Self management support for patients with CKD

Delphine S. Tuot, MDCM, MAS

November 15, 2017

2 PM – 3 PM EST

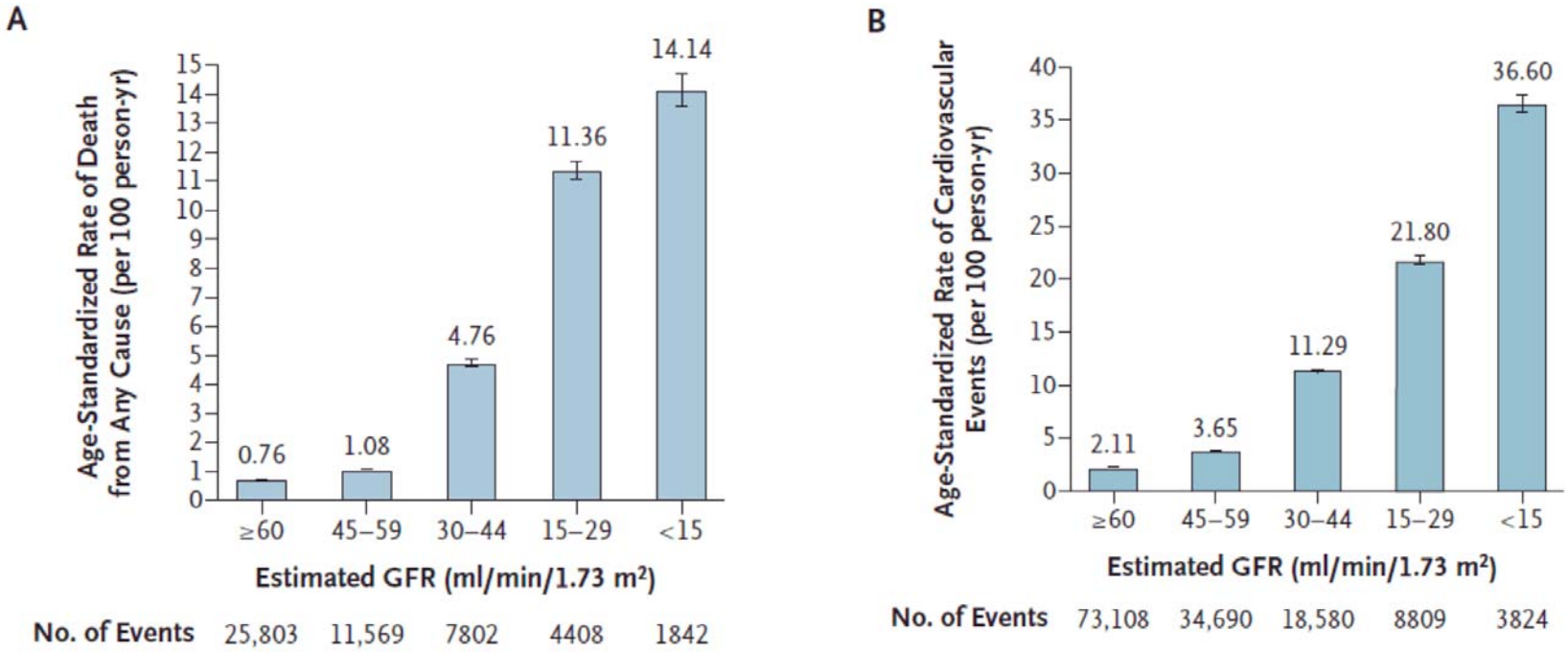
No disclosures

Objectives

- Appreciate low awareness of chronic kidney disease among patients with this condition.
- Identify potential health-system, provider and patient reasons for poor CKD awareness among patients.
- Learn about different self-management and educational programs that exist for patients with CKD.

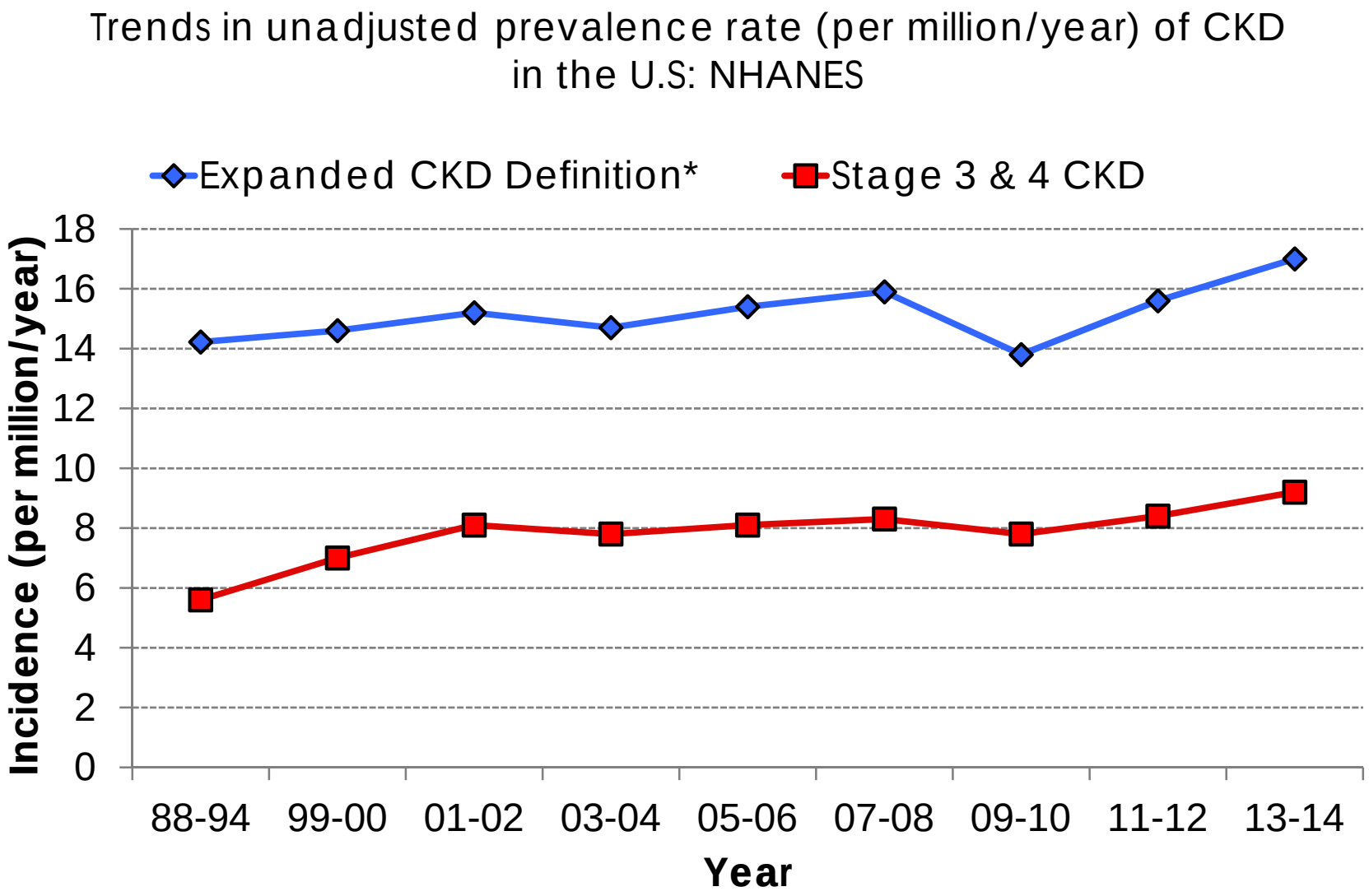
CKD is a public health concern

- affects ≥10% of the US population
- associated with greater risk of hospitalization, cardiovascular events and death



Go et al. NEJM. 2004

CKD is a public health concern



Murphy, Annals of IM, 2017.

Poor adoption of CKD therapies

- **Poor BP Control in CKD patients**
  - 48% with BP <140/90 mmHg, in NHANES, 2003-2006
- **Low AceI/ARB use in CKD patients**
  - 24% with ACEI/ARB in NHANES, 2003-2006
- **Poor glycemic control among patients with CKD**
  - 58% with diabetes had an A1c < 7.0%, NHANES 2005-2010
- **NSAID use is common**
  - 5% of individuals with CKD reports long-term use, NHANES 1999-2004

Tuot, AJN, 2012
Selvin, Annals Int Med. 2014
Plantinga, Hypertension, 2009
Plantinga, Annals Fam Med, 2011

How do we enhance adoption of CKD therapies to improve outcomes?

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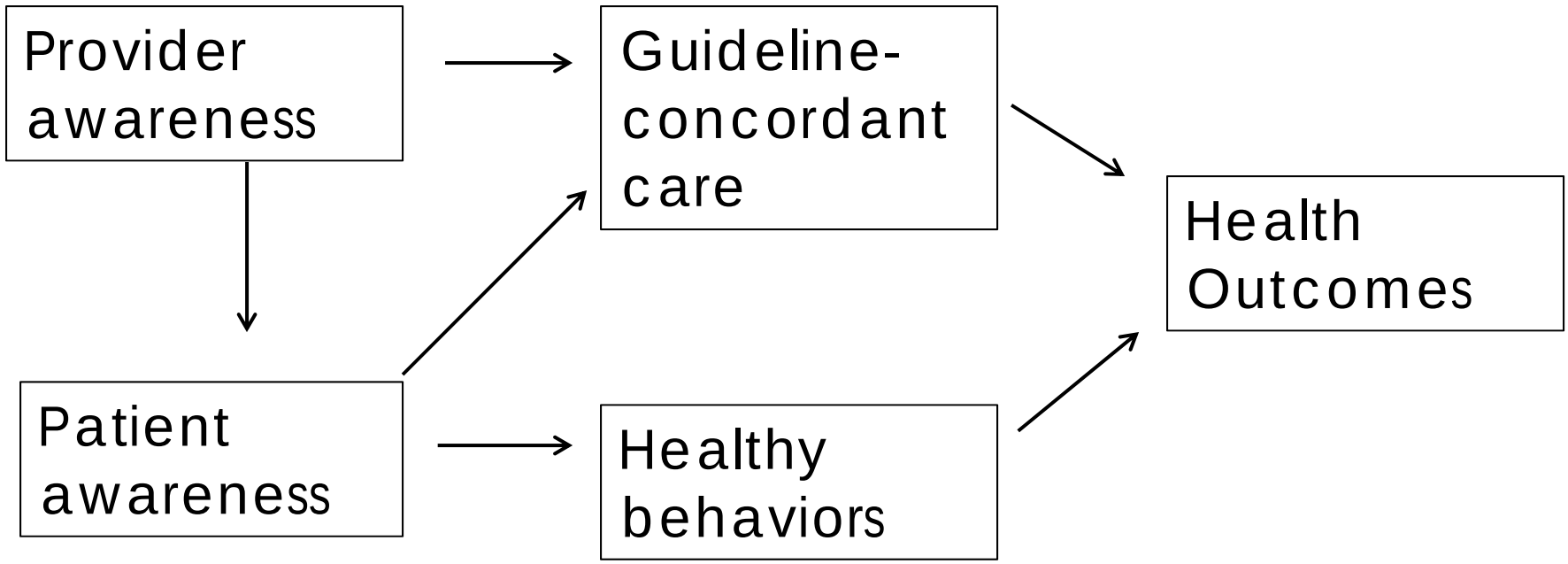
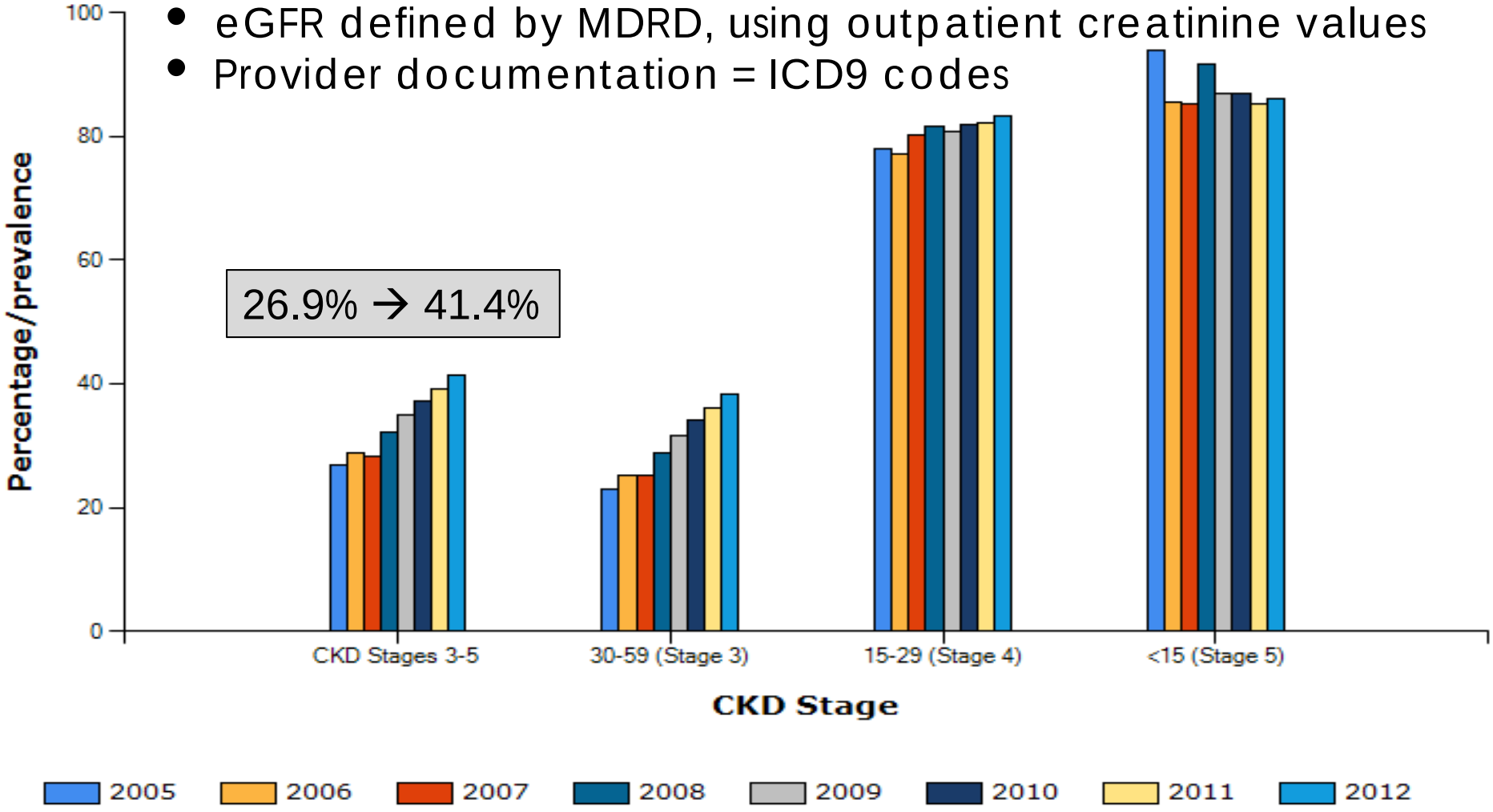


Outline

- Awareness of CKD status among providers
- Awareness of CKD status among patients
- Implications of CKD awareness
- Self-management support interventions for patients with CKD.

Provider awareness of CKD is suboptimal but increasing

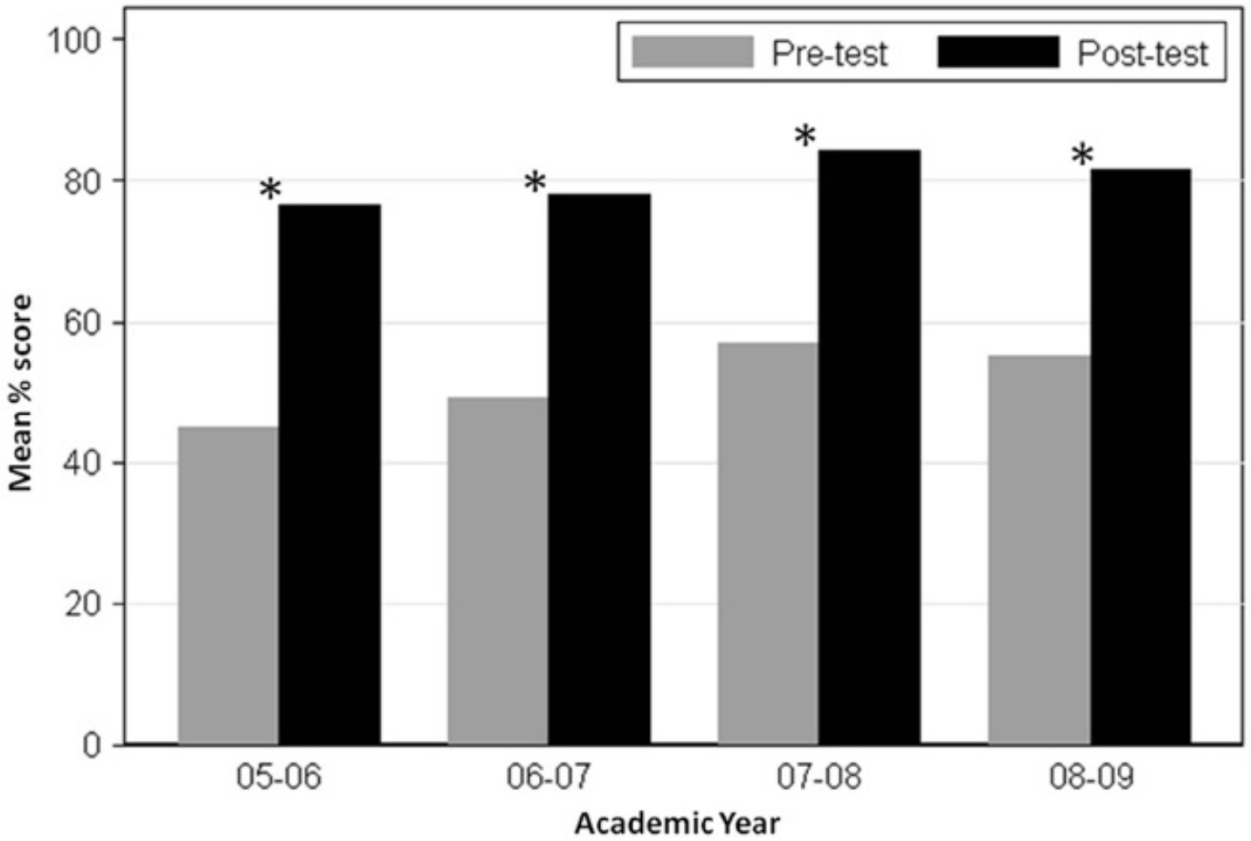
- 5% random sample from each VA region, 2005-2012
- eGFR defined by MDRD, using outpatient creatinine values
- Provider documentation = ICD9 codes



CKD Surveillance System- United States website: http://nccd.cdc.gov/CKD

CKD knowledge is improving among trainees

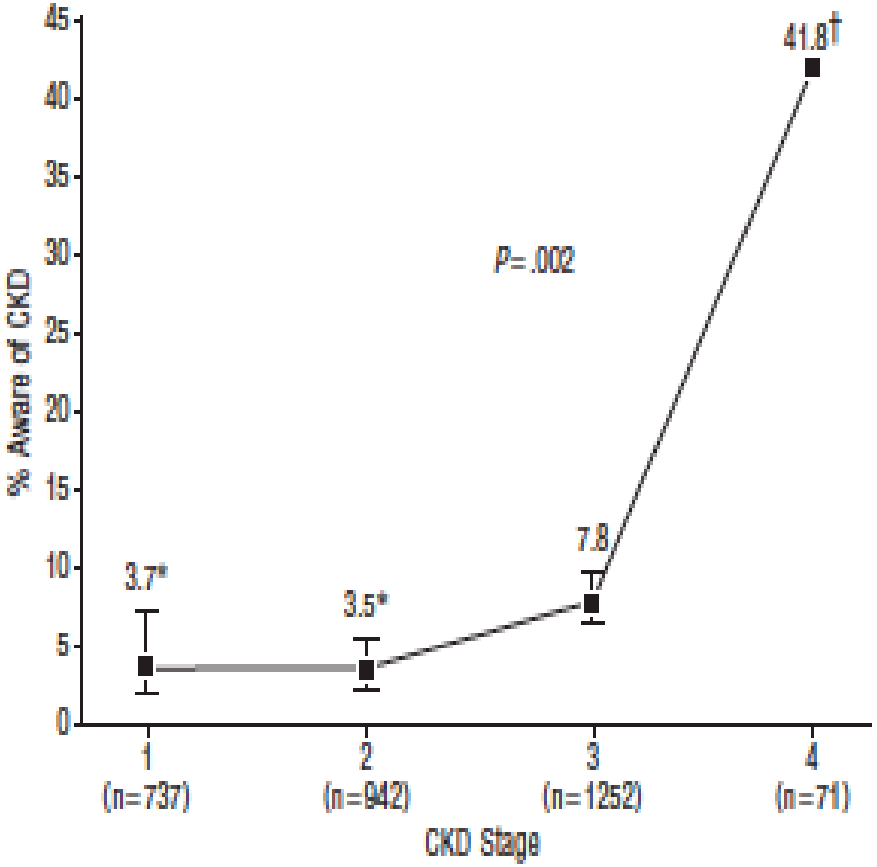
- CKD knowledge among internal medicine trainees (n=4702) who participated in an on-line CKD educational module
- Pre-participation knowledge increased over time (45%-55%)



Estrella. BMC Nephrology, 2012.

Patient Awareness of "weak or failing kidneys" CKD is low

- NHANES, 1999-2004
- Overall awareness: 6.2%



Factors associated with higher awareness

- Younger age
- African American
- Male gender
- Macroalbuminuria
- Diabetes
- Hypertension

Plantinga et al. Archives Med. 2008

but....patient awareness may be improving

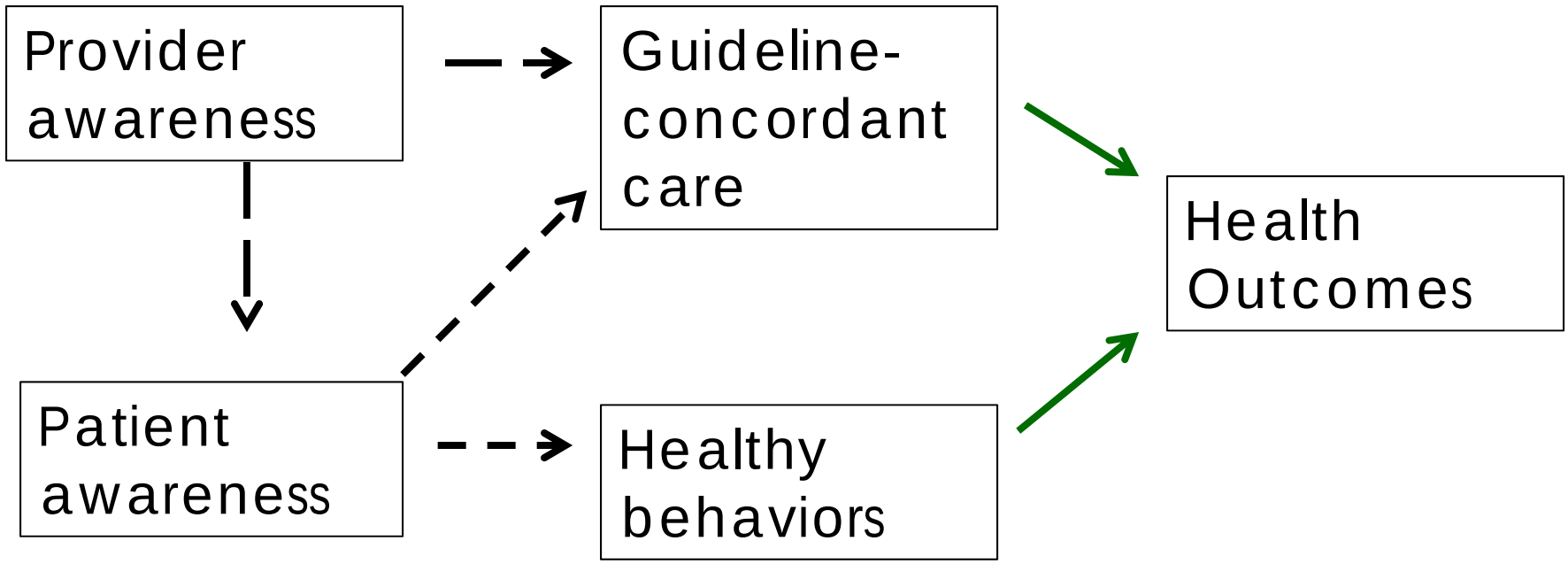
- NHANES, 2011-2012
- CKD awareness among patients: 8.6% (5.8-11.1)

	Self-reported kidney disease (BRFSS)		Imputed CKD prevalence (NHANES)		Estimated CKD awareness (BRFSS)	
Overall	**2.5% (2.4-2.6)**		**15.6% (15.1-16.2)**		**8.5% (7.7-9.5)**	
State	**Estimate (%)**	**SE**	**Estimate (%)**	**SE**	**Estimate (%)**	**SE**
Iowa	1.5	0.2	14.1	0.6	5.8	0.5
New Jersey	2	0.2	14.6	0.3	6.7	0.7
Minnesota	1.7	0.1	13.6	0.5	6.8	0.6
Georgia	2.8	0.2	14.1	0.4	11.1	1.2
New Mexico	3	0.2	14.2	0.5	11.2	1.2
Arizona	3.5	0.4	14.3	0.6	11.7	1

*BRFSS: Behavioral Risk Factor Surveillance System

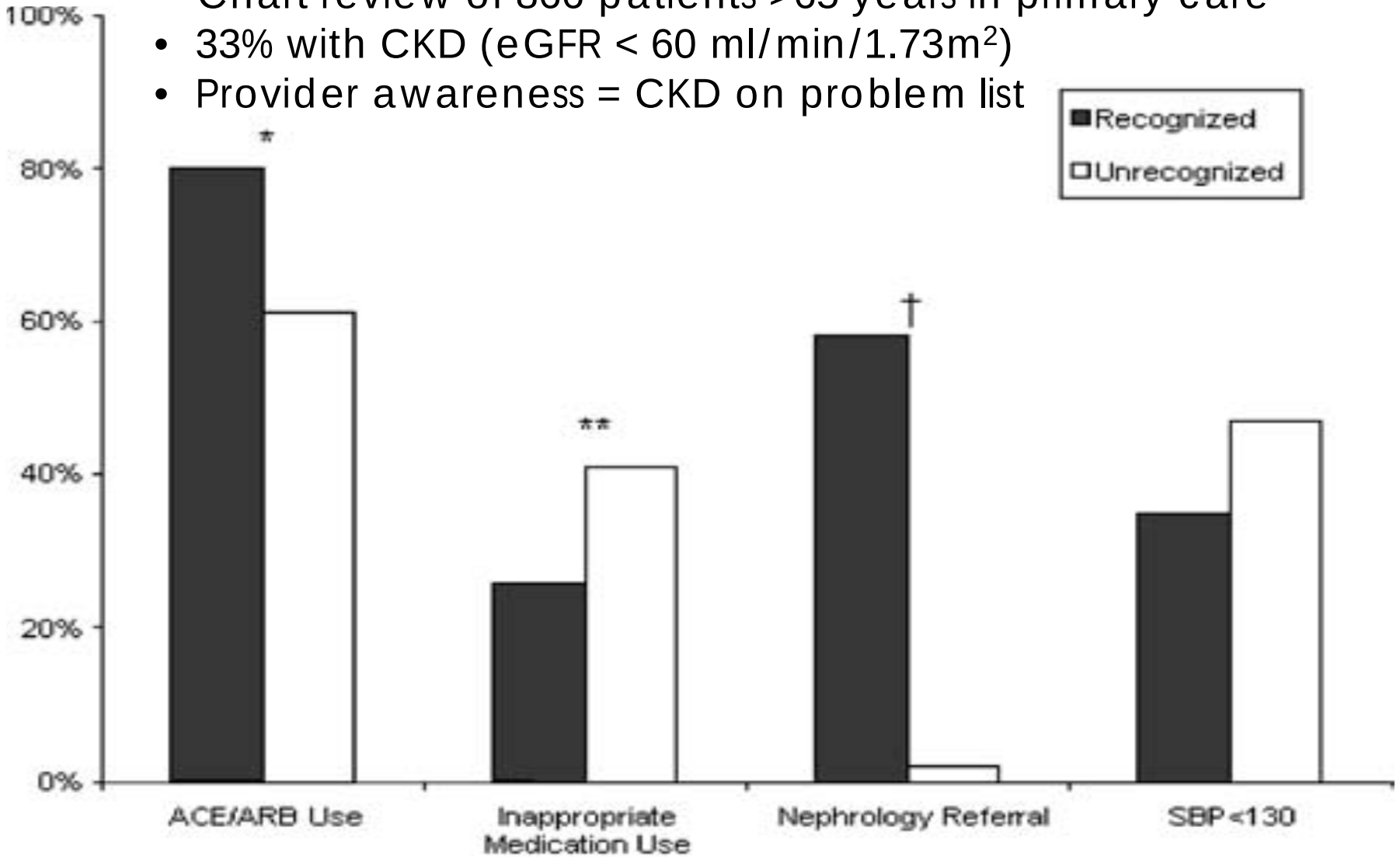
Dharmarajani, AJPM, 2017

What are the implications of CKD awareness among providers and patients?



Provider awareness is associated with delivery of guideline concordant CKD care

- Chart review of 866 patients >65 years in primary care
- 33% with CKD (eGFR < 60 ml/min/1.73m^2)
- Provider awareness = CKD on problem list



Rothberg, JGIM, 2008.

Provider awareness is associated with patient awareness

Awareness, Detection and Drug therapy in CKD (n=9307)

- Provider awareness (ICD10 code, problem list) = 12.1%
- Patient awareness (yes to “kidney disease”) = 12.1%

Patients with CKD = 5036		Provider awareness	
		Yes (n=607)	No (n=4425)
Patient awareness	Yes (n=609)	492 (81.1%)	117 (19.3%)
	No (n=4423)	115	4308
	Missing (n=4)	0	4

Szczech, Plos One, 2014.

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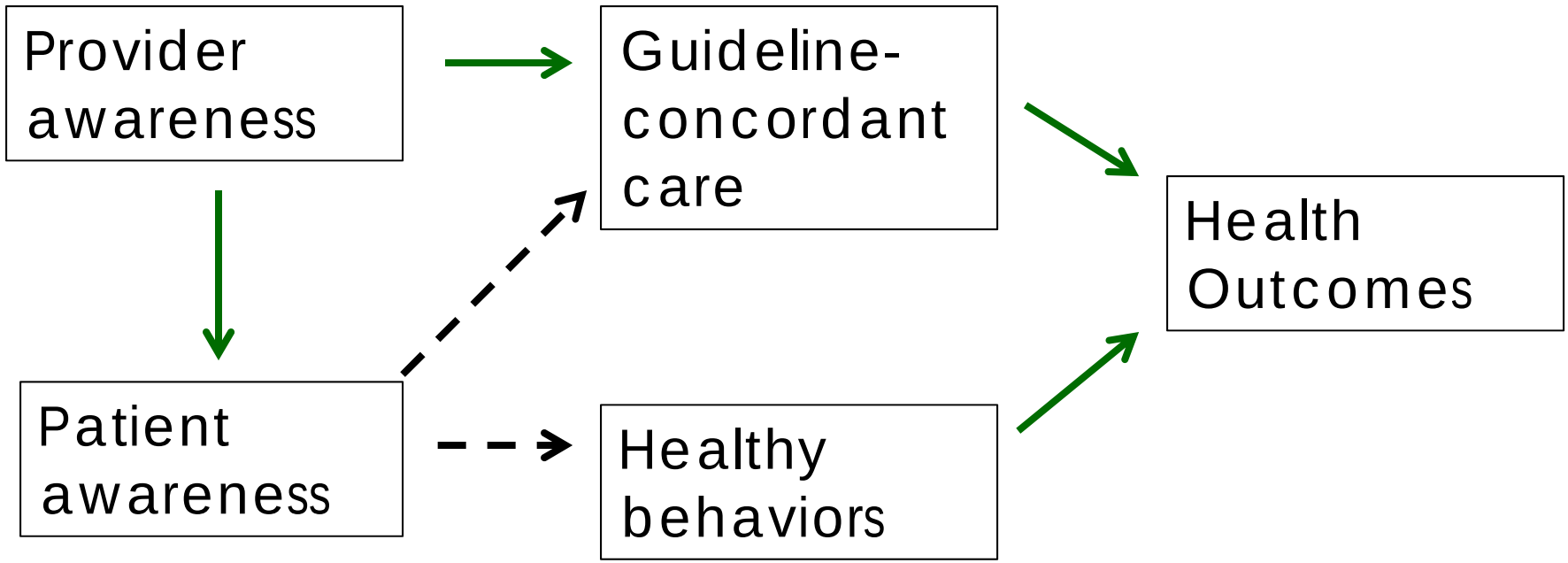
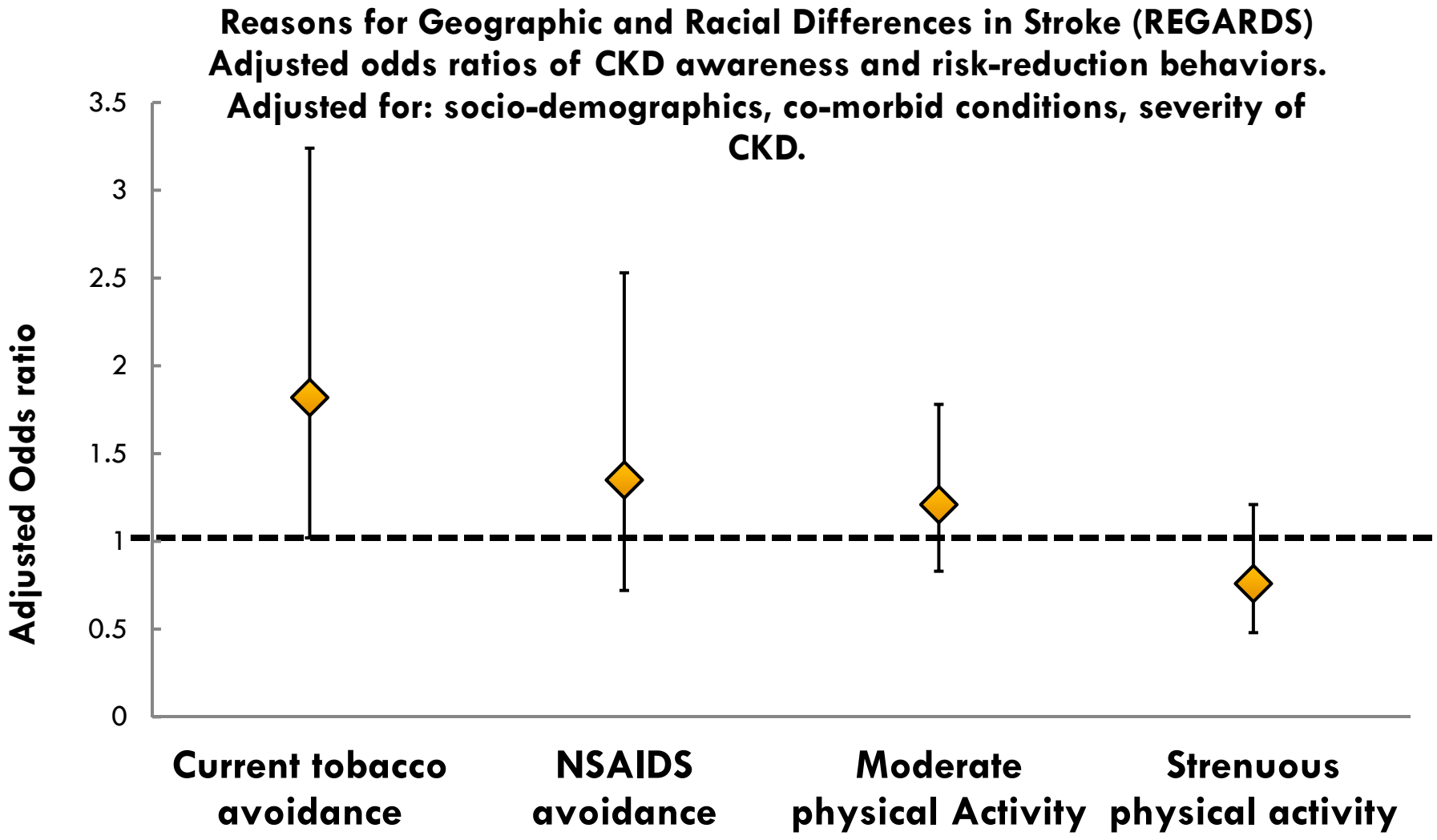
Primary care provider awareness of CKD is important

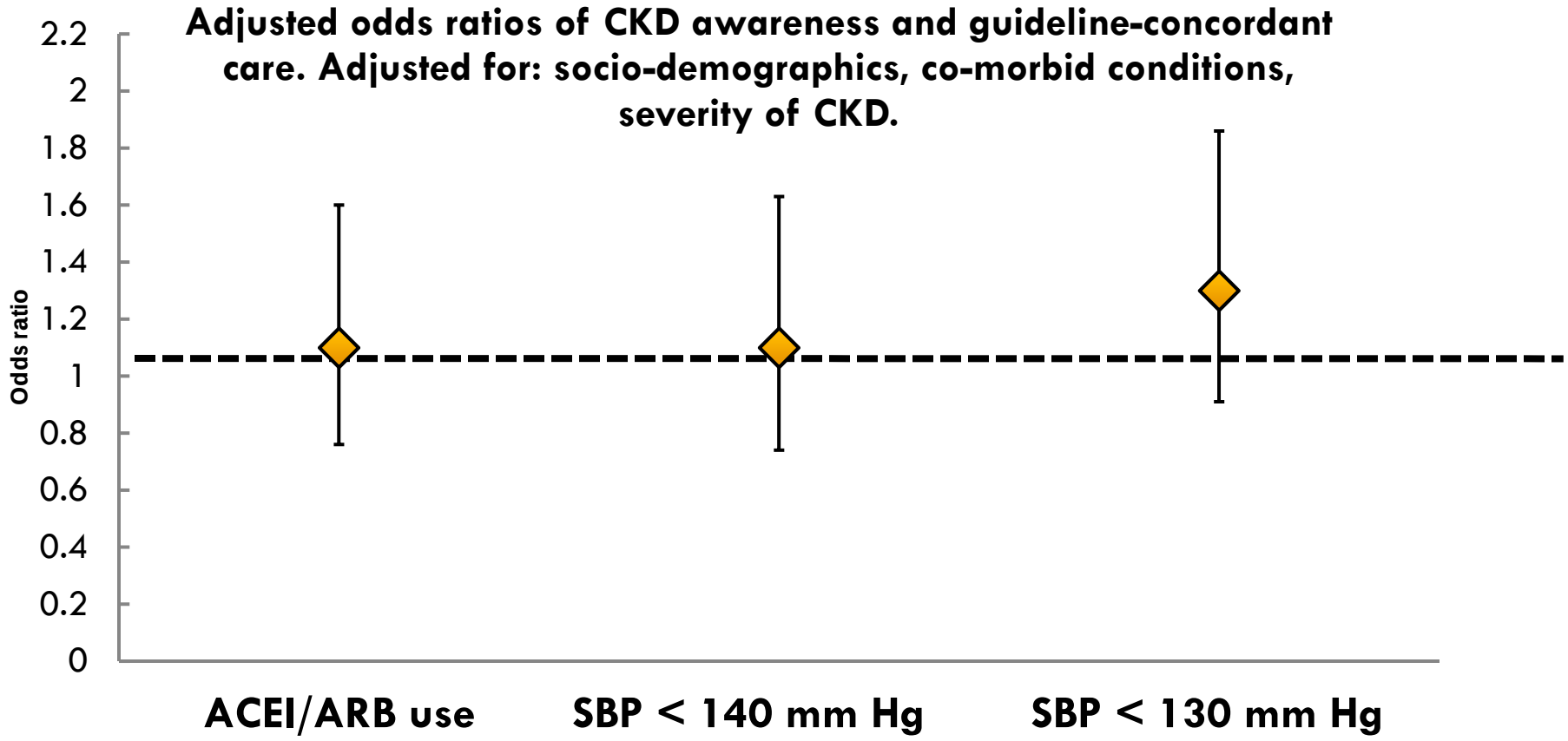


Patient awareness of “kidney disease” is not associated with healthy behaviors



Tuot, AJN, 2013.

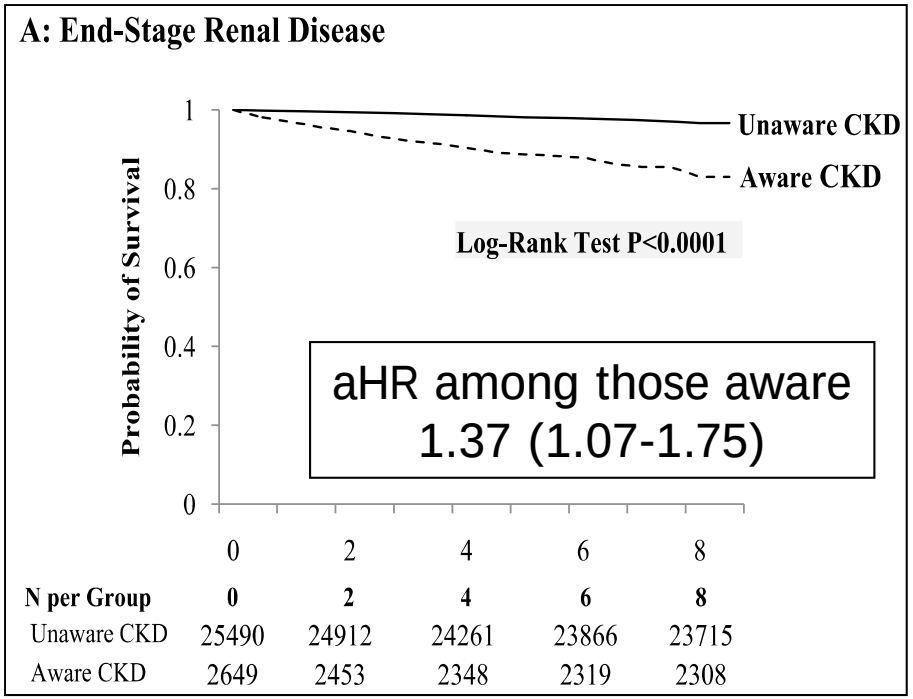
Patient awareness of “kidney disease” is not associated with receipt of guideline-concordant care

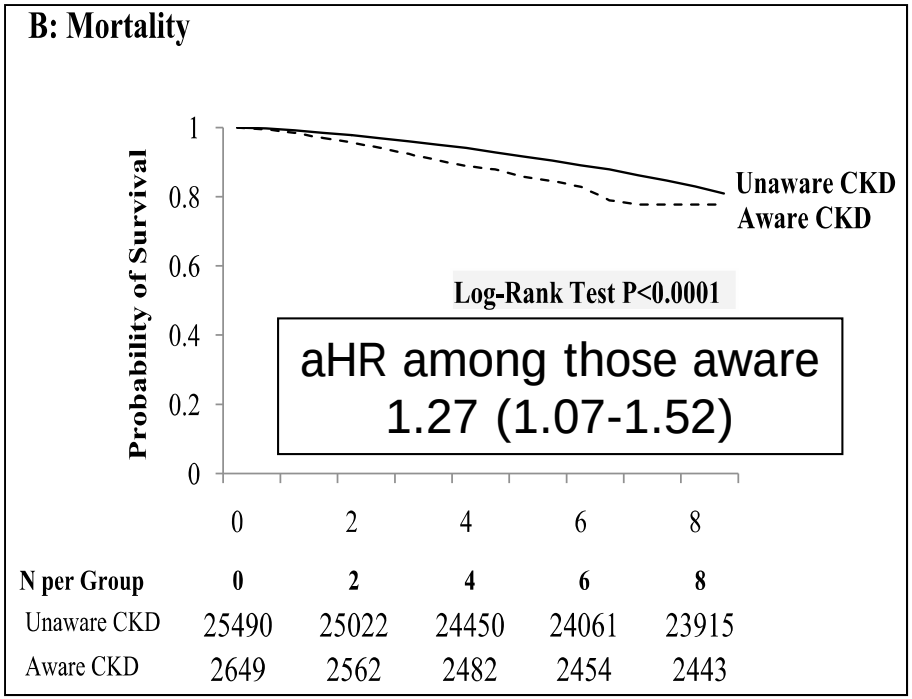


Tuot, AJN, 2013.

Patient awareness of "kidney disease" may be associated with worse health outcomes

Kidney Early Evaluation Program

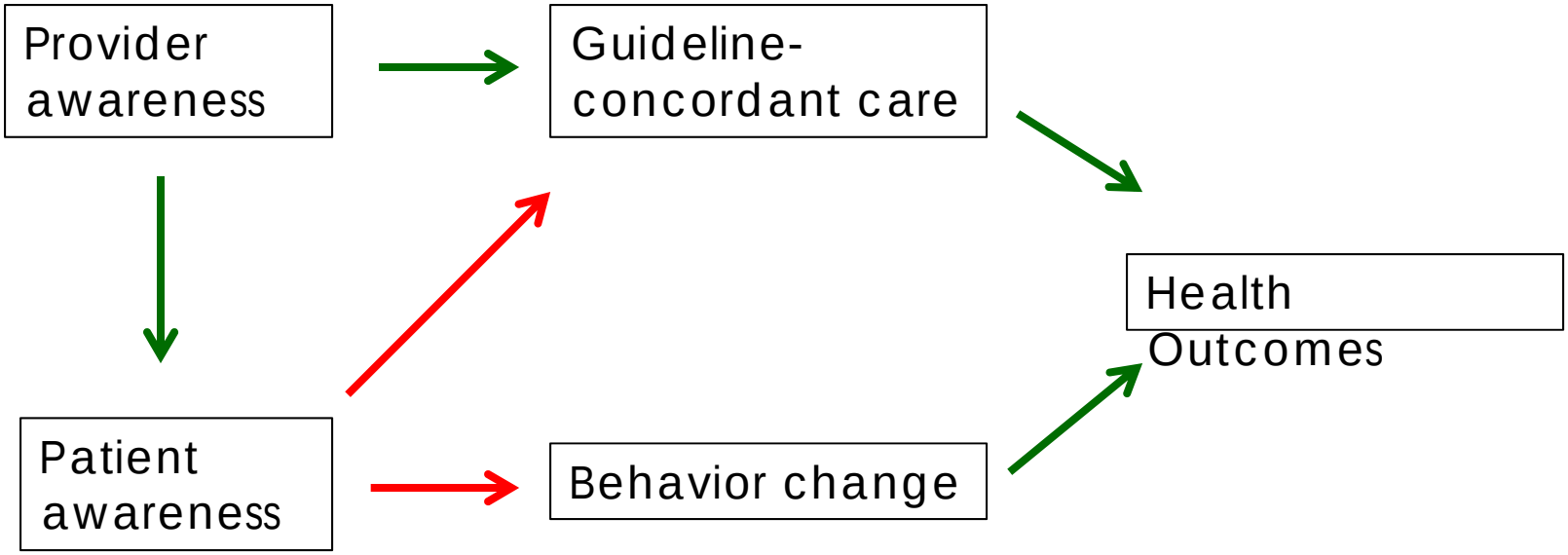




- 28,244 KEEP participants with CKD, 2000-2009
- CKD defined by eGFR or albuminuria
- CKD awareness = question asking about "kidney disease"
- Adjusted for socioeconomic variables, co-morbidities, access to care, CKD severity

Whaley-Connell, AJM, 2012

Why might we be seeing these negative associations among patients?



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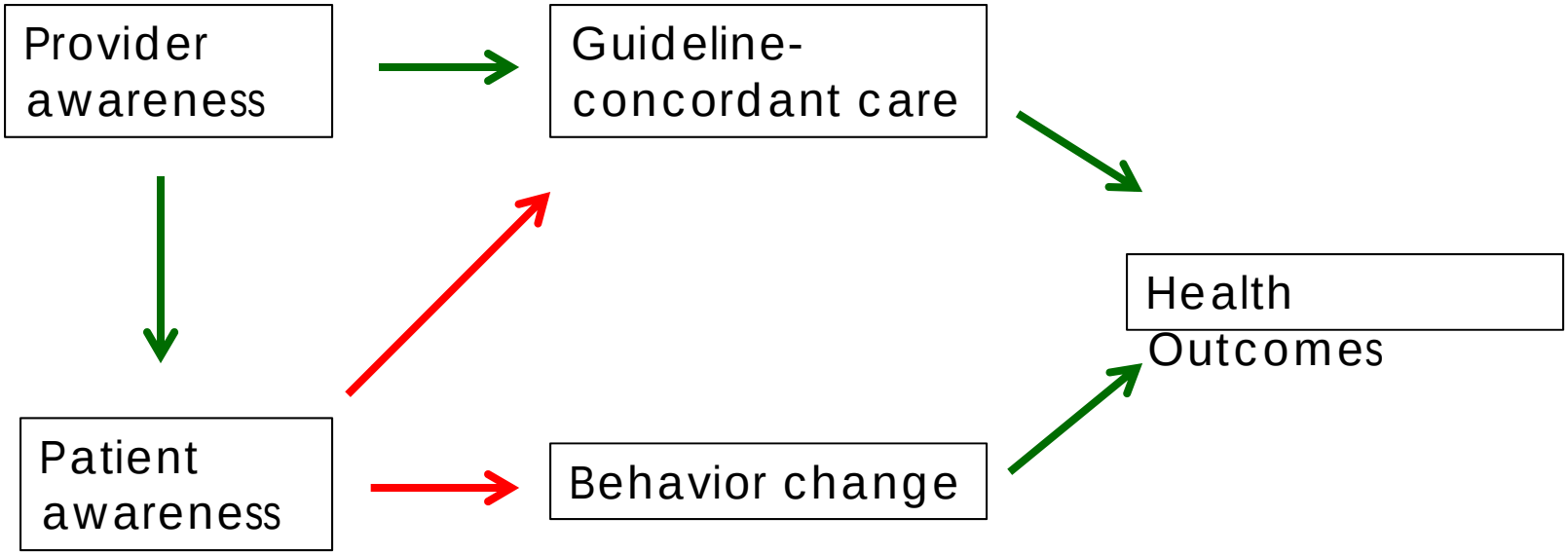


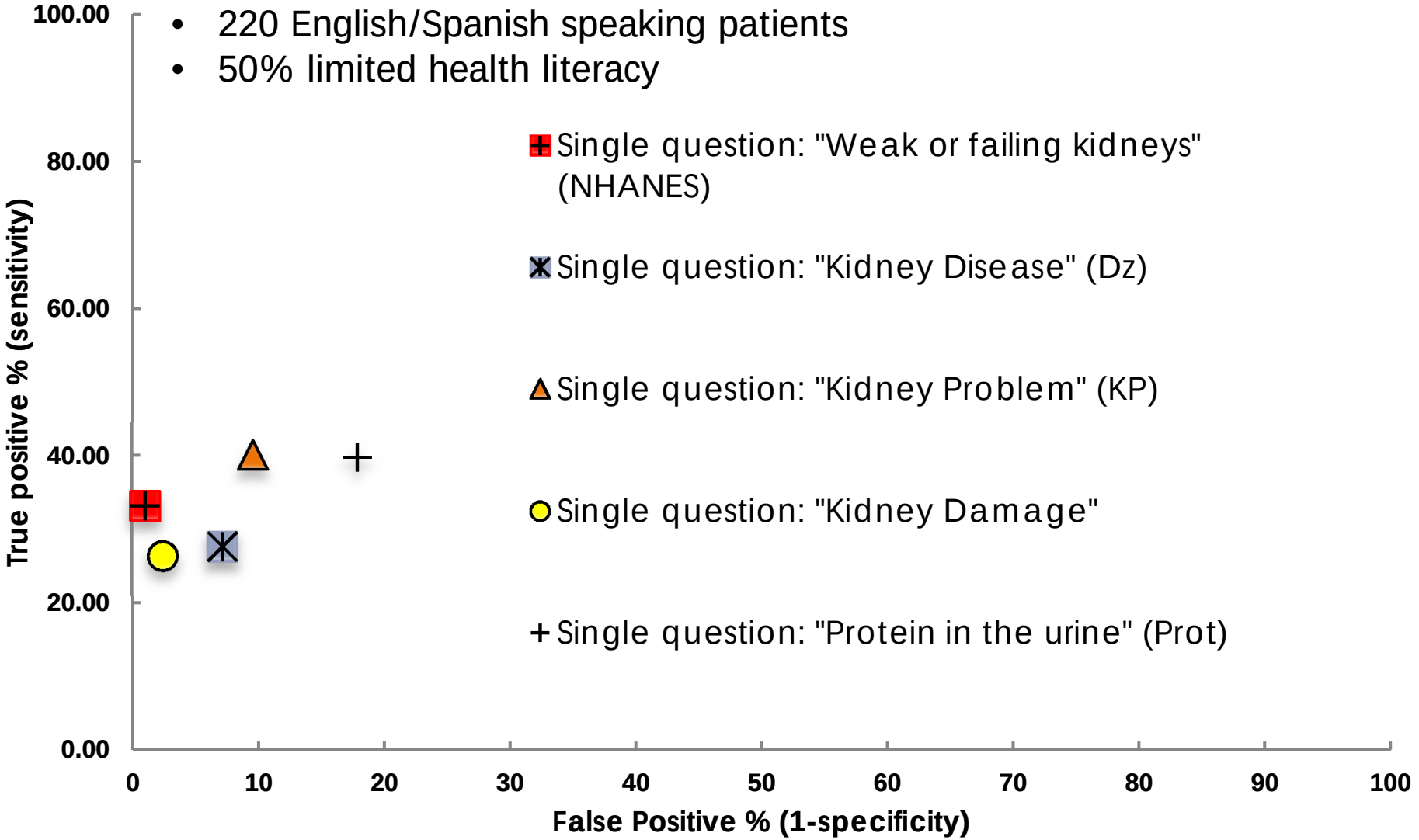
- CKD awareness is not important
- We are not measuring CKD awareness appropriately
- Studies have unmeasured confounders (i.e., health literacy, health numeracy, provider-patient communication)
- Awareness is not-sufficient; need self-management support

Perhaps we are measuring awareness of kidney disease incorrectly

When you talk to your patients about their CKD, which of the following phrases do you use?

1. “chronic kidney disease”
2. “Kidney disease”
3. “Weak or failing kidneys”
4. “Kidney problem”
5. “Kidney damage”

Prevalence of CKD awareness among patients depends on the question



Tuot, CJASN, 2016.

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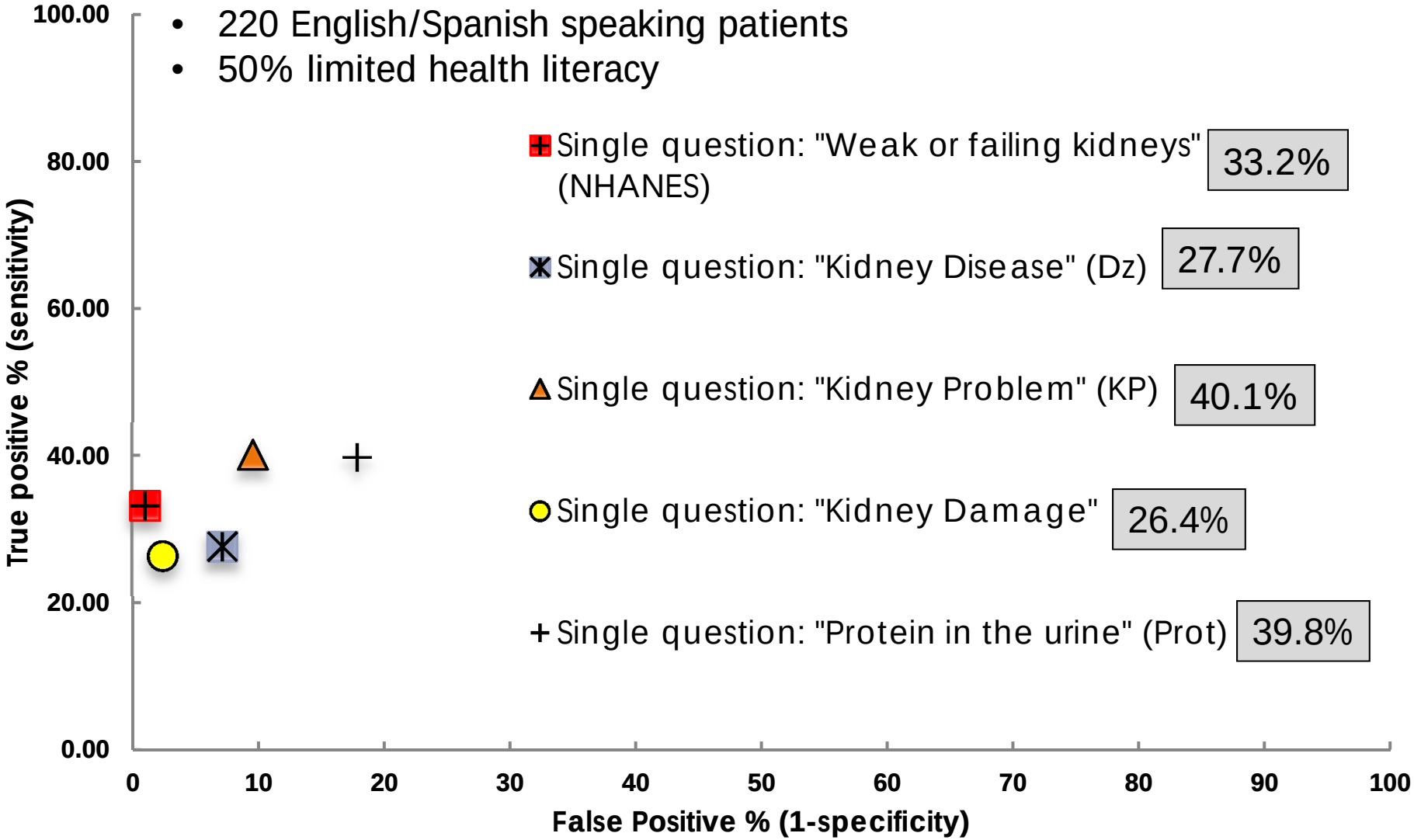

Tuot, CJASN, 2016.

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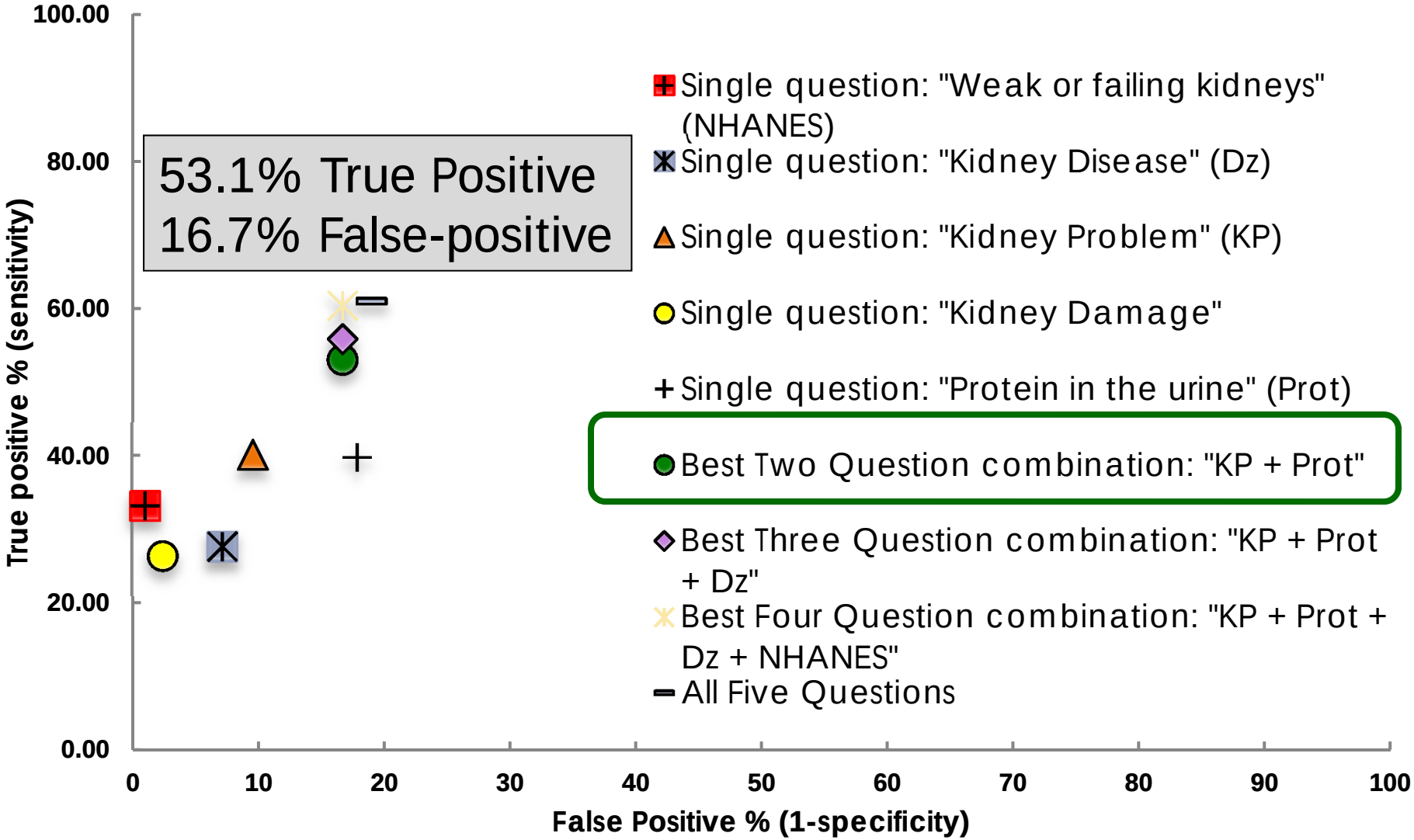


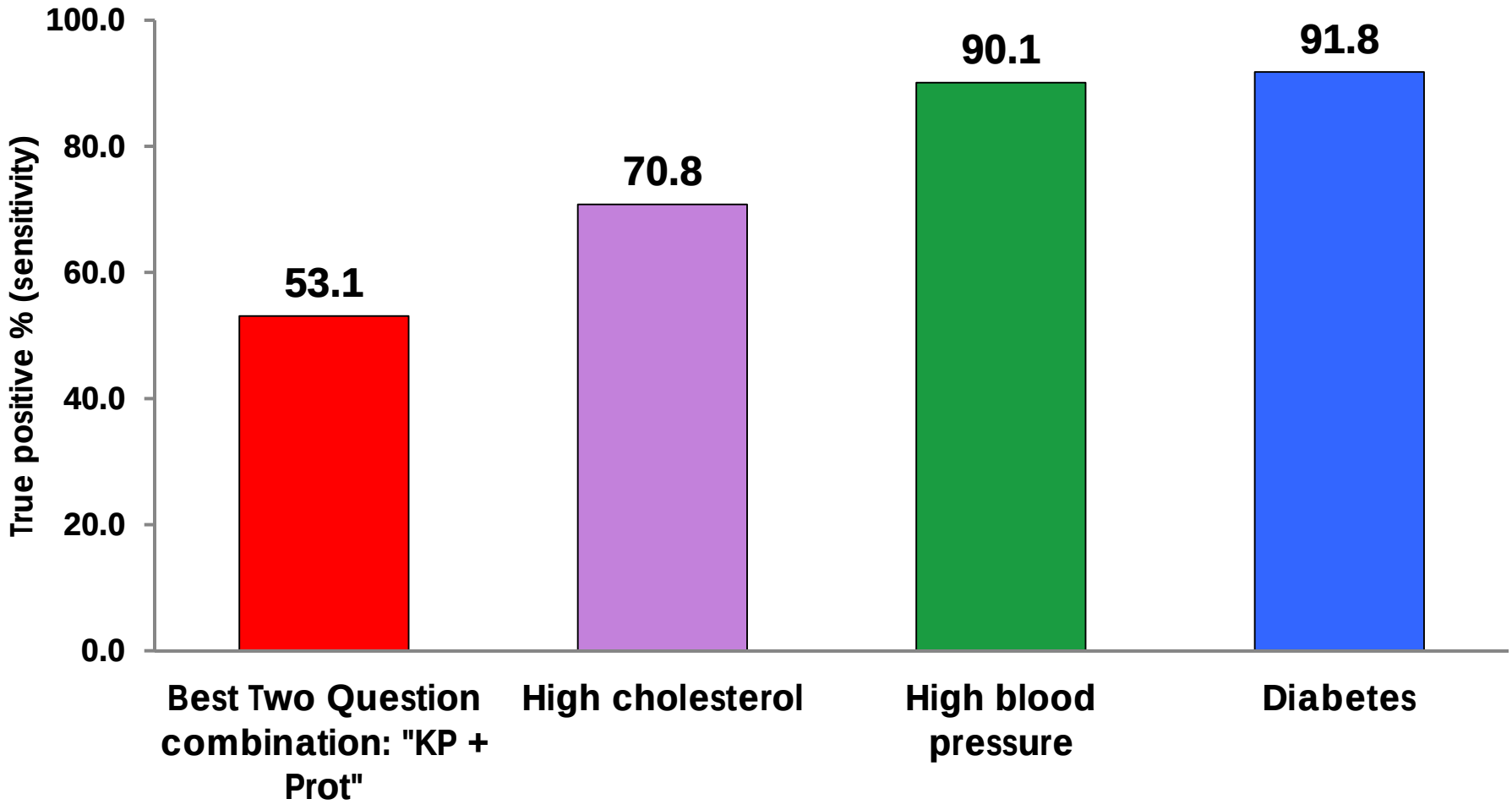
Tuot, CJASN, 2016.

Prevalence of awareness depends on how question is asked

Participant Characteristic	All Participants (N = 401)
Age (y)	58 (46, 68)
Men	213 (53)
Race	
White	333 (83)
Nonwhite	68 (17)
Formal educational attainment ≥high school graduate	375 (94)
Health literacy level ≥9th grade reading level	330 (82)
Annual household income	
≤$25,000	71 (19)
$25,001-$55,000	128 (34)
>$55,000	181 (48)
Self-reported kidney education class	67 (17)
≥3 Nephologist visits in past year	232 (58)
Know someone with CKD	198 (50)
Aware of "kidney problem"	375 (94)
Aware of CKD diagnosis	278 (69)
Self-reported diabetes (n = 380)	145 (38)
Self-reported high BP (n = 394)	338 (86)

Wright, AJKD, 2011.

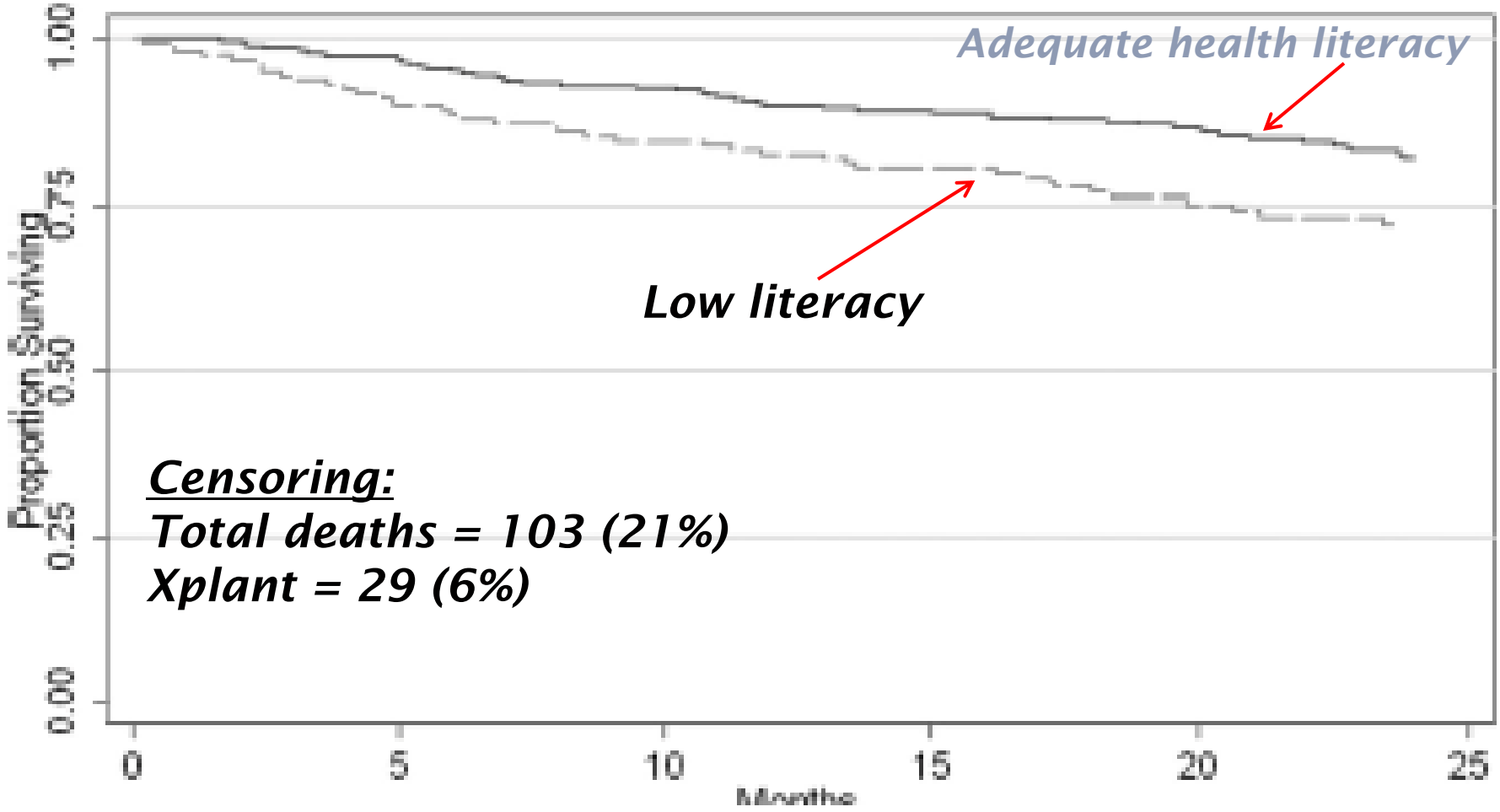
CKD Awareness is lower than awareness of other chronic health conditions



Tuot, CJASN, 2016.

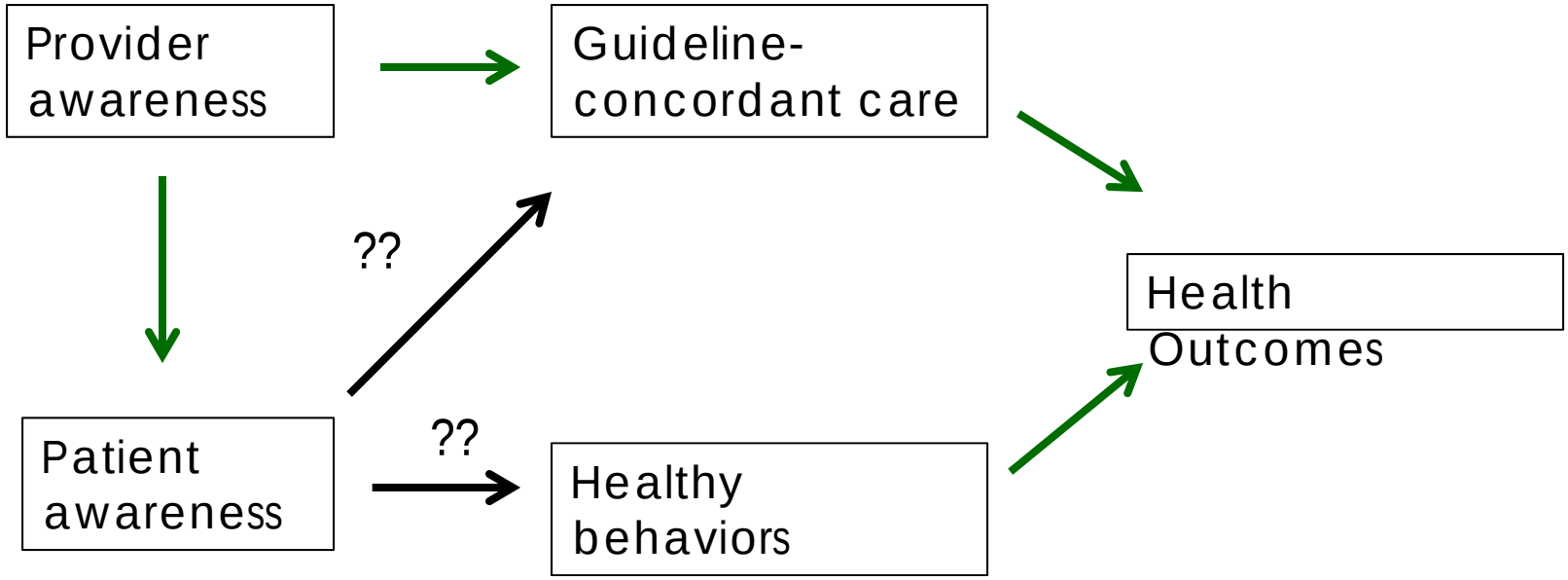
Limited health literacy is prevalent among patients with CKD

- 25% patients with CKD/ESRD have limited health literacy
- Greater mortality among ESRD pts with low health literacy



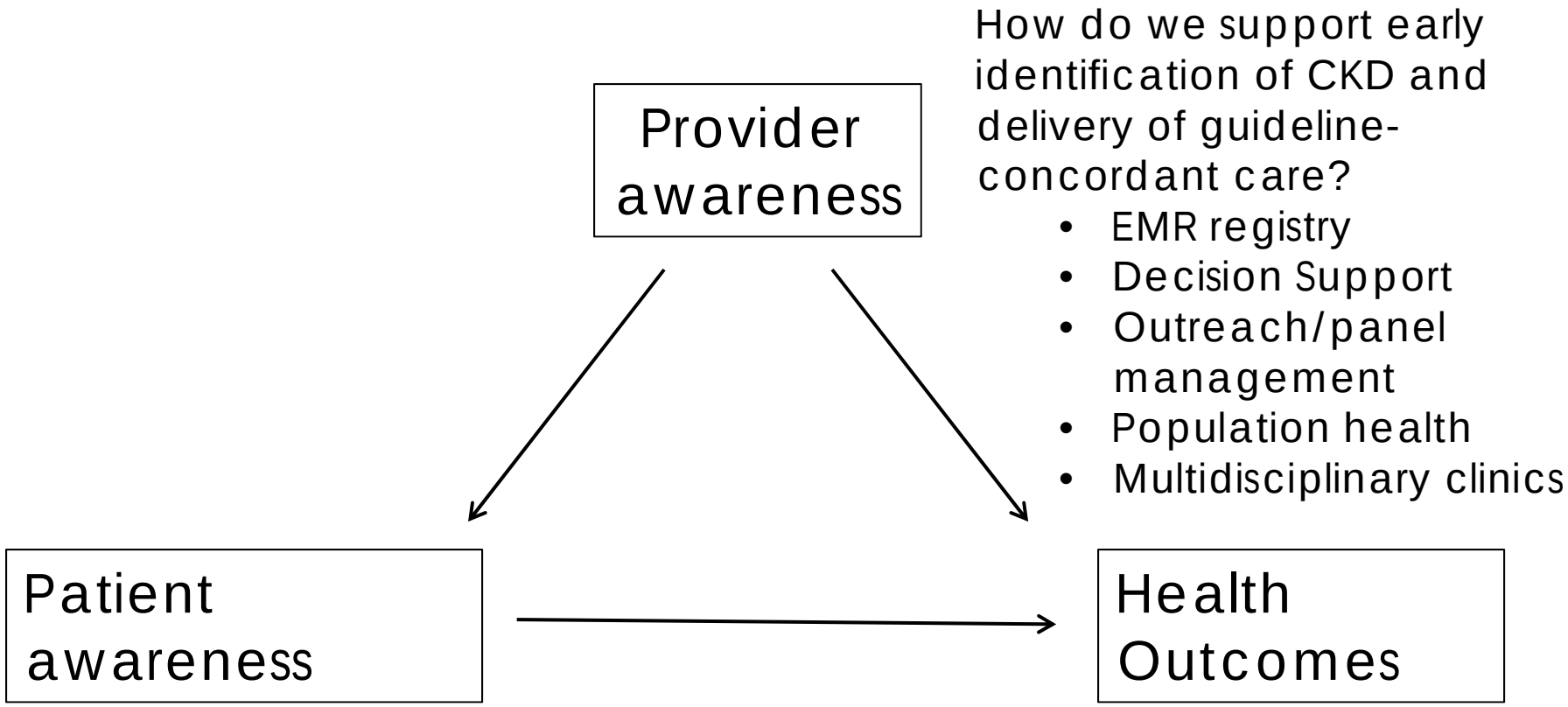
Cavanaugh, JASN, 2010

The implications of patient awareness of CKD are not clear and require further study.




Opportunity
NEXT EXIT

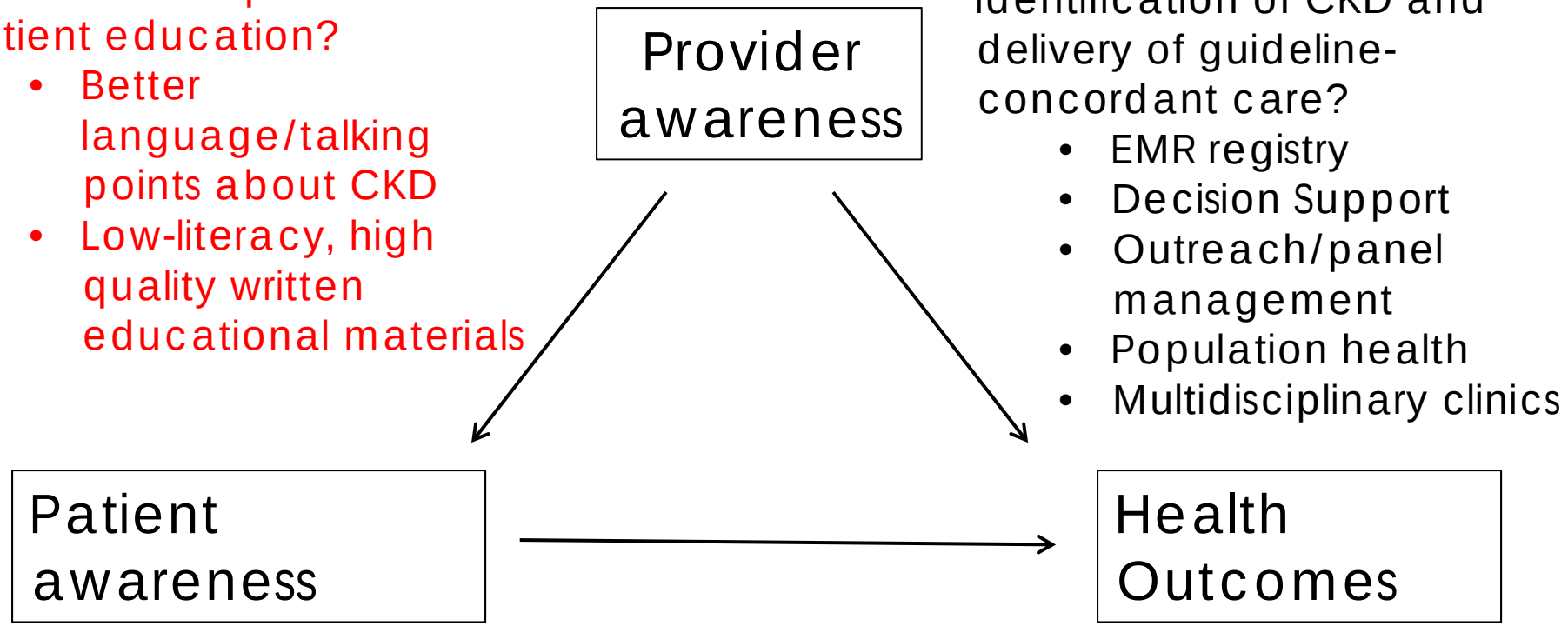
Opportunity to improve health outcomes through awareness



Opportunity to improve health outcomes through awareness

How do we support primary care teams to provide patient education?

- Better language/talking points about CKD
- Low-literacy, high quality written educational materials



How do we support early identification of CKD and delivery of guideline-concordant care?

- EMR registry
- Decision Support
- Outreach/panel management
- Population health
- Multidisciplinary clinics

What is the quality of existing CKD patient educational materials (PEMs)?

- Content analysis of existing written English PEMs
  - Patient
  - Internist
  - Nephrologist
- 19 sources
  - national organizations (NKF, NKDEP)
  - patient groups, foundations (AAKP, AKF)
  - Dialysis companies/pharmaceutical companies (Amgen)
- Over 120 different materials, covering 5 topics:
  - Description of kidney and CKD
  - Risk factors for CKD development
  - Risk factors for CKD progression
  - Healthy behaviors/Self-management tools
  - Consequences/complications of CKD

Tuot. AJN. 2013

PEM content analysis

- Evaluation using Suitability Assessment of Materials (SAM)
  - Educational content and embedded self-management tools
  - Literacy level/complexity
  - Text appearance
  - Use of visuals
  - Layout and design

- Example questions from the SAM:

Does the material explain the purpose and benefits from the patient's view?	☐ Inadequate ☐ Adequate ☐ Superior
Is the content limited to a few essential main points that the majority of the target population will benefit from?	☐ Inadequate ☐ Adequate ☐ Superior
Are behaviors and skills emphasized rather than just facts?	☐ Inadequate ☐ Adequate ☐ Superior

Tuot. AJN. 2013

Patient Educational Materials (PEMs)

				Content area covered			
Source	**PEM topic**	**population (Minority/ethnic)**	**reading level (< 6th grade)**	Basics of CKD	Risk factors for Development	Risk factors for progression	Early complications
					Self-management strategies	Self-management strategies	Self-management strategies
NKDEP	What is CKD						
NKDEP	CKD test results		*				
NKDEP	AA brochure	*	*				
AKF	Causes and risk factors						
Kidney school	Anemia						
NKF	Are you at risk for CKD?	*	*				
Kidney School	Risk factors						
NKDEP	CKD and meds		*				
NKF	Iron/anemia and CKD		*				
AKF	Living well with CKD		*				
Kidney school	Module 12: staying active		*				

All above PEMs are in English and received a “Superior” (>70/100) rating by Suitability of Assessment of Materials criteria

Tuot. AJN. 2013

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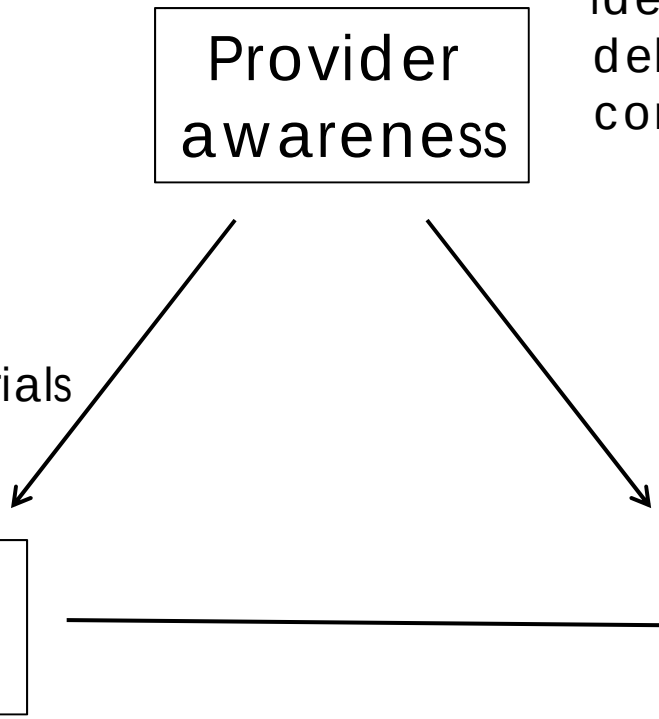

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- Outreach/panel management
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Translating patient awareness into healthy behaviors

- Self-management support programs
- Health navigation/health coaching
- Peer education

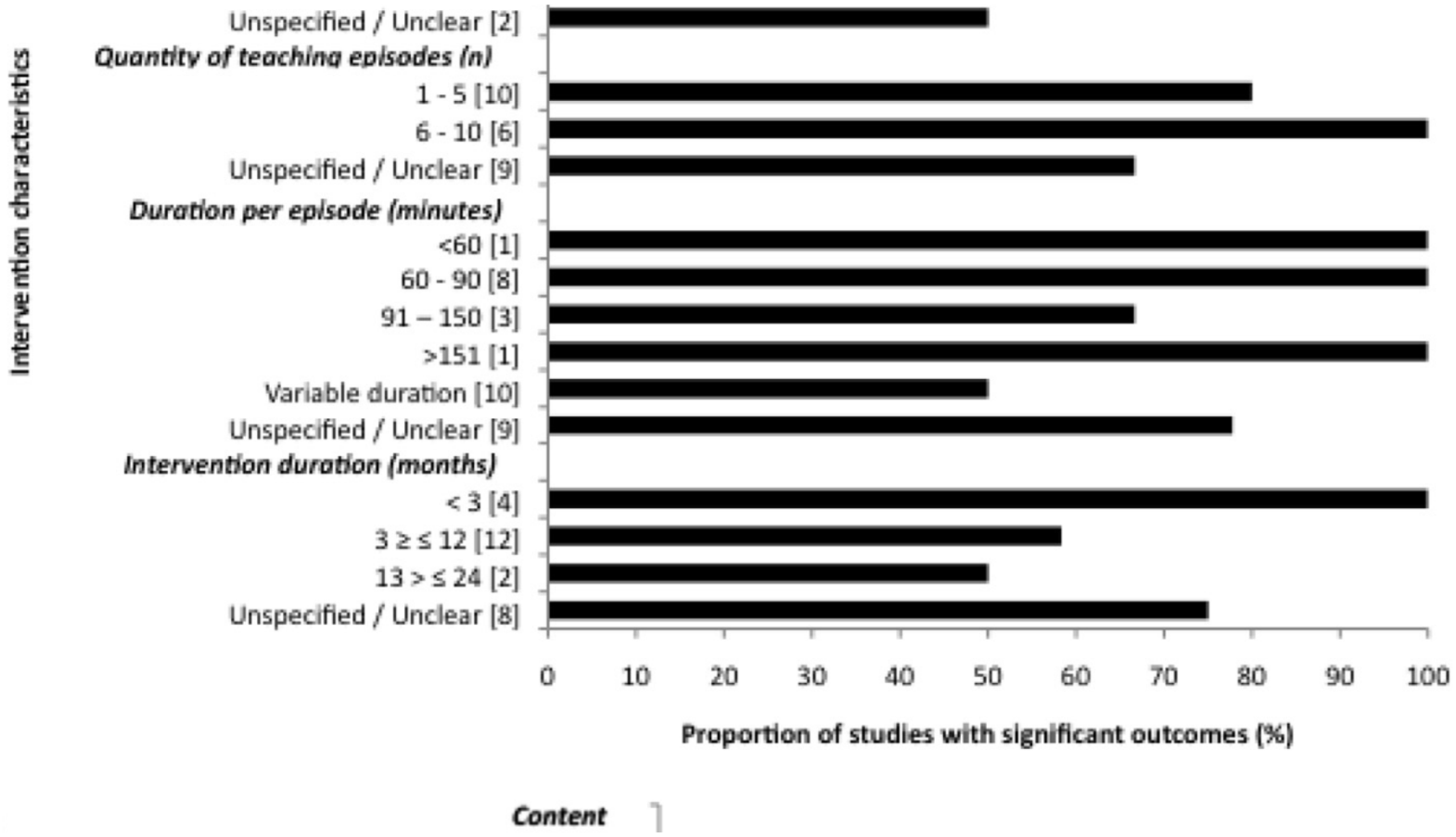
Do CKD self-management support (SMS) programs exist?

- Comprehensive review
  - 26 studies: 12 trials, 14 observational studies
  - 5403 patients with CKD 1-5
- Types of interventions
  - Face-to-face teaching (n=26)
  - Written information (n=20)
  - Telephone follow-up (n=13)
- Delivery
  - 1:1 interaction with educator (n=20)
  - Group sessions (n=14)
- Outcomes
  - Higher QOL, CKD knowledge and self management skills (n=9)
  - Improved clinical endpoints (i.e. eGFR decline, BP, LDL) (n=9)
  - Improved patient-reported and clinical outcomes (n=2)

Lopez Vargas, AJKD< 2016

Characteristics of successful SMS interventions

- Interactive
- Integrated goal setting
- Involved groups of patients and families
- Included multi-disciplinary team members
- Frequent encounters (weekly or monthly)



Lopez Vargas, AJKD, 2016

Enhancing SMS programs with technology

Integrating a Smartphone–Based Self–Management System into Usual Care of Advanced CKD

Stephanie W. Ong,[*†] *Sarbjit V. Jassal,*[‡†§‖] *Judith A. Miller,*[‡†‖] *Eveline C. Porter,*[¶†] *Joseph A. Cafazzo,*[**††§‡‡] *Emily Seto,*[§**††] *Kevin E. Thorpe,*[§§‖‖] *and Alexander G. Logan*[‡†¶¶‖]

The Kidney Awareness Registry and Education (KARE) study: protocol of a randomized controlled trial to enhance provider and patient engagement with chronic kidney disease

Delphine S. Tuot[1,4,5*], Alexandra Velasquez[1], Charles E. McCulloch[3], Tanushree Banerjee[2,4], Yunnuo Zhu[2], Chi-yuan Hsu[1], Margaret Handley[2,3], Dean Schillinger[3,4] and Neil R. Powe[2,4]

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Design: usability/acceptability study over 6 months

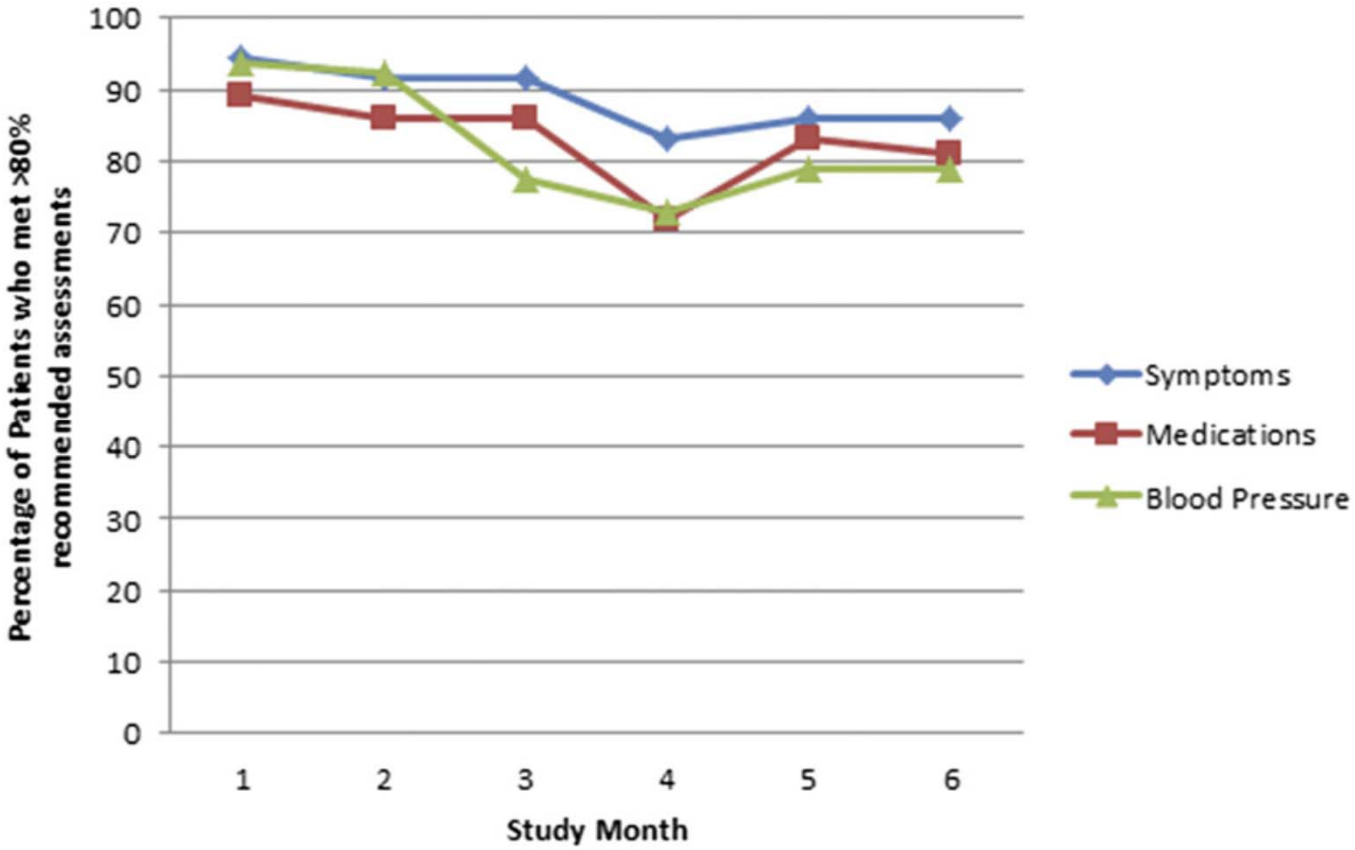
Intervention

- Use of an application designed to be an adjunct to nephrology care
- Targets 4 behaviors:
  - BP monitoring (including a wireless BP device)
  - Managing medications and discrepancies with medical record
  - Assessing symptoms
  - Tracking laboratory results (linked to medical record)

Patient population

- 47 English-speaking patients with CD stages 4-5, mean age=59 years
- 64% had some college or graduate school
- 80% had a computer; 40% had a smartphone; 73% had a cellphone
- Mean sBP: 131 mmHg +/- 17
- Mean of 10 medications

Ong, CJASN, 2016.



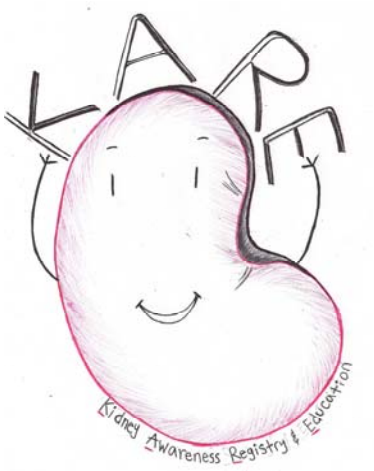
BP: no change in clinic BP; home SBP decreased by -3.4 mmHg (-5.0 to -1.8)

Meds: clinical relevant discrepancies dropped from 80% → 72%

Symptoms: 13 patients had additional telephone contact and interventions with care team b/c of noted symptoms

Lab tests: no change in percentage of patients in target ranges of potassium, phosphate or hemoglobin

Ong, CJASN, 2016.



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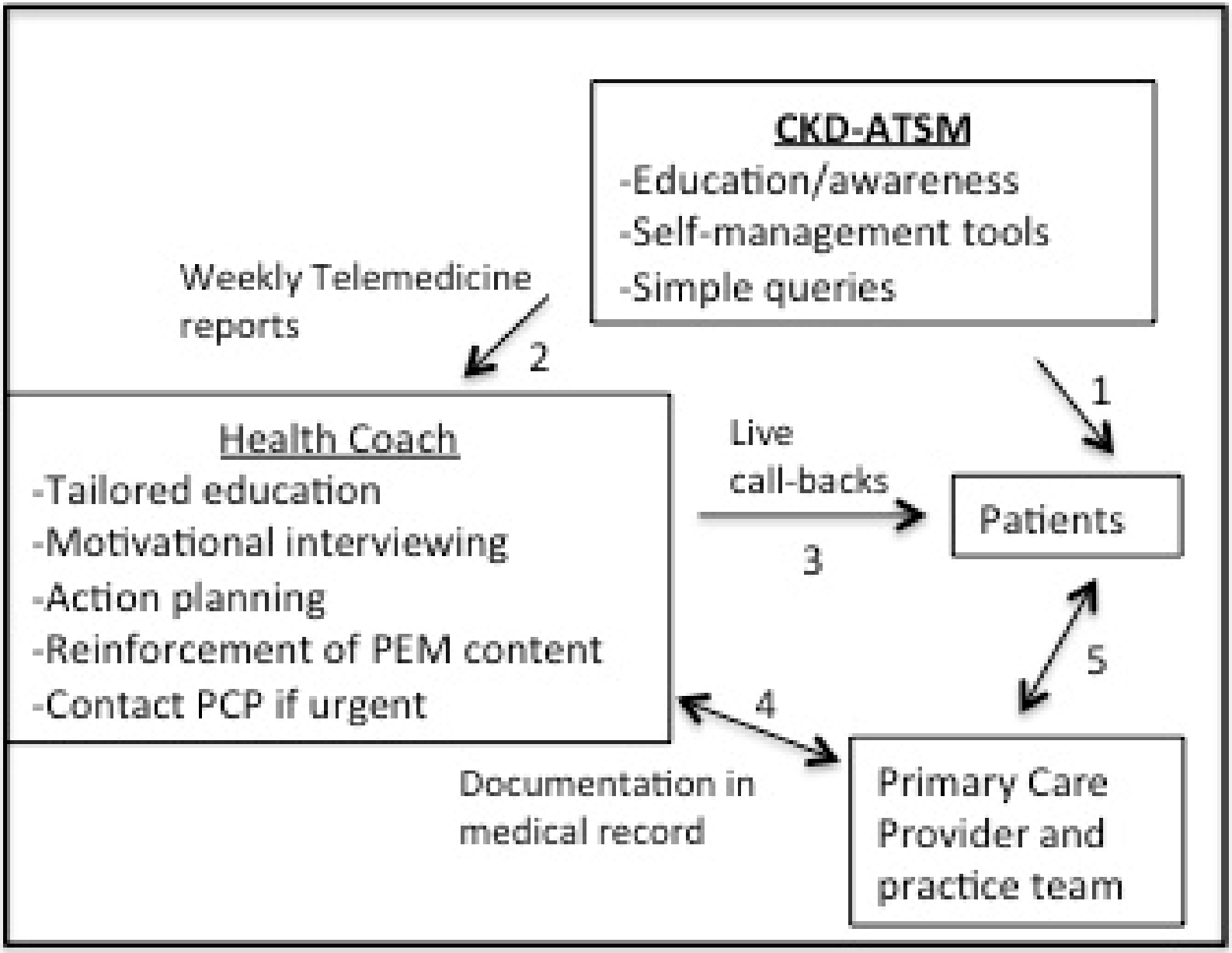
Comprehensive CKD self-management program

- Printed high-quality, low-literacy patient educational materials (PEMs)
- Language-concordant automated telephone self-management (CKD-ATSM)
- Language-concordant telephone health coaching

Tuot, BMC Nephrology, 2015.

CKD-ATSM


CKD-ATSM
-Education/awareness
-Self-management tools
-Simple queries
Weekly Telemedicine reports
2
1
Health Coach
-Tailored education
-Motivational interviewing
-Action planning
-Reinforcement of PEM content
-Contact PCP if urgent
Live call-backs
3
Patients
5
4
Documentation in medical record
Primary Care Provider and practice team

CKD-ATSM example-NSAID Avoidance

Label	Wording	Trigger
Week 4 Q1	"During the past 7 days, how many days have you taken any of the following prescription or over-the-counter pain relievers: Ibuprofen, Advil, Motrin, Aleve, Excedrin?	
	Press the number of days." If 0-1 pressed: "That's great. Did you know that certain pain pills, such as Ibuprofen, Advil, Motrin, Aleve, Excedrin may cause kidney injury? Remember that Aspirin for your heart is ok. Please talk to your doctor about whether these medications are safe for you." If 2 or more pressed:(skip to next question)	
Week 4 Q2	"Sounds like you have had some pain this past week. Do you take these medications for arthritis pain?	
	If yes, press 1 If no, press 2 If press 1: (go to clinical vignette) You might be going through something similar to Mrs. Jones. Mrs. Jones has arthritis in her knees and used to tak Aleve every day to treat the pain and keep up with her grandchildren. When she saw her doctor for a check-up, he told her that her kidneys were not working well. He told her that certain pain pills, such as Ibuprofen, Advil, Aleve, could cause some kidney injury. Mrs. Jones now ices her knee every afternoon for 10 minutes before she meets up with her grandchildren and no longer needs Aleve everyday."	
Week 4 Q3	Do you want to talk to a member of your health care team about ways to avoid these types of pain pills? If yes, press 1 If no, press 2	CALL BACK

Health coach protocol

Nonjudgmental: "It's important for the doctors to understand how their patients are taking all their prescription and over-the-counter medications."
Check accuracy: "In this week's call, you answered that take these pain pills for arthritis pain and would like to avoid these types of pain pills if possible. Is that correct?
Check understanding about pain pills:
• "What over-the-counter pills are you currently taking now? For each one, tell me their names, how much you take, and what they are for?"
• Do you have the bottles? Can you get them and read the name / instructions on them?"
• "Tell me more about your pain and what you have tried to treat it."
• NSAIDs may be a risk factor for progressive CKD. It is associated with an acute decline in GFR and kidney function.
• "What have you noticed about your health condition since you started taking the pills?" (Possible side effects include stomach pin, nausea, heart burn, increased BP and risks for diabetes and elderly patients)
Assess prior care:
• "Does your doctor know about this?"
• "Is your doctor or someone else (like social worker or pharmacist) helping you with the pain?"
Community resources:
• Local swimming pools(Balboa, Sava, Coffman, Garfield, Hamilton, MLK Jr, Mission Community, North Beach, Rossi)

Help patient problem solve:
• Provide education about medications and reasons to take.
Problem: must walk for exercise; can't go in pool
Solution(s): non-weight bearing activities: biking or water aerobics.
Problem: only Aleve works.
Solution(s): try Tylenol, heat/cold packs (can use dish towels that you run under scalding or really cold water); talk to doctor about getting a joint injection if it's a knee/wrist/elbow/ shoulder
• Help patient set an action plan, using triggers or cues for remembering. (What small steps would you like to take to get started? What, when, how much, how often, how confident are you?)
• Talk to your doctor and see what to do to avoid taking NSAIDs for a long period of time and understand if any risk factors apply to you
• Alternatives for NSAIDs: meditation, behavioral modification, relaxation techniques, light exercise, deep breathing, music therapy
Follow-up:
• "Talk with your doctor more about this. He/she wants to know and to help you find a way to put you on the best possible treatment plan"
• "I will check back to see how you are doing."

CKD-ATSM topics

- Kidney knowledge (eGFR, albuminuria, connection with HTN, DM and CV disease)
- BP education and medication adherence
- Engagement in health care
- Importance of physical activity
- NSAID avoidance and alternatives
- Smoking cessation
- Healthy diet
  - Food insecurity, meal preparation
  - Sweetened drinks
  - Low salt
- Stressors
- Complementary/alternative medicine use
- DM education and medication adherence

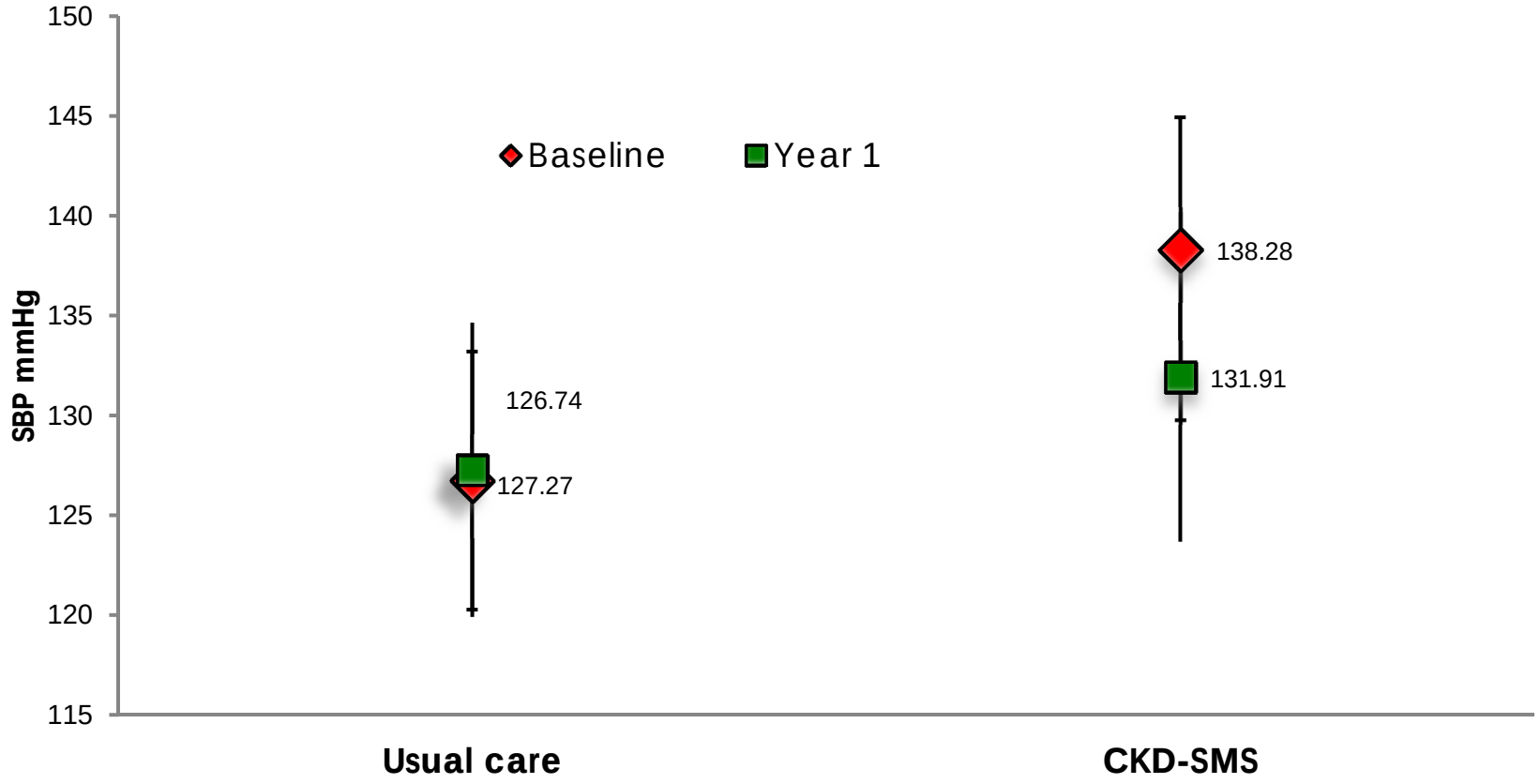
Tuot, BMC Nephrology, 2015.

Patient characteristics	All (n=137)
Age, mean (SD)	55.32 (12.2)
Female gender, %	51.8
Race/ethnicity	
Caucasian/white	6.6
Black or African American	42.3
Asian/Pacific Islander	14.6
Hispanic	36.5
English as preferred language, %	60.6
Greater than high school educational attainment, %	36.5
Limited health literacy, %	23.4
Food Insecurity, %	52.6
Insurance, %	
None	27.7
Public insurance	72.3
Self-reported diabetes, %	38
CKD Stage, %	
Stage 1-2	51.10
Stage 3-4	48.9
ACR categories (mg/g), %	
A1 <30	26.3
A2 30-300	41.6
A3 >300	31.4

- Study design: RCT
- Intervention: 12 months of comprehensive CKD-SMS vs. usual care as adjunct to primary care
- Patient population
  - Mean age=55 yrs
  - 40% non-English
  - 66% ≤ high school education
  - 23% limited health literacy

Tuot, under preparation

Results: Patients in SMS group showed a trend towards improved BP compared to usual care (but not statistically significant)



Tuot, under preparation

Results: Participation in SMS was NOT associated with statistically significant changes in healthy behaviors

	baseline	year 1	beta	CI	p-value
Morisky Medication Adherence [Scale: 0 (great adherence) - 4 (low adherence)]					
Usual care	1.34 (0.98,1.71)	1.11 (0.75,1.47)	ref	ref	.
SMS Only	1.38 (0.92,1.83)	1.17 (0.72,1.62)	0.03	(-0.48,0.53)	0.91
Stanford Chronic Disease Self-efficacy [scale of 1 (not confident) -10 (very confident)]					
Usual care	7.94 (7.39,8.48)	8.19 (7.63,8.74)	ref	ref	.
SMS Only	7.91 (7.23,8.59)	8.31 (7.78,8.85)	0.15	(-0.60,0.91)	0.69
Lorig Communication [Scale: 0 (poor communication) - 5 (excellent communication]					
Usual care	2.86 (2.46,3.26)	2.79 (2.41,3.18)	ref	ref	.
SMS Only	2.95 (2.56,3.35)	2.7 (2.28,3.12)	-0.18	(-0.74,0.38)	0.53
SF-12 [Scale: 0 (lowest) - 100 (highest)]					
Usual care	57.4 (50.47,64.33)	61.61 (54.30,68.92)	ref	ref	.
SMS Only	51.52 (41.69,61.34)	53.81 (43.99,63.63)	-1.92	(-8.31,4.47)	0.56
SF-12: Physical Health Component [Scale: 0 (lowest) - 100 (highest)]					
Usual care	54.33 (46.08,62.58)	58.16 (49.79,66.52)	ref	ref	.
SMS Only	46.99 (36.37,57.62)	49.88 (38.65,61.12)	-0.94	(-9.23,7.36)	0.82
SF-12: Mental Health Component [Scale: 0 (lowest) - 100 (highest)]					
Usual care	63.57 (56.78,70.36)	68.57 (61.88,75.27)	ref	ref	.
SMS Only	60.59 (51.02,70.16)	61.72 (53.52,69.92)	-3.87	(-11.13,3.39)	0.3

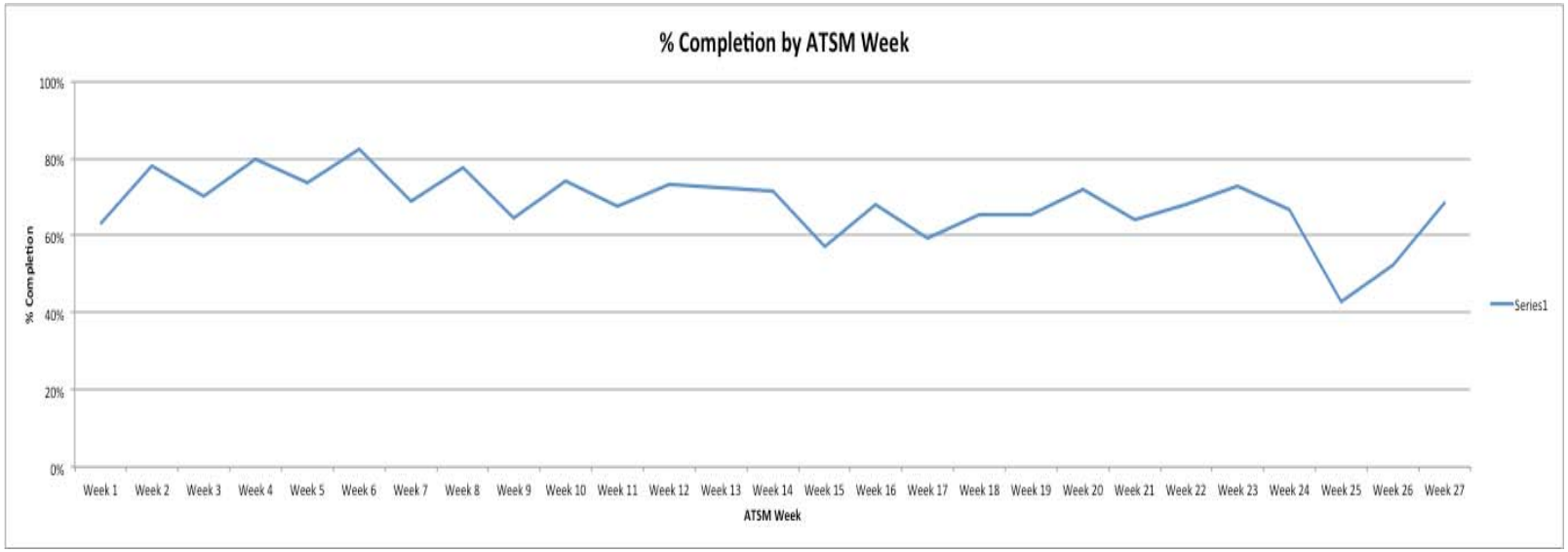
Tuot, under preparation

Results: self-management support intervention was acceptable and helpful to patients

Themes from patient focus groups (n=8)

- Appreciate the language-concordance
- Automated calls were easy to understand and convenient, though impersonal
- Health coaches were very supportive
- The ATSM could be enhanced with additional diet information and texts
- Diverse opinions about telephone vs. in-person health coaching

Patient engagement (automated call completion) is around 60-70%



Strait, CKD, In press.

Take-aways from technology-enhanced SMS

- We are still figuring out how to enhance SMS to meet our patients' and providers' needs
- There is no one size fits all
- Future work should including choice of SMS vehicle

Overall take home points

- Awareness of CKD among providers is suboptimal but increasing.
- Patient awareness of CKD is low, though common measures may be flawed.
  - “Kidney Problem” and “Protein in the Urine” may be better ways to discuss and measure awareness.
- Translating awareness into healthier outcomes will require different interventions among patients and health teams.
- Many CD-SMS interventions for patients are being tested; much work remains.

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