

PATIENT-REPORTED OUTCOMES IN STUDIES PUBLISHED IN 2014: WHICH TOOLS HAVE BEEN MOST COMMONLY USED IN STUDIES OF RESPIRATORY DISORDERS?



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Objectives

To determine which patient-reported outcome (PRO) tools were used in studies on respiratory diseases that were published in 2014 and indexed in the PubMed database.

Methods

An evidence surveillance process was established based on a systematic search of PubMed, incorporating all studies published from 2010 and updated weekly, with a final search on 18 May 2015.

Abstracts identified by the search that reported quality of life outcomes in respiratory disorders were identified, based on ICD-10 classifications.

Articles were included if they reported results or a study protocol from a primary research study or were a systematic review. PRO tools were identified, where possible, from the abstract alone.

Search strategy

("quality of life"[tiab] OR QOL[tiab] OR HRQOL[tiab] OR "patient reported outcome"[tiab] OR PRO[tiab] OR "patient-reported"[tiab] OR "clinician-reported"[tiab] OR "carer-reported"[tiab])

AND

(questionnaire[tiab] OR tool[tiab] OR instrument[tiab] OR survey[tiab] OR randomised[tiab] OR randomized[tiab] OR controlled [tiab])

Limits

The search was limited to studies indexed in the PubMed database, in humans, with abstract, published in English in the previous 5 years before the search date of 18 May 2015; study methodology was limited to clinical trial, comparative study, controlled clinical trial, evaluation study, observational study, RCT, systematic review or validation study.

Results

The search identified 1,980 articles published in 2014, 1,713 of which met the inclusion criteria. Of these, 171 (10%) were in respiratory disorders. Overall, 90 different PRO or clinician-reported instruments were cited across 23 diseases, with 65 articles citing more than one tool.

The most commonly researched diseases were COPD (60 abstracts), asthma (36 abstracts), allergic rhinitis or rhinosinusitis (26 abstracts), obstructive sleep apnoea (8 abstracts) and bronchiectasis and cystic fibrosis (7 abstracts each).

The St. George's Respiratory Questionnaire (SGRQ) was the most commonly used PRO tool, in studies of COPD, asthma, bronchiectasis and emphysema (36 abstracts), followed by the Asthma Quality of Life Questionnaire (13 abstracts) and the Rhinoconjunctivitis Quality of Life tool (10 abstracts).

Utilities were measured in only 3 studies, with SF-36 used twice and EQ-5D once. The PRO used was not specified in 46 article abstracts: 20 of the 129 primary research articles, 3 of 7 study protocols and 23 of 35 systematic reviews.

Evidence map showing most widely-used PRO tools by type of respiratory disease in studies published in 2014

Numbers refer to number of abstracts citing each tool, each abstract may cite more than one tool

	SGRQ	AQLQ	RQLQ	ACQ	HADS	CAT	SNOT-20, 22	PAQLQ	CRDQ	LCQ	Sleep or fatigue scores	PROMIS	NSSS, TNSS	MRCDS	CCQ	ACT	Utility (EQ-5D, SF-36)	No. of other PROs	PRO not specified
COPD	30				4	8			2	2	4	2		6	6		2	21	16
Asthma	1	16		10			1	6				1				6		9	10
Allergic rhinitis			9										4					9	3
Rhino-sinusitis			1				6										1	2	1
Obstructive sleep apnoea											5							4	2
Cystic fibrosis							2											3	2
Bronchiectasis	4				2				1	1								3	1
Voice disorders																		2	
Nose deformities																		4	
Interstitial lung disease																		1	2
Emphysema, chronic respiratory failure	1																	3	2
Acute respiratory infections																		3	3
Other Respiratory disease			1							1								2	4

Key:

ACQ: Asthma Control Questionnaire

ACT: Asthma Control Test

AQLQ: Asthma Quality of Life Questionnaire

cACT: Children's Asthma Control Test

CAT: COPD Assessment Test

CCQ: Clinical COPD Questionnaire

CRDQ: Chronic Respiratory Disease Questionnaire

EQ-5D: European Quality of Life Questionnaire, 5 dimensions

HADS: Hospital Anxiety and Depression Scale

LCQ: Leicester Cough Questionnaire

MRCDS: Medical Research Council Dyspnea Scale

NSSS: Nasal Symptom Severity Score

PAQLQ: Pediatric Asthma Quality of Life Questionnaire

PROMIS: Patient-Reported Outcomes Measurement Information System

RQLQ: Rhinoconjunctivitis Quality of Life score

SF-36: Short-form 36

SGRQ: St George's Respiratory Questionnaire

SNOT-20, 22: Sino-Nasal Outcome Test

TNSS: Total Nasal Symptom Score

Conclusions

COPD and asthma were the most widely researched respiratory diseases in 2014, with the SGRQ the most widely used PRO. Utility values were rarely assessed directly, which, with the wide range of PRO tools used, provides a challenge to assessing and comparing cost-effectiveness of interventions across studies.