

RESPONSIBLE DATA REFLECTION STORIES I

A collection of real-life examples of the risks that are faced when using data in advocacy work, along with mitigation strategies to overcome these challenges.

Access to treatment for HIV/AIDS patients

**Challenges faced when trying
to improve public health systems
to help HIV/AIDS patients in Buenos
Aires receive better treatment.**

CONTEXT

Fundacion Huesped¹ works in Buenos Aires on issues relating to people accessing treatment for HIV, HIV/AIDS and related illnesses as Hepatitis, Tuberculosis and more. In 2015, they set up an Innovation Lab, recognising the growing relationship between health and technology. It is not the main focus of the organisation though, and it is a very new initiative within the organisation.

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Fundacion Huesped, a non-profit organisation based in Buenos Aires, Argentina was started 26 years ago by a group of doctors working in a public hospital in Buenos Aires. They work in Public Health, specifically on infectology, from a human rights perspective.

THE PROBLEM *Although receiving treatment for HIV/AIDS is paid for by the government, research has shown that almost half of the people living with HIV/AIDS are not receiving treatment. As part of the work of the Innovation Lab, they wanted to look at the role that technology could play in improving these processes, and making the system easier for patients.*

After talking to patients, doctors and those treating people living with HIV/AIDS, they identified a number of key problems. They talk about this in terms of a ‘**care cascade**’.² For people to successfully receive ongoing treatment for HIV/AIDS, a hypothetical patient would need to go through multiple steps, realising they have the virus, knowing what to do next, visiting a doctor and getting tests done, understanding what their status is, and—most importantly—committing to lifelong treatment.

HIV/AIDS: AN INTELLIGENT VIRUS *HIV/AIDS is an intelligent virus; if a specific form of treatment is stopped, the virus will come back immune to that specific treatment, so the treatment then needs to be changed for the next course of action. This means that even if symptoms have stopped, patients need to keep taking their treatment, which can be difficult to ensure.*

Challenge: patients getting lost within the public health system

They identified that a major problem is that people get “lost” within the Public Health system—starting treatment, but then not showing up for their next appointment, for example. So, they decided to look at interventions around supporting people as they go through their treatment, looking at potential points at which they drop off or stop their treatment.

To start with, they began looking at the appointment system. Currently, patients have to go in person to make an appointment, between the 1st and the 3rd day of every month, and appointments are only made within the following two months. This is a difficult task for many people; going during certain days, and there are just **THREE DAYS PER MONTH** when appointments can be made. They used to be able to make appointments within a six month window, but realised that too many patients were simply not turning up.

“LOST”
WITHIN
THE PUBLIC
HEALTH
SYSTEM

REMINDERS They identified a specific way to mitigate this: sending reminders to patients that their appointment was coming up, to make sure that appointments were being used, and people were getting the treatment they were scheduled to have.

HOW TO GET ‘REMINDERS’ TO PATIENTS, WITHOUT VIOLATING THEIR PRIVACY?

Patients at this hospital fit into quite a specific demographic; they are attending public hospitals, which means they are likely to be from a low-income background—otherwise they would go to the better resourced, and more expensive, private hospitals. This means they are unlikely to have smartphones, but often feature phones or access to shared landlines, and are big users of Facebook. Many potential users say they “don’t have an email, but they have a Facebook.”

Fundacion Huesped went to a hackathon and developed a calendar tool sending reminders via SMS and email, and potentially Interactive Voice Response (IVR) as well. Their aim with this tool is to remind the patients of their appointments so that they don’t miss them, and decrease the rate of unattended appointments; so naturally, they want to get reminders to the patients using communications channels that are already used by their target demographic.

But most, if not all, of the most commonly used communications channels are largely insecure. Without knowing who has access to those communications channels, how can they be sure that only the person in question will get the message, and not be read or heard by someone else? In the case of shared landlines, they thought about leaving cryptic messages that would mean something to the patient, but be incomprehensible to others who might hear it.

NATIONAL AIDS LAW *In Argentina, there is a National AIDS law that prohibiting anybody from identifying HIV/AIDS patients by their name or DNI (national identity number.)*

With more than half of the people living with HIV/AIDS not receiving treatment, it’s clear that there are problems here; clearly, there is a lack of adequate systems in place, such as a digitised appointments system, or reminders to those with appointments. Though Fundacion Huesped have done a lot of work towards identifying concrete problems, and working towards solutions, actually implementing the solutions in a responsible way is proving difficult.

NGOs AND THE GOVERNMENT

As an organisation, they are faced also with resource and time constraints; they are an NGO, not the government, so they are subject to any changes that government might make. The tech solution that they have come up with is dependent upon the current system in place, so if the government choose to change this system, their work would be totally useless.

Mitigation strategy

Although they have now developed a tool to address some of the issues associated with making an appointment and receiving reminders to attend the appointment, they are not rolling it out yet. They are very cognisant of the risks here—both in terms of the patients as individuals, and for them as an organisation, due to the National AIDS law that prohibits anyone from identifying people living with HIV/AIDS.

What next?

They have met with the Ministry of Health to discuss this law, and what this means for their potential technology solutions. The Ministry of Health encouraged them to go ahead with the project, as “not everybody looking for an appointment at the department was living with HIV/AIDS”—so, essentially encouraging them to base their project on a potential legal loophole.

CONFLICTING MESSAGES *They noted, though, that the Ministry of Health themselves have an electronic appointment system that they use in other types of department, but not in Infectology Departments. This could imply that they don't want to rely on that loophole themselves.*

They are gathering together a group of IT Security experts to work on an architectural solution for this problem, looking at where the connections are between the systems in the hospital, and which security layers need to be in place to be sure that there are no security breaches.

They are also speaking to **private hospitals**³ to work out how they deal with these issues, and see if they can gain some insights from the technology solution that they already have in place. Their strategy at the moment is to gather experience and expertise from others, and try and come up with a solution together.



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the engine room

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