

# Patient Reported Outcome Measures

## PROMs

**HISTORY**

Quality of Life: The Assessment, Analysis and Interpretation of Patient Reported Outcome Measures. By Peter M. Fayers, David Machin 2007, 2nd Ed.

## CHECK IN

- 1. PROMs attempt to capture the clinician's and patient's joint expectations for the patients progress. True or False**
- 2. PROMs measure success or failure of the Tx plan. True or False**
- 3. One difficulty in measuring PROMs is that they are subjective. True or False**
- 4. Subjective outcomes cannot be measured as well as objective ones. True or False**

## The Elusive QoL

What are the **Red Flags** in Capturing Patient Impressions?

Who is asking  
Who answering  
Why are they asking

**Large Degree of Subjectivity**  
Is it Worth Measuring?

"observers are poor judges of patients' opinions"



## PROMs

**Definition**

Patient-reported outcome measure (PROM) captures provider's perspective of the impact of care, patient's perception of quality of life and ability to function. These data are used to supplement traditional medical outcome measures, such as laboratory, radiology and mortality rates, to help clinicians understand and improve patient health.

Chris Curney

## Quality of Life QoL

- Do not consider a differentiator for health related quality of life outcomes
- Pain, nausea and vomiting unmet/medicated considered a barrier for Tx by technicians & pts
- Symptoms & consequences
- Most doctors report they would not rate them

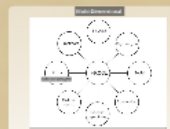
## A REVELATION

A Correlation was Found Between...  
Assessing QoL & Adherence to Tx



# THE SPHERE OF CARE

## What is The Role Of Hospital Registries?



We can **measure**...  
We can **control**...  
We can **improve**... our program!  
P.S. PROMs Are Evidence

## How Do We Measure Quality & Patient-Centered Care?

1. Clinical Outcomes  
2. Patient-Centered Care

**P**atient  
**R**eported  
**O**utcome  
**M**easures

# PROMs



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# Quality of Life

## QoL

- Pts consider a different bar for health related quality of life when ill
- Pain, nausea and vomiting underestimated considered a trade-off for Tx by both clinicians & pts
- Symptoms as consequences
- Most clinicians report they would not tolerate them

# The Elusive QoL

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# PROMs

## Definition

Patient-reported outcome measures (PROMs) capture the patient's perspective of the impact of care intervention on quality of life and ability to function. These statistically-valid patient-centered measures complement traditional medical outcome measures, such as surgical complications and mortality rates, to help clinicians understand long-term patient results.

Press Ganey



## THINK PATIENT-FOCUSED QUESTIONS:

- (1) "Given my personal characteristics, conditions and preferences, what should I expect to happen to me?"
- (2) "What are my options and what are the benefits and harms of those options?"
- (3) "What can I do to improve the outcomes that are most important to me?"
- 4) "How can the health care system improve my chances of achieving the outcomes I prefer?"

## All Outcomes are Commonly & Broadly Classified Into-

**CLINICAL** (e.g. cure, survival), C,CG,Pt

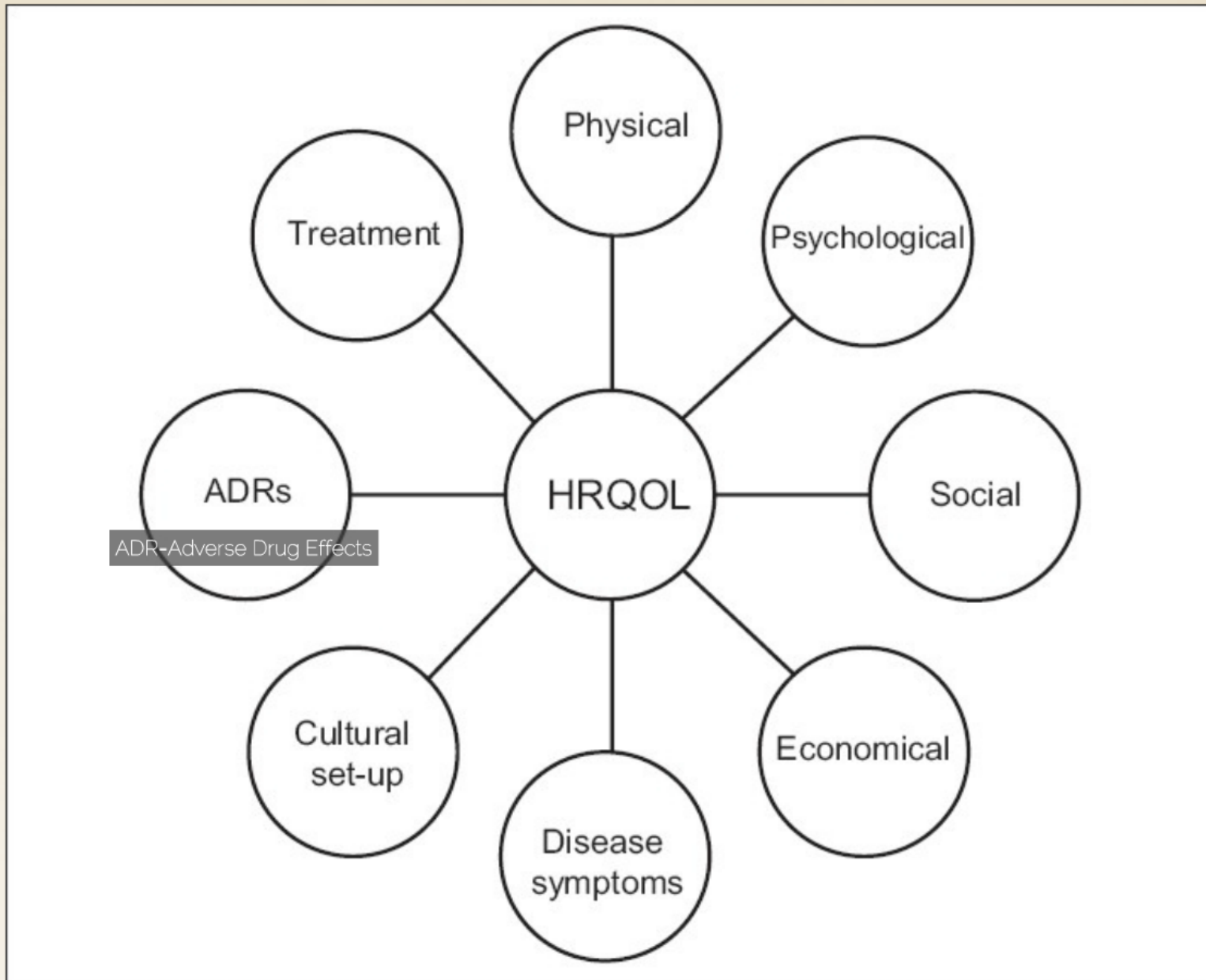
**HUMANISTIC** (e.g. role performance, emotional status) CG, Pt

**ECONOMICAL** (e.g. expenses, saving) CG, Pt

C- Clinician  
CG=Care Giver  
Pt= Patient



# Multi-Dimensional



NCCN

# Distress

NCCN NATIONAL COMPREHENSIVE CANCER NETWORK  
FOUNDATION®  
*Guiding Treatment, Changing Lives.*

gooddays



<https://www.nccn.org/patients/guidelines/distress/files/assets/basic-html/page-1.html>

5 STEPS:  
1. Identify the  
2. Review the  
3. Review the  
4. Review the  
5. Review the

# What Is The Role Of Hospital Registries?





## PURPOSE OF REGISTRIES?

describing the natural history of disease, determining effectiveness, measuring or monitoring safety or harm, and measuring quality. As one reads down the list of nominated purposes of registries, the substantive role of PROs in registry design becomes increasingly clear

We can **measure it** --

We can **collect it** --

We can **use it** in our programs !

**P.S. PROMs Are Evidence**





## Patient-Centered Outcomes Research Institute

RECENT STUDIES USED DATA + PROMs TO EVALUATE

**-Surveillance**

**-Shared Decision Making**

**-Technology**

**-Compliance (for Oral Chemo)**

**-Palliative Care**

**-Communication & Perception**

# Ask The Questions

Identify The Problem/s

Are There Existing Data Sets?

Can A PROM Add Value

**WARNING: DO NOT START WITH WHO WILL DO IT**



# How To Measure

Develop the Measuring Tool or Instrument

Consider Who Will Use It

Who Will Be Measured

For How Long & When



MONTH						
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
NOTES:						



# How Will the Results Be Used & Reported?

The screenshot displays a medical website interface with the following components:

- Header:** "Follow Us:" with social media icons for Facebook, RSS, Twitter, and YouTube. A "Login /" link is visible on the right.
- Search Section:** Four search boxes labeled "Hospital Search", "Treatment Search", "Doctor Search", and "Enter Specialist". Each box contains a placeholder image of a hospital building and a "Select a location" dropdown menu.
- Patient Details Section:** Two identical "Patient Details" forms. Each form includes a photo of a doctor and a patient, the name "Lisa Collings, UK", and a message: "To all the staff so kindly AMRI. Thank you for your service and tender treatment..". A "Search" button is located below each form.
- News & Event Section:** A section titled "News & Event" listing several events with dates and titles, such as "26th September 2011 Competition and Conference" and "21st September 2011 Ragini Khanna visits AMRI Women". A "Search" button is located below this section.
- Form Fields:** A "Patient Details" form on the right side includes input fields for "Name", "Email", and "Phone", and dropdown menus for "Select hospital", "Select department", and "Select doctor". A "Gurey" label is present below the "Select doctor" dropdown, and a "Search" button is at the bottom.


5 STEPS  
1. Initial history of disease.  
2. Assessment, measuring or  
of harm and measuring  
3. As down the list of nominated  
4. As the substantive ratio of  
5. As the ratio becomes increasingly

# What Is The Role Of Hospital Registries?




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Photo: Getty

## Quality of Life QoL

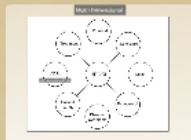
- It's considered a differentiator for health-related quality of life (HRQL)
- Many measure and wording underestimated, considered a trade-off for both clinicians & pts
- Symptoms as consequences
- Most clinicians report they would not forecast them.

## A REVELATION

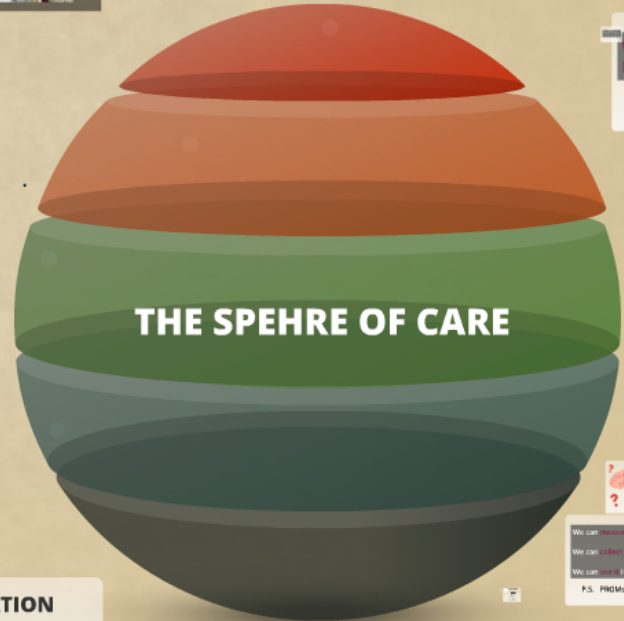
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## QoL Measures are Commonly & Easily Classified Into:

- **Physical** - e.g. pain, weakness, fatigue
- **Psychological** - e.g. mood, stress, emotional distress, etc.
- **Social** - e.g. relationships, support, etc.
- **Functional** - e.g. ability to perform activities of daily living
- **Overall** - e.g. overall quality of life



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We can capture it -  
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# **Which of the following might be considered measurable for PROMs?**

post Tx sexual function

exercise frequency & duration

religious beliefs

depression