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A Unique Consent

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In healthcare, there are many quality metrics that are assessed: infection, bleeding, and length of stay being a few examples. Transplant centers are heavily regulated by the Centers for Medicare and Medicaid Services (CMS) and the United Network for Organ Sharing (UNOS) with specific transplant metrics. Transplant volumes, average wait time for transplant, and survival statistics are some of the most significant factors that are used to gauge the quality of the program. In fact, it is a requirement to inform the public about some of those metrics as a matter of providing informed consent for patients who are considering a transplant at our institution. We are required to provide all solid organ transplant prospective patients specific information prior to beginning the transplant evaluation process to allow them to make an informed decision about their care. This represents a positive shift in the field of healthcare overall as it helps patients to be more engaged with their healthcare decisions. Being more transparent with our outcomes, hopefully leads to a better educated and more involved patient. Some people believe this culture is due, in part, to consumerism, the internet, and the ability to “shop around” for different of goods and services. Whatever the origin may be, it is required that we report our quality measures and outcomes to our patients as they seek care.

The transparency concept becomes evident in the process of

informed consent for transplant. Transplant centers are required to obtain permission before initiating any part of a transplant work-up on a patient. The goal being that patients know their rights, their options, and the potential risks and benefits of a transplant before any testing or evaluation would even begin. As such, the first step in the transplant process is for our transplant nurses to obtain a signed acknowledgement and informed consent for transplant candidates. Although routinely signed by patients, in some urgent cases, the informed consent is done with family members and then eventually with the patient, if and when possible.

There are multiple elements that are required to be included in the consent for all the solid organ types; some of these include the surgical procedure, the options for treatment of their end-organ disease, potential medical or surgical risks, and the right to refuse transplant.

One section that is required to be included with documentation specifically includes the one year post transplant survival rates for both the patient and the organ. This is a nationwide standard that patients can use to evaluate our ability to perform the surgery and verify our success rate. This detailed information is tracked by the Organ Procurement and Transplantation Network (OPTN) and made available to the public via the online national database the Scientific Registry of Transplant Recipients (<https://www.srtr.org>)

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is a relatively new to UC San Diego Health, but has worked in the field of transplant for over 20 years. Previously, she worked with kidney and pancreas transplant patients and is now the manager of the UCSD Heart and Lung Transplant and VAD programs. She finds transplant an amazing journey and enjoys the fact that we are able to give patients hope in some of their most challenging times.

The SRTR reports have specific transplantation details that are available to the public, including: age of patients that are added to the waiting list for a kidney transplant or how many women were transplanted with hearts in the past year. This website provides a wide variety of characteristics for patients that UC San Diego has added to waitlists and transplanted over specified periods of time.

For the purpose of informing our patients, we are specifically required to report one year survival for organs and patients, which is a pretty amazing concept. For example, when a patient is admitted for an appendectomy, they can ask about their surgeon's success rate, the hospital's overall quality data and metrics. However, the onus is on the patient to seek out that information. For transplants, we have to make sure the patient is given that information upfront and has the opportunity to obtain more information if they would like it. We give them the actual survival of our patients at one year post transplant, expected survival based on the characteristics (disease, age, demographics) of our waitlisted patients, as well as the national survival average. The SRTR attempts to adjust for the risk level of transplants by accounting for many characteristics of the transplant recipients and the donors. Our center is given credit for accepting higher age recipients and those with higher surgical risk profiles, such as those with diabetes, and /or peripheral vascular disease.

As an example, patients may learn that UCSD's actual one year organ survival rate is 98%; our expected rate could be 97%, and the national average would be 96.5%. In this scenario, our actual survival is above both our expected and the national average survival rate, which may instill further confidence in selecting our transplant program. These numbers are updated, calculated and reported twice a year. Once they are published, we are required to inform all of our listed patients of each respective program and all new patients who are entering our programs for evaluation. This guarantees that patients are always kept apprised of our center's survival rates.

Patients also have the option of searching the SRTR website and researching other transplant centers to easily compare data in the event that they are considering multiple transplant centers.

Potential living donors for kidney and liver have additional specific criteria for informed consent. A living donor consent includes the recipient's medical alternatives to transplant; this is to ensure that the donor knows if their intended recipient has options outside of transplant. The living donor consent also contains the SRTR statistics so they are cognizant of the success of the transplant center. The living donor consent also addresses potential medical or psychosocial risks and that future health problems may arise due to the donation. All of these criteria and elements

are to confirm that our patients are informed when they make the decision to proceed with a transplant evaluation.

As a multi organ transplant center, UCSD has a huge responsibility to our community and to our patients to provide accessible and high quality care. The fascinating thing about transplant is that the actual transplant surgery is not everything. The medicine is not everything. The dieticians, social workers, pharmacists, nurses, administrative assistants, respiratory therapists, insurance councilors, data analysts, regulatory teams, and numerous other transplant team members and hospital staff are not everything. It's everyone. Every single person matters. Every episode of care matters. Every lab draw, every detail. We rely on each other to make positive outcomes for our patients. It truly is all about the whole team working together to create the patient's success.