

Patient Primer for the Kidney Precision Medicine Project

1. Roles and Responsibilities of the Community Engagement Work Group

We are equal partners in leadership, oversight, and direction for all aspects of the Kidney Precision Medicine Project (KPMP). Our deep expertise is in the lived experience of kidney diseases. We are a group with unique and varied talents to support the KPMP. Our team is comprised of individuals with expertise in journalism, law, healthcare, business, government and policy, education, and many other areas.

As beneficiaries of prior research leading to diagnostics and treatments for kidney diseases, we have unique perspectives to inform scientists, clinicians, patients, and the public. We will advise about the rationale and justification for research kidney biopsies among other topics. We will contribute content for the KPMP website and other communications. In particular, we will provide patient stories, educational information about kidney diseases, and input regarding the guiding principles, mission, vision, and values for the KPMP.

2. Partnership with Recruitment Sites

We will lead development and execution of the informed consent process and protections for KPMP research participants. Our work will take a deep dive into understanding the kidney biopsy procedures and the hoped-for benefits, as well as the risks, to KPMP participants.

We will assist the Recruitment Sites in design of the study protocol and plans for recruitment. The burden of participation, e.g. sample and data collection and follow-up assessments, will be carefully considered in relation to the importance of knowledge to be gained. We will assess and respond to needs of the sites to facilitate enrollment, retention, and adherence. This work will include outreach strategies to communities comprised of patient stakeholders and the clinicians who treat them.

3. Partnership with Tissue Interrogation Sites

We will participate in discussion, deliberation, and decisions to guide focus for the state-of-the-art science that will be promising to solve problems that matter most to patients. As KPMP research results accrue, we will propose a plan on how best to return results of biological profiling in an ethically- and culturally-sensitive manner to patients and clinicians.

We will craft and present educational materials for public domains in order to communicate the need for a comprehensive kidney atlas. This effort will enhance KPMP participation by conveying how this endeavor will address large unmet needs for new discovery that leads to better treatments and biomarkers for kidney diseases.

4. Advancing the Science of Scientific Inquiry

We will be leaders in patient-centered aspects of the KPMP science and reporting of new knowledge. For example, we plan to present research findings at professional meetings and in publications about patient engagement in the informed consent process for precision medicine. With patients at-center, we will advance the science of scientific inquiry itself.