Public policies on information and open access to scientific information on health and neglected diseases: an exploratory study

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Abstract

The present study discusses access to scientific information on neglected diseases in the Oswaldo Cruz Foundation (Fundação Oswaldo Cruz - Fiocruz) with respect to the Open Access Movement. Although neglected diseases are responsible for nearly half of the disease burden in developing countries, investments into the research on these diseases are limited and fall short of what is needed to produce necessary and urgent innovations in the field of public health. The free flow of scientific information is presented as imperative to sustaining research and innovation in the field. This discussion is guided by the central role of communication in science, its social commitment and recent changes in the sector of scientific publications that demonstrate, among other things, the low international visibility of scientific production in developing countries. The Budapest Meeting of 2002 represented a significant landmark for the movement of resistance to this scenario. The research presented was based on the concept of scientific communication, emphasizing interlinked pillars of communication: legitimacy or reliability, peer review, accessibility and publicity. From theory to empirical reality, the challenge posed to researchers was to identify the obstacles to and favorable aspects for the development of a policy of open access to scientific information on neglected diseases within Fiocruz. Indications that could support or even sustain the defining parameters of a public policy toward open access to scientific information in health were sought in the literature and in empirical reality to guide the present study. The results confirm the potential for open access to such information while suggesting the importance of a movement toward awareness and critical reflection on the topic to both guide and contribute to the proposition of a public policy of open access to scientific information about health, especially concerning neglected diseases.

Keywords: Public Policies on Information. Health Information. Neglected Diseases. Open Access.
**Introduction**

In the early 1990s, the restricted access to scientific information recorded and expressed in scientific journals fostered the emergence of an international movement in favor of free access, which is the subject of the present study.\(^1\)

For more than three centuries, the international academic community has recognized the scientific journal as the preferred channel for the communication and legitimization of the results of scientific research, confirming Meadows’ assertion (1999) that “communication is at the very heart of science”. From its initial division into natural and exact sciences, the scope of science has been simultaneously expanding and fragmenting with the development and specialization of distinct fields.

Over time, the journal consolidated its position in the monopoly of the publishing industry of scientific communication. At the beginning of the 21st century, within the scenario of changes caused by the advent of the Internet, among other significant factors, new and promising horizons appeared for the universalization of free access to scientific information.

The so-called “journal crisis” that preceded the international economic crisis of the 1990s and then intensified was due to the high subscription prices of international journals; the prices underwent such drastic increases that subscription renewal became impractical for several academic and research institutions, even in wealthy countries. The situation was even worse in poor and developing countries. Conversely, the development of information and communication technologies (ICT) enabled the creation of low-cost, widely circulated publication alternatives that favored the emergence of the movement toward open access to information in science and technology.

The present study aimed to highlight the need for further reflection to base the development of actions in a comprehensive coordinated and collaborative program within the Oswaldo Cruz Foundation (Fiocruz), using the framework of a Brazilian policy in favor of expanding the visibility of scientific information about health through open access, with an emphasis on “neglected diseases”. The Brazilian Ministry of Health defines neglected diseases as “diseases that only prevail in poverty but also contribute to maintaining inequality, as they represent a strong barrier to country development” (BRAZIL, 2010).\(^2\)

More specifically, the present study intended to provide elements that could contribute to strengthening Fiocruz’s adherence to relevant initiatives in favor of open access to information in Science and Health Technology (S&HT).

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1 This article was written based on NORONHA, I.H.N. *O livre acesso à informação científica em doenças negligenciadas: um estudo exploratório.* [Open access to scientific information on neglected diseases: an exploratory study]. 2011. 140 f. Dissertation (Master’s Program in Information Science) – Fluminense Federal University (Universidade Federal Fluminense), Niterói, 2011.

2 The aggravation of poverty and the health of people affected by these diseases has led the World Health Organization (WHO) and the Non-Governmental Organization (NGO) Doctors Without Borders (“Médicos Sem Fronteira” - MSF) to propose new classifications for these diseases: Global Diseases, which occur worldwide; Neglected Diseases, which present a higher incidence in developing countries; and Most Neglected Diseases, which are exclusive to developing countries. This classification is an improvement over the old and simplistic term “Tropical Diseases”, which indicates a merely geographic connotation for this group of diseases without considering the political, economic and social contexts of their occurrence.
Fiocruz was created in the beginning of the 20th century with a mission to develop research activities, provide education, produce pharmaceuticals and immunobiological products and assist the Brazilian population. For more than a century, the institution has expanded its field of expertise and the production of knowledge. Currently, Fiocruz’s social commitment provides open access to scientific productions developed within the institution using public funds.

Within the scientific community and in the management of science and health technology, there has been much, although perhaps not enough, reflection in publications and at scientific events on the potential of open access as a strategy for expanding, sharing scientific information and possibly as a way to produce innovation.

In view of this conclusion, an investigation of the factors enabling the understanding of institutions’ and researchers’ low adherence to strategies of open access to scientific health information in Brazil, as initially identified in the literature, proved necessary. Emphasis was placed on neglected diseases, given their social determination and the restricted circulation of scientific production on such diseases.

Therefore, the question raised in the present study was the following: what are the obstacles to and favorable aspects for the elaboration and development of a public policy of open access to scientific information in the field of neglected diseases, particularly in Fiocruz?

To answer this question, we attempted, in an exploratory manner, to identify indications in the literature and the empirical reality targeted in the present study that could support or even sustain the proposition of a public policy on open access to scientific health information within Fiocruz. This investigation constituted the aim of the present study.

Given the extent of the field of public health in Brazil, we chose to focus the study on an institution and specifically observe Fiocruz’s perspective regarding neglected diseases.

**Public policies on information and open access to scientific information in Brazil**

The late 20th century presented an ongoing economic crisis in developed countries with serious repercussions for poor and developing countries that depended on a globalized economy. In times of international crisis, great powers’ tendency is to direct investments toward strengthening the financial sector, among other activities of high social cost, at the expense of activities aimed to strengthen public policies in the social and scientific arena that are aimed at the common good.

Despite the international economic situation and its impact on the national economy, the 1980s was a period of political liberalization and redemocratization for Brazil and led to the drafting of the new Brazilian Constitution, established in 1988. With the end of the dictatorial regime and the return to democracy, it was possible to discuss topics like freedom of expression, participation, public policies, social control and the right to information. As a result of this broad social mobilization, the new Brazilian Constitution advanced in its recognition of civil rights and promoted access to information as the State’s duty and the citizens’ right. Accordingly, the State should invest in the development of public policies that will raise the country to a new technical-scientific and cultural level capable of responding to the huge social debts and deficit of available information for individual and/or collective decision making.
In this environment, the formulation and development of public policies in Brazil increasingly became the object of bargaining among politicians, managers and organized social groups. These subjects also became the subject of reflection for researchers in various fields of knowledge, including Information Science, in view of the analysis of information policies. According to Muller et al. (2004, p.14), “a public policy is both a social construct and a research construct”:

Public policy constitutes a "local order"; i.e., a relatively autonomous political construct that operates, in its level, the regulation of conflicts between stakeholders, and ensures the coordination and harmonization of their interests and their individual purposes, as well as collective interests and purposes (FRIEDBERT, 1993 apud MULLER et al. 2004)

Regarding this discussion, Jardim (2009, p.9-11) explains that

[...] the study of public policies falls today within the efforts for understanding the role of the State and its implications for contemporary society. This means observing the existing logic in the different forms of interaction between State and Society, identifying the current relationships between the various actors, and understanding the dynamics of public action.

The author also clarifies that public policy scholars are especially concerned with the effects of formulated and implemented policies that constitute tangible objects of evaluation.

In the context of Brazilian scientific production, Ortellado (2008) analyzes the Brazilian government’s action in proposing and developing public policies on access to information that, according to the author’s perception, still lacks articulation and organization, considering the current scenario of an international policy on free access to information. While agreeing with Ortellado’s analysis (2008) of the need for a national policy on open access to scientific information to be coordinated with international efforts in this field, one must consider that toward the success of a Brazilian policy, the country’s own knowledge and experience constitute a fundamental element.

In this sense, Higino, Araujo and Scott’s (2008) criticism of the design of the Green Book proposal (“proposta do Livro Verde”) – Brazilian Information Society (“Sociedade da Informação no Brasil” – 2000) – should be noted. This book was released in 2002 by the Ministry of Science and Technology (“Ministério da Ciência e Tecnologia” – MCT) and emphasizes strategies for applying ICTs at the expense of reflection on the content of a project called “Information Society” (“Sociedade da Informação”).

When observing the possible relationships between the characteristics of a public policy and the concerns of the open access to information movement, certain elements may be observed that are present in both the policy and the movement, although they may occur to different degrees. These include the relationship of power and legitimacy, trading spaces, elements of value and knowledge, rules, regulations and procedures, the production of meanings and cultural values and, especially, “an ideology that generates and sustains them” (SILVA, 1998 apud JARDIM et al., 2009). The latter is thought to be one of the pillars of open access.

Therefore, the primary elements described by Silva (1998) and Jardim et al. (2009) in an accurate survey of the literature on public policies on information indicate the relevance of considering the strategies touted by the open access movement as important elements of composing a public policy on information in Brazil.
It should be noted that one of these strategies consists of making the self-archiving\(^3\) of scientific production developed with public funds mandatory via the green route strategy of open access\(^4\).

Among the arguments justifying open access to scientific information, Ortellado (2008, p.186) describes the link to scientific values or the academic ethos of the “communism of results”; i.e., the understanding of information and knowledge as a “common good” to be shared as a heritage feature.

In the case of Brazilian public health, sharing results obtained from the research on neglected diseases in the country becomes even more crucial, given the risks of resurgence of these diseases and the emergence of new diseases. In this sense, one cannot disregard the consequences of failures in scientific communication caused by restricted access to scientific information on these diseases.

The process of scientific communication is supported by certain pillars that include legitimacy, peer review and accessibility. According to Bobbio (2008, p.675), legitimacy has “the sense of justice or rationality” (regarding the legitimacy of a decision or attitude). Legitimacy refers to consensus and, accordingly, it can be stated that the ritual or process of peer review is consensual among members of the scientific community and legitimizes the process of scientific communication (MUELLER, 2006).

Peer review aims to ensure the quality of research and the appraiser’s exemption from the dissemination of the achieved results, earning the trust or “legitimacy” of the scientific community in particular and society in general (MUELER, 2006).

In accordance with Ferreira (2008), accessibility “refers to the organization, permanence and access to scientific content by the scientific community”. In terms of digital information, these three aspects, which are strengthened by open access, assume a special nature when considering the precepts of the open access movement.

According to Weitzel (2005), the three pillars of communication in science are accessibility, reliability (which would include legitimacy and peer review, according to our definition) and advertising.

Having highlighted the pillars upon which scientific communication rests, it can be stated that the scientific community is legitimized by the application of the scientific method and rules of conduct through which, by consensus, a level of strictness is maintained that could be classified as “eternal vigilance”. These secular rules have been updated by Robert Merton, who is considered the founder of the modern sociology of science.

The concepts described above have theoretically supported research by guiding privileged aspects of interviews with social actors at Fiocruz, given that in the context of Brazilian public

\(^3\) In the open access movement, the purpose of suggesting authors’ self-archiving of their studies is to ensure the author’s autonomy over his own work. However, archiving in an Institutional Repository (IR) can be performed by the librarian with the author’s permission.

\(^4\) The Green Route (“Via Verde”) is a strategy that enables open access to scientific information through the self-archiving of papers that have been already published or accepted for publication in an institutional repository, along with papers undergoing peer review, reports and other documents that authors wish to share publicly.
health, the institution aims to make the scientific information it produces using public funds publicly available.

Following the trajectory of the social phenomenon of information since the recognition of its strategic role in science and contemporary society and according to Gonzáles de Gómez (2002, p.2), in the 20th century, information assumed “a double representation of its areas of territorial, social and symbolic intervention”. On the one hand, through its inclusion in the State’s sphere of intervention, information is not only a dimension of administrative rationality but a strategic factor of scientific and technological development. On the other hand, considering that the modern form of sovereignty would not diminish in State matters, information constitutes the structuring factor of social integration and the construction of the new citizenship. The new order, which should include an informed citizenry, required the organization of a system of rights that guarantees the flow of information to various social actors and the expansion of educational and informational institutions such as schools, universities, libraries and museums.

In Brazil, one of the factors restricting access to the results of studies developed in public institutions results from the current criteria for the evaluation of scientific merit adopted by Brazilian fostering agencies, which are used to assess scientific production in developed countries. These criteria do not address the specific characteristics of Brazilian research on neglected diseases. Consequently, these criteria restrict the author’s visibility and access to national scientific productions that are also of great interest to other developing countries.

To prove the importance of open access publishing, Machado (2005) used data collected by Brody (2004) from the database of the Institute for Scientific Information (ISI) to elaborate a comparative table of the impact percentages among open access and restricted access articles. The result reveals that in the biomedical field, the difference of impact through open access is 218%, while in the field of history it exceeds 1000%; this outcome demonstrates the increased visibility of articles freely available on the Internet at an infinitely lower cost. Accordingly, Swan (2008) emphasizes the opportunity for and necessity of adopting an open access policy in Brazil, reporting the expectations of managers, funders and researchers performing research in open access and information and knowledge-sharing environments. According to the author,

> Universities and research institutes, and public and private research funders, all expect to see a track record of publications from each researcher that reports their work, shows that they have carried out work of a standard sufficient to merit publication and disseminates the findings so that others can build upon them. Researchers find that this track record is weighed very heavily when it comes to obtaining a position, gaining tenure or winning promotion. And so it should be: the published output is a legitimate and sensible measure of a researcher’s ability and contribution to his or her field. (SWAN, 2008, p.160)

On the international scene in the mid-twentieth century, the advance of information technology led to the development of the first projects of open access to digital contents, which, as noted by Machado (2005, p.7), “are confounded with the very history of the Internet”. It is worth noting that authors such as Machado (2005), Carvalho (2006) and others credit the birth of the Internet to the emergence of the first computer networks in the mid-1960s; these authors consider the emergence of the first initiatives to be the beginning of the history of the giant network.

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5 A phenomenon that is the basis of the modern State and, therefore, that has its origins in the nineteenth century.
Social Movements for Open Access to Scientific Information

From letter reading at society meetings in the seventeenth century to the systematic reading of journal articles and the emergence of electronic publications, each stage of scientific communication has been accompanied by the development and circulation of scientific information recorded in different media and formats. Therefore, from physical meetings to the universal access to literature so strongly desired by Paul Otlet in the late nineteenth century, the journal has consolidated its position in the monopoly of the international publishing industry of scientific communication. The journal currently indicates signs of a new qualitative leap toward the open access of scientific information, which relies on significant contributions from the Internet.

As noted, the origins of the scientific community’s movement toward open access in the 1970s coincided with a severe economic crisis affecting capitalist countries in the global North and South. At the beginning of the crisis, before the advent of the web, libraries from academic and research institutions were forced to become more selective in their acquisition of monographs and periodicals, given their significantly increased prices. As a consequence, access to research findings was restricted even further, while additional researchers produced new findings, resulting in significant changes in the flow of information.

The onset of the economic crisis was perceived in the United States in the rising costs of scientific journals, which reached a greater scale than the economic indicators and financing predicted by subscriptions. According to Kuramoto (2006), between 1989 and 2001, the increase in subscription costs for some titles surpassed one thousand percent, risking the collections’ continued presence in university and research libraries. Faced with the magnitude of this problem, North American researchers searched for alternatives for the dissemination of their research findings.

The first signs of a reaction to this crisis from a segment of the scientific community arose in the United States in the early 1990s, creating the foundation from which the researchers’ movement emerged and evolved in favor of open access to scientific information.

An important event that occurred in 1991 in the Physics Laboratory in Los Alamos, New Mexico, United States gave rise to the possibility of alternatives to the problem of restricted access to scientific information. The ArXiv.org Repository was developed under the guidance of Paul Ginsparg to address the need to archive so-called “e-prints”. A similar initiative emerged in Southampton, United Kingdom. While speaking about the establishment of the ArXiv to the participants of a 2001 conference at the headquarters of the United Nations Educational, Scientific and Cultural Organization (UNESCO) in Paris, Ginsparg (2001) confirmed that the initial goal of the e-print ArXiv was to develop new features to provide fair competition for

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6 In 1966, the first U.S. initiative to create a database of electronic literature was introduced: the Educational Resources Information Center (ERI). This database, funded by the Institute of Education Sciences (IES) of the U.S. Department of Education, evolved into a digital education library. Many projects now populating cyberspace emerged from that source.

7 The open access movement arose from the reactions of a group of researchers against the restricted access to scientific literature caused by the cuts in journal subscriptions of the 1990s. Two alternative approaches to make access to scientific literature free were built into the core of the movement. The participants in this movement have met regularly in Santa Fe to assess the progress of open access.

researchers at different academic levels located in different places. According to Ginsparg, “the drastic reduction in the costs of dissemination came as an unexpected bonus”.

Since that time, e-print repository initiatives have multiplied and strengthened so that in July 1999, Paul Ginsparg, Rick Luce and Herbert Van Somple called a meeting with the heads of the primary e-print repositories for an evaluation of the initiative. This meeting, the “Santa Fe Convention” (SOMPEL et al., 2000), was held in the United States and approved the creation of the OAI (Open Archives Initiative), with the purpose of developing alternative strategies for scientific communication by defining specific technical and administrative aspects to enable interoperability between academic e-print repositories.

It can be noted from this sequence of events that the foundational moment in the international movement toward open access was the Santa Fe Convention, which aimed to “contribute to the transformation of scientific communication in a concentrated manner”. The group formulated and covenanted the adoption of the strategy of “open philosophy” or OAI, involving the use of free or open-source software for the development of applications, open files for interoperability between systems and open access for the wide and unrestricted dissemination of scientific information. According to Costa (2006), the use of these tools, strategies and methodologies represents “a new model for representing an equally new process of scientific communication, while serving as a basis for its interpretation” (p.40). English researchers and researchers from other countries in both the Northern and Southern Hemispheres joined this movement, which reached countries far from the center of the discussion, including Brazil.

Given the increasing restrictions and pressures imposed by those who, motivated by some specific interest or an orthodox view of science, resisted change and defended the maintenance of the current communication system, the adoption of distention strategies between actors involved in this dispute became necessary. In this case, the philosophical perspective of “openness” was sought as an alternative. According to this perspective, one of the implications of open access to scientific literature concerns the choice of a rupture with the notion of constraint. The principle of “openness” was to be adopted in the field of scientific information as a value to be shared by all, from the point of view of both human relations and technology or informational content.

Authors such as Costa (2006) and Machado (2005) note that despite its statements in favor of open access, in practice, the movement has not yet reached its expected magnitude in Brazil. Machado (2005) lists a lack of knowledge among researchers regarding strategies of open access and a lack of institutional support among the reasons for the low adherence of the Brazilian scientific community to open access principles. He also notes the inexistence of a culture of digital sharing among broad sectors of the academic community, especially in the human and biological sciences, and the lack of an institutional policy that fosters digital publications and self-archiving, among other causes.

The difficulties faced by researchers and managers of specialized libraries since the so-called “journal crisis” strengthened a significant segment of the scientific community’s understanding of information as a public good that is essential for human and social development and should, therefore, be freely accessible. Although the nature of this understanding has not yet reached consensus, fertile ground exists for reflection on the importance of open access to scientific
Information, especially in the health field, which is undoubtedly a crucial issue for the advancement of science in poor and developing countries such as Brazil.

In the context of Brazilian public health, national health and scientific conferences are emphasized among the institutional spaces for participation in organized social movements. It was this environment in which the primary actors in health mobilized around the negotiation of political and technological strategies for open access and the open access movement in the field of health, which is the subject of the present study.

In discussing the current challenges for scientific communication, the high costs of international publications and the inadequate evaluation criteria of scientific merit adopted in Brazil – based on the scientific standards of developed countries – favor the exclusion of Brazilian researchers from the international scenario of science and accentuate the low visibility of national scientific production on neglected diseases. Faced with this impasse, the Institutional Repository (IR) emerges as an alternative, resting on two pillars that provide visibility and the author’s autonomy over his work: self-archiving and copyright.

**Open Access in Health**

Information plays an important role in health activities, in medical records, in developing information systems for monitoring epidemiological profiles as strategic inputs for clinical decision-making and in the fruitful field of research and its application. As one of the first electronic database projects, MedLine was developed by the National Library of Medicine in the United States and emerged in 1966 in the biomedical field. MedLine provides access to bibliographic references and abstracts from more than 4,000 biomedical journals published in the United States and 70 other countries. This database is considered the most important referential database in the field; in Brazil, it can be freely accessed through the Virtual Health Library (VHL). Launched in 1995, the VHL is characterized as an online digital library for research, education and information, and it was the first open access project in Brazilian public health. The development of the VHL arose from a Bireme initiative in partnership with the School of Public Health of the University of São Paulo (“Universidade de São Paulo”; USP) and the Institute of Communication and Scientific and Technological Information (“Instituto de Comunicação e Informação Científica e Tecnológica”; ICICT) at Fiocruz.

**The perspective of key actors at Fiocruz on open access to information: focus on neglected diseases**

In the face of challenges to scientific communication, particularly with regard to neglected diseases, it appeared relevant to the present study to obtain and present the perspectives and positions of managers and researchers at Fiocruz (from a sample taken as representative of these segments) regarding the possibility of the institution’s adherence to initiatives concerning open access to scientific and technological information.

It was hypothesized that these actors’ positions on the ideas advocated by the movement toward open access to information in Science and Technology (S&T) can offer elements that contribute to strengthening Fiocruz’s adherence to their premises. These concern the self-archiving of scientific papers in repositories (Green Route) and open access electronic journals (Golden Route; “via dourada”).
To obtain the statements mentioned above, the researchers adopted an exploratory study with a qualitative approach. According to Minayo, Gomes and Deslandes (2007, p. 62), in qualitative research, a “field should be understood as the spatial area with respect to the coverage in empirical terms of the theoretical framework corresponding to the object of investigation”. In agreement with Mills (2009) on the role of empirical research, Minayo et al. (2007, p. 61) emphasize the importance of field work in allowing the researcher to approach the reality on which his question was formulated and to highlight the opportunity to “interact with the actors that compose reality”, allowing the researcher to develop a “very important empirical knowledge for those conducting social research”.

In total, the methodological procedures utilized in the present study consisted of documentary research for the assessment of aspects that characterize the health field, highlighting the events in this field. The literature search performed to theoretically support the study also allowed a survey of national and international experiences regarding open access. Interviews with institutional managers and researchers were used to address historical and institutional policy issues at Fiocruz in light of the possible adoption of measures related to increasing open access within the institution, specifically concerning neglected diseases.

A semi-structured interview design was selected for the primary data collection. To obtain the statements of the social actors described above, two profiles were defined for the interviews: researchers-managers in science and technology and researchers conducting research activities, who were considered key actors in data collection and analysis.

An understanding of current views and positions regarding the open access alternative was sought by interviewing two institutional managers in science and technology and five researchers equally linked to Fiocruz and working in the field of neglected diseases. Therefore, these seven actors comprised the small but representative research sample.

The interviews conducted with the two managers, coded as G1 and G2, addressed a topic that is complex but essential to the development of this research and relates to investment. When asked about the percentage of funds invested in research at Fiocruz, G1 explained that it is difficult to precisely determine the budget intended exclusively for this activity, as there is no specific research budget value. According to G1:

“It depends. You may have infrastructure costs, which are not seen as research and are fundamental for research. You have a confluence of some activities: for instance, teaching and research, research and development”.

Regarding the development of a new project for the induction of health innovation at Fiocruz, the Center for Technological Development in Health (Centro de Desenvolvimento Tecnológico em Saúde; CDTS), which required the construction of a building in the Manguinhos campus, G2 stated that

“I did not even include the construction of the [CDTS] [in the budget] because it is one hundred percent Brazilian Government”.

A high degree of unanimity was observed among the researchers in the Health Sciences – identified as P1, P2 and so on – with regard to their research habits, especially their use of information sources. The result of the study confirms a trend that points to PubMed as the primary source of information for health research.
On the possible influence, or lack thereof, of the topic of a research study on its acceptance for publication, P1 noted that

"Surely it interferes. That is why we do not publish anywhere; there is no way, you have to choose the niche."

The discussion regarding the influence or lack of influence of the research subject on its publication is inconclusive. According to P2, "It does not interfere". In agreement with this view, P3 stated, "Regarding the theme that I work with, I think not. It is widely accepted." According to P4, "The subject does not interfere". However, from P5's perspective, "I have no doubt that today it interferes".

There is no doubt that the ISI criteria interfere with researchers’ decisions when choosing an outlet for publication, given that these criteria are traditionally viewed as intrinsically linked to the recognition of scientific merit. The interviews revealed the respondents’ concern with the importance placed on the impact factor, although different strategies are adopted to address this issue.

Concerning the possibility of Fiocruz’s adherence to open access strategies, the “obstacles and favorable aspects to the elaboration and development of a public policy on open access to scientific information in the context of neglected diseases at Fiocruz” were highlighted. According to the respondents, the publication of studies on neglected diseases faces difficulties due to several factors. Both G1 and G2 described their very clear views of the problems faced with the adoption of the current criteria for recognizing the merit of research. In agreement with the hypothesis developed in the present study, G1 stated that such rules create limitations that result in damage to the advance of science in developing countries and amplify inequities, especially by restricting access to scientific information. It is commonly known that information can contribute to the generation of new products and materials than can lead to an improved quality of health and life in the most neglected populations.

According to G1, to arrive at a more equitable proposal on the rules for assessing scientific merit in the country:

"It starts with the modification of the criteria for recognition of research and development processes. [...] We have started to create certain types of partnerships and incentives to break this closure. We then need specific policies that go against the strengthening of closure that produces inequality".

Respondent G1 also analyzed the difficulty of promoting cultural change in a community that is jealous of their values and criteria for scientific merit, as is the case within the scientific community at Fiocruz. In this sense, G1 created a parallel between the orientation toward the induction of change in the current traditional model of research and the adoption of strategic research, which can also be applied in the case of changes in institutional scientific communication:

"One does not change culture by decree. You change it with a process of persuasion, which often involves the building of a lot of awareness and the encouragement of labor".

To contextualize his response, G2 provided an account of an exemplary case for Fiocruz involving his experience as a consultant to a scientific institution in a highly developed European country. The predominant cultural values in that scientific community were so
ingrained that they hindered the adoption of new publication habits in spite of their proven ability to increase the results of their research through open access and use, maintaining a certain resemblance to the Brazilian case discussed in this research:

"Three weeks ago I was in Switzerland for the evaluation of the Swiss Tropical Institute [...] One of the things I noticed is where they are publishing. And in both 2007 and 2010, the magazine that they used the most was the American Journal of Tropical Medicine and Hygiene. In the final analysis I said: 'I think it's time for you to reconsider [...] Because there is open access.' The reasons are historical. [...] If you want a high impact factor, it is, nowadays, no longer a barrier for you to publish in open access. On the contrary, you have open access journals of high impact. However, there is still prejudice."

When asked about the adoption of open access at Fiocruz, P2 expressed his assurance on the issue of freedom of research in a manner consistent with his autonomy regarding the external scientific policy guidelines:

"I see no problem in that. It's another way to make knowledge accessible to people and greatly expand the access to information".

The same can be observed in P4's analysis based on his personal experience as the editor of a scientific journal, in which he cited copyright issues as a major obstacle. In the case of publication under restricted access, the author gives up his rights, transferring them to the publication's editor:

"Now, obstacles ... I see no obstacle unless the question is of rights ... I mean that maybe the issue is that the magazine does not want to release everything. It allows you to consult it, but access is not free; you cannot copy the article that interests you. I think it has to be something very open, you know?"

Respondent P5 expressed his concern about the barriers that hinder the adherence of traditional journals to open access. According to P5, in scientific journals, a series of commercial interests are involved, which should not be the case for publications that receive public funds. These publications must commit to strengthening open access to scientific production in the area of health that are financed by public funds:

"Ah! But I am certain of this. Any science. I am paid by the Brazilian people. [...] I allow free access to my slides for everyone to copy. The only caution I have, even because of the Brazilian people, is with regard to a slide containing results that I am generating that will serve for a patent, which I will ensure for Brazil, for the health care service ("Sistema Único de Saúde"; SUS). Then I will have to be careful. Because in that case, I would also be irresponsible to the people who funded me. The knowledge that I have was not borne through spontaneous generation; I was not enlightened, it was learned from someone, so it is not mine."

**Final considerations**

The present study was designed with the purpose of understanding the obstacles to and favorable aspects for the development of a policy of open access to scientific information at Fiocruz, emphasizing information related to neglected diseases. The present study also aimed to contribute to studies in the area of Information Science regarding the analysis of public information policies and their impact on the process of scientific communication. In this sense, the present study presents a summary of the reflections on the policy of open access in the
literature and, subsequently, from the statements of key actors at Fiocruz who shape the empirical field of research.

The purpose of developing a study at Fiocruz to reflect on the elements of a policy of open access to information at this important institution and examine the peculiarities of these policies and of the neglected diseases proved relevant to the key actors at the research institution who were interviewed for the study. This study may contribute to similar initiatives by other Brazilian public institutions.

When analyzing the context of the occurrence of neglected diseases in Brazil and in the interests of the present study, it was possible to note that the rich informational dimensions of health allows the acknowledgement of the inseparability of the development of scientific research from the communication of its findings, thus enabling their sharing and use and generating a cycle in which information is both input and output.

We wish to emphasize that scientific communication, as addressed in the research, is characterized as a collective and interactive activity and, accordingly, that the social aspects of science involved in this process should be considered. Among the social aspects of science, the legitimizing process has been emphasized, which, in the case of scientific production, occurs through the application of the scientific method and rules of conduct, ensuring the consistency and reliability of the new knowledge generated. Once shared, this knowledge may enhance the generation of additional knowledge. Likewise, the idea of legitimization was considered during the examination of the channels chosen by the scientific community and their limits and possibilities for the broad communication of research conducted at Fiocruz, according to these actors.

The philosophical principle of “openness” was contemplated as a way of organizing social activities that favor universal access and collaborative production, translated into information policies with an emphasis on the role and functioning of ICTs. In this sense, we believe in the strengthening of the idea of an “open science”; free information is believed to play a fundamental role in this concept. We sought to use the statements of key actors at Fiocruz, which comprised our empirical field research, to reveal the actors’ views and positions on policies of open access to scientific health information. In this way, we aimed to identify the possibilities of adherence to the premises of the open access movement while considering whether and how to identify the IR as a device for enabling such policies.

Although the importance of adherence to open access was unanimously confirmed in the respondents’ statements and because accessibility and advertising are highly valued by the actors, it is important to clarify that survey data revealed that although most of the researchers interviewed had heard of open access, they were unaware (or barely aware) of its mode of operation or the results achieved by researchers who have adopted this new form of free publication.

These statements from key actors were revealing, especially the unanimous position regarding adherence to open access to scientific information with the creation of an IR at Fiocruz.

From the consulted literature and the statements from managers and researchers, this study reveals that the managers of Brazilian institutions of science and technology in health and researchers in the area of neglected diseases are in favor of, if not completely committed to,
the new free form of publishing the results of their research; the interviewees stated their support for a policy of open access to scientific information. Still, accessibility to scientific information on neglected diseases continues to face limitations, although concrete and successful international experiences already exist, including the publication of articles in PLoS and the NIH IR development, PubMed.

The researchers’ arguments supporting the maintenance of the current mode of publication, which some of the respondents justified as cultural problems, may, in most cases, be linked to the lack of a deeper understanding about the successful experiences recorded in the literature on open access publication. These arguments may also occur because the shift to a new way of publishing is very recent and awaits legitimization in the Brazilian scientific community and internationally. The claim regarding cultural issues was identified by the majority of respondents and should absolutely be considered when formulating policies on open access in general and at Fiocruz in particular. Within this institution, some statements revealed ample possible methods of addressing the identified cultural barriers.

The opening and broadening of the discussion on the difficulties and positive aspects of open access is, therefore, recommended among the deliberative collegiate bodies of the research units at Fiocruz. A careful examination of the barriers inherent in the current model of scientific communication and the adoption of open access in the institution is proposed, and the importance of the legitimacy of a new social contract of science based on open access to scientific information in health is highlighted.

We hope that this study will enable the generation of support and guidelines to enlighten and orient similar policies in Brazilian health institutions, gradually strengthening a movement toward expanding the visibility of Brazilian scientific production through open access, based on the experience at Fiocruz.

In this sense, it is deemed appropriate that Brazilian managers and researchers conduct a careful examination of the factors contributing to the current situation of scientific communication in developing countries such as Brazil. The potential of open access should also be assessed, as should the possibility of promoting a gradual break from the current model of scientific communication, creating the necessary conditions for a leap toward innovation in science through the legitimization of a new social contract for science with open access to scientific information as its principle.

References


