Patient Reported Outcomes in Clinical Care

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Objectives

- What are patient reported outcomes?
- How are patient reported outcomes used outside of nephrology?
- How might patient reported outcomes used in nephrology and PD?

What are PROMs

What are Patient Reported Outcome Measures (PROMS)?

- Instrument completed by a patient to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health

What are Patient Reported Outcome Measures (PROMS)?

- Questions patient asked to gauge their own views on their own health

Devlin and Appleby. Getting the most out of PROMS. The Kings Fund. 2010

Key Aspects of PROMs

- Completed by the patient
- Represent the patient's view of their health
  - Not their health care provider's
  - Not their family member's
- May be paper, interview, electronic
- Thousands of varieties
  - Variable function
  - Variable quality

Key Aspects of PROMs

Generic

- Measures overall health through general domains
- Typically able to compare to general population

Specific

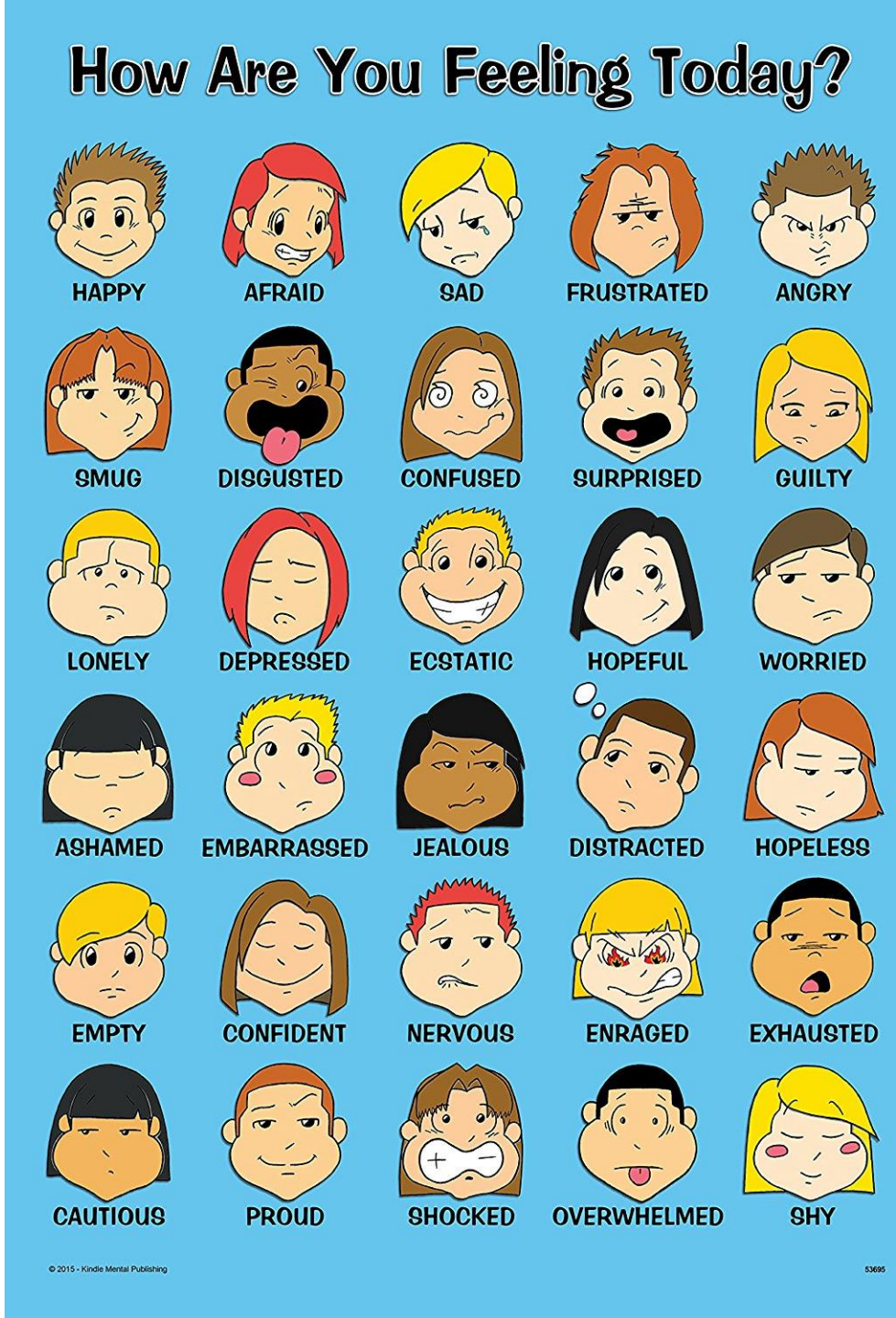
- Measures health related to a particular disease or body part
- Typically perception of symptom severity or impact on life

Generic PROMs

- Short Form – 36, 12
- EQ-5D
- Health Utility Index

Anchor Based Utilities

- Limitations
  - Can miss important aspects of health
  - Often require complex scoring
  - Can be difficult to identify actionable issues



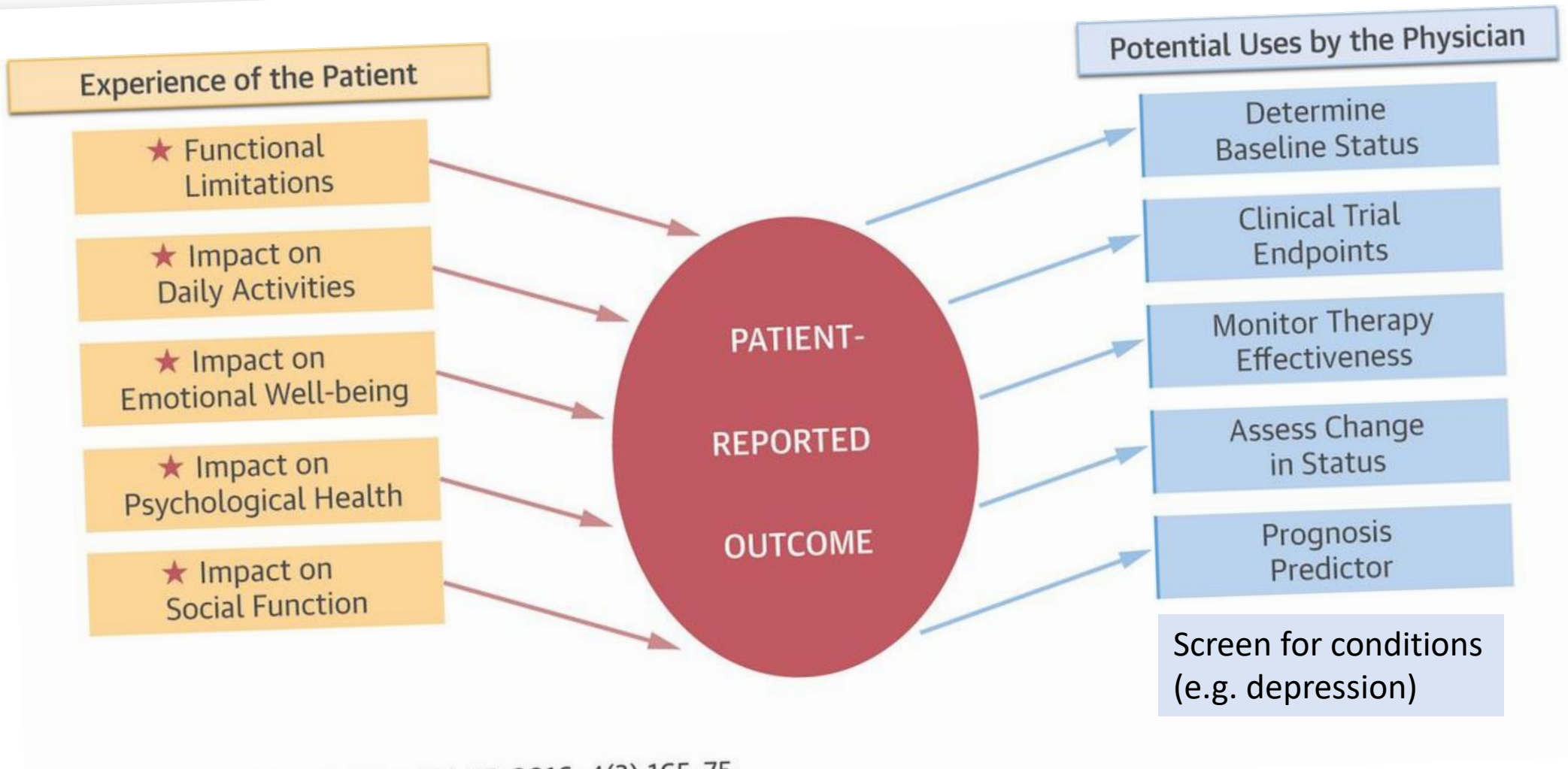
Condition Specific PROMs

- Kidney Disease
  - KDQoL – 36
- Specific Symptoms
  - International Restless Leg Syndrome Study Group rating scale

KDQoL - 36

- 36 questions
- 12 from SF-12
- 4 on burden of kidney disease
  - Life interference, time dealing with disease, frustration, burden on family
- 12 on symptoms
  - Includes access (PD or HD)
- 8 on effects
  - Bothered by fluid/dietary restriction, ability to do house work, ability to travel, dependency on medical system, stress, sex life, appearance

How are PROMs Used in Routine Care?



Kelkar, A.A. et al. J Am Coll Cardiol HF. 2016; 4(3):165–75.

How might PROMs be used

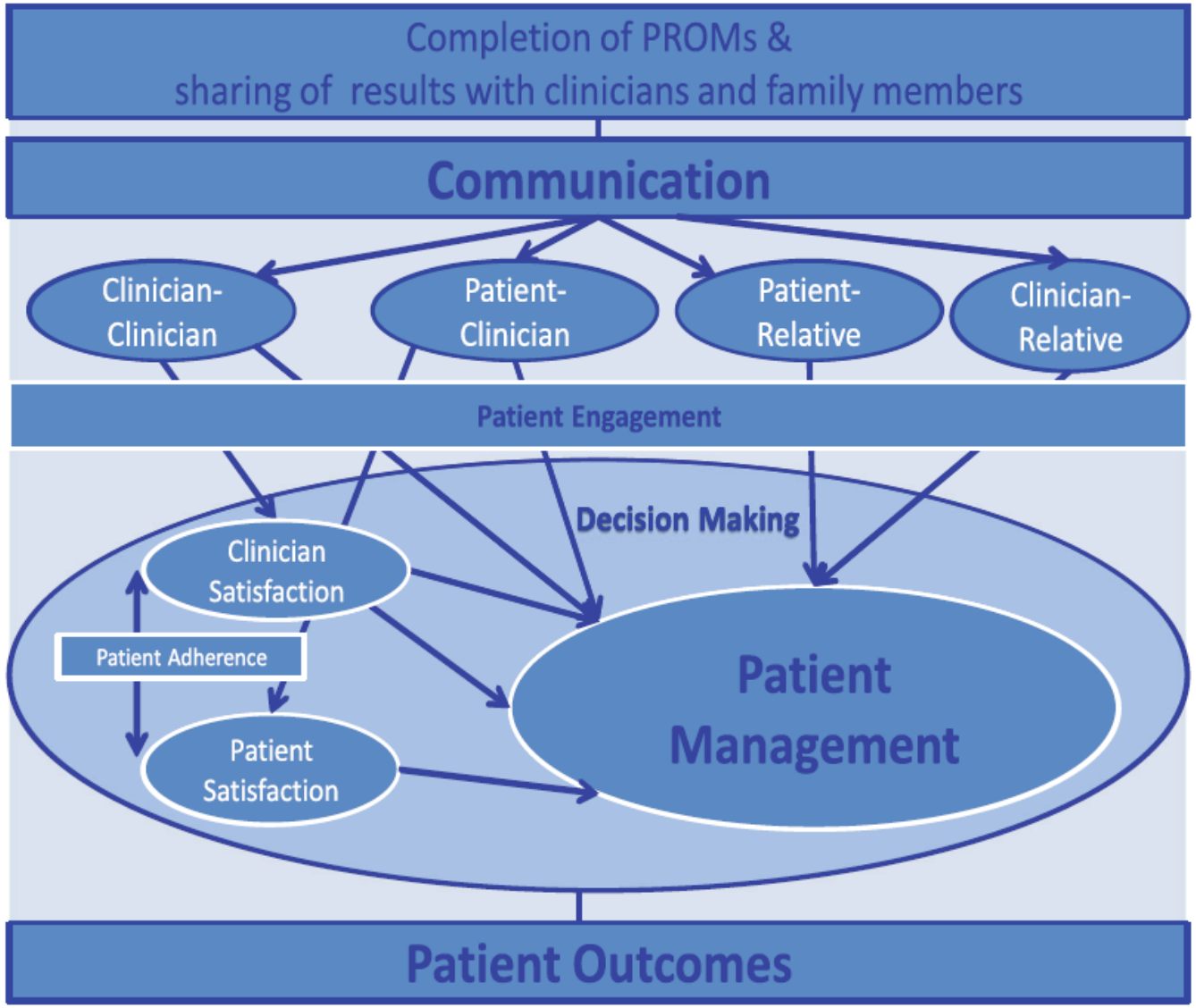
By Patients

- Help deciding amongst treatment options

By Health Systems

- Identifying care gaps
- Identifying performance issues

Potential Benefits of PROMs



Considerations for Incorporating PROMs

1. What are the goals of use of PROMs?
2. What questionnaire best suits your needs?
3. Which patients will be assessed?
4. How often will patients complete the PROM?
5. How will the PROM be administered and scored?
6. How will the results be presented and are interpretation aids needed?
7. When and where will the results of the PROM be reviewed?
8. Who will receive the scores?
9. How will issues identified by the PROMs be responded to?
10. How will the value of using the PROM be identified?

International Society of Quality of Life Research. User's Guide to Implementing PROs in Clinical Practice. 2015.

PROMs in Non-Kidney Care

PROMs in Cancer Care

- Increased probability of discussion symptoms ($p=0.03$)
- Reduced symptom burden ($p=0.02$)
- Didn’t change physician behaviour (verbal response patterns)
- No significant increase in appointment time

Velicova et al. J Clin Onc. 2004.
Berry et al. J Clin Onc. 2011.
Berry et al. J Clin Onc. 2014.

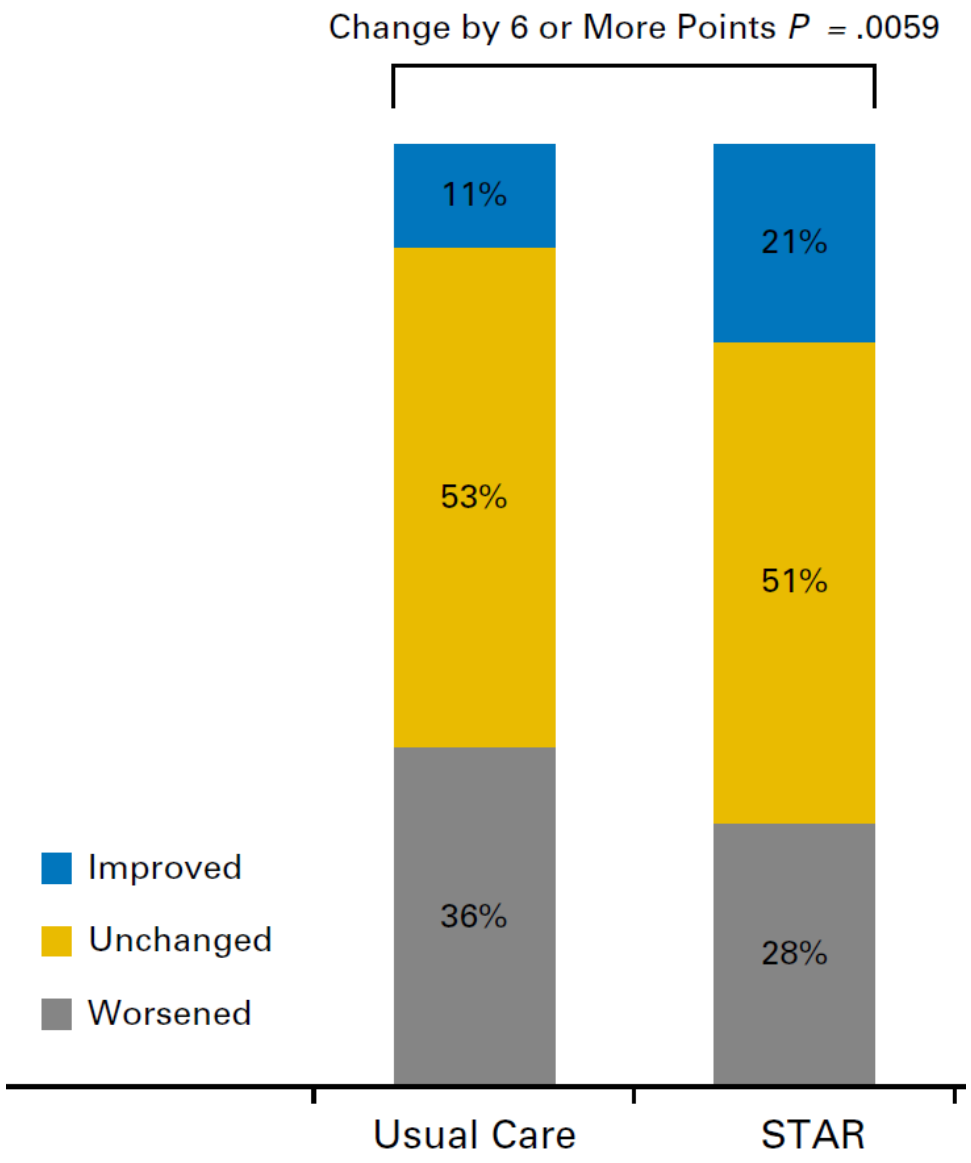
PROMs in Cancer Care

- English speaking patients with metastatic breast, GU, gynecologic, or lung cancer starting treatment with chemotherapy
- Symptom Tracking and Reporting (STAR) system
  - Appetite loss, constipation, cough, diarrhea, dyspnea, dysuria, fatigue, hot flashes, nausea, pain, neuropathy and vomiting.
  - 5 point scale (0 = not present; 4 = disabling)
  - Used at clinic visits and at home
- Nursing email alerted to 2 point rise or score ≥3 (no emergency responses)
- Report generated for each clinic visit
- No specific guidance to clinicians

Basch et al. J Clin Onc. 2016.
Basch et al. JAMA. 2017.

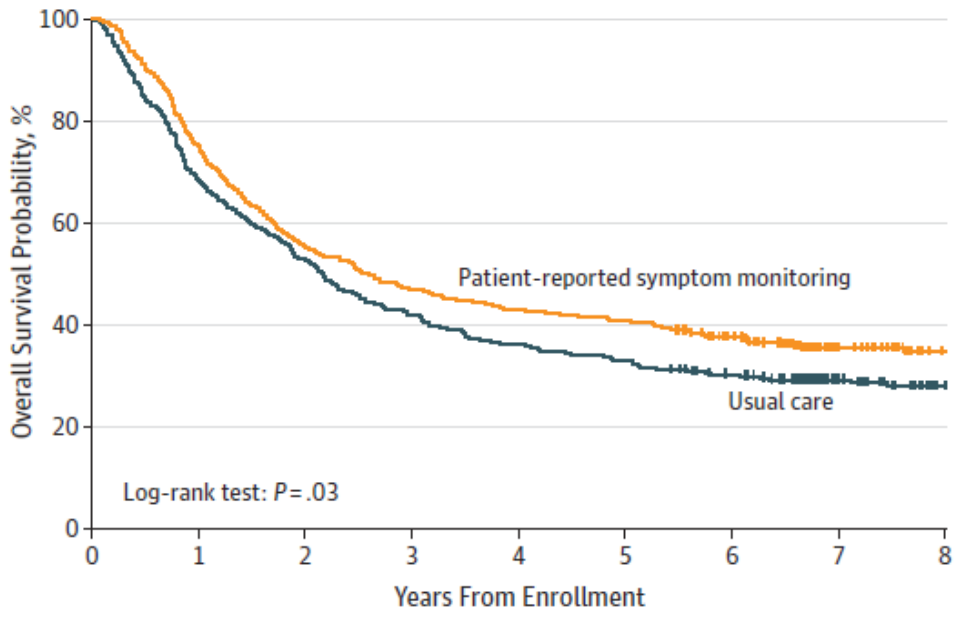
PROMs in Cancer Care: Effect on Quality of Life

- 766 participants randomized
- Primary outcome change in overall HRQoL
- No difference in nursing calls between groups (about 13 calls per patient)



PROMs in Cancer Care: Effect on Survival

- Hazard Ratio 0.83 (95% CI 0.70 to 0.99; p=0.04)
- Reduction in emergency room use and hospitalizations



No. at risk									
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27

PROMs in Nephrology

European Consensus Statement

Purpose: To support improvement in care

	Consensus
Which instruments	
Generic	SF-12
Preference-based	EQ-5D-5L
Kidney specific	KDQOL™-36
Practical issues	
Who?	All patients on RRT
When?	At least annually
	Preferably not during dialysis
How?	Unassisted self-report
	No clear preference for paper/web
Other issues	Consider ethics/consent/data protection
	Conduct initial pilot study

How do we use this information to improve care?

Breckenridge. NDT. 2015.

International Consortium for Health Outcomes Measurement (ICHOM)

"We urge all providers around the world to start measuring these outcomes to better understand how to improve the lives of their patients."

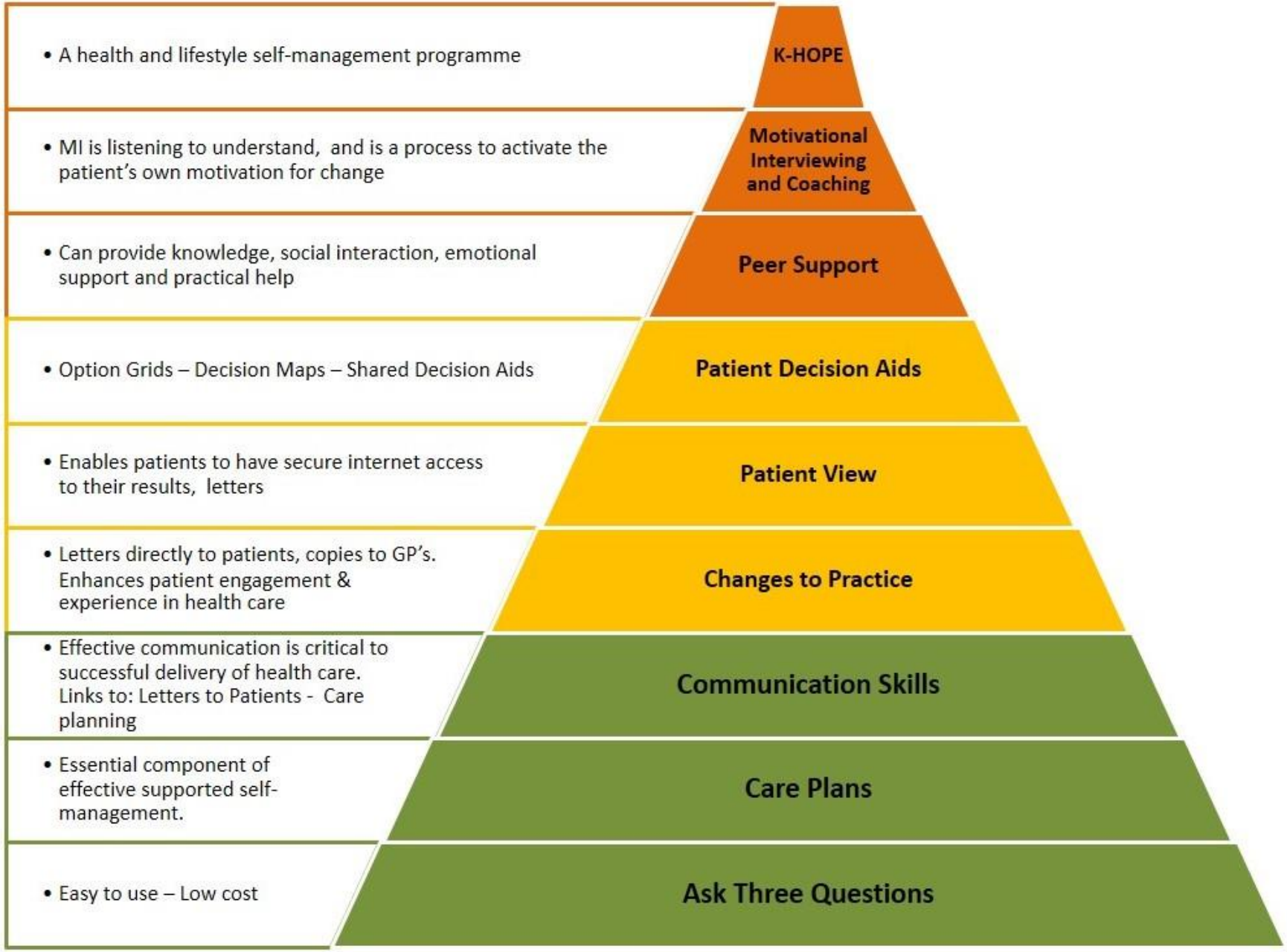
Transforming Participation in CKD

- Goal to improve self-management
- Administered
  - Generic PROM (EQ-5D)
  - Symptom assessment (POS-S Renal)
  - Measure of patient activation (PAM)
- Cross section of 10 renal units (1,053 patients)

Transforming Participation in CKD

- Most common symptoms
  - Weakness/lack of energy (58%)
  - Poor mobility (49%)
  - Pain (39%)
  - Sleeping difficulty (38%)
  - Shortness of breath (36%)
- EQ-5D
  - 27% moderate to overwhelming anxiety/depression

Transforming Participating in CKD

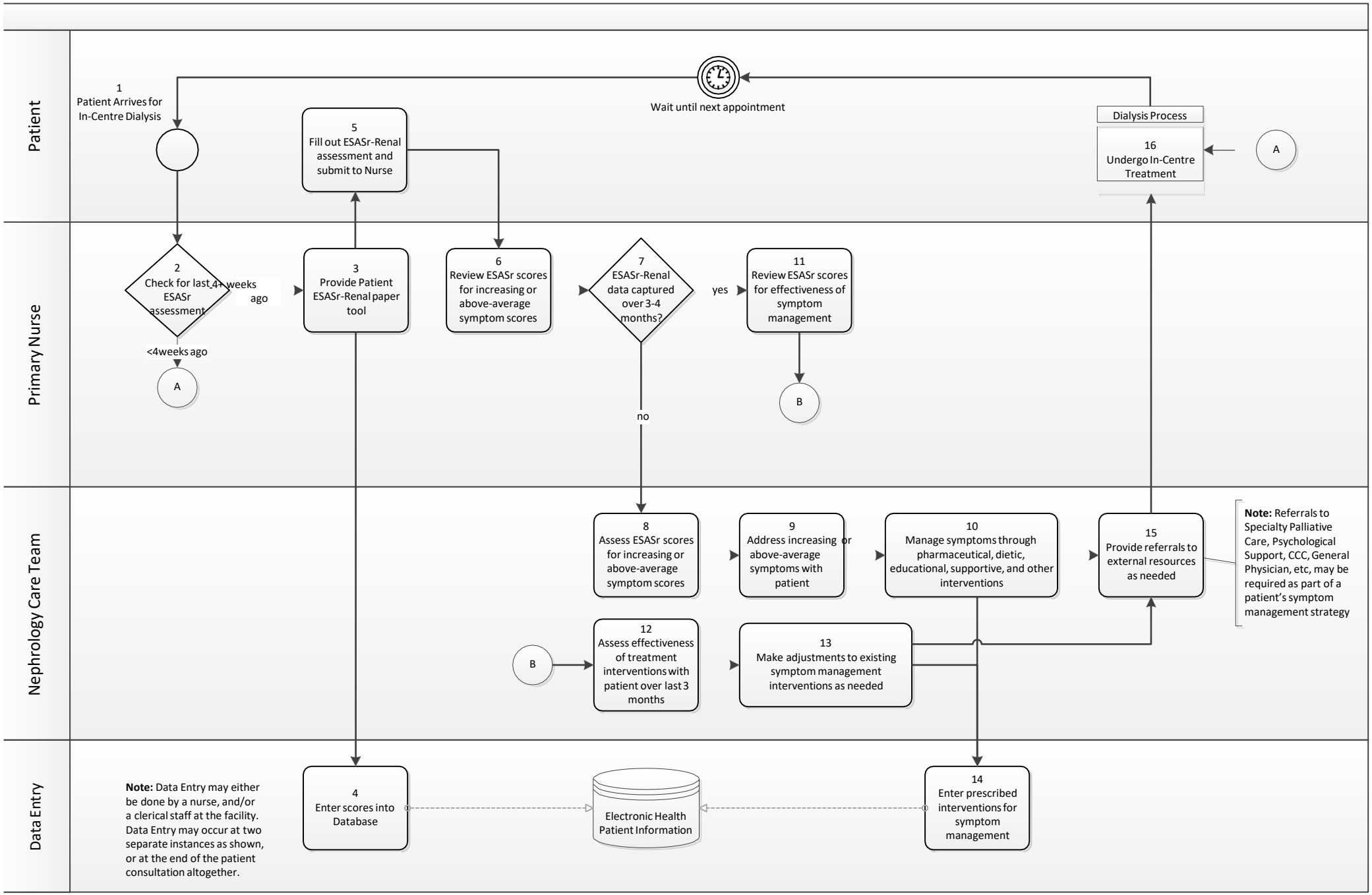


Your Symptoms Matter

CCO Ontario Renal Network

- Pilot program in Ontario
- 9 hemodialysis units
  - Academic/community
  - Hubs/satellites
  - Differing models of care
- Modified Edmonton Symptom Assessment System:Renal
  - Administered by bedside nurses
  - Every 4 – 6 weeks

Symptom Management and Assessment – ESASr Renal

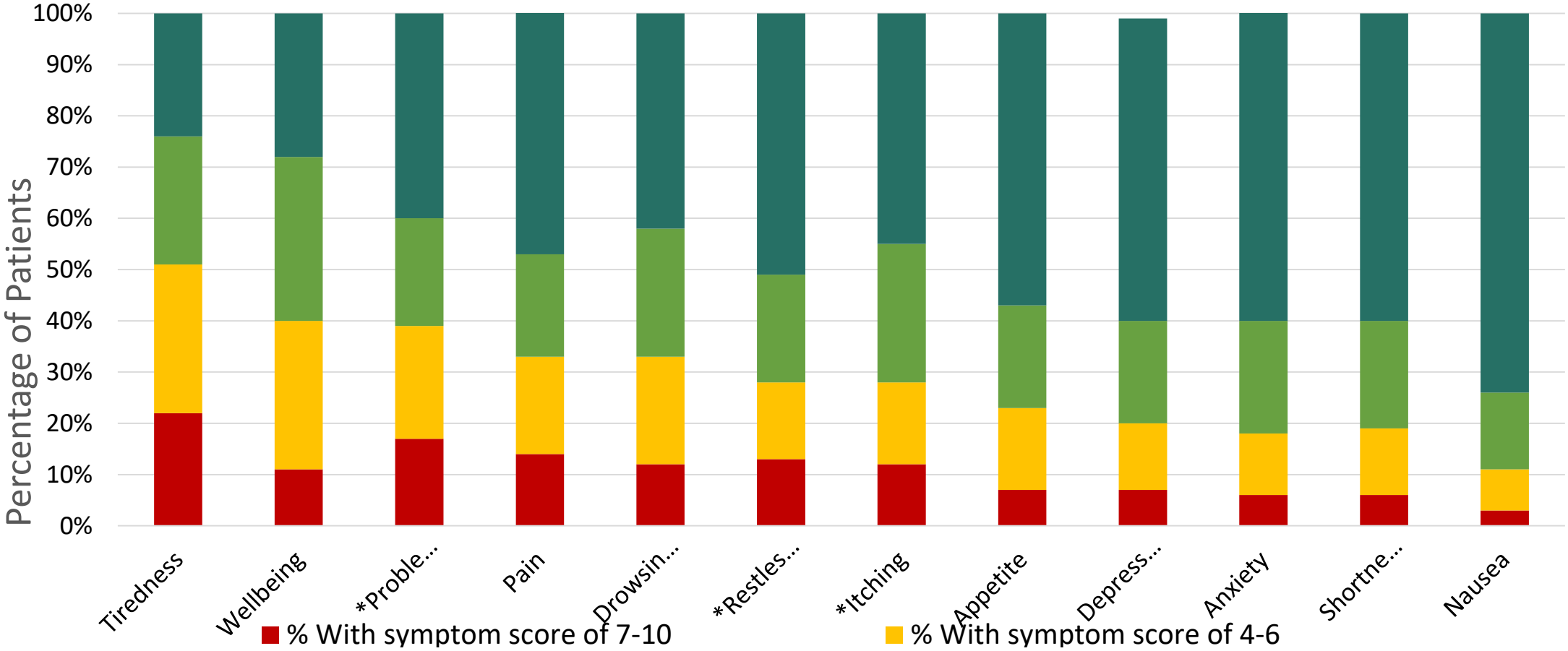


Your Symptoms Matter

1,267 patients in 9 dialysis units

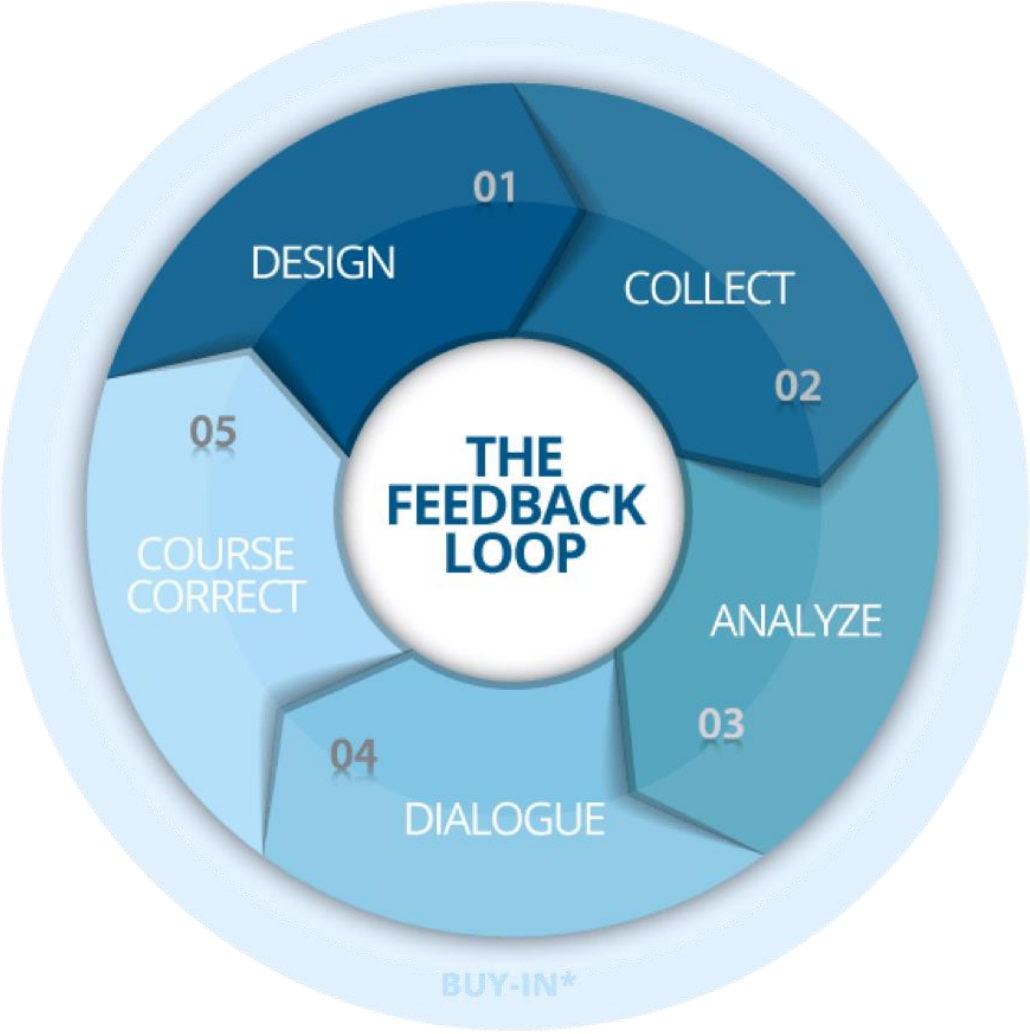
Mean age		67.2
Sex (%)	Female	42%
Comorbidities at dialysis initiation (%)	Myocardial Infarct	17%
	Cerebrovascular Disease	11%
	Diabetes Type 2	44%
	Malignancy	11%
	Peripheral Vascular Disease	13%
Time on dialysis (%)	Less than 1 year	25%
	1-5 years	43%
	5 years and above	32%

Your Symptoms Matter



Your Symptoms Matter

- Act of measuring is straightforward
- Need to develop skills and systems to deal with new information
- Expectations need to be clearly set



based on the Constituent Voice Methodology™

Conclusions

1

PROMs help patients to report components of their subjective wellbeing

2

PROMs may aid patients, family and care providers

- Address unvoiced concerns
- Monitor
- Choose treatments

3

PROMs may aid health systems

- Identify areas of need

4

Successful use of PROMs requires thought on implementation and ongoing evaluation