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POLICIES REGARDING PUBLIC AVAILABILITY OF PUBLISHED RESEARCH DATA IN PEDIATRICS JOURNALS

Rafael Aleixandre-Benavent (1,2); Antonia Ferrer Sapena (3); Silvia Coronado Ferrer (4); Fernanda Peset (3); Alicia García García (1)

1. UISYS, Joint Research Unit (CSIC – Universitat de València). Pza. Cisneros 4. 46003 Valencia (Spain).
2. Ingenio (CSIC-Universitat Politècnica de València). Pza. Cisneros 4. 46003 Valencia (Spain).
3. DCADHA. Universitat Politècnica de València. (Spain)
4. Pediatric Department. Hospital de la Ribera. Alzira (Valencia). (Spain)

Corresponding autor:

Rafael Aleixandre-Benavent
Pza. Cisneros 4. 46003 Valencia (Spain).
Rafael.aleixandre@uv.es

ABSTRACT

Background. Sharing research data is an increasingly necessary requirement for the advancement of science. The goal of this paper is twofold. First, to analyze the policies on openness in sharing scientific research data in a sample of pediatric journals and to determine whether there is any correlation with a journal's impact factor; second, to determine if there have been changes in the opening policies from 2013 to 2016.

Methods. Journals included in the Pediatrics area of the *Journal Citation Reports* were used for the analysis, with reference to the instructions to authors published on the journals' websites. These instructions were revised in 2012 and in 2016.

Results. The majority of pediatric journals advise authors to deposit their data but do not provide specific instructions on how to do so. No correlation was found between the value of the impact factor of the journals and their open data policies. Deposit policies vary among publishing entities, with predominantly PubMed Central and repositories of clinical trials among those suggested for data deposit.

Conclusions. Most pediatric journals recommend that authors deposit their data in a repository, but they do not provide clear instructions for doing so. No correlation was found between the value of a journal's impact factor and the availability of open data. Policies regarding deposit in specific repositories vary among publishing entities, with PubMed Central and various clinical trial repositories being those primarily suggested for deposit.

Key words. Journals policies; Data sharing; Raw research data; Re-use; Pediatric journals

BACKGROUND

In the last few years, the assumption that scientists and most industry and pharmaceutical companies were in possession of the largest amounts of patient data derived from clinical trials has been progressively replaced by one in which society is the owner of the data. The National Institutes of Health, The National Science Foundation, scientific journals and many professional societies have taken steps to support or even require scientists to share their research materials and data with other researchers. However, some questions remain unanswered, as scientists try to learn how to carry out this requirement in a successful, proficient and ethically sound manner[1]. This shift has occurred due to different scientific and cultural factors, including the emergence of a movement to promote open data sharing. At this time, there are many data sharing initiatives in the world, such as the Human Genome Project, the Framingham study and the dbGaP database of the National Institutes of Health (NIH)[2]. Some databases or repositories that promote data sharing indicate which journals have signed agreements with them, as in the case of Dryad. There is also the inverse case, where journal policies recommend the deposit of data in one or several specific repositories or databases.

In addition to the above-mentioned initiatives, scientific journals play a very important role in the promotion and implementation of data sharing, as they are currently the main means of disseminating research. Many manuscripts published in scientific journals consist of complete text plus supplementary data to support the information presented. In some cases, these additional data are too extensive or "boring" to include them in the full text of the article, but other researchers may require these data to ensure that the reported experiment has been conducted correctly and the appropriate conclusions drawn[3]. Moreover, these data can also be useful, if reused, to supplement other work, make comparisons or generate new hypotheses. In short, reuse is the use of the data, usually without explicit permission, for studies intended or unintended by the original creator[3-6].

Data sharing is particularly important in biomedical research because underutilizing or not utilizing all of the available data can lead to the unnecessary exposure of individuals participating in clinical trials for which data already exist[7]. Improving data management so data can be shared is a first step to reducing shorter, less healthy lives and thus favors the interests of public health and the faster advancement of knowledge[8]. On the other hand, data sharing could increase transparency and possibly also reduce the risk of research fraud. However, it is very essential to take into account the ethical and legal implications, so data can only be shared if study subjects have given consent for data sharing.

Scientific journals play an important role in this process because most of them have digital editions, and current technology allows for the deposit of data and supplementary materials accompanying the published work. It is unknown, however, which biomedical journals have open-data policies. In the scientific literature, only few works has been found that specifically analyzes the public availability of research data published in high-impact journals[9-11]. The goal of this paper is twofold. First, to analyze the policies on openness in sharing scientific research data in a sample of pediatric journals with impact factor listed in the Pediatrics area of the Journal Citation Reports (JCR) and to determine whether there is any correlation with a journal's impact factor and quartile; second, to determine if there have been changes in the opening policies from 2013 to 2017.

METHODS

We reviewed the websites of the 115 journals included in the Pediatrics category of the Journal Citation Reports, referring specifically to the instructions to authors. As the number of journals in JCR has not remained stable over the 6-year period (115 en 2011, 122 in 2012, 118 in 2013, 120 in 2014 and 2015, 125 in 2016), we have only analyzed 115 journals to keep the number of journals analyzed consistent. On the other hand, when the journals' websites were reviewed in 2012, the last edition of the JCR published corresponded to 2011 and contained these 115 journals.

For each journal, we documented the policies related to public availability of sharing of data, where available. Two different researchers reviewed each web site: from January to March 2013 the first review was done, and from January to March 2017, four years later, the second review. When there were discrepancies, the web site was reviewed again and by the two researchers to resolve disputes and reach a consensus. The discrepancies were due to different interpretations of the information provided by the websites and these discrepancies were resolved by agreement between two reviewers. Since the different abilities of the observers could influence a different allocation of responses, in order to avoid discrepancies as much as possible, both reviewers were trained in the methodology to be followed for the correct interpretation of the information included in the websites.

The following data were collected for each journal: a) Journal name; b) Journal Website adress; c) Information on policies admitting the deposit of complementary material in the journal; d) Instructions on the reuse of supplementary material; e) Possibility of storage the final version of their article manuscript in thematic (pediatric, biomedical or multidisciplinary) repositories, or in a repository of the institution of the authors; f) Policy regarding that authors may publish their articles on the institutional website or on the author's personal website; g) Journal impact factor (IF) (in 2016 edition of JCR); h) Quartile in JCR journal impact factors, to know if data sharing policies are related to the journals that have the highest quality in their category according to this indicator. The items d), e) and f) refer to the availability of the article content, while c) is the item related to the availability of raw data. For the items c, d, e and f, the following variables were included: A: Accepted; NA: Not Accepted; NS: Not Specified, when there is no clear information on the item. This information was collected from January to March 2013 for the information referring to 2012, and from January to March 2017 for the information referring to 2016. Journals were classified in quartiles according to the JCR.

RESULTS

Table 1 presents the results obtained in accordance with the four main variables analyzed in the two years studied in the 115 journals. In 2012, the variable "Statement of complementary material" appeared in 94 journals, whereas the remaining 21 did not specify a preference. In 2016, the statement increased to 96, whereas the not specify decreased to 18 journals.

The following results were obtained regarding the reuse of data: in 2012, 35 the journals support this possibility, 4 do not allow it and 76 did not specify. In 2016, 58 supported, 3 do not allow it and 54 did not specify.

The variable "Storage in thematic or institutional repositories", obtained the following results: in 2012, 77 journals specified that it was possible, whereas in 2016 it was 56. In 2012, 38 did not specify such a possibility, whereas in 2016 it was 59. That option was not denied by any journal.

The variable regarding the possibility of publishing data on a website presented greater ambiguity, as three quarters of the journals (n=86) did not specify a policy on this option in 2012, and this number increased to 99 in 2016. The accepted option decreased form 27 in 2012 to 15 in 2016. Figure 1 shows graphically the data from table 1.

Tables 2 and 3 present the results of the four variables according to the quartile of the journals in JCR. In 2012, for the variable "Statement of complementary material", no significant differences were observed in this indicator in the first three quartiles by impact factor in the JCR Pediatrics area, but the percentage of journals that did not specify this information was higher in the fourth quartile journals. In 2016, the percentage of journals that accepted is similar in the four quartiles but the percentage of journals that did not specify this information was lower in the first quartile journals.

Regarding the reuse of data, the greatest number of journals in the first quartile of impact factors that did not specify the reuse of data was in the year 2012. On

the contrary, the number of journals in the first two quartiles of impact factors that accept the reuse of data is almost three times higher in 2016 than in 2012 (16 journals in 2016 versus 6 journals in 2012).

For "Storage in thematic or institutional repositories", no significant differences were observed in the first three quartiles by impact factor in 2012, but the percentage of journals that did not specify this information was 4 points higher in the fourth quartile journals. In 2016, the percentage of journals that accepted is quite similar in the four quartiles.

The possibility of “publishing data on a website” it was not specified in most of the journals of all the quartiles, both in 2012 and in 2016.

The 115 journals included in the study are published by 37 different publishing entities, of which 26 (72%) publish only one journal (Table 4). The entity that publishes the most pediatric journals is Elsevier (n=23), followed by Wiley-Blackwell (n=19), Lippincott Williams (n=11) and Springer (n=9). Within each entity, the policies on depositing data in repositories are variable. In 58 journals (50.43%), PubMed Central is specified as repository, and in 11 journals (9.57%), the repositories were related to clinical trial registries, including Australian New Zealand Clinical Trials Registry, Clinical Trials, ISRCTN Register, Netherlands Trial Register, and UMIN Clinical. Finally, another five (4.35%) indicated other repositories, such as Geo or CIF, ArXiv, NCBI's GenBank and Protein Data Bank Nucleotide Sequence Database Collaboration (GenBank), the European Molecular Biology Laboratory (EMBL) and the DNA DataBank of Japan (DDBJ). For 16 publishers, publishing 26 journals, no repository was advised.

Wiley-Blackwell indicated in all their journals that they "will support our authors by posting the accepted version of articles by NIH grant-holders to PubMed Central upon acceptance by the journal". In contrast, Elsevier specified mostly clinical trials repositories (Australian New Zealand Clinical Trials Registry, Clinical Trials, ISRCTN Register, Netherlands Trial Register, WHO International Clinical Trials), only once referring to PubMed Central, and did not indicate any

repository in 17 of its 23 journals. Lippincott Williams and Springer specified PubMed Central as a data deposit repository in all of their journals. In addition, Information Healthcare advised similar repositories to those suggested by Elsevier, whereas five other publishers indicated only PubMed Central (Karger, Mary Ann Liebert Inc, Sage Publications Inc, Walter de Gruyter & Co. and Wiley-Blackwell).

DISCUSSION

This work, which analyzes open-data policies for journals listed in the Journal Citation Reports of the Pediatrics area, has allowed for the identification of four main characteristics concerning these policies. The first is that most of the journals support the possibility of depositing data in specific or institutional repositories and that the journals accept additional material. The second feature is that most journals did not specify whether they supported data reuse, nor provided researchers specific instructions on how to do so. The third is the lack of a direct relationship between openness policies and the impact of the journals according to their quartile or position ranking by impact factor in the JCR Pediatrics area. It was observed that no journal requires the public deposit of the data as a condition for publication. The fourth relates to the deposit of data in specific repositories. There is a strong preference for deposit in PubMed Central, a digital repository of biomedical literature operated by the National Library of Medicine.

One finding that stands out is the heterogeneity in the instructions to authors, with language used that is not always accurate relative to the journal's sharing policy. In some cases, permission to deposit the data is only granted for manuscripts reporting research funded by not-for-profit organizations and that deposit must be made in not-for-profit, publicly available repositories. The NIH policy mandates a data-sharing plan and requires that these papers must be accessible to the public no later than 12 months from final publication (6 months if the research is funded by the Wellcome Trust).

Publishers such as Lippincott Williams and Wilkins indicate explicitly that they offer, as a service to the authors, the deposit to PubMed Central of articles subsidized by the National Institutes of Health, Wellcome Trust, Howard Hughes Medical Institute, or other funding agencies. Moreover, some journals, such as those run by Information Healthcare, request as a consideration of publication that clinical trials are registered in a public repository at their inception and prior to patient enrollment. Trial registration numbers should be included in the abstract, with full details provided in the methods section. The registry must be accessible to the public at no charge, open to all prospective registrants and managed by a not-for-profit organization.

Some journals specify that raw data should be made available as a prerequisite to publication. The journal Nature requires authors to make data, materials and associated protocols available to researchers (http://www.nature.com/authors/policies/availability.html). National Institute of Health dictates that raw data should be available at a public archive within a specified period after project conclusion (https://grants.nih.gov/grants/policy/data_sharing/)[4].

Although most of the published studies on this topic speak in favor of the benefits of sharing, some disagree with this direction. Davis (2013)[12] indicated that those journals who share data in PubMed Central are loosing readers and PDF downloads of web journals, resulting in negative effects on both readers and the journal. On the one hand, the capacity of the journal to build communities of interest around research is weakened, preventing communication of news, events, educational materials and other services; on the other hand, the opportunity to lead readers to related articles is lost, and the perceived value of the journal to institutional subscribers is reduced. PubMed Central provides a printer-friendly version of the article, which decreases the number of PDF downloads from the website of the publisher.

Standardization of definitions and data elements is an important step toward accelerating the process of data sharing that will ultimately lead to a stronger evidence base for treatment advances[13,14]. An important requirement that must

also be considered is that data should be deposited in institutional repositories rather than on individual websites, as it has been shown that some of these latter links may became unavailable within a few years[15].

This work has focused on the analysis of raw patient data that journals mandate or recommend authors share. However, there are numerous other initiatives for data sharing outside journals because promoting the exchange of data between researchers is especially important in pediatrics, particularly in such fields as child and adolescent psychiatry, where it is more laborious than in other age groups to achieve broad clinical samples[5]. An example of possible applications of open data sharing in the field of pediatrics is represented by the Phyllis Green and Randolph Cowen Institute for Pediatric Neuroscience at the NYU Child Study Center (New York, USA), a pioneer in open-access data sharing in the functional neuroimaging community[5]. The International Neuroimaging Datasharing Initiative (INDI), conceived in 2009 and supported by Child Mind Institute (https://childmind.org), allows access to thousands of clinical and non-clinical imaging datasets, showing the feasibility of large-scale data aggregation for hypothesis generation and testing. Another examples of the importance of these initiatives are the ADHD-200 Consortium and PediDBS. ADHD-200 Consortium (http://fcon_1000.projects.nitrc.org/indi/adhd200) is a grassroots initiative dedicated to accelerating the scientific community's understanding of the neural basis of Attention Deficit Hyperactivity Disorder (ADHD) through the implementation of open data-sharing and discovery-based science. It comprises several independent imaging sites, including phenotypic data for typically developing children and children with ADHD. The scientific results obtained from these clinical samples can be clearly observed, and it is demonstrated by some published studies that have used these data, such as Tomasi and Volkow (2012) on ADHD[16]. PediDBS is a platform for data sharing, designed as a tool to foster collaborative learning and research in the field of paediatric deep brain stimulation by centres around the world. The ultimate goal is to develop evidence based practice guidelines elucidating the role of deep brain stimulation in paediatric patients[17,18]. On the other hand, platforms connecting several research projects have been developed in order to obtain new findings about patients that suffered from more than one tumour (horizontal integration),

or linking clinical trial data with biological data from biobanks (vertical integration). This is of particular importance in rare disease areas like paediatric oncology[19].

Despite the success of projects such as the International Neuroimaging Initiative Datasharing, there are many misgivings and controversies regarding open-access data sharing, including, among others, fears about privacy as well as the logistical and cultural challenges to building an open-minded science[20,21]. It has also been suggested that effective data sharing does not depend solely on the beliefs and attitudes of researchers; even some of those who agree indicate that there are many extraneous factors that prevent them from sharing their data[6,22].

The ethical and legal implications of sharing data from research involving human participants should always be considered, and protecting patient privacy must be a priority[23]. The issue of confidentiality and consent is more complicated when the sample of data comes from a pediatric population[24]. Whereas some researchers believe that it is enough that parents give consent to share their children's data, others disagree with this interpretation and suggest that it should be the children themselves who give their express consent when they reach adult age[25,26]. In addition, some argue that exchanging data introduces an additional risk to subjects because the danger of losing the protection of privacy is greater once the data have been shared. Researchers who reuse the data may not maintain the same zeal in protecting the subjects as the original investigators, although they are bound by science to this legal and ethical responsibility[11,20,21]. A study that examines genomic research participants' attitudes to explore differences in data sharing preferences between parents of pediatric parents and adult patients[27] conclude that parents are more concerned about future risk to their child, which motivate them to choose more restrictive data sharing options. In the same line, protections for confidentiality were significantly addressed by data sharing organizations researching on complex health conditions such as neurodevelopmental disorders and biomaterials obtained from children[28]. Some reports have revealed that participants are concerned about hypothetical

privacy invasions when participating in genomic research[29,30]. Nevertheless, McGuire et al[30], that perform a randomized trial of consent for data sharing in genome research, suggest that, despite confidentiality concerns, the majority of participants in the study are “information altruists” regarding to the public publication of their genomic data. Another remark is that parents are less inclined to consent to the public release of their child’s DNA data. However, the majority is disposed to share the data with the broader scientific community via controlled access databases[31]. In this line, based on a systematic review of reasons drawing on the data sharing literature and subsequently refined by a consensus working group, Rahimzade et al (2011)[32] discuss how and why allowing access to pediatric genomic and associated clinical data is beneficial to patients. They establish 10 policy points to consider, including ethical, legal and social implications, categorized in four primary themes: children’s involvement, parental consent, consideration of benefits and risks, and data protection and publication requirements.

Another concern in data sharing is the researcher/data attribution. Researchers cite lack of attribution to the effort needed to collect and analyze data as one of the main reasons for not sharing data it. This concern is closely related to the often-expressed that data sharing could allow secondary analysts to publish key results from a data set before the “owners” of the data are able to do so. This problem has generally been addressed by letting a regulated period of exclusive use for the primary researchers, usually a year[1].

This study has some limitations that should be discussed. First, this study analyzes only pediatric journals included in the JCR; it is possible that different policies exist regarding other journals with high impact that also publish pediatric articles, as New England Journal of Medicine, Nature, Science, etc. However, we consider that the exclusive analysis of pediatric journals is a good starting point given the large number of journals indexed in the databases and the articles included in them. In addition, some of these specialized journals hold discussion forums on a wide variety of topics of interest, including common dissemination and sharing practices of research. Second, it is likely that journals policies regarding data sharing were not fully explained in the journal web sites,

or a similar policy could be explained differently, and therefore produces small variations in the descriptive data presented. Third, if journals are an appropriate location for data sharing, it would be helpful to know not only what journals' policies are but also what their actual practices are. Fourth, supplementary data does not always contain raw data, as sometimes it is only additional material accompanying the articles such as extensive tables, questionnaires, supplementary images or pdf files.

Conclusions

Among the conclusions of this work, it should be noted that the majority of pediatric journals advise authors to deposit their data but do not provide specific instructions on how to do so. No correlation was found between the value of the impact factor of the journals and their open data policies. Deposit policies vary among publishing entities, with predominantly PubMed Central and repositories of clinical trials among those suggested for data deposit.

Barriers to participation in data sharing and effective data preservation are deeply rooted in the customs and culture of both the research process and the researchers themselves. We do not know the actual prevalence of data sharing among researchers, so future work in this line could analyze the practices and perceptions of pediatricians regarding data accessibility, reuse, preservation and data sharing in an effort to identify barriers to effective data sharing. On the other hand, there are considerably different data protection policies and standards when data involves special populations as the pediatric population specifically.

The comparative analysis between 2012 and 2016 shows that one of the biggest differences occurs in the reuse of data, which has increased 20 points in percentage in four years. In contrast, we have seen a decrease in the variable storage in thematic or institutional repositories and an increase in the variable regarding the possibility of publishing data on a website.

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