

# What's important to patients with glomerular disease and their caregivers?

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Patients with glomerular disease and their caregivers highly prioritize kidney health and survival when it comes to treatment, but they also stress the importance of addressing factors related to life participation, fatigue, anxiety, and family impact. The findings come from a study that will appear in an upcoming issue of *CJASN*.

Glomerular diseases affect the glomeruli, or the tiny filters within the kidney where blood is cleaned, and patients can have a range of symptoms and unpredictable disease course. Patients commonly have poor kidney function, [high blood pressure](#), protein or blood in their urine, and diabetes. They also have a higher chance of kidney failure, cardiovascular conditions, serious infections, broken bones, and even death. Affected patients and their caregivers have had little input into which [health measures](#) are assessed in clinical trials.

To identify and better understand key health outcomes that are important to these individuals, Simon Carter, MBBS (The University of Sydney) and his colleagues conducted the SONG-GD initiative, which included 16 focus groups of adult patients with glomerular disease and their caregivers from Australia, Hong Kong, the United Kingdom, and the United States. The 101 patients and 33 caregivers in the study identified 58 outcomes. The 10 highest ranked outcomes were kidney function, death, dialysis or transplant requirement, life participation, fatigue, anxiety, family impact, infection and immunity, ability to work, and blood pressure. Three themes explained the reasons for these rankings: constraining day-to-day experience, impaired agency and control over

health, and threats to future health and family.

"The reasons why these outcomes were so highly prioritized were because they restricted and limited people's day-to-day living, reduced their ability to control or influence their own health, and threatened either their own future health or the health of their family," said Dr. Carter. "These life and family-related concerns are poorly studied so far in trials in glomerular [disease](#), but they are more important to patients and caregivers than other commonly reported outcomes such as relapse, remission, and proteinuria."

This study is part of the international Standardized Outcomes in Nephrology-Glomerular Disease project (SONG-GD) that is developing a core outcome set for [clinical trials](#) in adults with [glomerular disease](#). A core outcome set is a small number of outcomes that should be reported in all trials in a particular health domain because that knowledge is critically important to all stakeholders and users of the research. SONG-GD is part of the SONG initiative, which was launched in 2014 to develop core outcome sets for trials in all [kidney](#) diseases. "With the help of many international patient and professional organizations, the SONG initiative has now involved more than 9,000 participants internationally across its various streams—including 4,500 [patients](#) and caregivers, but also healthcare professionals such as doctors, nurses, allied health, researchers and industry partners, policy makers, funders, and regulators," said Dr. Carter.

**More information:** "Identifying Outcomes Important to Patients with Glomerular Disease and their Caregivers," *CJASN*, [DOI: 10.2215/CJN.13101019](#)

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