

PRO INSTRUMENTS USED IN STUDIES OF PULMONARY HYPERTENSION SINCE 1960

Alison Martin¹

¹Crystallise Ltd, Essex, UK alison.martin@crystallise.com

Objectives

To create an evidence map of the different patient-reported outcome instruments used in studies of patients with pulmonary arterial hypertension (PAH), the geographical settings in which these studies were conducted and the interventions assessed.

Results Map of studies by publication year

Year	1960-1999	2000-2004	2005-2010	2011-2015	2015-2017
Abstracts	1	5	25	25	14

Methods

We searched the heoro.com database (www.heoro.com) for PRO studies on PAH published between 1960 and May 16 2017, and analysed the abstracts identified by the search to determine the different PRO instruments cited across the range of geographical locations and interventions. We presented the findings as an evidence map.

- AQ20 – Airways Questionnaire 20
- AQOL – Australian Quality of Life
- BDI – Borg Dyspnoea Index
- CAMPHOR – Cambridge Pulmonary Hypertension Outcome Review
- CHD – Congenital heart disease (inc Eisenmenger syndrome)
- CHFQ – Congestive Heart Failure Questionnaire
- CHQ-PF50 – Child Health Questionnaire – Parent Form
- COPD – Chronic obstructive pulmonary disease
- CTEPH – Chronic thromboembolic pulmonary hypertension
- D-12 – Dyspnoea-12
- EQ-5D – EuroQol Questionnaire
- EscSG – European Scleroderma Study Group activity index
- ERA – Endothelin receptor antagonist
- GAD-7 – General Anxiety Disorder Scale
- HADS – Hospital Anxiety and Depression Scale
- HAQ-DI – Health Assessment Questionnaire – Disability Index
- ILD – Interstitial lung disease
- KCQ – Kansas City Questionnaire
- MLHFQ – Minnesota Living with Heart Failure Questionnaire
- NHP – Nottingham Health Profile
- PAH – Pulmonary arterial hypertension
- PAHSIS – PAH Symptom Interference Scale
- PAH-SSS – PAH Symptom Severity Scale
- PDE-5 – Phosphodiesterase-5 inhibitor
- POMS – Profile Of Mood States
- RSS – Rodnan Skin Score
- SF-6D – Short Form 6 items
- SF-12 – Short Form 12 items
- SF-36 – Short Form 36 items
- SG – Standard Gamble
- SGRQ – St. George's Respiratory Questionnaire
- SLE – Systemic lupus erythematosus
- TSQM – Treatment Satisfaction Questionnaire for Medication
- TTO – Time Trade-Off
- UCSD-SBQ – University of California San Diego Shortness of Breath Questionnaire
- VAS – Visual Analogue Scale

Map of type of PAH by PRO instrument

	AQ20	AQOL	BDI	CAMPHOR	CHFQ	CHQ-PF50	D-12	EmPHasis	EQ-5D	EscSG	GAD-7	HADS	HAQ-DI	KCQ	MLHFQ
CTEPH	0	0	1	0	0	0	0	0	1	0	1	0	0	0	3
Any PAH	1	2	1	7	1	1	1	1	5	1	1	2	0	1	6
ILD	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0
CHD	0	0	1	1	0	0	0	0	0	0	0	1	0	0	0
Sarcoid	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Systemic sclerosis	0	0	1	0	0	0	0	0	0	1	0	0	4	0	0
COPD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
SLE	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Other causes	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0

	NHP	PAHSIS	PAH-SSS	PHQ-9	POMS	RSS	SF-6D	SF-12	SF-36	SG	SGRQ	TSQM	TTO	UCSD-SBQ	VAS
CTEPH	0	0	0	1	0	0	0	0	6	0	1	0	0	0	0
Any PAH	1	1	1	1	1	0	1	0	25	1	2	1	1	0	1
ILD	0	0	0	0	0	0	0	0	3	1	1	0	0	1	1
CHD	0	0	0	0	0	0	0	1	3	0	0	0	0	0	0
Sarcoid	0	0	0	0	0	0	0	0	1	0	2	0	0	0	0
Systemic sclerosis	0	0	0	0	0	2	0	0	2	0	0	0	0	0	0
COPD	0	0	0	0	0	0	0	0	2	0	2	0	0	0	0
SLE	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0
Other causes	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Map of geographical location by intervention

	Surgery	Lung transplant	Exercise	Any ERA	Any PDE-5	Acetazolamide	Ambrisentan	Aspirin	Bosentan	Epoprostanol	Iloprost	Macitentan	Oxygen	Sildenafil	Simvastatin	Tadalafil	Treprostanil	Other /none
Australia	0	0	0	0	0	0	0	0	3	0	0	0	0	1	0	0	1	1
Belgium	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0
Brazil	0	0	0	1	1	0	0	0	1	0	0	0	0	0	0	0	0	0
Canada	0	1	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	1
China	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0
France	1	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	2
Germany	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
Hungary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
India	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0
International	1	0	2	1	0	0	0	0	1	1	0	1	0	1	0	0	0	4
Italy	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Japan	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Korea	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Netherlands	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0
New Zealand	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Portugal	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Spain	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Switzerland	0	0	0	0	0	1	0	0	1	0	0	0	1	0	0	0	0	1
Turkey	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
UK	0	0	0	0	0	0	0	0	1	0	0	0	0	3	0	2	0	4
USA	1	0	1	0	0	0	1	1	0	1	1	0	0	0	1	0	1	8
Unknown	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0

Numbers refer to number of studies identified for each category. Where a study is set in two or three locations, these are all listed separately. Studies set in five or more jurisdictions, or systematic reviews are classified as International. Studies are mapped to all relevant subcategories.

Conclusions

A wide range of PRO tools have been used in studies of PAH, but most used the SF-36 with the US or UK the most common locations.