	numbers			
	DLCOcorr (ml/min/mmHg)*	numbers			
	KCO (ml/min/mmHg)	numbers			
Blood Gases					
Blood Gases					
	Test date	date	00/00/0000		Blood Gases can be added using '+' in top right hand corner. Sites will determine how much data is entered.
	Fi02	number			
	Pa02 (mmHg)	number			
	PC02 (mmHg)	number			
	Sa02	number			
	pH	number			
	HC03	number			
ECHO					
ECHO Tests					ECHO tests can be added using '+' in top right hand corner. Sites will determine how much data is entered.
	Echo Test Date	date	00/00/0000		
	Age at test	number		auto-populates from DOB	

Study Name: Australasian Interstitial Lung Disease Registry

	TR Jet Visible	*dropdown*	*Y/N*		
	Pulm. Acceleration Time	*number*	*0-200*		*if not reported, leave blank*
	RA Diameter	*dropdown*	*Normal/ Mildly-Moderately Dilated/Severely Dilated*		*if not reported, leave blank*
	RV Diameter	*dropdown*	*Normal/ Mildly-Moderately Dilated/Severely Dilated*		*if not reported, leave blank*
	RV/RA (Tricuspid) Gradient	*number*	*0-200*		*There will either be RV/RA gradient (Triscupid Gradient) reported, or there will be Right Ventricular Systolic Pressure. There will not be both values reported on one report.*
	RVSP	*number*	*0-200*		
	Left Ventricular Ejection Fraction	*number*	*0-100*		*%*
	RV Dysfunction	Y/N			*if not reported, leave blank*
	Notes				Sites to determine what information is written in this section
Bronchoscopy/Biopsy					
Bronchoscopy					Bronchoscopies can be added using '+' in top right hand corner. Sites will determine how much data is entered.
	Bronchoscopy date	*date*	*00/00/0000*		
	Age at Test	*number*		*auto-populates from DOB*	
	BAL Macrophage	*number*			
	BAL Neutrophil	*number*			
	BAL Lymphocyte	*number*			
	BAL Eosinophil	*number*			
	BAL Microbiology	*number*			

Study Name: Australasian Interstitial Lung Disease Registry

Surgical Biopsy	Biopsy Date	date	00/00/0000		
	Biopsy type	dropdown	VATS/Cryobiopsy/Transbronchial/ Endobronchial	add in EBUS, non-respiratory site	
	Age at test	number		auto-populates from DOB	
	Result	free text			
Additional Tests					
Sleep Studies					*Sleep studies can be added using '+' in top right hand corner. Sites will determine how much data is entered.*
	Test Date	date	00/00/0000		
	Age at Test	date	00/00/0000	auto-populates from DOB	
	Diagnosis	dropdown	No sleep Disorder/Obstructive Sleep Apnoea/Central Sleep Apnoea/Nocturnal Hypoventilation/Obstructive Sleep Apnoea & Nocturnal Sleep Apnoea/ Central Sleep Apnoea and Nocturnal Hypoventilation/ Other		
	Sp02 Nadir	number			
	Fi02	number			
	RDI	number			
	REM RDI	number			
	NREM RDI	number			
	Sleep Efficiency	number			
	Notes	free text			

Right Heart Catheter Tests					Right Heart Catheter Test can be added using '+' in top right hand corner. Sites will determine how much data is entered.
	Test Date	date	00/00/0000		
	Age at Test	number		auto-populates from DOB	
	SPAP	number		Systolic Pulmonary Artery Pressure	
	DPAP	number		Diastolic Pulmonary Artery Pressure	
	MPAP	number		Mean Pulmonary Artery Pressure (may be documented as PA)	
	MRAP	number		Mean Right Atrial Pressure (may be documented as RA)	
	MPCWP	number		Mean Pulmonary Capillary Wedge Pressure (may be documented as PAW or wedge)	
	MLVEDP	number		Mean Left Ventricular End Diastolic Pressure	
	CO	number		Cardiac Output	
	PVR	number		Peripheral Vascular Resistance (auto-calculated using mPAP - MPCWP/CO)	
	Notes	free text			
CPET					CPET can be added using '+' in top right hand corner. Sites will determine how much data is entered.

Study Name: Australasian Interstitial Lung Disease Registry

	Test Date	date	00/00/0000		
	Age at Test	number		auto-populates from DOB	
	Vo2 Peak	number			
	Vo2 Peak/Kg	number			
	Vo2 Predicted	number			
	Sp02 Nadir (%)	number			
	Notes	free text			
Bone Density Scans					Bone Density Scans can be added using '+' in top right hand corner. Sites will determine how much data is entered.
	Test Date	date	00/00/0000		
	Age at Test	date		auto-populates from DOB	
	Lumbar Spine	free text	- 10 to 10		t score as reported on DEXA scan.
	Femoral Neck	free text	- 10 to 10		t score as reported on DEXA scan.
	Notes	free text	- 10 to 10		t score as reported on DEXA scan.
Genomic Reporting					
	DATE	date	00/00/0000		
	VARIANT	Number			
	GENE	Text			
	RESULT	radio	Yes/no/unclear		
	VARIANT CLASSIFICATION	radio	Pathogenic / Likely pathogenic / VUS / likely benign		
	TRANSCRIPT	Text			
	NOMENCLATURE	Text			
	CONSEQUENCES	Text			
	GENOTYPE	radio	Heterozygous / Homozygous / compund heterozygous/ mitochondrial		
	ASSEMBLY	Text			
	POSITION	Text	Text		

Study Name: Australasian Interstitial Lung Disease Registry

	LAB	Text			
	PANEL/WES/WGS	Text			
	FAMILY HISTORY	Text			
	OTHER FAMILY MEMBERS TESTED	radio	Yes/no		
	RESULT	Text			

Mandatory Fields Notes:		
For all mandatory fields, "not done" or "not known" or "pending" needs to be an option		
Date of clinic attendance	All dates should be entered but not all detail required	
Medication: anti-fibrotic and immunosuppression drugs should be mandatory		
Medication dose probably not necessary but perhaps for steroids - pulse / induction v maintenance as an option		
For transplanted patients, only complete data entry for events until date of transplant		
PFTs	only need first, last and annual (or six monthly)	
6MWT	only need first, last and annual (or six monthly)	
Extra Mandatory Fields		
First clinic / contact date	date	either first clinic or first ED / inpatient review date
ILD referral diagnosis	ie. Diagnosis from referrer - drop down box	
Source of initial referral	drop down box	GP, other respiratory specialist, other non-respiratory specilist, transition from other clinic (ie. From gen resp or private but same provider), ED, other?
Incident / prevalent case	drop down box	Incident (newly identified ILD), prevalent (ILD known but not necessarily specifically diagnosed)
Serious adverse events	Date	can be multiple events
	Type	tick box - multiple options available
	Outcome	tick box - multiple options available