**An Interview with Courtney Jane Lightfoot, BSc, Msc, PhD, the second-place winner of the 2021 CJASN Trainee of the Year competition.**

CJASN Editor-in-Chief Rajnish Mehrotra interviewed Courtney Jane Lightfoot on the findings from her CJASN article, "Reliability and Validity of the Patient Activation Measure in Kidney Disease," as well as her outlook on the field and advice for trainees. Listen now!

Courtney Jane Lightfoot, BSc, Msc, PhD, is a mixed methods researcher working with the Leicester Kidney Lifestyle Team at University of Leicester, UK. She has an interest in patient activation, self-management, health and lifestyle behavior change, remote health care, and experiences of living with kidney disease. Lightfoot has led on the development of a theory- and evidence-based online self-management program for people with kidney disease called "My Kidneys & Me." She is now leading on both the evaluation and implementation of My Kidneys & Me.

**RM: Can you briefly introduce yourself to the CJASN audience?**

**CL:** I'm Courtney Lightfoot, and I'm a mixed-methods researcher working with the Leicester Kidney Lifestyle Team in the University of Leicester in the UK.

**RM: What sparked your interest in research in validating the Patient Activation Measure (PAM) in people with kidney disease?**

**CL:** There is increasing prioritization of the promotion of the concept of patient activation in nephrology with the hope of facilitating person-centered care. Patient activation is measured by an instrument called the PAM, the Patient Activation Measure. The PAM is increasingly being used in research and promoted by the British National Health Service (NHS). However, its relevance to individuals with kidney disease was unknown.

When using measures to assess constructs such as patient activation, it is important to consider the psychometric properties of a measure or instrument to ensure that it is an appropriate and suitable measure for the population in question, as failure to do this can result in measures not accurately capturing the construct.

**RM: That makes sense. What is the gap in knowledge that you were hoping to bridge with your work?**

**CL:** While the PAM has been validated for use in other chronic conditions such as COPD, diabetes, etc., this may not transfer across to kidney disease. We aimed to critically evaluate

the PAM and its applicability to CKD, so in other words, does PAM accurately capture the construct of patient activation in people with kidney disease. By describing the psychometric properties of the PAM for people with CKD, this enables clinicians and researchers to confidently use the PAM to assess patient activation in people with CKD.

**RM: So, what did you find?**

**CL:** Our findings showed that the PAM is highly reliable and a suitably valid instrument for assessing patient activation in CKD. However, we did observe a high ceiling effect, and this occurs when a large proportion of respondents score near the upper limit of the questionnaire. And this may be a problem if you are using the PAM to measure change over time. We also didn't observe a presence differential item functioning, so in other words, difference in the item characteristic curves between groups. We didn't observe this for CKD stage or for sex, although we did see differential functioning for some of the items between disease type and age. Whilst PAM-13 scores were identical between disease groups, this suggests that transplant recipients are more confident in taking actions to manage their health. And the difference between age groups suggests that older patients may lack the confidence in dealing with new or unfamiliar health problems. It may be assumed that self-management requirements change as disease progresses, although given the relatively nonspecific statements, patients may be able to appropriately adapt perceptions of their current health status with each item. In the absence of a kidney-specific instrument, the PAM-13 remains the best measure to assess patient activation.

**RM: There are a large number of patient-reported outcome instruments that are available. And many of them can provide valuable information to the care team. Where do you think the PAM fits in the care delivery for people with kidney diseases?**

**CL:** PAM can be used to assess activation levels and can be used as a screening tool for tailoring self-management interventions, or it can be used as a quality indicator for delivery of care. Patient responses to the individual items may help better guide specific clinical management than using the PAM levels generated alone. Using the PAM-13 could enable for more customized approach to tailoring interventions and preparing appropriate education for patients. Tailoring care to activation levels may facilitate more productive health care interactions and enable empowerment for the patients.

**RM: Your work is a meaningful advance with the validation of an important instrument in this patient population. What are the next steps in your research? And more broadly, for the field?**

**CL:** Thank you. The next steps of my research include using the PAM as a primary outcome in a multicenter randomized controlled trial called SMILE-K, which has been designed to assess the effect of a structured online self-management program for people with kidney disease, which is called "My Kidneys & Me." We are assessing the effect of My Kidneys & Me on patient activation levels and subsequent self-management behaviors.

And as for the field, further research is needed to develop interventions aimed at increasing patient activation and to determine if doing so improves health outcomes for people with CKD. It is also important to establish the relationship between PAM-13 with kidney disease-specific self-management tasks.

**RM: Thank you, this is important work. Congratulations again! What words of advice or wisdom do you have for people that are contemplating or just starting their research training with a focus on kidney diseases?**

**CL:** Thank you very much. I think it is important to remember why you started and what matters most to you. For me, it's to be able to help people with kidney disease live the best life that they can.