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A response under pressure

Hivos has worked to tackle HIV/AIDS in Guatemala from a human rights perspective since the early '90s. We have worked to ensure that people who live with, at risk of, and affected by HIV have the skills, knowledge and opportunities to claim and defend their rights. Major strides have been made since then: more people are aware of their status and are receiving treatment, and the number of AIDS-related deaths is at an all-time low.

However, infection rates are rising again in Guatemala among Key Populations (KPs).[1] Due to stigma, high levels of violence, discrimination and criminalization, these groups are hard to reach. Because of this, they are most at risk of contracting HIV and are lacking appropriate treatment. Approximately 46,000 people in the country are living with HIV, while only 18,000 of them have access to treatment.[2]

International donors are increasingly stressing the need for Guatemala and other Lower and Middle Income Countries to sustain their own infectious diseases prevention and treatment programs. This shift towards more national responsibility is challenging. Countries don't always have sufficient resources, and the competition for scarce resources can be politicized. In addition to this, in Guatemala, patents on antiretroviral medicine (ARVs) are preventing the country from obtaining generic products that are less expensive than big pharma products.

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[1] For readability purposes we use the term Key Populations (KPs) to refer to people living with, at risk of and affected by HIV, followed by an appeal to allocate funds towards these groups more efficiently. We use the term to refer to gay men, men who have sex with men, sex workers, transgender people, women and girls, young people and people who use drugs, as they have been disproportionately affected by HIV. We acknowledge that the definition of KP depends on the epidemiological and social context of the country and the dynamic in relation to HIV. We are also aware the concept has its downsides, as it risks stigmatizing people living with HIV even further. The concept also implies that these are exclusive groups, whereas they are interrelated and mutually constitutive.

[2] WHO (2017)

Spending the existing resources in an efficient and effective way is vital in order to address this epidemic. This requires accountability in planning, budgeting and spending of public resources. Public procurement (from planning, to tendering, awarding, contracting, and implementing) is particularly vulnerable to mismanagement and corruption. This deeply affects the pricing and accessibility of vital medicines. Also, it requires a high level of expertise to monitor these processes.

Meaningful and inclusive participation from civil society in HIV decision-making processes has proved to be both a necessary social justice imperative and a promising way to build more responsive health systems. There is evidence that civic engagement in these processes can have positive effects: In Ukraine, HIV activists were key actors in supporting the adoption of an open public e-procurement system in the health sector (especially at local levels), as well as in the monitoring of facilities and procurement, and on data-driven advocacy for better services. These actions resulted in more responsive services and significant savings on drug purchases.[3]

Linking unusual allies

Inspired by this example, Hivos brought together qualities and strengths of different social movements in a pilot to work towards a more equitable access to treatment and quality health services for people living with HIV in Guatemala. The pilot combined on the one hand, the innovative developments within the open data and civic-tech communities within the transparency and accountability (T&A) movement; and the passion and commitment for human rights of the HIV/AIDS community, on the other.

Hivos brought together 10 organizations from both these movements[4] at an exploratory event for the organizations to first establish a joint understanding of the problem they wanted to solve. Then, the organizations identified synergies and generated ideas for possible collaborations. This helped to highlight the key objectives: 1) strengthen the data (evidence) based advocacy capacities of the organizations to more effectively engage with authorities, and 2) significantly optimize the purchase costs of ARVs for the Guatemalan Ministry of Health. The premise behind these objectives was that with more data and information, everyone would be able to make better decisions.

After identifying synergies, activities of the pilot focused on providing direct support for strengthening the strategic and technical capacities of the 10 HIV- and KP activist organizations. A series of workshops took place to improve the ability of the organizations to translate and contextualize complex contracting data and documents into meaningful information that they could use to strengthen their advocacy work.

Using data for evidence-based advocacy

There was no previous collaboration between the organizations before this program. This was due to the fact that they were operating on different platforms, with different social movements, different working cultures. One of the underlying assumptions of the pilot was that initiating these linkages would prove useful for organizations from both the civic tech community, as well as the HIV-AIDS

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[3] Hivos, TI Ukraine and 100% Network (2018)
[4] The organizations SOMOS, OTRANS, OMES, ODASA, CAS, REDSO, ITPC-LATCA, Laboratorio de Medios, ILDA, Red Legal, and PODER

community. Hivos acted as an intermediary to bridge the gap and create a safe space for the organizations to get together, explore alliances, and learn from each other.

One example of how this resulted in a successful collaboration, is the alliance between the data and accountability organization PODER of Mexico and the HIV activist organizations ITPC-LATCA and legal network Red Legal. PODER analyzed the ARV purchase contracts in Guatemala, with information that ITPC-LATCA and Red Legal provided. This was translated by PODER into visualizations that can be found on the Spanish www.vivirconvih.org and English www.livingwithhiv.org versions of the user-friendly website.

ITPC-LATCA and Red Legal used data visualizations from PODER in building a case to advocate for Guatemala's accession to the amendment of the WTO TRIPS agreement. This amendment will ease Intellectual Property rights restrictions to enable countries to purchase or manufacture medicines that are essential for the response to public health crises. The Guatemala's Health Commission of the Guatemalan Congress has given a positive ruling and put the amendment to the Congress for ratification. Once ratified, this will allow the production of generic and less expensive versions of patented ARVs.[5] It also allows transparent and non-monopolized purchase of – local or imported - ARVs.

One of the issues to tackle was that the government and other public health service providers didn't have correct figures about the number of total infections in the country and per area. This ignorance in turn led to stigma and making it more difficult to meet the needs of KPs. From the data on ARV purchase contracts, ITPC-LATCA got the evidence for their advocacy towards the government. They used the data to inform the government on the needs and demands of people living with HIV. Also, they used data to advocate for using the available resources in a more efficient way, to choose the best price-quality combination, to change public policies, and so, to ultimately save lives.

Hivos and partners in the Open up Contracting program have worked in parallel with the Ministry of Finance towards a reform of the Public Procurement system, evidenced by a commitment of the Government in the country's 2018-2020 OGP National Action Plan.[6] This will positively impact advocacy efforts on health procurement as it will embed these achievements into reformed procurement processes and systems.

Lessons to build on
The assumption that both social movements would have something to gain when they would come together, proved to be true. Capacity building was needed to come to a common understanding of HIV/AIDS and open data, but the goal was not to turn the HIV-activist organizations into data or procurement experts – or vice versa. The goal was to bring individuals with different skills and

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[5] Protocolo de Enmienda del Acuerdo Sobre los Aspectos de los Derechos de Propiedad Intelectual relacionados con el Comercio (2017)
[6] Guatemala National Action Plan 2018-2020 (2018) page 133

perspectives together and create a new community of practice with a shared vision and with space for experimentation.

We know that transparency in itself does not generate accountability. Transparency and access to data mean nothing if citizens are not able to make informed decisions and take action to hold their governments accountable. Data and technology, however, can be used as part of the advocacy strategy of issue focused organizations. Evidence generated from data can be used by policy makers and authorities to initiate meaningful reforms.[7]

In the pilot, the skills from civic tech organizations helped HIV activists to gain insights into the data related to HIV procurement. This made it possible for the HIV activists to match different pieces of information from the last 20 years of research and get a more complete picture. This made it easier to advocate for more efficient spending of resources. While technology did play a role, the policy changes could not have taken place without the advocacy work of the HIV activists. They were able to stress how to do more with the resources at hand, rather than to use the insights simply to spend less.

The Spanish version of the website has become a regular used platform for CSOs, journalists, and government actors. Previously there was a gap between information from the government and civil society. This has been improved with the arrival of the user-friendly website that has better estimates. It has made people realize that by sharing their status, they can improve their access to medicine, and ultimately, their lives.

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[7] Hivos (2018