



PRESS RELEASE

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PATIENT AND CAREGIVER EXPERIENCES AND ATTITUDES ABOUT THEIR INVOLVEMENT IN KIDNEY DISEASE RESEARCH

Highlight

- Interviews of adults with chronic kidney disease and their caregivers who had previously been involved in kidney disease–related research identified various factors that supported their involvement or created challenges to participation.

Washington, DC (February 7, 2022) — Results published in *CJASN* that describe patients' and caregivers' experiences and attitudes while being involved in kidney disease–related studies may help strengthen efforts to involve patients in clinical research.

It's becoming increasingly clear to scientists that efforts to improve health outcomes for patients should consider what's important to the patients themselves, along with their caregivers. "Without speaking directly to patients and their families and actively including them in our research, we are missing an enormous opportunity to optimize our resources and make our research more meaningful," says Talia Gutman, PhD, of the University of Sydney, in Australia. "However, to be able to do this we need to understand their motivations for becoming involved and how to address barriers and support."

To address this, Dr. Gutman and her colleagues conducted interviews of 23 adults with chronic kidney disease (CKD) and caregivers who had previously been involved in research in Australia, the United States, the United Kingdom, and Denmark.

"We wanted to speak to patients and caregivers with lived experience of kidney disease to find out what drives their involvement, the challenges they've faced, and what has worked well to support them," Dr. Gutman explains.

The team found that participants faced challenges including the burden of living with kidney disease, the responsibility to seek out involvement opportunities, and obstructions of involvement by big agendas and power dynamics. Interview responses also highlighted opportunities to maximize patient and caregiver involvement through seeing the whole

person rather than just a patient, being sensitive to the complexities associated with financial reimbursements, and recognizing the importance of the patient voice.

The researchers used the results to develop a practical framework for investigators that may help them involve more patients and their families or caregivers in research.

“These findings highlight the need to include us—consumers—as early and as often as possible in the study design, bringing about benefits for the study, the researchers, and the consumers,” noted co-author Nicole Scholes-Robertson, BAppSci, a patient involved in the study. “I have learnt so much as a consumer involved in many different types of research.” Scholes-Robertson, who is a physiotherapist and a PhD candidate at The University of Sydney, added that a statement regarding the degree of consumer involvement (or lack thereof) should be a compulsory part of research publication.

Any accompanying Patient Voice article offers insights from Kevin Fowler, who received a kidney transplant in 2004 and is principal of The Voice of the Patient, Inc., a patient advocacy and patient-engagement consulting business.

Study authors include Talia Gutman, PhD, Ayano Kelly, PhD, Nicole Scholes-Robertson, BAppSci, Jonathan C. Craig, PhD, Shilpanjali Jesudason, PhD, and Allison Tong, PhD.

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The article, titled “Patient and Caregiver Experiences and Attitudes about Their Involvement in Research in Chronic Kidney Disease,” will appear online at <http://cjasn.asnjournals.org/> on February 7, 2022, doi: 10.2215/CJN.05960521.

The Patient Voice article, titled “Advancing Patient-Centered Research: Enabling the Patient Voice to Be Heard,” will appear online at <http://cjasn.asnjournals.org/> on February 7, 2022, doi: 10.2215/CJN.16401221.

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