Advancing Kidney Health
Through Optimal Medication Management

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Part 3: Medication-Related NEEDS: What Black Persons with CKD say they need from healthcare practitioners and the healthcare system

Glossary of Terms

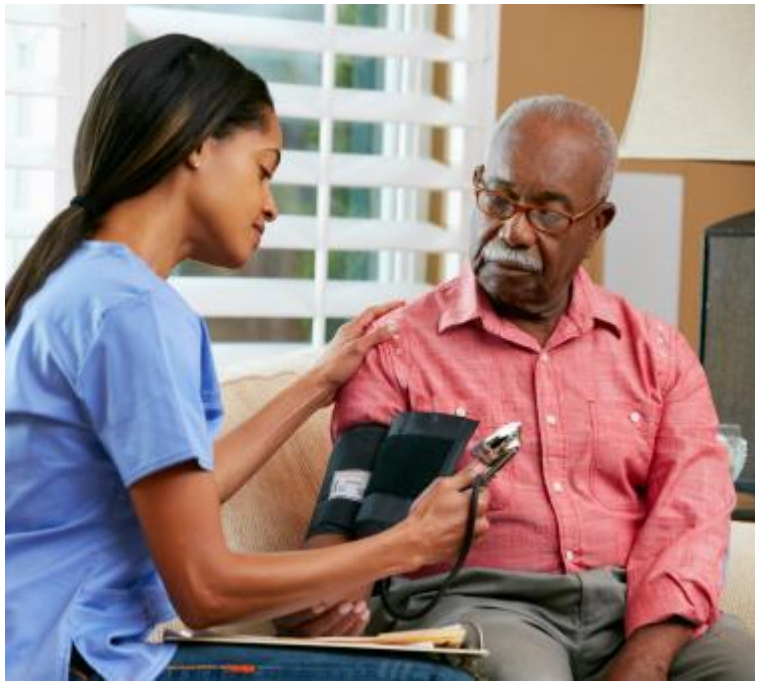
- **CKD** = chronic kidney disease
- **CKD-EPI** = Chronic Kidney Disease Epidemiology Collaboration
- **cys** = cystatin C
- **GFR** = glomerular filtration rate, either estimated (e) or measured (m)

Roadmap

1. Why this matters
2. Awareness and identification:

   Screening for CKD
3. Medication-related needs and desires for alternatives
4. Key takeaways

Why this matters



- High CKD prevalence in Black persons[1]
- Early identification key to prevent and delay progression[2]
- Effective CKD self-management requires active patient engagement[2]
- Awareness of CKD remains low[3,4]

1. https://usrds-adr.niddk.nih.gov/2022/supplements-covid-19-disparities/14-racial-and-ethnic-disparities, accessed 4.17.2023
2. https://kdigo.org/wp-content/uploads/2017/02/KDIGO_2012_CKD_GL.pdf, accessed 4.17.2023
3. Chu et. al. AJKD 2020; 76(2):174-183
4. Murphy et. al. J Gen Intern Med 2019; 35(1):298-306

Patients are not aware of CKD

"It's [kidney disease] not monitored regularly like high blood pressure. Had mine been monitored earlier, I may not have had the impact that it had. When…my nephrologist, … she looked at me and she said, '[name], you're going to have to go on dialysis.' And it was like, what are you talking about?"

Female, age 66, KTx (Previously PD, IHD)

"And I says, 'Oh no, I'm not going to do any dialysis'…Can't you give me a pill or something to reverse this?...' She looked at me, she said, 'Fine.' She said, 'You will die.' And then I said, 'Whoa, this is serious.' I'll always remember that conversation."

"I have never been given anything that the doctor says, 'This is going to help your kidney.'"

Female, age 56, ND-CKD

IHD = incenter hemodialysis
KTx = kidney transplant
PD = peritoneal dialysis
ND-CKD = non-dialysis CKD

St. Peter et al. University of Minnesota, Office of Discovery and Translation grant, interviews conducted in summer 2022

What patients recall early in the diagnosis

"And my kidney function was slowly decreasing … I did not get into the seriousness of it. I wish that I had that class right at that stage. … If I had taken that class, which showed the progression of the disease, I probably would've taken it more seriously."

Female, age 67, IHD

"Well, as far as my kidney disease is concerned, there is no starting point. He [nephrologist] has not said, 'Take this medicine,' or, 'This is what's going to happen to your kidney tomorrow,' or, 'This is what we're trying to prevent.' Or 'This is where we're going to.' He has no endgame."

Female, age 72, ND-CKD

"…it was high blood pressure that they said caused my chronic kidney disease. Initially, when it was at stage three, I didn't inquire more about what I should do to slow the progression."

Male, age 70, ND-CKD (previously IHD)

IHD = incenter hemodialysis
ND-CKD = non-dialysis dependent CKD

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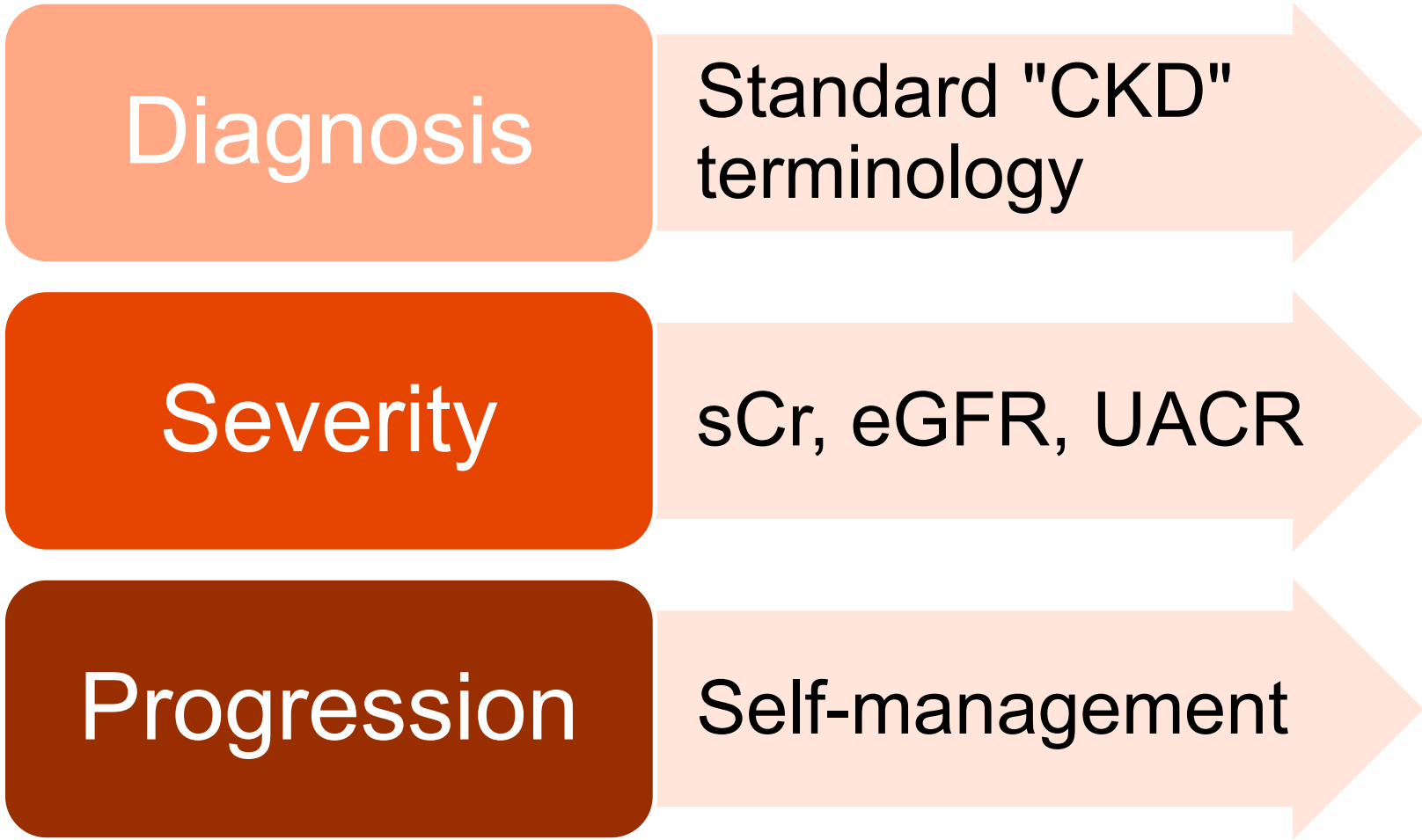
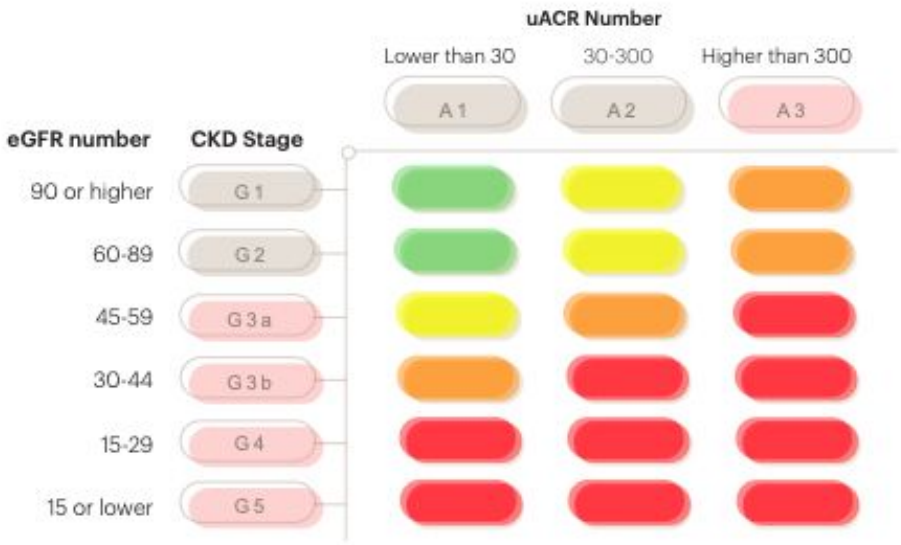
What does this mean for patients?



Know Your Numbers to:
Screen, Diagnose, Monitor CKD progression

Labs	**sCr** Serum creatinine to estimate eGFR **UACR** Urine albumin to creatinine ratio
Practitioner	**Order** labs [clinic or point-of-care in pharmacy] **Educate** and **engage** patient
Patient	**Know** their numbers **Track** their numbers

Practitioner Tools



CKD HEAT MAP

On the *left side* of the map, your eGFR number matches up with a CKD stage. A higher eGFR number is better because it means you have a lower CKD stage.

On the *top* of the map, your uACR number matches up with a uACR level. A lower uACR is better because that means less albumin in the urine.

Green you do not have CKD, or you are at the lowest risk for CKD getting worse

Yellow you are at increased risk for CKD getting worse and are at risk for heart disease

Orange you are at high risk for CKD getting worse and at greater risk for heart disease

Red you are at the highest risk for CKD getting worse or your kidneys to fail, and you are at a greater risk for heart disease

https://www.kidney.org/sites/default/files/kidney-numbers-ckd-heatmap.pdf, accessed 4.17.2023

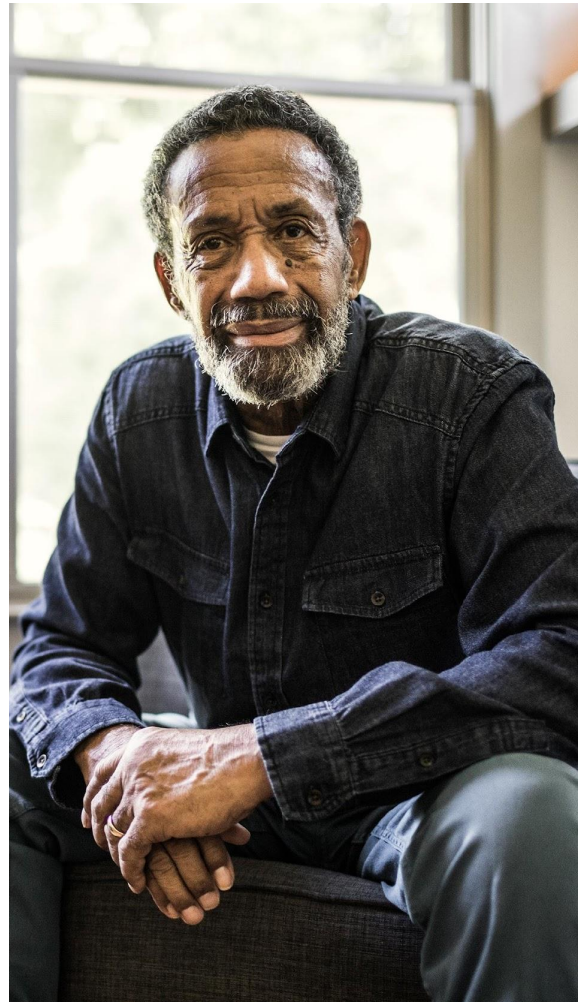
Screening and identification of high- risk patients

Recognize systemic bias

- Older race-based MDRD and CKD-EPIcr (2009) for Black persons
  - Overestimation of measured GFR
- New non-race based equations
  - CKD-EPIcr (2021), CKD-EPIcys (2012), CKD-EPIcr-cys (2021)

Potential consequences

- Lack of early detection
- Undertreatment



https://www.kidney.org/newsletter/what-new-egfr-calculation-means-your-kidney-disease-diagnosis-and-treatment, accessed 4.17.203

Delgado C et al. JASN 2021; 32(12):2994-3015

Practitioner-Level Bias: Assumptions

"[Patient had] a high school education, very little income, and brittle diabetic, and needed to start kidney replacement therapy. In the conversation with her physician there, transplant never came up and peritoneal dialysis never came up as options for her."

"In the conversation, it became very clear to me that there were a lot of assumptions that were made based upon her education. The fact that he knew, financially, that she didn't have a lot of means and assumptions as to would she be able to handle it."

Physician, Female, Age 40-49, African American

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What practitioners say about patient understanding

May be reasons patients don’t ask questions (i.e., fear of judgement)

Don’t know if don’t ask

Don’t assume patients know why they are at an office visit

Practitioner reflections

"but, what questions do you have. Trying to just... Because I think a lot of people have them. And when you're asked, do you have a question?, well, if I say yes, maybe that means I'm going to be judged for it."

Physician, Female, Age 30-39, Asian/Caucasian

"And so, I thought with me, as well as my other colleagues who had been taking care of him, that he was understanding, and I guess that was a misconception on my part."

Physician, Female, Age 40-49, African American

"If I'm seeing somebody for the first time, whether they've seen other nephrologist, whether this is the first time or they were referral…Tell me what you understand about why you're here."

Physician, Female, Age 30-39, Asian/Caucasian

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Choice with medications

- Determine patient autonomy
  - See ‘Don’t Assume’ module 2
- Include patients
  - Offer choices
  - Incorporate other things they can do alongside taking medications

“And I always ask for an alternative, I just like to call it a second opinion, because if I've heard something about a medication and this doctor wants to prescribe it, I'm like, "Hey, is there anything else that I can take? Because I've heard this medication does this." Sometimes there is an alternative choice. Sometimes there's not.”

Female, age 44, HHD (previously IHD, KTx, x 2)

1. Abel, W. M., & Barksdale, D. J. Advances in Nursing Science 2012; *35*(4): E1–E8.
2. St. Peter et al. University of Minnesota, Office of Discovery and Translation grant, interviews conducted in summer 2022

IHD = incenter hemodialysis
KTx = kidney transplant
HHD = home hemodialysis

Patients want alternatives to medications

"I had adopted this whole idea of trying to keep all the chemicals out of my system. So, most of the stuff that I did was all natural. I had to learn how to cook…, I got rid of processed foods and all this other stuff. Number one, because I didn't really want to take the pain meds that were associated with gout."

Male, age 55, KTx (IHD)

"I just wish that they would also consider CBD oil and cannabis products as far as dealing with your depression."

Female, age 67, IHD

IHD = incenter hemodialysis
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How alternative treatments are discussed with patients

"My doctor, … that's one of the things that has kept me with her, is the fact that she is willing to discuss the medications with me…, but she doesn't really discuss alternatives. "

Female, age 67, IHD

"Now I have not ever been offered alternative choices. … [my] nephrologist discourages that because we never know how that might impact the kidney function. So, the discussions are always open. … but unfortunately, I haven't found any other alternative options. I would love to find natural options."

Female, age 54, ND-CKD (previously HHD, IHD)

"I hadn't really been given alternatives for different medication, but for lifestyle changes, … But the doctor has never really given me an alternative to the medications that they prescribed. It's pretty much you take the medication and then you do these additional things to help yourself and that's about it."

Female, age 59, ND-CKD

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Synergistic diet and medication strategies: Involve a dietitian!

Blood Pressure	• Reduce Sodium
Blood Glucose	• Improve blood glucose and A1c
Weight Management	• Weight control strategies
Potassium	• Optimize dietary k+
Lipids	• Reduce LDL
Calcium and Phosphorus	• Reduce phosphorus intake
Bowel Regimen	• Increase dietary fiber

Having the discussion: alternatives for Medical Nutrition Therapy (MNT)

Check the evidence	KDIGO	KDOQI
NKF	https://www.kidney.org/nutrition	
Consult	RDN at www.eatright.org	Medicare*

Ikizler et al. AJKD 2020;76(3)(suppl 1):S1-S107
Rossing et al. Kidney International Suppl 2022; 102(5): S1-S127

Patients *want* to know and *deserve* to know they are on the best and safest medications for *them*

"I had a good relationship with my pharmacist and so I was able to have my group of individuals to answer my questions and give me some comfort and knowing that what was being prescribed was the best medicine for the transplant to survive."

Female, age 68, KTx (IHD)

IHD = incenter hemodialysis
KTx = kidney transplant
HHD = home hemodialysis

"And I also don't let my nephrologist rush me. ... We are going to sit and talk about this. This is my body. I only have one me. It's not like I can go on Amazon and order another me, even though Amazon has everything, trust me, I've looked, but there is not another me on Amazon."

Female, age 44, HHD (previously IHD, KTx X 2)

"letting your doctors know, 'Hey, I'm on these medications. You want me to take this. Is there going to be any type of issue with this and these?' And a lot of doctors will say, 'I don't know.' And it's like, 'Okay, well, until you can find out, I'm not going to take this.'"

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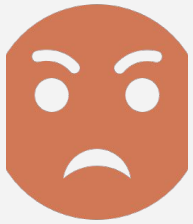
Drug Safety: from the patient perspective



What are the side effects?

Is this safe for dialysis?

Did you check?

"But the first question I always ask, if they offer me something, I say, "What are the side effects?"

Female, age 70, IHD (previously PD)

"I'm taking these medications and I'm on dialysis. Is this going to be a problem with me taking this?"

Female, age 66, KTx (previously PD, IHD)

"Okay, well, can you find out first? Because I'm not going to take something that's going to cancel the effect of another medication."

Female, age 44, HHD (previously IHD, KTx X 2)

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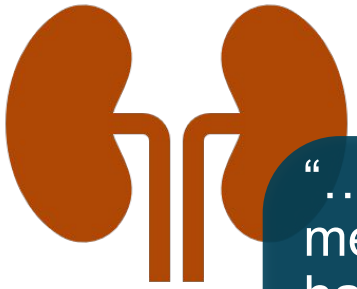
Impact to CKD progression: How will this help? How will I know?



"…I didn't realize [that by not taking my meds] it was killing my kidneys. If somebody had told me that, like my A1C, 'Mr. X, you don't get your A1C under control, you going to be on dialysis.' That never was told to me by no physician."

Male, age 58, IHD

"Nothing. They just told me that, 'You need to get your A1C together. It's running too high.' They always tell you about diabetes and vision, but nobody really had told me related to kidney failure."

"it was my primary care physician who talked to me about stress and how that affected my kidneys. …and how the blood pressure would work to lessen the work of the kidneys, and hopefully that will slow it down a little bit."

Male, age 55, KTx (previously IHD)

IHD = incenter hemodialysis
KTx = kidney transplant

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What happens if medications are not taken?

"But my thing is telling me the knowledge of the effect the medicine have on me. ... Okay, I can handle that, but why I'm taking it twice a day. What'll happen if I don't take it twice a day?"

Male, age 58, IHD

"I researched the medications and I speak to my doctor and find out why I need this medication. What would happen if I didn't take it?"

Male, age 55, KTx (previously IHD)

IHD = incenter hemodialysis
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Patients need cost of medications addressed

"Well, one of the medications I had stopped taking because the copay was so high, but it's not just the medications. I have other support things like the type of soap I need to use and all of that, the kind of lotion I'm supposed to use."

Female, age 72, ND-CKD

"But it's just the cost of the medication. Sometimes I have to decide which one is more important to take, which one do I have to take every single day?"

Female, age 56, ND-CKD

"Don't make it like it's just a big secret to where I have to go to dialysis and find out that this person here is getting assistance for a medication and they don't have to pay anything. Meanwhile, I'm having to make a life choice between getting the medication or buying a loaf for bread to eat."

Female, age 44, HHD (previously IHD, KTx X 2)

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Patients want practitioners to communicate with each other

"And so my doctor and pharmacist and everyone, they all see everything. That's one of the benefits that I love about it [the portal]. So, when we talk about different doctors, communicating...they actually do that through… the portal system…"

Female, age 48, ND-CKD

"What angered me was … you have so many physicians. …neurologist, urologists, nephrologists, primary care, psychologists, all of these physicians and different physicians, they're ordering medication and they're not communicating, or they're not looking at your record."

Female, age 66, KTx (previously PD, IHD)

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Expectations patients have of practitioners about their medications

- Why are you giving me this?
- What are the side effects?
- Does the good outweigh the bad?
- What if I miss a dose?
- What happens if I don't take this?
- How does this affect my kidneys?

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Summary

ELICIT

- Health and medication priorities

ASSESS

- Desire for involvement and knowledge level

PROVIDE

- Tools for CKD awareness and understanding

COMMUNICATE

- Consistent messages to patient

DISCUSS

- Alternatives and fit with overall therapy plan

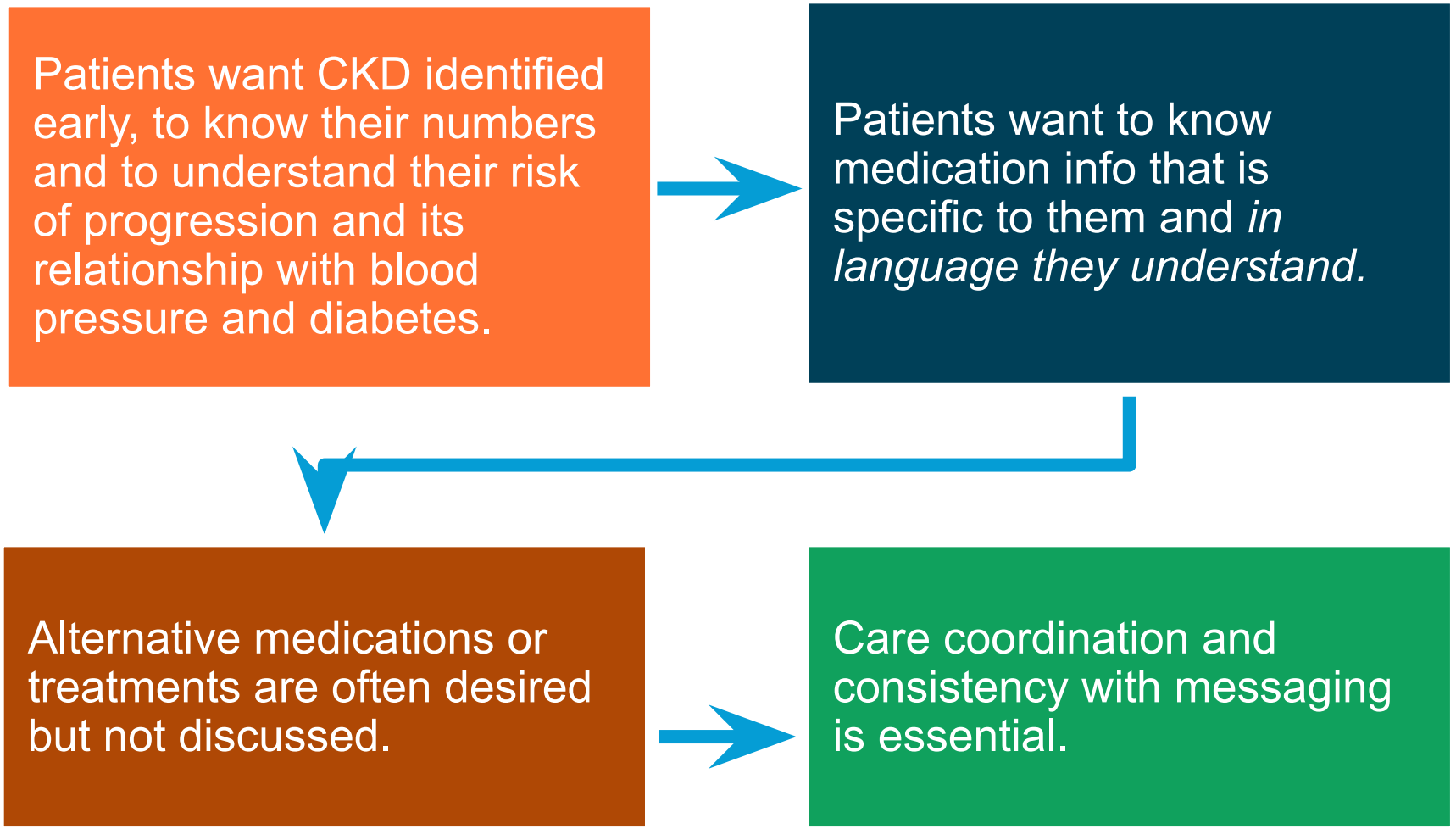
EDUCATE

- About expectations of medications and safety

TAILOR

- To desire for involvement and literacy level

Key Takeaways



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Thank you!

https://twitter.com/kidneymedmgmt

Additional References

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