



What sort of platform will the KidneyCARE Study use?

The NKF has partnered with HHS Technology Group, LLC (HTG), a software and solutions company founded on the principles of agility, innovation, and transparency. All data collected through the KidneyCARE Study will be stored on the HTG's platform, Discover Your Data (DyD®), that is highly secure and meets all established standards for security of health information. The DyD® platform has the capability to connect to a myriad of health information systems safely and seamlessly.

What stage of kidney disease will be eligible to sign up?

The KidneyCARE Study welcomes patients at all stages of kidney disease, including dialysis and transplant patients.

How can I get more information on the KidneyCARE Study?

To learn more, visit the KidneyCareStudy.org. You can also contact the KidneyCARE Study team at **212.889.2210 x134**, M-F 10:00am–4:00pm CT, or by email at KidneyCareStudy@kidney.org.

KidneyCARE Study

Community Access to Research Equity™

National Kidney Foundation



30 East 33rd Street
New York, NY 10016
kidney.org



KidneyCareStudy.org

FAQs



KidneyCARE Study

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Get to know the
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What is the KidneyCARE Study?

The KidneyCARE Study is the first nationwide kidney disease patient registry that will advance both patient education and kidney disease treatment. This registry is a powerful research tool which can improve the lives of patients with kidney disease by better informing research, clinical care, drug development, and health policy decisions, as well as giving patients the tools they need to stay educated and healthy.

How does the KidneyCARE Study plan to gather research data and why is it considered to be innovative?

The KidneyCARE Study will collect both rigorous clinical and laboratory data from electronic health records (EHR) in addition to patient-entered data, which together allow for a “complete picture” of the patient. This model is considered innovative in that most research initiatives follow one path or the other—EHR or patient self-reporting. The KidneyCARE Study will compile data on demographics, medical history, lifestyle, medications; in addition to extensive data on patient perceptions, challenges, and priorities. The KidneyCARE Study data will also be linked to other data

sources, such as clinical trial study data that KidneyCARE Study participants participated in or data that is purchased commercially. The evidence-based data generated from this centralized platform will enable collaboration across NKF affiliates.

How will patients be invited to participate?

Healthcare professionals are critical to the Study’s success—help introduce your patients to the KidneyCARE Study and invite them to join by visiting us at KidneyCareStudy.org

NKF will also collaborate with health systems to obtain both electronic health care records (EHR) and patient-centered data. In parallel, patient enrollment will be achieved through a comprehensive outreach program that includes links from various other NKF programs, local NKF field office recruitment, links from clinical trials for kidney disease treatments, referrals from other participants and partners, and a direct public relations campaign.

To learn more, come visit us at

KidneyCareStudy.org

Why should I ask my patients to participate?

When patients participate in research, they are often required to share their medical history, which can be extensive. With the KidneyCARE Study, it’s simple for them to enter their health data through a secure patient portal, allowing researchers to quickly access and use it to develop new kidney disease treatments. Through the KidneyCARE Study, your patients will be able to contribute data that will aid in the success of clinical trials and ultimately patient outcomes.

What are other benefits of the KidneyCARE Study?

The KidneyCARE Study offers a simple way for your patients to access a wide variety of individualized kidney care resources—all of which have been verified and vetted by the National Kidney Foundation. In addition, through the Study, patients will be able to provide real time feedback to the research community on their condition and healthcare experiences. This information creates new opportunities for medicine and research that can target and help a wider range of patients based on their perspectives, priorities, and activities.