BiblioPRO

Fundació IMIM cïberesp

Online library of Patient Reported Outcomes (PRO) in Spanish

Mireya García-Durán, Montserrat Ferrer, Jordi Alonso
and the BiblioPRO Scientific Committee
Fundació IMIM and CIBERESP

Aims

BiblioPRO is an online library of Patient Reported Outcomes (PRO) instruments in **Spanish**.

Aims:

- To facilitate **information and access** to PRO questionnaires and user manuals

- To promote their **appropriate use** in research, clinical practice, and socio-sanitary management

- To recognize the value of **intellectual property**, and the effort made in the **adaptation and validation** of instruments.

Methods

- **Systematic literature reviews** for instruments' identification

- **Scientific taxonomy classification:**
  - **Constructs** measured (Table1)
  - **Target population** (Table2)
  - **Disease-specific category** (Table3)
  - **Measurement model** (psycho, eco, clinimetric, other)
  - **Dimensions** and number of Items

- **Intellectual Property protection**
BiblioPRO requests formal authorisations to digitalise, reproduce and distribute instruments to authors of original and derivate works.

Results

Information on 524 PRO instruments in Spanish
Most are Disease Specific and 62 Generics (Table 3)

Authorisation to reproduce over 120 instruments
Permissions of use management

Additional downloadable information
Educational training programs

User-friendly search engine:

FIND Instruments

BiblioPRO instruments according to original taxonomy:

Table 1 Construct Measured

Construct	Total
Health Related Quality of Life or Perceived Health	273
Symptom Scales	48
Satisfaction with Care	18
Functional Status or Activities of Daily Living (ADL)	12
Social Support	5
Constructs related with Treatment (adherence, expectations or beliefs)	2
Resilience	1
Environmental	1
Other	164

Table 2 Target Population

Gender	Total
Male	18
Female	21
All genders	485

Age-group	Total
Seniors	8
Adolescents	12
Children	24
Adults	480

Table 3 Disease Specific category based on ICD-10

Disease	Total
Mental and behavioural disorders	156
Generic or any disease	62
Nervous system	55
Genitourinary system	34
Neoplasms	34
Musculoskeletal system and connective tissue	32
Digestive system	27
Respiratory system	26
Circulatory system	19
Endocrine, nutritional and metabolic diseases	14
Eye and adnexa	11
Certain infectious and parasitic diseases	10
Codes for special purposes	9
Skin and subcutaneous tissue	8
Factors influencing health status and contact with health services	7
Injury, poisoning and certain other consequences of external causes	6
External causes of morbidity and mortality	5
Ear and mastoid process	5
Blood, blood-forming organs and certain disorders involving the immune mechanism	2
Pregnancy, childbirth and the puerperium	1
Congenital malformations, deformations and chromosomal abnormalities	1

Conclusions

✓ **Knowledge transfer:**
Facilitates access to potential users of PRO instruments in Spanish speaking countries, including Latin America

✓ **Recommendations on the robustness of the metric properties**: Impact of the library will be enhanced by providing standardised evidence-based evaluations (EMPRO).

Bibliography

- Valderas JM, Alonso J. Patient reported outcome measures: a model-based classification system for research and clinical practice. **Qual Life Res** 2008;17:1125-35.

- Valderas JM, Ferrer M, et al. Development of EMPRO: a tool for the standardized assessment of patient reported outcome measures. **Value Health** 2008; 11(4): 700-708.

http://bibliopro.imim.es