

Open data on kidney transplantation

Nuno Moreira Fonseca

Nephrology Department, Centro Hospitalar Lisboa Central, Hospital de Curry Cabral, Lisboa, Portugal

Received for publication: Oct 2, 2017

Accepted in revised form: Nov 15, 2017

To the Editor,

In his recent article “A call for open data of renal transplantation in Portugal” Lima calls for free, accessible, and disaggregated data on kidney transplantation. While I fully support this request, I must take issue with the stakeholders it addresses.

The data on Portuguese transplantation currently available to the general public is clearly insufficient. Renal patients are not diligently provided with transplant waiting-list times nor outcomes of individual transplant centers. In addition, at a time when discussion over a new kidney allocation policy has already been started, the absence of disaggregated data on donors and recipients is more pressing than ever. The lack of access to this information hinders the development of new allocation policies, as new proposals require real data in order to be simulated before actual implementation.

While Lima acknowledges the meritorious work that the Portuguese societies of nephrology and transplantation have undertaken over the last decades in making transplant information available to the public, it should be noticed that the obligation to disclose such data rests with the Portuguese government, and not these

societies. For example, the open data reported by the United States Renal Data System, as mentioned by Lima, is in fact the responsibility of the American government. Likewise, it should be expected that such data should be published regularly by the Ministry of Health as transplantation is an enterprise fully funded by the Portuguese National Health System. In this sense, and in accordance with the spirit of Ordinance number 165/2012, it falls on the Portuguese Institute of Blood and Transplantation to organize, maintain, and publish national data on transplantation.¹

Like Lima, I too hope that open data on transplantation will soon be a reality in Portugal. Access to information will benefit patients individually and improve the transplantation system, boosting research.

References

- ¹ Portaria nº 165/2012, Diário da República, 1ª série — Nº 99 — 22 de maio de 2012. Available at: <https://dre.pt/application/file/a/551939>

Correspondence to:

Nuno Moreira Fonseca, MD
Nephrology Department, Centro Hospitalar Lisboa Central,
Hospital de Curry Cabral, Lisboa, Portugal.
e-mail: nuno.mf@nyu.edu