KidneyCancerAssociation®

Kidney Cancer Data Federation

Our Story

For more than three decades, the Kidney Cancer Association (KCA) has stood for excellence in research and education as well as services for patients and caregivers.

Fueling research has been a pillar of the KCA's mission since its inception in 1990 by a small group of patients and doctors in Chicago, Illinois. The organization has accelerated kidney cancer research by funding innovative research projects, awarding over 60 grants in 30 years.

In that time, therapeutic options for people with kidney cancer have increased. For so many more patients, the choice is no longer surgery or death. Thanks to the tireless work of researchers, advocates, and the thousands of patients who participate in clinical research, newly diagnosed kidney cancer patients may benefit from over a dozen treatments, including targeted therapies and immunotherapies.

The KCA is now leading the next era of kidney cancer research by harnessing new technology.

ERIC'S STORY

As a trained data scientist and health information expert, Dr. Eric Perakslis did his own analysis after his rare papillary renal cell carcinoma diagnosis in the mid-2000s.

"I looked at my stats, they were all horrible. My daughter was three years old and I roughly had about a 1/3 chance to see her reach her 8th birthday."

Although he was treated at a large cancer center, there was little existing data to help guide Eric and his care team about which treatments might be more effective than others or how to keep his constant migraines at bay. Surgery and physical activity helped Eric through to survivorship, but with more patient data, his journey could have been faster, easier, and more predictable.

We Need Data

When it comes to research, data is power. The more we know about the collective medical history, demographics, lifestyle, tumor types, treatments, and other outcomes among people with kidney cancer, the more powerful the toolbox for answering a wider variety of cancer questions.

The good news is that a lot of data about kidney cancer already exists thanks to decades of clinical trials, sizeable patient databases, and medical record keeping during routine treatment and care. Ideally, this information should be accessible to all researchers. However, there are three key obstacles that prevent access:

OBSTACLE #1

Siloed data

Hospitals or other commercial institutions with patient information databases make it laborious and expensive for outside research to access their internal data.

OBSTACLE #2

Limited data

The existing data can be limited in scope. For example, one database may only represent a few types of kidney cancer, treatments, or patient demographics.

OBSTACLE #3

Patient privacy

Institutions lack solutions for effective, collaborative data sharing while maintaining personal health information privacy.

These obstacles make it difficult for researchers to capture the wider clinical picture of the kidney cancer journey necessary to significantly move the needle forward.

Our Solution: The KCA Data Federation

The KCA Data Federation can overcome these three obstacles. Through a collaborative new research model, more researchers can access a larger, more diverse data set from disparate institutions quickly and efficiently without compromising data ownership or patient privacy.

> The KCA Data Federation has the potential for unprecedented breakthroughs that will make a meaningful difference to patients and families.

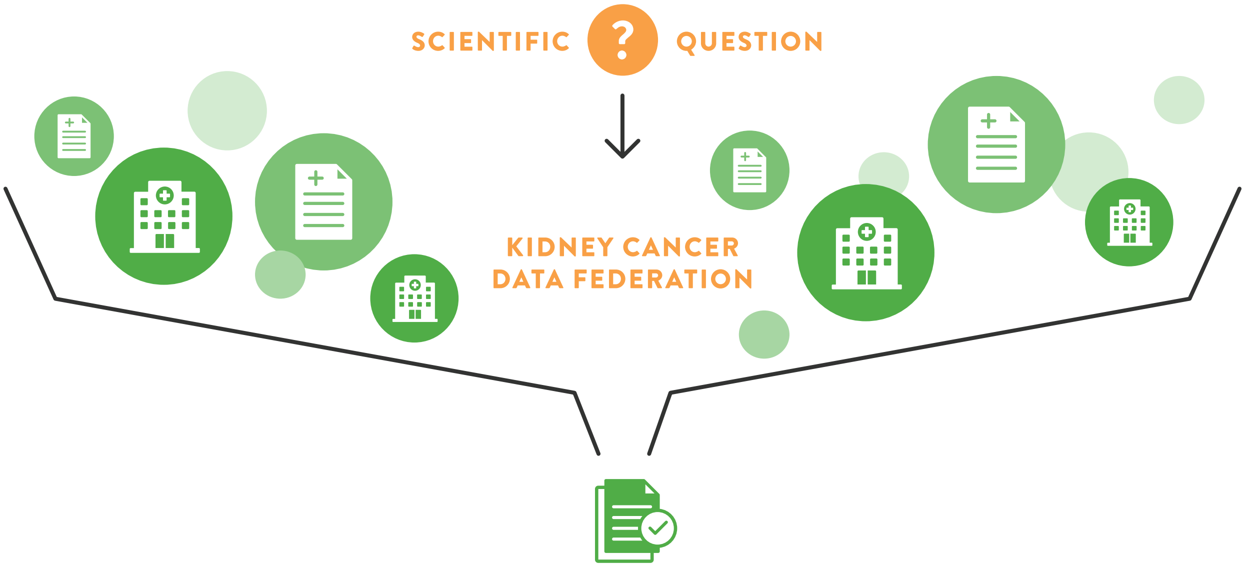
This type of access promises robust research with the potential for unprecedented breakthroughs in kidney cancer treatment and care that will make a meaningful difference to patients and families. For example, more diverse and robust data sets will bring to light never-before-seen trends and patterns in kidney cancer that will make it easier to identify who is more susceptible to developing kidney cancer, how factors like ethnicity or tumor type impact treatment response, or who might respond well to specific treatments.

This is particularly important among people with rare kidney cancer subtypes, where existing research is sparse and for whom treatment options are limited.

The KCA's Data Federation has limitless possibility to improve our understanding of kidney cancer and increase quality of life across the global kidney cancer community.

How Does The KCA Data Federation Work?

Suppose a researcher wants to know whether an individual will develop a rare type of kidney cancer. Uncovering a pattern would require a significant amount of patient data, but in this scenario only 10,000 people spread across thousands of hospitals in the US have this cancer type. Traditionally, a researcher would need to contact hospitals one by one and ask for data from those patients—an expensive and time-consuming process.



COMPILED AND ANALYZED DATA

(Maintaining patient privacy and removing institutional bias)

In simple terms, the KCA acts as a hub from which researchers can request data to fulfill a specific question. For example, a researcher may want to study the side effects of a certain treatment in relation to how often kidney cancer reoccurs in a specific age group. The researcher would submit their query to the Kidney Cancer Data Federation, which can access relevant data across all partner institutions. The data federation "hub" would collect all the applicable data points for this query and return the anonymized combined data, already analyzed, to the researcher. The researcher would benefit from expansive data points across the country allowing the data to be less biased compared to data from a single institution or source. Queries could include questions about treatment success, recurrence, impact of previous health conditions, regional trends, etc.

With the KCA Data Federation, researchers can connect to data from multiple institutions at once through a process called federated learning. In this process, a researcher asks a federated learning platform to analyze partnered databases, within those institutions' secure information systems. The aggregate results are then returned to the researcher.

The results from a federated learning model are powerful because they are based in expansive, organized data sets that go beyond basics like age, tumor type, and treatments; they can include variables such as side effects and comorbidities. The datapoints could expand within RCC and even to other cancers to look for additional causes and modes of prevention, diagnosis, and treatment.

Unlike the process of consolidating clinical data from different hospitals in one place, as in a cancer registry, federated learning keeps patient information private since partner institutions don't share any raw data. Neither the researcher nor the other federation partners would ever "see" the raw data.

The KCA has partnered with Secure AI Labs (SAIL), a Cambridge, Massachusetts-based healthcare data security company, to provide the Data Federation's federated learning infrastructure. Additionally, seven large cancer centers will serve as the KCA's hospital partners in the first phase.

> *"When it comes to accessing patient registries and other health information, privacy and security is key. By using our secure federated learning platform, the KCA is able to query medical data across the country without direct data access. That keeps patient information protected while also giving more statistical power to researchers in their efforts to find a cure for kidney cancer."*
>
> Anne Kim, CEO, SAIL

The research made possible through the KCA Data Federation has the potential to accelerate research with data that reflects the breadth of the kidney cancer experience so that future breakthroughs such as earlier detection and diagnosis or curative therapy will make a meaningful difference to patients and families.

KidneyCancerAssociation™

THE KIDNEY CANCER ASSOCIATION

The global community is dedicated to serving and empowering patients and caregivers, and leading change through advocacy, research, and education in order to be the universal leader in finding a cure for kidney cancer.

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