

# A call for open data of renal transplantation in Portugal

Bruno A Lima

Oficina de Bioestatística, Vilar Formoso, Portugal

Received for publication: Aug 14, 2017

Accepted in revised form: Sep 09, 2017

## INTRODUCTION

Open data refers to data that can be accessed, used, modified and shared by any person and for any purpose, without any restrictions. Over the last decade, publication of open data has gained increasing importance. As examples, the Obama administration, the European Union and several European countries at a local level have increased the availability access to government data. Open data fuels innovation and highlights benefits of public administration transparency<sup>1</sup>.

Transparency, regarding open data, means that the data is accessible, processable and presented clearly. However, this always depends on the capabilities of those who will use open data. Furthermore, transparency in open data should not be seen as an end in itself but as a mean to facilitate innovation, build trust, permit access to information, and evaluate public policies and decision-making by allowing transparency of governance<sup>2</sup>.

## OPEN GOVERNANCE

Open data is a key strategy within the European Union. The publication of public data – electronically stored information, available in a non-proprietary format with metadata that allows for automatic processing – facilitates access to information, stimulates transparency and cooperation between institutions and promotes useful applications to the community<sup>3</sup>. Open government data is a current movement that seeks to open up governance data and make it available in machine-readable formats for public and private re-use.

In Portugal, the Administrative Modernization Agency (AMA) provides a website ([data.gov](http://data.gov))<sup>4</sup>, for the collection of data shared by Portuguese Public Administration institutions.

Regarding health data, the AMA website identifies the page Transparency from the National Health Service Portal (NHS)<sup>5</sup> as the place to obtain open data. It contains a section on organ transplantation, where some statistics related to transplantation activity since 2011 are available. Moreover, it should be noted that there is more information about Portuguese renal transplantation on the Global Observatory on Donation and Transplantation<sup>6</sup> website than on the above-mentioned NHS portal<sup>7</sup>.

The availability of open data must guarantee the individual privacy of those who may be the subjects of the data. It must also be based on a secure and fair structure for data sharing. Accordingly, the digitization of health information requires the adoption of appropriate security measures and the formalization of jurisdiction to treat and protect personal data<sup>3</sup>. But this search for privacy cannot excuse the lack of usefulness of the data made available<sup>8</sup>.

The definition of objective and systematic metrics for transplantation<sup>9</sup> is the first step to be taken when we want to make available this type of data. Consequently, open data solutions will require well-defined data models that enable interoperability and end-user interest in these data<sup>10</sup>.

Organizacion Nacional de Trasplantes<sup>11</sup>, UK Transplant Registry<sup>12</sup>, ScandiaTransplant<sup>13</sup> and Eurotransplant<sup>14</sup> are just a few examples of European public institutions that provide open data on their renal transplantation work.

## ■ OPEN SCIENCE

The open data movement calls for scientists and researchers to share online all the data behind their findings. For example, since 2014, PLOS journal editors<sup>15</sup> require authors who publish in their journals to share online all the data necessary for the replication of their studies<sup>16</sup>.

Biomedical research reliability and reproducibility are under constant scrutiny. The availability publicly or on request, of (anonymous) studied patients' data not only prevents reprehensible behaviour but also validates authors' findings. Further, available data allows other authors to answer secondary questions or even data aggregation in large-scale meta-analyses. Data sharing avoids wasting efforts, not only those of researchers who collected the data originally but also of the patients exposed to such data collection<sup>17</sup>.

Open science's idea relies on making research as transparent as possible. This includes the free and open provision of data collection information, the data itself and the code used to analyse it. Commonly, researchers who openly offer their methods, data and analyses tend to be more careful and more conscientious of their results<sup>18</sup>.

Peer review as a system for evaluating scientific publications will always be subject to errors as long as reviewers do not have access to the data supporting the publications. It is plausible that well-meaning researchers are fooled by their own positive results just because of inconsistencies in laboratory techniques or failures in the statistical analysis. It is only by making the study data available that some of these errors can be detected, as well as by scrutinizing the scientific findings more closely<sup>19</sup>.

The availability of open data from published research is also an antidote to selective reporting of results. Furthermore, it would allow the replication of the analyses and the use of such alternative analysis approaches as defining different cut-off points, or categories of data, or statistical techniques<sup>20</sup>.

In 2016, the International Committee of Medical Journal Editors<sup>21</sup> proposed that medical journals should require public disclosure of data from the clinical studies they publish, as a way to promote transparency. However, it is not enough to offer data to promote transparency; available data must have utility for those who can get access to them<sup>22</sup>.

The Portuguese Society of Transplantation and the Portuguese Society of Nephrology make available on their

websites some information about transplantation activities<sup>23</sup> and information about chronic kidney disease patients<sup>24</sup>, respectively. Unfortunately, the data from which this information is generated are not available. These scientific societies undertake work that deserves public recognition, but they can go even further by adhering to open data policies. See the example of the United States Renal Data System<sup>25</sup> that publishes their reports with open data, where we can even find data related to Portugal.

The use of open data, created and made available by others, as the sole source of a scientific publication can still be seen by some as a form of parasitism. Nevertheless, there is no reason to believe that findings made with public data are, per se, of less value than findings based on private data<sup>26</sup>. When open data is used in secondary publications, the original authors are also recognized and should feel valued and not exploited.

The availability of data from published research contributes to the transparency and quality of these publications. Those data would permit more analyses that could aid in interpreting the reported results as well as allowing additional findings that were not recorded in the original results. Therefore, it would be possible to test the robustness of the results and would also be an incentive for a more careful check of the results before they are published<sup>27</sup>.

Here is a challenge to the editor of this journal. Implement measures that encourage the authors who publish in the Portuguese Journal of Nephrology and Hypertension also to disclose their data.

## ■ BARRIERS TO OVERCOME

With the possibility of openly providing individual patient data, we face concerns about patient privacy, consent, intellectual property, academic credit, costs, infrastructures, data format, and the likelihood of making erroneous conclusions from a superficial analysis. All these concerns should be taken into account when idealizing how the data can be made available, but should not be an obstacle to their availability<sup>22</sup>.

We cannot ignore some unrest that researchers are exposed to when they are instigated to share data from their studies. Privacy is one such concern and should be safeguarded by avoiding the identification of study subjects. Whenever possible, the study subjects' permissions should also be guaranteed prior the dissemination of their data. The concern to give strangers

something that we consider ours has been an obstacle to open data. The fear that we may not only be copied but outdated in our study intentions by making our data available; and the fear of being scrutinized can lead to a sense of risk and vulnerability. But it is this vulnerability that guarantee a better scientific practice<sup>18</sup>.

Arguments about patient confidentiality or the risk of ‘parasitism’ from other investigators are often invoked against the availability of open data from published studies. Notwithstanding, third-party use of proprietary data should be seen as a way of recognition and to increase the visibility of performed work<sup>28</sup>.

Large-scale government organizations, such as the National Institute of Health or the European Medicines Agency, and non-governmental organizations as World Health Organization, the National Academy of Medicine or the Gates Foundation, encourage open data availability of clinical studies they sponsor<sup>29</sup>.

Data financed with public money should be made available as open data. Research can then be democratized, since it is not confined to exclusive academic or institutional environments. This also promotes the interaction of several research groups that may have several ways of addressing the same data<sup>19</sup>.

## CONCLUSION

Open data can improve the quality of health care and reduce its cost. Moreover, open data availability can also help increase health literacy and community involvement when new public policies must be defined<sup>30</sup>.

This open data movement is irreversible, although its future impact is difficult to predict. In Portugal, and in the specific case of renal transplantation, there is still a long way to go, but the NHS portal is a good start that deserves to be used.

Public accessibility, availability in non-proprietary formats, being free of charge, and have unrestricted use and distribution rights are conditions for open data<sup>31</sup>. The entities responsible for publishing available data should also promote the use of these data. Consequently, how third parties use available data can measure the success of these entities.

**Disclosure of potential conflicts of interest:** none declared.

## References

- Meijer R, Conradie P, Choenni S. Reconciling contradictions of open data regarding transparency, privacy, security and trust. *J Theor Appl Electron Commer Res* 2014; 9(3):32-44
- Zuiderwijk A, Gasco M, Parycek P, Janssen M. Special issue on transparency and open data policies: guest editors' introduction. *J Theor Appl Electron Commer Res*. 2014; 9(3):1-1X
- Brighi R, Virone MG. EHR and Usability of health data to benefit patient and public health. *Stud Health Technol Inform*. 2014; 205(i):965-969
- Dados.gov. Agência para a Modernização Administrativa. Available at <http://www.dados.gov.pt>. Accessed August 9, 2017
- Serviço Nacional de Saúde, Transparência. Available at <https://www.sns.gov.pt/transparencia>. Accessed August 9, 2017
- Global Observatory on Donation and Transplantation. WHO-ONT. Available at <http://data.transplant-observatory.org>. Accessed August 9, 2017
- Lima BA, Alves H. Evolução da atividade de transplantação renal em Portugal: dados públicos de 2003 a 2015. *Obs – Bol Epidemiológico*. 2017; 18:24-27
- Kostkova P, Brewer H, de Lusignan S, et al. Who owns the data? Open data for healthcare. *Front Public Heal*. 2016; Vol 4.
- Lima BA, Mendes M, Alves H. Measuring kidney transplantation activity. *Port J Nephrol Hypert*. 2014; 28:171-176
- Turbelin C, Boëlle P. Exposing public health surveillance data using existing standards. *Stud Health Technol Inform* 2013; 192:802-806
- Organización Nacional de Trasplantes. Available at <http://www.ont.es/Paginas/Home.aspx>. Accessed August 9, 2017
- UK Transplant Registry, Organ Donation and Transplantation. NHSBT. Available at <http://odt.nhs.uk/uk-transplant-registry/data>. Accessed August 9, 2017
- ScandiaTransplant Available at <http://www.scandiatransplant.org/data>. Accessed August 9, 2017
- EuroTransplant. Statistics Report Library. Available at [http://statistics.eurotransplant.org/index.php?search\\_type=waiting+list&search\\_organ=&search\\_region=All+ET&search\\_period=by+year&search\\_characteristic=&search\\_text=](http://statistics.eurotransplant.org/index.php?search_type=waiting+list&search_organ=&search_region=All+ET&search_period=by+year&search_characteristic=&search_text=). Accessed August 9, 2017
- PLOS. Editorial and Publishing Policies. Available at <https://www.plos.org/editorial-publishing-policies>. Accessed August 9, 2017
- VanNoorden R. Confusion over open-data rules. *Nature*. 2014; 515:478
- Myers PO. Open data: Can it prevent research fraud, promote reproducibility, and enable big data analytics in clinical research? *Ann Thorac Surg*. 2015; 100(5):1539-1540
- Rouder JN. The what, why, and how of born-open data. *Behav Res Methods*. 2016; 48(3):1062-1069
- Moseley ET, Hsu DJ, Stone DJ, Celi LA. Beyond open big data: addressing unreliable research. *J Med Internet Res*. 2014; 16(11):1-11
- Bouter LM. Open data are not enough to realize full transparency. *J Clin Epidemiol*. 2016; 70:256-257
- International Committee of Medical Journal Editors. News & Editorials. Available at <http://www.icmje.org/news-and-editorials>. Accessed August 9, 2017
- Rockhold F. Data Access and Sharing: Are we being transparent about clinical research? Let's do what's right for patients. *Ann Oncol*. 2017;
- Sociedade Portuguesa de Transplantação. Registo do Transplante Renal. Available at <http://www.spt.pt/site/desktop/webpage-58.php>. Accessed August 9, 2017
- Sociedade Portuguesa de Nefrologia. Tratamento da Doença Renal Terminal. Available at [http://www.spnephro.pt/tratamento\\_da\\_doenca\\_renal\\_terminal](http://www.spnephro.pt/tratamento_da_doenca_renal_terminal). Accessed August 9, 2017
- United States Renal Data System. Annual Data Report Reference Tables. Available at <https://www.usrds.org/reference.aspx>. Accessed August 9, 2017
- Dalton L. On the reporting of new information from open data sets. *Am J Surg Pathol*. 2014; 38(3):433-434
- West R. Data and statistical commands should be routinely disclosed in order to promote greater transparency and accountability in clinical and behavioral research. *J Clin Epidemiol*. 2016; 70:254-255
- Pisani E, Aaby P, Breugelmans JG, et al. Beyond open data: realising the health benefits of sharing data. *BMJ Br Med J*. 2016; 5295:i5295
- Krumholz HM, Waldstreicher J. The Yale Open Data Access (YODA) project – A mechanism for data sharing. *N Engl J Med*. 2016; 375(5):403-405
- Martin EG, Begany GM. Opening government health data to the public: benefits, challenges, and lessons learned from early innovators. *J Am Med Informatics Assoc*. 2017; 24(2):345-351
- Martin EG, Law J, Ran W, Helbig N, Birkhead GS. Evaluating the quality and usability of open data for public health research: a systematic review of data offerings on 3 open data platforms. *J Public Health Manag Pract*. 2016; 23(4):e5-e13

## Correspondence to:

Bruno A Lima

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