



Australasian Interstitial Lung Disease Registry

Data Dictionary

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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		

	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	<u>Referring Specialist</u>				
	Physician	Asterix to search/add physicians			
	Specialty				
	Suburb				
	Phone				
	<u>General Practitioner (GP)</u>				
	Name	Asterix to search/add physicians			
	Specialty				
	Suburb				
	Phone				
	<u>ILD Treating Physician</u>				
	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Consents	Registry	dropdown	Yes/No/Withdrawn		If "Yes" or "Withdrawn" entered, date will be requested
	Blood Sub-study	dropdown	Yes/No/Withdrawn		
	Blood Collected	dropdown	Yes/No/Withdrawn		
	BAL	dropdown	Yes/No/Withdrawn		
	Lung Tissue	dropdown	Yes/No/Withdrawn		
	DNA	dropdown	Yes/No/Withdrawn		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		

	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 consultation 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		

			Raynaud's, Sicca, Other (free text), Inflammatory Arthritis, Uveitis, Morning Stiffness, Proximal Weakness, Rash/skin changes, Telangiectasia, GORD/Dysphagia, Digital ulcer/fissuring/oedema		
	CTD Symptoms	Check boxes			
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				
	<i>Examination Date</i>	<i>date</i>	<i>00/00/0000</i>	<i>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</i>	
	<i>ILD Physician</i>	<i>Asterix to search/add physicians</i>			
<i>Oxygen Saturation</i>	<i>Resting O2 Saturation %</i>	<i>number</i>	<i>50-100</i>		
	<i>on</i>	<i>dropdown</i>	<i>R/A, L/min (prompt for numerical value once entered)</i>		
	<i>WHO Functional Class</i>	<i>dropdown</i>	<i>1, 2, 3, 4</i>	<i>Only record if documented per visit. Do not continue to record value from initial consultation.</i>	

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

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		
	<i>Date commenced O2</i>	<i>date</i>	<i>00/00/0000</i>		<i>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 - O2 History log will be generated below</i>

	<i>When</i>	<i>dropdown</i>			<i>Continuous (24hrs, most of the day (16hrs), Some of the day (as needed), Only at night, Only exercise, During exercise and at night</i>
	<i>Flow rate</i>	<i>number</i>			
Medication History	<i>see notes on final tab</i>				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	<i>Base Medication</i>	<i>dropdown/free text</i>			<i>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**</i>
	<i>Category</i>	<i>Automatic</i>			<i>Auto-populates based on 'base medication' field.</i>
	<i>Dose</i>	<i>free text</i>			<i>Enter free text instead of dropdown</i>

			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		
	<i>Times per day</i>	<i>dropdown/free text</i>			<i>Ensure frequency required is not available before adding new frequency</i>
	<i>Current</i>	<i>Check box</i>			
	<i>Started</i>	<i>date</i>	<i>00/00/0000</i>		
	<i>Stopped</i>	<i>date</i>	<i>00/00/0000</i>		
	<i>Notes</i>	<i>free text</i>			

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.
<i>HRCT Results</i>	<i>HRCT date</i>	<i>date</i>	<i>00/00/0000</i>		
	<i>Scan Available</i>	dropdown	<i>No/Digital/Film</i>	<i>Used to indicate if scans are available on site either in digital or film format</i>	<i>Sites can add their own fields as desired</i>
	<i>HRCT Results</i>	<i>free text</i>			<i>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</i>
6MWT					

					6MWT can be added using '+' in top right hand corner. Minimum data entered should be initial and most recent 6MWT
<i>6 Minute Walk Tests</i>					
	Test date	<i>date</i>	<i>00/00/0000</i>		
<i>see notes</i>	<i>SpO2 (start)</i>	<i>number</i>	<i>0-100</i>		
	<i>SpO2 (finish)</i>	<i>number</i>	<i>0-100</i>		
	<i>HR (start)</i>	<i>number</i>	<i>0-250</i>		
	<i>HR (finish)</i>	<i>number</i>	<i>0-250</i>		
	<i>Borg Dyspnea Score (start)</i>	<i>number</i>	<i>0-10</i>		
	<i>Borg Dyspnea Score (finish)</i>	<i>number</i>	<i>0-10</i>		
	<i>Min. SpO2</i>	<i>number</i>	<i>0-100</i>		
	<i>O2</i>	<i>number</i>	<i>0-15</i>		
	<i>Distance</i>	<i>number</i>	<i>0-1000</i>		
	<i>Limiting Symptoms</i>	<i>free text</i>			
	<i>Comments</i>	<i>free text</i>			
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.
<i>Pulmonary Function Tests</i>					PFTs can be added using '+' in top right hand corner. Minimum data entered should be initial and most recent PFTs.
	Test date	<i>date</i>	<i>00/00/0000</i>		
<i>see notes</i>	Height at test	<i>number</i>	<i>0 - 250</i>		
	Weight at test	<i>number</i>	<i>0 - 250</i>		
	<i>BMI</i>			<i>auto-populates from height and weight</i>	
	<i>Age at Test</i>			<i>auto-populates from DOB</i>	
	<i>Outside Lab</i>	<i>check box</i>			

	FVC - Forced Vital Capacity (L)	numbers		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
	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.
	FiO2	number			
	PaO2 (mmHg)	number			
	PCO2 (mmHg)	number			
	SaO2	number			
	pH	number			
	HCO3	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	

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

<i>Surgical Biopsy</i>	<i>Biopsy Date</i>	<i>date</i>	<i>00/00/0000</i>		
	<i>Biopsy type</i>	<i>dropdown</i>	<i>VATS/Cryobiopsy/Transbronchial/Endobronchial</i>	<i>add in EBUS, non-respiratory site</i>	
	<i>Age at test</i>	<i>number</i>		<i>auto-populates from DOB</i>	
	<i>Result</i>	<i>free text</i>			
Additional Tests					
<i>Sleep Studies</i>					<i>Sleep studies can be added using '+' in top right hand corner. Sites will determine how much data is entered.</i>
	<i>Test Date</i>	<i>date</i>	<i>00/00/0000</i>		
	<i>Age at Test</i>	<i>date</i>	<i>00/00/0000</i>	<i>auto-populates from DOB</i>	
	<i>Diagnosis</i>	<i>dropdown</i>	<i>No sleep Disorder/Obstructive Sleep Apnoea/Central Sleep Apnoea/Nocturnal Hypoventilation/Obstructive Sleep Apnoea & Nocturnal Sleep Apnoea/Central Sleep Apnoea and Nocturnal Hypoventilation/ Other</i>		
	<i>SpO2 Nadir</i>	<i>number</i>			
	<i>FiO2</i>	<i>number</i>			
	<i>RDI</i>	<i>number</i>			
	<i>REM RDI</i>	<i>number</i>			
	<i>NREM RDI</i>	<i>number</i>			
	<i>Sleep Efficiency</i>	<i>number</i>			
	<i>Notes</i>	<i>free text</i>			

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

	Test Date	date	00/00/0000		
	Age at Test	number		auto-populates from DOB	
	Vo2 Peak	number			
	Vo2 Peak/Kg	number			
	Vo2 Predicted	number			
	SpO2 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 / compound heterozygous / mitochondrial		
	ASSEMBLY	Text			
	POSITION	Text	Text		

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

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 specialist, 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