

## 11 Governing Open Health Data in Latin America

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### Introduction

Civil society and governments around the world have recognized the potential developmental benefits that data released in open format could bring to the Global South. This *open data*, released in digital format, publicly available for anyone to use—promise to contribute to global development goals, such as economic growth, job creation, social and economic inclusion, and access to public services such as healthcare. Although emergent, there is growing evidence that in the right circumstances, open data could contribute to these goals (see Verhulst and Young 2016, as well as chapter 10 in this volume).

Despite the potential, there is also a body of literature suggesting that most open data initiatives are not having the desired impact, particularly in the Global South, for a variety of reasons. These include poor-quality or incomplete data, data in hard-to-use formats, and a mismatch between the data that are published and the data that are actually needed (World Wide Web Foundation 2017). Thus, it is becoming paramount to understand how to improve the connection between making the data available, sharing it, and fostering the actual uptake of open data to solve developmental problems. Recent evidence has shown that the governance relationship is an important factor in this equation. For example, in a review of twenty-three digital monitoring platforms of public services, Peixoto and Fox (2016) show that the existence of institutional arrangements increases the use and responsiveness of these initiatives. While valuable, these studies show broad patterns of the overall picture. In this chapter, we aim to delve into these patterns in detail.

This discussion explores the role of governance arrangements in fostering civic engagement and open data-use outcomes in the Global South by looking at three case studies. The cases all originate in Latin America: Mexico's *La Rebelión de los Enfermos*,<sup>1</sup> Uruguay's *A Tu Servicio*, and Peru's *Cuidados Intensivos*. All three share the use of

digital technologies and open data and have the aim of improving health outcomes by producing and distributing information on health services. These cases also represent particular types of open data initiatives, where the resources are made open through the leading efforts of local activists and nongovernmental organizations (NGOs) instead of governments.

We apply the knowledge commons research framework developed by Madison, Frischmann, and Strandburg (2010; also see Frischmann, Madison, and Strandburg 2014c), which builds on the work of Elinor Ostrom and colleagues (Hess and Ostrom 2006; Ostrom 1990; Ostrom and Hess 2006). The framework provides a lens through which to understand the governance of open data and, in these cases, how bottom-up processes that build open data commons are related to stakeholder engagement and use of open data. For each case, we show in detail the different paths that bottom-up processes follow, how the community gets organized to build and sustain the commons, and the importance that governance arrangements can have to take the projects to the next level. The cases reveal that *collaboration among stakeholders promises better chances to scale and improve how open data can be used to solve social and developmental problems*. They also suggest that *the existence of rules to govern the process of sharing and producing resources in the data commons is important to increase the levels of engagement and use within the community*.

The chapter proceeds as follows. In the first section, we briefly introduce the linkages between open data and their potential to contribute to better health outcomes in international development. We then introduce the knowledge commons framework, link it to the field that we study, and expand on the relevant dimensions to analyze our empirical cases. An overview of our research methods, data collection, and analysis follows, and we then present the narrative of the three cases. Next, we discuss our findings, reflecting on three important dimensions: what problem is being solved, what institutional forms are chosen, and how these forms lead to modes of engagement. In the conclusion, we reflect on the main lessons and the value of the framework for this and similar studies.

### **Open Data Ecosystems in Public Health Services**

As with the case of open government, open data can be conceived of in several ways, and often in ambiguous terms (Yu and Robinson 2012). The origins of open data can be traced to the open-source software community, although the connections between both communities of research have not materialized to a great extent yet (Lindman,

Rossi, and Tuunainen 2013; Willinsky 2005). In practice, within the open data community, open data are generally understood as *objects*—that is, a piece of data is open if it is accessible, with no limitations on the user's identity or intent; provided in digital, machine-readable format capable of being linked with other data; and provided free of restriction on use, reuse, or redistribution according to its actual licensing conditions. Nevertheless, as Scrollini (2018) notes, there are other ways of conceiving and using the term *open data*, such as a policy, a community of practice, or a problem-solving approach. More recently, some literature refers to open data as an entire ecosystem (e.g., Dawes, Vidasova, and Parkhimovich 2016) composed of data objects, data infrastructure, and a set of actors that release, reuse, or consume open data.

Among the many potential benefits of open government are in how it contributes to improving healthcare systems. According to a recent mandate from the Sustainable Development Goals of the United Nations (UN)—specifically Goal 3—countries should aim to provide universal health coverage and access to quality essential healthcare services to their population by 2030. Further, corruption and inefficiency affect developing countries, leading to estimated losses of \$1.26 trillion (UN 2015). As observed by Scrollini (2018), the promise is that open data approaches will contribute to these goals by delivering transparency and accountability to the health sector. The rationale is that open data can be particularly beneficial for increasing transparency, fighting corruption, and encouraging democratic values, which are all drivers for many open government data initiatives in Latin America (World Wide Web Foundation 2017). Through transparency and appropriate contextual information, open government data can contribute to holding health providers accountable.

The pathway from open data to transparency and accountability, however, is seldom straightforward. Open data portals prove themselves good repositories, but the demand for data sets is still low. There were (and are) several constraints about the provision of data, such as availability, quality, timeliness of the provision, and the will to open data in the first place (Attard et al. 2015; Charalabidis et al. 2016; Zuiderwijk et al. 2012). Furthermore, not all countries have the legal framework and the capacity to release open data in ways that are meaningful, particularly in the Global South (Davies and Perini 2016).

In sum, despite the potential benefits, the evidence is incomplete and inconclusive on how, to what extent, and in what contexts open data initiatives contribute to improved healthcare systems. As the cases presented in this chapter show, the way that open data ecosystems are mobilized and governed are critical factors that affect their influence on healthcare systems.

## The Knowledge Commons Framework for Studying Open Data in Latin America

This chapter applies the knowledge commons framework that Frischmann and colleagues have proposed in recent years (Frischmann, Madison, and Strandburg 2014b). The framework builds on the Institutional Analysis and Development (IAD) framework that Elinor Ostrom developed to study community management arrangements for shared resources in natural environments (Ostrom 1990). Ostrom's IAD approach provided a seminal contribution to addressing collective action problems in settings of shareable but depletable natural resources such as water, trees, and fish. But governing shared knowledge and information resources, such as many of the examples covered in this volume, requires accounting for mechanisms or characteristics that are no longer constrained by geographic or physical boundaries. This new type of commons—knowledge and cultural commons— attracted the attention of scholars, including Ostrom herself (Hess and Ostrom 2006). The knowledge commons is thus “shorthand for the institutionalized community governance of the sharing and, in some cases, creation, of information, science, knowledge, data, and other types of intellectual and cultural resources” (Frischmann et al. 2014b, 3).

The knowledge commons framework is therefore proposed as a way to systematically investigate governance regimes in broader cultural environments, which, as opposed to natural environments, require dealing with producing or sharing information, innovation, or creative works.<sup>2</sup> The cases presented in this chapter represent interesting cases of the knowledge commons because of two characteristics. First, all three cases deal with knowledge and information resources that are largely nondepletable. This is mainly because the resources are either produced or reproduced digitally, in machine-readable, open formats—in other words, the health resources are made into, or sourced from, open data. Second, as happens with other digitally enabled commons (i.e., online creation communities like Wikipedia), the knowledge resources did not exist as *open* but had to be created in all three cases. Therefore, we can study and learn from the various arrangements put in place to produce and preserve these resources.<sup>3</sup>

### Dimensions of the Knowledge Commons Framework for Open Data Cases

In their conceptualization, Frischmann et al. (2014b) suggest conducting comparative institutional analysis with a proposed series of commons-related questions, some of which are adapted from Ostrom's IAD framework and others are developed specifically to study knowledge commons. Table 11.1 summarizes the full list, which are grouped in four areas: background environment, attributes, governance, and patterns and outcomes. We then present an overview of an abbreviated set of relevant questions that guide our empirical analysis, together with an introduction of the categories in relation to our cases.

**Table 11.1**

Representative research questions of the knowledge commons framework.

Framework element	Research questions
Background environment	<p>What is the background context (legal, cultural, etc.) of this particular commons?</p> <p>What is the default status of knowledge resources in this context (patented, copyrighted, open, etc.)?</p> <p>What is the culture of openness in this policy, and the social and cultural context?</p>
Attributes:	
Resources	<p>What resources are pooled, and how are they created or obtained?</p> <p>What are the characteristics of the resources? Are they rival or nonrival, tangible or intangible? Is there shared infrastructure?</p> <p>What technologies and skills are needed to create, obtain, maintain, and use the resources at stake?</p>
Community members	<p>What members of the community are managing commons resources, and what are their roles?</p> <p>Are there any community members that benefit from openness (women, disabled, etc.)?</p> <p>How does a culture of openness affect your project's engagement with the general public?</p>
Goals and objectives	<p>What are the goals and objectives of the commons and its members, including obstacles or dilemmas to be overcome?</p>
Governance	<p>What are the relevant action arenas, and how do they relate to the goals and objective of the commons and the relationships among various types of participants and with the general public?</p> <p>What are the governance mechanisms (e.g., membership rules, resource contribution or extraction standards and requirements, conflict resolution mechanisms, and sanctions for rule violations)?</p> <p>Who are the decision-makers, and how are they selected?</p> <p>What are the institutions and technological infrastructures that structure and govern decision-making?</p> <p>What informal norms govern the commons?</p>
Patterns and outcomes	<p>What benefits (e.g., innovations and creative output, production, sharing and dissemination of knowledge, and social interactions) are delivered to members of the community?</p> <p>What costs and risks are associated with collaboration, including negative externalities?</p>

*Source:* Adapted from Frischmann et al. (2014b, 20–21).

**Background Environment** The initial dimension aims to set the background context and the default status of the resources involved. This includes the characterization of the environment in which the case takes place, such as prevalent social norms, laws, or traditions, as well as the differentiation of whether the resources available are patented, open, or something in between. In the empirical analysis in the section “Three Cases of Opening up Health Data in Latin America,” we review the current healthcare system context, as well as the histories and motivations to build open, sharable resources as the characterization of the background environment of each case.

**Basic Attributes: Resources, Community Members, and Goals and Objectives** The second cluster of questions focuses on identifying and describing the basic attributes of the commons—that is, the type and characteristics of the resources and skills needed to produce, maintain, or use them; who the community members are and what their roles are; and what goals and objectives are pursued. The framework allows for flexibility; some cases may have precise and fixed definitions of both resources and community membership, while others may be more fluid, with less clear boundaries or rules (Frischmann et al. 2014b).

In contrast to what happens with natural commons resources that are already there to be preserved, the pooled resources in the cases that we analyze in this chapter need to be built and then preserved. In general, it can be argued that the three cases consist of pooling dispersed data about health services—whether public or proprietary—and bringing together technical and cognitive capabilities to make data available as open knowledge resources. The resource characteristics entail a combination of nonrival, intangible resources (i.e., open and/or accessible data sets), with information available only in paper format, or closed data sets, to be shared over a digital infrastructure that has to be created and maintained.

As for their community members, the three cases entail small communities with similar attributes—their members are identified clearly and relatively simply. The communities mostly consist of civil society organizations (CSOs) seeking to open up information; government bodies with different levels of involvement; and technology experts who develop tools to contribute to the expansion of the knowledge resources. Because of the nature of the knowledge commons in these three cases, people from the general public are the default users, who in some instances may contribute to the commons with feedback and use cases.

The last set of questions in this cluster refers to understanding the goals and objectives of a knowledge commons—that is, what problems and social dilemmas are being solved. As the framework suggests, often, knowledge commons are purpose-built. Examples of problems that knowledge commons have tried to solve include the production

of shareable resources for further creativity and the production of intellectual products to be shared (Frischmann et al. 2014b, 25). In the cases analyzed here, the goals are actually what trigger the commons to emerge: they all aim to produce and sustain open information and knowledge resources that may be beneficial for users of health services in their contexts.

**Governance** This set of questions is used to investigate the dynamics of knowledge commons governance—what Ostrom refers to as the *rules-in-use* of commons, or the interactions of knowledge commons participants and resources. Frischmann et al. (2014b) suggest three angles that are separated for analytical purposes, as some elements overlap: (1) the commons approach to openness, both with respect to resources and community; (2) the commons general governance structures, such as formal or informal entitlements and decision-making structures, legal structures, and institutional settings; and (3) those rules and norms that apply to particular action arenas.

In the analysis that follows, we focus on the relevant action arenas—that is, the spaces where goals, resources, and community members interact, constituting action situations. Ostrom (2008, 52) defines action situations as being “composed of participants in positions choosing among actions at a particular stage of a decision process in light of their control over a choice node, the information they have, the outcomes that are likely, and the benefits and costs they perceive for these outcomes.” Action arenas result in patterns of interaction, and ultimately, those patterns may result in particular outcomes.

**Patterns and Outcomes** The framework suggests identifying and assessing the benefits that are delivered to members and nonmembers that emerge from the knowledge commons. For example, this may include innovations and creative outputs, production and dissemination of knowledge resources to a broader audience, and new social interactions that emerge from the commons. In the cases that we analyze, outcomes include the production, management, and maintenance of information resources in open digital format.

### Research Methods and Significance of the Empirical Setting

Our analysis<sup>4</sup> applies a comparative, multiple-case-study method and reports findings from three cases in Latin America: specifically, in Mexico, Peru, and Uruguay (see table 11.2). The Mexican La Rebelion de los Enfermos and the Uruguayan A Tu Servicio cases were part of the Open Data for Development (OD4D) research program supported by IDRC, and the Peruvian case was originally supported by the International Center for Journalists (ICFJ). These cases represent different modes of engagement, in which citizen groups could foster transparency and accountability to improve service delivery (Scrollini 2018).

**Table 11.2**

General description of the cases.

Case	Description
La Rebelión de los Enfermos (Mexico)	An online-offline platform to express citizens' grievances with Mexico's healthcare system
Cuidados Intensivos (Peru)	A website on health service delivery capable to expose potential corruption issues through the dissemination of public information
A Tu Servicio (Uruguay)	A digital platform to help citizens choose their health service provider

**Data Collection and Analysis**

These three cases were researched under the umbrella of the *Iniciativa Latinoamericana por los Datos Abiertos* (ILDA, or the Latin American Open Data Initiative) and were previously documented in a paper published by the U4 Anti-Corruption Resource Centre (Scrollini 2018). The research design included a participatory action research approach, in which authors worked alongside their counterparts in the initiatives to generate evidence and develop practical solutions to identified issues (Herr and Anderson 2005). The research also included interviews with government champions and leaders of the initiatives, as well as extensive revision of resources available online, including blogs and news articles, narratives available on the cases' websites, and social media. We studied the cases retrospectively, covering a two-year period from 2014 to 2016.

To analyze the cases, this investigation used the set of relevant questions from the knowledge commons framework, which proceeded in an iterative manner. We first examined the narrative of the cases to understand the context and the basic features of their environment, the attributes of the resources, and their goals and governance. We paid particular attention to goals and objectives, following our understanding of the framework. Because the knowledge resources have to be built rather than governed in a particular community or geographical setting, starting with an understanding of the goals and objectives was useful to identify the narratives and action arenas, as well as the participants and the rules in place. We then reflected on the relevant questions and dimensions of the knowledge commons framework to elucidate findings based on a comparative analysis. In the analysis, we stress three points: What problem is being solved? What institutional forms did the cases choose to follow? What were the ways that those choices led to modes of engagement and problem-solving?



### Three Cases of Opening up Health Data in Latin America

Latin American countries offer an interesting setting for studying open data and civic technology, given its rapid growth and importance in a variety of policy arenas (World Wide Web Foundation 2017). Countries like Mexico, Uruguay, and Brazil, for example, are top performers among countries in the Global South. They are among the top fourteen best-performing countries in the global Open Data Barometer of 2017—a global ranking that ranks countries according to the publication, readiness, and impact of open government data sets (World Wide Web Foundation 2018). In addition, Latin America now has five countries among the top twenty of the Open Data Index 2017, a survey coordinated by the Open Knowledge Foundation that measures the state of open government data around the world.<sup>5</sup> Moreover, the health service delivery sector has been considered strategic in consecutive open data conferences held in the region (known as *Abrelatam/Condatos*). In this section, we explore cases from Mexico (*La Rebelión de los Enfermos*), Peru (*Cuidados Intensivos*), and Uruguay (*A Tu Servicio*).

#### **La Rebelión de los Enfermos: Engaging Mexico's Healthcare System**

**Background Environment** Mexico's healthcare system is complex and fragmented. While it is meant to cover the entire Mexican population, the system underserves or does not cover a significant portion of the population due to differences in who has access and how they seek care. A recent Organization for Economic Co-operation and Development (OECD) report notes: "Mexico's massive public investment in its health system ... has failed to translate into better health and health system performance to the extent wished and a program of continued, extensive reform is needed" (OECD 2016, 13). There are six institutions that deliver health services in Mexico, and each has its own independent network of doctors, clinics, hospitals, and pharmacies (ManattJones 2015). As a result, this creates a large structure with several implementation problems.

At the same time, when it comes to open data, Mexico was ranked the sixth best performer by the Open Data Barometer (World Wide Web Foundation 2018), and the country leads the region. But the implementation of the open data policy faces several challenges (OECD 2016).

**Goals and Objectives, Resources, and Community Members** Sonora Ciudadana—an NGO based in the state of Sonora in the north of Mexico working on transparency and human rights in Mexico—developed the initiative *La Rebelión de los Enfermos* with the objective of raising awareness about the difficult conditions that Mexican hospitals face, as well as providing a channel for grievances with health services. The motivation goes back to 2008, when Sonora Ciudadana received a complaint from an individual

who was denied access to medicine and other services at ISSSTESON (one of the six Mexican institutions), on the basis of his previous health condition. Sonora Ciudadana filed litigation, taking the case to Mexico's Supreme Court of Justice (this was a rather common practice in the sector), and decided to push more cases before the Court as well.

The central resources of this commons—data or information on health services—are very limited, nonexistent, or very difficult to access, given the system's related high transactional costs. They consist of pooling dispersed data in the Mexican healthcare system, together with technical and cognitive capabilities to make it available for a wider audience. The activities and skills needed to do so typically entailed digitizing paper-based data, using tools to clean up data, and using digital tools and infrastructure to publish the information in a meaningful way.

The community member in this case is Sonora Ciudadana, which is a traditional human rights organization working on human rights and transparency issues, but not necessarily linked to the open data community (or the technology community overall). The NGO took on the role of translating or pooling the information resources, based on its own organizational identity.

**Governance and Action Arena** To expand on the case of 2008, Sonora Ciudadana launched a set of access to information requests to obtain data about ISSSTESON's performance. The organization monitored a set of indicators about health performance through these requests. Interestingly, ISSSTESON did not deny the information that Sonora Ciudadana obtained, but the fact that requests were filed on paper made the process difficult for all parties involved. Because it was not a particularly tech-savvy organization, a common obstacle that it faced was to systematize the information and make it accessible in formats that could reach and benefit a wide range of people in the Mexican population.

With significant evidence collected, Sonora Ciudadana launched a campaign under the banner "La Rebelion de los Enfermos," which aimed to showcase the difficulties that users had when trying to get access to the healthcare system, as well as to document new cases of potential injustice in the sector. As the campaign advanced, they set up a website where users could document their complaints, which in turn became a useful endeavor in itself. The website used part of the information that Sonora Ciudadana obtained through freedom of information (FOI) requests, combined with available data sets from the federal government. The effort allowed people to map and understand the way that clinics and hospitals work across Mexico, as well as to put forward user complaints. The NGO decided to build a tool that would provide information and also allow people to denounce situations, which made sense in the context of the organization's longer-term litigation strategy. Further, Sonora Ciudadana decided that the new tool would cover all healthcare systems, not only ISSSTESON.

Most of the information came from FOI requests that were mostly paper based. As a result, Sonora Ciudadana had to invest in digitalizing this information, at significant cost. To explore how this data could be structured and eventually used, Sonora Ciudadana collaborated with ILDA and Codeando Mexico, a civic technology organization, to explore if and how Sonora Ciudadana could access better data from the public sector.

This process helped to identify significant problems in the government data available through FOI requests: there is no data structure, the formats are inconsistent or incompatible, and there are missing sources that otherwise would allow data reliability tracking. In short, while data were available, there was a significant cost to process that data, as well as to develop a tool that would enable comparisons across the systems. Codeando Mexico conducted an extensive review of the data infrastructure of ISSSTESON and other Mexican authorities, developing a standard to publish data about medical institutions, basic infrastructure, service metrics, human resources metrics, and cost metrics (Codeando Mexico 2015). The standard was designed to structure information in ways that could foster comparison and be realistically adopted by health institutions. While the standard is available (and open for all interested parties), the lack of resources to fully implement it and the difficulties in collecting the data prevented the project from scaling up.

**Outcomes** An important outcome of this initiative has been the joint work of Codeando Mexico and Sonora Ciudadana to create an open data standard for health service delivery. The standard provided a template on how to scale and develop basic data infrastructure. The process of standardization proved to be complex due to the difficulties of structuring the data and getting accurate data to work with. But the work served as the basis to guide other iterations of related projects, such as *A Tu Servicio*, currently deployed in Colombia and Uruguay. In addition, the significant work put toward the creation of the standard, and the fact that it is freely shared online, are contributions that enhance the work in the long run.

*La Rebelion de los Enfermos* offers an example of how traditional campaigning is needed to deliver results for citizens' rights in a context of open data. The decision to embark on a digital journey also represents a change in strategy for a rather traditional, accountability-oriented organization. Nevertheless, better data alone would not help Sonora Ciudadana to follow and improve the monitoring and transparency of the sector. The initiative relies on the collaboration of users, who need to provide more data to enrich the system.

## Cuidados Intensivos: Checking on the Peruvian Healthcare System

**Background Environment** Peru is one of the fastest-growing economies in Latin America, with an average of 5.3 percent growth in gross domestic product (GDP) and a rapidly expanding middle class (OECD 2016). Such growth is putting pressure on the public sector to deliver better social outcomes. Further, while open government efforts have been part of Peru's agenda for at least twenty years, there are several challenges in terms of integrity, corruption in public procurement, and access to information (OECD 2016). Peru is a member of the Open Government Partnership and has committed to the Open Government Principles, but, in practice, the lack of a unified open government policy (Casas 2012) has led to a fragmentation and poor implementation of open government initiatives. The result is that there is limited (or nonexistent) room for dialogue between government and civil society around the open government process. When it comes to open data, Peru has a medium score—forty-eighth globally and seventh in the region (World Wide Web Foundation 2017).

Like Mexico, the healthcare system in Peru is also fragmented. There are five entities coordinating health service delivery, including the Ministry of Health, EsSalud (the National Health Insurance system), the armed forces, the police, and the private sector. EsSalud and the private sector combined cover around 40 percent of the population. EsSalud contracts out part of its services and provides its own clinic services. In recent years, private providers have become critical for the provision of health services (Torres López and Huacles 2015).

**Goals and Objectives, Resources, and Community Members** OjoPúblico is an independent digital media outlet carrying out investigative journalism in Peru. Founded in 2014 by a group of journalists and programmers and evolving into an online journalism venture, it delivers traditional investigative reporting but also uses new digital tools and data journalism practices in the Peruvian context.

OjoPúblico decided to research the lack of transparency in the health sector and the powerful corporate interests operating in the private sector. Similar to the previous case, the information resources had to be pooled from different sources. Through the process, OjoPúblico encountered many problems with the official data. Most of the data were outdated, the formats in which they were provided were not open, and the team had to correct mistakes by hand and scrape Portable Document Format (PDF) files.<sup>6</sup> The Peruvian state organizations had problems handling the data due to its own lack of information technology (IT) systems and the legacy systems in place. Thus, the issue was not only about the will to be more open, but also about the capacity to engage.

**Action Arena** OjoPúblico engaged in an investigative reporting strategy that included traditional journalism and the use of FOI laws and data journalism practices to explore the complex subject of health service provision. Cuidados Intensivos was part of this strategy, as OjoPúblico identified an opportunity to obtain and use data about health providers in order to provide more transparency, as well as to promote better choices. The project was supported by the ICFJ, the Knight Foundation, Hacklabs, and Friends of OjoPúblico.

OjoPúblico's strategy was to expose the complex situation of the healthcare system in Peru. Their investigative reporting uncovered three key issues: lack of regulation in the private sector to prevent potential abusive practices, lack of transparency and enforcement of fines for breaching terms of service, and lack of an effective redress mechanism for grievances. OjoPúblico's research also identified a private-sector concentration process, whereby eight economic groups developed systems wherein they provide the insurance, the clinic service, and the pharmaceuticals, effectively creating a vertical integration with little control by public authorities (López and Huacles 2015). OjoPúblico also identified the clinics with the most fines and established a ranking. Finally, their research established that none of these clinics paid their fines—they owed the Peruvian state around 10 million soles (approximately \$3 million).

The website was designed to take advantage of the information released to raise awareness among the issues covered in the investigative reporting pieces. In other words, the website was supposed to be the *actionable* item of OjoPúblico's strategy. The website would allow people to understand who had permission to practice and the fines that they had accumulated over the years. The Peruvian open data portal had no information about these topics, nor was there an attempt to engage with the initiative from the Peruvian office of e-Government in order to obtain the data. The leaders of the project attributed the latter to the fact that the e-Government office has little political influence, as well as to the fact that sensitive health data could not be obtained via the mobilization of an open data agenda in that way. This seems plausible in light of a recent OECD review that noted the limited capacity of the e-Government agency to influence digital policies in Peru (OECD 2016).

OjoPúblico decided to follow an eclectic strategy to get the data. First, they filed fifty-two FOI requests, directed to several institutions including the National Competition Authority, the Copyright Authority, and agencies that were part of the National Authority on Health (SuSalud, EsSalud, the Ministry of Health, and the police). Furthermore, the news organization collected available reports that these sources published online. As in the Mexican case, most of the replies to the FOI requests were on paper. Once OjoPúblico got the data into whatever format was available, they compiled a

database and started to systematize the information. Furthermore, hard-copy data (on paper) were crucial to obtain more reliable data, as the authorities were not processing the files. OjoPúblico had also to deal with the complex jargon, which had consequences for the way that data was presented. For instance, the concept of *operational risk* was a relevant one. As Hidalgo and Torres (2016, 83) observe:

In the official jargon, this [operational risk] concept refers to the result of the evolution of private services and measures their degree of compliance with the standards of patient care (conditions and equipping of emergency services, intensive care units, pharmacies). *Susalud* inspectors registered a percentage for each service provider and this actually corresponded to the percentage of compliance. So, when reports said that a clinic had “operational risk level: 6%”, what it actually meant was that the establishment did not meet 94% of the care standards. The impact of the data collected changed the knowledge radically.

The databases were later combined with relevant databases from the private and public sectors such as the National Health Institute, the Peruvian Stock Exchange, the tax authority, the judiciary, and the media. In some cases, OjoPúblico had to pay for the data. The key elements used to build *Ciudadanos Intensivos* were data on private clinics, data on insurance companies, and data on public health investments (Hidalgo and Torres 2016). OjoPúblico built its own open data commons collecting, treating, establishing categories, and eventually using the data.

**Outcomes** OjoPúblico managed to gather information about 61,372 doctors, 9,920 clinics, and twenty-one insurance companies. They created an open data commons by merging available disparate databases or those obtained through different legal or social processes. In doing so, OjoPúblico collected better data than the government had, and the initiative allowed access to an unprecedented amount of information about the private healthcare sector in Peru. The launch of the story put OjoPúblico on the journalism map, as the healthcare system is one of the country’s key controversies. *Cuidados Intensivos* also gave OjoPúblico more visibility nationally, establishing its reputation as a young and professional news outlet. Furthermore, it helped the group reach out to users’ rights organizations working in the health field. OjoPúblico collected stories from these organizations and gave voice to issues surrounding malpractice and abuse in the healthcare system. As a result of this engagement, OjoPúblico also improved the capabilities of its own organization, equipped journalists with new skills, and managed to develop other projects.

Overall, the project improved the accountability of the Peruvian healthcare system by exposing several conflicts of interest and forcing authorities to correct data and to improve the control of the system. With more information available, more people were able to check the status of clinics in Peru and find out which were the best and worst

performing. Surprisingly, the general public's use of the tools was relatively low, considering its potential. The main obstacle was reaching a general audience and sustaining efforts to release data on a relatively small budget. Nevertheless this was the first time that information was systematized in a way that could be used for accountability. As in the Mexican case, the lack of formal (or even informal) governance arrangements to secure and use the data conditioned the way that the project could have progressed.

### **Atuservicio.uy: Coproducing a Health Application**

**Background Environment** Every February, Uruguayans get to choose whether to change their health service provider. This opportunity is the result of a series of major reforms in the Uruguayan national healthcare system that lead to almost full coverage of the country's population. As a result, significant amounts of public funding go into the system, which offers a mix of public, semipublic, and private providers. The more customers a health provider gets, the more funding the provider obtains from the government. As a result, health providers compete relentlessly for every person. Health providers develop aggressive marketing campaigns through the media, and in some cases offer cash rewards to people if they switch services—the latter is illegal under Uruguayan regulations.

Concerned about these practices, the Ministry of Public Health, in 2008, started publishing information about various performance indicators for the system. The ministry published this data on its website using Microsoft Excel tables. This is not surprising—Uruguay has been among the top performers in open data, both in the region and globally. The press used these tables to produce news pieces about the system, but users seldom retrieved the tables. The language was difficult to understand, in part because the information was not displayed in a manner that was friendly to nonexperts and because it was difficult to make comparisons among providers. Moreover, the government assumed that users would have access to some kind of proprietary software in order to make sense of the information published.

**Goals and Objectives, Resources, and Community Members** In 2013, a CSO called DATA Uruguay identified an opportunity to work with available data from the Ministry of Health. The organization partnered with a local online media outlet, 180 Ciencia, and developed a tool to visualize and rank providers according to user preferences. The project was aptly named *Temporada de Pases* (Transfer season), in reference to the short time frame that Uruguayans had to choose their health providers. DATA Uruguay extracted the data sets from the ministry's websites, cleaned them, and designed an interphase in which users were able to understand the data easily. The online media

outlet helped to spread the word, and the website got around 6,000 visits in February 2014. The project was built using open-source software, with the rationale that the data could be audited by anyone in the community. The overall goal in the Uruguayan case, therefore, could be summarized as an effort to provide an online tool to inform health users about their choices at a critical time.

Temporada de Pases did not involve the Ministry of Public Health, but, because of the presence in the media and the reaction from early users, the government eventually began to work with them. Thus, the community included DATA Uruguay and collaborators, but also the government. A notable absentee from this commons, however, were users. Initially, DATA and the Ministry of Public Health aimed to include them, but due to the time and resource constraints to develop the app, they were not considered as relevant actors in the design phase. Yet users later become crucial in reporting missing data, as well as demanding that new data be incorporated.

**Action Arena** The initiative Temporada de Pases created a baseline to which members of DATA and collaborators could scale the newly created open resources. DATA and the Ministry of Public Health explored making an alliance in 2015. The ministry had the intention to create a similar website to the one that DATA had created, but it was not possible to find a suitable provider. DATA had the expertise to carry forward this mission, but it had only a basic understanding of the technical and policy nuances of health data. Eventually, the Ministry of Public Health and DATA set up a formal partnership to cocreate and coproduce the web application. The partnership featured the ministry's commitment in terms of human and financial resources to assist DATA on the one hand, and the commitment of DATA to assist the ministry on the other. In turn, DATA pushed for developing this work on open-source software to allow the eventual replication and transparency of the process.

The initiative was an emergent and bottom-up process. DATA engaged with a group of midlevel managers who had the political support to proceed. DATA and the ministry's team held meetings defining the scope of the information to include. DATA would normally push for more information to be published, while the Ministry of Public Health would be more cautious about what to publish. The ministry had initially classified part of the information that they released as "reserved," following the provisions of the access to information law in the country. To solve this problem, DATA and the Ministry of Public Health constructively bargained for what information to include on the website.<sup>7</sup>

DATA had an initial bias toward user choice. In DATA's view, the more people exercising the right to switch providers, the better. On the other hand, the Ministry of Public Health argued that switching providers should not be the ultimate policy goal,



as it could jeopardize the stability and sustainability of the healthcare system. Instead, the ultimate goal for the ministry was to encourage users to express their concerns to the health authority in order to improve the way that health services are offered.<sup>8</sup> DATA agreed to work within the framework of the ministry's policy objectives to move forward.

This discussion was important, as it affected several decisions about how information was represented, as well as about what health information users could eventually compare on the website. Once there was an agreement on what information to include, the ministry's team went to look for the sources of information. The government team found that most of the data was compartmentalized across the Ministry of Public Health, and it was not available in open format. Furthermore, collection processes were often manual. Through the identification and collection process, the ministry discovered that some of the data sources had quality problems or raised conflicts among different sources. The process of collecting data helped the ministry to understand its own sources of information and put them in order. On DATA's side, the team initially developed the back end of the app to import and process the data. Initial tests were run with data sets from the Ministry of Public Health to ensure compatibility. This process was lengthy and technically challenging for both parties. Problems with data standardization haunted the project until its first launch.

As the project evolved, DATA developed the first mock-ups (drafts) of the website and began the validation process with the ministry's team. Middle managers working on this project were usually on board with the design choices. The process also involved other managers and political appointees who were data providers. Most of them wanted to ensure that the data that they collected or created would not be misrepresented on the website. The discussion showed the asymmetry of technical knowledge between managers and technologists. Members of DATA would act as translators to ensure that all parties were on the same page.

DATA and the ministry made a set of basic decisions on which data to showcase and how to do it. Users would get to see data about wait times, prices, users' rights, the location of services, and performance targets on the home screen. Users then would be able to compare up to three providers from their administrative jurisdiction, allowing them to delve extensively into the data. The standardization of the data set on the government's side and technical capacity on both sides were considerable obstacles to the project.

The final stage was a sprint to get the site published before February 1, when Uruguayans would have an opportunity to choose between providers. At the end, with these challenges overcome, all the standardized data were added to the Uruguayan national open data portal, which received around 2,000 downloads in the rest of 2016.

**Outcomes** As a result of the initiative, in the first year, around 35,000 Uruguayans got access to the data published via the A Tu Servicio portal. In the second year, the number of A Tu Servicio users increased to 60,000. In addition, the website was used to inform public debate and taken up by several media outlets with an interest in the subject (Sangakoya et al. 2016). Both government and the opposition used A Tu Servicio to argue about health policy in the Uruguayan parliament. The project also survived a change of government. In 2016, the ministry's team was able to increase its audience and impact. Table 11.3 provides the set of impacts on various intended beneficiaries of the project according to Sangakoya et al. (2016) and Scrollini (2016).

### Governing Open Data Health Commons

Using the knowledge commons framework, we will now analyze these cases from a comparative perspective (see table 11.4). Following Madison (2014), we stress three points in the analysis: the problem that is being solved, the choice of institutional forms (including views on infrastructure), and the ways that those choices led to modes of engagement.

As we hinted at the beginning, all these cases try to solve a rather typical knowledge commons dilemma: the projects exist to manage existing resources and to sustain the production and contribution to a shared resource of open data pools in health services.

Arguably, the strategies on cooperation and confrontation contributed to the differences in outcome. For example, despite the initial interest from the government, the Peruvian case was never able to collaborate with the Ministry of Public Health. Likewise, the Mexican case was unsuccessful in getting the government on board to engage and respond to the initiative. Closer collaboration with government authorities and the provision of better data could have improved the process that Sonora Ciudadana developed. On the other hand, the Uruguay case showed that the initial willingness and open data capacities of the government contributed to building the initiative as a coproduction process.

Overall, the cases show different ways of engaging in the production of the commons. In these three cases, the more collaborative approach between leading actors in a given action area led to better use of the data to address the issue at hand. Nevertheless, confrontational approaches—that is, those in which civil society uses tools to hold the government to account—also offer value, as the commons are still available as a result of FOI requests or data scraping, as the Peruvian case demonstrates. In general, a mix of both approaches could be considered when starting a process in a given action arena.

The cases analyzed here also show that without a cooperation arrangement—whether formal or informal—to sustain the data commons, most of the applications

**Table 11.3** Summary of A Tu Servicio's main outcomes.

Intended beneficiaries	Results	Indicators
Average citizens	<p>Enabling the people of Uruguay to make better-informed health decisions as a result of actionable information</p> <p>Equipping citizens with data-driven evidence and tools to make better decisions on health-care choice</p> <p>Catalyzing citizens to act as agents of monitoring and evaluation around the health services they receive</p>	<p>Previous to the existence of this initiative there was no way to compare providers in a systematic way</p> <p>80,000 users in the last edition of A Tu Servicio in 2016</p> <p>Six reports on service delivery issues and requests of more information through social media</p>
Health providers	Improving the quality and responsiveness of service based on data-driven demands from citizens	Providers adjusted at least five prices as a result of data publication
Media	Encouraging better data journalism efforts and data-driven arguments for public debate on healthcare	180 media reports using Atuservicio.uy data or quoting it
Civil Society, unions and politicians	Enabling better-informed argumentation and advocacy round the status of the healthcare system	At least six documented uses by MPs, Senators, union leaders, providers and citizens about Atuservicio.uy in public debates and discussions
Ministry of Health	<p>Enhancement of the Ministry's regulatory role</p> <p>Improvement of Ministry's own data sources and processes</p>	<p>Data from health providers for the second edition arrived on time to the Ministry</p> <p>The Ministry formalized data collection procedures</p>
Open Data policy	<p>Contribution to the Uruguayan open data portal in terms of data</p> <p>Case study to showcase to other state institutions to promote the use of the portal</p>	During February 2015, it was the most demanded data set of the Uruguayan national open data portal Atuservicio.uy is used by the e-Government agency as an exemplar for other agencies

*Source:* Based on Scrollini (2016) and Sangakoya et al. (2016).

**Table 11.4**

Summary of case analysis.

	Mexico La Rebelion de los Enfermos	Peru Cuidados Intensivos	Uruguay A Tu Servicio
Problem to be solved	Lack of public data to check health service delivery in Peru and expose potential corruption issues	Lack of an accountability channel to monitor exclusion and discrimination in Mexico's healthcare system	Lack of reliable, public, and accurate data to make decisions on Uruguay's health service providers
Background environment and existing resources	Country signed on to the Open Government Partnership, but lack of a unified open government policy Low levels of transparency in the health sector Low-to-nonexistent open data or shared knowledge resources Data obtained through several methods, including scraping	Country leading in open data policies in the developing world Complex, nontransparent, and corrupt healthcare system Some public data exist, but not structured in ways that can be used by the public Some data under protected licenses (proprietary systems), and some accessed through FOI requests	Existing capacities to produce open data in government Open data sets exist, but are poorly structured or incomplete
Choice of institutional form and rules	Largely local arrangements; network of activists contributing to maintaining the commons (OjoPúblico) No shared objectives with government and no institutional or legal arrangements in place to scale the project outside the organization	Largely informal network of users governed by Sonora Ciudadana; collaborative partnership with technical capabilities provided by an external community member (Codeando). No shared objective with government and no defined legal mechanisms to scale the project outside the initiative	Shared policy objectives and collaborative arrangement set between a leading NGO and government, governed by the existence of informal and formal rules Shared technical infrastructure of open characteristics
Results in engagement	Low Emerging engagement in the form of citizen control. Emerging engagement with interested but not digitally savvy communities in the space Some reactions from government but co-creation nonexistent	Low Limited engagement in the form of raised awareness of health injustices in Mexico, with changes in the provision of health service delivery in Sonora No engagement from government	Medium to high Notable engagement from government; limited engagement from users, who are able to use the data but not to contribute to the commons

are likely to disappear. For this reason, as Peixoto and Fox (2016) note, the involvement of the government in some form is crucial.

The cases also illustrate the different ways that institutional choices are made, particularly in regard to building a community. While the Peruvian and Uruguayan cases are confined to a small community of members (mainly NGOs governing the processes), the Mexican case required a broader community to engage with criticisms and the provision of data. Uruguay's *A Tu Servicio* and Peru's *Cuidados Intensivos* may be seen comparatively to be more successful in the ways that they achieve new forms of engagement because, in order to build and preserve the common resource, they have controlled and small communities with clear roles, with the potential to reach out to the wider community through media and civil society channels. This does not mean that to be successful, open data initiatives need small communities controlling the resources, but it reflects the well-known challenges of keeping a community engaged and motivated when there are no labor contracts or financial incentives in place (e.g., Benkler and Nissenbaum 2006; Madison 2014). When a voluntary or collaborative relationship is a precondition for producing the open resources, the chance to get it done will depend on the rules and arrangements put in place to manage the community.

Knowledge commons also often depend on shared infrastructure (Frischmann, Madison, and Strandburg 2014a). In some cases, technical infrastructure may be a substitute for formal rule-based governance (Fuster Morell 2014) and may be critical for the development of new uses (Scrollini 2018; Moncecchi 2012). The three cases in this chapter all included the development of open data sets held on different types of shared infrastructure that could (or should) be improved by actors in the ecosystem. However, in the absence of collaborative relationships and institutional mechanisms, the reutilization of the shared knowledge resources may not scale. For example, the way *La Rebelion* is organized suggests that users can contribute only in certain ways (i.e., what is defined in the technical standard). The community of users does not have control over the design of the platform of participation, and it may not define rules or licenses. In the Uruguayan case, on the other hand, the choice of developing the web application in open-source software, as well as sharing the new open resource on the national open data portal, meant that the initiative contributed to less dependency and more openness in terms of decision-making processes. In the Peruvian case, the data are open, but the tool is not. Thus, although the open-source nature of a commons project may enable better outcomes in terms of engagement and sustainability, it does not guarantee the sustainability or the replicability of the initiative.

Finally, the cases show the importance of politics—an evident factor, given the highly political character of healthcare systems anywhere. Although this is hardly novel, what

the framework helps to stress is that in order to build open data commons, a shared vision of the value of openness and the mechanism to dispute the absence of or lack of quality of public data matter. The Mexican case serves to exemplify this point. The process of scraping all the data and setting up the portal, La Rebelion de los Enfermos, was almost heroic, taking into account how the data were initially structured. A governance setting that ensures access to basic data and incentives to the public sector to use that data could have changed the way that the project evolved, generating traction. Having said this, the dynamics to build trust and exchanges between parties remain elusive.

### Conclusions

It is not a surprise that open data and open knowledge, and their potential impact for development and inclusion, have captured the interest of governments, civil society, and communities. The considerable enthusiasm created by open data in the Global South, however, has yet to translate into more systematized results and lessons to be shared and embraced. As in the case of other information and communication technologies for development initiatives, open data projects do not exist independent of ideas, techniques, technologies, systems, people, and contexts (Kitchin 2014). Understanding what goals and objectives drive open data initiatives, what arrangements they have in place, and what they can deliver in their context is critical to design effective governance arrangements and effective open data policies.

The three cases discussed in this chapter, while differing in scope and results, offer valuable lessons. The cases are useful to highlight that, as opposed to the prevalent government-centric, top-down view of knowledge production and distribution, innovation and problem-solving with open data can happen in distributed ways, with practices that could be best described as bottom-up and emerging from the activists in a local community. In addition, and in light of the available evidence, our empirical work shows that *collaboration among stakeholders promises better chances to scale and improve how open data can be used to solve social and developmental problems*. This echoes findings from related work on digital platforms for civic engagement suggesting that involving the government and achieving institutional responsiveness may be an enabling condition for success (Peixoto and Fox 2016).

At this point, we want to make a final comment on the knowledge commons framework that we applied. Despite its suitability for analyzing and understanding open data initiatives, it remains largely under the radar of open data students. We believe that through a knowledge commons lens, researchers and analysts could help to uncover important openness characteristics and governance traits that may increase the value of opening up welfare-enhancing resources such as healthcare services. We also recognize that there is no

single way to apply a framework, and that poses challenges on researchers, as Frischmann et al. (2014a) appreciate. For example, the interconnected and evolving character of key variables such as resources, community members, and goals and objectives makes the operationalization of the framework rather difficult. Despite the complexities of the framework, we encourage scholars to perform more work on the subject by adding new comparative cases in other regions or by extending similar analysis to other sectors.

Given the centrality to the success of open data commons, future work should focus on understanding the role that shared infrastructure may have on open development initiatives, either as a substitute or complement for formal and rule-based governance and decision-making processes (Fuster Morell 2014). Although we have tried to offer some glimpses of the infrastructural resources created or used in the cases (i.e., the open-source software deployed), future studies could concentrate on identifying governance constraints or specific arrangements in this space. Future work could also explore questions related to the sustainability of open resource initiatives. The knowledge commons framework can offer a valuable lens to understand what emerging sustainable models underlie similar initiatives, by looking at the linkages between governance arrangements, commons resources, and outcomes. We believe that this could be a plausible alternative to the current debate around business models of open data and open resource projects. Overall, we hope that this work can inspire the building of more systematic explorations of the relationship between open data initiatives and developmental outcomes in the Global South.

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### Notes

1. A loose English translation of this phrase is “the rebellion of the sick.”
2. The knowledge commons framework generally assumes that intangible information and knowledge resources are nonrival and nonexcludable public goods, and therefore nondepletable in character. See Madison (2014) for more information.
3. Note that the cases we studied involve small communities—small organizations or groups of people that open up health data to distribute it or to give control back to their users to improve their knowledge on health services, to raise awareness, and contribute to accountability or transparency. These open data initiatives are different in scale from the usual examples in the knowledge commons literature, such as Wikipedia, the Human Genome Project, and ZooGalaxy.

However, they all have in common practices to produce, distribute, or consume open knowledge resources to achieve a social or public interest good.

4. This section is an adapted version of sections 3, 4, and 5 of Scrollini (2017). Here, we use the empirical material with a different framework to explain other dynamics of open data production and collaboration. We gratefully thank the U4 Anti-Corruption Resource Centre for its permission to reproduce parts of that work in this chapter.

5. See <https://index.okfn.org/>.

6. In a nutshell, parsing and scraping are methods for extracting data from the Internet.

7. One particular piece of information that was heavily debated was the number of affiliates at each institution.

8. The initial project contemplated feedback monitoring, which has not been possible to implement to date.

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# Making Open Development Inclusive

## Lessons from IDRC Research

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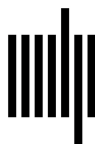
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