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For patients: FAQs about eGFR waiting time modifications

What Black kidney candidates impacted by race-inclusive eGFR calculations need to know about the OPTN policy action.

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Are you Black or African American and waiting for a kidney transplant? If so, you could qualify for more waiting time to help you get a transplant sooner as the result of an <u>OPTN policy action</u>.

This page has additional information about what's involved and what patients on the waiting list can expect.

Background

What is "waiting time"?

- Waiting time is the time you earn after you meet specific requirements and are listed by your hospital for a transplant in the OPTN Computer System.
- It is one of many factors used to match organs to patients on the waiting list (patients on the waiting list are known as **candidates**).
- Having more waiting time may help you get a transplant sooner.

What is a "waiting time modification"?

- It is a way to adjust a candidate's wait time in the OPTN Waiting List.
- Transplant hospitals request waiting time modifications (PDF) on behalf of their candidates.

What is eGFR and how is it used?

- The estimated glomerular filtration rate, or eGFR for short, measures how slowly or quickly kidneys remove a waste product called creatinine from the blood. This calculation helps doctors understand how sick a kidney patient is.
 - Some calculated GFRs that use a race factor are called **race-inclusive calculations**
 - Calculated GFRs that do not use a race factor are **race-neutral calculations**
- OPTN policies formerly did not specify the type of calculation that transplant hospitals must use when assessing patients for kidney transplant.
- Race- inclusive eGFR calculations give different results for Black patients that make Black patients' kidney function look better than it is and may have had an impact on when you began to accrue waiting time for a kidney transplant.
- Not all Black kidney candidates have had their eGFR measured with a race-inclusive calculation.
- Learn more about race and eGFR.

What is changing?

- The OPTN changed policy to require that transplant hospitals must use a race-neutral calculation to determine a kidney transplant candidate's eGFR. Transplant hospitals are <u>no longer allowed to use a race factor</u> in calculations that estimate your kidney function.
- If you are Black, your treatment provider may have measured your kidney function with a race- inclusive eGFR.
- If your doctor used a race-inclusive eGFR calculation, you may qualify for a waiting time modification.

Will affected candidates be receiving any additional prioritization?

- Some candidates could gain more waiting time, which is an important factor in receiving a kidney offer.
- Your transplant program should provide documentation to support increasing your waiting time to the amount it would have been using a race-neutral eGFR calculation.

Who qualifies

Who qualifies for a waiting time modification?

Kidney candidates qualify if all the following apply:

- Their transplant program registered them as Black or African American on the OPTN waiting list.
- Their transplant program has laboratory values or documentation showing that the candidate's eGFR value was over 20 mL/min when their treatment provider used a race-inclusive eGFR calculation.
- Their transplant program can show that their eGFR value would be 20 mL/min or less if their treatment provider used a race-neutral eGFR calculation.

Could my waiting time be decreased?

• No. Your waiting time will not be decreased for any reason. It will either stay the same or be increased.

Is this just for adult kidney patients?

• No. Adult and pediatric kidney patients may qualify for additional waiting time if they meet qualifying criteria according to OPTN policy.

What kidney candidates can expect

What happens next?
Your transplant team will contact you to tell you two things:
That they are they are checking your records

- That your waiting time will or will not increase
- After they assess their waitlist, your transplant hospital will submit any requests for waiting time modifications to the OPTN.

How long does my transplant hospital have to submit eGFR waiting time modifications?

- Transplant programs are required to submit eGFR waiting time modifications by Jan. 3, 2024, but can do so any time.
- This timeframe allows transplant programs enough time to:
 - assess their waiting list candidates.
 - notify you and all other candidates.
 - get labs or documentation.
 - submit eGFR waiting time modification requests to the OPTN.
 - tell the OPTN they have completed the policy requirements.
- Your transplant hospital is required to take all of these steps within this timeframe.
- Only your transplant hospital can submit a request for a waiting time modification to the OPTN.

What your transplant hospital is looking at

What documentation is my transplant team looking for?

- Your transplant team is looking for evidence that you were disadvantaged due to the use of a race-inclusive eGFR calculation.
- Required documentation can include:
 - a lab report that shows a candidate's eGFR value for Black and non-Black candidates (widely available at larger labs) with a race-inclusive calculated value of greater than 20 for Black candidates, and a value of less than 20 for non-Black candidates

OR

- a documented re-estimation of the candidate's GFR with a race-neutral eGFR calculation, which shows an eGFR value of 20 or less
- It is the transplant program's responsibility to look for labs or documentation and while candidate participation is encouraged, it is not required.
- Learn more about <u>race and eGFR</u>.

I think I might have copies of my labs and documentation. Can I share any of it with my transplant hospital?

- Yes, you should communicate with your transplant team if you feel you have information that would assist the evaluation.
- It is the transplant program's responsibility to look for labs or documentation and while candidate participation is encouraged, it is not required.
- Your transplant program must submit your documentation to the OPTN. Please do not send your materials to the OPTN Contractor (known as United Network for Organ Sharing, or UNOS).

How can I get copies of my labs or documentation if I don't have them?

- You may need to contact your referring doctor, your dialysis center, or other prior medical providers.
- These providers may have labs or documentation that your transplant hospital does not have in their system.
- It is the transplant program's responsibility to look for labs or documentation and while candidate participation is encouraged, it is not required.

What if I find supporting documentation after Jan. 3, 2024?

- Candidates may provide their transplant program with supporting documentation at any time.
- While Jan. 3, 2024, is the deadline for programs to comply with this policy, is not a cutoff date for modifying waiting times.

• If you find supporting documentation after Jan. 3, 2024, contact your transplant team.

More questions

I'm Black. How do I know if my doctor used my race as a factor to calculate my eGFR?

- It is possible that your treatment provider used a race-inclusive eGFR if your eGFR was calculated before July 27, 2022.
- Before that date, OPTN policy did not specify how transplant programs must calculate your eGFR.
- Talk to the transplant team where you are registered on the kidney transplant waiting list for more information about how your transplant program calculated your eGFR.

I'm not Black or African American but I am waiting for a kidney transplant. How does this policy impact me?

- Waiting time for non-Black candidates will not be impacted.
- Non-Black candidates do not qualify for eGFR waiting time modifications as those candidates would not have had their kidney function measured with a race-inclusive eGFR calculation.
- Black candidates who qualify for eGFR waiting time modification will get more waiting time. Waiting time is an important factor in receiving a kidney transplant. Black candidates who receive an eGFR waiting time modification may move higher up the <u>matching system</u> than other candidates with less waiting time.

I have more questions. Who can I talk to?

- Talk to your transplant team. They are the best resource for specific information about your treatment including the calculation of your waiting time.
- If you receive care from a kidney doctor outside of your transplant hospital, ask your kidney doctor if they used a race-inclusive calculation of your kidney function. Share this information with your transplant team.
- For general questions, call the OPTN Patient Services line at <u>(888) 894-6361</u>. They are available Monday Friday, 8:30 a.m. to 5 p.m. (ET).