



# Patient Perspectives on Integrating Risk Prediction Into Kidney Care: Opinion Piece

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## Abstract

Although Chronic Kidney Disease is common, only a relatively small proportion of individuals will reach kidney failure requiring dialysis or transplantation. Validated risk equations using routine laboratory tests have been developed that can easily be used at the bedside to help clinicians accurately predict the risk of kidney failure in their patient population, in turn informing patient-centered conversations, guiding appropriate nephrology referrals, improving the timing of dialysis treatment planning, and identifying individuals who are most likely to benefit from interventions. In this article, individuals living with kidney disease share why access to individualized prediction of kidney failure risk can help patients manage their disease and why it should be considered an essential component of kidney care.

## Keywords

patient perspectives, opinion, kidney failure risk equation, KFRE, risk prediction

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## Introduction

To reduce the risk of progression of chronic kidney disease (CKD) to kidney failure, early detection and management of CKD is critical, especially for individuals who are at highest risk of progression. The Kidney Failure Risk Equation (KFRE) is a simple, externally validated predictive model for kidney failure, and has been shown to outperform the level of risk estimated by patients and physicians.<sup>1</sup> The 4-variable equation incorporates age, sex, estimated glomerular filtration rate (eGFR), and urine albumin-to-creatinine ratio (ACR), whereas the 8-variable version additionally incorporates albumin, bicarbonate, calcium, and phosphate.<sup>2,3</sup> The KFRE (Figure 1) can be used at the bedside to help clinicians accurately stratify patients according to their level of risk of kidney failure, consequently allowing for clinicians to appropriately treat high-risk patients while safely monitoring low-risk patients, and can also be used as a tool to assess health care resource utilization and associated costs.<sup>4</sup> The KFRE is also a valuable resource to guide CKD education and shared decision-making between clinicians and patients, and provides patients with accurate information about their prognosis. In this article, we share the journeys of 3 individuals living

with CKD and their reactions to the use of risk prediction equations. Their comments highlight how sharing prognosis can inform honest, patient-centered conversations between patients and clinicians and why it should be considered an essential component of kidney care.

## Dwight Sparkes

*I was diagnosed with Systemic Vasculitis and Interstitial Nephritis in 2014. Soon after my kidney function dipped into the low thirties but, by watching my diet and keeping my blood*

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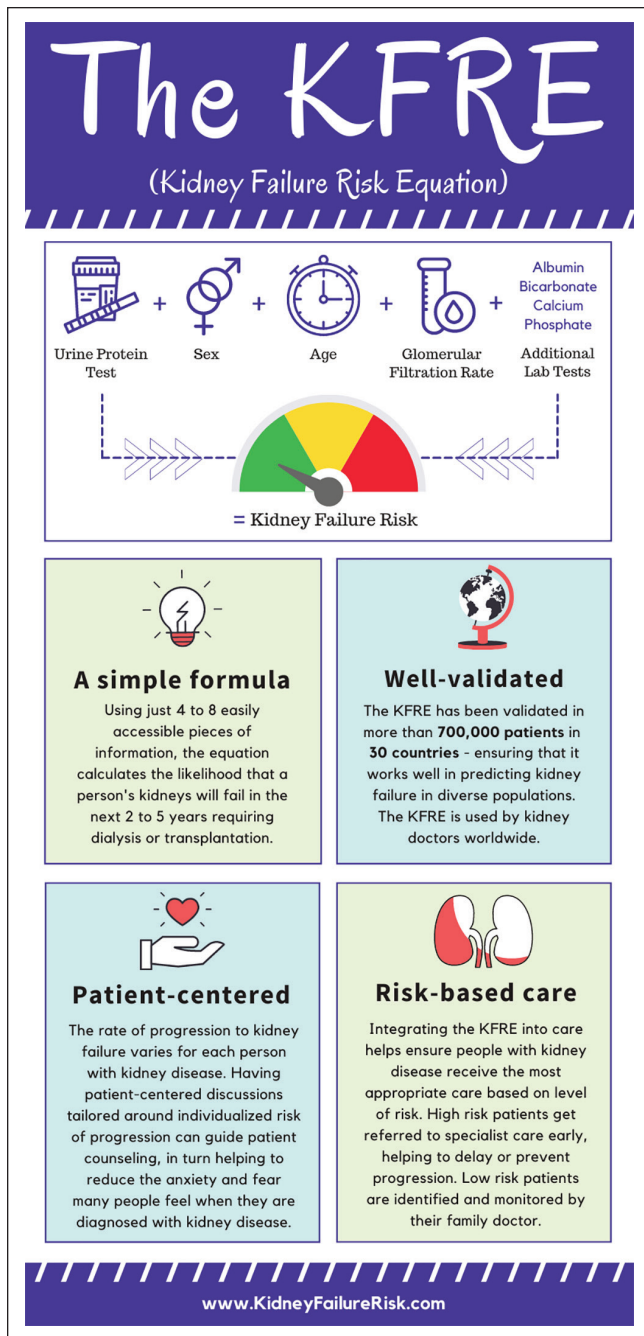
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**Figure 1.** Key facts about the KFRE. The KFRE incorporates age, sex, eGFR, and urine ACR to predict risk.

Note. The 8-variable version also incorporates additional laboratory tests albumin, bicarbonate, calcium, and phosphate. KFRE = Kidney Failure Risk Equation; eGFR = estimated glomerular filtration rate; ACR = albumin-creatinine ratio.

pressure low, has since rebounded to the high forties/low fifties. Since then my vasculitis has gone into remission but I still live with the effects of CKD every day. When my nephrologist diagnosed me with CKD, I was devastated. He basically told not to eat salt and sent me on my way. Every day I woke up

thinking that my kidneys were going to fail at any point and that I would require a transplant, or even worse, I would be hooked to a machine for 3 or 4 times a week for hours on end for dialysis. For an active person like myself the prospect of this life was terrifying. If the KFRE was used, I am certain that I would not have had the mental anguish I endured up to that point. Three years after I was diagnosed, I remember receiving the results of my actual risk of kidney failure, and learned that the odds of my kidneys failing were very, very low, actually less than 5%, and a wave of relief washed over me. It did not mean that I could stop following my renal diet, exercising, and controlling my blood pressure, but it removed the fear and worry that I was feeling.

I think patients should be told of their risk of kidney failure when they are diagnosed with CKD. The KFRE can give patients some peace of mind about the risk of their kidneys failing. A nephrologist might tell a patient that their chances of their kidneys failing are low, but what does "low" mean? 30%, 15%, or 5%? It is a very relative term. The KFRE can actually give the patient a fairly precise value. I think this information should be delivered to patients using digital infographics with graphics and short bullet points, and made as interactive as possible for patients. As long as patients successfully manage their disease by following their diet and controlling their blood pressure, the equation can give patients peace of mind and motivation to follow their doctor's guidelines.

Providing patients with their risk of kidney failure can motivate them to keep it low, as well as give patients back some control over their life. By knowing that they can reduce their kidney failure risk, they can enjoy their life more fully and not have to be consumed with worry over their kidneys failing. The KFRE is an amazing tool that can reduce patients' fears and worry and can lead to improved quality care.

### Loretta Lee

I was diagnosed with CKD in 1992 and there was no KFRE in use. I think that had it been available, it would have helped me understand the trajectory of the disease progression. In this way, I could have perhaps been more invested in education and learning what the "no-no's" are.

Advising people of their kidney failure risk would give them the option of coming to terms with it sooner and therefore following all the advice from the nephrology team. This is especially important given that you often don't really find out about the state of the kidneys until it's too late, so there is a frantic change of course to medically manage the disease to extend the life of the kidneys. Also, this information is important in care planning and to ensure family understands the gravity of their relative's health.

I think the KFRE should be presented in-person so that the patient/family have the opportunity to receive further direction, connect with the kidney community and resources which include one-on-one supports. This is the pivotal point.

The news is often met with some degree of denial or shock so the more we can soften and educate with a positive spin is essential. More importantly, is that the patient/family need to understand what they can do to stay healthy as long as possible with the best kidney function. This often means managing other comorbidities such as hypertension and diabetes. In other words, the people need a team of care.

Ideally, people should have their kidney function level, blood pressure, and diabetes routinely monitored. People should be educated early on in their disease course about kidney disease so they don't get that big surprise at some point where they finally have their healthcare provider test their kidney function and low and behold, they are sitting at CKD Stage G3 A3 (eGFR 30–59 mL/min/1.73 m<sup>2</sup>, and a urine ACR ≥30 mg/mmol). The KFRE tool should be used early with changes noted, and routinely in someone who has moderate disease according to the KDIGO guidelines.

### Blair Rutter

I was first diagnosed with CKD in 2012 when my family doctor noted I had a high creatinine level during an annual check-up and referred me to a kidney specialist. I was diagnosed with stage 3 CKD which has slowly progressed to stage 4. The cause of my CKD is unknown, although I did have a car accident with major internal injuries in my late twenties so perhaps that was a contributing factor. I've also had hypertension since my early thirties which has been controlled by medication. Now retired, my hypertension medication has been reduced and my blood pressure has remained good.

I see the KFRE as a good tool for clinicians and their patients to assess risk. That said, it is only effective if doctors provide patients with all the relevant information that would allow them to assess their risk and track it over time. I see too that the equation has been further refined (by adding albumin, phosphorus, bicarbonate and corrected calcium measures) and so providing this information to patients is important too—for one thing, it will prompt patients to ask about the importance of these factors and what steps (diet or lifestyle changes) that might be taken to improve these measures.

As an example, this past winter I unwittingly started to take vitamin D supplements (because the pandemic meant we did not have our usual winter vacation to a sunny locale, and because I had heard that vitamin D was helpful in combatting COVID-19). Unfortunately, this had an adverse impact on my calcium levels. It served as a reminder that kidney patients should never take over-the-counter supplements or medications without first consulting with their family doctor or specialist. In my view, this is something clinicians need to stress with their patients – who knew something as innocuous (or so I thought) as vitamin D would have an adverse impact on my kidney health?

I believe the improvements I have made in my diet, weight control and (admittedly modest) exercise has helped slow the

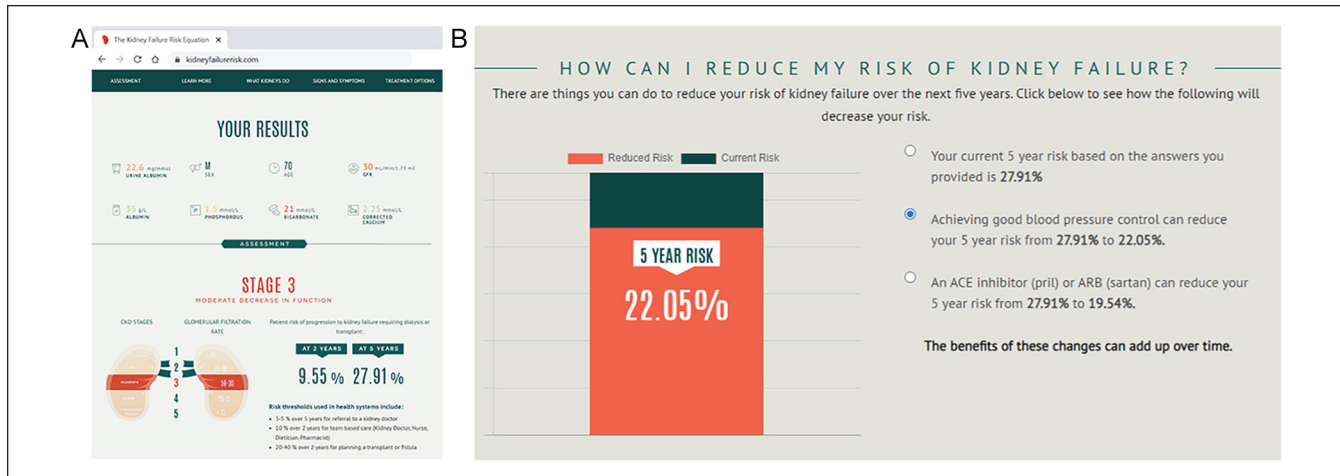
progress of my kidney disease. At the outset of my CKD diagnosis I was given a 10% chance of having kidney failure within 5 years. Nine years later, while my risk of failure is now higher, I am optimistic that continuing a healthier lifestyle will give me several more years of kidney function. To me, it's a case of needing to provide patients with the information in the format that best suits them. I'm good with pamphlets, dietary guides and conversations with my doctors, although I do think it would be good to sometimes involve the patient's partner (or caregiver) in the conversation so they too can be aware of helpful strategies, and help "monitor" the patient's diet and lifestyle choices.

My experience with CKD has (so far) been a positive one, and with continued monitoring, information and advice, I hope to have several more years of travelling and spending time with grandchildren.

### Conclusion

Although the prevalence of CKD in the general population is high, only a relatively small number of individuals will reach kidney failure requiring dialysis or transplantation. Integrating tools directly into clinical care that can aid in accurately predicting the risk of CKD progression can improve the transition from primary care to nephrology, ensuring that the individuals who are most likely to progress are referred<sup>5-8</sup> and that the care being provided is appropriate to the level of risk. The KFRE should be built into electronic health records in primary and nephrology care settings to provide tailored alerts and prepopulated order sets based on guideline-based recommendations, allowing for upstream risk-based care and treatment. Risk scores should be integrated into care plans for patients to follow, based on no current risk, low, intermediate, and high using established cut-off points. Preventative lifestyle interventions and yearly screening in primary care should be recommended for those at low risk, whereas disease-modifying treatments and referrals to nephrology should be encouraged for those at intermediate and high risk, as per regional guidelines.

The KFRE is currently used as one of the criteria to determine need for nephrology referral in several Canadian provinces, as well as in health systems in the United States such as Kaiser Permanente.<sup>6,9</sup> In the United Kingdom in 2021, the KFRE was integrated into the updated CKD guidelines from the National Institute for Health and Care Excellence (NICE), with the suggestion of a threshold of >5% over 5 years for referrals.<sup>10</sup> In Manitoba, a 5-year kidney failure risk of >3% was introduced in 2012 as part of the nephrology referral process, resulting in a significant reduction in wait times to see a nephrologist, helping improve access to care for individuals with the highest risk of CKD progression.<sup>6</sup> There is ongoing research evaluating risk-based kidney care in various health care settings, including an ongoing multiphase



**Figure 2.** An example of how to present personalized risk and risk reduction strategies to a patient with kidney disease.<sup>8</sup>

mixed-methods study evaluating the implementation of a risk-based CKD care model in Alberta,<sup>11-13</sup> and an ongoing randomized controlled trial evaluating whether a risk-based approach improves CKD care in Canadian primary care clinics.<sup>14</sup>

The patient narratives surrounding risk prediction featured in this article highlight the benefits of integrating risk-based approaches into kidney care. Although only 3 narratives are presented in this article, and may not represent the general population of people living with CKD, the opinions align closely with a recent qualitative study exploring patients with CKD desire for prognostic information and its value.<sup>15</sup> Providing objective and accurate education to patients and caregivers through infographics and decision aids on the risk of kidney failure with information on how to modify and reduce risk factors has the potential to improve patient-provider communication (see Figure 2 for an example from [www.kidneyfailurerisk.com](http://www.kidneyfailurerisk.com)), and can ease some of the anxiety patients face when receiving a diagnosis of CKD, empowering patients to take control of their disease and improving their quality of life.

### Ethics Approval and Consent to Participate

No ethics approval or consent to participate were sought for this opinion piece.

### Consent for Publication

No consent for publication was sought for this narrative review.

### Availability of Data and Materials

Materials presented in this publication are available by contacting the corresponding author.


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