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EMPOWERING CITIZENS TO MAKE DATA-DRIVEN
DECISIONS ON HEALTH CARE



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by David Sangokoya, Ali Clare, Stefaan Verhulst and Andrew Young*

January 2016

Special thanks to Akash Kapur who provided crucial editorial support for this case study,
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Empowering Citizens to Make Data-Driven Decisions on Health Care

Dimension of Impact

- ✓ Empowering Citizens
- ✓ Informed Decision-making

Every February, Uruguayan citizens are given the opportunity to choose whether to change or stay with their existing health care provider. In the country's mixed public-private health care system, several factors come into play when making this decision: the location of the health provider, number of doctors and pediatricians available, hours open, etc. How can Uruguayan citizens make data-driven, informed decisions on choosing health care providers? Datos Abiertos, Transparencia y Acceso a la Inform (DATA) Uruguay, an open data civil society organization, partnered with the Uruguayan Ministry of Health to create A Tu Servicio (<http://atuservicio.uy>), a website providing easily digestible, searchable and visualized infographics based on open government

health data. The Web platform allows users to select their location and then to compare local health care providers based on a wide range of parameters and indicators, such as facility type, medical specialty, care goals, wait times and patient rights. A Tu Servicio has introduced a new paradigm of patient choice into Uruguay's health care sector, enabling citizens not only to navigate through a range of options but also generating a healthy and informed debate on how more generally to improve the country's health care sector.

Key Takeaways

- Open data initiatives, including but not limited to those focused in health care, stand to benefit greatly from collaboration between intermediaries – including civil society, the media and, in this case, health care data providers – and government.

- While increasing access to information is an important first step in efforts to unlock the value of open data, simply making information available is not sufficient: information needs to be standardized, machine-readable and visualizable to be truly useful to citizens.
- Successful open data projects have viral potential and can quickly spread to other sectors and applications, or be replicated in other countries.

I. CONTEXT AND BACKGROUND

With an Internet penetration rate of 60.5 percent,¹ Uruguay is considered an “emerging and advancing” country, according to the Open Data Barometer.² Uruguay has been a member of the Open Government Partnership (OGP) since 2011, and is ranked 12th on the Open Knowledge Foundation’s Global Open Data Index, making it one of the more advanced open data countries in Latin America.³ National data from a variety of units and agencies is made available for reuse through the national open data portal (<http://www.agesic.gub.uy/>), led by AGESIC, the national agency for eGovernment. While recognizing the “great potential” for Uruguay to innovate around open data, the Sunlight Foundation noted recently that many challenges lie ahead for the country as it seeks to transform open data efforts into a mainstream, sustainable government practice.⁴ Despite these challenges, the case study below illustrates the emerging impact of Uruguay’s opening up of government data.

Health care in Uruguay is delivered through a mixed public-private framework, with private insurers and hospitals working alongside a public health care infrastructure. Citizens can choose their health care service providers. Once an individual has been with a service provider for three years, they are eligible to change their provider at the beginning of the following February. Fabrizio Scrollini, chairman of DATA Uruguay, noted that, as a result, the month of February is typically marked by public debate and discussion over the factors that influence citizens to choose (or leave) a provider. He adds that February is also typically marked by heavy advertising on the part of providers, many of whom “encourage citizens to join them and leave others, and even potentially pay” users to switch providers.⁵

At the time A Tu Servicio (“At Your Service”) was launched in February 2015, the Ministry of Health was starting to experiment with open data, collecting raw data on service quality from every service provider and publishing these and other health data annually. Data management

1 <http://www.internetworldstats.com/sa/uy.htm> (2014).

2 <http://www.opendatabarometer.org/report/about/index.html>.

3 <http://global.census.okfn.org/>.

4 Keserú, Júlia and James Kin-sing Chan. “The Social Impact of Open Data.” Sunlight Foundation. 2015. <http://www.open-data-research.org/dl/symposium2015/odrs2015-paper20.pdf>

5 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

was generally poor, however, with data frequently out of date, and data sharing hampered by incompatible information management systems. Health care data wasn't available in a format that would allow citizens to make informed decisions. Additionally, according to Daniel Carranza, cofounder of DATA Uruguay, the pressures from competing health providers led citizens to “rely on marketing and advertising campaigns based on opinion rather than actual data.”⁶

II. PRODUCT DESCRIPTION AND INCEPTION



Figure 1: A Tu Servicio home page

First launched as a pilot program in February 2015 by DATA Uruguay and the Ministry of Health, A Tu Servicio is a Web application based on open government data that provides easily digestible, searchable and visualized infographics of key performance indicators such as facility type, available medical specialties, procedures performed, wait times, goals of care, patient rights and human resources. This platform allows users to compare these indicators across all health care providers in the country, enabling users to make well-informed decisions about their health care providers through machine-readable, interoperable and accessible data that was previously unavailable. For example, users can search across public health care providers (such as Medica Uruguay and CAMCEL) and private providers (such as Blue Cross Blue Shield) in Montevideo and compare data on the cost of birth control, average wait times and patient

6 GovLab interview with Daniel Carranza, Co-Founder, Data Uruguay, June 8, 2015.

satisfaction. Such comparisons can allow a citizen to decide whether to stick with his or her current provider or switch to a new one. Enabling this type of comparison was not always easy, however, since, as Scrollini notes, “private providers were the worst in terms of compliance when sending the data to the Ministry.”⁷

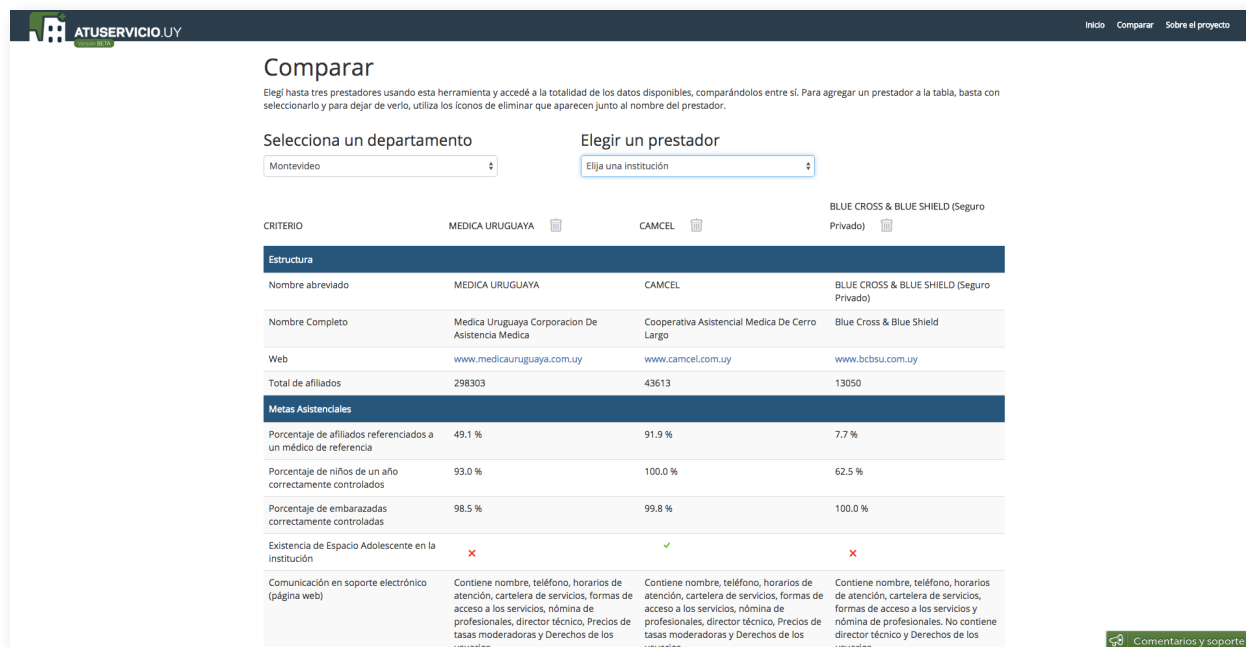


Figure 2: A Tu Servicio health service comparisons

The project emerged from a public consultation between the government and DATA Uruguay, a volunteer-based civil society organization committed to promoting open data, transparency, and access to information (<http://datauy.org/>). In 2013, DATA Uruguay had begun working with 180 Ciencia, a journalism portal, to create the application “Temporada de pases”⁸ (“Transfer season”) as part of a public service project to inform and empower citizens considering changing health care providers. The application relied on existing data published by the Ministry of Health; however, that data was generally of poor quality, often available only in closed formats, and included little metadata. The need for more open health care data quickly became apparent.⁹

Spurred by the evident shortcomings of the “Temporada de pases” application, the Ministry of Health initiated a discussion with Data Uruguay about ways to make more data available to citizens. This discussion, held under the auspices of the ongoing Open Government Partnership (OGP) roundtable discussions about the Alliance for Open Government, soon resulted in a modest government grant (about \$13,000) to create a pilot application that later

7 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

8 <http://mutualistas.datauy.org/>

9 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

became A Tu Servicio.¹⁰ DATA Uruguay also won additional funding from Avina Americas, an organization promoting sustainable development,¹¹ and the Iniciativa Latinoamericana por los Datos Abiertos (“Latin American Open Data Initiative,” ILDA), a network of organizations seeking to promote research on and use of open data in the region.¹²

The key role played by DATA Uruguay is one of the most interesting and important aspects of the A Tu Servicio story. It shows the vital function of intermediaries and civil society in promoting open data, facilitating discussions with the state, and nudging government agencies to release more and higher quality data.

At the same time, the role of the state itself cannot be underestimated. A Tu Servicio was supported from the outset by the Ministry of Health, whose encouragement and input (including in product design) was deemed critical to the success of the project.¹³ Even after the website was launched, DATA Uruguay and the state acted together in collecting user feedback and instituting improvements. This included working directly with health institutions to defuse their resistance to opening up data for comparison with other providers.¹⁴ Ultimately, the success and impact of A Tu Servicio (see next section for a discussion of impact) is testament to the importance of inter-sectoral partnership, and particularly collaboration between the state and civil society.

10 GovLab interview with Daniel Carranza, Co-Founder, Data Uruguay, June 8, 2015.

11 <http://www.avinaamericas.org/>

12 <http://datosabiertos.org/at-your-service-open-data-for-health-service-delivery/>

13 GovLab Interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

14 GovLab interview with Diego Soria, Ministry of Health Uruguay, August 18, 2015.

III. IMPACT

In this section, we consider some indicators of impact to determine the success of A Tu Servicio. Since the project – initiated in 2015 and scheduled to run until 2020 – is still in its infancy, any measurements of impact should be considered highly preliminary.

INTENDED BENEFICIARIES

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>
Health Providers	<p>Making clear to citizens which health options are best suited to their needs.</p> <p>Improving the quality and responsiveness of service based on data-driven demand from citizens.</p>
Government Agencies	Improving the public health system through greater efficiency, transparency and accountability.
Media	Encouraging better data journalism efforts and data driven arguments for public debate on health care.
Civil Society and Unions	Enabling better informed argumentation and advocacy around the status of the health care system.

In measuring impact within and across these targeted beneficiaries, we consider three categories:

Use and Awareness

In 2014, before the launch of the application, health care provider data made available by the Ministry of Public Health received fewer than 500 downloads. This low uptake was probably due to limited awareness of the availability of data as well as poor data quality.

Following its launch, the impact of A Tu Servicio was almost immediately apparent. In the first month alone, the site received approximately 35,000 visits, a number equivalent to 1 percent of

the total population of Uruguay.¹⁵ The average time spent on the platform was five minutes, and visitors accessed on average five pages per visit.¹⁶

The launch of A Tu Servicio also increased awareness among Uruguayans regarding the availability of data, and its potential to improve their health care. The application's launch received widespread media coverage, thanks to a press conference held by DATA Uruguay and the Ministry of Health in which the virtues of the initiative were emphasized. Social media was also employed strategically to disseminate information about the initiative and maintain interest after the launch. Additionally, several unions, including a doctors' union, endorsed the website, stating the need for more health care information to be made available and accessible.¹⁷

One aspect in particular of A Tu Servicio received considerable press coverage.¹⁸ Shortly after the launch, journalists and citizens began noticing and drawing attention to long wait times at public hospitals, almost all of which were in contravention of maximum wait times established by the government.¹⁹ The resulting public and media furor resulted in several hospitals changing their practices, and more generally, led to a vigorous public debate about wait times and quality of care in Uruguay.²⁰

A Tu Servicio has also played an important role in stimulating and facilitating more informed debate within Uruguay's Parliament about the future of the nation's health care system. For example, on August 11, 2015, a nationalist deputy leader of Montevideo, Martin Lema, spoke out against proposed reforms to the National Resources Fund (FNR), which protects citizens against extraordinary health care expenses in Uruguay.²¹ In making his case, Lema utilized data from the A Tu Servicio platform to refute the government's claims that proposed health care reforms would benefit vulnerable populations. He stated that the data showed anyone making this claim was "lying or misinformed."²² Lema also publicly criticized the proposed reforms via social media²³ and public interviews, where he continued to cite data from the A Tu Servicio platform to back his case.

15 GovLab Interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

16 GovLab Interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

17 GovLab Interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

18 "No vas a comparar." Montevideo Portal. February 2, 2015. <http://www.montevideo.com.uy/auc.aspx?259222>.

19 See, for example, "¿Cuánto es el tiempo de espera para especialistas en ASSE y mutualistas?" El Observador. February 2, 2015; "Conozca el tiempo de espera de las mutualistas para ver un medico." Subrayado. January 31, 2014. <http://subrayado.com.uy/Site/noticia/30503/conozca-el-tiempo-de-espera-de-las-mutualistas-para-ver-un-medico>

20 Keserú, Júlía. "How open data is changing the way Uruguayans choose their health care" Sunlight Foundation. May 13, 2015. <https://sunlightfoundation.com/blog/2015/05/13/how-open-data-is-changing-the-way-uruguayans-choose-their-health-care/>

21 "Ministro de Salud Pública, Fondo Nacional de Recursos." Uruguay Parliament Transcript. August 11, 2015. <http://www.parlamento.gub.uy/indexdb/Distribuidos/ListarDistribuido.asp?URL=/distribuidos/contenido/camara/D20150811-0218-0212.htm&TIPO=CON>

22 "Lema: Basso "está desinformado o miente" sobre medicamentos de alto costo." Espectador. August 13, 2015. <http://www.espectador.com/salud/321257/lema-basso-esta-desinformado-o-miente-sobre-medicamentos-de-alto-costo>

23 <https://twitter.com/MartinLema404/status/629645255286091776/photo/1>

Data Quality

As noted earlier, health provider data previously made available by the government was of poor quality, limiting its usability and citizen interest. A Tu Servicio spurred vast improvements in data quality through increased public scrutiny and demand for machine-readable, interoperable and accessible information.

The tool's user-friendly visualizations helped citizens understand the data in new ways and led to greater public scrutiny and discovery of erroneous data. For the first time, citizens were able to spot errors in the data provided by health providers and, through feedback loops built into the application, request corrections. Instances where health providers had not provided sufficient information were labeled as “not available”; in many cases, citizens could identify such holes in the data and make public requests to the Ministry and private providers for the data to be updated. In addition, the Ministry of Health was able to identify instances where provider data was possibly misrepresented as well as instances where provider data did not agree with crowdsourced user information.²⁴ Providers made aware of errors have also been able to submit revised and corrected data. After the platform's launch, Fabrizio Scrollini recalls, “Many [providers] were willing to update their data and standardize it according to our preferences.”²⁵ Overall, the launch of the application led to a new commitment to data quality on the part of providers, citizens and politicians.

Impact on Other Open Data Projects

Success often breeds success, and the A Tu Servicio project is a good example of how an effective project in one country and sector can spur positive developments in open data elsewhere. The impact of A Tu Servicio on open data progress can be seen in two ways: in other regional projects encouraged by Uruguay's example; and in other open data projects within Uruguay itself.

Regional and global impact: The most direct evidence of A Tu Servicio's regional spillover is evident in the Mexican state of Sonora, where DATA Uruguay and Codeando Mexico, another Mexican NGO, have been collaborating with a civil society group on the development of a health care data reporting website aiming to promote a standard for health service delivery.²⁶ This website, La Rebelion de los Enfermos,²⁷ gives citizens the ability to report on hospital incidents and provides them with essential information for filing formal complaints. The focus is on creating data standards and exploring further opportunities to open health care information to the public. DATA Uruguay also presented the platform at the Pan American Health Organization, which has used A Tu Servicio as an example of good practice for other

24 GovLab interview with Daniel Carranza, Co-Founder, Data Uruguay, June 8, 2015.

25 GovLab Interview with Fabrizio Scrollini, Chairman, Data Uruguay, October 1, 2015.

26 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

27 <http://www.rebeliondeenfermos.org/>

health systems in the region. Following international recognition this project has received (for example, as a finalist in the Open Data Institute's Open Data Awards),²⁸ DATA Uruguay has received interest in creating similar platforms in Europe and Africa.²⁹

National impact: Within Uruguay, too, A Tu Servicio's success has opened up new possibilities for open data and citizen empowerment through access to information. In the wake of the application's release, other government ministries and departments have either initiated new open data projects or shown interest in doing so. The impact of A Tu Servicio on other parts of the government is evident at AGESIC, the national eGovernment agency, which is using A Tu Servicio as a "best case" to present to various ministries and other organizations to promote open government and open data.³⁰ Additionally, the Ministry of Health has been ramping up its own efforts and commitment to open data, establishing new standards for openness and quality, and publishing new information about how data is collected, stored and made available for reuse. In addition, several new open projects are scheduled to be released between now and 2010.³¹ A Tu Servicio's national impact is also evidenced by the fact that it survived a change of administration – something that is, as Scrollini puts it, "very unlikely in some polities (including Uruguay)."³²

In the months following the release of A Tu Servicio, the open data movement has continued to pick up steam in Uruguay. At the Open Data Day in Latin America and the Caribbean, a group of developers analyzed open geographical data in order to analyze and visualize the number of streets in Montevideo named after notable women.³³ Upon coming to the unfortunate conclusion that only 100 out of 5,000 streets in the city are named for women, the group developed an interactive website, Calles de Mujeres, providing citizens with more information on the important contributions these women made to Uruguayan history.³⁴ Additionally, the portal located at Datos.gub.uy continues to collect applications and platforms created through the country's open data, including apps focused on transportation, culture and local history.

28 <http://awards.theodi.org/2015-finalists/>

29 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, July 14, 2015.

30 GovLab interview with Diego Soria, Ministry of Health Uruguay, August 18, 2015.

31 GovLab interview with Diego Soria, Ministry of Health Uruguay, August 18, 2015.

32 GovLab interview with Fabrizio Scrollini Chairman, Data Uruguay, October 1, 2015.

33 Open Data Day was an event for journalists, researchers, entrepreneurs, students and technologists to learn about open data tools, data visualization, storytelling, and to discuss the open data movement in Latin America and the Caribbean. <http://blog.okfn.org/category/events/open-data-day/>

34 Garcia, Yas. "Open Data Day 2015 in Latin América and The Caribbean | Open Knowledge Argentina." Open Knowledge Argentina. April 15, 2015. <http://ar.okfn.org/2015/04/15/open-data-day-2015-in-latin-america-and-the-caribbean/>.

IV. CHALLENGES

A Tu Servicio has been remarkably successful, especially given the limited time since its launch. A number of challenges, however, are still acting as a barrier to greater impact. Two, in particular, are worth examining in some detail.

Timing constraints

A Tu Servicio's period of peak usefulness is very short, limited to the month of February (and the weeks immediately preceding), when citizens can change their service providers. If the service is to scale up and attract more users, it needs to overcome two hurdles:

- Find a way of maximizing exposure and reach during its limited period of peak usefulness. In particular, site administrators need to ensure that the application contains all necessary data during this time and that the application is widely disseminated through media and other channels.
- Find ways of engaging users outside the period of peak usefulness. While citizens may only be able to change providers at a certain time of the year, health concerns and the need for health-related information are not time-bound. Ultimately, A Tu Servicio may be able to establish itself as a more general-purpose health-information portal, one that could be useful throughout the year.

Outreach and communication

Despite a widely publicized press conference and several mentions in the national media, the outreach campaign for A Tu Servicio was in fact rather hasty and somewhat ad hoc. Future efforts should not only be more sustained, but also focused on reaching under-served and under-privileged populations. These populations may not only lack access to health care; they are also least likely to be Internet savvy, and thus A Tu Servicio must confront something of a double challenge in reaching out to them.

In this regard, A Tu Servicio may find it useful to engage and collaborate with intermediaries, both in the media and especially in civil society. A Tu Servicio's success is itself testament to the power of inter-sectoral collaboration and the powerful part that can be played by civil society. Several other examples included in this series of case studies also offer testament to the ability of intermediaries and civil society groups to spread awareness of new applications and websites, particularly among traditionally underserved groups. A Tu Servicio could apply some of those lessons, spreading its usefulness and expanding the potential of open data beyond the 1 percent of Uruguayans who currently use the application.

V. LOOKING FORWARD

Since the launch of A Tu Servicio, DATA Uruguay and the Ministry of Health have worked on a number of initiatives and features to improve the platform. These initiatives focus on increasing usability, particularly through the development of a mobile application; creating better feedback mechanisms for incorporating and crowdsourcing user data; and providing a kind of “TripAdvisor” for users to describe and rate their experiences at specific hospitals. Overall, A Tu Servicio is seen as the first step in a broader scheme of projects within the Ministry of Health to disseminate open government health data. For example, the government is also considering disseminating information related to vaccinations more widely.³⁵

As we see the broad-based adoption of “wearables”, allowing for devices such as smartphones to collect personal data and “quantify oneself,” the possibility of adding a “small data” element to the application may be considered. Small data refers to the practice of collecting individual-level information and then providing that data back to those individuals in a more readily understandable way to improve personal health decision-making. For instance, the application could collect information on an individual’s heart health or glucose levels and then offer that information in a visualized, time-charted way, allowing individuals to track their health and keep chronic conditions under control. This feature is but one of the potential avenues for achieving the broader goal of moving A Tu Servicio towards more of a generalized health information portal. Though, as Scrollini notes, “Uruguay has a very stringent personal data protection law. As a result, the cost of developing [such a small data effort] could be high for a lightweight initiative.”³⁶

On current planning, A Tu Servicio is scheduled to run until 2020. Given its impact and general popularity, however, there is little doubt that this specific platform, in its current form, represents just the start of a much longer process of transformation and opening up in Uruguay’s health care sector.

35 GovLab interview with Daniel Carranza, Co-Founder, Data Uruguay, June 8, 2015.

36 GovLab interview with Fabrizio Scrollini, Chairman, Data Uruguay, October 1, 2015.