Expanding Perspectives on Open Science: Communities, Cultures and Diversity in Concepts and Practices
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What Is at Stake? Public Participation and the Co-Production of Open Scientific Knowledge

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Abstract. Openness has become an explicit subject across science policy and scholarly practice, where it is often vindicated in a rhetoric of optimism. In political discourse, as much as in the scholarly literature, open access to research data and publications is expected to enable what policy has typically failed to achieve by other means: that is, to overcome material, class, and political barriers that stand in the way of knowledge circulation. However, whether openness in science is a good thing or not also seems to depend on what is being opened, to what extent and for whom. In this paper I draw on different critical areas of Latin American science, technology and society studies (LASTS) to suggest that the current dominant views around open science can be limiting, as much as they could be enabling, more inclusive dynamics of access to and uses of scientific knowledge, especially in the peripheral (or non-hegemonic) contexts of science. These limiting views around openness, I argue, are linked with restrictive conceptions about science and its products: scientific activity is understood, by this token, as an invariably universal enterprise. In consequence, science outputs are conceived as self-contained knowledge products, and the processes and practices that account for their production and use are only partly taken into consideration. The aim is hence to elaborate on different forms of participation and exclusion to the processes of knowledge production which could help us understand how different stakeholders become engaged or excluded in the production of knowledge. To do so, I take the case of genomic research and drug development for neglected diseases as my empirical background. The argument draws on two concepts from LASTS. The first one is cognitive exploitation, according to which scientific outputs are used in for-profit contexts by third-parties, but without compensating the original producers. In this way, it is not only producers, users and appropriators of knowledge who become key in the dynamics of knowledge circulation, but also those acting as intermediaries. The other concept is integrated subordination, which refers, on the one hand, to the dynamics by which peripheral regions collaborate with elite research networks, and the difficulties that stand in the way of industrializing scientific knowledge, on the other. These difficulties spawn from the lack of capacities, but also from adherence to international research agendas, which are not necessarily connected with those required to attend to social needs in peripheral contexts. By putting into question the nature and the limits of openness, and by re-examining the types of knowledge at stake (beyond research data and publications), the actors, and their involvement, I suggest other ways in which open scientific knowledge could become effectively used.

Keywords. participation, open access, co-production of knowledge, policy, discourse

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1. Introduction

Scientific knowledge has long been understood as *universal*. From the *philosophes* of the Enlightenment to Robert K. Merton's first systematic attempts into the sociology of science [1], at least, scientific knowledge was more often than not idealized as belonging to the final commitment to universal human reason. Scientific universality, as I understand it, was (and still is) intended to impart at least two interrelated norms: scientific knowledge has to transcended personal *ownership*, but it also has to be reducible to *context-free* accounts of the reality.

More controversial depictions of science emerged towards the 1970s when the social sciences and the humanities gave up on the concept of scientific knowledge as something necessarily true and invariably universal. "Post-Mertonian" waves of science studies broke into the sites of knowledge production, then, to gather traces of contingency, arbitrariness, negotiation, chance, belief and secrecy that govern the making of scientific knowledge and order scientific practices. "Laboratory studies", as these were dubbed later on, owed partly to the post-structalists' wider reaction to realism and the autonomous individual that served as an underpinning for the universal (Western) logos, although the starting point for these new waves of science studies can also be traced back to less radical efforts (including Thomas Kuhn's *Structure of scientific revolutions* [2] and David Bloor's *Knowledge and social imagery* [3]), aimed at dragging scientific knowledge into the realm of relativism, precisely, because of its association with human history and the social.

The deeper epistemological implications of making scientific knowledge an object of social inquiry shall not (and could not) be discussed here further, as it remains, yet, a matter of dispute within the field of science, technology and society studies (and mostly everywhere else) [see, for instance, 4–9]. Instead, in this paper I shall elaborate on the overall critique to the two aforementioned norms that are expected to regulate the pretended universality of scientific knowledge, and which still seem to be vindicated in the dominating discourses of open science. My critique can be synthesised as follows: the ownership of scientific knowledge can be realized through its *effective use* and de facto exclusiveness in spite of its formal openness; in addition to this, the possibility of producing and effectively using scientific knowledge is for the most part *context-dependent*, in spite of its intended universality. In putting forward this critique I draw on several proposals stemming chiefly from Latin American science, technology and society studies (LASTS). The overall orientation of this paper is to identify the implications of ownership and the contextual factors in scientific openness, especially in its ability to attend to social needs in peripheral societies and developing regions. To do so, I focus mainly on the case of Chagas disease research and open-access drug development initiatives. The data comes from my doctoral dissertation [10] and from the outputs of the Open and Collaborative Science in Development Network project "Can open and collaborative science meet social needs?". This line of enquiry would be, in the last instance, aimed at elaborating on different forms of participation and exclusion in science that are seldom contemplated in the analyses of open science and its related initiatives. In doing so, I present a set of conceptual tools that can help us understand (and potentially foster) the participation of stakeholders in the face of producing usable scientific knowledge. These tools are derived from the concepts of *cognitive exploitation* and *integrated subordination*, both found in LASTS.

The next section introduces the case study and the idea of *cognitive exploitation* to understand forms of knowledge ownership and exclusion that might subsist precisely because of scientific openness, rather than in spite of it.

2. Neglected Tropical Diseases Research and the Exploitation of Open Scientific Knowledge

Chagas disease or *American Trypanosomiasis* is endemic in the Americas and affects over 15 million individuals. While its forms of transmission are mostly vector-borne and occur in rural areas with deficient housing conditions, migratory processes of the last 40 years have render the disease as a public health concern in urban areas traditionally and non-endemic regions [11–16]. Chagas is also classified by the World Health Organization (WHO) as one the 17 neglected tropical diseases, meaning it prevails in tropical conditions and lacks of effective, affordable, and widely-available treatment options.

In spite of this discouraging scenario, Chagas has been a target of sustained international research efforts, aimed, in part, at making up for the lack of commercial interest shown by pharmaceutical firms [17–20]. Since its launching by the WHO in 1975, support for research and development activities in Chagas and other similar diseases has come, mainly, from the Special Programme for Research and Training in Neglected Tropical Diseases (TDR). Other research centres and funding bodies include the Rockefeller Foundation, The Bill & Melinda Gates Foundation and Doctors Without Borders.

The problem of cognitive exploitation, as well as the potential problems with open access in Chagas disease research, surfaces with the completion of the Trypanosome cruzi Genome project (TcGP), an initiative aimed at mapping the genomic sequence of the Chagas' causing organism. Almost in parallel with the Human Genome Project, the TcGP was devised as a means for fostering the development of medical applications against Chagas disease. All the obtained sequences and the research data from the project is stored in open access, publicly available databases: GenBank is one [21], although other genomics resources have been specifically dedicated to Chagas disease research and oriented towards drug development effort such as TDR Targets and TriTrypDB.

TDR Targets, for instance, operates as a web-accessible open access resource developed "to facilitate the rapid identification and prioritization of molecular targets for drug development, focusing on pathogens responsible for neglected human diseases" [22]. The project was envisaged soon after the completion of the TcGP and owed, partly, to the valuation made by TDR working groups on therapeutic options available for neglected diseases, especially after the completion of the TcGP and other *Trypanosomatidae* genome projects [10]. Through the TDR, the WHO managed to set up and define the initial outlines of TDR Targets, but also expected other stakeholders –representatives from research laboratories and the pharmaceutical industry – to become responsible for the project funding and execution. In its initial planning, however, open access was not a requirement specified by the WHO but a collective proposition made by the participating researchers [23].

2.1. Cognitive Exploitation: Production, Use and Contextualization of Collaborative Scientific Outputs

In previous work, I followed the hypothesis that open access resources such as TDR Targets could be subject to processes of *cognitive exploitation* [10]. The concept of cognitive exploitation refers to the utilization of non-profit knowledge outputs in for-profit operations without providing compensation for the original knowledge producers [24]. In this way, pharmaceutical firms can, at least in principle, take advantage of the knowledge produced from publicly funded research efforts without having to face the costs of the initial (and more uncertain) development stages themselves.

Cognitive exploitation is not a phenomenon exclusive to science or to open access. A typology of the processes involving cognitive exploitation has been proposed by Kreimer and Zukerfeld [24] according to the kinds of knowledge at stake: these include *scientific* but also *indigenous*, *labouring*, and *informational* (*digital*) knowledge. Different types of cognitive exploitation involve different classes of *producers* and *appropriators* of knowledge, as well as different *mediators* and *intermediaries* that operate under certain *regulatory frameworks.* Here, however, I am concerned chiefly with the exploitation of scientific and digital knowledge.

The exploitation of the scientific and the digital kinds of knowledge have been extensively addressed in the scholarly literature, although, logically, not always by means of the term "cognitive exploitation" (and not necessarily through the approach followed here). In what respects to scientific knowledge, for instance, Lefèvre [25] understands science as a form of *universal labour* that is freely appropriated by private producers once it is stable enough to become profitable. Codner, Becerra & Díaz [26], on the other hand, proposed the term *blind technological transfer* to refer to the utilization of publicly funded research publications in patent documents; however, their study only samples the area of biotechnology at the University of Quilmes in Argentina. In a different sense, documents from the International Union for Conservation of Nature [27] have drawn attention to the possible abuses of open data in the field of wildlife conservation, while Fecher & Friesike [28] note the widespread utilization of unpaid workforce within open scientific practice.

A more extensive debate has taken place around the exploitation of digital knowledge. The issues stem mostly from the dynamics of collaborative production and digital economy brought about with more "recent" phenomena such as user-generated content, social networking platforms, and free software licences [29–36].

Zukerfeld [31], for that matter, makes a distinction between different subtypes of exploitation of digital knowledge based on the production of *data*, *software* or *contents*. In any case, central to the idea conveyed with the exploitation of digital knowledge is what the author understands to be the material economy of digital knowledge and its inherent "double freedom":

> Whereas the usual voices (from management literature to hackers) emphasize one freedom (the shiny side of copying and sharing informational goods), we think we are unwittingly discussing about two very different but inseparable freedoms. Here is where Marx comes back. One of the key factors for the birth of Capitalism has been what Marx called the double freedom of labor power. On the one hand, the worker is freed from the feudal order, free to move and free to sell his labor-power where, when and how he wants to. By the time of Marx, this had been the only freedom mentioned by Political Economy, Contractualism and Liberalism. But, on the other hand the worker is also freed

> from the means of production, as it is well known… Marx highlights the necessity of two contradictory freedoms. In the first case, freedom refers to empowerment; in the second, to the lack of power [p. 146].

The dynamics through which free knowledge is, in these two senses, incorporated into the capitalist machinery is therefore characterized as processes of *inclusive appropriation*: while freely produced digital knowledge is only made profitable by the third-parties, it nonetheless remains non-rival and, in this cases, also non-exclusive [31]. Processes of cognitive exploitation, in sum, necessarily entail asymmetrical exchanges that take place under contingent legal frameworks and exclude physical coercion as a means [24,29]. The next section relates the problem of cognitive exploitation with the problem of drug development for neglected tropical diseases.

2.2. Cognitive Exploitation in the Field of Neglected Tropical Diseases Research

Open access genomic databases represent particularly meaningful resources of scientific knowledge that may be problematised under the concept of cognitive exploitation, especially in what respects to drug development for neglected diseases. Three main points can support this claim:

- First, genomic databases are both *products and means of producing* scientific and digital knowledge, the latter of which encompasses the three subtypes defined above as data, software and contents. While the last decade has made out of openness a more explicit subject across science policy and scholarly practice, the focus, I argued, is usually put on the scientific outputs represented by research data and publications (contents). This means, in other words, that the debates on its constraints and opportunities have remained tied to the problem of access to outputs [28,37–42]. For example, without recurring to the idea of cognitive exploitation, the publishing industry has been long criticized (now especially in the digital era) for hindering the dissemination of scientific knowledge, indirectly favouring economically privileged actors, and making profits out of scientific production at the expense of knowledge sharing (43). More recently, however, private publishers have began to align with open access-based business models as long as it will not endanger traditional editorial privileges and profits [44–47]. This does not necessarily hold true for drug development-related databases.
- Second, the potential intermediaries and (or) appropriators of the knowledge produced from genomic databases oriented to drug development goals are primarily pharmaceutical firms. In spite of this, the motivations sustaining neglected tropical diseases research are also knowledge-driven and supported via government and NGO funding (as is the case with TriTrypDB and TDR Targets). The ability, interests, and frameworks available to enforce intellectual property protection, on the one hand, and the capacities to industrialize scientific knowledge, on the other, are markedly asymmetrical.
- Third, and related to the last point, neglected tropical diseases prevail, by definition, in tropical and subtropical contexts, meaning that their incidence is significantly higher in the contexts of development. This not only reinforces its asymmetrical position in relation to the leading centres of technological development and scientific research, but also pose very different interests in

terms of knowledge production and in defining what is at stake. Neglected tropical diseases constitute a subject for scientific research but also a social and political issue in both endemic and non-endemic contexts. By circumscribing what the issue in the last instance *is*, then, global health organization and research centres can pre-define certain solutions as possible, and therefore restrict the types of knowledge and stakeholders than may (or can) become involved.

In spite of appearing as a suitable target for cognitive exploitation, our research [10] suggests that no commercial utilization of knowledge produced from genomic databases for neglected tropical diseases is actually taking place. In these cases, however, this might be occurring for all the "wrong" reasons, as there is no locally produced open scientific knowledge being industrialized, be it by means of asymmetrical exploitation or not. In other words, unrestricted access to the research outputs (as represented in the double freedom of open digital knowledge) can be a necessary condition for utilizing scientific knowledge, but certainly not a sufficient one. As a matter of fact, in the field of drug development for neglected tropical diseases, the costs and uncertainty of initial research efforts –not compensated by the relatively low purchase power of the affected populations – did not appear as the main factor hampering the development of new drugs.

The two points discussed above can also synthesise what is conveyed in the idea of *integrated subordination*. This idea refers to the dynamics by which peripheral regions succeed in integrating to the mainstream research networks, but fail to industrialize scientific knowledge and connect scientific research with local social needs. As it has been proposed in LASTS [48], this failure spawns from insufficient technological capacities, but also from the adherence to international research interests and agendas which are not necessarily connected with local needs and demands in spite of its rhetoric of "social relevance".

3. Open Science in (Asymmetrical) Contexts: Which Knowledge Outputs and For Whose Needs?

One of the limitations in conceptualizing open science, I argued, is its engagement with the products of science rather than with its processes. Fecher & Friesike [28] offer an initial approach to this limitation by making a distinction between the *democratic* and the *public school* of open science: while the former is concerned with *access* to knowledge, the second one is concerned with processes and *accessibility*.

The idea of accessibility involves at least two different aspects. One of them is communication and exchanges between lay and scientific actors, an aspect which has often been conceptualized as a problem of "conveying" scientific knowledge "to" lay audiences. The other aspect has to do with what has been often portrayed as *citizen* science, and refers to the participation of non-experts in certain processes of data collection or analysis. These views, I argue, pose at least two problems.

The first one has to do with the possession of skills and capacities that are required to utilize scientific knowledge. Arza & Fressoli [37] refer to accessibility in this same sense as "the lack of [other] more informal restrictions, such as the specific skills, capacities, and capital resource required to understand or utilize the products of open science" [p. 3]. I would add that it is not just the possession *cognitive* or *material*

resources what defines actual accessibility to scientific knowledge, but also –and even more importantly– *political* and *symbolic* resources.

The second problem has to do with the stage of knowledge production at which participation is enabled in science. While citizen science contemplates non-expert participation, the core stages of knowledge production –such as defining the problem and its approach, the research priorities and type of knowledge outputs expected – remains, for the most part, exclusive to expert circles. For sure, the problem of public participation in science has long been analysed in science technology and society studies, moving beyond limited notions of citizen science described above. Diverse approaches and models have been proposed to understand and facilitate the engagement of non-expert and scientists in co-producing scientific knowledge. These could not, of course, be discussed here in detail, as they normally do not touch the specific issues that stem from open access [7,49,50].

Nonetheless, in the field of neglected diseases, the precise implications of open access have been critically addressed by Masum and Harris in an institutional document titled "Open source for neglected diseases: Magic bullet or mirage?" [51]. The authors review a series of initiatives linked with drug development to analyse, along with the dimension of access, the dimensions of *collaboration* and *governance*. In the field of neglected diseases, they note, drug development is complicated further due to the recent expansion of legal and market regulations [p. 1]. For example, while 1394 new drugs had been commercialized between 1975 and 1999, only 16 where destined for neglected diseases, and even those few "new" drugs put on the market have been proved to be deficient, or simply modified copies of pre-existing drugs [17].

In the face of commercial disadvantage, then, open access could theoretically contribute to overall productivity in drug development, mainly by means of facilitating decentralised operations and data sharing [28,52,53]. However, there are significant differences between the dynamics of pharmaceutical business and other domains where open access and practices occur more "naturally", such as in the realm of software development. Masum and Harris, for instance, describe how the two business dynamics are very different in terms of regulation, risks and costs, or even in terms of safety and time requirements. On the other hand, while software firms can rely on *copyright protection*, in principle, without major difficulties, biomedical and pharmaceutical firms, instead, depend on extensive clinical trials and costly *patent filing* processes on the road to putting a new product on the market. An open access approach, they argue at last, works well with *discovery* or *pre-competitive* stages of biomedical research, but has been rarely been known to succeed during the phases of *technology transfer* and *delivery*.

From the obstacles standing in the way of drug development, it is clear that the signifier "open science" may convey fundamentally dissimilar meanings across the various techno-scientific spaces engaged in drug development. As the authors illustrate this polysemy:

> What is the "source code" at each stage of neglected-disease research? While some working in synthetic biology make the analogy of DNA as source code, the situation is actually more complex. In software, the source code *is* the product, while in biology, there are many relevant levels of description and analysis, from DNA to structural genomics, protein interactions, metabolism, and so forth—all interacting in complex ways and requiring a long and expensive process to go from description to approved product [52, p.3].

This contextual approach suggests that the difficulties that hold back the utilization of locally produced, open scientific knowledge do not just illustrate "mismatchings" between the dominating discourses on open science, on the one hand, and its realization through effective scientific practices, on the other. It also suggests that these notions, in their limited and universalising conceptualization of access, have omitted the contextual and dynamic factors affecting the production and social use of scientific knowledge. These contextual factors do necessarily have an effect on scientific openness and its ability to meet social needs, and depend on possessing the required skills and capacities to face changing constraints and regulations, as well as with the possibilities of engaging stakeholders in the different stages of research. In other words, there are different dynamics of openness and accessibility that exceed the question of accessing (or opening up) scientific data and publications.

In the case of TDR Targets, the tensions that result from the asymmetrical position between the producers, the potential appropriators, and the intended end-users of scientific knowledge in the specific context of drug development for neglected tropical diseases have been noted by researchers, firm directors and representatives from health-related NGOs, although the potential solutions they might pose are different. As a laboratory director with more than ten years of experience in developing genomic databases for neglected tropical diseases put it:

> I never worked for a private [pharmaceutical] firm. But from my meetings, and from all the experience I had from different people in different levels, I believe in the first place that there's no market. So even if firms are interested in us doing all the work and then taking advantage of the results, as you say, the day they get those results they are going to realize that they are developing a product that maybe didn't cost them a lot, but that they have to sell to demographics with no income ... Governments have to buy it for them, and every government is different, just as everything else. I don't know if it's a great business or not ... It's different, for example, if someone has diabetes, which needs to be treated permanently ... a person suffering from Chagas, instead, you treat them, they're cured, and it's over, they won't be taking that drug ever again … In addition to that, firms... invest and need to get the money back in ten, twenty years, which is what patents last for. ... And even then, I hear this isn't their motivation; the motivation is another kind of intangible benefit, which has to do with public image. ... One of the things being blamed [for the lack of new drugs] is excessive regulation... controls, safety issues... there are many and every drug has a problem. So if you have a life or death situation, say, if you're dying from cancer, they'll get approval.... But for other things they may face many problems [23].

Here, the role of *mediators* and *intermediaries* – necessary to enable a successful industrialization of scientific knowledge – is, again, clearly not limited to the possession of technological or cognitive resources alone. The WHO appears in this case as the mediator: it is the *obligatory passage point* – recurring to Callon's terminology [54] – through which pharmaceutical firms, research centres, government offices and funding bodies become, at least in principle, enrolled in collaboration. Pharmaceutical firms, instead, are the *intermediaries* capable (again, in principle) of introducing the *translations* necessary for industrializing knowledge. Translation, as it has been shown, entails a few things more than just technical capacities: it entails practical know-how and expertise on how market and health regulations, public

expectations, and intellectual property protection might or might not work for a certain disease, product, population, government, and so on.

3.1. Opening Up Participation: Defining What Is at Stake

At this point it might be useful, at last, to rethink participation as part of a more comprehensive idea of openness.

In its role as a mediator, the WHO, through the TDR, has favoured a biomedical approach to the problem of neglected tropical diseases –and arguably more so in the case of Chagas. A working paper issued by the TDR in 1979 depicted the issue of Chagas disease as problem that was rooted in the lack of biomedical advancements. Conversely, the possibility of intervening and improving the living and environmental conditions of the affected population conditions were, in this same paper, seen as uncertain, so the necessary path to attending to the problem of Chagas disease had to be pursued through a knowledge-driven approach from the biomedical sciences [55].

The same type of justification was put forward again 15 years later with the launching of the TcGP in the 1990s [56]. As a matter of fact – and in spite of its ongoing rhetoric of social relevance –, it is until today that the research dynamics around Chagas disease adhere to the rule of universal mainstream science: political intervention remains outside the scope of "legitimate" scientific involvement, and the affected populations –discursively regarded as the "beneficiaries" of research efforts – rarely become engaged in relevant spaces of scientific and political decision-making [10,57,58].

In this sense, even if openness does enable unrestricted access to the research data and publications in the field of neglected tropical diseases research, it is hard to see, in the face of the aforementioned limitations and exclusions to the overall scientific process – including the very definition of and the approach to the problem itself –, how the dominant dynamics of openness could help in fostering scientific outcomes that effectively connect with local social needs and demands.

4. Conclusions

In this paper I suggested that the dominant views on open science could be limiting the local utilization of scientific knowledge in non-hegemonic contexts of science. These limiting views around openness, I argued, are linked with restrictive conceptions about science and its products, which fail to account for the practices and processes involved in their production and use. Instead, I discussed the case of genomic research and drug development for neglected tropical diseases, trying to show how different classes of resources and stakeholders – actual, ideal or potential – become engaged or excluded. To do so, I drew on two concepts put forward by Latin American Studies of science, technology and society. The first one was cognitive exploitation, a concept that allows to detect how and which scientific outputs are used in for-profit contexts by third-parties, but without objectively compensating the original producers. The second concept revolved around the idea of integrated subordination, according to which peripheral regions may successfully integrate international research networks but fail, at the same time, to industrialize the scientific knowledge that would attend to local social needs. In the case of drug development for neglected tropical diseases no processes of actual exploitation of scientific knowledge has been found to take place.

However, the concept of cognitive exploitation allowed to detect how regulatory frameworks, actors and relations shaped (and hindered) the dynamics of knowledge production. On the other hand, the issues underlying the inability to meet social needs did not stem here from mere access restrictions to material or cognitive resources. Instead, it was political, legal, and symbolic resources (typically possessed by mediators and intermediaries) which played a more crucial role and posed strong contextual asymmetries between international and local stakeholders, on the one hand, and between experts and potential beneficiaries of knowledge, on the other.

These underlying issues suggest, in sum, that capacities and participation need to be put in context and conceived as an inseparable aspect of access when discussing open science and its ability to meet social needs in non-hegemonic spaces.

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