

PROMs for the ESKD Patient:
Rethinking our Approach

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Patient Centered Care and Personalized Medicine

New focus in health care delivery worldwide:
*understand each patient's experience via effective
use of Patient Reported Outcome Measures
(PROMs) with appropriate adjustment of
therapeutic goals*

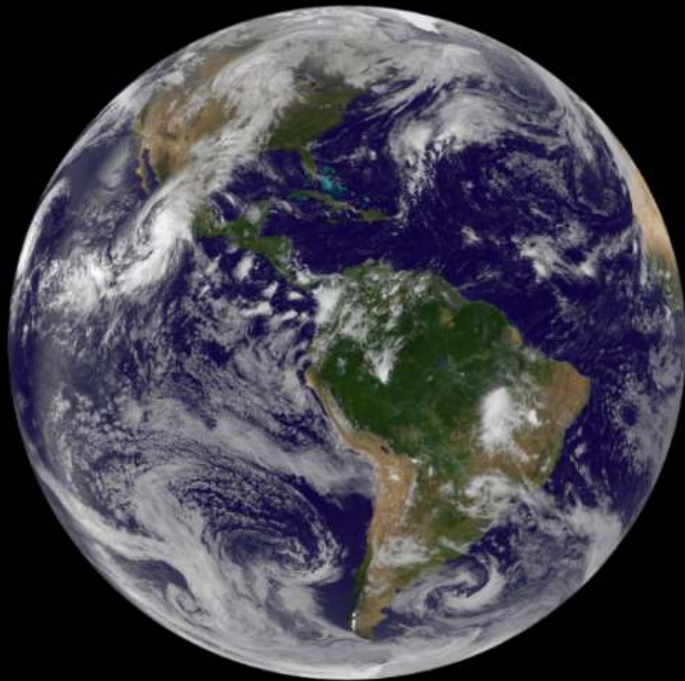
Each Person's Experience is Unique: *Lessons from the Art World*

Michael Kimmelman: NY Times 6/16/11 “Art is not just about what’s great or famous...It’s a mirror we hold up that looks different to everyone who sees it, and whose beauty lies in us and our capacity to dream...”

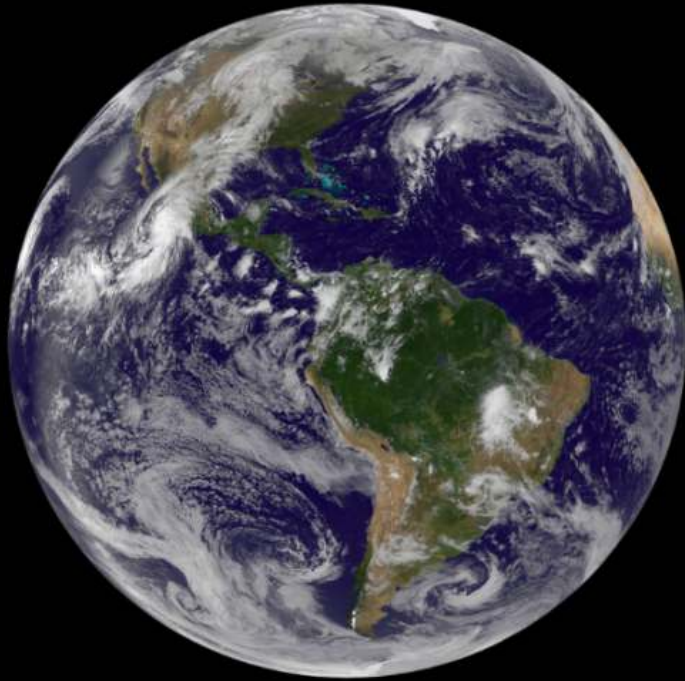


Eric Kandel, the Nobel Prize neuroscientist in the book *The Age of Insight*, notes that we need to understand that each individual, because of unconscious and conscious processes, sees the same painting (or experiences the same event) differently, uniquely interpreted/reconstructed by his or her brain.

A Major Gap in Nephrology
has been our reliance on “big
data” to provide care – not
focusing on the individual
patient and personalized care

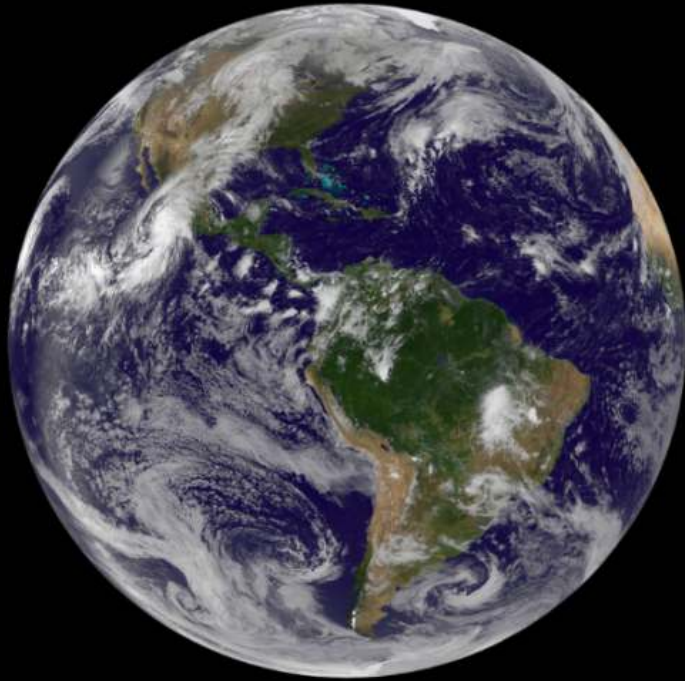


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“In medicine, we get very good about talking about the human body, but we get dumber and dumber about paying attention to the individual.” *Rita Charon, Chair Department of Medical Humanities and Ethics, College of Physicians and Surgeons, Columbia*

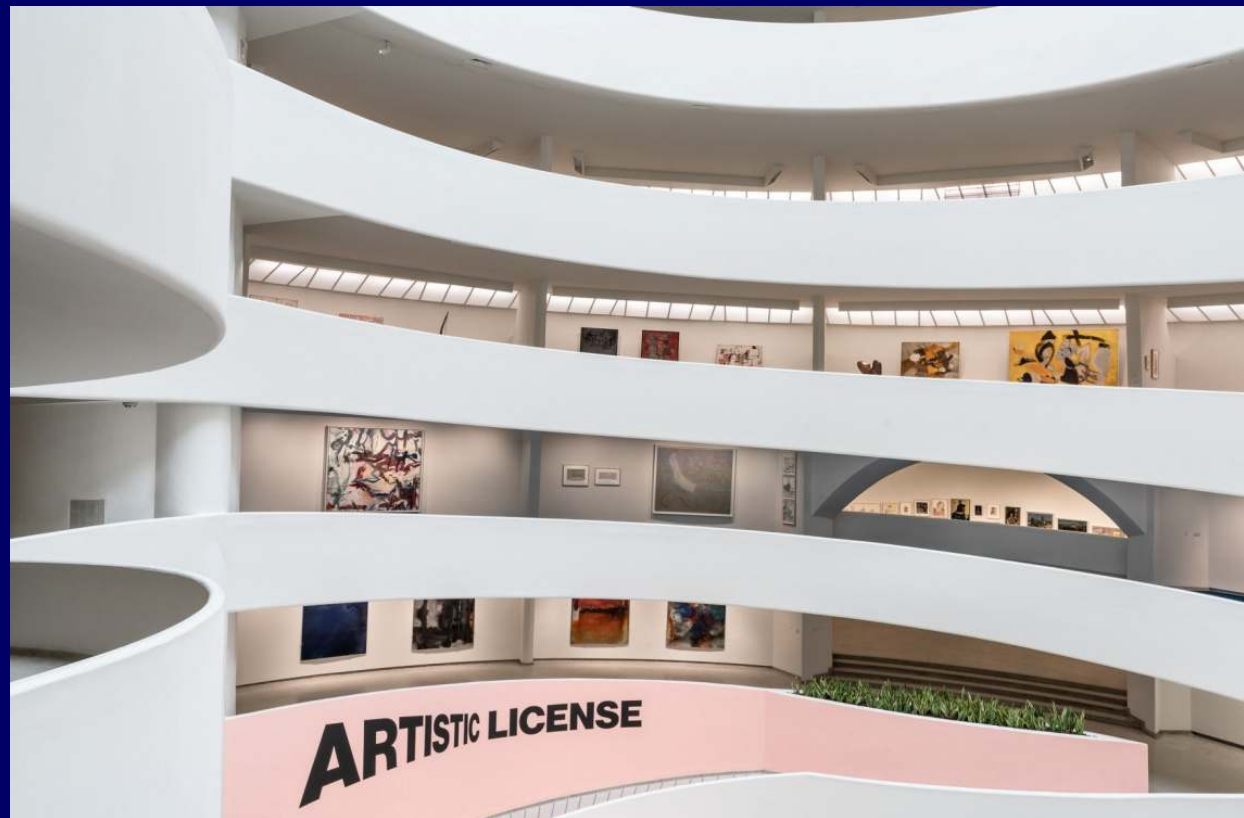
A Major Gap in Nephrology has been our reliance on “big data” to provide care – not focusing on the individual patient and personalized care



ARTISTIC LICENSE

**SIX TAKES ON THE
GUGGENHEIM COLLECTION**

6 Artists



Richard Prince

- “Art witnesses and demands accountability but it also envisages the possible”
- “An art history written from a global perspective must acknowledge the myriad and diverse ... voices of the individual... and the poetic and miraculous inventions of each of these individuals...”



Focus on Personalized Therapy

- Focus on individual patient needs
- Routinely assess patients' Health Related Quality of Life (HRQOL) using patient reported outcome measures (PROMs) and incorporating these into routine patient care
- Tailor and adjust therapy based on assessments of individual patient's needs and goals

Can This Be Integrated into Routine Care??

- The routine use of PROMs in routine care results in improved physician satisfaction, improved communication between patient and doctor, enhanced shared decision, and enhanced work flow efficiency

Rottenstein NEJM 377:14, 2017



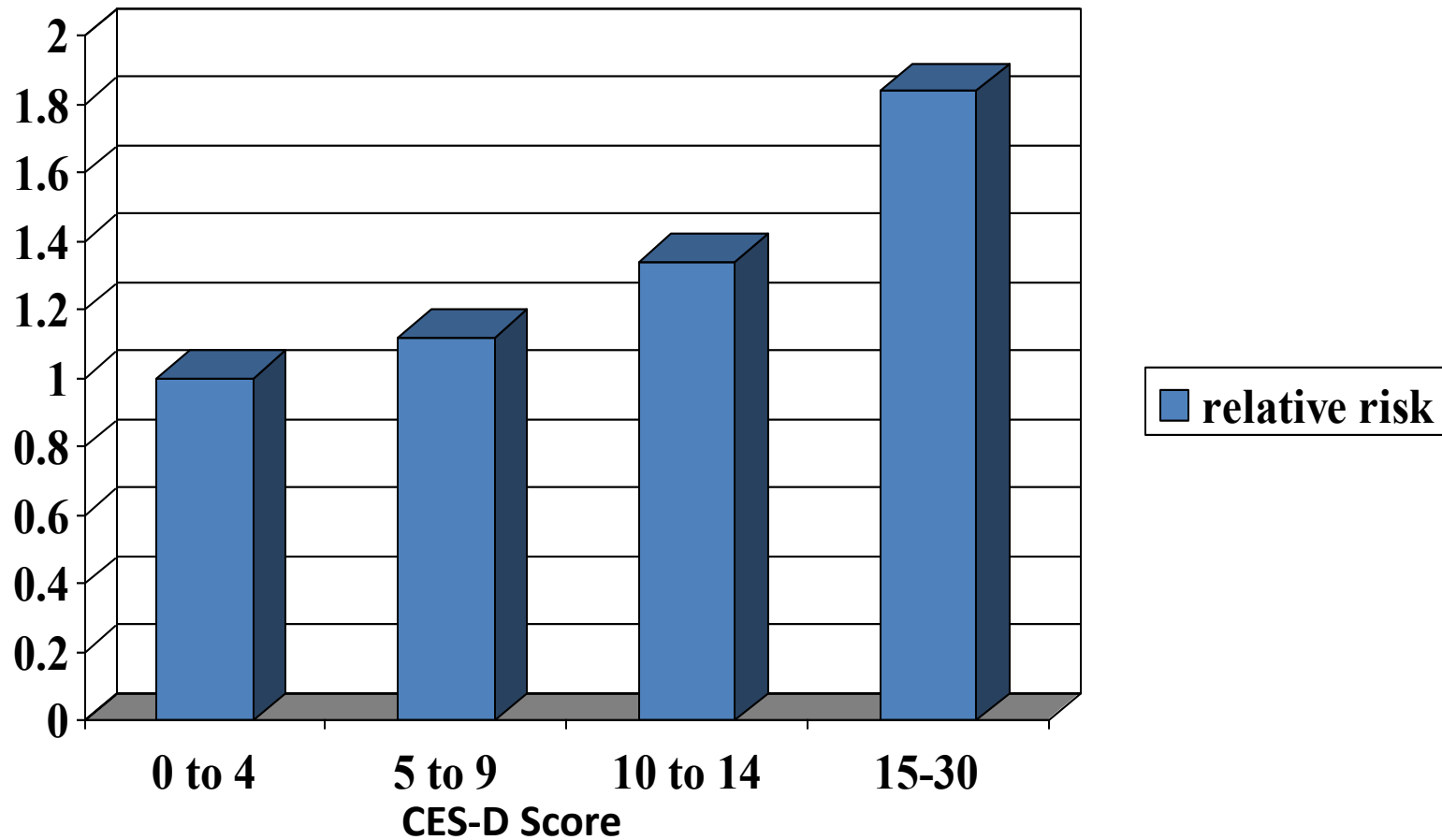
Why The Increasing Interest Now HRQOL and PROMs in Nephrology ?

- Association of patient reported outcomes (PROMs) with mortality and hospitalizations
- The focus of health care delivery is changing—*even for nephrology*
- Nephrology has lagged far behind other specialties in developing and elaborating a patient centered approach utilizing PROMs to direct care

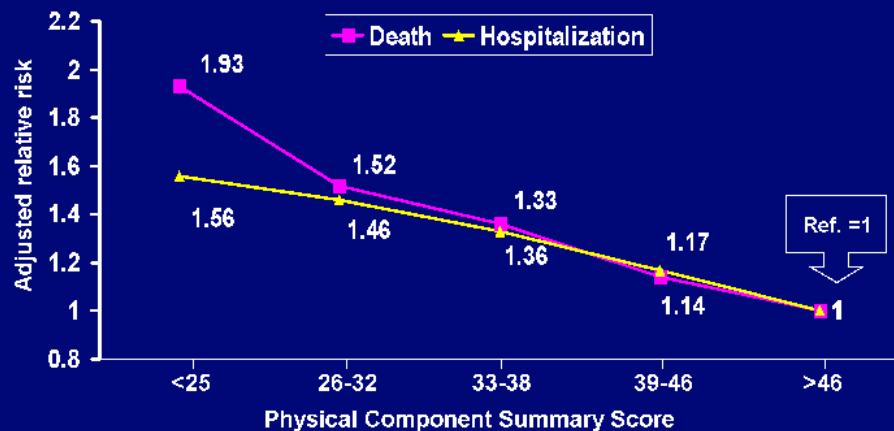
ALL CAUSE MORTALITY: overall relative risk per 5 point increase in CES-D score

(adjusted for country, years on dialysis, age, sex, co-morbidities, albumin, hemoglobin, KT/V)

Lopes: KI. 66:2047, 2004: 9382 randomly selected patients from 12 countries



Adjusted Relative Risk of Death and Hospitalization by Physical Component Summary Score, with Adjustment for Albumin

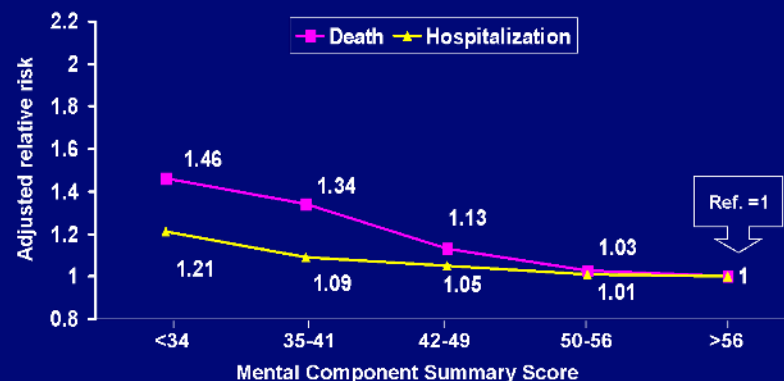


There was a statistically significant trend (each $p < 0.001$) in the risks of both outcomes to increase.



Mapes DL et al. *Kidney Int* 64:339-349, 2003

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Recent Reassessment of the Importance of PROMs and How to Incorporate Them into Routine Care of CKD/ESRD Patients

- Series of papers in CJASN—November, 2017
- Major focus in the U.S.
 - *CMS plans: in evolution*
 - *Position statement: 2017 Kidney Care Quality Alliance*
- K/DIGO conference – January, 2018
- Redefinition of goals for assessing adequacy of PD therapy: New ISPD guidelines developed –2020, PDI

K/DIGO Meeting Madrid, January, 2018

Chan et al Kidney Int 2019 96:37-47

- Reassessment of goals of ESRD care
- Shift to recognize that primary goal of treatment is to understand, identify, and try to meet individual patient goals and objectives
- Provide basic level of ESRD care, including amount of dialysis, anemia management, etc
- But, look at these in the context of the individual patient's experience

Goals of Care

Traditional

- Kt/V
- Anemia
- Ca, Ph, PTH
- BP control
- Hospitalization rates
- Infection rates
- Catheter related problems

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Patient Centered

- Unique patient goals
- Focus on individual symptoms (*e.g. pain, pruritis, restless legs, sleep, etc*)
- Depression
- Anxiety
- Burden of therapy on the patient
- Burden of therapy on the caregiver

5 Star Ratings

- Standardized Mortality Ratio (SMR)
- Standardized Hospitalization Ratio (SHR)
- Standardized Transfusion Ratio (STrR)
- % of patients with adequate KT/V
- % of adult dialysis patients who had hypercalcemia
- % of adult HD patients who received rx with an AVF
- % of adult patients who had a catheter left in longer than 90 days for their regular HD rx

Quality Improvement Reimbursement Program

- Dialysis Adequacy
- Hb and ESA reporting
- Hypercalcemia
- % AVFs
- Bloodstream infections
- Readmissions
- Phosphorus reporting

ISPD Guidelines for High Quality Dialysis

Brown et al PDI, 2020 May;40(3):244-253

- Holistic approach to assessing adequacy of PD
- Move away from the focus on labs, such as Kt/V and Hb
- Focus on each patient's goals with an emphasis on adjusting the targets of therapy and the dialysis regimen to permit the patient to achieve these goals

Patient Priorities Aligned Decision Making

Tinetti et al JAMA Int Med 179:1688, 2019

- Nonrandomized clinical trial of 366 patients with 3 or more co-morbidities” usual care vs focused care
- There were significant improvements in health care and reductions in treatment burden and unwanted health care in those receiving care focused on individual patient care priorities
- “Too often we see patient (care) focused on labs, such as Hb or HbA1C, that are generic, designed to improve the health care team’s performance measures and disconnected from the realities and complexities of the patient’s situation.” Margraves and Montori JAMA Int Med 179: 1697, 2019

Patient Perceptions of Diabetes Guidelines

Scoenborn JAMA Int Med 2019 179:1642

- Study of 836 randomly recruited patients ≥ 65 years with diabetes and how they perceive factors used in guidelines for diabetic care.
- “Many older adults do not place high importance on factors recommended by guidelines ...many older adults weighted (various) factors in the opposite direction than the guidelines.”

..Treatment Preferences for Older Adults with Advanced CKD Baddour et al JASN 30:2252, 2019

- 382 advanced CKD (Stage 4-5) patients > 60 years of age responded to the question “If you had a serious illness, what would be important to you?”
- Diverse replies
- Only 20% opted for “Live as long as possible”
- Most common responses:
 - 35% said do not suffer
 - 33% wanted care to focus on comfort

Challenges: How to Capture an Individual's Experience and Incorporate This Into Standard Care

- Discordance between provider and patient perceptions of health status
- Variability in results over time in individual patients
- Appreciate the burdens on patients of completing PROMs and on providers of processing PROMs
- Limitations in terms of translating and utilizing PROMs in the management of patients:
 - a) *what do you do with the reports?*
 - b) *How do you insure that utilization of PROMs results in improved communication between patient and providers, resulting in effective interventions in individual care?*

Provider Recognition of Symptoms of HD Pts 75 pts, 18 providers – MDs, PAs, NPs (Weisbord: CJASN: 2:960, 2007)

symptom	sensitivity
SOB	52%
Nausea	50%
Headache	25%
Vomiting	25%
Muscle cramps	17%
Feeling sad	17%
Dry skin	10%
Feeling anxious	6%
↓ interest in sex	6%

Questions were asked on the same day of patient and provider concerning sx present in the preceding 7 days

Sensitivity: proportion of pts with sx correctly identified by provider as having the sx

Summary of Discrepancies Between CKD/ESRD Patients' and Providers' Reporting of Symptoms, Global QoL, General Health and Depression

Data from New Haven; Finkelstein et al: presented at ASN 2016

<u>DIFFERENCE IN NET GENERAL SYMPTOM SCORE</u>	n
Different (>5)	94
Same (<5)	<u>99</u>
	193

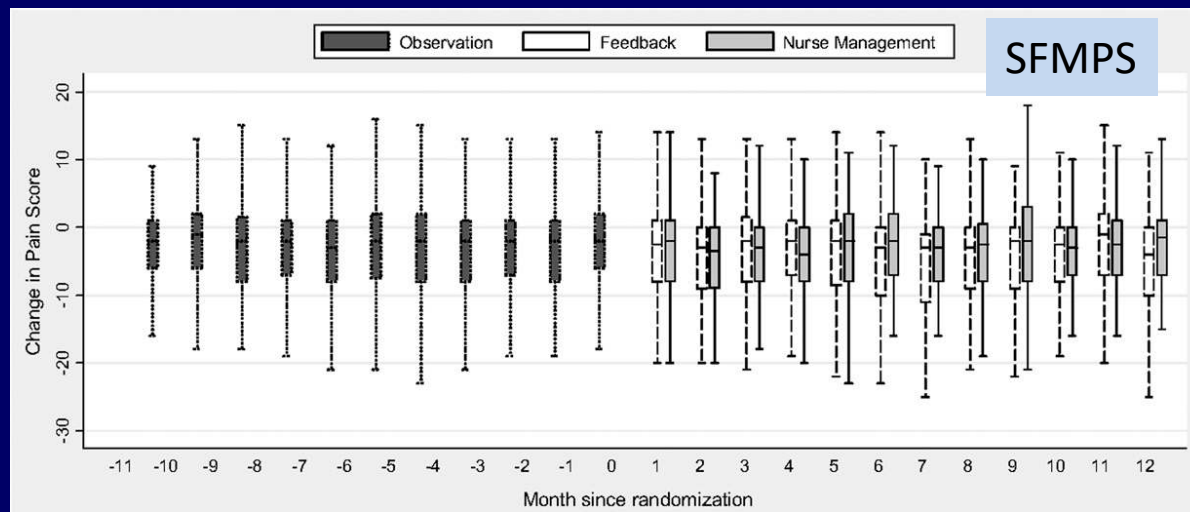
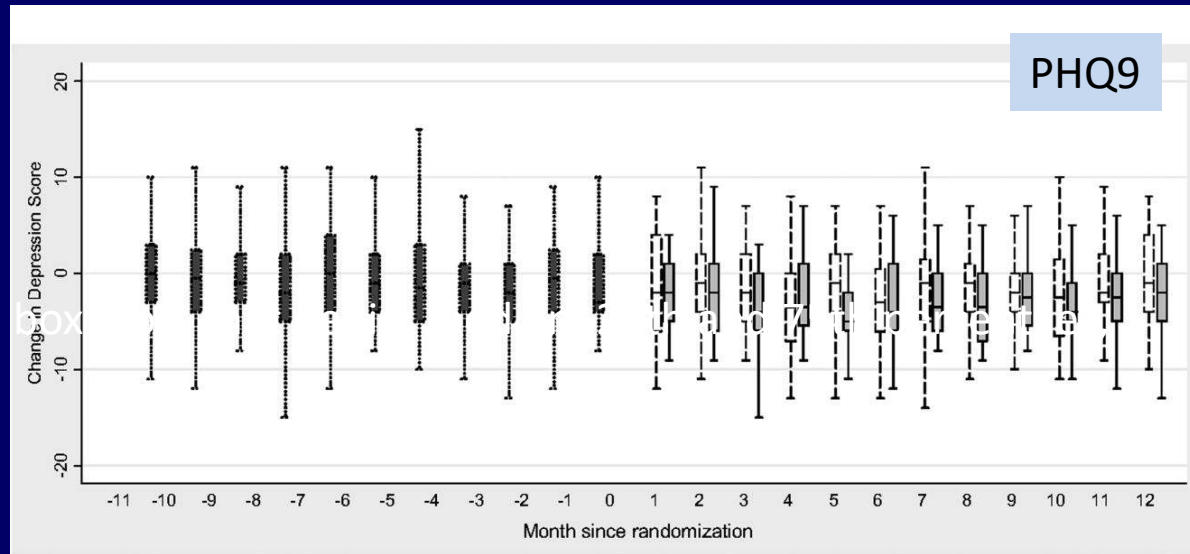
<u>DIFFERENCE IN GENERAL HEALTH</u>	n
SAME	72
DIFFERENT (>1)	120
	<u>192</u>

<u>DIFFERENCE IN GLOBAL QOL SCORE</u>	n
Different ≥ 2	82
Same ≤ 1	<u>106</u>
	188

	<u>PHQ2 SCORE</u>	n	
	SAME	97	
	DIFFERENT	<u>95</u>	
		192	

Longitudinal change in depression and pain scores (PHQ9, Short Form McGill Pain Score) by study phase and intervention arm

Weisbord et al. CJASN 2013;8:90-99



Domains to be Addressed for the Patient

Maintained on PD Finkelstein and Foo, PDI, 2020 in press

- Cognitive dysfunction
- Family and marital discord
- Depression
- Anxiety
- Fatigue
- Lethargy
- Physical functioning
- Sexual dysfunction
- Symptoms of neuropathy
- Pain
- Sleep disturbances
- Uremic pruritus
- Anorexia, nausea
- Restless legs
- Satisfaction with dialysis treatment regimen
- Impact of the treatment regimen on their life
- Satisfaction with care provided
- Caregiver burden
- Appetite, abdominal discomfort, nausea, vomiting
- Additional physical symptoms

HRQOL Instruments Used in ESRD

1. RAND 36-Item Health Survey SF-36 or SF 12 (kidney specific)
2. The Kidney Disease Quality of Life (KDOQL) Instrument
3. EuroQol 5 Dimension 5 Level Health Utility Index (EQ-5D-5L)
4. Patient Global Impression of Severity Scale (PGI-S)
5. Functional Assessment of Cancer Therapy- Anemia (FACT-An)
6. Work Productivity and Activity Impairment –Anemic Symptoms Score-
(WPAI:ANS)
7. Sickness Impact Profile (SIP)
8. Kidney Disease Questionnaire (KDQ)
9. Illness Effects Questionnaire (IEQ)
10. Satisfaction with Life Scale (SWLS)
11. Single Question QOL Score
12. Various depression and anxiety questionnaires

Examples of PROM Questionnaires Used in Clinical Studies

Finkelstein and Foo: PDI, 2020 May;40(3):270-273.

General Questionnaires

- SF-36
- SF-12
- KDQOL-36
- EQ5D
- Choice Health Experience Questionnaire (CHEQ)
- Dialysis Symptom Index)

Depression and Anxiety Screening and Caregiver Burden:

- Beck Depression Inventory
- Patient health questionnaire 9
- Center for Epidemiologic Studies Depression Scale
- Hospital anxiety and depression score
- Caregiver Burden: Zarit Burden Interview

Lessons From Other Specialties

- The routine use of PROMs in routine care results in improved physician satisfaction, improved communication between patient and doctor, enhanced shared decision, and enhanced work flow efficiency

Rottenstein NEJM 377:14, 2017

- What about computerized PROM testing?

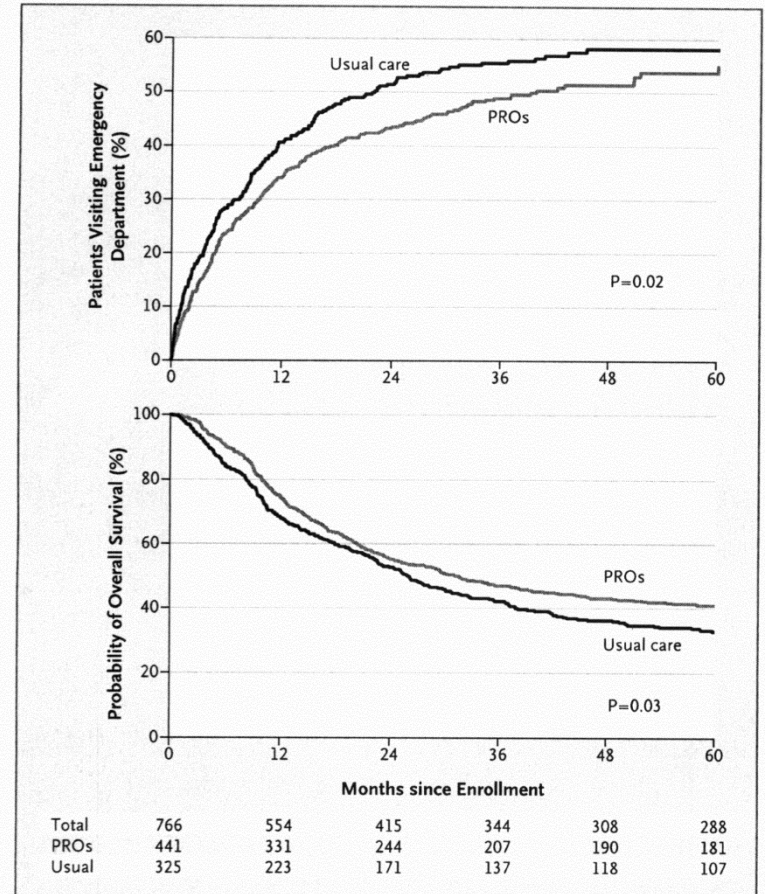
Oncology

(Basch: Patient-Reported Outcomes - Harnessing Patients' Voices to Improve Clinical Care. NEJM, 2017 12;376(2):105-108)

- For patients undergoing chemotherapy, treatment value cannot be summarized in an individual metric -- a multifaceted approach is necessary focusing on what is important to the individual patient
- Focus on electronic testing of PROMs, which has been shown to be of benefit in 3 domains:
 - *a) they are useful in informing clinicians of patients' perception of symptoms and quality of life.*
 - *b) they provide feedback to patients about how to communicate with and inform clinicians about the presence of symptoms*
 - *c) they have a positive impact on "hard" outcomes, such as emergency department visits and hospitalizations.*

Electronic PROMS in Oncology

randomized trial (n= 766) of pts receiving chemotherapy-- assigned to usual care or electronically reported symptoms with alerts of severe or worsening symptoms sent to the health care team; resulted in lower mortality rates, improved quality of life, and reduced emergency department visits (Basch: NEJM, 2017).



Emergency Department Visits and Probability of Survival Associated with Integrating Patient-Reported Outcomes (PROs) into Cancer Care.

Analysis of a randomized, controlled trial reveals that among 766 patients receiving chemotherapy and assigned either to usual care or to regularly reporting common symptoms over the Internet with automated alerts e-mailed to their nurses for severe or worsening symptoms, the PRO intervention was associated with significantly fewer emergency department visits and improved overall survival, as well as improvements in quality of life. Nurses responded to patients reports of symptoms with clinical actions such as telephone advice and new prescriptions in 76% of cases.⁵

Psychiatry: Computerized Adaptive Testing (CAT)

- Diagnosis: CAT can diagnose a major depressive, anxiety, or bipolar disorder with a high sensitivity and specificity
- Computerized testing results used to screen patients on a regular basis and results given to clinics with warnings sent if scores change for the worse
- Reduced burden: 50-90% reduction in the number of items that need to be administered.
- Repeated administration: no response set bias
- Monitoring: CAT has been used to monitor patients with psychiatric illness

Nephrology Patient Perspective on Electronic PROMs

Aiyebbusi et al: AJKD 74:167, 2019—Birmingham UK

- This study explored patient and clinician views on the use of a renal ePROM system.
- Semi-structured interviews and focus group discussions during which patients received paper versions of the Kidney Disease Quality of Life-36 and the Integrated Patient Outcome Scale-Renal to exemplify the type of content that could be included in an ePROM. Thematic analysis of interview transcripts.
- “Patients were willing to complete ePROMs on a regular basis as part of their care despite clinician concerns about patient burden. Patients assessed the questionnaires favorably.”

6 Month Pilot Project for CAT in CKD/PD Patients

Finkelstein et al ASN 2019, Perit Dial Int: in press

CAT Survey-20 Questions

- General Questions 4:

General health

Overall quality of life,

Impact of kidney disease,

Satisfaction with care.

- Physical symptoms 9:

itching/pruritis

loss of appetite

fatigue

loss of energy

bone/joint pain

muscle soreness

numbness in hands or feet

restless legs

- CAT 6

*Depression: Patient Health
Questionnaire-2 (PHQ-9)*

*Anxiety: General Anxiety
disorder-2 (GAD-7)*

*Pain: (severity, proprioceptive,
nociceptive)*

*Sleep (Insomnia Severity
Index)*

- free text any problems you
wanted to discuss at this visit

6 Month Pilot Project for CAT in CKD/PD Patients

Finkelstein et al ASN 2019, Perit Dial Int: in press

- 195 CKD and 55 PD patients screened with routine CAT resting; 95% agreed to participate
- Mean and median age 70 (range 26-93)
- Mean time to complete the questionnaire: 10 minutes
- 69% completed the questionnaire without assistance
- 90% completed a second questionnaire 2-3 months after the initial questionnaire
- Staff (*doctors, PAs, nurses, social works, dieticians*) universally found the results helpful in structuring their visit

SONG-HD Initiative

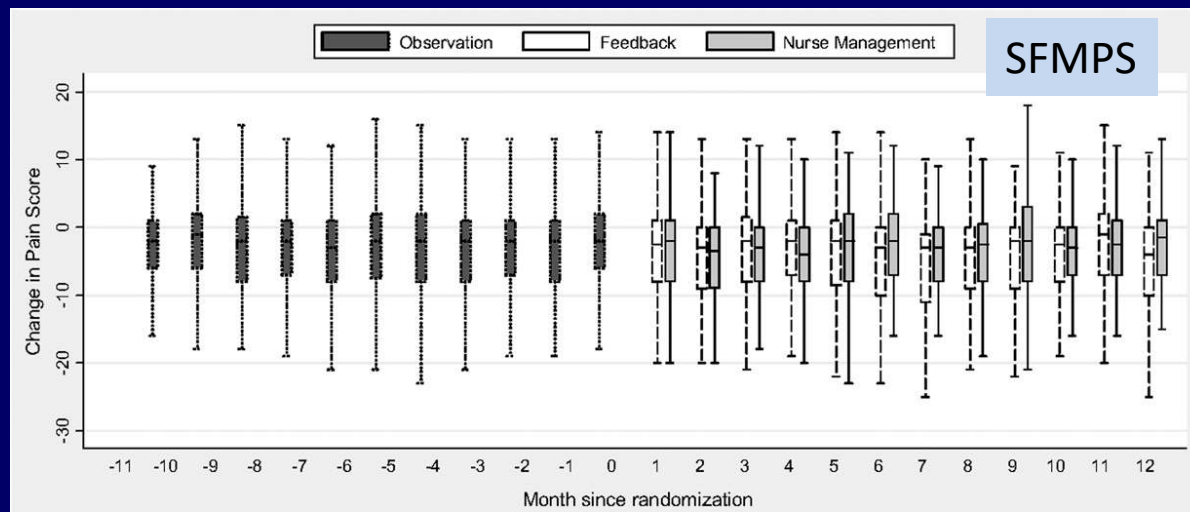
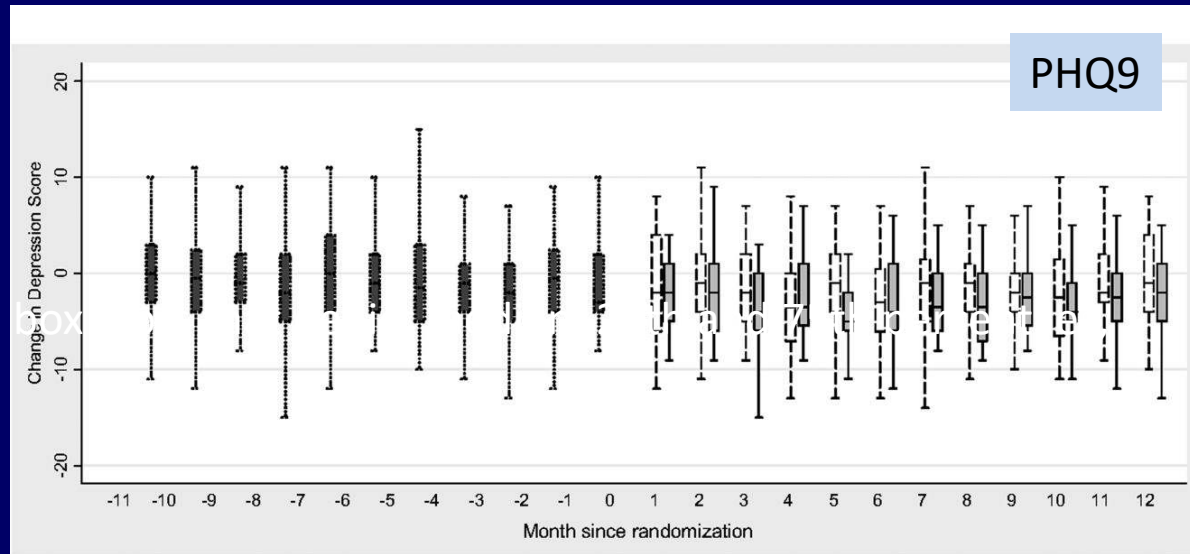
- There has been no substantial improvement in HRQOL outcomes for pts on HD— due to problems in the selection of outcomes— which usually focus on biochemical measures – which are of little or no relevance to patients
- The SONG-HD initiative is trying to develop outcomes of relevance to patients, caregivers, and health professionals.

But What Do We Do With The
PROM Results Once We Have
Obtained Them????

This Is Indeed a Challenge

Longitudinal change in depression and pain scores (PHQ9, Short Form McGill Pain Score) by study phase and intervention arm

Weisbord et al. CJASN 2013;8:90-99



Issues to Consider

- Make sure the problem area identified on testing is recognized by the patient as being important to him/her
- What are the treatment options for problem areas identified?
- What are the hazards of treating the area of difficulty *(such as pain, depression, etc)* ?

Recommendations

- Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues discussed

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- Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
- Encourage innovative approaches given the lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences

Recommendations

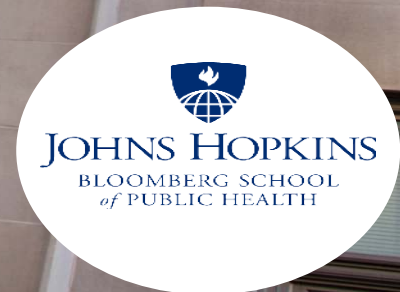
- Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues discussed
- Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
- Encourage innovative approaches given the lack of clear data on how PROMs should be incorporated into routine care and translated into improved patient experiences
- Require that there be documentation that domains of individual patient concerns have been acknowledged and that a plan to address these concerns has been noted. Plans could include addressing the problem using facility resources or making referrals to other health care providers or community resources.

What are PROMs and Why Do We Need Them?

Annual Dialysis Conference 2021

Session: Patient Reported Outcome Measures (PROMs)

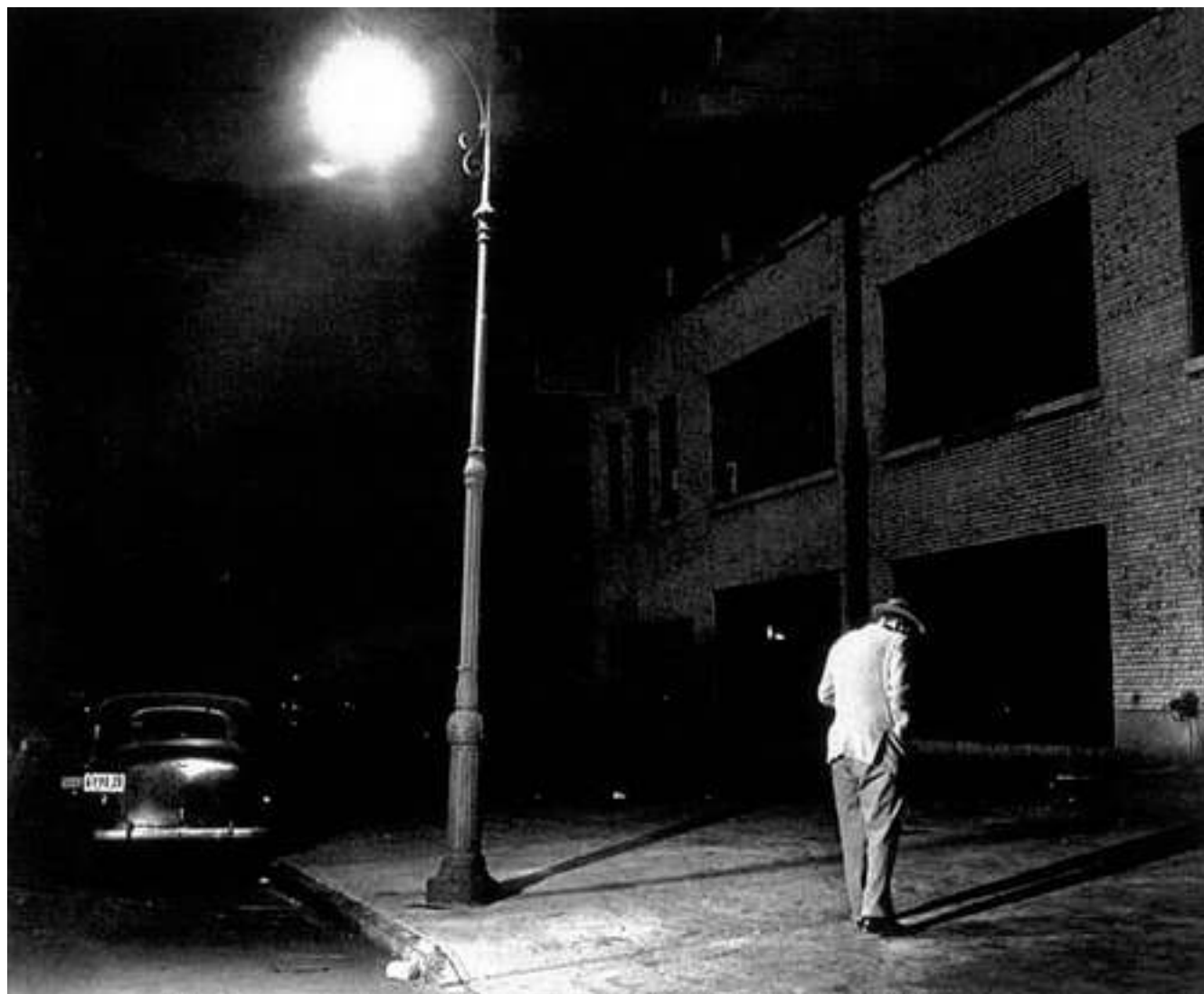
March 6, 2021 Albert W. Wu, MD, MPH



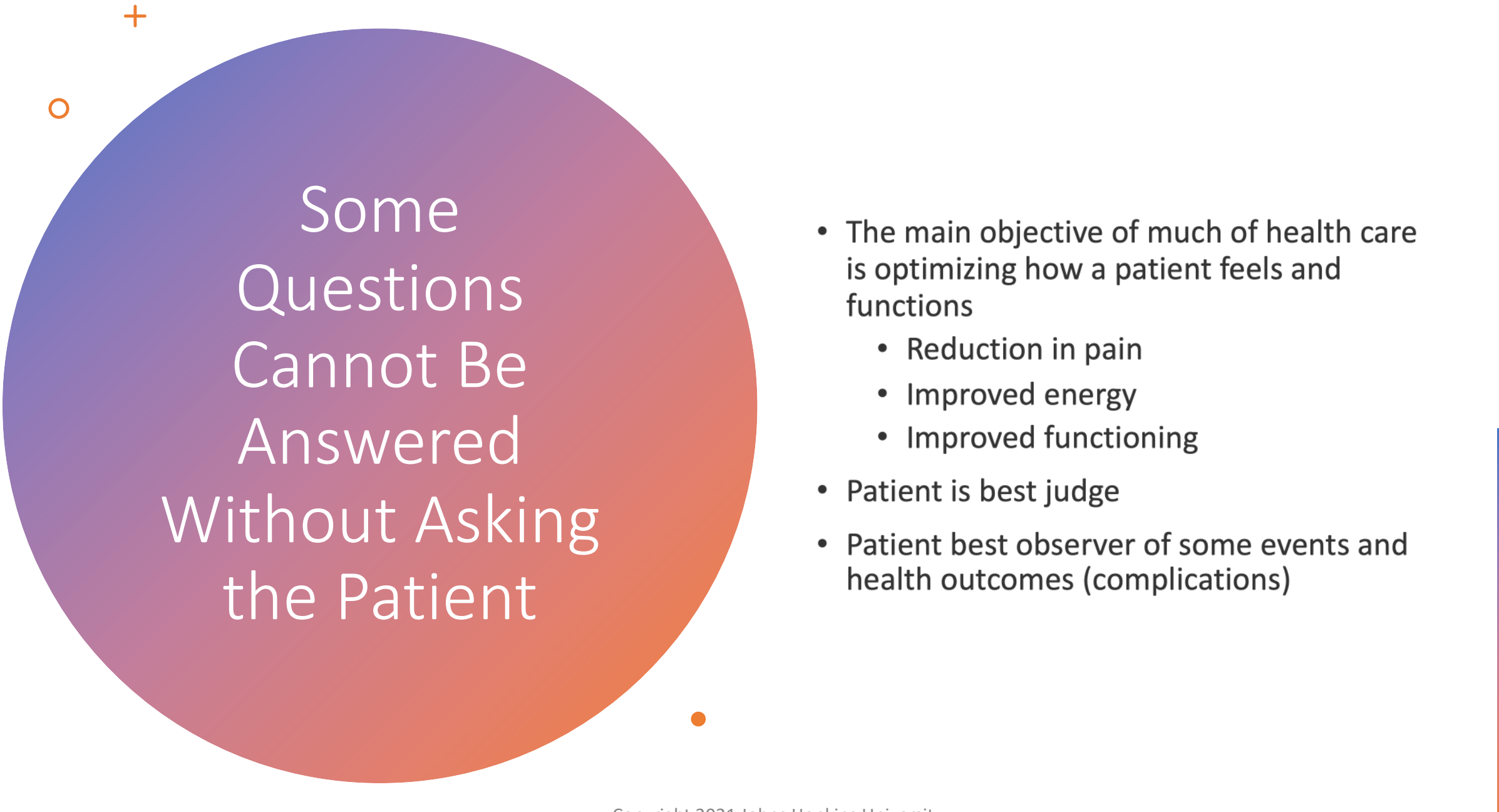
- No relevant conflicts to disclose

Objectives

1. Define patient reported outcome and patient reported outcome measure
2. Explain how PRO measures can be used in research, clinical practice, and evaluation
3. Give an example of a commonly use PRO instrument for use in renal dialysis.



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Some
Questions
Cannot Be
Answered
Without Asking
the Patient

- The main objective of much of health care is optimizing how a patient feels and functions
 - Reduction in pain
 - Improved energy
 - Improved functioning
- Patient is best judge
- Patient best observer of some events and health outcomes (complications)

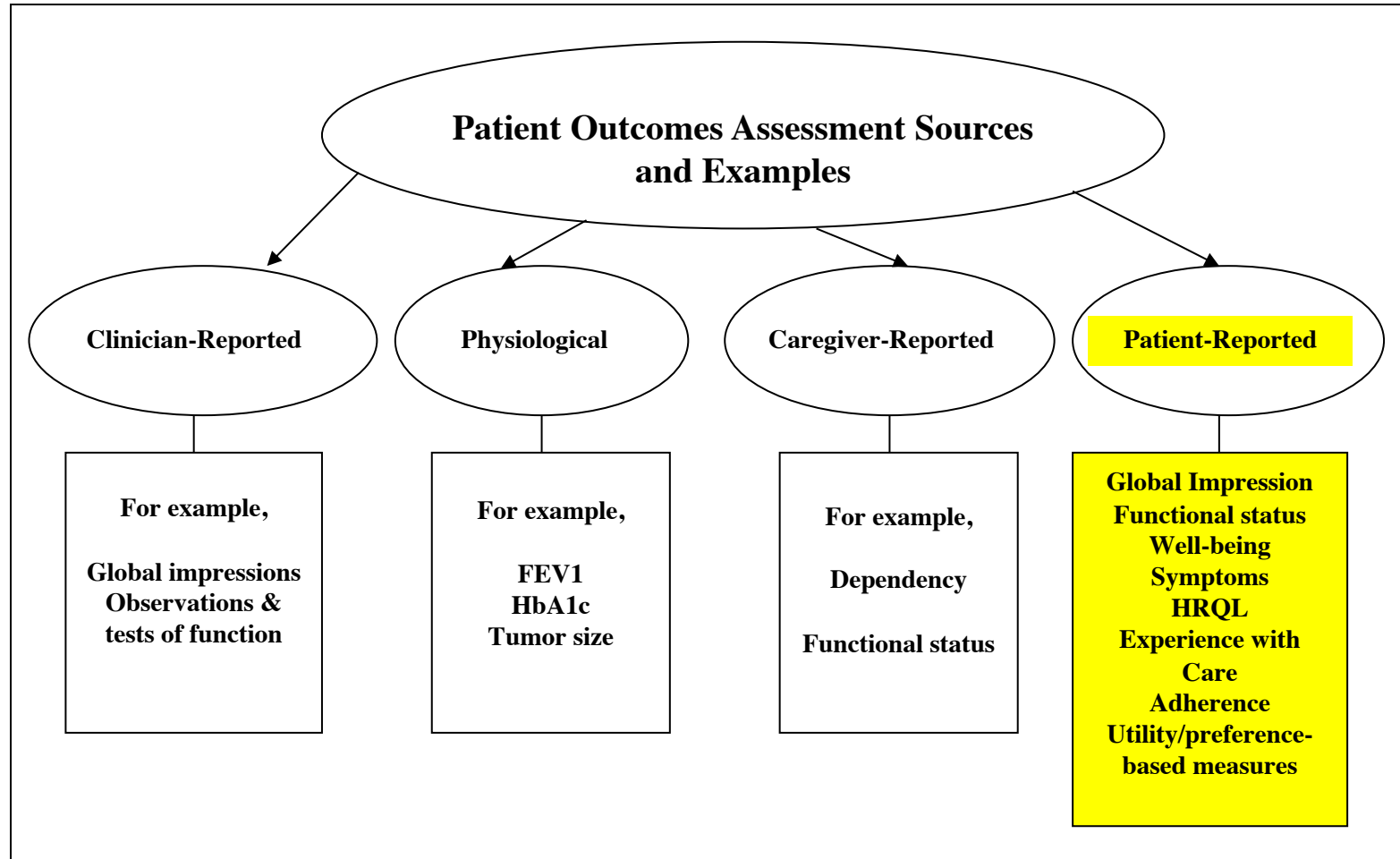
What is a PRO?

- “Patient-reported outcomes represent the patient’s report of a health condition and its treatment” (*Acquadro et al. Value in Health 2003;5:522-531*)
- “Any report of the status of a patient (person)’s health condition, health behavior, or experience with healthcare that comes directly from patient, without interpretation of the patient’s response by a clinician or anyone else”

U.S. Food and Drug Administration, Guidance for Industry, Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims, *Fed Regist.* 2009;74(35):65132-133

<http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>

Categories of Patient Outcomes

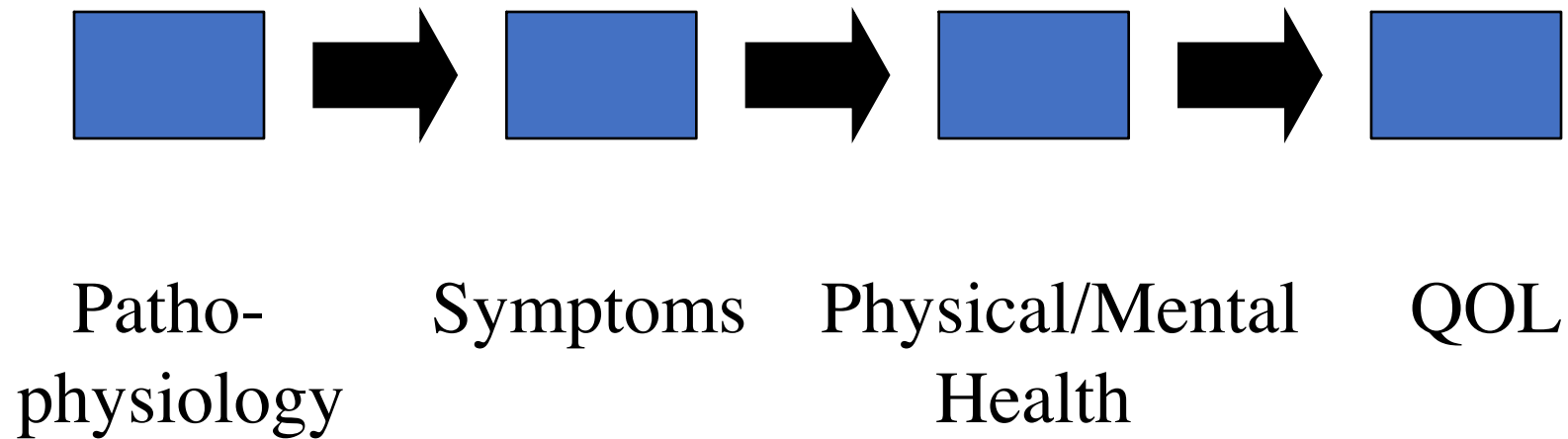


Source: Acquadro et al. Value in Health 2003;5:522-531

PROs vs PROMs vs PRO-PMs

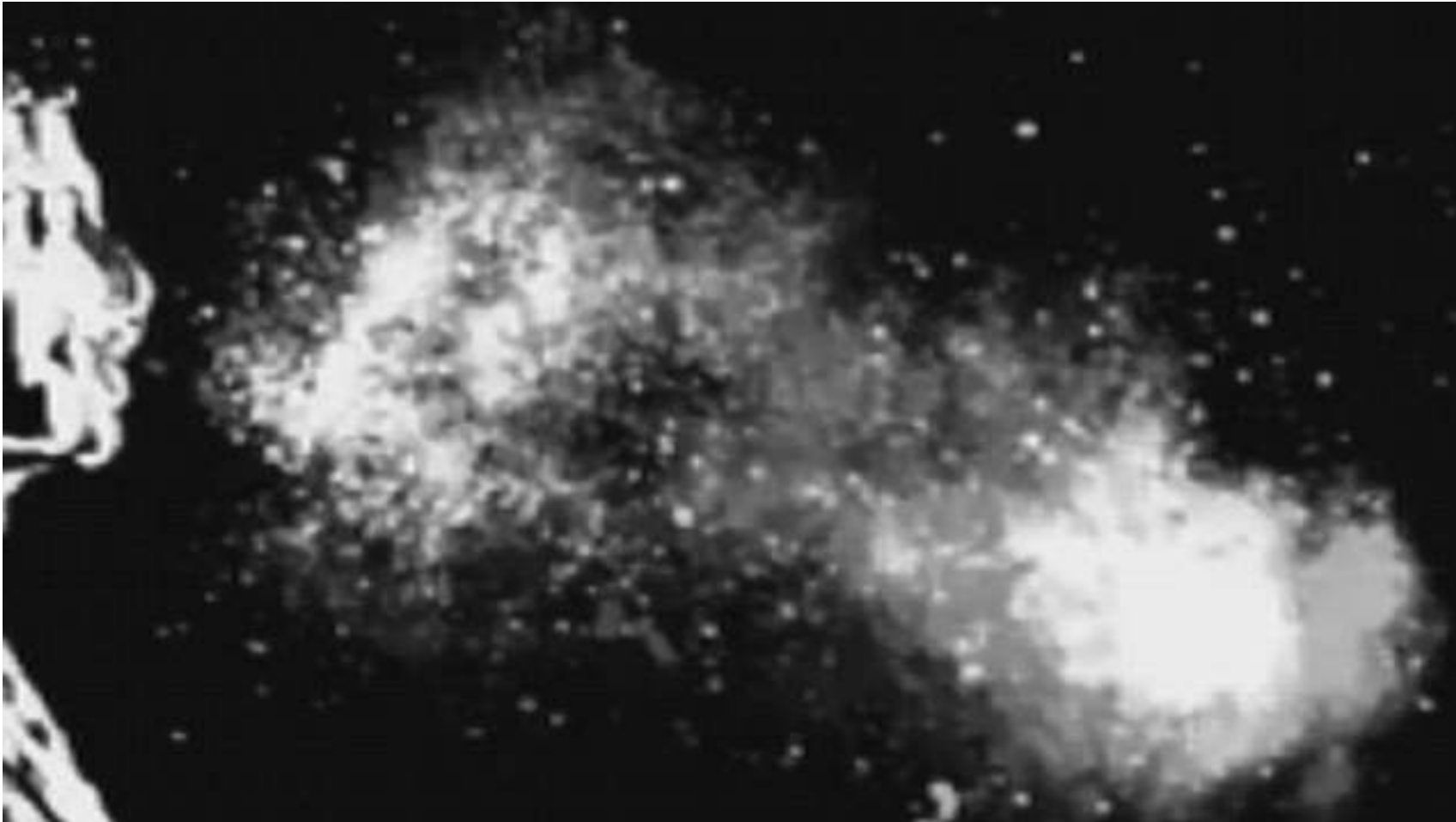
Concept	Definition	Example in ESRD
PRO Patient-reported outcome	Outcome	Depression
PROM Patient-reported outcome measure	Standardized, validated assessment tool	PHQ-9, a standardized survey tool to assess depression
PRO-PM PRO based performance measure	Performance measure based on patient responses to a PROM	Percentage of ESRD patients with a diagnosis of depression with a baseline PHQ-9 score >9, and a followup PHQ-9 score of <5 at month 6

Relationship of Pathophysiology to Subjective Health and Quality of Life

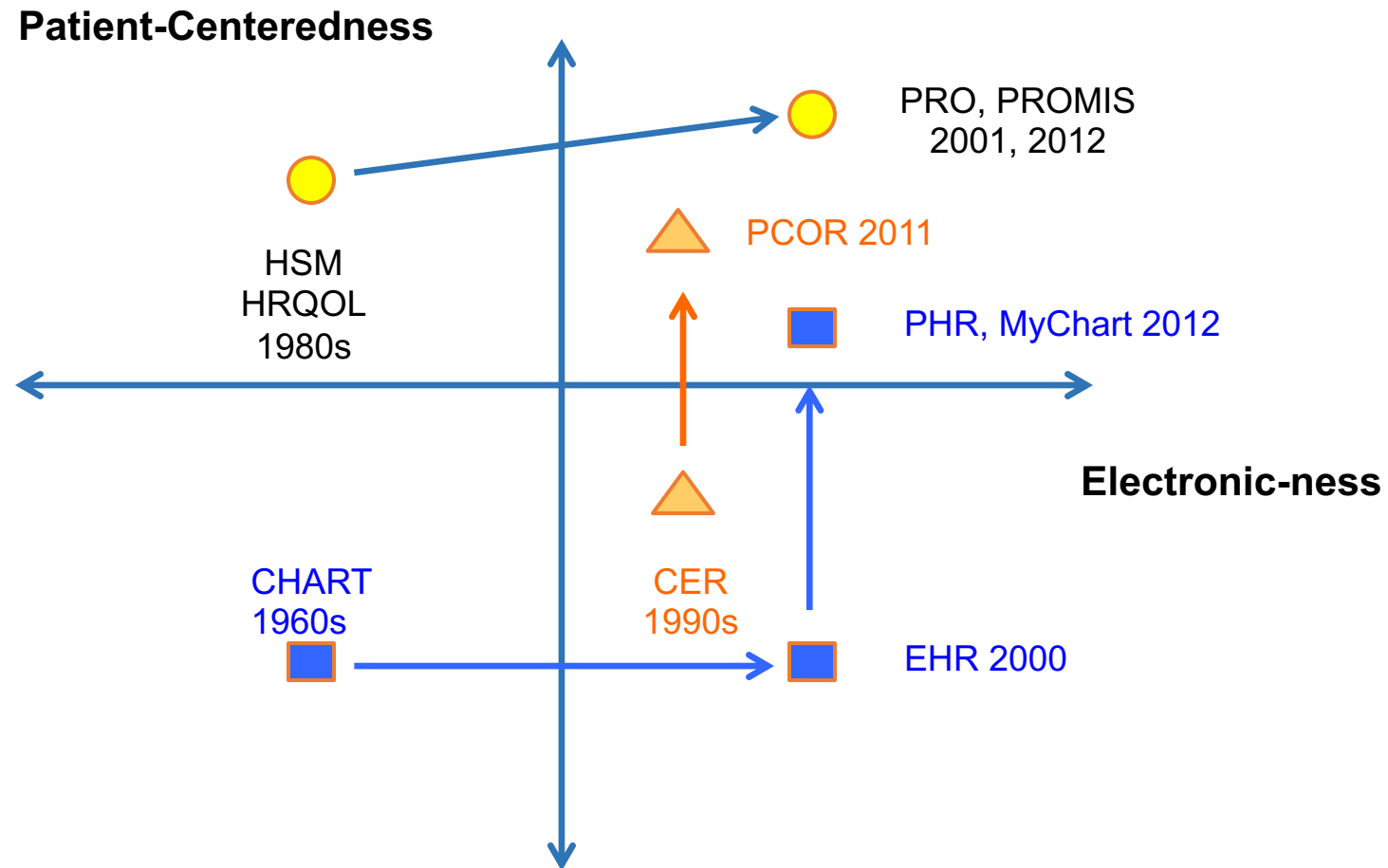


Wilson & Cleary, JAMA 1995

PROs are Going Viral



Convergence PRO + CER + EHR



Wu AW, Snyder C, Clancy CM, Steinwachs DM. Adding the patient perspective to comparative effectiveness research. *Health Aff (Millwood)*. 2010;29:1863



ESRD Patients Are Special

- Burden of disease and treatment on nearly every aspect of daily life
- Unique domains e.g. Independence, Burden on family
- High frequency of clinical encounters
- Multiple treatment options
- Payment policy in the US



ELSEVIER

Journal of Clinical Epidemiology 66 (2013) S12–S20

**Journal of
Clinical
Epidemiology**

Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research

Albert W. Wu*, Hadi Kharrazi, L. Ebony Boulware, Claire F. Snyder

Departments of Health Policy & Management and Medicine, Johns Hopkins University, Baltimore, MD, USA

Accepted 19 April 2013

Abstract

Objective: This article presents the current state of patient-reported outcome measures and explains new opportunities for leveraging the recent adoption of electronic health records to expand the application of patient-reported outcomes in both clinical care and comparative effectiveness research.

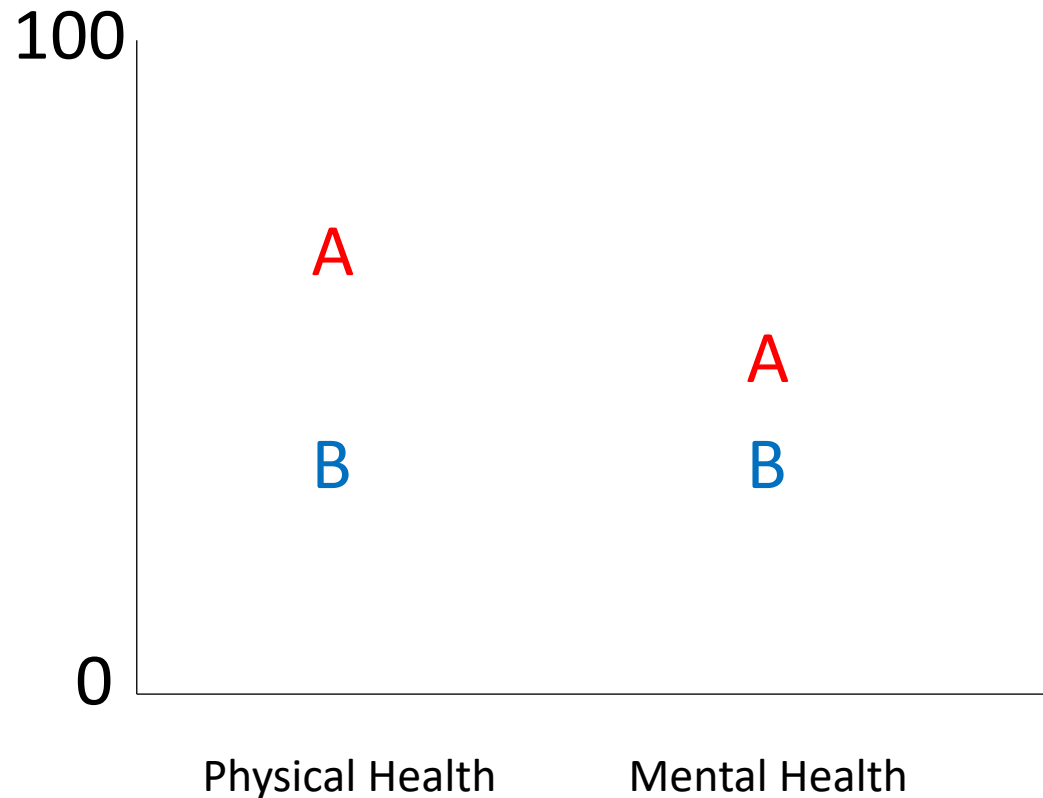
Study Design and Setting: Historic developments of patient-reported outcome, electronic health record, and comparative effectiveness research are analyzed in two dimensions: patient centeredness and digitization. We pose the question, “What needs to be standardized around the collection of patient-reported outcomes in electronic health records for comparative effectiveness research?”

Results: We identified three converging trends: the progression of patient-reported outcomes toward greater patient centeredness and electronic adaptation; the evolution of electronic health records into personalized and fully digitized solutions; and the shift toward patient-oriented comparative effectiveness research. Related to this convergence, we propose an architecture for patient-reported outcome standardization that could serve as a first step toward a more comprehensive integration of patient-reported outcomes with electronic health record for both practice and research.

Conclusion: The science of patient-reported outcome measurement has matured sufficiently to be integrated routinely into electronic health records and other electronic health solutions to collect data on an ongoing basis for clinical care and comparative effectiveness research. Further efforts and ideally coordinated efforts from various stakeholders are needed to refine the details of the proposed framework for standardization. © 2013 Elsevier Inc. All rights reserved.

USE IN RESEARCH

Is treatment innovation A better than standard treatment B?



USE IN EVALUATION

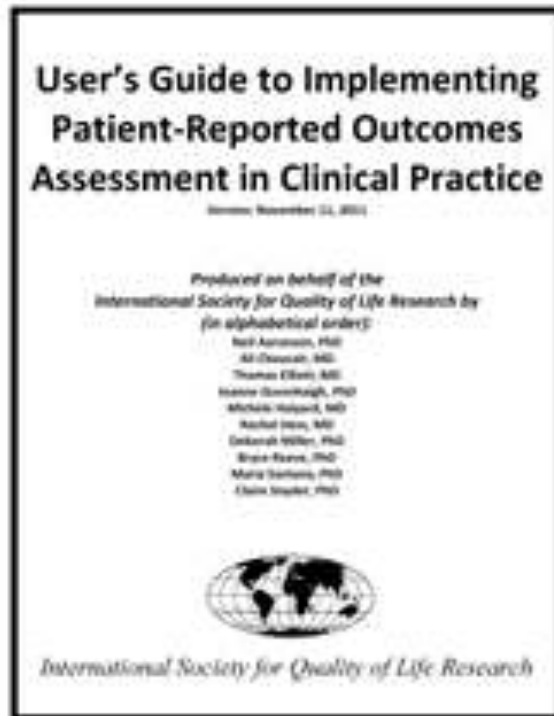
- Evaluate the person-centered experience and outcomes produced by ESRD Seamless Care Organizations (ESCOs)

USE IN CLINICAL PRACTICE

- Screening
- Monitoring
- Prediction
- Shared Decision Making

PRO Integration with Electronic Health Record





Available at:

<http://www.isoqol.org/UserFiles/2015/UsersGuide-Version2.pdf>

- Helps clinicians and researchers interested in implementing PRO assessment to aid patient care

- Includes
 - ▶ Considerations
 - ▶ Options
 - ▶ Resource requirements
 - ▶ Relative advantages and disadvantages

Clinician's Checklist for Reading and Using an Article About Patient-Reported Outcomes

Albert W. Wu, MD, MPH, FACP; Anna N. Bradford, PhD, MSW, LCSW;
Vic Velanovich, MD; Mirjam A.G. Sprangers, PhD; Michael Brundage, MD, FRCP, MSc;
and Claire Snyder, PhD

Abstract

Clinicians need evidence-based medicine to help them make clinical decisions with their patients. For many health problems, the goal of treatment is to help the patient to function and feel better. To measure patient functioning, well-being, and symptoms, questionnaires referred to as patient-reported outcome (PRO) measures are often used. Clinicians are generally not trained in survey design, scale development, and questionnaire administration, making it difficult for them to interpret and effectively use PROs as clinical evidence. It is increasingly important that clinicians be able to understand and use outcomes measured from both the clinical and patient perspectives to inform their practice. We aim to provide a "Clinician's Checklist" to help practicing clinicians understand clinical research articles that include PROs so that the information can be used for decision making. This checklist provides an itemization of important areas for the reader to consider in evaluating research articles. We propose that clinicians consider 5 elements when reading a study using PROs: study design and PRO assessment strategy, PRO measure performance, validity of results, context of the findings, and generalizability to their own patient population. Patient-reported outcomes play an increasingly prominent role in clinical research and practice, and this trend has the potential to improve the patient-centeredness of care. Clinicians will need to understand how to use PROs to partner with patients and help them function and feel better. The proposed Clinician's Checklist can help clinicians systematically evaluate PRO studies by determining whether the study design was appropriate and whether the measurement approach was adequate and properly executed as well as by assisting in the interpretation and application of the results to a specific patient population.

© 2014 Mayo Foundation for Medical Education and Research ■ Mayo Clin Proc. 2014;89(5):653-661

EXAMPLE – KDQOL-36™

- Developed by RAND
- 36 questions on overall quality of life and kidney disease-specific quality of life
- 5 subscales
 - Physical functioning SF-12
 - Mental health
 - Burden of kidney disease (4)
 - Symptoms and problems (12)
 - Effects of kidney disease on daily life (8)
- Scored on 0-100 scale

Hays Qual Life Res. 1994 PMID 7841967

Peipert Am J Kidney Dis. 2018 PMID 29128411

Your Kidney Disease

12. How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a My kidney disease interferes too much with my life	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Too much of my time is spent dealing with my kidney disease	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c I feel frustrated dealing with my kidney disease	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d I feel like a burden on my family	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

https://www.rand.org/health-care/surveys_tools/kdqol.html

Effects of Kidney Disease on Your Daily Life

15. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
a Fluid restriction?....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Dietary restriction?.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Your ability to work around the house?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Your ability to travel?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e Being dependent on doctors and other medical staff?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f Stress or worries caused by kidney disease?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g Your sex life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h Your personal appearance?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

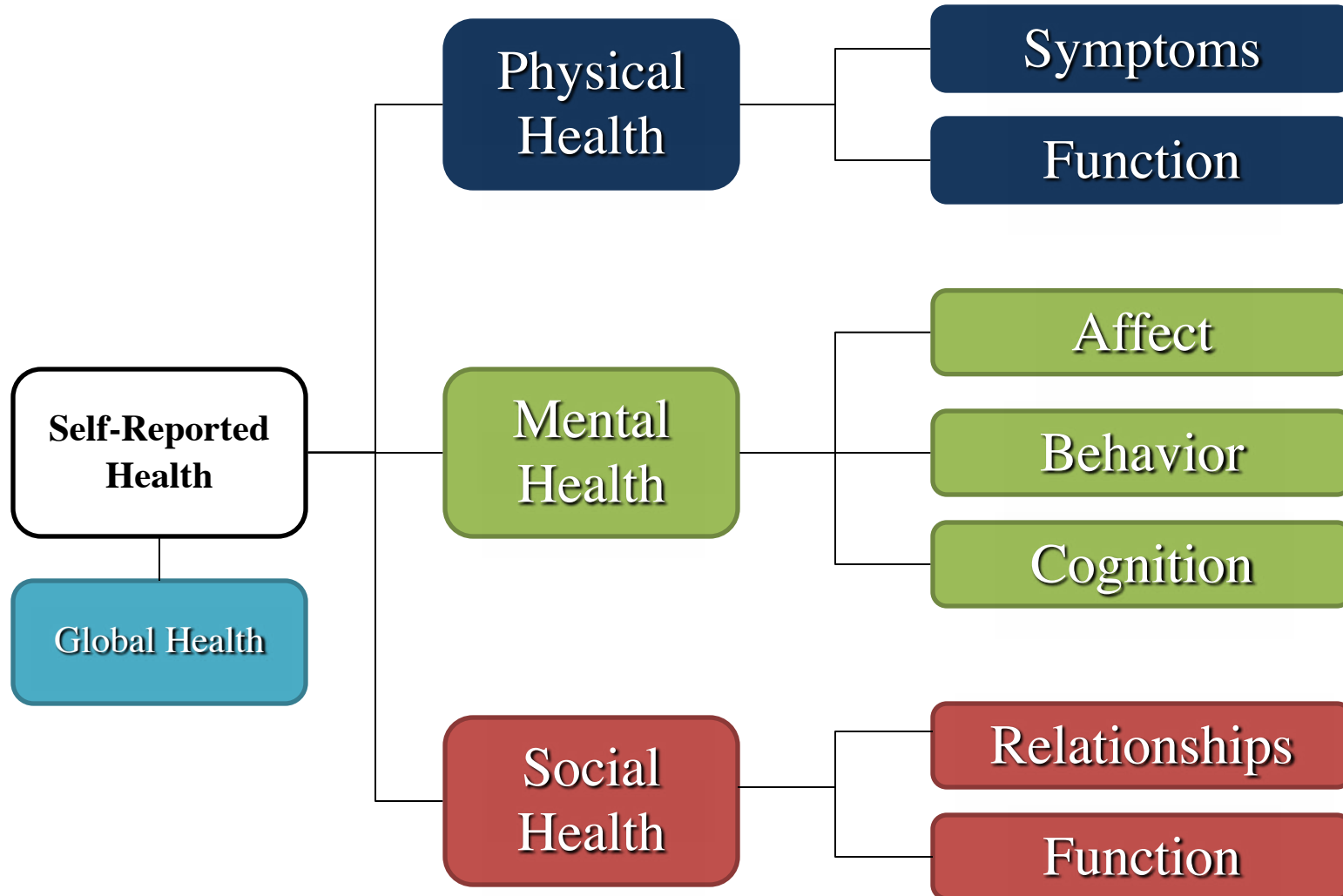
USES OF KDQOL

- KDQOL provides patient perspective
- Can differentiate
- Can a KDQOL-based performance measure be used to
 - Fairly evaluate the quality of ESRD care
 - Promote patient-centered care
 - Improve outcomes
- Can be used to identify problems
 - What can I do?
 - E.g. low mental health score, refer to social work/mental health

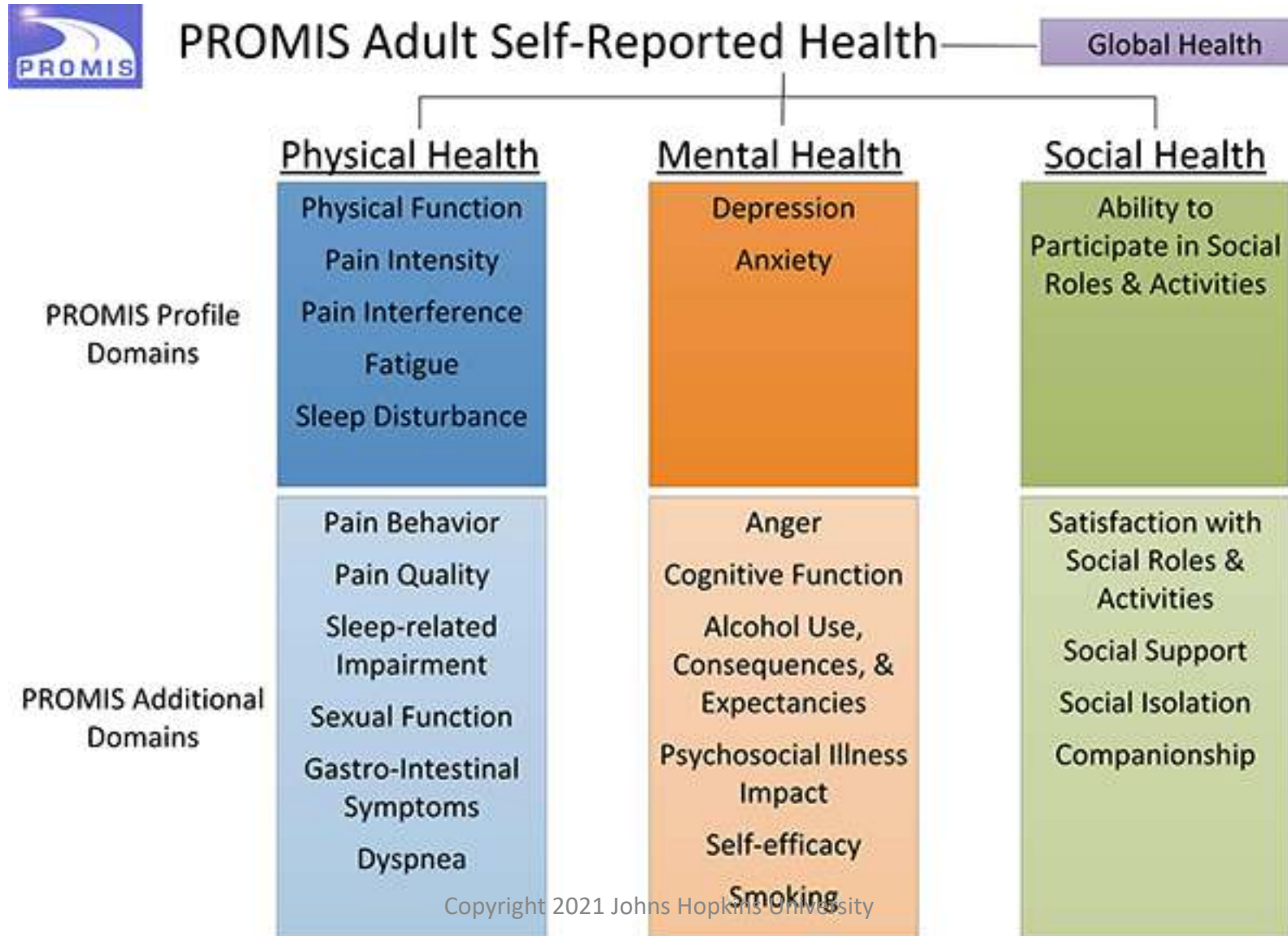
EXAMPLE - PROMIS

- Patient Reported Outcomes Measurement Information System
 - Supported by NIH since 2004
- Family of items banks to standardize patient reports of HRQOL domains
- Scoring based on item-response theory
- Available as static short and longer forms and computerized adaptive tests

PROMIS Domains



PROMIS Domains (Detail)



Conclusion

- PROMs are reports coming directly from patients about a health condition and its treatment
- Provide an important (patient) perspective
- PROM can be useful in research, evaluation and clinical practice
- Examples include KDQOL and PROMIS



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