

Preface

The system of solid organ transplantation in the United States involves a wide and complex network of participants, including donor families, surgeons, physicians, nurses, hospitals, transplant centers, organ procurement organizations, and federal agencies and contractors. These individuals and organizations strive to optimize the health and survival of patients who have received or are waiting for transplanted solid organs. Under ideal circumstances, there would be a suitable donor organ for every person who needs one. Despite the best efforts of all involved, however, the availability of organs falls significantly short of current demand. Moreover, despite the best-intentioned efforts of those involved, many patients find the system confusing and difficult to understand—leading, in some cases, to distrust of the very system designed to help them.

In February 1999, the Institute of Medicine (IOM) formed the Committee on Organ Procurement and Transplantation Policy in response to a request from Congress to review proposed changes in the current system of organ procurement and transplantation. The so-called “Final Rule” of the Department of Health and Human Services would make several such changes as part of the stated purpose of achieving an organ allocation system that (a) functions as much as technologically feasible on a nationwide basis, (b) provides for effective oversight of the current network of operations, and (c) offers better information about transplantation to patients, families, and health care providers. The impetus behind parts of the Final Rule is a desire to correct apparent geographic disparities in the amount of time a given individual must wait for a transplant and to ensure that minorities and the economically disadvantaged receive equitable access to transplants.

Evaluating the potential impact of the Final Rule on organ procurement and transplantation was a difficult task for many reasons. Among these is the fact that the Final Rule does not specify what the new organ allocation rules should

be, but instead establishes criteria and performance goals for the transplant community to meet through the development of appropriate policies. Conducting an evidence-based assessment was also difficult because of limitations both in the availability of data and, in some cases, in the data themselves. These data, the testimony provided to the committee, and the other information available to it, although quite voluminous in some areas, ranged in usefulness from helpful to contradictory or confusing. Moreover, as is often the case with complex data, its content and the way it is characterized by participants in the public discourse are often at odds.

A large part of the committee's work focused on a review and analysis of approximately 68,000 liver transplant waiting list records that describe every change in status made by every patient on the Organ Procurement and Transplantation Network (OPTN) waiting list for liver transplants from 1995 through the first quarter of 1999. In addition, the committee held two public meetings and solicited additional input from a broad range of interested individuals and organizations.

Based on its assessment of available data and other information, the committee finds that the current system is reasonably effective and equitable, but that it operates without effective supervision and oversight and could be more efficient in its allocation of livers to those with most urgent medical needs. Moreover, a lack of effective communication among the interested parties has polarized the discussions of various issues, such as those related to organ allocation, making them less productive than they could be and thus leaving significant room for improvement.

In the end, the committee emerged from its deliberations generally supporting the concepts presented in the Final Rule—for example, broader sharing of organs and enhanced oversight—tempered by the practicalities of the transplantation process. The committee's recommendations, if implemented, could go a long way toward facilitating the development of improved principles of allocation and improving what everyone agrees should be a patient-centered system.

The committee believes strongly that the federal government should provide effective oversight and review of the organ procurement and transplantation system, and that the system can be improved. This oversight and review should focus on assuring that the system is equitable, is grounded on sound medical sciences, and always places highest priority on the needs of the patients it serves. It is not the role of this oversight to micromanage day-to-day patient care.

Government oversight should also ensure that information about the system is available to the research community and the public. Although the United Network for Organ Sharing (UNOS) currently collects, analyzes, and disseminates a great deal of information about the OPTN—more data than are available for most other medical procedures—many people feel that these data should be more timely and more broadly available, and that independent review and analysis would be of added value. In this regard, as the committee tried to work quickly in reaching its assessment, it was struck by the paucity of readily avail-

able public information and the apparent lack of accountability and peer review of the data system. To answer questions properly about the adequacy of the organ procurement and transplantation system, data collection and dissemination must be improved, and information must be made widely available to the public and the research community, while respecting the confidentiality and privacy of both donors and recipients.

Finally, a perception of fairness is important to every aspect of this fragile system of procurement and transplantation. The system, therefore, not only has to be fair, but its fairness must be readily perceived by the public for many of the objectives to be accomplished, including increasing organ donations and improving minority access to transplantation.

As the committee was putting final touches on the report, the governing board of the OPTN announced a change in its liver allocation rules, designed to increase the number of organs going to the patients in greatest medical need. The change seems to be an incremental improvement over the prior policy with respect to status 1 patients, but still leaves room for improvement.

The short time frame of this study and the relative dearth of high-quality public information presented formidable challenges. The committee responded extremely well to these challenges and performed its task in a very professional manner. This would not have been possible without the help of many other people. I would especially like to thank the research staff at UNOS—Mary Ellison, Ann Harper, and Erick Edwards—who responded quickly and effectively to our numerous and complex data requests throughout the study. Their cooperation eased our task immeasurably. In addition, I would like to thank our colleagues at the General Accounting Office—Marcia Crosse, Roy Hogberg, and Donna Bulvin—who provided us with data on the costs of transplantation.

Last, the staff who supported this activity are in large part responsible for both its quality and its timeliness. In this regard, I wish to acknowledge in particular the efforts of the IOM project staff—Andrew Pope, Kathi Hanna, Mike Edington, Sarah Pitluck, and Thelma Cox—as well as the staff of the National Academy Press, Sally Stanfield, Jim Gormley, Dawn Eichenlaub, and Ron Weeks. Without their tireless assistance, we would not have been able to complete this project in the time frame requested by Congress or to the standards required by the Institute of Medicine.

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Chair