

EDITOR'S PAGE

Spinal Cord authors have a moral obligation to share their data

MP Dijkers

Department of Physical Medicine and Rehabilitation, Wayne State University, Detroit, MI, USA

Authors submitting to *Spinal Cord* or considering submission will come across the following on page 10 of the Instructions for Authors: “Availability of Data and Materials: An inherent principle of publication is that others should be able to replicate and build upon the authors’ published claims. Therefore, a condition of publication is that authors are required to make materials, data, and associated protocols available in a publicly accessible database. Where one does not exist, the information must be made available to referees at submission and to readers promptly upon request. Any restrictions on material availability or other relevant information must be disclosed in the manuscript’s Methods section and should include details of how materials and information may be obtained”.¹

Apparently, not many authors read this far. In 2015, *Spinal Cord* published a total of 205 editorial elements, of which 150 were primary research (original research articles) and 8 were secondary research (systematic reviews). The others were editorials, corrigenda, book reviews, non-systematic reviews and other elements one would not expect to have ‘materials, data, and associated protocols’. Even if we exclude from primary research the 14 case studies (the data for which might not easily be de-identified), there remain 144 studies that could have shared materials. Only one (0.7%) did: Biglari *et al.* specified under the heading ‘Data archiving’: ‘All patient data were archived anonymously according to guidelines set forth by the ethics committee, and serum was frozen at -80° for future study.’² All other authors entered ‘There were no data to deposit’, or the heading did not appear at all in the article, or in the *Spinal Cord* website HTML version.

The *Spinal Cord* instructions are in line with the policies of public research funding agencies (e.g. the *National Institutes of Health* in the USA), private grantmakers (e.g. the *Wellcome Trust* in England), professional groups (e.g. the international *Cochrane Collaboration* and *Campbell Collaboration*), and publishers (e.g. the *Public Library of Science* or *PLoS*) to keep the fruits of research efforts as a public good. The latest to weigh in is the International Committee of Medical Journal Editors, who published a notice that the participating journals plan to make information on data sharing plans as well as actual sharing within 6 months from publication part of the conditions for accepting a paper on an intervention trial.³ All of these groups want to make sure that the findings as well as the data and methodologies of research that is paid for by public or even private (e.g. big pharma) money and/or is based on voluntary efforts of patients and other research subjects can be used to check on the research, extend it, and otherwise remain a building block in the edifice of science. The recent emphasis on the avoidance of ‘waste’ in biomedical and health care research reinforces that message.⁴ And it is not just the data from randomized controlled trials that deserve to be public;⁵ all research, even that which is small or flawed or seemingly time-sensitive needs to be shared. The confidential information of patients and other subjects should be protected, but there is much guidance on how datasets can be deidentified.⁶ Even the problems inherent in anonymizing qualitative research and case studies are not insurmountable, especially if researchers have the public posting of their data in mind when they first write their informed consent documents.

I call upon the scientists and clinicians submitting research to *Spinal Cord* to take seriously the Editorial Policy on sharing. I call upon the editors and my fellow-referees to make part of the routine they use for evaluating articles the following question: what of the ‘materials, data, and associated protocols’ used in this study is shared, and where? Should this article be published if the authors do not indicate where these items are archived? Do they give valid reasons why archiving is not (yet) feasible? Working together, we can do much better extending the life of our research materials. In the end, the persons with spinal cord injury we all serve will be the better for it.

1 ‘Spinal Cord’ Instructions for Authors, http://www.nature.com/sc/sc_new_gta.pdf. Accessed 01/06, 2016.

2 Biglari B, Swing T, Child C, Büchler A, Westhauser F, Bruckner T *et al.* A pilot study on temporal changes in IL-1beta and TNF-alpha serum levels after spinal cord injury: the serum level of TNF-alpha in acute SCI patients as a possible marker for neurological remission. *Spinal Cord* 2015; **53**: 510–514.

3 Taichman DB, Backus J, Baethge C, Bauchner H, de Leeuw PW, Drazen JM *et al.* Sharing clinical trial data - A proposal from the International Committee of Medical Journal Editors. *N Engl J Med* 2016; **374**: 384–386.

4 Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. *Lancet* 2009; **374**: 86–89.

5 AllTrials, <http://www.alltrials.net/> Accessed 01/06, 2016.

6 Hrynaszkiwicz I, Norton ML, Vickers AJ, Altman DG. Preparing raw clinical data for publication: guidance for journal editors, authors, and peer reviewers. *BMJ* 2010; **340**: c181.