The Northwestern University Transplant Outcomes Research Collaborative (NUTORC) reaches across campus and has created a transdisciplinary group of content experts, health services and outcomes researchers, and transplant clinicians. NUTORC aims to create innovative research at the intersection of seemingly disparate disciplines and has successfully engaged scientists from within the Feinberg School of Medicine, the McCormick School of Engineering, and the Kellogg Graduate School of Management. Presently there are eight NUTORC teams: patient safety, quality of life, risk & econometrics, informed consent & disparities, health informatics, access & allocation, medication adherence, and aging. Since its inception four years ago, NUTORC has enjoyed remarkable transdisciplinary academic productivity, securing more than $11 million in grant funding, mostly from federal agencies, such as NIH, AHRQ, NSF, and HRSA; publishing over 70 peer-reviewed manuscripts; and presenting over 160 papers and posters at national meetings. We encourage students, fellows, and faculty to join us in this exciting and growing enterprise as we offer diverse and closely mentored opportunities (e.g., T-32 postdoctoral fellowship, summer students) for students at any level. We feature Elisa J. Gordon, PhD, MPH and Juan Carlos Caicedo, MD and the highlights of their ongoing research in informed consent & disparities.

Daniela Ladner, MD, MPH
Director NUTORC

Informed Consent and Disparities Workgroup

Drs. Elisa J. Gordon (Research Associate Professor, Surgery) and Juan Carlos Caicedo (Assistant Professor, Surgery and Director, Hispanic Transplantation Program) co-chair the Informed Consent and Disparities Workgroup. The workgroup focuses on advancing scientific knowledge of ethical issues in organ donation and transplantation. Transplantation is replete with ethical issues, including organ allocation, informed consent for living donors, and disparities in transplant outcomes. Ensuring that transplant policies and clinical practices are ethically sound is essential for maintaining quality of care and public trust in the transplant enterprise. The co-chairs lead groups of and consult with multidisciplinary researchers in conducting intervention and descriptive research on informed consent, health disparities, communication, and education in kidney and liver donation and transplantation. The NUTORC Informed Consent and Disparities Workgroup has received funding from NIH and HRSA as well as NMH to develop interactive, educational tools and decision aids to optimize the informed consent process for living liver donors and kidney transplant candidates, and to develop a culturally sensitive website tailored to Hispanics on living kidney donation. The workgroup meets in subgroups for each project on a weekly basis to develop grant-related materials, review study progress, and plan next steps. By describing current practices, constructing measures to assess knowledge, and developing innovative interventions to improve communication, self-care management, and health care delivery, our research strives to improve donor and recipient decision-making, and ultimately improve long-term health outcomes. Furthermore, the group is evaluating the culturally sensitive and congruent Hispanic Liver and Kidney Transplant Program, established by Dr. Caicedo, to further improve the needs of our patients and to define which elements are the key to generalizable success. Other projects include assessing transplant patients’ engagement in shared decision-making, and the use of the Internet in our care.