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Chapter 7

The Politics of Industrial Transparency. Constructing a Database on the Pharmaceutical Funding of the Health Sector

Henri Boullier

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Abstract

This chapter examines the politics of transparency through the case of a government website that discloses the potential conflicts of interest (COIs) between pharmaceutical companies and health professionals. Since the late 2000s, several US and European initiatives have endeavored to meet the objective of transparency by putting together large publicly accessible databases that promise to prevent undue influence and misdemeanor by recording, classifying, and disclosing millions of transactions between firms and health professionals. France's Transparence Santé (Transparency in Healthcare) database, officially launched in 2014, is one of the first examples of these new tools. In the aftermath of a major public health scandal, disclosing all financial interests was seen as an obvious response. This chapter draws on interviews, observations, and analysis of the gray literature to trace the origins of the database, study the challenges faced by its developers at the Ministry of Health, and examine the effects of this "transparency device". We show that the construction of the database proved highly complex, especially given the time pressure, which may explain some of the issues with its quality. Despite its flaws, a group of open data activists have endeavored to improve its operation and to deliver on the promise of transparency, turning its data into a resource for journalists. In sum, this chapter argues that such disclosure devices embody a form of "industrial transparency" that allows the neoliberal state to regulate the private sector at a marginal level, limiting its own investment while outsourcing the responsibility for processing and monitoring the disclosed data.

For several years now, the health sector has seen a substantial rise in so-called transparency mechanisms. In keeping with the principles of open government, an initial series of measures took the form of "institutional transparency" with the opening up of public data (Coglianese, 2009; Moore, 2018). This government-led "data-driven transparency" (Birchall, 2015) purportedly offers a way of improving the traceability, auditability, and performance of public healthcare against a backdrop of declining public resources and managerialized healthcare policies (Blomgren, 2007; Bevan and Hood, 2006). However, the health sector is also the locus of another form of transparency with very different aims, particularly the re-establishing of trust in medicines among citizens and consumers. This trust has waned considerably in the wake of health scandals such as those involving Vioxx® or Mediator®, which revealed the extent to which health agencies, pharmaceutical companies, and physicians are structurally bound up together in conflicts of interest (COIs)¹.

This second form of transparency is based on the mandatory disclosure of information otherwise unknown to State agencies about the links between the private sector and health professionals. Experts' disclosure of their interests to the health agencies on whose committees they sit² is thus supposed to guarantee independence – although some consider the latter to be minimal (Lexchin and O'Donovan,

2010). More recently, this second type of transparency has taken an original form through websites disclosing the financial ties between industry and actors in the health sector: physicians, medical students, pharmacists, patient associations, healthcare professional associations, healthcare organizations, the media, etc. (Grundy et al., 2018). In June 2014, the French government launched the website Transparence Santé (Transparency in Healthcare) making all this information accessible. As the home page states, "this transparency initiative, run by the Ministry of Health, aims to preserve the necessary relationship of trust between citizens, public service users, and the various actors in the healthcare system".³ Between 2012 and September 2020, the database, which can be accessed via the website, registered over 18.5 million disclosures corresponding to a total of 6.5 billion euros. A similar website was launched the same year in the United States, making health one of the main areas of development of a new form of transparency that we call "industrial transparency", in which the disclosed data is produced by the targeted industries in our case – the pharmaceutical companies.

This chapter analyzes the process through which the promise of transparency embodied by the Transparence Santé website was fulfilled. In unpacking this process, we show the respective roles of the State, companies, and civil society actors in contemporary policies on the disclosure of industry data. In so doing, we follow the lead of studies that have focused on the political and organizational dimensions of the development of information infrastructures (Bowker and Star, 1999; Denis and Pontille, 2012) and we take up questions raised by "critical transparency studies" (Alloa and Thomä, 2018), a research field that has explored the implications of transparency in terms of government disengagement and the outsourcing of disclosed data processing (Birchall, 2015). As we shall see, data disclosure does not necessarily result in greater transparency, not to mention accountability, insofar as the data in question cannot automatically be used or analyzed. The journalists who tried to draw on the Transparence Santé website soon encountered a range of difficulties: there are mistakes in some of the data published, several hundred million euros are not justified, and it is impossible to obtain an overview of the sums in question (Hecketsweiler and Ferrer, 2017). We show that the Transparence Santé tool reproduces the model of "institutional transparency", promoting a voluntary form of regulation, but this time targeted at, and operated by, economic actors – thus embodying "industrial transparency".

The study on which this chapter is based was carried out between late 2018 and late 2019. Our aim was to retrace the process through which the database was constructed, paying close attention to the technical choices that determined its development, to the actors involved, and to the difficulties encountered. During this investigation, we met and interviewed nine people, sometimes several times, who were directly involved in developing the database. These respondents, with whom we conducted interviews lasting between one and four hours, were legal experts, computer scientists, and project managers at the Ministry of Health, the French association of pharmaceutical companies Les Entreprises du médicament (LEEM), and the French government's open data agency Etalab. We also attended numerous weekly meetings held by the association EurosForDocs over the course of more than a year and had more informal discussions with several of its members. In addition, we draw here on a

substantial body of technical literature that includes decrees but also technical manuals produced by the ministry and by LEEM, who drafted a series of documents analyzing the database for its members. Finally, we examined all press articles published on the subject of Transparence Santé.

Managing influence by disclosing interests: the origins of the Transparence Santé database

Over the past ten years, a wide range of tools have been put in place to document situations of COI that are likely to affect politicians, public experts and civil servants. Since 2011, the European Union has had a "transparency register" on which all interest groups (lobbying firms, companies, NGOs, think tanks etc.) that "directly or indirectly influenc[e] the formulation or implementation of policy and the decision-making processes of the EU institutions" are inventoried. The European register currently includes around 6,300 enterprises, 3,100 NGOs, and over 830 consultancies specializing in European legislative processes (European Commission, 2020). In France, similar arrangements have been put in place by means of a public register of lobbyists (répertoire des représentants d'intérêt). It is run by the Higher Authority for Transparency in Public Life (Haute Autorité pour la transparence de la vie publique), an organization that is also tasked with publishing the declarations of the assets owned by public officials. Transparency mechanisms have thus become an increasingly common response to regulating the lobbying of politicians, administrations, and regulatory agencies.

However, the field of healthcare shows us that the problem to which these transparency measures are supposed to provide an answer – in this instance, the influence of the pharmaceutical industry – is far more long-standing (on this, see Kefauver Committee, 1951; Comanor, 1966) and extends beyond the political and administrative spheres. From as early as the 1970s, physicians came together to criticize the ties that the pharmaceutical industry was seeking to create with researchers and healthcare professionals. This chorus of dissent resulted in the creation of organizations capable of producing information about medicines without funding from the pharmaceutical industry (e.g., the journal *Prescrire*, first published in 1981, and the Cochrane Library, since 1993). It also gave rise to activist associations specialized in fighting COI (e.g., No Free Lunch in the United States, founded in 2000) and in championing independent medical training (Formindep in France, founded in 2004). In this context, public authorities and healthcare actors progressively set up a multitude of systems (the mandatory disclosure of interests" before being able to sit on certain public expert committees, etc.) that promised to make the links between industry and health professionals more transparent in order to limit situations of COI.

In the 2010s, transparency mechanisms changed in nature and databases were developed offering exhaustive lists of "private" financial ties between pharmaceutical companies and health professionals (Hauray et al., introduction; Grundy et al., 2018). In France, the creation of the Transparence Santé

website was closely linked with the Mediator® scandal⁴. This appetite suppressant, marketed since 1976 as an adjuvant antidiabetic, was withdrawn from the market in 2011 for having caused the deaths of several hundred people. The investigation into the causes of the tragedy revealed systemic conflicts in the health sector. Xavier Bertrand, Minister of Health at the time, proposed a radical reform of the regulatory framework for the safety of medicines, introducing a series of new requirements aimed at fighting COIs (Légifrance, 2011). The most emblematic measure, which resulted in the Transparence Santé website, mandated that pharmaceutical companies make all their financial ties with health professionals public (Hauray, 2018).

When the "Bertrand Law" was adopted in 2011, the rules governing how financial ties were to be made public remained vague. Article 2 of the law, devoted to new transparency measures, stipulated that pharmaceutical companies were "obliged to make public the existence of *agreements*" (in other words, contracts) signed with a series of actors (professionals, associations, students), but also, above a certain threshold, the *benefits* – whether "in kind" or in cash (meals, travel expenses, etc.) – that they gave to these actors⁵. Many other aspects, however, remained to be defined by decree, such as the threshold above which *benefits* had to be made public, the precise nature of the information to be provided regarding *agreements*, and even the timeframe and modes of publication.

Implementing transparency: an unfinished process

When the "Bertrand Law" was adopted at the end of 2011, the conditions under which private industry data were to be made public had not yet been determined. Months later, the idea emerged of setting up a website that would make accessible the huge database constituted by pharmaceutical companies, following the model of the American Physician Payments Sunshine Act of 2010.⁶ Two factors disrupted the development of this tool, however. First, LEEM raised the issue of trade secrets and confidentiality with a view to influencing how detailed the data made available by the website would be. Technical, budgetary, and organizational constraints also further complicated the development of the Transparence Santé website, which was finally launched in the summer of 2014.

Negotiating the content of the database with pharmaceutical companies

The year after the "Bertrand Law" was passed was a key moment. The Ministry of Health began preparing the decrees determining exactly how this new healthcare transparency policy would be applied. Looking at the mobilization of the pharmaceutical industry around article 2 of the law during this period and at the compromises it managed to strike with the ministry over the course of regular exchanges reveals the substantial leeway that the industry benefited from when it came to determining the conditions under which the policy would be applied.

One question that remained unresolved in the law adopted in late 2011 was that of the threshold (i.e., the amount of money) above which *benefits* granted by pharmaceutical firms would need to be declared. This threshold had very practical implications both for the authorities and for the pharmaceutical companies: a low threshold implied registering a very large number of transactions (e.g., meals out, breakfasts in hospitals, etc.), if not all of them, and would also inflate the quantity of information that had to be entered into the future database. Representatives of the pharmaceutical industry told us that they had argued in favor of setting this threshold at \in 30, which presented the dual advantage of being the same amount as the value of gifts usually considered of "negligible value" (according to France's competition and fraud control authority) and of avoiding the publication of excessive numbers of small transactions.⁷ The ministry, however, decided instead to set the amount "as low as possible" with a view to exhaustiveness, excluding only the smallest of transactions such as coffees.

According to a legal expert involved in drafting the decree, in the aftermath of the Mediator® crisis her team "could not take into account"⁸ the issue of the workload that a low threshold would represent for companies. Such a concern seemed entirely trivial in light of the scale of the scandal. The administration therefore decided to opt for a threshold of $\in 10$, seen as a way of ensuring almost total transparency regarding the *benefits* granted by companies to other actors in the health sector, even though this would result in far more work for the companies.

Despite this setback for the industry, regular contact with staff at the Ministry of Health was maintained by legal experts from LEEM. From 2012 onwards, they produced a series of circulars in which they outlined their suggestions for interpreting the provisions relative to the transparency of interests. Between 2012 and 2017, the Department of Regulatory Affairs prepared seven long notes of between 10 and 67 pages in which LEEM's legal experts provided their analyses of the law, as well as a detailed account of their negotiations with government representatives. Their intention was to influence how certain measures would be interpreted when the legal texts governing their application were drafted, with a view to limiting the normative constraints weighing upon companies in the sector.

A good example of the way in which the pharmaceutical industry used the notion of trade secrets to influence the implementation of the 2011 law's transparency measures can be seen in the process leading to a typology of the content of *agreements* signed with health professionals. In late 2016, the Directorate General for Health (Direction générale de la Santé, DGS) prepared an *arrêté* (order) intended to offer a more detailed definition of the "precise subject matter" of research contracts linking pharmaceutical companies to health professionals. The aim was thus to drive companies to disclose not only the monetary value of the *agreements* in question and their beneficiaries, but also what exactly they were funding. LEEM's legal experts contacted the DGS to ensure that the content of these research contracts would remain confidential:

For us, publishing the subject matter of the contracts wasn't conceivable, in terms of local attractiveness, international competition, etc. But things were cleared up quickly, because the logic wasn't one of publishing the contracts in and of themselves, but rather one of defining categories.⁹

LEEM understood that what the DGS required was a series of categories, in other words a list of "types" of expenses, linked to *agreements*. The organization therefore prepared a typology of *agreements* that it sent to the DGS with a view to feeding into the *arrêté* at its draft stage. LEEM proposed 18 categories (ranging from "purchase of scientific documentation" to "conference registration fees", "hospitality", and "training" [LEEM, 2017]), all of which were retained in the *arrêté* published in March 2017. This new example illustrates how public authorities partly relied on the pharmaceutical companies to design this new disclosure tool and how the latter were also put in charge of recording the financial ties connecting them to other actors in the sector. While the whole process was "collaborative", it also illustrates how companies managed to reap the benefits of this situation: it gave them the capacity to influence how transparency principles were applied in practice, for example by defining the typology of *agreements* that best suited their needs with a view to making the recording process easier and to safeguarding what they believed fell into the category of trade secrets.

Developing a transparency tool with limited resources

Alongside the drafting of legal texts stipulating how the law would be enforced, the plan to set up a one-stop website soon emerged. Immediately after the law was passed, the industry still knew nothing about the technical modalities according to which *benefits* and *agreements* would be made public. The office of the new Minister of Health, Marisol Touraine, exhumed an idea that had first been discussed by parliamentarians in 2011, i.e., the idea of setting up a centralized database combined with an openly accessible website. In May 2013, a decree made this idea official and outlined "the nature of the information that must be made public by companies [. . .] via a one-stop public website", specifying that "this information is made available to the public free of charge and in an accessible format, and is updated every semester" (Légifrance, 2013). In the months that followed, the ministry staff also had to determine the website architecture, find a service provider to manage the project, and oversee its roll-out.

Creating the public website was a real challenge for the actors involved for at least three reasons. The first difficulty lay in the urgency with which it was designed. While the idea of a one-stop website emerged as early as 2012, the CNIL (France's data protection agency) was consulted on the issue of using personal data and then took more than a year to draft its opinion. Despite this extended timeframe, Touraine's office still deemed the publication of *benefits* to be a political priority that should be implemented as soon as possible. The May 2013 decree thus stipulated that data about signed *agreements* and granted *benefits* should be published from June 1, 2013 onwards, should include all transactions from 2012, and should appear on the websites of the pharmaceutical laboratories while the one-stop website had yet to be launched. For the ministry, this transitional period was not intended to last long and it was therefore important to put in place a system that allowed industry actors to register

their disclosures as soon as possible. The IT project was ultimately completed over only a few months, between autumn 2013 and spring 2014, during which time the service provider had to be chosen, discussions had to take place with both industry actors and professional bodies to collect their requests and remarks, and a test version of the site had to be launched.

A second difficulty concerned the limited financial resources allocated to the website. When the Transparence Santé website development began, it was just one IT project among others and the funds available to the Ministry of Health were limited. The people in charge of the project had to negotiate, sometimes on a case-by-case basis, funding for certain functions or modules to improve the interface, the quality of the data, or certain errors. The head of the IT project told us in an interview, for example, that she had not managed to obtain funding to develop a module that would have made it possible to systematically check the identity of the associations listed as beneficiaries by companies. According to her, this was typically the sort of function that would have avoided the duplications that today make the database difficult to navigate and use. The website was allocated a budget of €500,000, which seems relatively limited when compared to the €1.5 million allocated to the site hosting public disclosures of interests by experts working for health agencies. The latter project, while similar, in fact seems far less complex, at least insofar as it concerns a much smaller volume of data which are far more homogeneous. However, its development (and thus its budget) no doubt benefited from fact that its end users – civil servants and public experts – were directly involved in the implementation process, whereas the end users were absent from discussions about the Transparence Santé tool.

The limited human resources allocated to the one-stop website further complicated its development and publicization. At the end of 2013, during the most intense phase of the website design, only two people from the ministry were assigned to project management. They were only working on this parttime and had limited IT skills (one was a legal expert by training and the other an administrative assistant with one year's training in IT). The external service provider in charge of website development proper was also working with a small team, comprising only a project manager and a developer. In addition to the project being carried by a small number of people, its management was further complicated by the turnover of personnel, partly because the IT service provider was taken over by a bigger group and partly because, at the ministry, the project manager left for another position. When the website was launched in the following spring, these human and organizational resources faced additional cuts. Indeed, after the launch in early 2014, only one legal expert from the ministry devoted a small amount of her time to providing support to companies as they entered information into the database that would then appear on the website. According to her own description, in the absence of additional resources this task essentially consisted in providing a "hotline" managing companies' initial registration on the website.¹⁰

Taking an approach invoking the principles of open government – broadly inspired by the philosophy of open-source software –public authorities disclosed not their own data but that of a sector, with a view to providing transparency and, ultimately, to restoring citizens' trust by enabling them to

monitor the practices of that sector. At least this is what can be deduced implicitly from the ministry's approach in creating a minimalist tool for data access. Although the relationships between health professionals and the pharmaceutical industry were not directly transformed, public authorities did make them visible thanks to the Transparence Santé website in the hope that doing so would offer a safeguard against the harmful consequences of drugs manufacturers' strategies of influence.

Making the promise of transparency more effective: the work of activist groups

When the Transparence Santé website was launched in 2014, the data provided by companies could be consulted but transparency was far from effective. Despite the satisfaction reported by administrative staff involved in the development phase, the website still suffered from a certain number of flaws linked to the functions it offered and the quality of the information to which it gave access. Transparency nevertheless became more tangible following pressure and voluntary work on the part of activist engineers and computer scientists, defending, in particular, open-source software and the principles of open government. Thanks to their mobilization, the industry data was made downloadable and accessible via an alternative website.

External pressure and release of all the data in the form of a database

Although, from the outset, the ministry's tool did include an option allowing the public to download all the data, this option remained deactivated. Until 2016, any use of the data for statistical processing remained impossible. However, despite its concerns linked in particular to the CNIL's requirements, the ministry eventually changed its position thanks to the interventions of, first, an association specialized in promoting the opening up of public data and, second, Etalab, the administration responsible for coordinating governmental strategy with regard to open data.

As soon as the website was launched, members of the association Regards Citoyens started to campaign for the possibility to use the information in the database. Regards Citoyens was founded in 2009 and is made up of IT specialists and IT engineers whose objective is to reinforce "civic engagement by promoting open access public data and the re-use of that data"¹¹ through the furthering of "open content licensing and open-source formats".¹² In 2014, several members or sympathizers of this association took on the task of breaking through the Transparence Santé website's IT protections in order to collect all the data via crawlers, so as to make them available to the public as a complete set. They took this opportunity to clean the data substantially, for example bringing together all the ties of one given professional under one single identifier (despite spelling mistakes in last names, for example). When this data was first posted online, presenting a name-based summary, the Ministry of Health soon found out. The project manager was concerned because it revealed security issues with the website:

If the CNIL found out, we were done for. [...] We'd failed in our duty to ensure security, protection. Luckily, we managed to find the email address of the person behind it and we sent him a beautiful letter reminding him what he was exposing himself to if he did not remove the database the very minute he received that message.¹³

Shortly afterwards, Regards Citoyens made a summary of the amounts spent by pharmaceutical firms available to the public, highlighting the total value of *benefits* paid out and the companies spending the largest amounts.¹⁴ This overview was then reported by the press. Most importantly, although all the data had been made available, they had been "reluctantly" anonymized by the association, so they were not, strictly speaking, open data. This was framed as a militant act designed to push the ministry itself to release the information as open data.

According to the ministry staff, while this initial step taken by the association was somewhat embarrassing, it also revealed the wealth of data collected and the value of the statistical analyses that they made possible:

We saw what he'd done with the data he'd got hold of and it was fascinating. And we said to ourselves that it would, indeed, be good if people could use it. Only at that point we were supposed to be preventing the database from getting out into the open.¹⁵

This episode gave greater weight to the initiative of an Etalab IT specialist when he approached the ministry several months later, asking them to make all the data available to download as a set. While the ministry's position remained similar to that of the CNIL, stating that personal data could not be shared, both administrations began thinking about how the database content might be shared as a whole. The Council of State (Conseil d'État), consulted on this matter, did not disapprove of the initiative but concluded that there was no legal framework to govern the dissemination, and above all the use, of this information. Two legal experts at the ministry then began working on designing a specific license for the Transparence Santé data, restricting the ways in which it could be used. They stipulated that the database could be used freely for personal ends, but any online use would require respecting the same data protection regulations as the original database. This approach was ratified by the 2016 Health Law and since then the Transparence Santé database has been fully downloadable via Etalab's website.

It was therefore under pressure from actors outside the ministry that the data were made accessible and analyzable. Other outside actors, working in the same circles, then took a further step toward delivering on the promise of transparency.

Creation of a more effective tool to present and process the data

For many years, Regards Citoyens itself processed statistics for investigative journalists or for Formindep. However, its volunteers wanted to design an ergonomic tool that would allow researchers, journalists, or ordinary citizens to visualize and use the data themselves. The lack of resources may explain why the ministry did not pursue this particular avenue to provide a tool that would clean data, allow easier searches, or enable data to be visualized. Its tool was not designed for these purposes and its position was instead to leave this task to others.

We don't have the resources, internally, to develop these kinds of very fancy tools. And in fact that's why the transparency was put in place: to allow those who do have the resources to help us. [...] It's a way of calling for help. And if, afterwards, they want to sell us the application at a reasonable price, we'll be happy to take it.¹⁶

A tool for promoting the use of the data emerged at the initiative of a data scientist – an engineer from one of France's prestigious *grandes écoles* – who discovered the existence of the Transparence Santé website, along with its potential and its flaws, via the press in early 2018. He decided to develop a website called EurosForDocs, inspired by the American website Dollars for Docs. In order to secure help from other volunteers, he embedded his project within the "Data for Good" collective, whose developers and data scientists use data science to "provide associations with cutting edge technological tools to increase their societal impact".¹⁷ These IT specialists, often from *grandes écoles*, use their skills to further a project with a final goal that they find more palatable than that of their own well-paid jobs. On average, their involvement with EurosForDocs lasts a few months. The collective's main priority is to simplify access to existing data, in particular by allowing partly cleansed data to be presented more clearly and by enabling ad-hoc statistical analyses to be carried out.¹⁸ For its founder, this tool was mainly designed for journalists and researchers wanting to examine the data from a variety of different perspectives. In September 2020, 4,000 accounts had been opened to access this tool with approximately ten daily connections. Both these figures represent a sharp rise compared to the previous year.¹⁹

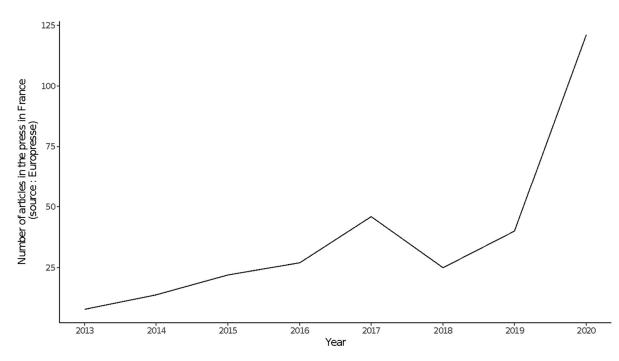
This is how engineers and IT specialists involved in collectives championing open data, transparency in public life, or open-source software drew on their IT skills – which were of a far higher level than those available internally at the Ministry of Health – managed to deliver on a promise of transparency that had thus far only been partially fulfilled. Their work made the data available in the form of a (cleaner) database and also made them much easier to use independently. It is probably no coincidence that there was a subsequent rise in references to the transparency database in the press.

The tool's main use: financial ties and COIs made increasingly visible by the press

For the most part, the general public is not aware of the Transparence Santé website. The number of users who connect to it, for example, is very low (300 per day). Certain State bodies – health agencies, first and foremost – have developed a greater interest in these data and consequently in a tool such as EurosForDocs, which can help them to monitor the interests disclosed by their experts. However, the

main quantifiable use of the data is by the press. Regularly, and increasingly, the press uses the website to examine the ties between health professionals and the pharmaceutical industry. Most often, it draws attention to *benefits* received by individual physicians who are cited by name. It is rare to see more indepth investigations, and there is currently very little academic research on these data.

Our analysis of press use of the data is based on a corpus created by searching in the Europresse database²⁰ for articles published in France and including the terms "Transparence Santé" or "EurosForDocs" (in their different forms). Once duplicate entries and off-topic articles had been excluded, this corpus comprised 303 articles published between 2013 and 2020 (Figure 1). Generally speaking, press interest in the Transparence Santé data has increased steadily over time, with a sharp rise in 2020 (over 125 articles were published during the first seven months of the year). A quarter of the articles (81) were published by the daily national press (including on their websites) – first and foremost *Le Monde* (23 articles) – and by the news agency Agence France-Presse. A small number (30) appeared in weekly or monthly national magazines (in particular *La Tribune* and *L'Express*). The vast majority of the articles were from daily regional press.



Source: Europresse (as of July 31, 2020).

If we turn now to how these articles refer to the transparency database and its data, using text-mining tools they can be broadly grouped into six classes²¹ according to their lexical similarities. The content of these classes can be summarized based on their ten characteristic documents and most frequent terms. The first group (57 articles, published from 2014 to 2017) refer to criticism of the Transparence Santé database, whether in terms of its ergonomics, the lack of actual amounts of money mentioned for the

Caption: Figure 1. Number of articles focusing on the Transparence Santé website and published in the French press, by year of publication.

agreements, or the impossibility of downloading the data. Its articles voice the concerns of various organizations (Regards Citoyens, Formindep, the national physicians' association) and relay the critical report produced by France's revenue court (Cour des Comptes) in 2017 concerning "the prevention of conflicts of interest in matters of health expertise" and examining the implementation of the Bertrand Law.

This first group, just like the second fairly heterogeneous group (108 articles), also contains articles published in 2018–2019, reporting on the campaigns by groups using the Transparence Santé data to point to the COIs of people whose positions they exposed. Two examples illustrate this: first, a complaint by an anticorruption association about experts at the National Authority for Health (Haute Autorité de Santé) denouncing by the same token the fact that the institution had not consulted the database; second, opposition from physicians to the HPV vaccine based, in part, on the exposure of the links between the vaccine's proponents (physicians, learned societies, the media) and its manufacturers. Sometimes the journalists themselves used the data, revealing, for example, the sums spent by a homeopathy manufacturer to train and influence physicians at a time when State reimbursement for its products was potentially about to be withdrawn, or underlining the links between a company selling an alternative breast cancer treatment and the physicians publicly promoting this kind of treatment.

The content of this type of article is similar to that of a third small group (17 articles, mainly published from 2015 to 2017 in the national press) focusing on the pharmaceutical company Servier or its drug, Mediator®. The Transparence Santé data were analyzed to point to persisting financial ties between this company and the world of cardiology (physicians or learned societies), the medical specialism within which the prescription of Mediator® fell. Once again, Formindep's points of view were foregrounded. This association was also behind a revelation that was widely covered in the national press: a physician belonging to future president Emmanuel Macron's campaign team had many interests tying him to Servier. This case, described as a problem of COI, led to the person resigning from the campaign. In general, Mediator® was widely mentioned in this corpus on the transparency data (in one article in three) and the same is true of Servier (one article in six).

The last three classes are extremely homogeneous. The fourth group (81 articles published in January 2020, in 15 regional daily newspapers) corresponds to a large local investigation, conducted by a collective of data journalists. The articles describe financial ties in 2018 between pharmaceutical companies and university hospitals (and their physicians), as well as the measures implemented to find out about and oversee these ties. Several articles point to problems with how clean the Transparence Santé data were and the lack of subsequent monitoring of their accuracy. The journalists used the EurosForDocs website, recognizing its usefulness in making the data accessible, although they only cited it in the page dedicated to their methodology. Immediately after this investigation, an opinion piece in *Le Monde* written by a group of physicians, including Irène Frachon, suggested a series of measures to fight COIs in the medical sphere, including the requirement for donations to associations to be "redistributed to each of their members and registered in the national database by name" so that

they would appear in the Transparence Santé database and for checks to be conducted on the comprehensiveness of disclosures.

The fifth series of articles (25 published in June and July 2020) focuses on the controversy around the use of hydroxychloroquine in treating COVID-19. They refer to the accusations of COI made by Didier Raoult, a physician championing the treatment, against its opponents in the medical world, particularly during a hearing at the Assemblée nationale (French parliament). He used the Transparence Santé database and the EurosForDocs website to underline its opponents' ties to Gilead, a company manufacturing a competing product. Certain journalists pursued this analysis using the same means to examine the links between Gilead and researchers working on infectious and tropical diseases.

Finally, one last small group of articles (15) from November 2019 reported the conclusions of a research paper published in the BMJ by a group of physicians, some of whom had close links with Formindep (Goupil et al., 2019). The authors showed that the French general practitioners who receive the most gifts tend to have the most costly and least efficient prescribing patterns. This is one of the rare academic publications to have used the Transparence Santé database on a large scale, along the same model as prior studies conducted in Anglo-American countries, the most recent of which no longer draw on private sector databases but rather on the public sector databases that arose from the Sunshine Act (e.g., Perlis and Perlis, 2016).²²

What this analysis of the press shows is that since the development of the EurosForDocs website, the Transparence Santé website data have been mentioned regularly and increasingly often by the media reporting its use either by physicians voicing criticisms, by associations such as Formindep, but also by journalists themselves. These different actors have used this data to shed light on various situations of COI, whether of a structural or a more one-off nature, giving rise to "scandals" in certain medical subsectors and therapeutic fields or concerning certain public figures and associations.

Conclusion

This chapter is in line with social science research that has studied the institutionalization of disclosure policies and practices in a multitude of domains and professions (Fung, Graham, and Weil, 2007; Schudson, 2015). This scholarship has discussed the kinds of transparency produced by the institutionalization of openness (Heald, 2006), while also providing critical analyses documenting both the limits of the "fuzzy" promise of transparency and its ability to make things visible without holding anyone or anything accountable (Ananny and Crawford, 2018; Birchall, 2011). This chapter wanted to contribute to this field of research by looking more closely at the invisible work performed "behind the scenes" to develop transparency tools, in the spirit of research on the politics of information infrastructures (Bowker and Star, 1999). To do so, we decided to follow in detail the development of a transparency tool targeted at, and operated by, the pharmaceutical industry.

We focused on a new system for disclosing data that has appeared recently in the healthcare sector, in the shape of websites providing inventories of the pharmaceutical funding of healthcare professionals. The example of France's Transparence Santé website, designed by the Ministry of Health and made accessible to the French public in 2014, shows that the people behind its construction had to make compromises with the demands of the pharmaceutical industry, obviously reluctant to divulging data that it considered sensitive, while also developing a website with limited resources. Activist groups that were unsatisfied with the end result then mobilized to deliver more effectively on the promise of transparency, endeavoring to make the data more accessible by improving the quality of the database and developing an alternative website that was more functional than its original iteration. Journalists have since made increasingly regular use of these data in their analyses of financial interests in the health sector, suggesting that the process has at least in part delivered on the promise to provide greater transparency regarding the ties between the pharmaceutical industry and health professionals.

The case of the Transparence Santé project thus allowed us to document a new form of data disclosure that we have called "industrial transparency". This form of transparency is based on privatesector data and aims to make strategies of influence visible, thereby restoring the trust of the public, following a logic that is quite similar to that of the mechanisms set up to reveal the lobbying of politicians by private parties. One of the merits of our example, however, is that it involves massive data, with tens of thousands of people involved and millions of transactions. The case raises, in sharper relief, the question of the role played by public authorities in achieving this form of transparency. In the process we analyzed, the State appears to be relatively disengaged, neutral, and, sometimes, to remain in the background. In the end, its ambitious disclosure project suffered from a number of flaws, with little to no monitoring of registered data, no tools to facilitate its use, and data remaining the property of the companies. The authorities did, however, succeed in creating a single website, whereas the companies would have preferred to publish the details of their transactions on their respective websites. After some struggle, this design made it possible for third parties to make actual use of the dataset. This example therefore enabled us to explore the hypothesis that the mechanisms of industrial transparency in fact allow the neoliberal state to regulate the private sector at a marginal level, limiting its own investment while outsourcing the responsibility for processing and monitoring the disclosed data.

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⁶ This law was adopted in 2010 at the same time as the Affordable Care Act (also known as Obamacare) and aimed to improve the transparency of financial ties between pharmaceutical firms and healthcare providers. It gave rise to the launch of Open Payments, an ambitious database providing an inventory of these ties: https://openpaymentsdata.cms.gov>.

⁷ Interview with a former legal officer at LEEM, May 2019.

⁸ Interview with a legal expert from the Ministry of Health, March 2019.

⁹ Interview with LEEM's legal officer, March 2019.

¹² The association has, in particular, developed tools making it possible to follow the activity of French members of parliament, changes in law during their parliamentary career, and lobbying at the French parliament, via summaries of the people given audiences by parliamentarians.

¹³ Interview with a legal expert at the Ministry of Health, March 2019.

14 <https://www.regardscitoyens.org/sunshine/>

¹⁵ Interview with a legal expert at the Ministry of Health, March 2019.

¹⁶ Interview with a legal expert at the DGS, October 2018.

¹⁷ <https://www.meetup.com/fr-FR/Data-for-Good-FR/>

¹⁸ <https://www.eurosfordocs.fr/presentation>

¹⁹ Figures provided by EurosForDocs.

¹ See introduction and chapter 1 of this volume.

² See chapter 4 in this volume.

³ <https://www.transparence.sante.gouv.fr/>

⁴ See chapter 9 in this volume.

⁵ Here we thought that *benefits* and *agreements* (voluntarily in *italics*) were the best way to translate the original terms: "avantages" and "conventions".

¹⁰ Interview with a legal expert at the DGS, October 2018.

¹¹ The association's statutes.

²⁰ This database is not exhaustive and does not contain all French press publications. The investigation conducted in 2018 by the online magazine *Basta* ! and the Multinationals Observatory, entitled "Pharma papers", is therefore not part of our corpus.

²¹ We used the R.TeMiS (R Text Mining Solution) package (<u>https://cran.r-project.org/web/packages/R.temis/index.html</u>) on our corpus to create a vocabulary table, from which function words were removed. We then used hierarchical clustering to identify six classes based on the principal components drawn from a correspondence analysis run on this table.

²² Along with two other publications: one unpublished, seeking to calculate the impact of benefits and payments on prescriptions (Farvaque, Garcon, and Samson, 2020); and the second published as a "pre-proof" (Roussel and Raoult, 2020), showing a correlation between the stance taken by physicians in the hydroxychloroquine debate and the extent of their private interests in Gilead.