

Looking for proposals on a new kidney allocation system

Bruno A Lima¹, Helena Alves²

¹ Oficina de Bioestatística, Vilar Formoso, Portugal

² Instituto Nacional de Saúde, Dr. Ricardo Jorge, Porto, Portugal

To the Editor:

The last issue of this journal brought a comment¹ on a paper we published here² in June, 2018. On reading that comment, we felt the need to clarify some of our paper's conclusions.

The principal aim of our paper² was to compare the current Portuguese kidney allocation system (KAS) on transplantation with other two systems: the United Kingdom KAS and the EuroTransplant system. We did not describe an alternative way to design a proposal for a new KAS. In fact, we did not question, at any moment, possible ways to define models for a new KAS. A new set of rules on donor-recipient pair selection in kidney transplantation is urgently needed, and to achieve this goal distinct sources can be used: evaluation of different data models, a systematic literature review; an idea based on empirical knowledge; or a consensus established at a brainstorm with a selected group of experts. We just want to see any proposal for a new KAS published as a peer review paper before is published in the Official Gazette of Portugal. Also, any proposal for a new KAS has to be submitted to a set of simulations in order to predict its outcomes as far as possible. Only publishing a new proposal in a peer reviewed paper will allow public scrutiny of its merits and its assessment with data from different sources.

In this context, we can define data as values, events, records or observations. An organ donor's age, his blood type, or a renal patient's time on dialysis are just some examples of data. When data are presented to us in a spreadsheet, organized in a tabular format (with identifiable rows and columns), we call it structured data. With enough data and the ability to process it, we can generate information. Mean age of a donor group, median waiting time for kidney transplantation from a patient group, or a bar chart with blood types' relative frequencies are just some examples of information we can glean from processable data. With enough information and the ability to process it, we can generate knowledge. A paper published in a scientific journal is the best example of analytical and objective knowledge.

Open data are accessible, usable, processable and modifiable data, shareable by any person and for any purpose without any restrictions. In Portugal, regarding kidney transplantation, there are no open data from which we can generate knowledge³. Also, when we compare available data and information on transplantation between Portugal and the remaining countries in the European Union⁴, we realize that Portugal is far removed from the best practices found in Northern Europe countries.

The only reason justifying a specific Portuguese KAS lies in the assumption that our kidney transplantation waitlist and our organ

donors are specific to our country and somehow different from transplant waitlists and organ donors from other countries with other KAS. So, based on these assumptions, we conclude that we need a specific set of rules to answer our specific problem. But, how different are Portuguese transplant candidates? Where is the data that allowed these conclusions to be drawn? We can't rely on a feeling in this matter. For instance, Belgium, Germany, Hungary and Croatia apply the same set of rules for kidney allocation (Eurotransplant rules), so we have to just assume that their transplant candidates are similar?

We will not discuss here who is in charge of displaying data and information on transplantation in Portugal⁵. However, we want to emphasize that we need to have access to useful metrics and indicators regarding transplant candidates, transplant recipients and organ donors⁶ if we want to make informed decisions. In renal transplantation, it is urgent to have available data³ allowing us to measure this objectively and to simulate new rules of action.

If nothing else, we should at least be conscious of the Council of Europe recommendations in this matter: '*Member states should guarantee that a system exists to provide equitable access to transplantation services for patients which ensures that organs and tissues are allocated in conformity with transparent and duly justifiable rules according to medical criteria*'. Also: '*The allocation rules should be changed when necessary to ensure similar waiting times for all groups of similar patients on the waiting list*'. And also: '*The organization responsible for managing the waiting list should provide information, on at least an annual basis, for health professionals and the public*'.⁷

Turning to another subject, panel-reactive antibody – complement dependent cytotoxicity (PRA - CDC) as a sensitization measure has several limitations: panels of cells are generally not representative of the population; its application and results vary according to the transplant centers; and it generally underestimates sensitization levels, in particular for highly sensitized candidates⁸. Nowadays, calculated PRA (cPRA) is used worldwide as a more accurate measure to define transplant candidates' immunization. The calculated panel-reactive antibody, provides an estimate of the percentage of deceased organ donors that will be crossmatch incompatible for a candidate once they have at least one HLA antigen identified as unacceptable on the candidate⁹. The cPRA should be computed from HLA frequencies from potential kidney donors in the country and thus represents the percentage of actual organ donors that express one or more of those unacceptable HLA antigens. In our paper, as we used simulated data, we were able to call our sensitization measure cPRA, although, in fact, the current Portuguese KAS uses the obsolete PRA measure. With the availability of the aforementioned data or at least detailed information on

transplant candidates and organ donors, it will be possible to generate simulated data more precisely and, with it, test different hypothetical scenarios.

The nonexistence of open data and useful information on transplantation should not be an excuse for settling for allocation rules which need to be changed. Nevertheless, we must highlight that if we look for simpler, more transparent and more equitable kidney distribution rules for transplantation, we must, at least, try to emulate the best practices found in Eurotransplant, Scandiatransplant or even France⁴.

In 2013, we published a proposal for an alternative KAS¹¹ and now we observe with satisfaction a growing awareness in transplantation health professionals of the need for fairer and equitable kidney allocation rules. We are pleased to add our modest contribution to this discussion, hoping that any new proposal can be assessed before it is implemented. Above all, in our paper, we describe a method to assess any new set of rules, allowing comparisons between different systems.

Disclosure of potential conflicts of interest: none declared.

References

1. Sampaio S. The Portuguese kidney transplant allocation system – a change is needed. *Port J Nephrol Hypert* 2018; 32(4): 337-338.
2. Lima BA, Alves H. Evaluation of the Portuguese kidney transplant allocation system: comparative results from a simulation. *Port J Nephrol Hypert*. 2018;32(2):201-207.
3. Lima BA. A call for open data of renal transplantation in Portugal. *Port J Nephrol Hypert*. 2017;31(3):155-157.
4. Lima BA, Alves H. Informação disponível sobre transplantação renal: Portugal na União Europeia a 28. *Obs ações - Bol Epidemiológico*. 2018;13:67-71.
5. Fonseca NM. Open data on kidney transplantation. *Port J Nephrol Hypert*. 2017;31(4):321.
6. Lima BA, Mendes M, Alves H. Measuring kidney transplantation activity. *Port J Nephrol Hypert*. 2014;28(June):171-176.
7. Council of Europe. Recommendation Rec (2001) 5 of the Committee of Ministers to member states on the management of organ transplant waiting lists and waiting times. Published in 2001. Available at: https://www.edqm.eu/sites/default/files/recommendation_no_2001_5_of_the_committee_of_ministers_to_member_states_on_the_management_of_organ_transplant_waiting_lists.pdf.
8. Leffell M. The calculated panel reactive antibody policy: an advancement improving organ allocation. *Curr Opin Organ Transpl*. 2011;16(4):404-409.
9. Cecka JM, Kucheryavaya AY, Reinsmoen NL, Leffell MS. Calculated PRA: Initial results show benefits for sensitized patients and a reduction in positive crossmatches. *Am J Transplant*. 2011;11(4):719-724.
10. Lima BA, Mendes M, Alves H. Hypersensitized candidates to kidney transplantation in Portugal. *Port J Nephrol Hypert*. 2013;27(2):77-81.
11. Lima BA, Mendes M, Alves H. Kidney Transplant allocation in Portugal. *Port J Nephrol Hypert*. 2013;27(4):313-316.

Correspondence to:

Bruno A Lima;
Oficina de Bioestatística, Rua do Comércio, 42, 6355-248 Vilar Formoso
E-mail: balima78@gmail.com