

Symptom Assessment in People Receiving Dialysis

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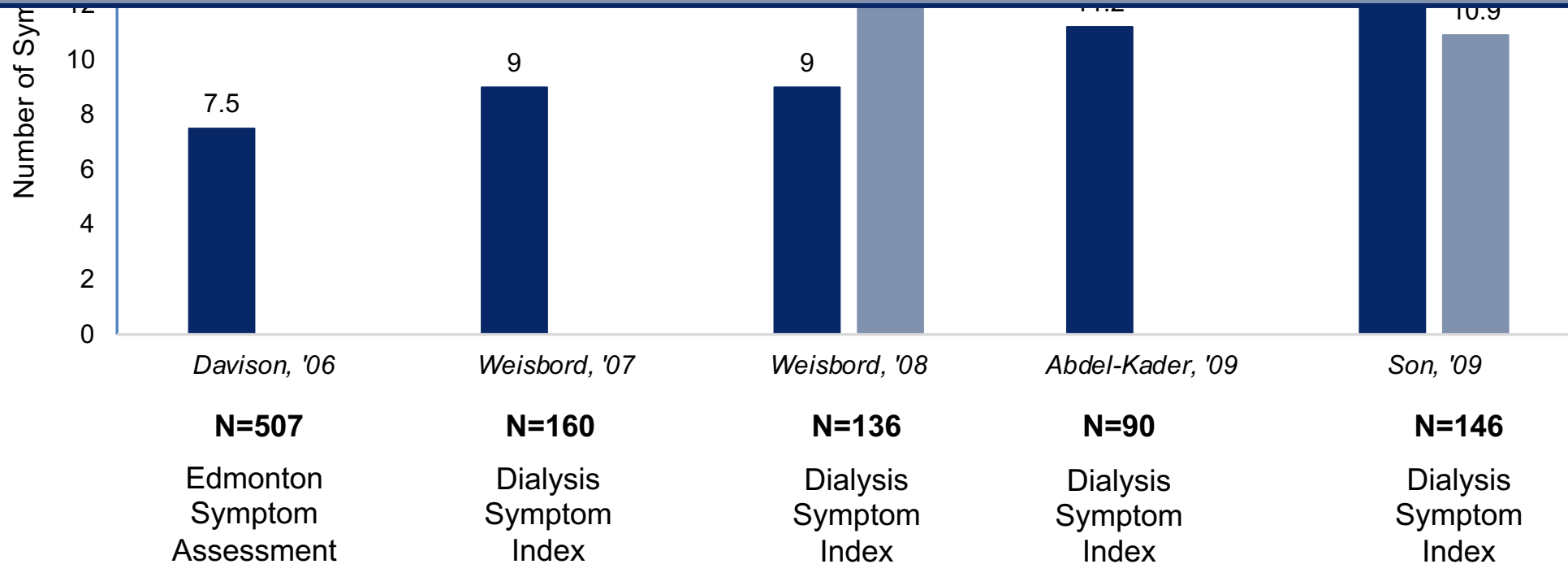
Overview

- Importance of symptoms
- Patient-reported outcome measures (PROMs)
- Symptom PROMs in dialysis
- KDIGO Controversies Conference consensus on symptom assessment in dialysis

Importance of symptoms

People on hemodialysis have many symptoms

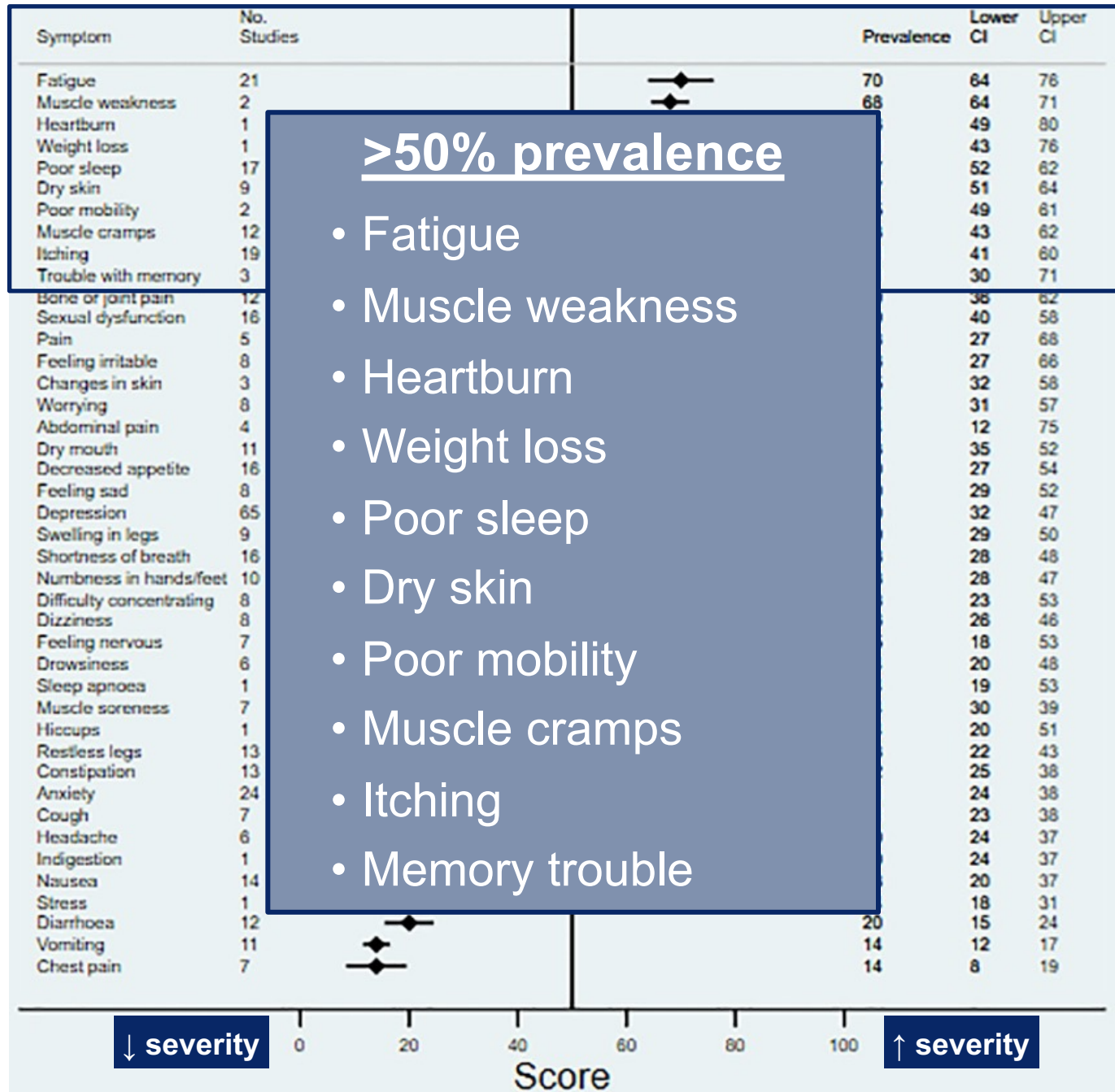
>90% of people receiving hemodialysis have at least one symptom



Symptom prevalence (dialysis)

Meta-analysis (2022)

- 274 studies
- >60 countries
- >50,000 patients
- 45 symptoms



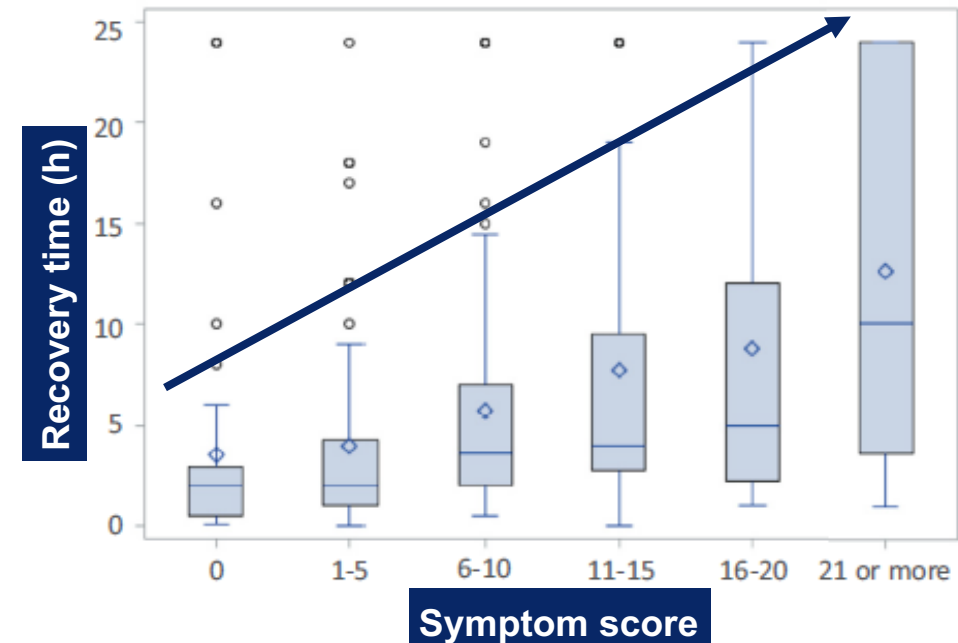
Many symptoms occur with hemodialysis

- Cramps, itching, headache, and post-dialysis fatigue are common

I can't stand up. Them cramps, they rough. I try not to come off the machine early... I fight it. This probably go against me on the transplant. I'm fighting it, but it ain't no fun to fight. [68y F]

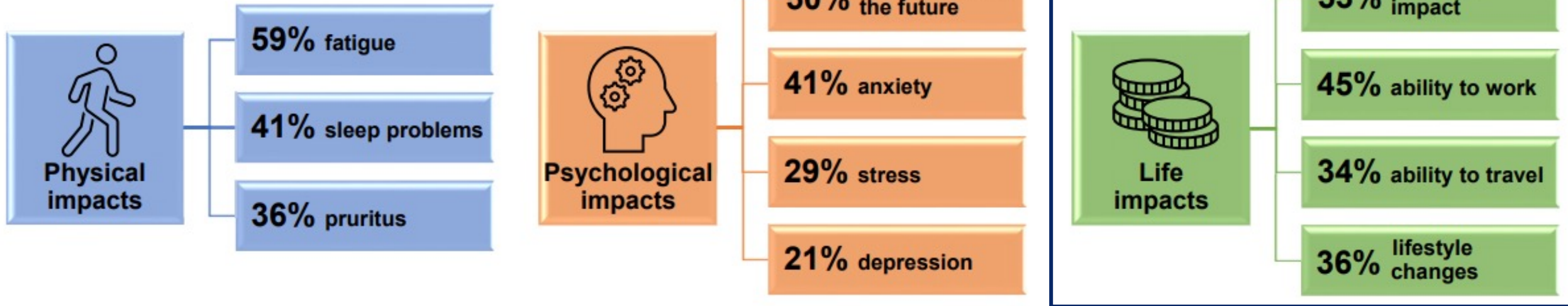
Normally, I'm fatigued, and it's like something's sitting up on your shoulders and you can't wait to get home to lay down. It's terrible. [58y M]

- Survey of 359 U.S. hemodialysis patients
 - 30% had ≥ 4 symptoms during dialysis
 - Longer post-HD recovery time correlated with \uparrow incidence and severity of intradialytic symptoms



Symptoms negatively affect health & well-being

Survey (N=4,800 patients)



- Interference with social relationships
- Loss of productivity and financial stability
 - Lower quality of life
- Higher risks of hospitalization and death

However, symptoms are often under-recognized & under-reported

- Survey of 75 patients and 18 clinicians
 - Clinicians had inadequate awareness of **27 of 30** patient-reported symptoms
 - Clinicians underestimated severity of 19 of 30 symptoms
- Interviews with 42 hemodialysis patients → patients often under-report symptoms
 - Futility of symptom reporting
 - Feeling of helplessness
 - Normalization of symptoms

They don't do anything about it, so I feel it's no use in telling if I get an upset stomach or I puked up. [52y M]

Sometimes I get a stomachache. It's just one of those things with dialysis... [67y F]

Patient-reported outcome measures

What is a patient-reported outcome?

- Patient-reported outcome (PRO)
 - Any report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by anyone else
- Example PRO measures (PROMs) used in dialysis
 - KDQOL
 - Includes a 12-item symptom domain (recall period: 4 weeks)
 - ICH-CAHPS

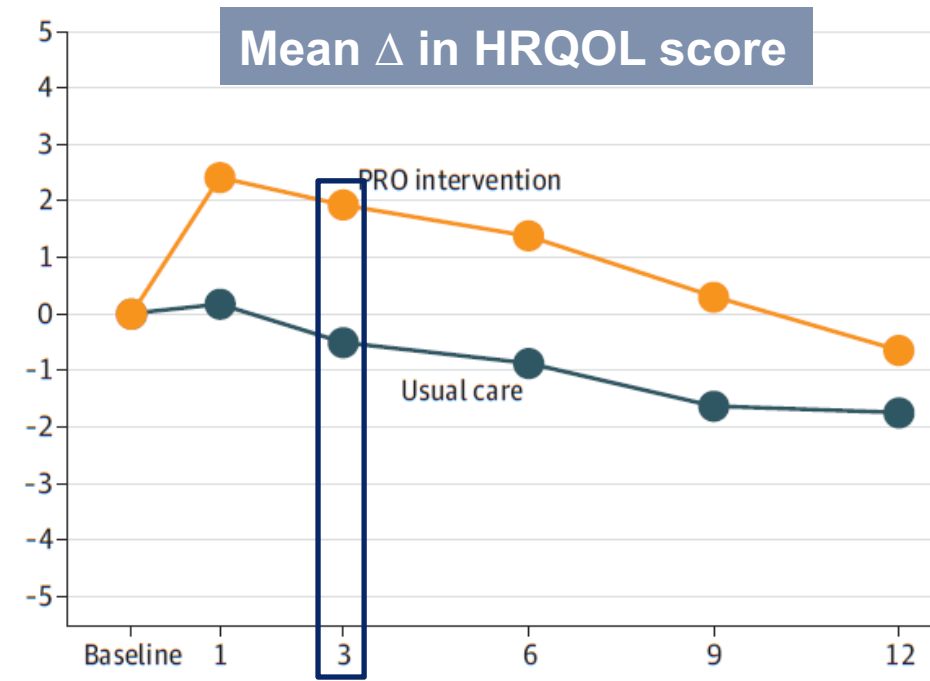
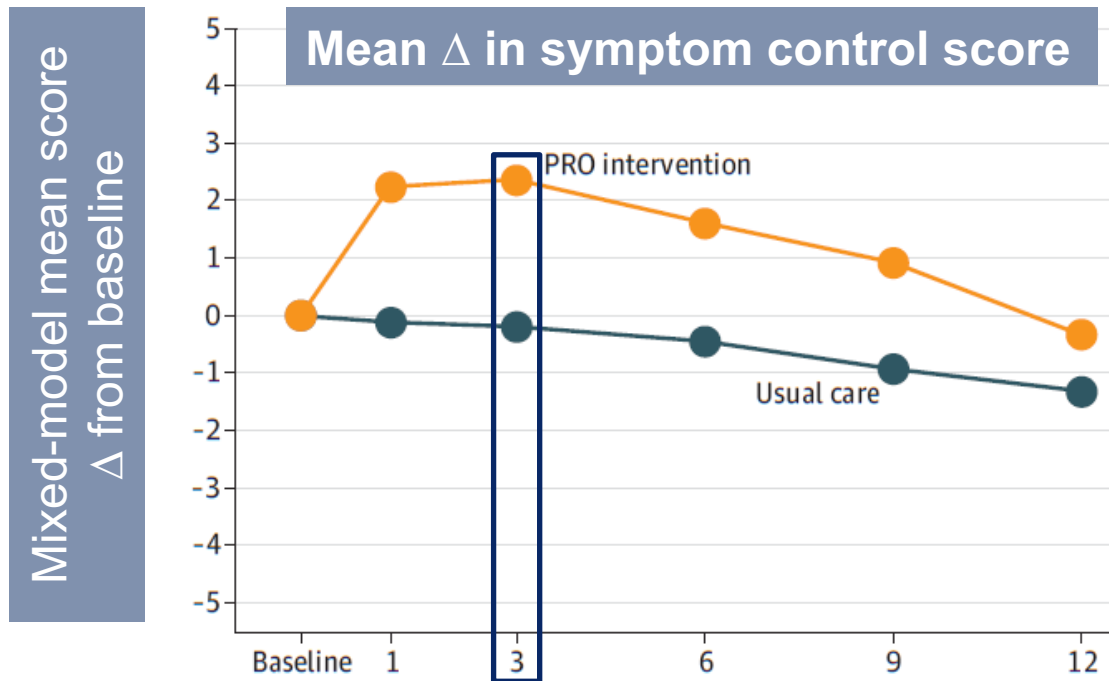
Routine use of PROMs may improve outcomes

JAMA | Original Investigation

Effect of Electronic Symptom Monitoring on Patient-Reported Outcomes
Among Patients With Metastatic Cancer
A Randomized Clinical Trial

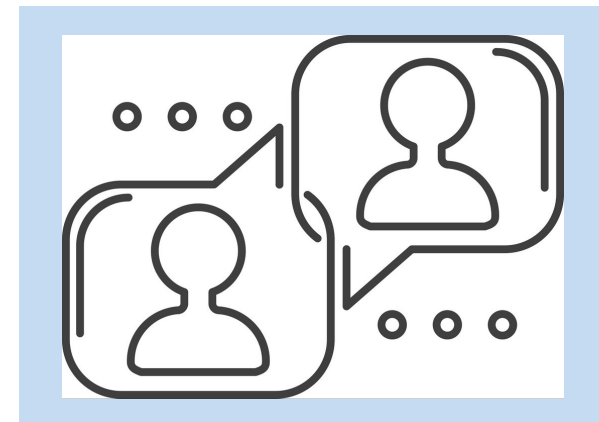


- 52 U.S. oncology practices (2017-2020); adults with metastatic cancer
 - n=593: Weekly symptom PROMs; severe/worsening symptoms triggered care team alerts
 - n=598: Usual care

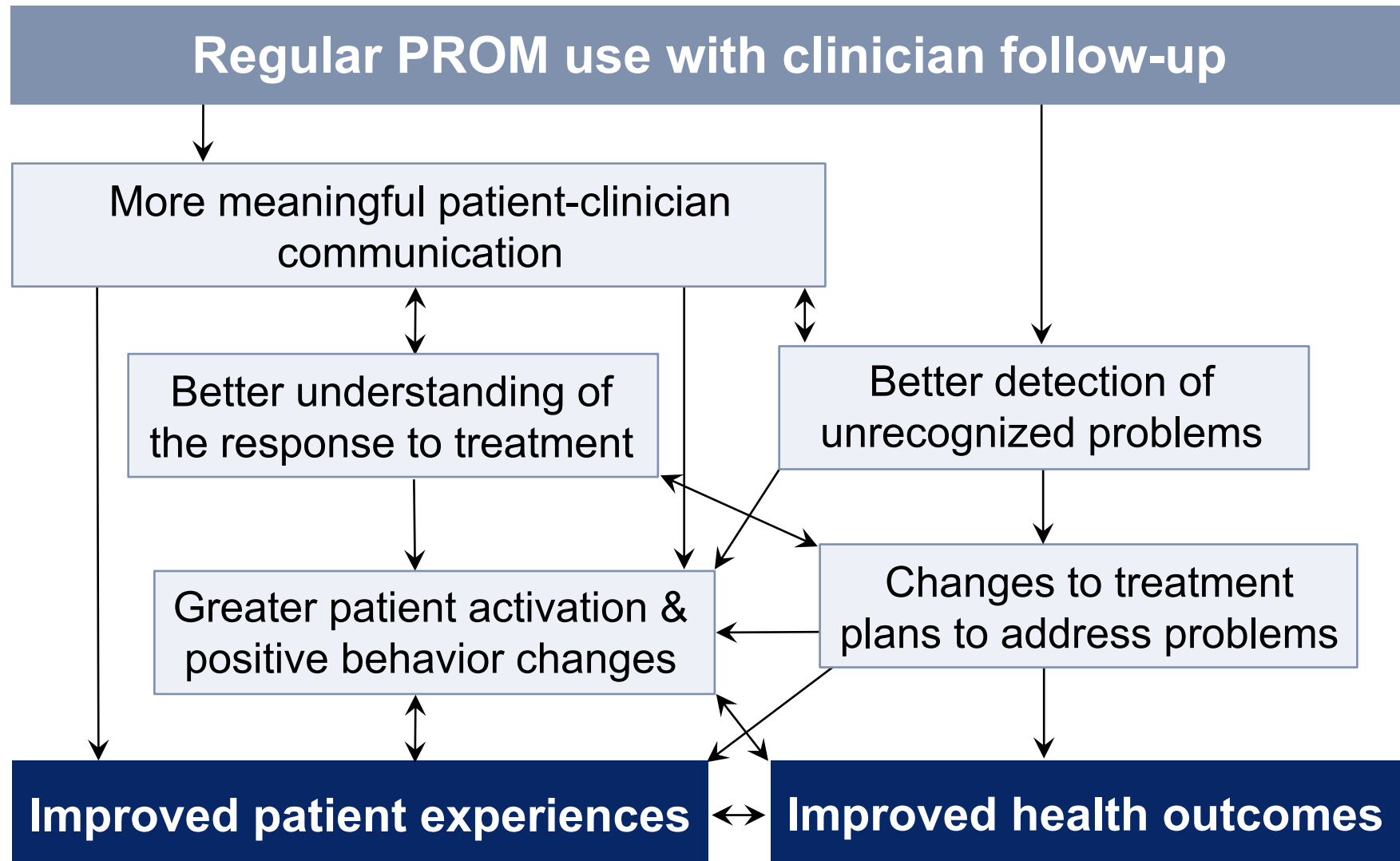


Routine use of PROMs may improve outcomes

- Systematic reviews of >50 trials testing regular PROM use with clinician follow-up →
 - Fewer hospitalizations
 - Improved symptoms and HRQOL
 - Improved patient activation and patient-clinician communication
- However, PROM use without follow-up can be detrimental
 - Patients perceive concerns as unimportant, forgotten
 - Time unvalued
 - Left with unresolved problems



How PROMs with follow-up may improve outcomes



Symptom PROMs in dialysis

Symptom PROMs used in dialysis

Instrument	Description (item #)
<i>Generic</i>	
Memorial Symptom Assessment Scale	Physical and emotional symptoms (32)
PROMIS-57	Physical function, anxiety, depression, fatigue, pain, sleep, and social functioning (57)
Symptom Distress Scale	Physical symptoms, appearance, outlook (13)
<i>Disease-specific</i>	
Dialysis Symptom Index (DSI)	Physical and emotional symptoms- bother (30)
Edmonton Symptom Assessment Rev.-Renal (ESA-r)	Physical and emotional symptoms- severity (10)
Integrated Palliative Care Outcome Scale-Renal (IPOS-Renal)	Physical and emotional symptoms- life effect (20)
Kidney Disease Quality of Life (KDQOL)	HRQOL; includes a symptom domain- bother (134)
Symptom Monitoring on Renal Replacement Therapy-Hemodialysis (SMaRRT-HD)	Physical symptoms during hemodialysis- severity (14)

Dialysis Symptom Index (DSI)

- **30** physical and emotional symptoms
- Degree of **bother** assessed over the past week.
- Primary use = research

Dialysis Symptom Index						
Instructions						
Below is a list of physical and emotional symptoms that people on dialysis may have. For each symptom, please indicate if you had the symptom <u>during the past week</u> by circling "yes" or "no." <u>If "yes,"</u> please indicate how much that symptom bothered you by circling the appropriate number.						
	<i>During the past week: Did you experience this symptom?</i>	<i>If "yes": How much did it <u>bother</u> you?</i>				
		Not At All	A Little Bit	Some- what	Quite a Bit	Very Much
1. Constipation	NO					
	YES →	0	1	2	3	4
2. Nausea	NO					
	YES →	0	1	2	3	4
3. Vomiting	NO					
	YES →	0	1	2	3	4
4. Diarrhea	NO					
	YES →	0	1	2	3	4
5. Decreased appetite	NO					
	YES →	0	1	2	3	4
6. Muscle cramps	NO					
	YES →	0	1	2	3	4
7. Swelling in legs	NO					
	YES →	0	1	2	3	4
8. Shortness of breath	NO					

Edmonton Symptom Assessment, revised: Renal (ESAS-r, Renal)

- **10** physical and emotional symptoms
- **Severity** at present time

Edmonton Symptom Assessment System: Numerical Scale		
Please circle the number that best describes:		
No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best feeling of wellbeing	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of wellbeing
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
Other problem	0 1 2 3 4 5 6 7 8 9 10	

Integrated Palliative Outcome Scale- Renal (IPOS-Renal)

- **20** physical and emotional symptoms
- **Life effect** assessed over the past week.

POS-S RENAL – PATIENT COMPLETION					
Below is a list of symptoms, which you may or may not have experienced. Please put a tick in the box to show how you feel each of these symptoms has affected you and how you been feeling over the past week.					
	Not at all No effect	Slightly but not bothered to be rid of it	Moderately limits some activity or concentration	Severely activities or concentration markedly affected	Overwhelmingly unable to think of anything else
Pain	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Shortness of breath	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Weakness or lack of energy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Nausea (feeling like you are going to be sick)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Vomiting (being sick)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Poor appetite	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Constipation	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Mouth problems	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Drowsiness	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Poor mobility	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Itching	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Difficulty sleeping	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Restless legs or difficulty keeping legs still	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Feeling anxious	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Feeling depressed	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Changes in skin	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Diarrhoea	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Any other symptoms:					
	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Kidney Disease Quality of Life (KDQOL)

- Health-related quality of life questionnaire
- Symptom domain: **12** physical symptoms
- Degree of **bother** assessed over the past 4 weeks



14. During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
a Soreness in your muscles?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Chest pain?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Cramps?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Itchy skin?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e Dry skin?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f Shortness of breath?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g Faintness or dizziness?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h Lack of appetite? ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i Washed out or drained?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
j Numbness in hands or feet?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
k Nausea or upset stomach?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
l (Hemodialysis patient only) Problems with your access site? ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Symptom Monitoring on Renal Replacement Therapy- Hemodialysis (SMaRRT-HD)

- **13** physical symptoms
- **Severity** during last hemodialysis treatment
- Time to recovery question (hours)
- Clinician follow-up supports:
 - Email alerts, symptom guidances, longitudinal symptom reports

Question 1 of 14

DURING your **LAST** dialysis treatment here, did you have

Cramping?

No Cramping Mild Cramping Moderate Cramping Severe Cramping Very Severe Cramping



SMaRRT-HD™

Symptom Monitoring in Renal Replacement Therapy-Hemodialysis

Does routine symptom PROM use improve outcomes in dialysis?

BMC Health
Services Research

Canada

NCT03535922

A cluster randomized controlled trial for the Evaluation of routinely Measured PATient reported outcomes in HemodialYsis care (EMPATHY): a study protocol



Aus-NZ

ACTRN12620001061921

The Symptom Monitoring with Feedback Trial (SWIFT): protocol for a registry-based cluster randomised controlled trial in haemodialysis

Lavern Greenham¹, Paul N. Bennett^{2,3}, Kathryn Dansie¹, Andrea K. Viecelli^{4,5}, Shilpanjali Jesudason^{6,7}, Rebecca Mister⁸, Brendan Smyth^{8,9}, Portia Westall⁸, Samuel Herzog⁸, Chris Brown⁸, William Handke¹⁰, Suetonia C. Palmer¹¹, Fergus J. Caskey¹², Cecile Couchoud¹³, John Simes⁸, Stephen P. McDonald^{1,6,7} and Rachael L. Morton^{8*}

Does use of patient-reported outcome measures (PROMs) improve patient-clinician communication?



17 HD centers
in Northern
Alberta



900 patients

Each HD center was
randomized to 1 of 4 arms

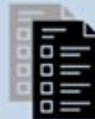
PROMs Assessment group
(N = 308)



Patients complete Edmonton Symptom Assessment System, revised: Renal (ESAS-r: Renal)



Patients complete EQ-5D-5L



Patients complete both EQ-5D-5L and ESAS-r: Renal



Control group (N = 109)
Usual care

Quantitative analysis with the Communication Assessment Tool (CAT) Score

Control group

0.21

12 mo improvement

PROMs Assessment group

0.25

12 mo improvement

Qualitative analysis from patient (10) and nurse (8) interviews, unit observations (6), and open-ended survey responses (779)



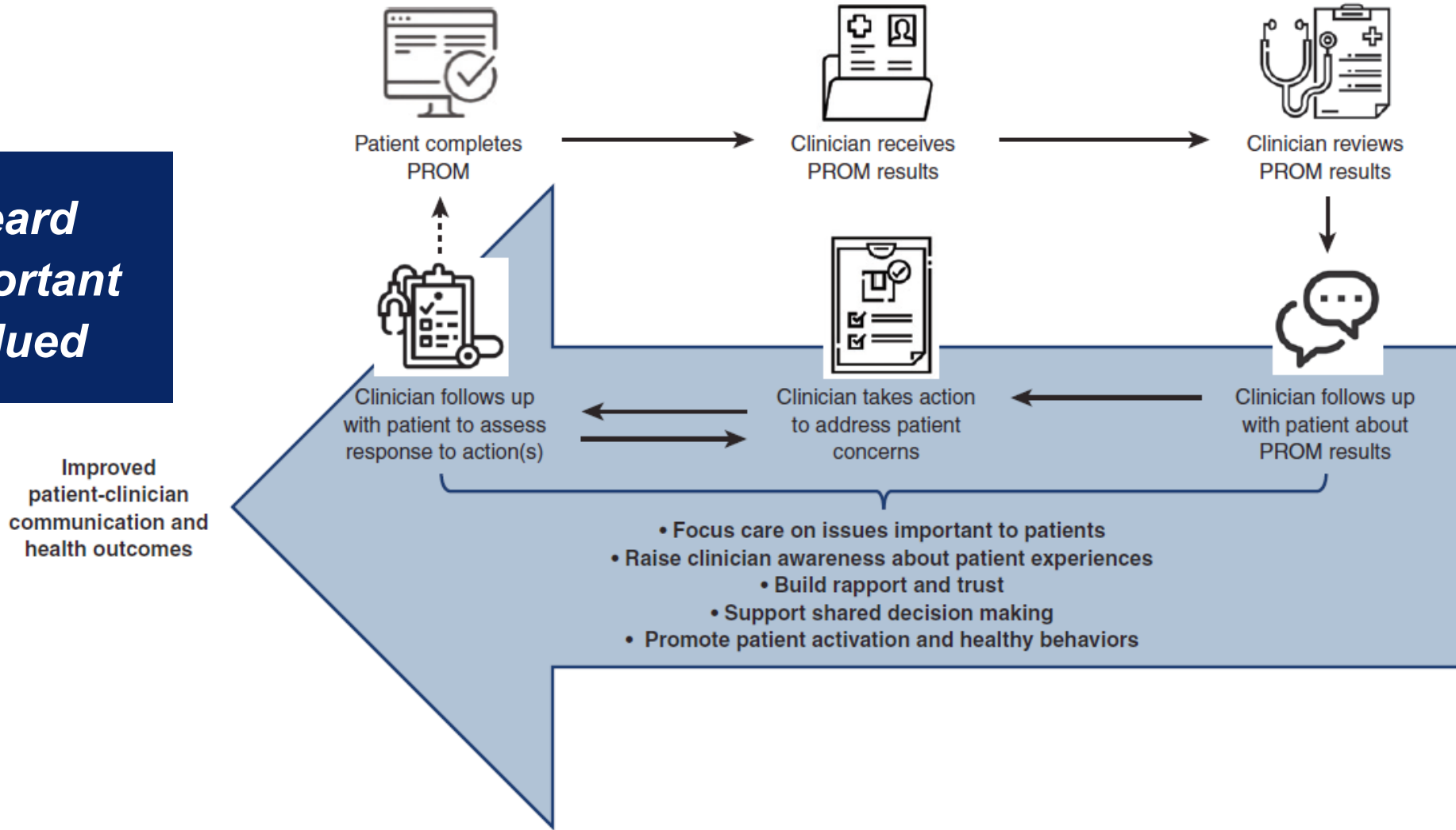
PROM use did not improve patient-clinician communication

Conclusions: Use of PROMs did not improve patient-clinician communication.

Kara Schick-Makaroff, Lisa A. Wozniak, Hilary Short, et al. ***How the Routine Use of Patient-Reported Outcome Measures for Hemodialysis Care Influences Patient-Clinician Communication: A Mixed-methods Study.*** CJASN doi: 10.2215/CJN.05940522. Visual Abstract by Joel Topf, MD, FACP

PROMs as communication tools

**Unheard
Unimportant
Unvalued**



KDIGO consensus on symptom assessment

Consensus points re: symptom assessment

1

Regular global symptom screening should be incorporated into routine practice. This should ideally involve both open-ended questions and use of PROMs.

- Resource availability and workforce burden are key considerations for implementation.

2

PROMs play an important role in identifying patient-prioritized symptoms but should not be used in isolation

- Most current PROMs are not specific for dialysis care.
- Existing PROMs have limitations (e.g., many do not assess life impact, some omit priority symptoms, some are burdensome to administer)

Consensus points re: symptom assessment

3

PROMs for guiding clinical care should be a) valid in people with kidney disease, b) short and simple, c) adaptable for language and vulnerable patients, and d) reliable and responsive to change.

- Optimal format for administering PROMs in dialysis is unclear.

4

Frequency of routine symptom screening should be individualized.

- Ideal frequency will optimize outcomes but limit burden on patients and clinicians.
- Every 1-3 months may be reasonable and feasible, but research needed to assess.

Consensus points re: symptom assessment

5

Symptom assessments should be incorporated into medical records to facilitate integration into overall clinical assessment and should be made available to all members of the patients care team (within and beyond dialysis).

- Optimal way to achieve this incorporation is unclear.
- Communication of symptom assessments should include the patient and require easy-to-understand visuals.
- Ideally, symptom scores/results would be reviewed routinely alongside lab results

Key unresolved questions re: symptom assessment

- What are patient attitudes about discussing symptoms, particularly anxiety-inducing symptoms (e.g., cognitive and sexual dysfunction, mood disorders)?
- How do we implement equitable symptom assessment in dialysis globally?
- Could standardized symptom assessment widen health inequities?
- How do we best adapt existing PROM implementation strategies to integrate PROMs and symptom assessment in dialysis across diverse, global healthcare systems?
- What is the optimal frequency of symptom assessment?



Symptom assessment foundational principles

- Regular symptom screening should be incorporated into practice.
- Although the primary purpose of screening is to identify and manage symptoms, *even when treatment options are limited*, acknowledging and discussing symptoms is important, because feeling heard and understood matters to people and can be of itself therapeutic.
- Symptom screening involves a dialogue between the patient and the clinician, with a focus on symptoms that are most important to the patient.



Summary

- Symptoms are of great importance to patients but are often under-recognized by clinicians.
- Among people with advanced cancer, routine use of symptom PROMs and clinician follow-up improves patient-reported and biomedical outcomes. Whether this finding extends to the dialysis setting is unknown.
- There are dialysis-specific PROMs, but their use has largely been restricted to research.
- Regular symptom assessment should likely be incorporated into routine dialysis care, but the frequency, format, and best approach to this requires further research.

Don't wait for research. Take action now.

- Ask your patients about their symptoms.
- The exact question or instrument likely does not matter. Dialogue about issues important to patients does matter.

Thank you. Questions?