Adherence to Guideline-Informed Care: Improving Patient Activation and Self-Care

Jamie Alton Green, MD, MS
Associate Professor
Department of Population Health Sciences
Co-Director, Center for Kidney Health Research
Geisinger Health System
Pennsylvania, USA

DISCLOSURES

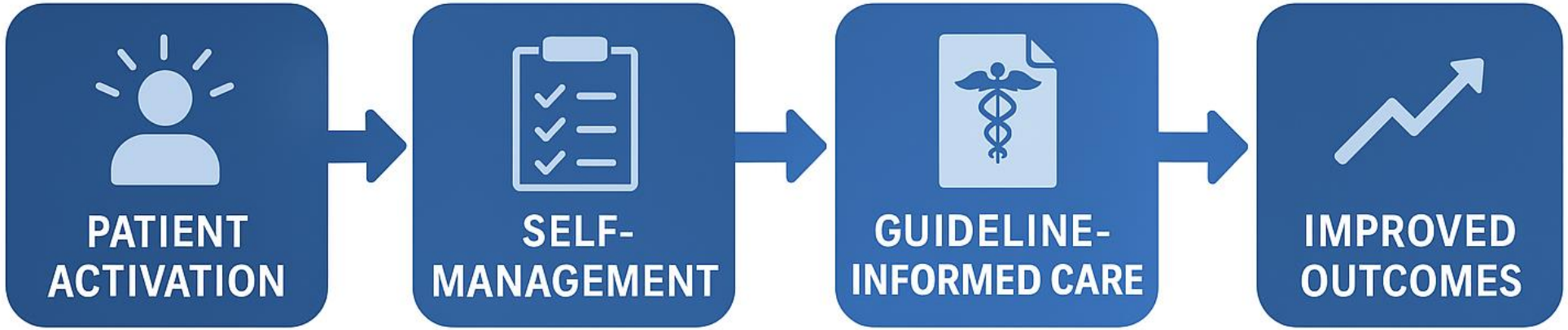
- Novartis
- Boehringer Ingelheim

OBJECTIVES

- Why patient activation and self-management matter
- Current patient-facing technologies
- Barriers to adoption

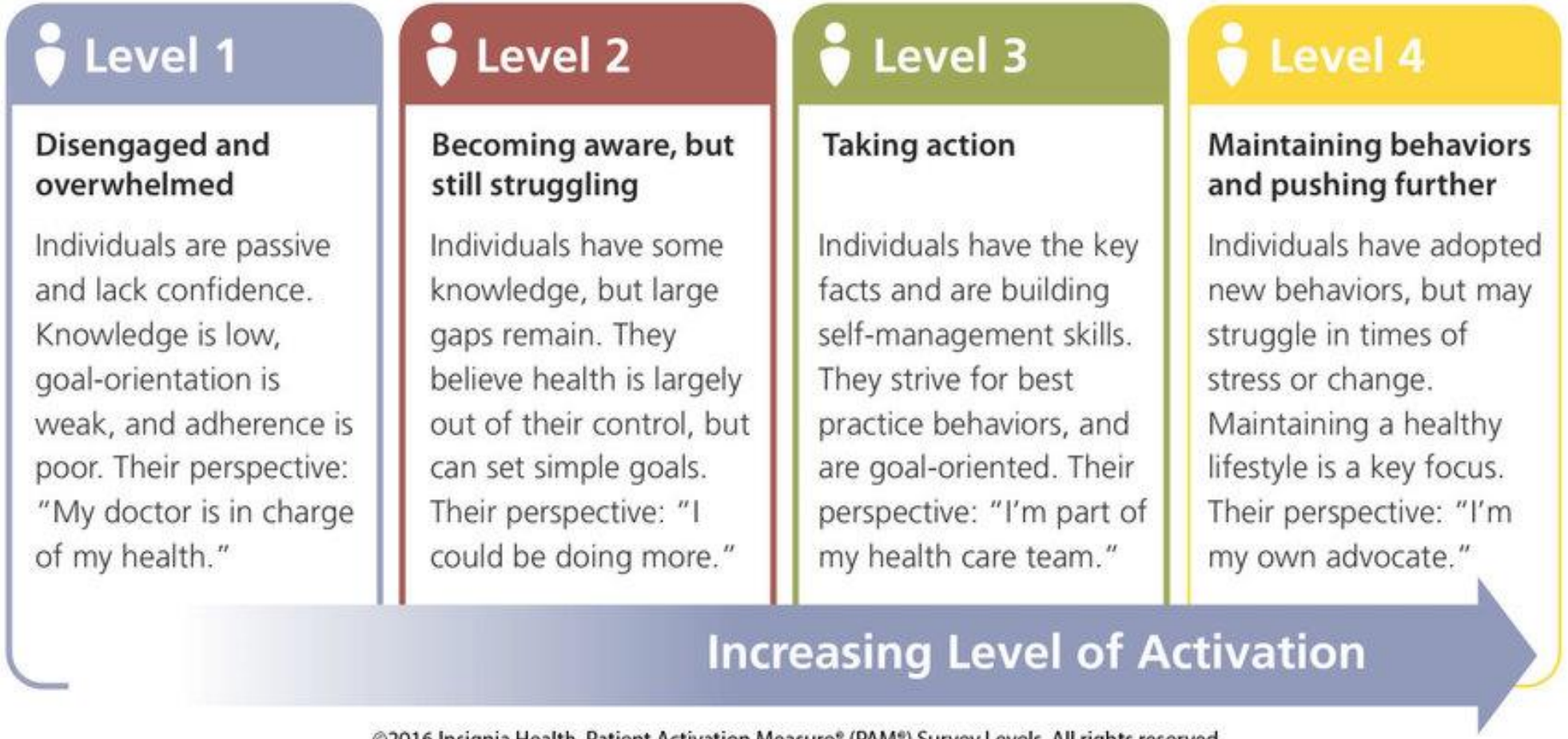
WHY THIS MATTERS

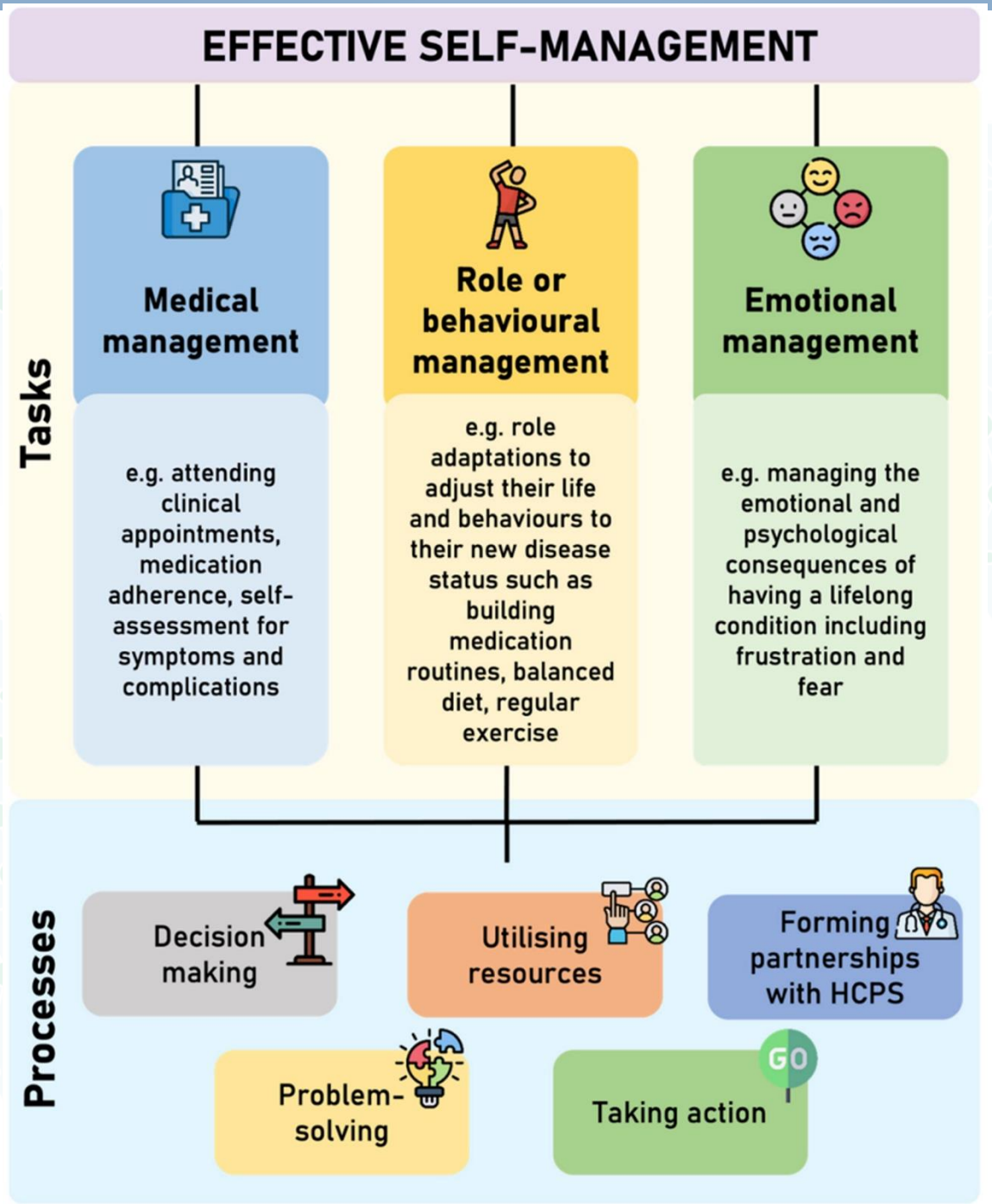
- CKD self-management requires active patient engagement
- Guideline adherence improves outcomes



WHAT IS PATIENT ACTIVATION?

- Patient activation = *knowledge*, *skills*, and *confidence* to manage one's health





Lightfoot CJ, et al. 2022

Lower Levels of Patient Activation in CKD

- Clinical characteristics
  - Lower educational attainment
  - Lower health literacy
  - Older age
  - Higher CKD stage
  - In-center HD vs. PD/transplant
- Outcomes
  - Lower medication adherence
  - Higher decisional conflict
  - Worse quality of life
  - Increased symptom burden

Unclear impact on CKD progression, disease control, utilization

Nair D and Cavanaugh KL, 2020l; Lightfoot CJ, et al. 2022

Support for the Importance of Patient Activation

- National Quality Forum (NQF) quality positioning system
- Centers for Medicare and Medicaid Services (CMS) payment models
- Kidney Care Quality Alliance- ESKD
- National Health Service (NHS) Five Year Forward View

NATIONAL QUALITY FORUM

NHS

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

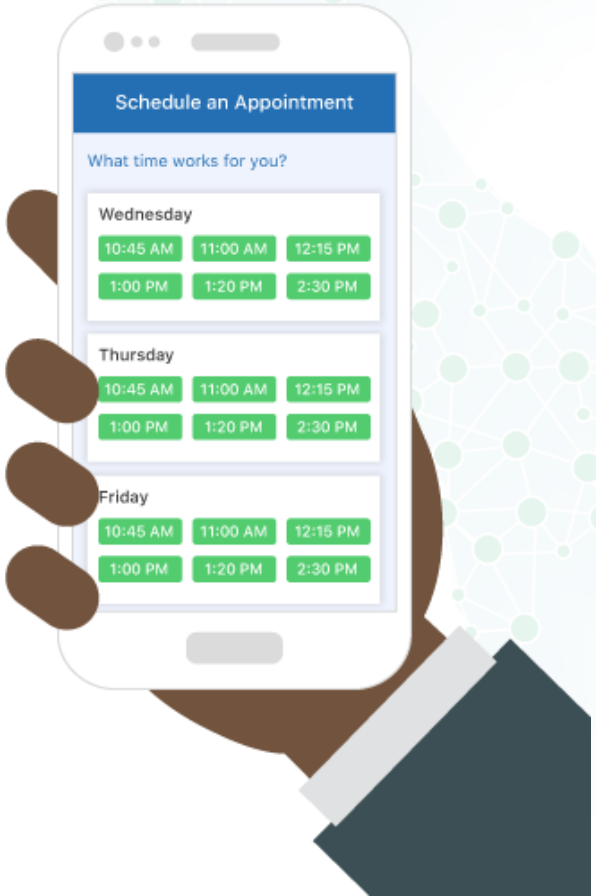
KDIGO
KIDNEY DISEASE · IMPROVING GLOBAL OUTCOMES

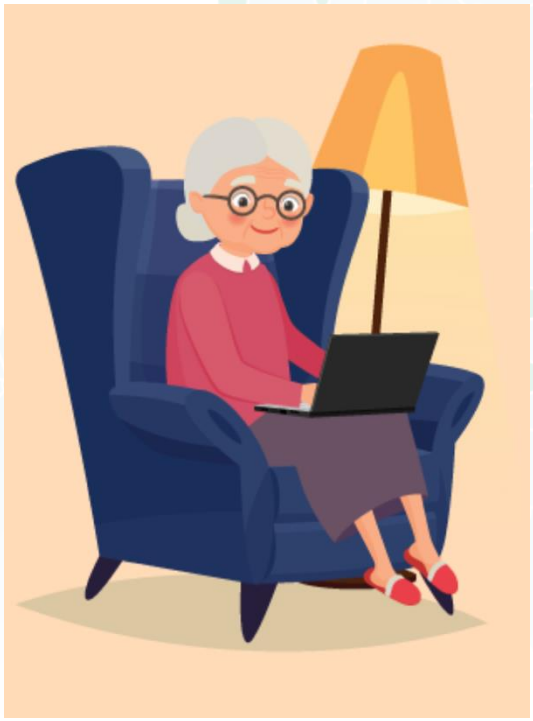
CURRENT PATIENT FACING TECHNOLOGIES

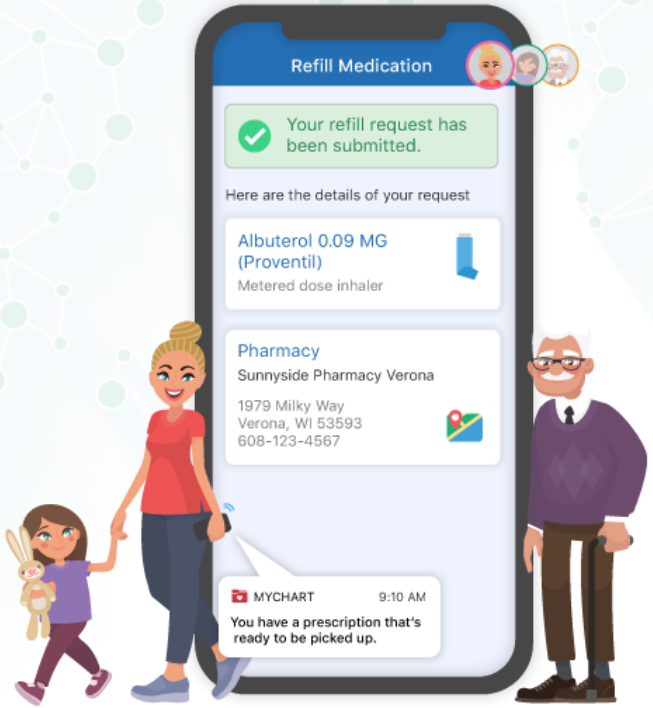
- Patient portals
- Mobile apps
- Remote monitoring tools
- Decision aids
- Online platforms

PATIENT PORTALS

MyChart powered by Epic







Clin J Am Soc Nephrol. 2015 Oct 22;10(11):2013–2022. doi: 10.2215/CJN.01640215

Disparities in Electronic Health Record Patient Portal Use in Nephrology Clinics

Manisha Jhamb [*], Kerri L Cavanaugh [†,‡], Aihua Bian [§], Guanhua Chen [§], T Alp Ikizler [†,‡], Mark L Unruh [‖], Khaled Abdel-Kader [†,‡,✉]

Results: Of 2803 patients, 1098 (39%) accessed the portal. Over 87% of users reviewed laboratory results, 85% reviewed their medical information (e.g., medical history), 85% reviewed or altered appointments, 77% reviewed medications, 65% requested medication refills, and 31% requested medical advice from their renal provider. In adjusted models, older age, African-American race (odds ratio [OR], 0.50; 95% confidence interval [95% CI], 0.39 to 0.64), Medicaid status (OR, 0.53; 95% CI, 0.36 to 0.77), and lower neighborhood median household income were associated with not accessing the portal. Portal adoption increased over time (2011 versus 2010: OR, 1.38 [95% CI, 1.09 to 1.75]; 2012 versus 2010: OR, 1.95 [95% CI, 1.44 to 2.64]). Portal adoption was correlated with BP control in patients with a diagnosis of hypertension; however, in the fully adjusted model this was somewhat attenuated and no longer statistically significant (OR, 1.11; 95% CI, 0.99 to 1.24).

Conclusion: While portal adoption appears to be increasing, greater attention is needed to understand why vulnerable populations do not access it. Future research should examine barriers to the use of e-health technologies in underserved patients with CKD, interventions to address them, and their potential to improve outcomes.

What is the association between electronic health record portal use and patient-centered outcomes in chronic kidney disease?

Kidney Medicine

Cross Sectional Study
One academic center
April 2015- March 2018

Patients with CKD (non-dialysis)
N = 245

60±17 yrs

121 (49%)
Female

182 (77%)
White

230 (96%)
High school diploma

ANALYSIS OUTCOME

Portal uses

- Labs
- Review medications
- Appointments
- Renewing meds
- Educational
- Communicate

Lower portal use

- African American vs. White: OR 0.34 (0.16-0.72)
- Lower education: OR 0.06 (0.01-0.36)
- <$25,000/ yr: OR 0.28 (0.13-0.60)
- $25,000-50,000/ yr: OR 0.26 (0.12-0.54)

Patient outcomes

Higher Portal Use
- Higher knowledge of personal health
- Higher rating of current health
- Lower CKD-related stress

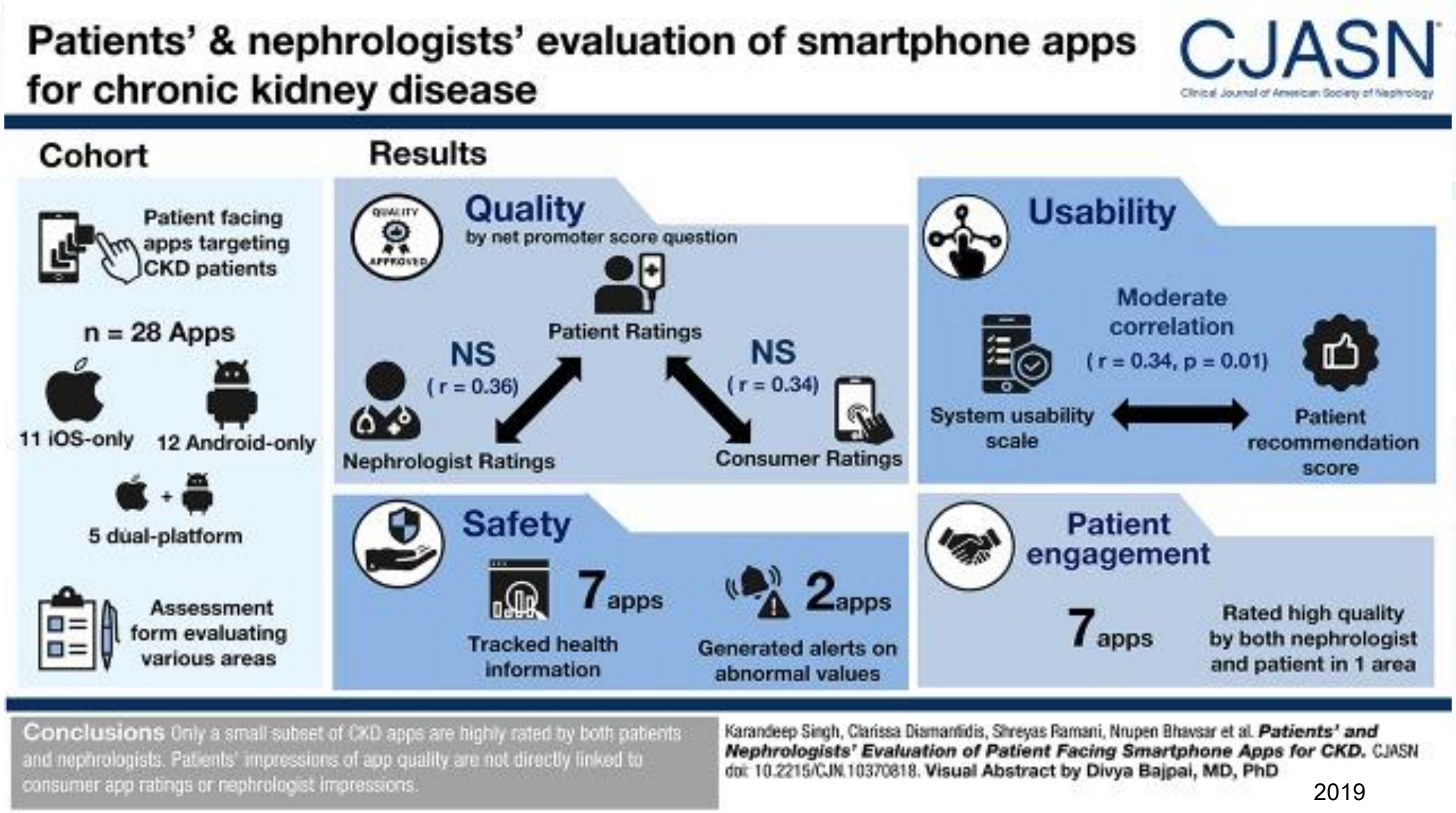
Conclusion: Interventions are needed to ensure all patients have access to health portals in order to mitigate disparities in health care delivery. Electronic health record portal users have higher knowledge & lower CKD-related stress.

Reference: Tome J, Ahmed S, Fagerlin A, et al. Patient electronic health record portal use and patient-centered outcomes in CKD. *Kidney Medicine*, 2021.

Visual Abstract by Anju Yadav MD

@docanjuyadav

MOBILE APPS



2019

SMARTPHONE ENABLED HOME uACR TESTING

Impact of smartphone-enabled home urinary albumin-to-creatinine ratio testing on albuminuria screening and management — **Zafar W et al.**

Design: Prospective propensity score-matched cohort study
Study Population: Adults receiving primary care with either HTN or DM without a UACR test in past 12 months
Primary endpoint: Any UACR test within 100 days

Participants enrolled (N=7996)

MINUTEFUL KIDNEY
Intervention
(n=3998)

Smart-phone enabled home urine albuminuria test kit using test vendor's patient engagement service (calls, texts, letters, emails)

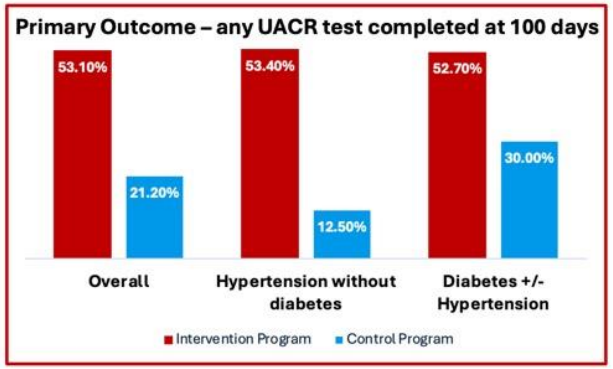
USUAL CARE
Control
(n=3998)

Matched 1:1 with propensity scores for socio-demographics and comorbidities.

Testing at PCP's discretion

RESULTS

- Completion of any UACR test was higher in the intervention group than the control group.
- Larger difference in hypertension subgroup



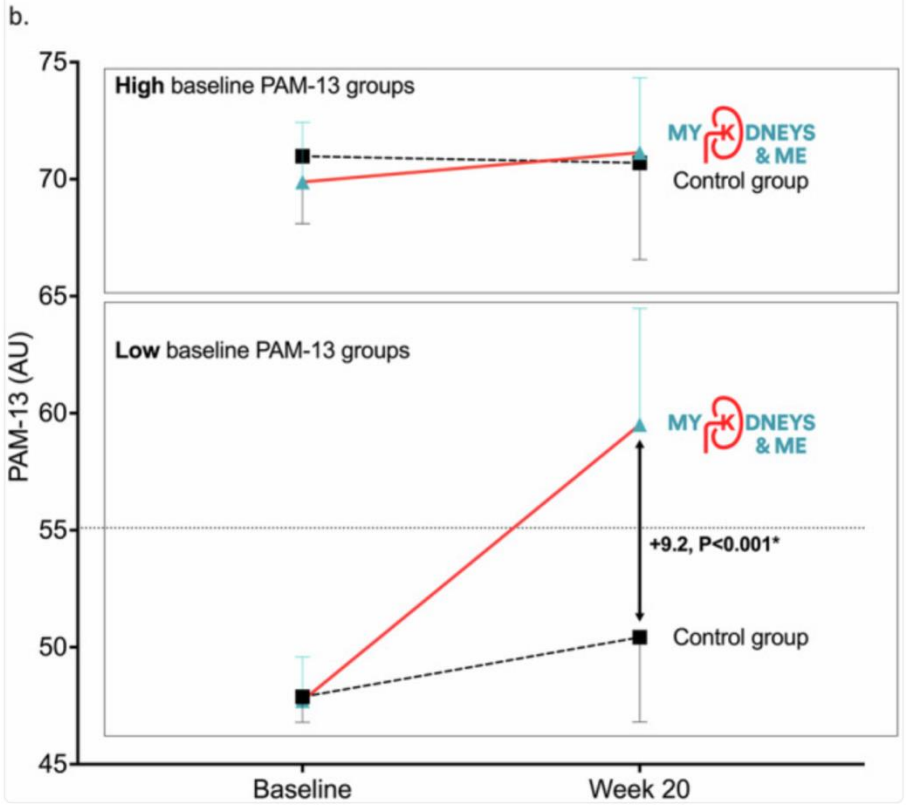
- Among Minuteful Kidney-tested individuals, those with abnormal UACR were more likely to have follow-up primary care and nephrology visits and new prescriptions of RAAS inhibitors than those with normal UACR.

CONCLUSIONS

- A convenient smartphone-enabled home albuminuria test is effective in increasing albuminuria screening among high-risk individuals.

SMILE-K

Self-Management Intervention through Lifestyle Education for Kidney health



b PP analysis - includes those who logged in, created an account and used the programme more than once.

Interactive educational sessions

Educational sessions (underpinned by behaviour change theories) contained information about the kidneys, CKD, its treatment, and different self-management techniques. Supplementing the learning sessions, **'How to' booster sessions** were released weekly over 10 weeks providing instructions on how to put learning into action

Information was provided in different formats (written, video, audio) and produced to accommodate those with low patient activation. The program was available to use on smartphones, tablets, and computers

Different formats

Ask questions

Users can ask health-related questions that were addressed by healthcare professionals and chat to other users

Goal setting

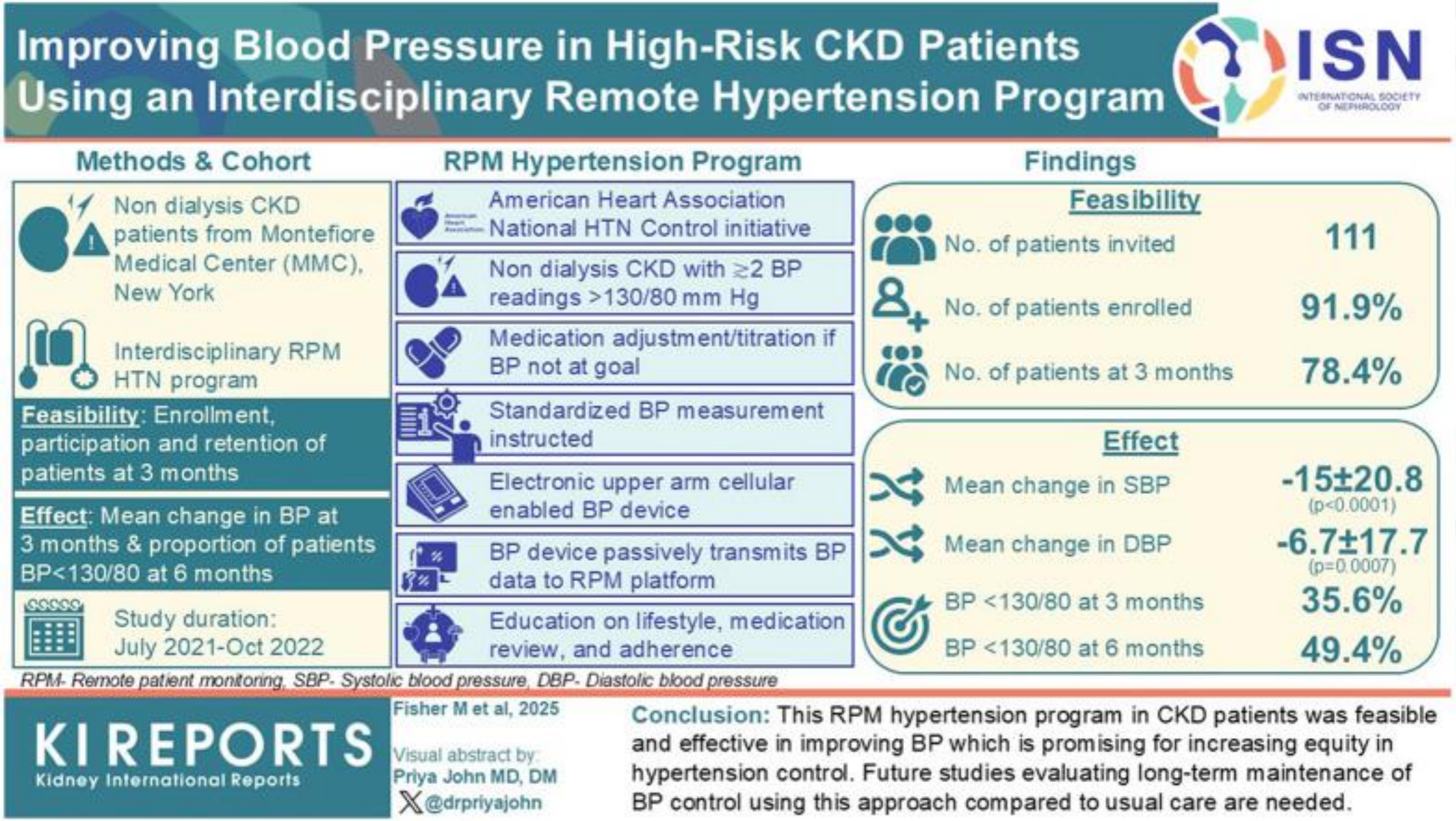
Individuals can set and track health-related S.M.A.R.T. goals using a 'decision maker' feature

Includes custom-made health trackers to allow monitoring of kidney-related **symptoms**, **blood pressure**, **diet**, **physical activity** (synched to wearable devices), and **exercise**, including strength training

Bespoke health trackers

Lightfoot CJ, Wilkinson TJ, Sohansoha GK, Gillies CL, Vadaszy N, Ford EC, Davies MJ, Yates T, Smith AC, Graham-Brown MPM; SMILE-K collaborators. The effects of a digital health intervention on patient activation in chronic kidney disease. NPJ Digit Med. 2024 Nov 12;7(1):318...

Remote Monitoring

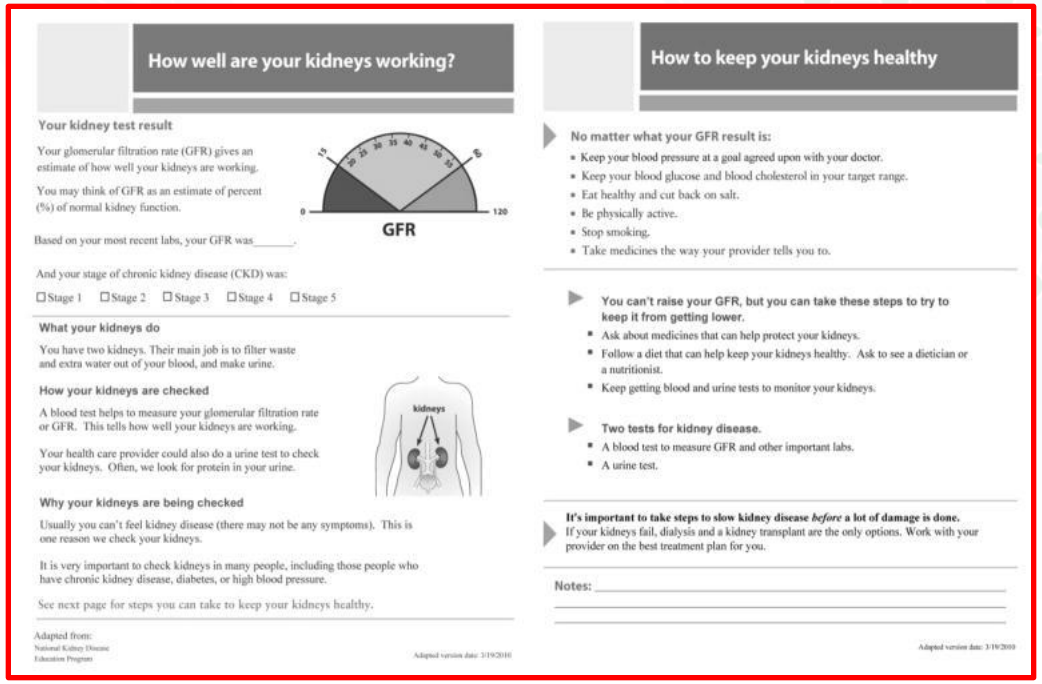


› Am J Kidney Dis. 2025 Mar;85(3):284-292. doi: 10.1053/j.ajkd.2024.10.005. Epub 2024 Dec 14.

Patient Education for CKD and Decision Support in Primary Care: Findings From the EPIK Pilot Study

Julie Wright Nunes [1], Eve Kerr [2], Akinlolu Ojo [3], Corey Powell [4], Audrey Fan [2], F John Brinley [2], Anita Devine [2], Tammy Ellies [2], Katie Grzyb [2], Luis Garcia-Guzman [5], Tejpreet Nakai [2], Andrea Oliverio [2], Emily Chen [6], Angela Fagerlin [7]

EDI (Encounter Decision Intervention): *A tool integrated into the electronic medical record for use during primary care visits to discuss CKD diagnosis and management.*



How well are your kidneys working?

Your kidney test result

Your glomerular filtration rate (GFR) gives an estimate of how well your kidneys are working.

You may think of GFR as an estimate of percent (%) of normal kidney function.

Based on your most recent labs, your GFR was_____.

GFR

And your stage of chronic kidney disease (CKD) was:

☐ Stage 1 ☐ Stage 2 ☐ Stage 3 ☐ Stage 4 ☐ Stage 5

What your kidneys do

You have two kidneys. Their main job is to filter waste and extra water out of your blood, and make urine.

How your kidneys are checked

A blood test helps to measure your glomerular filtration rate or GFR. This tells how well your kidneys are working.

Your health care provider could also do a urine test to check your kidneys. Often, we look for protein in your urine.

kidneys

Why your kidneys are being checked

Usually you can't feel kidney disease (there may not be any symptoms). This is one reason we check your kidneys.

It is very important to check kidneys in many people, including those people who have chronic kidney disease, diabetes, or high blood pressure.

See next page for steps you can take to keep your kidneys healthy.

Adapted from:

How to keep your kidneys healthy

No matter what your GFR result is:

- Keep your blood pressure at a goal agreed upon with your doctor.
- Keep your blood glucose and blood cholesterol in your target range.
- Eat healthy and cut back on salt.
- Be physically active.
- Stop smoking.
- Take medicines the way your provider tells you to.

You can't raise your GFR, but you can take these steps to try to keep it from getting lower.

- Ask about medicines that can help protect your kidneys.
- Follow a diet that can help keep your kidneys healthy. Ask to see a dietician or a nutritionist.
- Keep getting blood and urine tests to monitor your kidneys.

Two tests for kidney disease.

- A blood test to measure GFR and other important labs.
- A urine test.

It's important to take steps to slow kidney disease *before* a lot of damage is done.

If your kidneys fail, dialysis and a kidney transplant are the only options. Work with your provider on the best treatment plan for you.

Notes: _____

Patient Check-In

1. Patient identified with CKD via EMR registry
2. Medical assistant (MA) receives EMR notice that patient has arrived

Intake bay

MA gathers patient vital signs, queues up education worksheet:

1. Two key-strokes to brings worksheet into EMR
2. Worksheet is auto-populated with the patient's eGFR, Urine protein (albumin) and blood pressure measurements

Clinic Room – Clinician Visit

1. Clinician reviews worksheet with patient
2. Clinician adds 1-2 tailored messages to worksheet

Patient Check-Out

1. Worksheet prints automatically at check-out
2. Patient is provided additional reinforcement materials (e.g. how to contact clinician, how to access more CKD resources via portal

Post visit

1. Provider sends EMR message to nursing for patient follow up
2. Nursing may provide additional resources

ONLINE PEER MENTORING

Table 11 Changes in Mean PAM Scores Throughout the Study Period by Intervention Group (ITT Analysis)

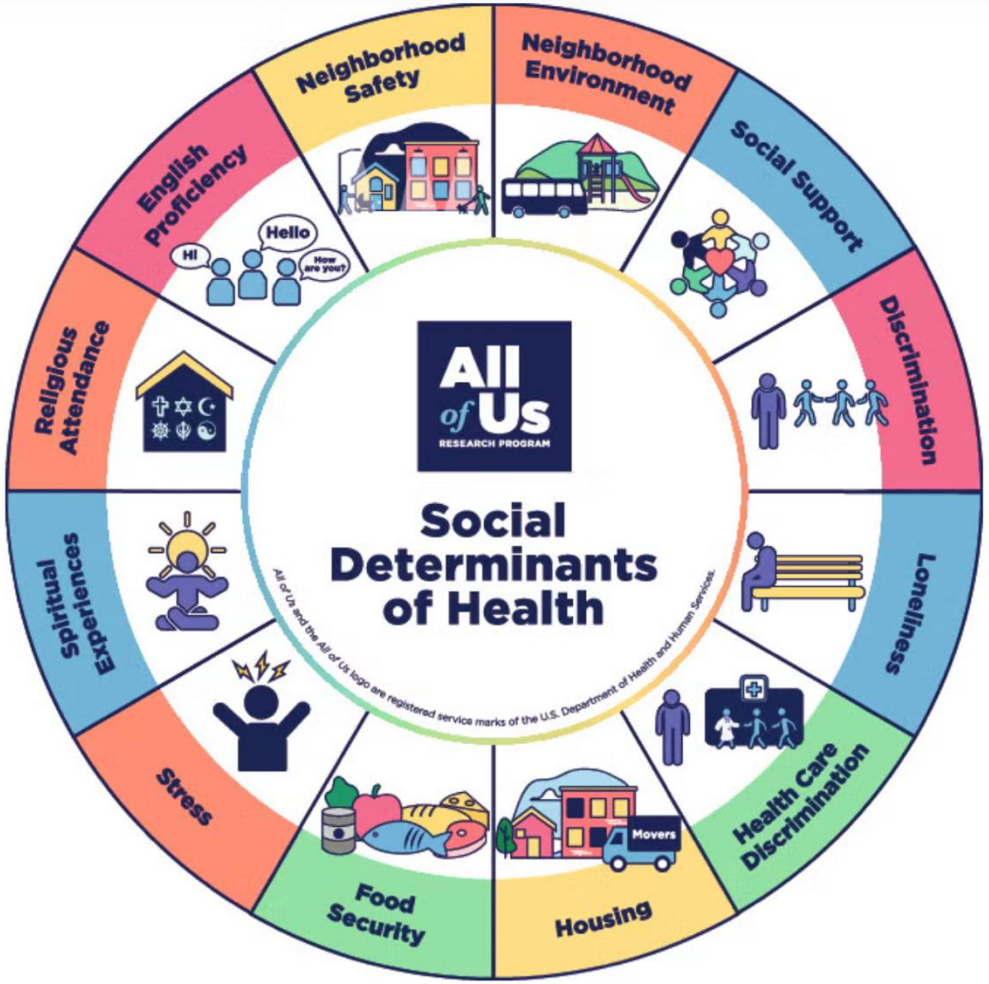
	FTF PM group			Online PM group			Textbook-only group		
Assessment points	Change in mean score ± SE	95% CI	*P* value	Change in mean score ± SE	95% CI	*P* value	Change in mean score ± SE	95% CI	*P* value
12 mo compared with baseline	3.4 ± 3.4	−3.4 to 10.2	.32	10.5 ± 3.1	4.5-16.6	.0009	0.8 ± 3.7	−6.6 to 8.2	.83
18 mo compared with 12 mo	−2.6 ± 3.9	−10.4 to 5.2	.52	0.5 ± 3.0	−5.5 to 6.5	.87	−1.2 ± 4.1	−9.5 to 6.9	.75
18 mo compared with baseline	0.8 ± 3.5	−6.1 to 7.7	.82	11.0 ± 3.2	4.7-17.3	.0008	−0.4 ± 3.8	−7.9 to 7.2	.92

Abbreviations: FTF, face to face; ITT, intention to treat; PAM, Patient Activation Measure; PM, peer mentoring.

Ghahramani N, et al. JL, Lengerich EJ, Chinchilli VM, Sciamanna CN. Comparing Three Ways to Improve Quality of Life for Patients with Kidney Disease and Their Caregivers [Internet]. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); 2020 Oct. PMID: 37535795.

Barriers to adoption

- Digital literacy gaps
- Health literacy challenges
- Privacy/security concerns
- Access to internet/devices
- Social determinants of health



Health Disparities

- **Risk of widening disparities** but also the **potential to overcome** certain barriers (transportation, language, etc.) and **differential impact** among populations

- Strategies to mitigate disparities:
  - Plain language
  - User-centered design
  - Availability in multiple languages
  - Multimodality formats
  - Low-bandwidth options
  - Digital literacy support

Key Takeaways

- Patient activation is essential to increase patient self-management and adherence to guideline-informed care
- Digital tools can facilitate patient activation and self-management, but barriers must be addressed
- More research is needed to determine if patient activation improves outcomes in in the CKD population

DISCUSSION