Involvement of the patient and the family

Jose M Valderas

GP and Professor of Health Services & Policy Research

UNIVERSITY OF EXETER | MEDICAL SCHOOL

Clinical applications of PROMs

- Screening
- Diagnosis
- Risk stratification and prognosis
- Goal setting
- Indication for treatment (medical/surgical)
- Monitoring
- Improving communication
  - With patients
  - Within teams and between professionals: consistent use along the care pathway

Reliability of clinical measures and PROMs

- Height (1.00)
- Weight (0.99)
- SF-36 Physical functioning (0.93)
- Bedside Glucose screening (0.92)
- PHQ 9 (0.85)
- SF-36 Pain (0.80)
- Heart rate (0.68)
- Diastolic Blood Pressure (0.60)
- SF-36 Social functioning (0.60)
- Tachypnea (0.60)

Hahn Mayo Clin Proc, 2007

By placing a checkmark in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

☐ I have no problems in walking about ☐

☐ I have some problems in walking about ☐

☐ I am confined to bed ☐

Self-Care

☐ I have no problems with self-care ☐

☐ I have some problems washing or dressing myself ☐

☐ I am unable to wash or dress myself ☐

Usual Activities (e.g., work, study, housework, family, or leisure activities)

☐ I have no problems with performing my usual activities ☐

☐ I have some problems with performing my usual activities ☐

☐ I am unable to perform my usual activities ☐

Pain/Discomfort

☐ I have no pain or discomfort ☐

☐ I have moderate pain or discomfort ☐

☐ I have extreme pain or discomfort ☐

Anxiety/Depression

☐ I am not anxious or depressed ☐

☐ I am moderately anxious or depressed ☐
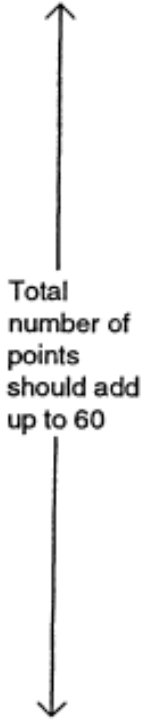
☐ I am extremely anxious or depressed ☐

Selecting the right PROM for clinical practice

- ..., but what if the problem is difficulty hearing? What if chronic cough? What if diabetes?

- ..., but what if there is more than one problem?

- ..., but what if the problem does not bother the patient? What if the problem is minor but impacts on areas of great importance? What if the areas are not even considered (most things that people enjoy doing!)?

Selecting the right PROM for clinical practice

Individualized PROMs give respondents the possibility **to tailor measurement to relevant and meaningful aspects of their life**

- Schedule for the Evaluation of Individual Quality of Life (SEIQOL)

- Patient Generated Index

- MYMOP

- Goal Attainment Scale

STAGE 1
area/ activity
(eg sport)

STAGE 2
score each area/
activity out of 100

STAGE 3
spend your
60 points between
the different areas

Total
number of
points
should add
up to 60

All other aspects of your life
not mentioned above

You must fill

in this box

100	Exactly as you would like to be
90	Close to how you would like to be
80	Very good but not how you would like to be
70	Good but not how you would like to be
60	Between fair and good
50	Fair
40	Between poor and fair
30	Poor but not the worst you could imagine
20	Very poor but not the worst you could imagine
10	Close to the worst you could imagine
0	The worst you could imagine

Research needs

- Testing different clinical applications of available tools:

  screening, diagnosing, risk stratification and prognosis, indication for treatment, monitoring, consistent use along the care pathway

- Identifying best methods for data collection

  Home vs HC settings, electronic data collection (item banks), timing, response shift

- Identification of best methods for feedback and interpretation

- Training needs of professionals

- Impact of feedback to individual patients