

# The copyright of translations of PRO instruments: the case of instruments used in lung diseases

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## Objectives

To evaluate how the copyright of Patient-Reported Outcome (PRO) instruments for lung diseases and their translations is handled by the developers of these instruments.

## Methods

The following method was used:

- (1) Search in the PROQOLID database to identify PRO measures developed for lung diseases. The search focused on "respiratory tract diseases," excluding common cold, influenza, rhinitis, sinusitis, and voice disorders;
- (2) Development of a survey to identify which copyright solutions developers adopted for the original questionnaires and their translations, and why; and
- (3) Mailing to the developers of the instruments identified in PROQOLID.

## Results

- Forty-five instruments were retrieved; nine were excluded (because they were not translated). See Table 1.
- In total, 36 surveys were sent, representing 18 different authors.
- Seventeen surveys were sent back (47.2%), representing eight authors (44.4%).
- The analysis of the surveys showed that the copyright of 13 questionnaires was owned either by the developer and coauthors (n=8), or by his/her/their institution (n=5). For the four remainders, the developers specified that either the instruments were not copyrighted (n=2), or in the public domain (n=1), or the issue was unclear because of the signature of a copyright transfer with the publisher (n=1). See Table 2.
- As for the translations, results show that those who owned the copyright of the original controlled the copy right of the translations: (1) to preserve the integrity of the translated measure, (2) to control its use, and (3) to provide easy access. When the copyright of the original is not owned by the developer, the translations' follow-up is unclear and the copyright ownership of the translations is not known making it difficult to access and use them. See Table 3.

Table 1. Lung Disease PRO Measures - PROQOLID search

Abbrev.	Full name	Translated
AAQOL	Adolescent Asthma Quality of Life Questionnaire	Yes
ABP	Asthma Bother Profile	Yes
ACQ	Asthma Control Questionnaire	Yes
ACSS	Asthma Control Scoring System	Yes
ACT	Asthma Control Test™	Yes
AQLQ	Asthma Quality of Life Questionnaire	Yes
AQLQ-M	Asthma Quality of Life Questionnaire - Marks	Yes
ASC	Asthma Symptom Checklist	Yes
CAQA	Childhood Asthma Questionnaire / 4 to 7 years	
CAQB	Childhood Asthma Questionnaire / 8 to 11 years	Yes
CAQC	Childhood Asthma Questionnaire / 12 to 16 years	
LWAQ	Living with Asthma Questionnaire	Yes
MiniAQLQ	Mini Asthma Quality of Life Questionnaire	Yes
PACQLQ	Paediatric Asthma Caregiver's Quality of Life Questionnaire	Yes
PAQLQ	Paediatric Asthma Quality of Life Questionnaire	Yes
AQ30/20	Airways Questionnaire	Yes
SGRQ	St George's Respiratory Questionnaire	Yes
BDI	Baseline Dyspnea Index	Yes
TDI	Transition Dyspnea Index	Yes
BPQ-LV	Breathing Problems Questionnaire - Long Version	Yes
BPQ-SV	Breathing Problems Questionnaire - Short Version	Yes
CCQ	Clinical COPD Questionnaire	Yes
CRQ-Original	Chronic Respiratory Disease Questionnaire (Interviewer-Administered, Individualized Activities)	
CRQ-SAS	Chronic Respiratory Disease Questionnaire - Self-Administered, Standardized activities	Yes
CRQ-SAI	Chronic Respiratory Disease Questionnaire - Self-Administered, Individualized Activities	
CRQ-IAS	Chronic Respiratory Disease Questionnaire - Interviewer-Administered, Standardized Activities	
PFSDQ	Pulmonary Functional Status & Dyspnea Questionnaire	Yes
PFSDQ-M	Pulmonary Functional Status & Dyspnea Questionnaire-modified	
SOLQ	Seattle Obstructive Lung Disease Questionnaire	Yes
CFQ	Cystic Fibrosis Questionnaire	Yes
CFQ-R	Cystic Fibrosis Questionnaire - Revised	Yes
LCSS	Lung Cancer Symptom Scale	Yes
LCSS-Meso	Lung Cancer Symptom Scale - Mesothelioma	Yes
CAP-Sym	Community-Acquired Pneumonia Symptom questionnaire	Yes
MRF26	Maugeri Foundation Respiratory Failure Questionnaire	Yes
MRF28	Maugeri Foundation Respiratory Failure Questionnaire (original)	Yes
AAQ	Attitudes to Asthma Questionnaire	No
AMA	About My Asthma	No
AQLQ-NAA	Asthma Quality of Life Questionnaire for Native American Adults	No
ASES	Asthma Self-Efficacy Scale	No
ASUI	Asthma Symptom Utility Index	No
KASE-AQ	Knowledge, Attitude and Self-Efficacy Asthma Questionnaire	No
QLQ-Asthma	Questionnaire for the Assessment of Quality of Life in Asthma Patients	No
PICQoL	Paediatric Intensive Care Quality of Life questionnaire	No
QUAL-E	Quality of Life at the End of Life Measure	No

Table 2. Survey Results - Copyright of original

Name of PRO measure	Copyright of original Questionnaire owned by?						Why?						Any Problems? Yes/No
	You	You + co-authors	University / Institution	Other sponsor	Don't know	Others	No particular reason	University policy	Integrity preservation	Control of use	Easy access	Other reason(s)	
BDI	1								1	1	1		N
TDI	1								1	1	1		N
AQLQ-M						1 (publisher)							Y
CRQ			1						1	1			N
CRQ-IAS			1						1	1			N
CRQ-SAI			1						1	1			N
CRQ-SAS			1						1	1			N
ABP	1									1			N
BPQ-LV		1								1			N
BPQ-SV		1								1			N
LWAQ	1												N
LCSS		1							1				N
LCSS-Meso		1							1				N
ACT			1										N
SOLQ						1 (public domain)							NA*
PFSDQ						1 (not copyrighted)						1 (best approach)	NA
PFSDQ-M						1 (not copyrighted)						1 (best approach)	NA
TOTAL	4	4	5	0	0	4	0	0	6	8	5	2	

Missing response

\*NA : Not Applicable

Table 3. Survey Results - Copyright of translations

Name of PRO measure	Copyright of original Questionnaire owned by?						
	You	You + co-authors	University / Institution	Other sponsor	Translation team	Don't know	Others
BDI	1						
TDI	1						
AQLQ-M							1
CRQ			1				
CRQ-IAS			1				
CRQ-SAI			1				
CRQ-SAS			1				
ABP		1					
BPQ-LV		1					
BPQ-SV		1					
LWAQ							
LCSS		1		1			
LCSS-Meso		1		1			
ACT			1				
SOLQ							1
PFSDQ							1
PFSDQ-M							1
TOTAL	2	5	5	2	0	4	0

Missing response

\*NA : Not Applicable

## Conclusion

The developer of the original instrument is key in determining the future of the translations of his/her instrument. A centralized control of the translations might facilitate the worldwide use of PRO instruments and avoid the multiplication of non-official translations per language.

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