Using patient reported outcome measures in Primary Care: evidence and challenges

Jose M Valderas
Professor of Health Services & Policy Research
General Practitioner
What are PROMs

• Quality of Life
• Health Related Quality of Life
• Functioning
• Symptoms
• Health perceptions
• Health status
• EQ5D, SF-36, Oxford Hip Score
What are PROMs

• “Any measurement of a patient health status that comes directly from the patient”
What are PROMs

• “Any measurement of a patient health status that comes directly from the patient”

• Any health measurement that comes directly from the patient
What are PROMs

• Stimulus (item):
  \textit{How much bodily pain} have you had during the \textit{past 2 weeks}?

• Response (scale)
  - None, Very mild, Mild, Moderate, Severe, Very severe

• Scoring (domains, weights)
  Bodily pain domain (\%, \t-score)
  Physical Health Summary
What are PROMs

- Self reported health status: “In general, how would you rate your health?” Excellent, very good, good, fair, poor
- Medical Outcomes Study short-form health surveys (SF-36, SF-12, SF-6D)
- EuroQoL (EQ-5D)
- McGill Pain Questionnaire
- KIDSCREEN
- Patient Health Questionnaire (PHQ-9)
- Schedule for the Evaluation of Individual Quality of Life (SEIQoL)
What are PROMs

Types of PROMs

• Construct:
  – Symptoms: patient’s perception of an abnormal physical, emotional or cognitive state
  – Functional status: ability of the individual to perform tasks
  – Health perceptions: subjective integration of information related to symptom status and functional status
  – HRQoL
  – Other

• Population: age, gender, condition, culture

• Measurement:
  – Metric: psychometric, econometric, clinimetric
  – Dimensionality: index, profile
  – Adaptability: standardized, individualized
<table>
<thead>
<tr>
<th>PRO measure</th>
<th>A. Construct (item level)</th>
<th>B. Population*</th>
<th>C. Measurement</th>
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<td>A.1. Symptoms (F00-F99, R00-R99)</td>
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<td>C.1.c. Index &amp;Profile</td>
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<td>B.2.a. All genders</td>
<td>C.2.a. Psychometric</td>
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<td>A.3. Health perceptions</td>
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<td>C.3.a. Completely standardized</td>
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<td>A.4. Quality of Life</td>
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<td>Sickness Impact Profile</td>
<td>A.1. Symptoms (F00-F99, R00-R99)</td>
<td>B.1.d. Adults</td>
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<td>EORTC QLQC30</td>
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Where to find PROMs

• Repositories
  – Catalogues:
    • I McDowell  2006
    • A Bowling  2004 and 2001
    • S Salek 1999
  – On-line libraries:
    • PROQOLID
    • PROMs group, Oxford
    • BiblioPRO

• Ad hoc literature search
Developed by MAPI Research Institute and managed by MAPI Research Trust (Lyon, France), ProQolid aims to identify and describe PRO and QOL instruments to help you choose appropriate instruments and facilitate your access to them.

**Free access**

This level is available to all ProQolid visitors at no charge. For each instrument in the database, you will find 14 categories of basic information (e.g., author, objective, mode of administration, original language, existing translations, pathology, number of items, etc.). Search

**Advanced access (members only)**

This level presents a greater degree of practical information on each instrument, most notably the author's details and contact information, conditions of use, psychometric properties, etc., and, when available, a review copy of the original instrument, its translations, and a user manual.

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**Highlights**

- Free two-week trials of ProQolid are available upon request.
- Please contact us for more details.

**ProQolid online subscription now available on an easy and secure platform**

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**Database**

**ProQolid currently contains**

- Descriptions of 706 instruments
- 540 review copies of original instruments
- Review copies of 1293 translations
- Review copies of 177 user manuals
- Descriptions of 82 databases

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**On-going developments**

**Include**

- **On-going update** in collaboration with the instruments' developers: complete description of the content validity documentation (previously named methodology of development)
- 13 new instruments added in 2011

**Instruments recently added**

- Asthma Control Diary (ACD)
- Nocturnal Rhinoconjunctivitis Quality of Life Questionnaire (NRQLQ)
- European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Cervical Cancer Module (EORTC QLQ-CX24)
- More

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**NB:** ProQolid's content is based on information taken from literature and/or validated by the authors of the instruments. The adequacy of study methodology and psychometric properties is not evaluated.

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Access to the disease-specific instruments by pathology/disease

The term "pathology" refers to a large therapeutic area and can cover several diseases. On the other hand, the term "disease" refers to a specific, precisely defined condition.

- Bacterial infections and mycoses
- Cardiovascular diseases
- Congenital, hereditary, and neonatal diseases and abnormalities
- Digestive system diseases
- Disorders of environmental origin
- Endocrine system diseases
- Eye diseases
- Female genital diseases and pregnancy complications
- Hemic and lymphatic diseases
- Immune system diseases
- Male genital diseases
- Musculoskeletal diseases
- Neoplasms
- Nervous system diseases
- Nutritional and metabolic diseases
- Otorhinolaryngologic diseases
- Pathological conditions signs and symptoms
- Psychiatry/psychology
- Respiratory tract diseases
- Skin and connective tissue diseases
- Stomatognathic diseases
- Surgical Procedures, Operative
- Urologic diseases
- Virus diseases

Choose a pathology
<table>
<thead>
<tr>
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<th>Abbrev.</th>
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<th>Author(s)</th>
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<tbody>
<tr>
<td>Generic for musculoskeletal diseases</td>
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<td>Granger Carl V, Hamilton Byron B, Keith Robert Allen et al.</td>
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<td>PASI</td>
<td>Patient-Specific Index</td>
<td>Wright James G</td>
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<td>SAT-16</td>
<td>SAT-16</td>
<td>Benevolo Emilio, Franzignoni Franco, MD Ottone Otello Marella et al.</td>
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<td>Western Ontario Rotator Cuff Index</td>
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<td>Duffy Ciaran M</td>
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<td>McMaster Toronto Arthritis Patient Preference Disability Questionnaire</td>
<td>Tugwell Peter</td>
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<td>Oxford Elbow Score</td>
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Muskuloskeletal diseases
(Diseases of the muscles and their associated ligaments and other connective tissue and of the bones and cartilage viewed collectively)

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Reports and Publications

The following reviews are available from this website.
The reviews were intended to inform Department of Health choices about PROMs that might be further tested for possible use in the NHS.
Currently a study is in progress which is to evaluate the feasibility of using PROMs in Long-term conditions (Asthma, COPD, Diabetes, Epilepsy, Heart Failure and Stroke) in Primary Care. For more information click here.

All files are in Adobe PDF format, to save them, please right-click and choose to save to your computer.

Reviews

Long-term conditions

- Asthma
  - 2010 review
  - 2006 review
- Epilepsy
  - 2010 review
  - 2006 review
- Heart Failure
  - 2010 review
  - 2006 review
- Stroke
  - 2010 review
  - 2006 review
- Chronic Kidney Disease
  - 2010 review
- PROMs and Children
  - 2009 review
- Chronic Obstructive Pulmonary Disease (COPD)
  - 2009 review
  - 2006 review
- Diabetes
  - 2009 review
  - 2006 review

CANCER Reviews

- Breast Cancer
  - 2010 review
- Colorectal Cancer
  - 2010 review
- Lung Cancer
  - 2010 review
- Prostate Cancer
  - 2010 review

Elective procedures

- Elective Cardiac Procedures
  - 2010 review
- Gynaecological Procedures
  - 2010 review
Quality of PROMs

• **Psychometric properties:**
  – **Validity (strength):** does the PROM measure really what it is expected to measure?
  – **Reliability:** is the variation in measurements of the same phenomenon as low as possible?
  – **Sensitivity to change:** can the PROM detect real differences?
Quality of PROMs

• **Interpretation:** What does this score mean?
  – Norms: population
  – Anchors (external): e.g., mortality
  – Content (internal): performance
  – Magnitude: Minimal Important Difference (MID), Standard Error of Measurement (SEM)

• **Ease of use**
  – Administration burden on patients
  – Administration burden on professionals

• **Adaptation**
Quality of PROMs

- Ad hoc evaluation
- Systematic comparisons
  - Ad hoc methods
  - Standardized methods:
    - EMPRO
    - COSMIN
Use of PROMs in clinical practice

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<thead>
<tr>
<th>Used at the clinician–patient interface</th>
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<td>Population monitoring and assessing quality of care</td>
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Greenhalgh J. Qual Life Res 2009
Impact of PROMs in clinical practice (individual use)

- Systematic reviews of randomized controlled trials, 2008 (1966-2007)
- 28 studies
- USA (21), UK (5), Canada (1), The Netherlands (1)
- Primary Care (19), Other settings (9)
- Generic (Short Form SF-36), Condition specific (Mental health, Neoplasms)
- Huge variation in instruments, patients, randomization, analyses
Impact of PROMs in clinical practice (individual use)

- In most trials, impact was limited.
- Changes in processes of care:
  - Increase in rates of advice, education, counselling, notations, diagnoses
  - Improvement of outcomes (health status)
  - Little evidence for change in consultations or referrals
- Non conclusive evidence for benefit
PROMs in the UK

• Routine use of PROMs for patients undergoing elective surgery:
  – hip replacements: EQ5D + Oxford Hip Score
  – knee replacements: EQ5D + Oxford Knee Score
  – Hernia: EQ5D
  – Varicose veins: EQ5D + Aberdeen Varicose Vein Questionnaire

• All NHS patients, all hospitals

• Objectives:
  – To assess the relative clinical quality of providers of elective procedures
  – To research what works
  – To aid demand management.
## Use of PROMs in clinical practice

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<td>- Facilitating communication within multidisciplinary teams</td>
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Greenhalgh J. Qual Life Res 2009
The diagram outlines the key components of the NHS Outcomes Framework, aligned with the Duty of Quality:

1. **Domain 1**: Preventing people from dying prematurely
2. **Domain 2**: Enhancing quality of life for people with long-term conditions
3. **Domain 3**: Helping people to recover from episodes of ill health or following injury
4. **Domain 4**: Ensuring that people have a positive experience of care
5. **Domain 5**: Treating and caring for people in a safe environment and protecting them from avoidable harm

Additionally, the diagram notes:

- **NICE Quality Standards**: Building a library of approx 150 over 5 years
- **Commissioning Outcomes Framework**
- **Commissioning Guidance**
- **Provider payment mechanisms**
  - tariff
  - standard contract
  - CQUIN
  - QOF

Lastly, the diagram mentions the responsibilities of the NHS Commissioning Board: certain specialist services and primary care, while GP consortia handle all other healthcare services.
## Overarching indicator

2 Health-related quality of life for people with long-term conditions (EQ-5D)**

## Improvement areas

**Ensuring people feel supported to manage their condition**

2.1 Proportion of people feeling supported to manage their condition***

**Improving functional ability in people with long-term conditions**

2.2 Employment of people with long-term conditions

**Reducing time spent in hospital by people with long-term conditions**

2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)

2.3.ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s

**Enhancing quality of life for carers**

2.4 Health-related quality of life for carers (EQ-5D)**

**Enhancing quality of life for people with mental illness**

2.5 Employment of people with mental illness
Use of PROMs in clinical practice

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Greenhalgh J. Qual Life Res 2009
Clinical applications of individual PROMs data

- 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
Evidence

- Systematic review of RCT (2008): 28 studies
- Intervention: feedback of PROMs to health professionals (+/- additional interventions) compared to no feedback
- Mental health (50%), generic health status, other
- 65% studies showed some impact on processes (diagnosis, advice/education/counselling)
- 47% studies showed some impact on outcomes (PROMs)
- Most clear benefit for screening/diagnosis of depression
- More recent additional studies are showing increased impact on outcomes

What seems to work?

- Specific PROMs training (validity, reliability, interpretation)
- Frequent and timely feed-back
- Feed-back process well aligned with routine care
- Information integrated into available information systems
- Information that is linked to specific action

The Quality and Outcomes Framework (QOF) has incentivized General Practitioners to **measure the severity of depression with a validated questionnaire** at the start of treatment in all diagnosed cases (since April 2006) (Recommended tools: PHQ-9, HADS, BDI-II)

<table>
<thead>
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<th>DEP 6</th>
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<tbody>
<tr>
<td>In those patients with a new diagnosis of depression, recorded between the preceding 1 April and 31 March, the percentage of patients who have had an assessment of severity at the time of diagnosis using an assessment tool validated for use in primary care.</td>
<td>17</td>
<td>50–90%</td>
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<th>DEP 7</th>
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<tr>
<td>In those patients with a new diagnosis of depression and assessment of severity recorded between the preceding 1 April to 31 March, the percentage of patients who have had a further assessment of severity 2–12 weeks (inclusive) after the initial recording of the assessment of severity. Both assessments should be completed using an assessment tool validated for use in primary care.</td>
<td>8</td>
<td>45–80%</td>
</tr>
</tbody>
</table>
PROMS for Depression in Primary Care

Mean: 78% patients

Mean: 15.8 points (out of 17)

Mean: 54% patients

Mean: 5.9 points (out of 8)
Patients favoured the measures.

They saw them as an efficient and structured supplement to medical judgment.

They saw them as evidence that general practitioners were taking their problems seriously through a full assessment.

Dowrick et al BMJ 2009; Leydon et al BJGP 2011
Both Patients and GPs considered that assessments of severity should be seen as one aspect of holistic care.

They both were aware of the potential for manipulation of indicators: for economic reasons (GPs), to avoid stigma or meet expectations for desired outcomes (patients).

Dowrick et al BMJ 2009; Leydon et al BJGP 2011
PROMS for Depression in Primary Care

- GPs were cautious about validity and utility and sceptical about the real motives behind their introduction.
- **Lack of specific training.**
- PROMs seen as an intrusion into the consultation, practical wisdom and clinical judgment more important than objective assessments
- Were concerned that the assessments reduced the human element of the consultation.
- GP concerns seemed to be shaped by a very practical concern of precisely how and when a measure should be introduced, without intruding into the consultation.
- The measure was not viewed as an integrated part of patient assessment and diagnosis.

Dowrick et al BMJ 2009; Leydon et al BJGP 2011
PROMS for Depression in Primary Care

• GPs managed the questionnaires differently
  – For patients to take away with them
  – For patients to complete in the waiting room
  – Completing them with the patient during the consultation
  – Memorizing answers and completing after the consultation
  – Completing them over the phone

• Pharmacological treatment and referral rates linked to severity but substantial variation within each stratum

What seems to work?

- Specific PROMs training (validity, reliability, interpretation)
- Frequent and timely feed-back
- Feed-back process well aligned with routine care
- Information integrated into available information systems
- Information that is linked to specific action

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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)
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
- [x] I am confined to bed

**Self-Care**
- [ ] I have no problems with self-care
- [ ] I have some problems washing or dressing myself
- [x] 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
- [x] I am unable to perform my usual activities

**Pain/Discomfort**
- [ ] I have no pain or discomfort
- [ ] I have moderate pain or discomfort
- [x] I have extreme pain or discomfort

**Anxiety/Depression**
- [ ] I am not anxious or depressed
- [ ] I am moderately anxious or depressed
- [x] 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)?
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
<table>
<thead>
<tr>
<th>STAGE 1</th>
<th>STAGE 2</th>
<th>STAGE 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>area/ activity (eg sport)</td>
<td>score each area/activity out of 100</td>
<td>spend your 60 points between the different areas</td>
</tr>
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</table>

Total number of points should add up to 60

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Exactly as you would like to be</td>
</tr>
<tr>
<td>90</td>
<td>Close to how you would like to be</td>
</tr>
<tr>
<td>80</td>
<td>Very good but not how you would like to be</td>
</tr>
<tr>
<td>70</td>
<td>Good but not how you would like to be</td>
</tr>
<tr>
<td>60</td>
<td>Between fair and good</td>
</tr>
<tr>
<td>50</td>
<td>Fair</td>
</tr>
<tr>
<td>40</td>
<td>Between poor and fair</td>
</tr>
<tr>
<td>30</td>
<td>Poor but not the worst you could imagine</td>
</tr>
<tr>
<td>20</td>
<td>Very poor but not the worst you could imagine</td>
</tr>
<tr>
<td>10</td>
<td>Close to the worst you could imagine</td>
</tr>
<tr>
<td>0</td>
<td>The worst you could imagine</td>
</tr>
</tbody>
</table>
Goal oriented care

- Patient reported outcome measures
- Patient
- General Practitioner
- Care plan
- Clinical targets
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
Routine clinical use of PROMs in Primary Care

- Funded by NIHR (2011-2016)
- Primary Care patients with multi-morbidity
- Goal setting and monitoring of care and outcomes with individualized and standardized (generic and condition specific) PROMs
- Refinements of the Intervention (published evidence, qualitative research and stakeholders involvement)
Disease models

- **Infectious disease**
  - One condition
  - One agent
  - One treatment

- **Chronic disease**
  - One condition
  - Multiple agents
  - Multiple treatments

- **Multimorbidity**
  - Multiple conditions
  - Multiple agents
  - Multiple treatments

Medical care models

- **Sequential model**
  - Diagnosis
  - Treatment
  - Follow up

- **Cycle model**
  - Diagnosis
  - Treatment
  - Monitoring

- **System model**
  - Trade-offs
  - Goals
  - Networks

Patient centredness
Efficiency vs relevance
Summary

• PROMs are health measurements elicited from the patients
• PROMs need to demonstrate good psychometric properties along with evidence for acceptability
• There are repositories and standardized tools to assist the identification of the best tool for a given purpose
• PROMs are here to stay
• Individualized measurement is necessary but not sufficient for an efficient use of PROMs in clinical practice