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PRO INSTRUMENTS USED IN STUDIES PUBLISHED SINCE 2005: WHICH POPULATIONS AND DISEASES HAVE HAD THE MOST TOOLS DEVELOPED?

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Objectives

To determine the number of unique patient- and clinician-reported outcome (PRO) tools that have been used in studies published since 2005 for different disease areas and populations.

Methods

We developed a PRO instrument ontology from those tools cited within the abstracts of over 100,000 studies identified by a systematic search of PubMed on the humanistic and economic burden of disease, which were stored in an online database (www.heoro.com). The ontology items are semantically indexed by general topic, population, disease or body area, symptom or treatment. Abstracts are tagged to each relevant ontology item during an automated process using text processing and tokenising approaches, and indexing is then checked by experts.

Results

A total of 4,272 instruments were identified from 22,254 relevant abstracts. Of these, most (2,648) were disease-specific, 309 related to non-disease-specific treatments, 246 to non-disease-specific symptoms, 243 were for use in children, 117 for caregivers or family members, 70 for the elderly and 13 for clinicians or researchers. Utility values were assessed by 38 instruments.

Of the **disease-specific instruments**, mental disorders had the largest number of different tools (434), followed by musculoskeletal diseases (344 tools), neurological disorders (292), cancers (243), gastrointestinal diseases (231), respiratory diseases (204) and urogenital disorders (172).

Treatment-related instruments generally assessed adverse events (100) or satisfaction or effectiveness (92 tools each).

Symptom-related instruments most commonly assessed pain (122 tools), urinary incontinence (62), sleep disorders (61) or fatigue (49).

Disease area	Number of instruments
Mental health	434
Musculoskeletal	344
Neurology	292
Cancer	243
Gastrointestinal	231
Respiratory	204
Urogenital	172
Cardiovascular	128
Skin	128
Endocrine	116
Eye	84
Infectious disease	42
Ear	40
Immune system	33
Trauma	21
Haematology	17
Genetic disorder	7
Critical illness	3
Metabolic disorder	3

Treatment impact	Number of instruments
Adverse events	100
Effectiveness	92
Satisfaction	92
Any	61
Organisational	43
Attitude to treatment	17
Adherence	14
Expectations	6
End of life	5

Symptom type	Number of instruments
Pain	122
Urinary incontinence	62
Sleep	61
Fatigue	49
Low visual acuity	35
Dyspepsia	31
Hearing impairment	28
Spasticity	24
Dyspnoea	21
Dysphagia	16
Faecal incontinence	16
Aphonia	12
Constipation	10
Cough	10
Gastrointestinal	10
Itch	6
Nausea/vomiting	6
Tinnitus	6
Lower urinary tract symptoms	5
Tremor	5
Aphasia	4
Anosmia	3
Dizziness	3
Drooling	3
Neuropathy	3

Conclusions

A vast number of different PRO tools have been developed and used in research published over the past 10 years, with a new instrument reported on average for every 5 PRO study publications. The reasons for the diversity remain unclear, but it makes it difficult to compare the impact of diseases on quality of life, or the efficacy and cost-effectiveness of interventions across studies.