KCQA Patient-Reported Outcome Initiative

May 16, 2017

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2016-2017 KCQA Initiative

- For patient-reported outcomes (PRO) for patients with ESRD, **identify:**
  1. **Framework for measurement,**
  2. **Guiding principles, and**
  3. **Priorities for patient-reported outcome measures (PROMs)**
- Measure development not a focus at this time

Today's Agenda

- Discuss commissioned papers
  - Dr. Fred Finkelstein—clinical issues
  - Dr. Ron Hays and Mr. John Peipert—methodological issues
- Review results of KCQA interviews and prioritization survey
- Convene in breakouts for more in-depth discussion

PROMS and the ESRD Patient:
A Time to Rethink Our Approach

Fredric Finkelstein

Clinical Professor of Medicine

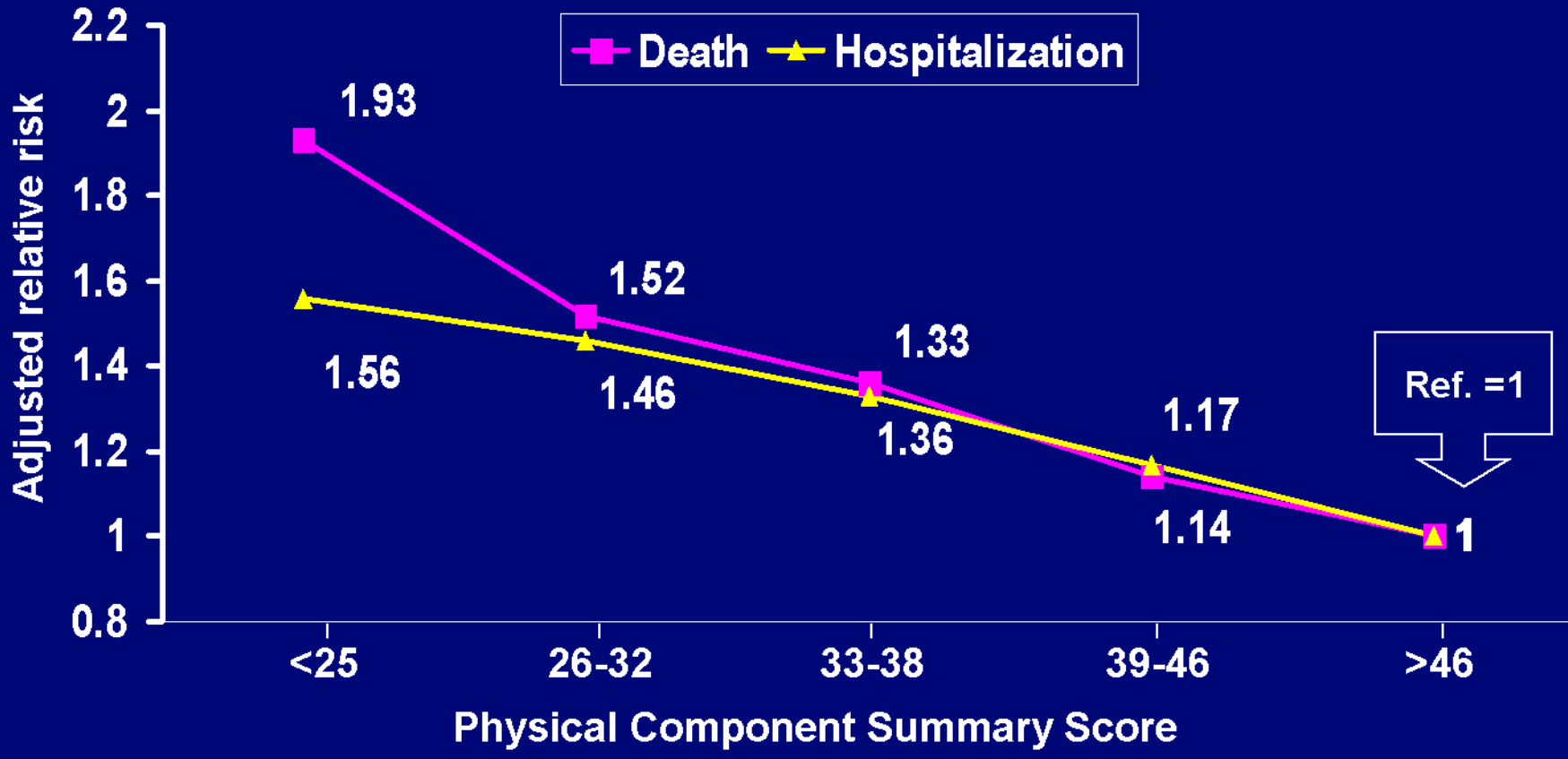
Yale University

New Haven, CT

Outline

- Association of PROs with "hard" outcomes
- Discordance between provider and patient perceptions of health status
- Challenges of utilizing PROMs
- Limitations of current approach
- Lessons from other specialties
- Problems of ESRD Care and PROM Use
- Recommendations of how to proceed

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.

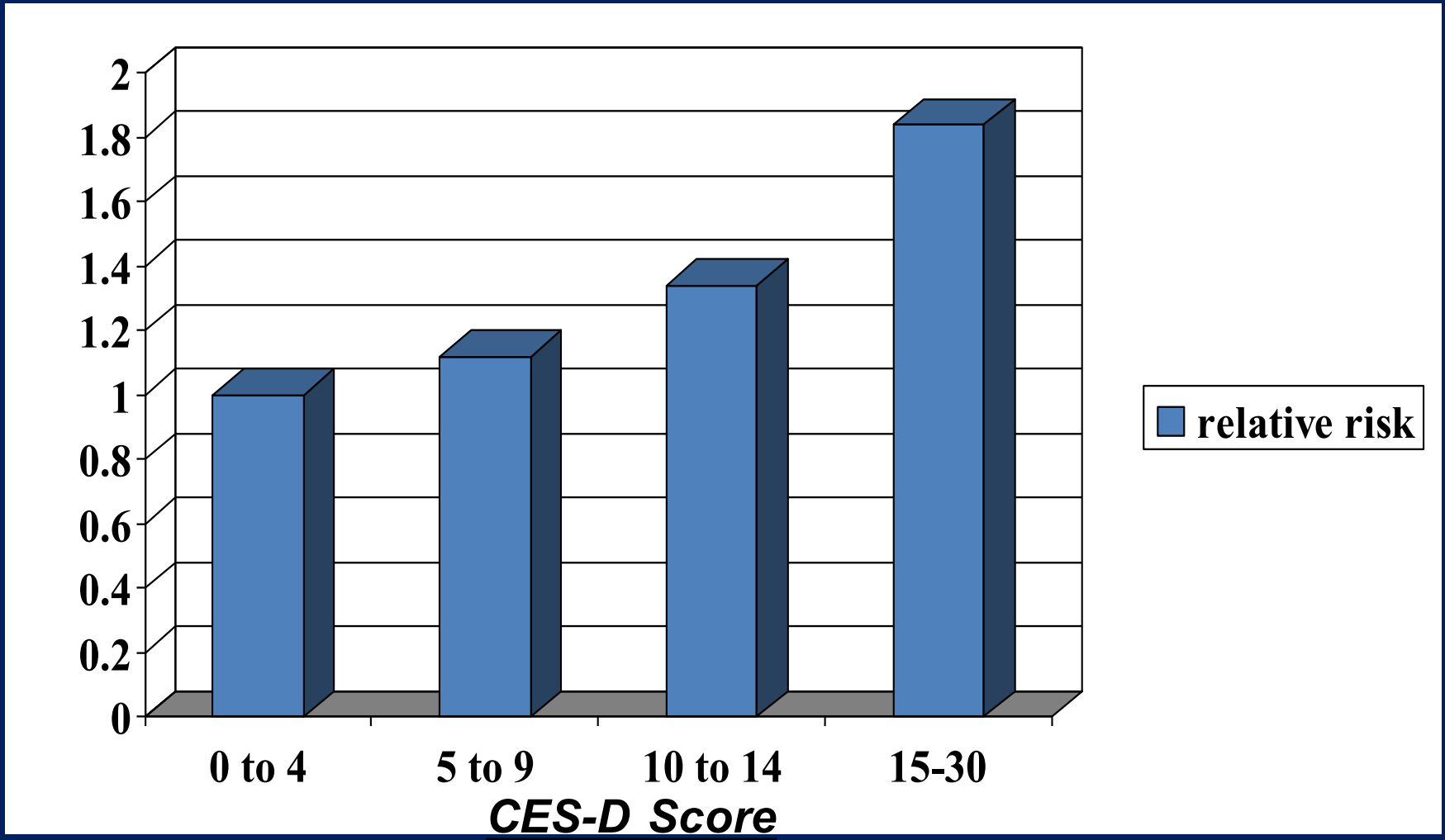
DOPPS

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

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



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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 QofL, General Health and Depression

Data from New Haven

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

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

DIFFERENCE IN GLOBAL QOL SCORE	n
Different ≥2	82
Same ≤ 1	106
	188

	PHQ2 SCORE	n	
	SAME	97	
	DIFFERENT	95	
		192	

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Challenges

- Focus not only on obtaining and recording PROMs but on understanding how their administration and analysis can translate into appropriate and meaningful management strategies.
- Appreciate the burdens on patients of completing PROMs and on providers of processing of PROMs
- Incorporate PROMs into routine care so that communication between providers and patients can result in effective interventions in individual patient care.

Outline

- Association of PROs with “hard” outcomes
- Discordance between provider and patient perceptions of health status
- Challenges of utilizing PROMs
- Limitations of current approach
- Recognition of the uniqueness of the individual
- Lessons from other specialties
- Problems of ESRD Care and PROM Use
- Recommendations of how to proceed

Current PROMs In Use

- **Consumer Assessment of Healthcare Providers and Systems (CAHPS) In-Center Hemodialysis (ICH) Survey questionnaire semi-annually**
- **KDQOL-36 annually:** ***PCS, MCS, burden of kidney disease, symptom and problem score, and the effect of kidney disease on daily life score.***
- **Screen for depression and pain annually**

Current Utilization of Patient Responses

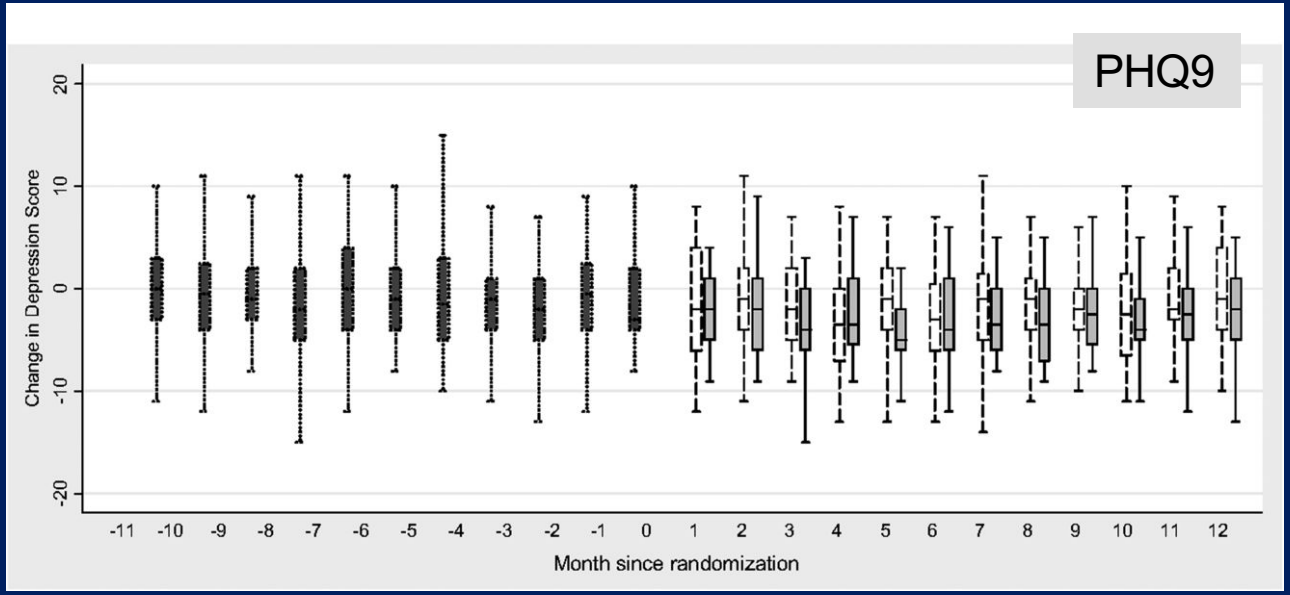
- Summarized in each patient's chart with scores recorded – including depression screen (PHQ-2) and pain
- Few, if any, comments generally made about the implications of the scoring
- No insight into the meaning or impact of the score for the patient

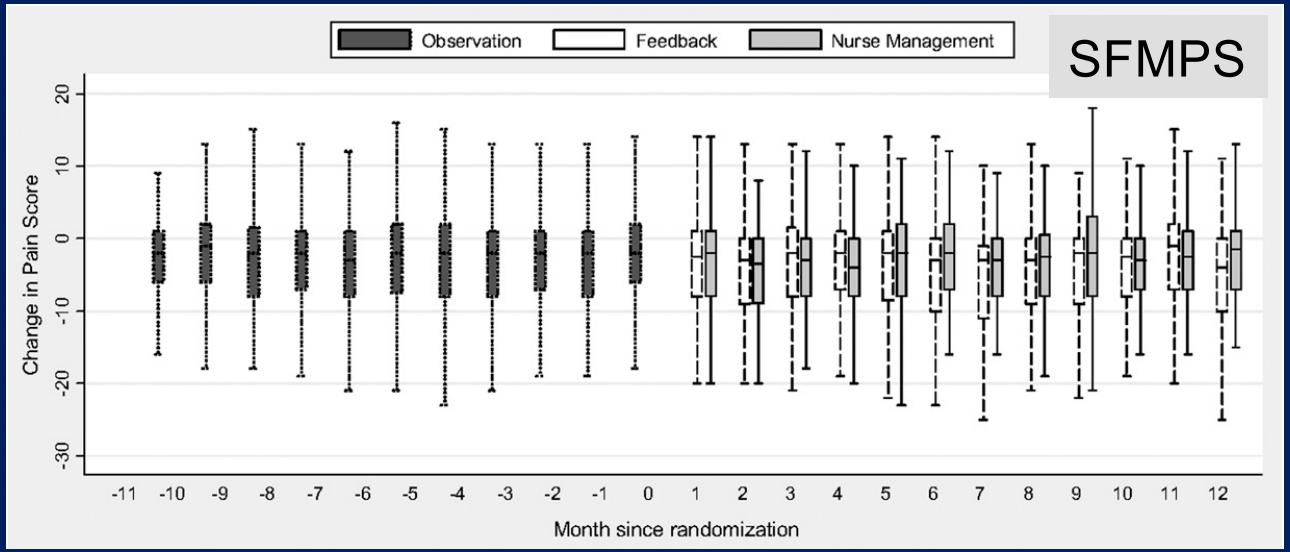
Other Limitations:

- **Variability in results over time in individual patients**
- **Problem in capturing an individual patient's experiences**
- **Limitations in terms of translating and utilizing the PROM in the management of patients: *what do you with the reports?***

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

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





Each Person's Experience is Unique

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.

FREEDOM Data : Patient Responses with Conversion to Home HD

	Month-4 (n=349)	Month-12 (n=228)
POSITIVE CATEGORIES	**percentages**	**percentages**
1. improved phys functioning	26	24
2. feeling generally better	24	22
3. flexibility of rx	24	25
4. improved overall QoL	16	22
5. Physiologic improvements	17	17
NEGATIVE CATEGORIES		
1. burden of therapy	4	3
2. burden of treatment time	5	6
3. disruption of daily routine	2	1
4. decreased phys functioning	1	2
5. Physiological decline	1	2
6. Unclassifiable	4	8
7. No response	20	15

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Lessons from Other Specialties

- **Neurology: routine use of electronic PROMs at Cleveland Clinic– high degree of patient satisfaction– uses both generic questionnaires *(PHQ9 [for depression] screening, the European Quality of Life [EQ5D])* questionnaire as well as clinic specific**
- **Gynecology: used a web based reporting system to capture PROs in the post operative period of women who had undergone gynecological surgery; given weekly x 6 weeks with alerts sent to nurses with problems; high degree of patient satisfaction**

Psychiatry: *Computerized Adaptive Testing (CAT)*

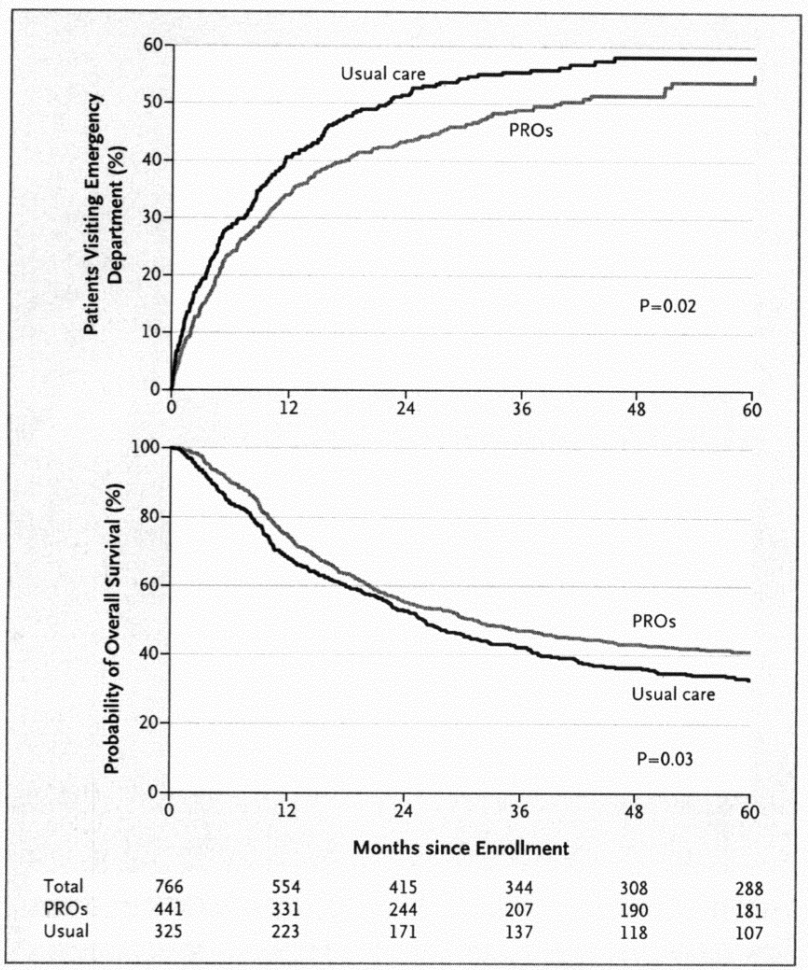
- **CAT has been shown to be able to diagnose a major depressive disorder, anxiety disorder, bipolar disorder in large cohorts of patients in a psychiatric clinic with a high sensitivity and specificity**
- **There is a 50-90% reduction in the number of items that need to be administered with no significant change in diagnostic accuracy.**
- **It can be repeatedly administered without response set bias because the questions adapt to the patient responses, which will vary over time**
- **CAT has been used to monitor patients with psychiatric illness over time with alerts sent to health care providers**

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

- Several studies have shown that the routine incorporation of PROMs into care enhances the patients' and the clinicians' experience.
- For patients undergoing chemotherapy, oncologists recognize that in assessing the value of an individual therapy, it is important to understand that treatment value cannot be summarized in an individual metric -- a multifaceted approach is necessary focusing on what is important to the individual patient
- The use of electronic testing has been shown 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]

General Quality of Life Assessment

Gibbons C, Bower P, Lovell K, Valderas J, Skevington S. Electronic Quality of Life Assessment Using Computer-Adaptive Testing J Med Internet Res. 2016 Sep 30;18(9):e240

- A recent publication proposed a model of screening for the World Health Organization Quality of Life-100 item questionnaire using a much reduced number of questions with individual adaptive responses and high degree of reliability.
- Three hundred and twenty WHOQOL-100 questionnaires were used and a CAT simulation model was developed to calibrate item banks using item response theory, which included psychometric assessments of differential item functioning, local dependency, unidimensionality, and reliability. Simulated assessments were as reliable as paper-based forms of the WHOQOL with a much reduced number of items used.

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Problems of ESRD Care and PROM Use

- Effort expended on conforming to the 5 Star Rating system and meeting QIP requirements
- Annual requirements for PROMs that are now mandated
- Challenges of addressing the multiple problems presented by ESRD patients – *co-morbid diseases, multiple medications, etc*
- Making sure the problem area identified on testing is recognized by the patient as being important to him/her
- Overcoming barriers of patients and dialysis facilities in developing treatment plans

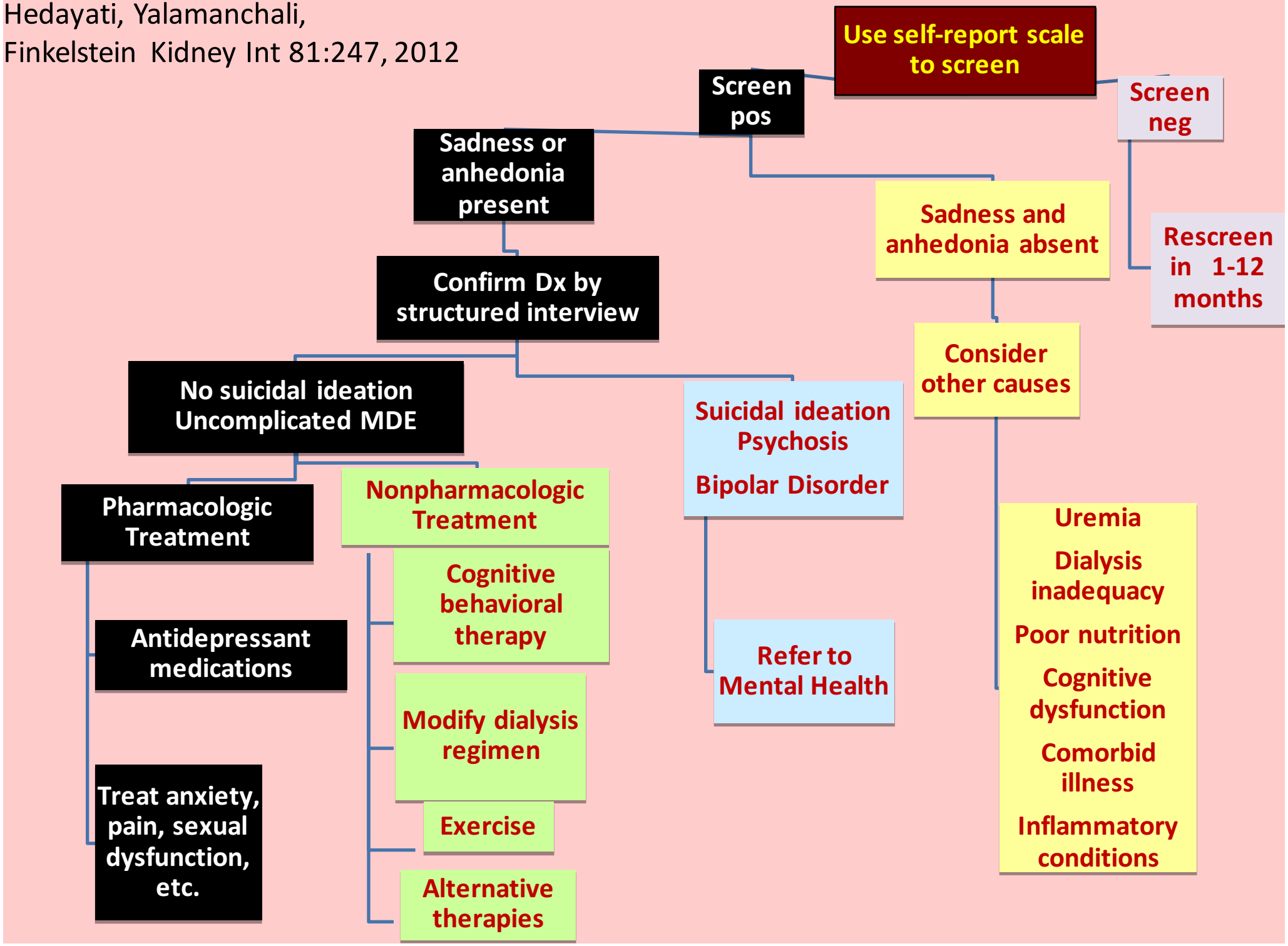
5 Star Ratings

- **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

QIP

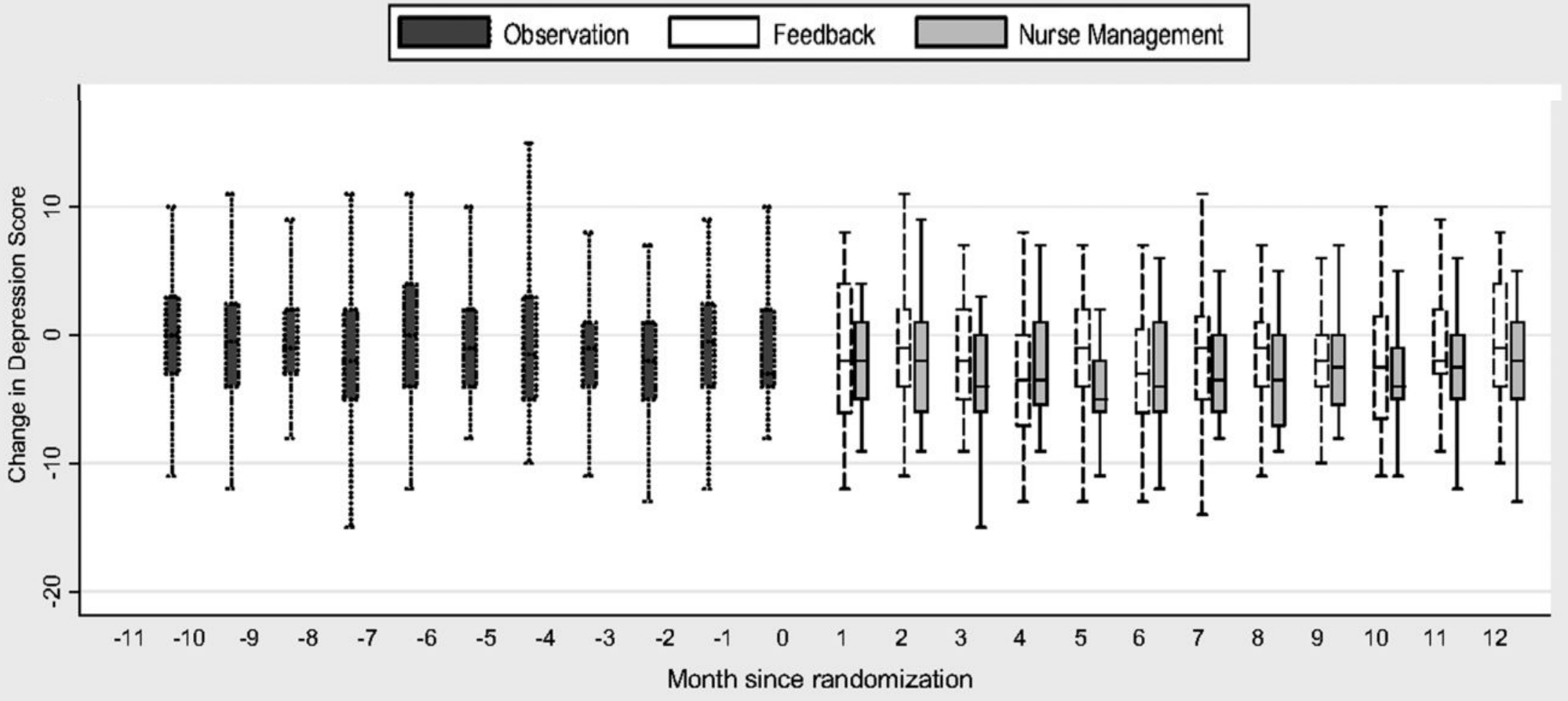
- Dialysis Adequacy
- Hb and ESA reporting
- Hypercalcemia
- % AVFs
- Bloodstream infections
- Readmissions
- Phosphorus reporting
- CAHPS survey (ICH CAHPS) on a twice-yearly basis, using a third-party CMS-approved vendor

Hedayati, Yalamanchali,
Finkelstein Kidney Int 81:247, 2012

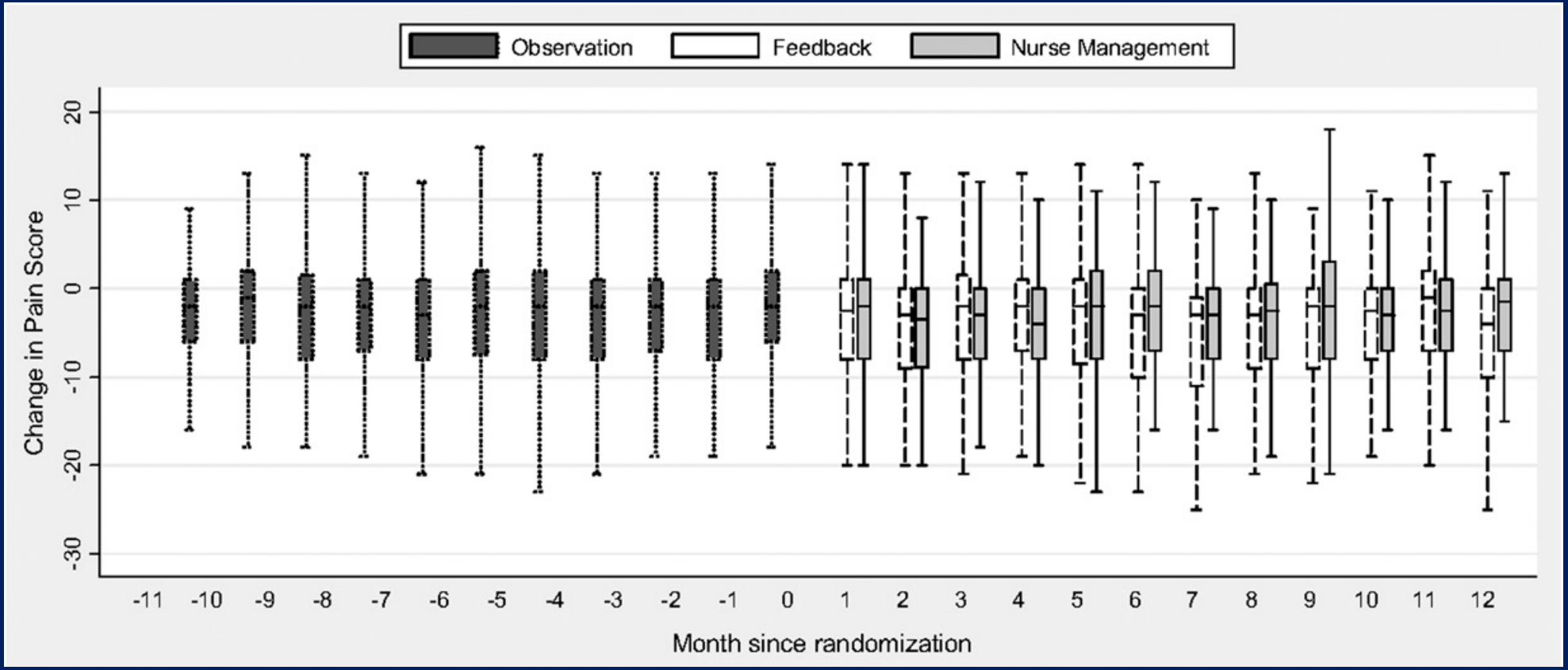


Longitudinal change in depressions scores (PHQ9) Weisbord et al. CJASN 2013;8:90-99

Nurse managers formulated pharmacologic and/or nonpharmacologic treatment recommendations based on well developed treatment algorithms and clinical judgment (Weisbord et al. CJASN 2013;8:90-99)

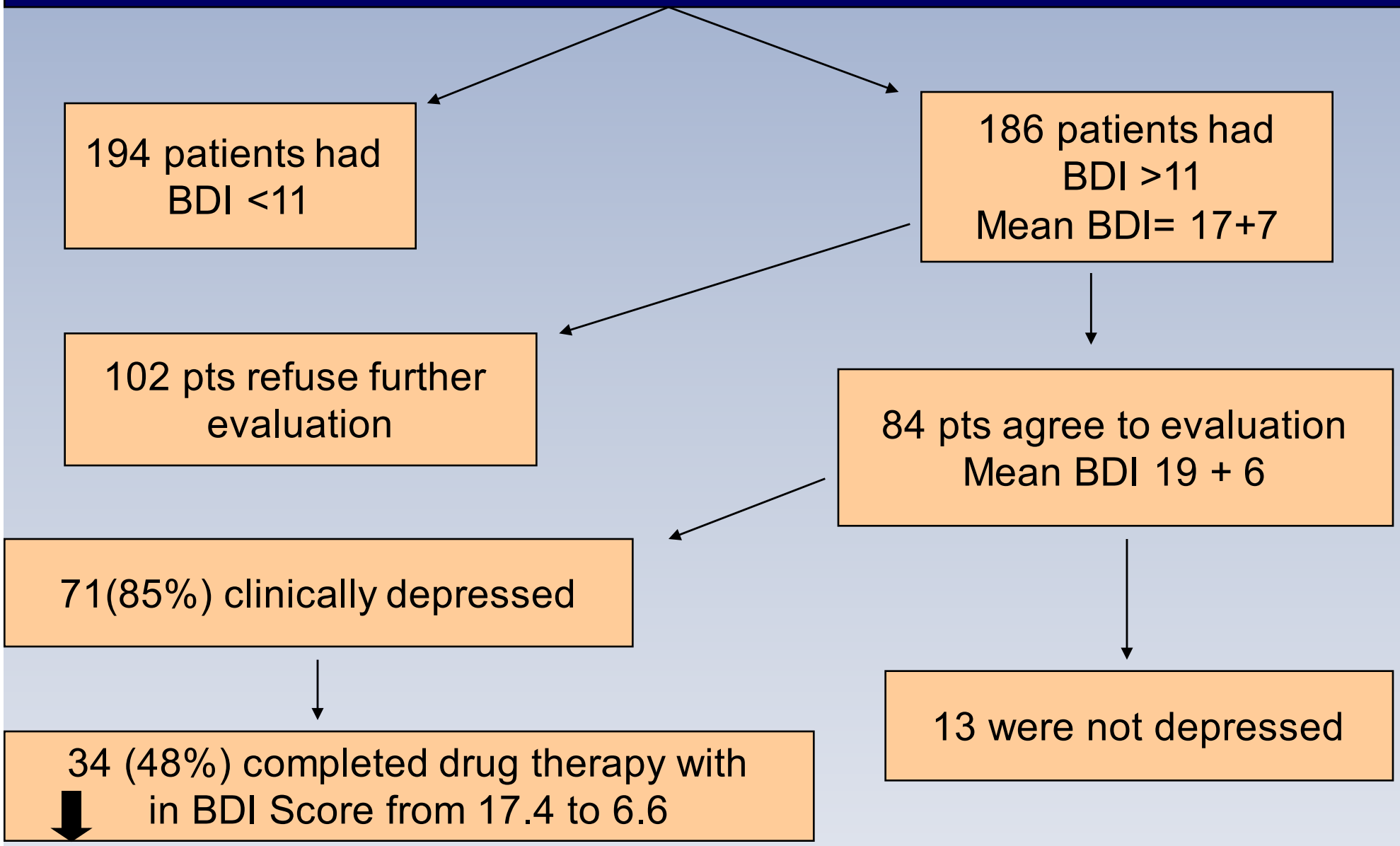


Longitudinal change in pain scores (SFMPQ) by study phase and intervention arm Weisbord et al. CJASN 2013;8:90-99



Short-Form McGill Pain Questionnaire: scored from 0 to 45

380 PD Patients Were Screened with the BDI
Mean BDI Score 12 +7



Sexual Activity in Women on HD

Mor et al CJASN 2014 9:128-34

- "Although many women receiving chronic hemodialysis are sexually inactive, few describe sexual difficulty. Most, including those with a lack of interest in sex, are satisfied with their sexual life and few wish to learn about treatment options. These findings suggest that true sexual dysfunction is uncommon in this population and that treatment opportunities are rare."

Barriers Presented by the Dialysis Facility

- Concern over the 5 Star Rating Program and QIP model
- Rigid adherence to established performance measures
- Documentation requirements
- Staffing patterns
- Lack of flexibility in developing a personalizing, patient-centered care approach

Domains to be Addressed

a) medication side effects

b) depression and anxiety

c) wide variety of physical symptoms

d) family and marital discord

e) sexual dysfunction

f) caregiver burden

g) satisfaction with care and dialysis treatment regimen

h) cognitive impairment

i) impact of treatment regimen on life

j) physical functioning

k) fatigue

l) other: unique problems for the individual patient

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The Regulatory Environment

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- An open dialogue between patient and provider should be encouraged
- Patients need to understand that their responses will be used by providers to address their needs and problems.
- Individual patient problems may be unrelated to the dialysis procedure itself and thus the ability of the dialysis facility to impact on these problems may be limited.
- Thus, using "scores" from PROMs to compare dialysis facilities is not appropriate and can in fact be counter-productive.

Recommendations

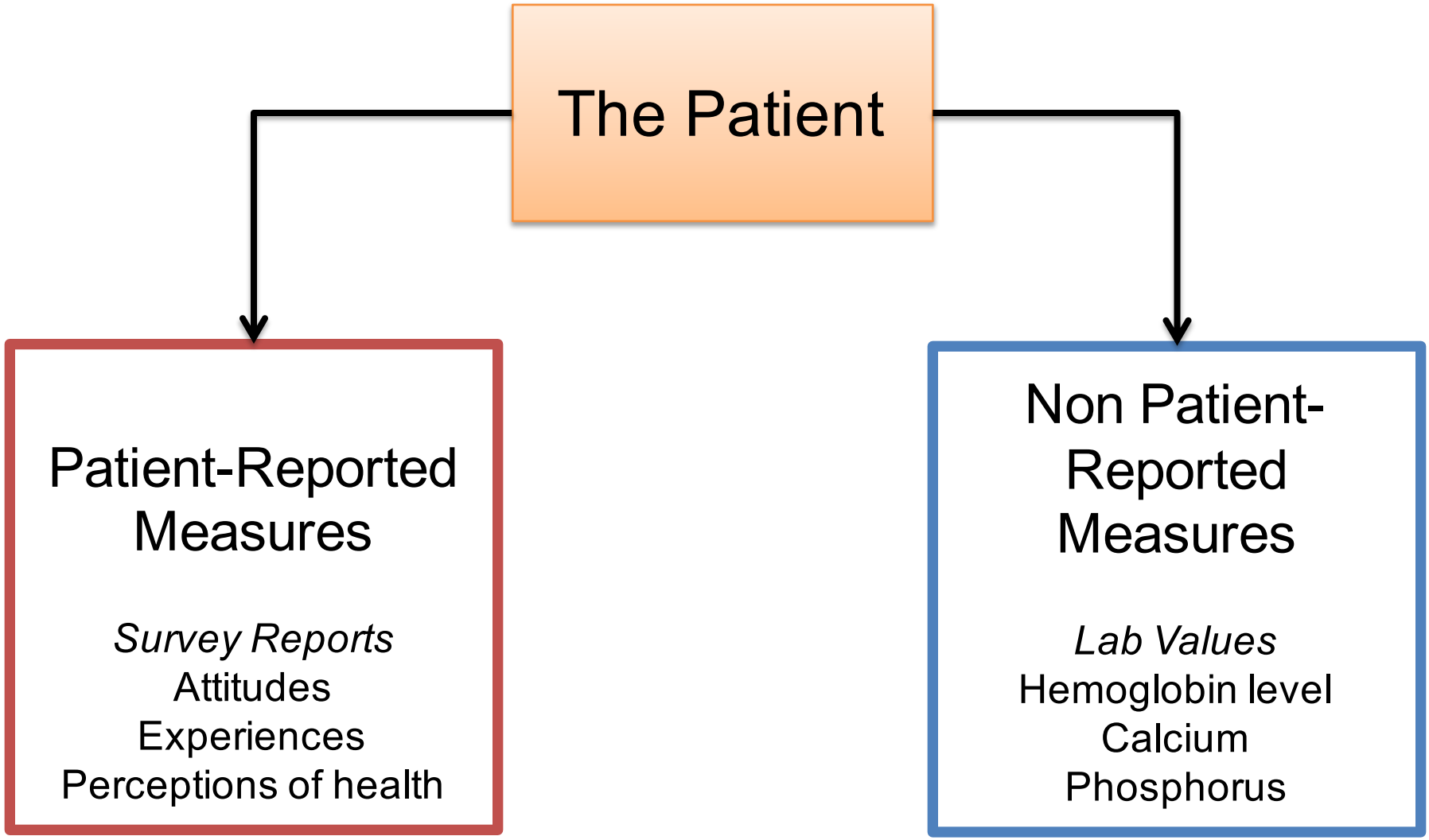
- Mandate that PROMs be incorporated into routine patient care, addressing some or all of the issues discussed
- Leave the mode and frequency of administration (paper, electronic, CAT) and the instruments to be used to the discretion of the facility
- Encourage innovative approaches given the lack of 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.

Methodological Considerations in Using Patient Reported Measures in Dialysis Clinics

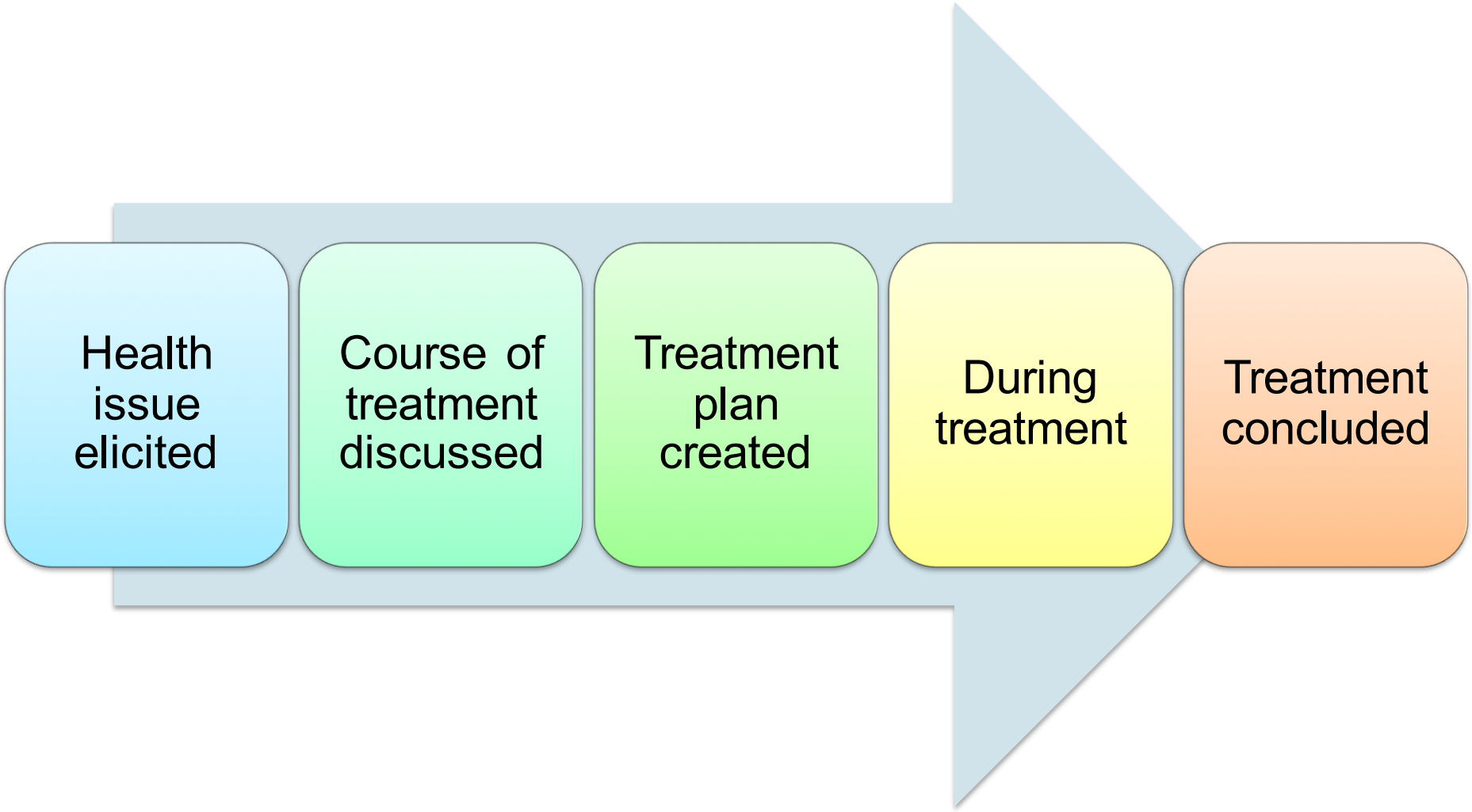
John D Peipert

Ron D Hays

Patient Reported Measures are Major Source of Data



Assessing PRMs along Stage of Provider-Patient Encounter



Successes & Challenges Administering PRMs in Clinic

- Patient-reported symptoms associated with fewer ER visits and increased 1- and 5-year survival[1]
- Systematic review of administering PRMs showed improvements in processes and outcomes of care 40-50% of the time[2]
- Some providers may not change their care plan even when presented with PRM data[3]

[1]Basch et al. *J Clin Oncol*. 2016; [2]Valderas et al. *Qual Life Res*. 2008;
[3]Fung & Hays. *Qual Life Res*. 2008

Definitions (1)

- Patient Reported Outcome (PRO): "any report coming from patients about a health condition and its treatment, without interpretation of the patient's response by a clinician or anyone else" (FDA)

- Patient-Reported Measures (PRMs): defined the same way, but more general and including PROs
  - *PROs are a type of PRM*

FDA. 2009.

Definitions (2)

- Patient Reported Outcome Measure (PROM): "Instrument, scale, or single-item measure used to assess the PRO concept as perceived by the patient, obtained by directly asking the patient to self-report" (NQF)

- PRO-based Performance Measures (PRO-PMs): "a performance measure that is based on PROM data aggregated for an accountable healthcare entity" (NQF)

http://www.qualityforum.org/Patient-Reported_Outcomes.aspx

PRMs in Dialysis

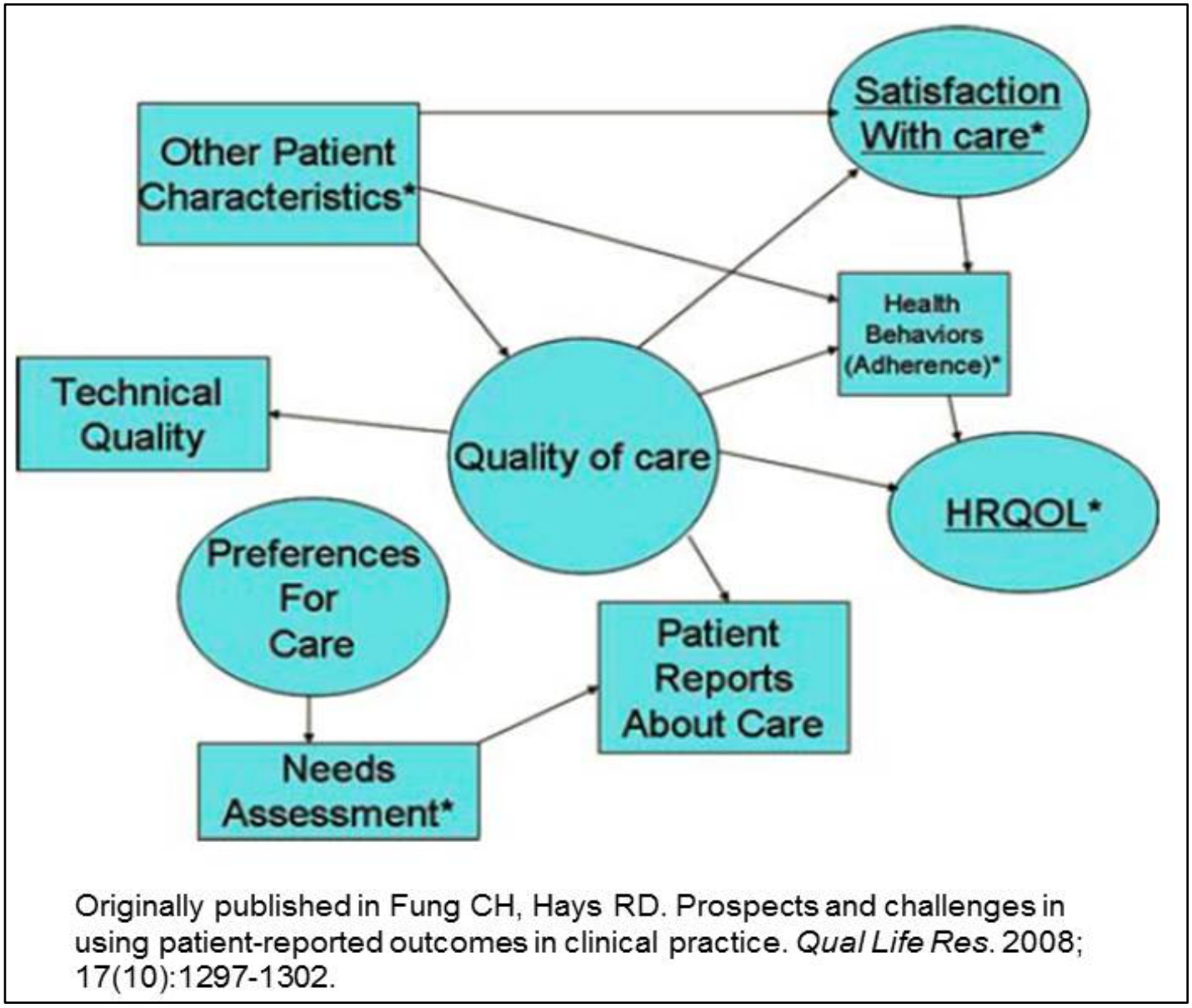
- Used as performance measures
  - CMS incorporation of ICH-CAHPS® in QIP
- Used for internal quality improvement
  - KDQOL™-36 incorporated into care plans

Objectives

- Identify key PRMs relevant to dialysis patients
- Review key methodological issues around the use of PRMs in dialysis
- Make recommendations for:
  - Selection of PRMs
  - Mode of Administration
  - Support for PRM Use in Dialysis

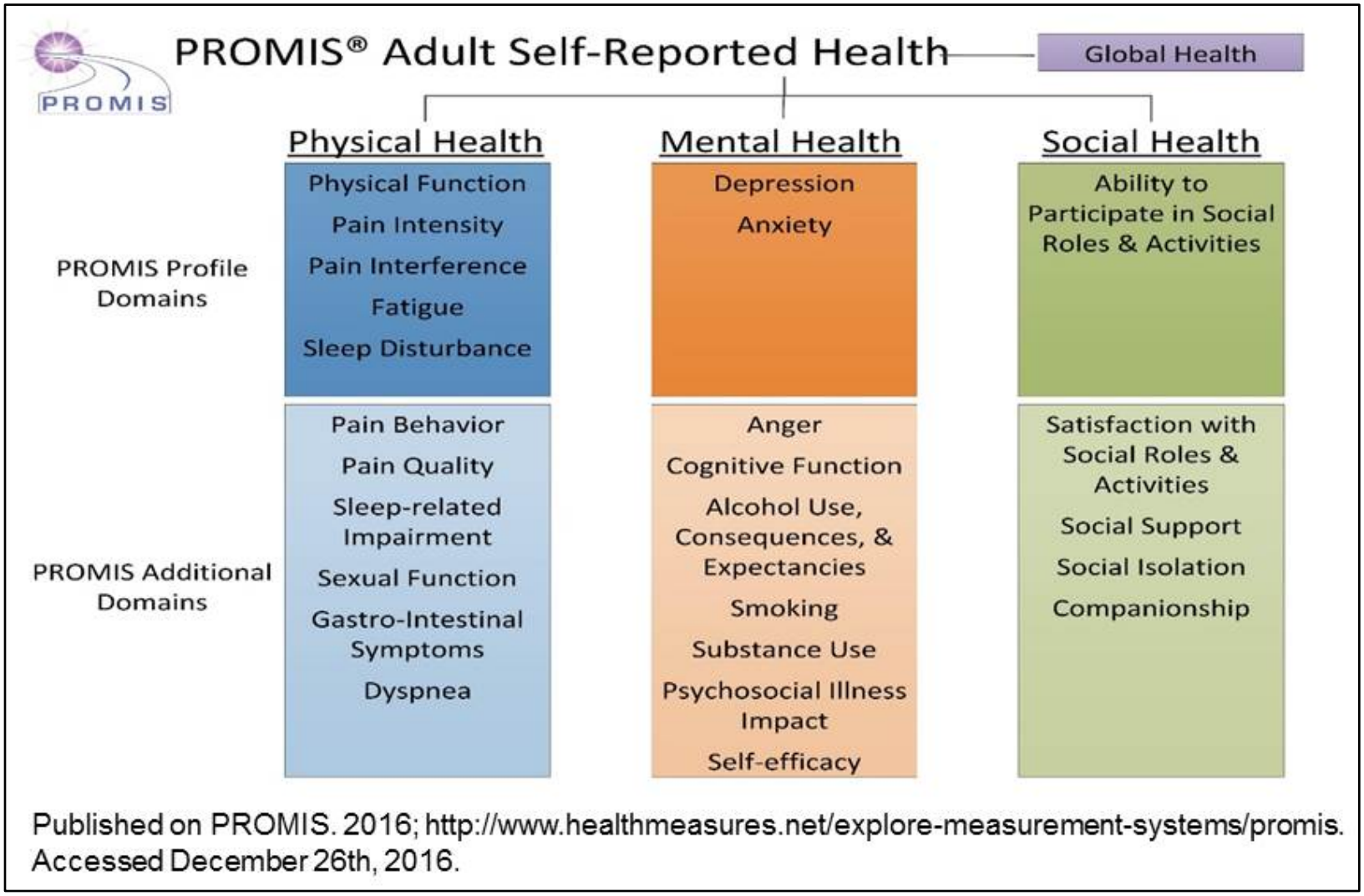
Identifying Key PRMs Relevant to Dialysis Patients

Fung & Hays PRM Framework



Originally published in Fung CH, Hays RD. Prospects and challenges in using patient-reported outcomes in clinical practice. *Qual Life Res*. 2008; 17(10):1297-1302.

Health-Related Quality of Life (HRQOL)



Published on PROMIS. 2016; http://www.healthmeasures.net/explore-measurement-systems/promis. Accessed December 26th, 2016.

PROMIS (1)

- Content area experts, methodological experts, clinicians from academia, and NIH project officers
- Can be assessed as static “short forms” or through computer adaptive testing (CAT)
- Scored on T-score metric
  - Mean of 50, SD of 10, with the mean referenced to the U.S. general population

PROMIS (2)

- Measures for both adult and pediatric patients
- PROMIS-29: Multi-domain profile measure:
  - Physical function
  - Anxiety
  - Depression
  - Fatigue
  - Sleep disturbance
  - Ability to participate in social roles and activities
  - Pain interference
  - Pain intensity

Kidney Disease Quality of Life 36-item (KDQOL-36)

- Derived from KDQOL-SF, Hays, et al[a]
- SF-12 (12 items)
- Burden of KD (4 items)
  - 5 point scale: “Definitely true” - “Definitely false”
  - E.g., “My kidney disease interferes too much with my life”
- Symptoms/Problems with KD (12 items)
  - 5 point scale: “Not at all bothered”-“Extremely bothered”
  - E.g., “To what extent are you bothered by chest pain?”
- Effects of KD (8 items)
  - 5 point scale: “Not at all bothered”-“Extremely bothered”
  - E.g., “How much does fluid restriction from KD bother you?”

[a]Hays, et al. *Qual Life Res*. 1994

KDQOL-36 Properties

- Developed with patient input
- Brief
- Contains generic and targeted HRQOL scales
- Evidence of reliability and validity
- Administered with 1000’s of dialysis patients; norms available for comparison

Recommendation 1

We recommend the continued use of the KDQOL-36 instrument with dialysis patients for the purposes of dialysis centers' internal quality improvement

Improve KDQOL-36 by replacing
SF-12 PCS & MCS with PROMIS items

Experience with Care

- “The range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities” (AHRQ)

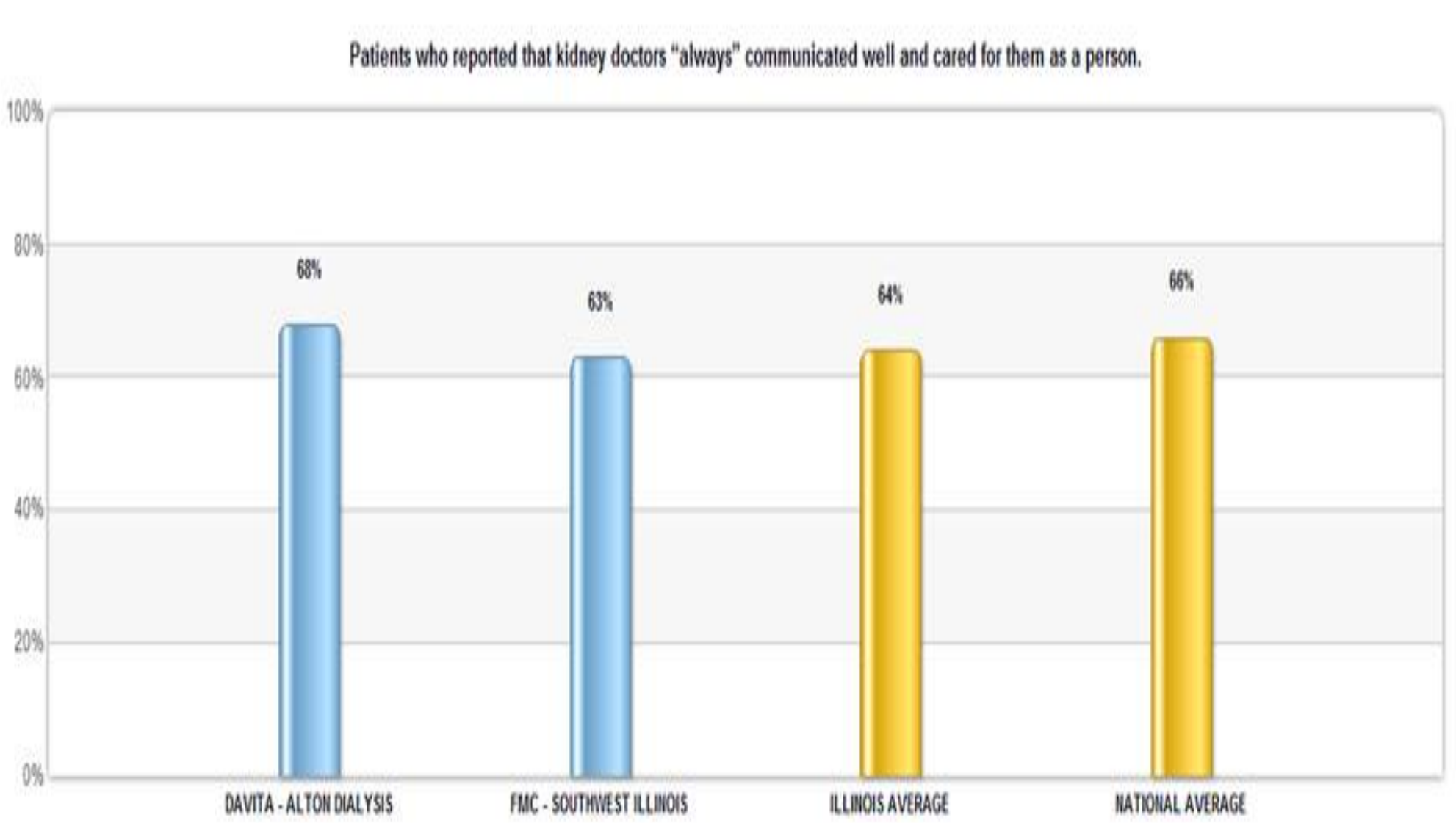
https://www.ahrq.gov/cahps/index.html

In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS®)

- 3 multi-item scales
  - Nephrologists Communication and Caring (α=0.89) (6 items; e.g., “In the last 3 months, how often did your kidney doctors explain things in a way that was easy for you to understand?”)
  - Providing Information to Patients (α=0.93) (9 items; “Did dialysis center staff at this center ever review your rights as a patient with you?”)
  - Quality of Dialysis Center Care & Operations (α=0.75) (17 items; “In the last 3 months, how often did the dialysis center staff show respect for what you had to say?")
- 3 global items

Weidmer, et al., AJKD. 2014

Inclusion in CMS QIP and Dialysis Facility Compare



ICH-CAHPS Properties

- Developed with patient input
- Evidence of reliability and validity
- Administered with 1000's of dialysis patients; norms available for comparison

Recommendation 2

We recommend the continued use of the ICH-CAHPS for CMS's dialysis center performance monitoring

Improve parsimony by reducing number of items in scales.

Other PRMs: Treatment Decision-Making

- Kidney patients can choose between multiple types of dialysis, multiple types of transplant
  - *All offer different additional length and quality of life*
- Understanding risks and benefits of all options is required for informed consent
- CMS requires that all dialysis patients be informed of their option for transplant

Are patients being informed?

Table 2. Patient- and provider-reported provision of information about KT

Patient-Reported KTPI	Provider-Reported KTPI		Total
	No	Yes	
No	30	108	138
Yes	32	218	250
Total	62	326	388

Provision of information about KT was reported by patient and provider in 56.2% of participants, provider only in 27.8%, patient only in 8.3%, and neither in 7.7%. The interrater agreement between patients and providers was only slightly better than what would be expected by chance alone (63.9% observed agreement versus 59.8% expected agreement; κ=0.10).

Salter, et al. *JASN*. 2014.

Recommendation 3

We recommend that a PRM of whether patients have been informed about their option for transplant be adopted

Mode of Administration

How are PRMs Administered?

	In-clinic	Mail	Phone	Web
Self Administered	X	X		X
Interview Administered	X		X	
Computer Administered	X			X
Voice Activated			X	

Web-Based/Electronic Administration (1)

- Pros
  - Efficient data capture with simultaneous data entry
  - Convenient for patient
  - Flexible timing for data collection
- Cons
  - Difficult to ensure privacy
  - Upfront costs for the PRO system and maintenance
  - Potential software problems

Web-Based/Electronic Administration (2)

- Many surveys were designed for paper/pencil
- Often no need to completely redevelop, but additional testing for equivalence should be conducted
- Minor changes
  - Updates to instructions and formatting

Recommendation 4

Evaluate equivalence between electronic and paper versions of PRMs prior to widespread use of electronic administration

Support for PRM Use in Dialysis

Cost of Administering PRMs

- Burdensome for dialysis providers and dialysis patients
  - Dialysis staff have heavy workload
- Material costs
  - Paper Surveys
  - Electronic admin systems
- Data entry

Recommendation 5

We recommend that new explorations be launched to identify mechanisms for CMS to reimburse these costs

Training for Administering PRMs

- Skills required for interview administration
  - Understanding of standardized survey administration techniques
  - Ways to elicit unbiased, accurate responses
  - Trouble shoot when patients have questions
  - Understand potentially complex skip-patterns

- Skills required for interview administration
  - Standardized data entry protocols

Recommendation 6

We recommend the continued development of effective, low-cost training programs to help providers administer PRMs, including e-learning programs

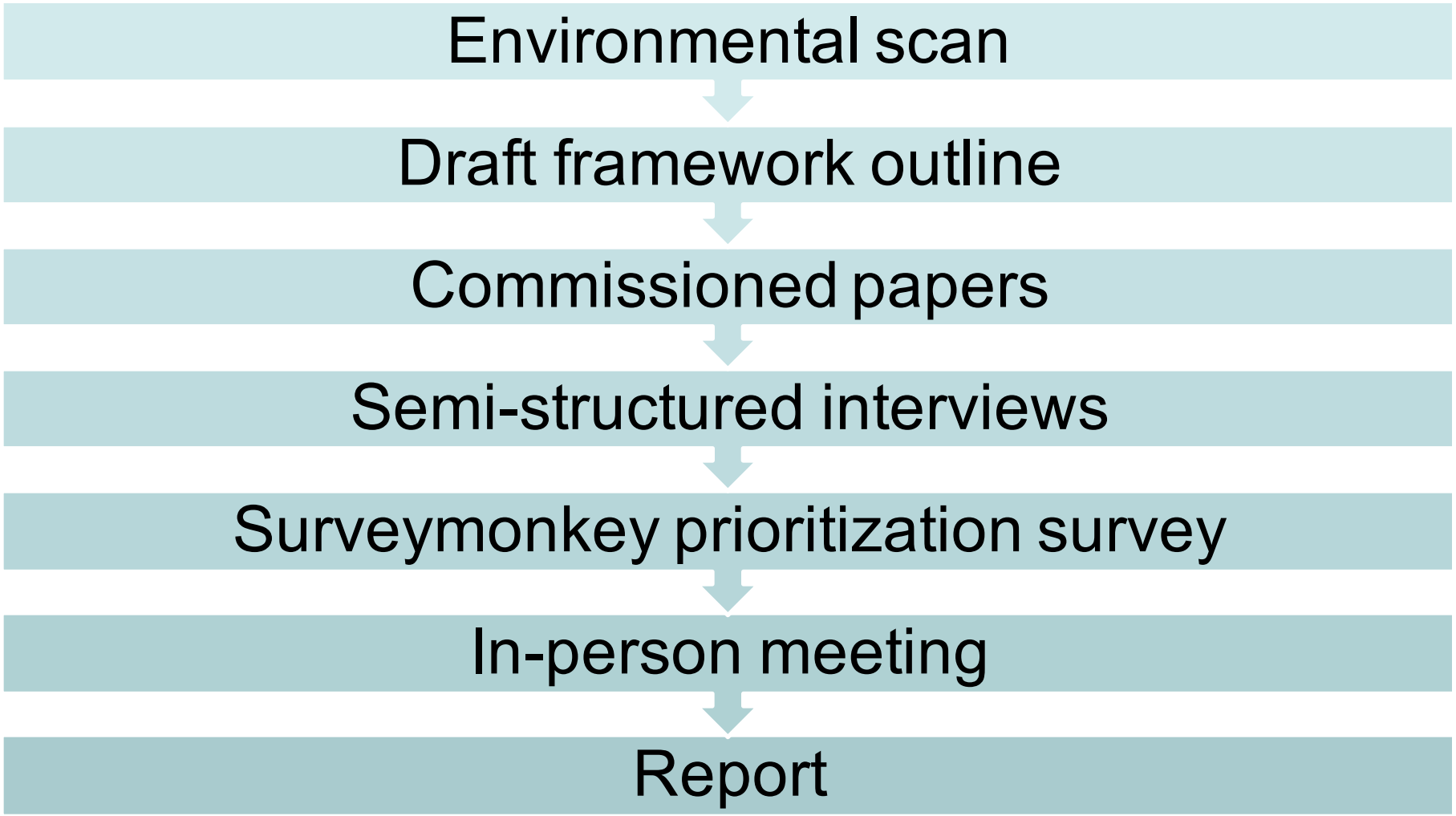
Conclusions

- A lot of successes in use of PRMs in dialysis
  - Good measures available
  - Use in dialysis is extensive
- Room to grow to improve
  - Measures
  - Administration methods
  - Support of staff administering PRMs

KCQA Interview/Survey Results

Dr. Allen R. Nissenson, KCQA Co-Chair
Dr. Paul M. Palevsky, KCQA Co-Chair

KCQA Interview/Survey Milestones



Environmental Scan

- Reviewed NQF, Avalere, AHRQ databases; peer-reviewed literature; grey literature; material provided by KCQA members.
- **Identified 139 Patient-Reported Outcome Measures (PROMs) and Patient-Reported Outcome Performance Measure (PRO-PMs), and 6 PROM-related registries/platforms**.
  - The vast majority are not ESRD-specific.
  - ICH CAHPS and KDQOL are two ESRD instruments.

Draft Framework Outline

- Based on NQF nomenclature, identified **four high-level categories: *Health-Related Quality of Life (HRQOL)*, *Symptoms and Symptom Burden*, *Patient Experience with Care*, *Health Behaviors***.
- Used environmental scan to build out subcategories/domains for each high-level category.
- Framework outline used for semi-structured interviews and surveymonkey prioritization.
- Well-received, but a few minor adjustments recommended following survey analysis.

Semi-Structured Interviews

- 52 interviews of KCQA members, patients, KCQA Steering Committee members, other experts
  - 19 patients (RSN and DPC, as well as referrals from AKF, NKF, DPC, and Forum of ESRD Networks)
  - 27 of 32 KCQA member organizations participated
  - 9 Steering Committee members interviewed

Semi-Structured Interviews (cont.)

- Interviews focused on
  - Completeness and appropriateness of draft framework outline
  - Priorities for PRO measurement for ESRD
  - Feedback on ICH CAHPS and KDQOL
  - Perceived challenges and potential solutions to PRO measurement for ESRD

Surveymonkey Prioritization

- Survey focused on prioritizing high-level PRO categories and domains from draft framework outline.
- Overall KCQA member response was excellent, exceeding 75%.
- Included enhanced outreach to patients (facilitated by AKF, DPC, NKF, Forum of ESRD Networks).
- Results analyzed by two cohorts: KCQA members and patients.

Surveymonkey Prioritization (cont.)

- 50 completed surveys (KCQA member organizations, patients, KCQA Steering Committee members)
  - Patient cohort (n=21); 19 referred patients and 2 KCQA member organization representatives who are patients
  - KCQA member cohort (n=25); all responding member organizations, including all representatives (patient and non-patient) from member patient organizations
  - Balance additional experts

Interview and Survey Results

1. Appropriateness of draft framework outline
2. Priorities for ESRD PRO measurement
3. Barriers to collecting PRO information
4. Experience with ICH CAHPS and KDQOL
5. Care aspect that could be most improved
6. Other issues

DRAFT FRAMEWORK OUTLINE

Appropriateness of Draft Framework

Patient Experience with Care measures address satisfaction with healthcare delivery and therapies, reflects actual experiences with healthcare services, and fosters patient activation.[1]

- **Respect for Patient/Family**
  - Caring from doctors/advanced practice registered nurses/nurses/staff
  - Respect for autonomy and preferences
  - Respect for privacy
  - Patient/family included in care planning and decision-making
- **Communication**
  - Between doctors/advanced practice registered nurses/nurses/staff and patient/family on medical condition/treatment options (e.g., modality education)
  - Between providers within and across care site (i.e., coordination of care)
- **Care Environment**
  - Safety
  - Cleanliness

CASE EXAMPLES

The *Patient Experience with Care* domains from the ICH CAHPS measure and Hospital Compare are provided here for reference:

ICH CAHPS Patient Experience Domains

- Nephrologists' Communication and Caring
- Quality of Dialysis Center Care and Operations
- Providing Information to Patients
- Global Rating of the Nephrologist
- Global Rating of Dialysis Center Staff
- Global Rating of the Dialysis Facility

Hospital Compare Patient Experience Domains

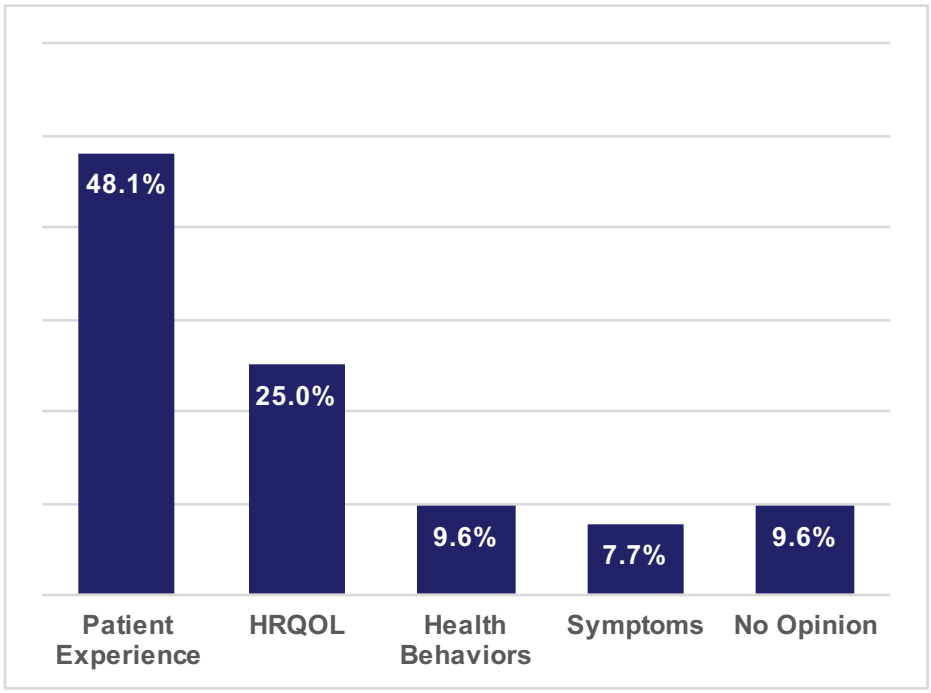
- Communication with Nurses
- Communication with Doctors
- Responsiveness of Hospital Staff
- Pain Management
- Cleanliness and Quietness of Hospital Environment
- Communication about Medicines
- Discharge Information
- Overall Rating of Hospital

- Interviewees considered comprehensive and appropriate
- Used for surveymonkey
- Some minor suggestions recommended; see tab in meeting materials

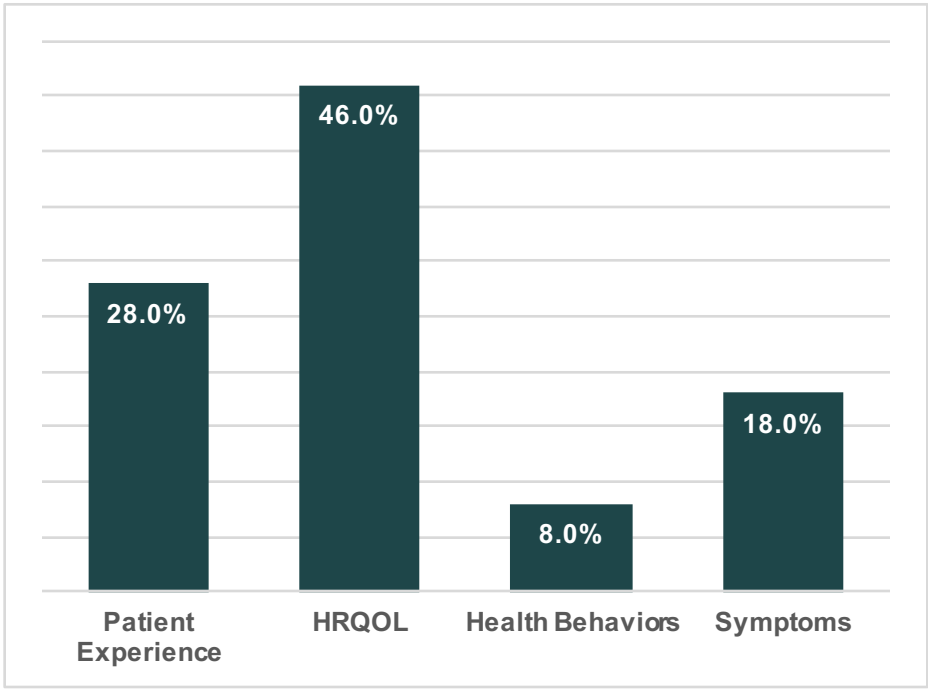
PRIORITIZATION
(INTERVEW & SURVEYMONKEY)

Priorities for ESRD PRO Measurement

Priorities based on interviews



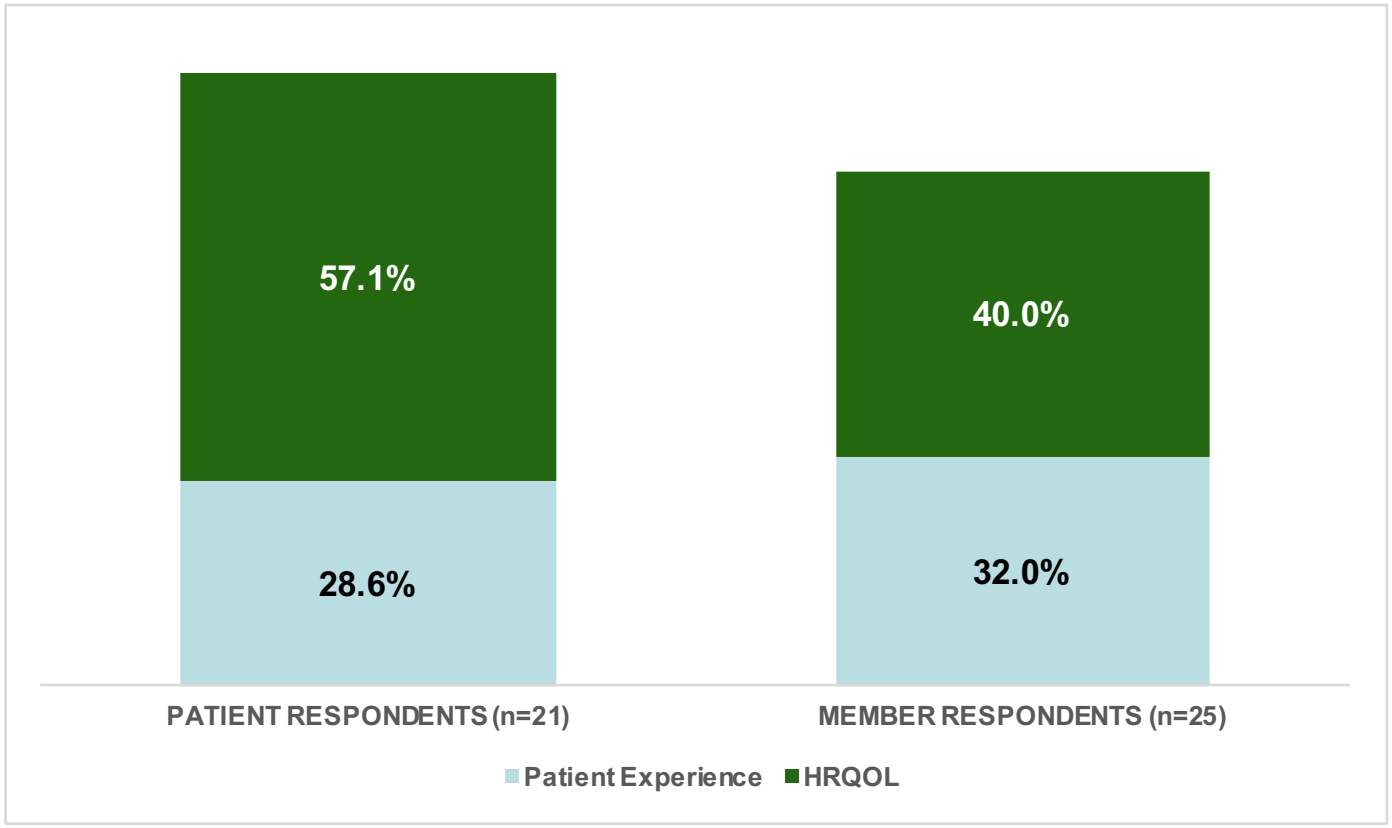
% ranking area #1 (of 4) in survey



Differences likely due to:

- Preliminary nature of interview (interviewees were told they would receive a formal surveymonkey link); some switching occurred
- Composition of two populations differed (~81% overlap)

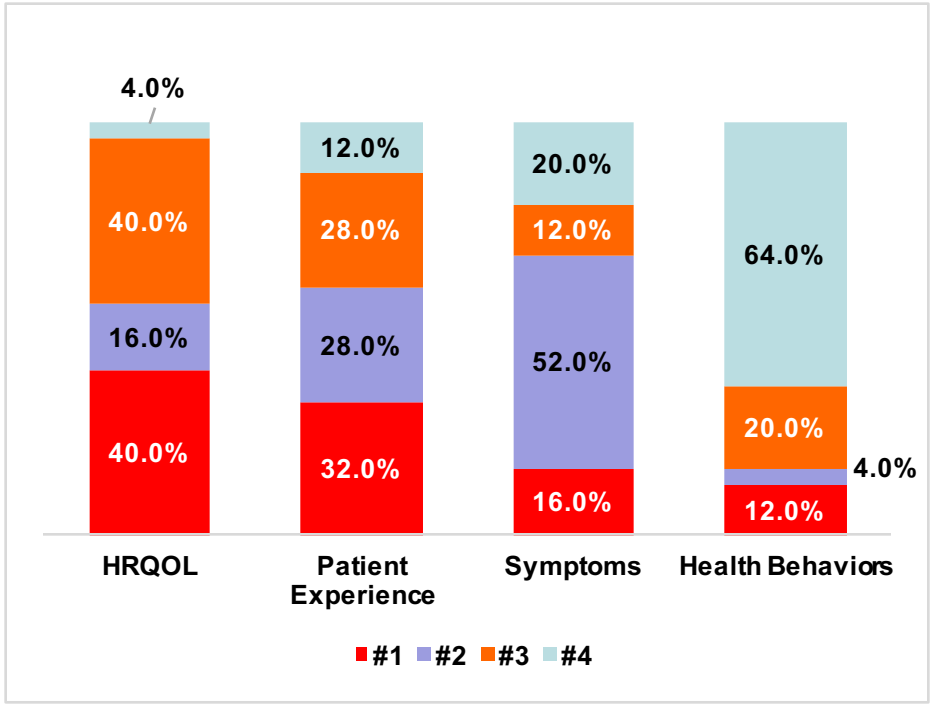
Priorities for ESRD PRO Measurement (cont.)



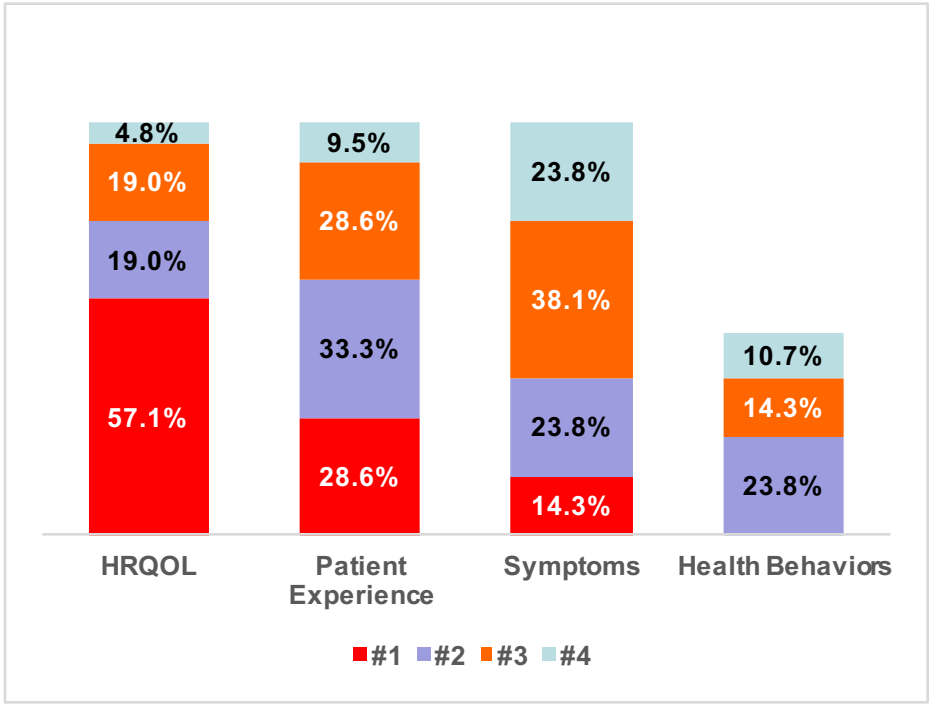
- *HRQOL* more highly favored by patients than KCQA member organizations
- Analyses also revealed differences in relative order/ranking between the two groups (i.e., not just #1 and #2)

Priorities for ESRD PRO Measurement (cont.)

High-Level Rankings, Members



High-Level Rankings, Patients



- Both populations rank *HRQOL* #1 most frequently
- Patients rank *Symptoms* as #2 significantly less than do KCQA members
- Patients most frequently rank *Patient Experience* #2

Priorities for ESRD PRO Measurement (cont.)

KCQA members and patients also differ slightly in views on priorities for Top 4 (of 13) *HRQOL* subcategories/domains

Ranking	ALL	KCQA Members	Patients
#1	Overall QOL*	Overall QOL	Overall QOL
#2	Well-Being*	Functional Status	Well-Being
#3	General Health*	Well-Being	General Health
#4	Functional Status	General Health	Mental Health

*Additional subdomains and definitions from framework delineated differences in the survey that may not be obvious with these short labels

Priorities for ESRD PRO Measurement (cont.)

Similarly, KCQA members and patients also differ slightly in priorities for subcategories for *Patient Experience with Care* (only 4 domains)

Ranking	ALL	KCQA Members	Patients
#1	Care Received	Care Received	Communication
#2	Communication	Communication	Care Received
#3	Respect for Patient/Family	Respect for Patient/Family	Respect for Patient/Family
#4	Care Environment	Care Environment	Care Environment

Rationales for Rankings

- *HRQOL*
  - Overall well-being and good health is the most important thing to patients
  - HRQOL PROMs are the best to guide patient care, but
    - HRQOL is a complex concept difficult to effectively measure
    - HRQOL is difficult to measurably impact
    - Inverse correlation between HRQOL and patient's decline as disease progresses compromises potential value as performance metric
- *Symptoms*
  - Gaining a better sense of symptoms might provide insight into how to more directly improve QOL

Rationales for Rankings

- *Patient Experience with Care*
  - Patient interviewees prioritized because is believed to be more actionable; patient survey respondents ranked HRQOL first, however
  - More positive interaction between patients and providers—especially communication—would improve other three PRO categories
  - Providers intervening to put patients at ease during care experience would improve other aspects
- *Health Behaviors*
  - Least likely to reflect a dialysis facility's quality
  - Increased focus could impact the three other categories
  - Patient behavior difficult to influence

BARRIERS TO COLLECTING PRO DATA

Barriers to Collecting PRO Data

- Patients and KCQA members nearly universally cited survey fatigue
- Other barriers cited by patients
  - Have more pressing concerns
  - Feel too ill to participate
  - Belief that nothing will or does change
  - Mistrust and reluctance to be honest due to fears of retribution
- KCQA members cited
  - Patient literacy
  - Burden of administration
  - Subjective nature makes responding difficult

Solutions to Barriers

- No easy answers
- Recommendations to overcome barriers often contradictory
  - Some recommended electronic, while others believe face-to-face preferable
  - Some feel anonymization key, while others feel identification important to permit facility to quickly address issues
  - Limiting survey length and options would improve, yet some patients recommend more opportunity for open-ended responses

TWO ESRD PRO TOOLS: PERSPECTIVES ON ICH CAHPS AND KDQOL

ICH CAHPS and KDQOL Findings

- Nearly all interviewees with prior experience view ICH CAHPS and KDQOL as
  - Not effective
  - Not providing meaningful patient-reported information on patients' experiences and/or quality of life
- ICH CAHPS
  - Burdensome
  - Gaps in content
  - Low response rate raises concern about validity of scoring
  - Patients feel categorical responses limit their ability to provide meaningful information

ICH CAHPS and KDQOL Findings (cont.)

- KDQOL
  - Compared to ICH CAHPS more interviewees were favorable (n=13)
  - Asks more meaningful questions
  - Provides more actionable information
  - Concerns about validity in modern populations, and no validation as a performance measure (vs. patient-specific assessment)
  - More effective instruments exist (e.g., SF-36, PROMIS)
  - Significant concern about use as performance measure

POTENTIAL IMPACT OF PRO MEASURES (PROMs)

Potential for PROM Impact

- No single (or even a few) areas emerged as prominent; areas cited ranged across the PRO framework categories
- Patient experience with care
  - Short-term, immediate issue (chair comfort, temperature, etc)
  - Longer-term issues (patient-provider communication, making patient feel respected, safe, heard)
- Identification and reduction of symptoms
- Effective detection of patients with depression, cognitive dysfunction, low functional status
- Identification of individuals who need more intensive education to improve health behaviors

OTHER ISSUES

Types of Other Issues Raised

- PRO evaluation of healthcare professionals should be specific, not general providers
- Important to address home dialysis
- Family and caregiver outcomes should be assessed
- Questions should focus on transactions, “What did _____ do to address your problem?”
- Focusing on how a patient feels immediately after treatment would improve QOL
- Validation of any HRQOL metric requires knowing prior QOL and health behaviors
- Patients feel not heard, not respected, not included in care decisions

DISCUSSION OF RESULTS

BREAKOUT INFORMATION

Breakout Context and Goals

- Discuss in greater depth the commissioned paper recommendations, KCQA prioritization findings, and recommended changes to framework outline.
- Identify points of consensus and, if any, disagreements.
- Discussion Guide with questions provided in packets.

Breakout Context and Goals

- Specifically discuss:
  - Are the current KCQA Principles salient and applicable to Patient-Reported Outcome Measures (PROMs)?
  - Is there consensus on a single priority (*Patient Experience with Care* or *HRQOL*) or does the group still feel both are of equal priority for PROM development for patients with ESRD?
  - For either or both categories, is there consensus on one or a few subcategories that merit exploration for measure development (by KCQA or other parties) in the near-term?

Breakout Rooms

- Group 1: Tera
- Group 2: Brennan

Please return to District View South for closing plenary.

LUNCH

Next Steps

- Summary of meeting will be prepared and distributed, particularly to KCQA members unable to attend.
- Draft outline for report and then report will be reviewed by Steering Committee.
- Report will be reviewed for approval by KCQA members.
- Issue report on KCQA framework, principles, and priorities – target June 2017.
- No commitment to fund measures; funding decisions TBD by KCP.

CLOSING REMARKS