



**STATEMENT OF THE DECLARATION OF ISTANBUL CUSTODIAN GROUP
CONCERNING ETHICAL OBJECTIONS TO THE PROPOSED GLOBAL KIDNEY EXCHANGE PROGRAM**

What is the ‘Global Kidney Exchange Program’?

The “Global Kidney Exchange Program”¹ (GKEP) is a term coined by Dr Michael Rees and colleagues to describe an international arrangement under which individuals from low and medium income countries (LMICs) who need a kidney transplant and have a willing related donor are offered free transplantation in a high income country (HIC), such as the United States. Such an arrangement would principally interest patients in LMIC who cannot afford the necessary surgery as well as those who live in countries that lack the ability to perform the transplant. In order to undergo a transplant in the HIC and to receive the medication to avoid rejection of the transplanted organ for a period of time, the recipient-donor pair from the LMIC would have to participate in a paired exchange with a patient in the HIC who needs a kidney transplant but is biologically incompatible with his or her potential living related donor. Two pairs from the Philippines have already participated in a “pilot” of the program in the US,² and proponents have recently urged expanding the program to include HICs in Europe.³ Proponents present the GKEP—which they have also called “reverse transplant tourism”⁴—as a solution to two different problems.

First, in most HICs, such as the United States, public and private medical insurance coverage makes it possible for kidney patients to undergo a transplant procedure if they have a suitably matched relative or close friend who is willing to donate a kidney to them (or if they are fortunate enough to be allocated a deceased donor kidney through the national organ donation system). Yet about a third of the patients with a potential living donor do not get a transplant because they are biologically incompatible with the donor.⁵ In recent years, these patients have benefitted from “kidney paired donation” (KPD) in which two incompatible recipient-donor pairs are matched, with each donor giving a kidney to the recipient in the other pair. In time, this exchange process has been extended to chains of incompatible recipient-donor

¹ Rees MA, Dunn TB, Kuhr CS, et al. (2017). Kidney exchange to overcome financial barriers to kidney transplantation. *American Journal of Transplantation*, 17(3):782-90.

² Rees M, Dunn T, Rees S, et al. (2017). Global Kidney Exchange. *American Journal of Transplantation* 17 (suppl 3). <http://atcmeetingabstracts.com/abstract/global-kidney-exchange-2/>. A third donor-recipient pair from Mexico was included in the abstract, but in that case, the transplant procedure was apparently paid for by their national health system, not the GKEP.

³ <http://paireddonation.org/about-us/global-kidney-exchange/>

⁴ Krawiec KD & Rees MA. (2014). Reverse Transplant Tourism. *Law and Contemporary Problems*, 77(1):145-73.

⁵ Gentry SE, Montgomery RA, Swihart BJ & Segev DL. (2009). The roles of dominos and nonsimultaneous chains in kidney paired donation. *American Journal of Transplantation*, 9:1330–36.



pairs, often initiated by a donor giving “altruistically” rather than to a relative.⁶ (Dr. Rees is among the physicians who pioneered such kidney donor chains.) However, even with KPD and chains, finding a match for certain recipients can be very difficult. The first argument for making kidney exchanges global is that by increasing the number of KPD participants, GKEP will improve the chance for patients in HICs to get a kidney transplant.

Second, hundreds of thousands of patients with end-stage kidney failure in HICs must undergo dialysis, an expensive and burdensome treatment, to survive. Obtaining a kidney transplant not only provides such patients with much better quality of life but in the typical case also saves hundreds of thousands of dollars for the health insurance provider which would otherwise be paying for years of dialysis. Proponents of the GKEP argue that the cost of performing surgery and providing post-transplant immunosuppressive medication should be covered for LMIC patients who bring a kidney donor to the GKEP, thus making it possible for a HIC patient to cease dialysis. The money saved, they argue, can subsidize medical treatment for poor people who are unable to get a transplant in the LMIC where they live.

Although attractive at first glance, the GKEP proposal should be rejected for many reasons. It is deceptive; it creates major ethical problems, such as disproportionately helping the rich over the poor and undermining rather than advancing the welfare of kidney patients in LMICs; it amounts to international organ trafficking; and it will be difficult to administer in a way that actually prevents unethical and even illegal acts. In the end, “reverse transplant tourism” differs from ordinary transplant tourism only with regards to the people who travel—organ recipients or organ donors—and not in the commercial nature of the organ “donation.”

What concerns are raised by the Global Kidney Exchange Program?

1. The Program is Deceptive

The GKEP uses a term, “financial incompatibility,”⁷ that sounds like the “biological incompatibility” that served as the justification for allowing donors who are not biologically well-matched with their intended recipient to trade a kidney with another biologically incompatible donor-recipient pair through KPD. The exchange of kidney-for-kidney by such pairs does not violate statutory prohibitions on receiving something of value in exchange for an organ for transplantation. But the LMIC donor-recipient pairs who are sought by the GKEP are not “incompatible” with each other; they are simply unable to afford the cost of a transplant and follow-up care in their own country. Further, GKEP proponents misrepresent the program’s principal aim. They claim it is a win-win proposition for both rich and poor nations. But the GKEP did not originate from any of the on-going intergovernmental and professional efforts to establish and foster kidney transplant programs in LMICs, nor from programs to include more people in KPD by cross-border collaboration. Instead, it was advanced as a means of giving potential kidney recipients in the US and other HICs access to

⁶ Rees MA, Kopke JE, Pelletier RP, et al. (2009). A nonsimultaneous, extended, altruistic-donor chain. *New England Journal of Medicine*, 360:1096–1101.

⁷ Rees M., et al., note 2 *supra*.



a wider pool of donors in other countries without having to become “transplant tourists” who travel, for example, to India, Mexico, Pakistan, the Philippines, or Sri Lanka, to purchase a kidney.

2. The benefits of the program flow disproportionately to patients in developed countries

The GKEP does nothing to help establish more accessible and equitable programs of transplantation in the countries from which its donors will be drawn. Indeed, the existence of the GKEP distracts from efforts to develop sustainable transplant programs within LMICs (e.g., promoting ethical living donation, developing deceased donation, or addressing the financial barriers to immunosuppression). Any benefits the GKEP provides for a selected few LMIC recipients will do little to reduce the burdens of end-stage kidney disease in such countries. Moreover, the chance to receive free transplantation and donation services will not be offered based on medical or even economic need. The LMIC patients who undergo transplantation in the program will be those with a willing donor who matches the need of a waiting transplant recipient in a HIC or who can trigger a chain of paired exchanges there and thus create significant savings for health insurance providers in that country. The fairest and most effective way to address the transplant needs of patients in LMICs is to develop transplant services in their own countries, rather than diverting the efforts of their physicians to the task of identifying potential donors who match the specific requirements of patients in the US or other HICs who are looking for a living kidney donor.

3. The program exploits poor countries and individuals

Exploitation occurs when someone takes advantage of a vulnerability in another person for their own benefit, creating a disparity in the benefits gained by the two parties. The GKEP takes advantage of the desperation of individuals in LMIC who are dying of end-stage kidney failure because they are unable to obtain transplantation or even dialysis. While the GKEP offers a significant benefit to selected recipients, the benefits accruing to HIC patients and their health care systems will be even greater. As Rees and colleagues observe, the American health care system may save US\$3 million from just one such transplant.⁸

Lacking other options, poor prospective transplant recipients and their donors from LMICs may feel compelled to participate in the program. Although prospective donors may genuinely wish to help patients to obtain a transplant, they may prefer not to participate in the GKEP, which would require them to travel abroad (along with the recipient) for surgery. Further, some LMIC recipients may receive a kidney from a donor who is not as optimal as the relative who would be their donor in the domestic setting. Having no choice but to participate in the GKEP reflects poor donors’ and recipients’ limited freedom regarding choices that patients in wealthy countries such as the US have as a matter of right.

The severe imbalance of benefits continues after transplantation occurs. Most kidney recipients and donors in developed countries can expect to receive on-going medical evaluation and treatment as needed, but those from LMICs will often lack access to such care once they return home. At the very least, the GKEP does not have any means of ensuring adequate follow-up care in the range of countries—with different ways of providing

⁸ Rees M, et al., note 2 *supra*.



and paying for health care—from which living donors may come. The same concerns arise for recipients, especially because of their need for expert post-transplant monitoring of their immunosuppressive regime. Although the GKEP pilot provided the initial participants additional funding to cover immunosuppression for five years, it is unclear the extent to which follow-up care for these patients was assured; this problem would be magnified were the GKEP to be adopted, involving a more wide-spread group of participants. The inability of many participants from LMICs to be assured of appropriate care once they return home underlines the exploitation of both donors and recipients from such countries and the hazards such a program would create for participants. The health risks and benefits of kidney transplantation and donation for people who live in HICs should not be assumed to predict those of people living in LMICs who may lack reliable long term access to care.⁹ Experience with living donors at the Sindh Institute for Urology and Transplantation in Pakistan has demonstrated that with sufficient local investment and commitment, kidney transplant programs in LMICs can provide excellent long-term outcomes for the poor.¹⁰ Yet the GKEP is not set up to address the risks for donors who return to localities where long-term care and early intervention in managing risks post donation are lacking.

4. GKEP transplants depends on paying for kidneys

It is, of course, ethically acceptable for charities and wealthy individuals in HICs to offer to pay transplant-related expenses for kidney donors and recipients in LMICs, including recipients' post-transplant immunosuppressive treatment. Ideally, such financial support would enable treatment within each patient's own country, but a long humanitarian tradition also exists of bringing patients from poorer countries to richer ones to receive specialized care for free. But this is not what the GKEP proposes to do, since it will only cover transplant-related costs for kidney recipients who provide a donor kidney for the program.

GKEP proponents suggest that their program is merely an extension of existing kidney paired-donation (KPD) programs, which were created to allow two biologically incompatible donor-recipient pairs to exchange kidneys with one another. When such swaps were first proposed, some officials questioned whether this procedure would result in each donor providing a kidney in exchange for “valuable consideration,” as the prohibition on paying for kidneys is described in the National Organ Transplant Act (NOTA) in the U.S. Although most commentators concluded that an in-kind exchange (a kidney for a kidney) would not violate NOTA, the U.S. Congress amended NOTA to make clear that paired kidney exchanges did not violate the rule against receiving “valuable consideration” for an organ.

In HICs, where government health programs or private insurance cover the cost of kidney transplantation, the only thing that a candidate for a kidney transplant—call this patient A—who has a biologically incompatible donor, B, needs is another donor-recipient pair, X and Y, where the donor is biologically compatible with A and the recipient could accept a kidney provided by B. Now suppose that the X-Y pair is not immediately inclined to enter into a swap with the A-B pair but agrees to do so if A pays Y \$100,000 “to facilitate the donation.”

⁹ Reese PP, Boudville N, & Garg AX. (2015). Living kidney donation: outcomes, ethics, and uncertainty. *The Lancet*, 385 (9981):2003-13.

¹⁰ Rizvi SAH, Zafar MN, Jawad F, et al. (2016) Long-term safety of living kidney donation in an emerging economy. *Transplantation*, 100(6):1284-1293.



There would be no question that such a payment is prohibited by NOTA, even though the pairs are also swapping kidneys.

Yet this is precisely how the GKEP would obtain kidneys for biologically incompatible pairs in HICs, the only difference being that rather than provide cash, the GKEP proposes to pay for the transplant surgery and immunosuppressive drugs for the kidney recipient from the LMIC in exchange for a kidney from his or her donor. Having the payment come from a government agency or private foundation would not change the violation of the principle—enshrined in international conventions¹¹ and professional standards¹²—that organs should not be treated as commodities because doing so exploits people who are vulnerable because of poverty and other adverse circumstances.

5. Helping poor patients in exchange for “donated” organs constitutes organ trafficking

The way in which the GKEP is actually a new case of international organ trafficking is also revealed by considering a hypothetical patient, C, in a LMIC who has a condition that will lead to organ failure if not cured but who lacks the funds needed to pay for such treatment. If a relative of C offered to sell his kidney in order to pay for C’s treatment, this would be organ trafficking and hence ethically and legally unacceptable. Yet the logic underpinning the GKEP suggests that the program should provide C with the organ-failure prevention treatment if her relative donates a kidney to the GKEP. No relevant difference exists between C and another patient from her country, D, who needs a kidney transplant and also has a relative willing to donate to the GKEP. Neither C nor D can obtain treatment in their country and both have someone who is willing to donate a kidney that would meet the needs of the GKEP.

From the developed country viewpoint, the incentive to pay for the needed treatment is the same in both cases, as it will lead to patients getting transplants from the donors supplied by C and D. The only difference is that the donor related to the patient who receives a kidney from C’s donor is still available to start a transplant chain, since C (unlike D) does not need a transplant with that donor’s kidney. From the LMIC perspective, the outcome—that is, the combination of “benefit” and “exploitation” previously described—would be the same, since in each case a patient would get life-saving treatment that would not have occurred without

¹¹ See, e.g., Article 4 (1)(b) of the *Council of Europe Convention against Trafficking in Human Organs* (Adopted by the Committee of Ministers on 9 July 2014), which requires signatory countries to establish a criminal offense “where, in exchange for the removal of organs, the living donor, or a third party, has been offered or has received a financial gain or comparable advantage.”

¹² See, e.g., *Declaration of Istanbul on Organ Trafficking and Transplant Tourism*. (2008). http://multivu.prnewswire.com/mnr/transplantationociety/33914/docs/33914-Declaration_of_Istanbul-Lancet.pdf, which states that “transplant commercialism”—“a policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain”—should be prohibited because “it targets impoverished and otherwise vulnerable donors” and hence “leads inexorably to inequity and injustice.”



her donor's participation in the GKEP. The claim of GKEP proponents that it is ethically and legally legitimate to provide free treatment to an LMIC patient like D who receives a kidney transplant applies equally to C who instead receives some other medical treatment. In fact, it would seem better to pay for treatment that will prevent development of organ failure and the need for transplantation, in exchange for donor kidneys, rather than waiting to cover the costs of transplants for recipients who have a donor able to participate in the GKEP. It would not only be cheaper overall, but better for patients like C to avoid the need for transplantation altogether. Thus the logic of the GKEP suggests it would be appropriate to fund programs preventing chronic kidney disease in LMICs in exchange for kidneys donated by people in those countries.

This example makes clear what is the central feature of the GKEP: it pays for treatment that a patient from a LMIC could not afford in exchange for that patient supplying another person to donate a kidney for transplantation into a HIC recipient. While the proposal may initially seem appealing, since it promises to help people in LMICs gain access to health care, it effectively conditions access to care on organ selling.

6. The GKEP increases the risk that organs will come from paid sources, not relatives

Once it is recognized that providing a LMIC patient free treatment if he or she supplies a suitable donor kidney amounts to purchasing that organ (*i.e.*, exchanging that kidney for another kidney along with money that pays for the transplant surgery and post-transplant medication), then a further danger becomes apparent, namely, that some of the donors produced by LMIC patients may not actually be relatives who are acting out of love but people recruited to provide a kidney for cash.

The prospect of being flown to a developed country and receiving free treatment once there could well be enough incentive to cause some patients in LMICs to expend considerable effort and whatever funds they have available to obtain a paid donor and then to disguise the commercial nature of the relationship. The LMIC patients most likely to qualify to participate in the GKEP are those with some financial means, social connections, and access to at least basic nephrological care; likewise, they are likely to be able to pay a potential donor.

Many of the countries from which poor donors and recipients would be drawn to participate in the GKEP are struggling to combat domestic organ trafficking. Cases have been reported across many countries where a transplant was performed using such a paid donor whose claimed family relationship to the recipient was based on forged documentation. Transplant programs in developed countries will face more difficulty in ascertaining whether or not the relationships claimed between potential recipients and their purported related donors are genuine when these pairs are foreigners than when they are evaluated within a domestic program. The risk of deception is compounded by the difficulties that language and cultural differences pose for those who carry out the screening protocols.

In sum, the GKEP may be a well-intentioned effort to increase the pool of organ donors and hence to facilitate transplants, but its description of the donor-recipient pairs who would come from LMICs as “financially incompatible” rings false. The true issue is that the medical as well as financial barriers that keep patients in LMICs from receiving treatments they



need—particularly but not solely organ transplants—may prompt potential kidney recipients in those countries to act in a way that commodifies their donors, potentially undervalues the benefit those donors’ kidneys could have for them, inequitably benefits patients in the rich country, undermines rather than aids the development of robust and ethical transplant programs in low and medium income countries, and creates a new category of international organ trafficking.¹³ Health authorities in both HICs and LMICs should make clear that the statutes and regulations which prohibit exchanging organs for something of value preclude the acceptance of the GKEP in their countries. At the very least, they should place a moratorium on any implementation of the GKEP and instead find other means of increasing deceased and living related donation, developing domestic KPD programs, and generally improving access to transplantation in their countries.

Are there alternatives to the proposed Global Kidney Exchange Program?

In accordance with the principles of the *Declaration of Istanbul* and the *Guiding Principles*¹⁴ of the World Health Organization (WHO), the Declaration of Istanbul Custodian Group (DICG) is committed not only to discouraging practices and policies that directly or indirectly contribute to organ trafficking and transplant tourism but also to supporting the development and strengthening of equitable programs of donation and transplantation around the world. Working with WHO and other intergovernmental bodies such as the Council of Europe and with professional societies such as TTS and ISN, the DICG strongly supports efforts to establish transplantation programs appropriate to each country, within a system of universal healthcare coverage and, in particular, equitable access to nephrology care that can reduce the need for transplantation.

To effectively and fairly meet the need for transplantation in emerging economies requires fostering public health programs to prevent and manage chronic kidney disease, investing in systems to facilitate deceased donation, creating carefully operated living donation programs (including thorough medical and psychosocial screening and long-term follow-up for donors as well as recipients), and intersectoral and transnational efforts to prevent organ trafficking.

To assist in addressing barriers to transplantation that arise from the difficulties of finding immunologically compatible donors for certain potential recipients, the DICG supports efforts to establish equitable kidney paired exchange programs among countries. Such programs will not take advantage of financial inequalities between countries, but will instead address mutual problems of immunological incompatibility that require cross-border solutions.

¹³ Wiseman AC & Gill JS. (2017). Financial Incompatibility and Paired Kidney Exchange: Walking a Tightrope or Blazing a Trail? *American Journal of Transplantation*, 17(3): 597-98.

¹⁴ World Health Assembly. (2010) *Guiding Principles on Human Cell, Tissue and Organ Transplantation*. Available at: http://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf?ua=1



As two leaders of the DICG and TTS observed in a recent commentary on the GKEP, the organs of poor people in emerging economies should not be considered “assets” to be exchanged for the provision of funds or healthcare services by patients or governments in developed economies.¹⁵ Organ donation and transplantation represents an opportunity for people to meet on an equal footing and, in particular, for donors to share, without prospect for economic benefit, a lifesaving resource with fellow human beings regardless of any difference in their economic status. When opportunities to participate in such exchanges are determined by financial status, the poor are held hostage to wealthy patients’ need for organs for transplantation.

¹⁵ Delmonico FL & Ascher NL. (2017) Opposition to irresponsible Global Kidney Exchange. *American Journal of Transplantation*, 17(10): 2745-46.