Open Data in Developing Economies

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Published by African Minds

Verhulst, G.
Open Data in Developing Economies: Toward Building an Evidence Base on What Works and How.
Project MUSE. muse.jhu.edu/book/57263.

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CHAPTER 8

Uganda’s iParticipate
Open data for achieving better health outcomes

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Summary

Uganda has among the worst systems for providing health care in the world, and, as a result, among the poorest health outcomes for its citizens. Several factors contribute significantly to poor health outcomes—a lack of health workers to attend to the needs of a growing population; pervasive corruption in the health service sector; and a lack of data (e.g., related to disease prevalence, health care service delivery indicators, and health outcomes) that could be used for informed judgment and prioritization.

In 2011, the Collaboration on International ICT Policy for East and Southern Africa (CIPESA) began promoting the use of ICT to monitor governance and service delivery in Uganda. The project was funded by the Swedish Program for ICT in Developing Regions (SPIDER). Building on the experience and networks developed by CIPESA through this earlier project, the iParticipate project seeks to leverage the use of open government data to enable citizen participation and more accountable governance. CIPESA used open data available from government portals and sources to analyze service delivery and public investments, especially but not exclusively in the health sector.

The most tangible outcome of this initiative has been better training for civil society organizations and journalists in using data to advance health care advocacy. This has led to increased public awareness about poor public investments in health. Beyond this, however, there is little evidence of tangible improvements in health care service delivery. The initiative has encountered

numerous challenges—including those related to technical infrastructure and low ICT capacity—and the future of iParticipate remains somewhat unclear.

**Context and Background**

**Problem Focus / Country Context**

According to the World Health Organization (WHO), Uganda has among the worst health service delivery provisions in the world, resulting in poor health outcomes for its citizens. The country has among the lowest life expectancy (54 years in 2015) and highest mortality rates (344 in 2013) in the world.\(^{189}\) As of 2015, one in every 300 births ends a mother’s life, and one of every 30 children born will not be able to survive beyond one year.\(^{190}\) Communicable diseases, especially tuberculosis, claim the largest portion of lives in the country. HIV prevalence is high, with at least 1.5 million people affected, and the country is among those with the highest new cases of HIV/AIDS globally.\(^{191}\)

Several factors contribute to such poor health outcomes. First, there is a serious dearth of health workers who can attend to the needs of a growing population. A recent study pointed, for instance, to the very low ratio of health care providers to population in the country, coupled and aggravated by an insufficient budget.\(^{192}\) Most medical personnel are concentrated in urban areas, to the disadvantage of patients in rural areas. Another problem is pervasive corruption in the health service sector—manifested in a variety of ways, including paid workers failing to arrive at work on time with no fear of repercussion\(^{193}\) and the misappropriation of public funds for construction of health service facilities.\(^{194}\)

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A lack of data also hampers the quality of service delivery. Studies point in particular to a shortage of data related to disease prevalence, service delivery indicators, and health outcomes. While some forms of health data are collected, these are largely in paper formats and not shared publicly. The Ugandan Ministry of Health Website, which is supposedly the repository of publicly accessible data on health in the country, publishes all information as PDF files. The data is often insufficiently granular to contribute to useful analysis and access to much information, including health human resource data, is often restricted.

Open Data in Uganda

According to the 2015 Open Data Barometer, Uganda ranked 70th out of 92 countries surveyed. The government has made some efforts to use information technology and e-government practices to improve the delivery of public services. In addition, several of its ministries, especially health, environment, and national statistics, have practiced proactive disclosure of data online, though in separate, unlinked websites, and in incompatible formats that make the data difficult to use.

In 2015, the World Bank report on open data readiness in Uganda emphasized that while the country is well-positioned to implement an open data initiative, its ability to actually do so will depend on several issues related to policy, data capacity, and civic engagement. To date, there is no policy which mandates disclosure of government data and protects privacy. In addition, there is a definite lack of technology skills on the part of government employees. Citizens are also limited in their ability to access data by poor broadband access and low data literacy.

A review funded by the Indigo Trust, a funding organization focused on transparency and accountability in Sub-Saharan Africa, found that there exist more than 10 data disclosure mechanisms within the Ugandan


government, but that these cover only a few government agencies, namely public finance, water and environment and national statistics. The absence of a centralized open government data portal prompted several actors to publish data relevant to Ugandan governance and public life in different portals like data.ug (supported by UNICEF), uganda.opendataforafrica.org (supported by the African Development Bank) and several other sector-focused initiatives initiated by civil society organizations, international agencies, and academia. The tendency of actors from non-governmental sectors to step up to fill open data gaps left by governments is a common theme across this series of case studies.

Data Collection and Disclosure in the Ugandan Health Care System

Uganda’s Ministry of Health is responsible for one of the important sectors in the country. Its primary mandate is to formulate policies related to health, manage partnerships, resource mobilization, capacity building, and quality control on health service delivery, as well as to monitor and evaluate overall health sector performance across the country and at every level of government.

Health care provision in Uganda is undertaken by both public and private actors. Public health service providers have a decentralized structure which consists of national referral hospitals, semi-autonomous regional referral hospitals, and a well-established District Health System under the leadership of the District Directorate of Health Services in each of the country’s 111 districts. The intent behind decentralization was to make services reach even the most remote communities, and health centers in the country are broken up into four categories (ranging from the most rudimentary facilities, Health Center 1, to the more advanced, Health Center 4). Health service delivery is based on a referral system, with cases escalated up the categories depending on their level of complexity and facilities required.

Private sector health service provision is offered by a number of actors. These include facility-based private providers, not for profit (PNFP) providers, non-facility based PNFPs, private health practitioners, and traditional medical service providers. Facility-based PNFPs are those who own or operate their own hospitals and clinics; an example of a non-facility based PNFP would be an NGO offering medical services. Private health practitioners refer to those that provide primary and secondary level health services and include a wide range of actors, such as diagnostic centers, private medical and dental clinics, and pharmacies.

The capacity of Ugandans to seek treatment from private sector health service providers, without having to go through the long process of referral in the government system, is affected by their financial capacity and geographic
location. In some areas, especially in rural Uganda, there are no private PNFPs or private health practitioners. For residents of these areas, many of whom also lack the financial capacity to pay for private health care, government health centers are the only option (they may also submit themselves for treatment to traditional herbalists or other “informal” healers without formal training).

The government collects health care data from both the public and private sectors (though it does not collect information from the informal sector). The data collected is largely stored in paper-based formats,\(^{201}\) based on a set of standardized forms issued by the Ministry of Health (MoH). Aggregation of data is done at the level of MOH, through a Health Management Information System (HMIS\(^{202}\)) which aims to ensure timely aggregation, storage and retrieval of health information. Data quality is largely (and often negatively) affected by the capacity of lower-level administrative agencies to collect and report data in an effective manner. As a WHO report puts it: “lower administrative levels chronically lack the capacity to capture and report vital events such as community births and deaths.”\(^{203}\) Another study\(^ {204}\) reported that data collected regarding inpatient, outpatient, and health coverage indicators was less than 85 percent complete.

The MOH has made several noteworthy attempts to address these issues. For example, in 2010 the MOH launched the Human Resource for Health Information System (HRHIS),\(^ {205}\) a database platform developed in partnership with USAID that paved the way for comprehensively identifying staffing gaps down to the district level. The MOH has also sought to address data shortcomings by increasing the budget for human resources in public health centers.\(^ {206}\) Despite improvements, however, most of the data collected is not available to the public, and even when available, is difficult for ordinary citizens to understand. HMIS data, for example, requires registration for access and is available only to authorized users through a dashboard. HRHIS data, on the other hand, can be downloaded in spreadsheets format, but needs a trained user for the spreadsheets to be understood.


KEY ACTORS

Key Data Providers

The Ugandan government, through different portals, makes accessible the majority of data used for iParticipate. In particular, open data provided through the portal by the Ministry of Health plays an important enabling role. The project also leverages some limited data from private sector health providers, demonstrating the potential for more cross-sector data collaborative arrangements.

Key Data Users and Intermediaries

Established under the United Kingdom Department for International Development-funded Catalysing Access to Information and Communications Technologies in Africa (CATIA) initiative, the Collaboration on International ICT Policy in East and Southern Africa (CIPESA) is a civil society organization that “facilitates the use of ICT in support of development and poverty reduction.” CIPESA’s iParticipate project was established with funding from the Swedish Program for ICT in Developing Regions (SPIDER), a resource center working across sectors to leverage ICTs for development purposes. SPIDER, in particular, seeks to enable “the collaboration and sharing of experience between different actors in the field to reach better development results.”

Intended Beneficiaries

The iParticipate initiative aims to catalyze the use of ICT in citizen’s engagement and participation in governance. The project intends to build the capacity primarily of journalists and civil society organizations to use ICT tools in increasing public awareness on government issues, especially related to health, as well as potential solutions. iParticipate trains NGOs and journalists to conduct more data-driven analyses of the government information so that they can use these skills to advocate for public service reform, with the view that ordinary Ugandans will enjoy better services in the future.

Project Description

Initiation of the Open Data Activity

In 2011, the Collaboration on International ICT Policy for East and Southern Africa (CIPESA), a technology for development NGO, began promoting the

use of ICT in monitoring good governance and service delivery in Uganda. The project, called Catalyzing Civic Participation and Democracy Monitoring Using ICTs, was funded by the Swedish Program for ICT in Developing Regions (SPIDER), a development resource center. It established partnerships with three grassroots-based organizations, namely, the Busoga Rural Open Source and Development Initiative (BROSDI) in the Mayuge district (Eastern Uganda); the e-Society Resource Centre (eSRC) in the Kasese district (Western Uganda); and the Northern Uganda Media Club (NUMEC), in Gulu (Northern Uganda). These organizations had been working directly with communities to promote the use of ICTs as tools for citizens to engage with decision-makers and demand accountability. Under their projects, citizens used various tools in engaging with local government officials, including radio (NUMEC), email, blogs, social media (BROSDI), and geo-coded mapping for eSRC.

Informed by the experience and networks developed by CIPESA through these previous efforts, iParticipate, the project under study here, sought to support these existing efforts and to build on them by leveraging open government data (much of it already available in various portals but often in incompatible or inaccessible formats) as an enabler of citizen participation and accountable governance, focusing especially on the health sector. CIPESA’s interest in open governance started when it conducted research on open governance network building in Uganda, funded by the International Development Research Center in 2012. Among other results, the research helped identify key datasets that citizen groups would like the government to proactively disclose, as well as the general level of government readiness to implement open governance in the country.

Much of the work undertaken under the iParticipate initiative focused on training intermediaries – particularly media and civil society actors – to enable and promote citizen participation in Ugandan governance. iParticipate also provided support to grassroots citizen-focused ICT centres like eSRC in Kasese. Finally, the project engaged with government officials and policymakers to help communicate the opportunities, tools and tenets of open data and open governance processes to push forward the supply side of open data and ensure that the institutional culture acted as an enabler of greater participation in governance and service delivery. This multi-audience focus helped iParticipate to diversify its offerings, engage relevant stakeholders in a targeted way, and avoid the “if you build it, will they come” question that

210 Ibid.
often plagues open data efforts focused solely on citizens with little attention paid to intermediaries or actors on the supply side.

As explained further below, iParticipate provides detailed GIS-maps and visualizations to present mashed up datasets from a number of government data sources, in the process making clear where, how and why health care resources are being used across the country. Much of the project’s offerings are real-world rather than digital. iParticipate efforts have included, for example, multi-stakeholder meetings between government officials and educators focused on the challenge of implementing tools to improve community participation.\(^213\) Traditional media outlets are also leveraged – including through the previously mentioned radio broadcasts. The effort also involves the use of a number of training and engagement centers, including the eSRC in Kasese, which “provides ICT training programmes...aimed at enhancing citizens' competence in monitoring government services, promoting accountability, civic participation and good governance.”\(^214\)

One specific initiative undertaken in collaboration with NUMEC aimed at making government information more accessible to citizens in the districts of Gulu, Nwoya and Amuru – the regions most affected by Lord’s Resistance Army’s (LRA) destruction. The project set out to “document service delivery failures as a result of donor aid cuts to the Peace, Recovery and Development Plan (PRDP), and to generate debate by citizens through community debates, radio talk shows and ICT-based engagements on improving service delivery needs of post-conflict communities.” The PRDP was launched by the government in 2009 to “revitalise the economy and livelihoods of communities in the post-conflict region” through health service delivery, new infrastructure, clean energy and education initiatives, but widespread allegations of corruption destroyed citizen trust in the effort.\(^215\)

The project’s overarching goal was to increase citizen participation in monitoring government service delivery through the use of ICT; advocate for government stakeholders to practice open governance; and document and propagate to the wider public the results of these processes. CIPESA performs the role of an intermediary that gathers government data and translates it into useful, relevant, and meaningful information for citizens. CIPESA’s aim is also to increase the capacity and ability of citizen groups and the media to demand


better data, and to use this data to exact accountability from governments, especially in the health and education sectors.

**Funding**

The Swedish Program for ICT in Developing Regions (SPIDER) provided CIPESA with 500,000 SEK (approximately 55,480 USD) for a two-year implementation beginning 2013. The project from which this new initiative was built was also supported by SPIDER at the same funding level. In addition, Indigo Trust also provided 12,000 GBP (14,870 USD) for the initiative.

**Demand and Supply of Data Type(s) and Sources**

iParticipate’s health advocacy was focused on health service delivery and how access to health care, especially by the poor and marginalized in rural areas, is affected by government investments in people and facilities. There were a few primary data sets that were used by CIPESA in this process—those related to health clinics, health centers, and general hospitals, including the location and number of beds for each of these facilities. This existing data originated on the Ministry of Health website and was made accessible through Uganda’s Open Data for Africa portal.\(^{216}\)

The Open Data for Africa portal allowed for online search and query, with the capacity to filter and visualize results (see Figure 1). The platform also allows downloading of data as CSV, XLS, or OData files. Similar datasets are also available at the Electronic Health Management Information System (eHMIS),\(^{217}\) though this portal requires formal log-on procedures to be able to get access to the data.

To see investments in health per jurisdiction, CIPESA used budget data from the Ministry of Finance Planning and Economic Development available at the ministry’s budget portal.\(^{218}\) The portal has an elaborate query facility and also publishes PDF reports of spending performance for each sector. Access to the data, however, is not fully open, as it requires registration with the data providers, and acceptance of registration is not assured.

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Open Data Use

CIPESA used the data available in these portals and from other sources to analyze health service delivery and public investments in health projects. Much of iParticipate’s training efforts, for example, focused on providing individuals and journalists with the capacity to access and use geocoded maps made possible by open government data.

CIPESA used data to identify a number of features related to health service delivery. For example, iParticipate’s maps could help identify populations with limited access to health care, as well as health facilities that had limited or no beds. This information was cross-
tabulated with funding information. As a result, iParticipate was able to show the need for more data sharing at all levels of the health service delivery infrastructure in Uganda. As Lillian Kisembo, the Assistant Town Clerk in Kasese, put it: “If we can embark upon sharing information at the local level, we can reduce these challenges at District planning.”

In addition, CIPESA also made use of open data coming from different sources to build a platform to show how projects implemented through the PRDP, described above, collect reports coming from the field through users with Android phones, and aggregate different reports on health issues and health-related information. Community residents can report information using the Ushahidi crowsource mapping application and this, together with different reports and information, are consolidated in a crowd-mapping portal (see Figure 3).

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Impact

The CIPESA project had three main objectives: (a) increasing citizen participation in monitoring government service delivery through the use of ICT; (b) advocating for government stakeholders to practice open governance; and (c) documenting and propagating to the wider public the learning that resulted from these processes. In our analysis, we find that impact is primarily evident only in the area of advocacy, increased engagement of citizens in health governance and information dissemination. In addition, a certain (though limited) impact is evident in the other areas.

Advocacy

Although impact remains relatively limited and difficult to assess, there is some evidence that iParticipate’s data offerings and training efforts with civil society and the media have made some impact. By enabling these intermediaries to better understand the conditions of the health sector, highlight issues associated with poor investments in health and publicize the poor’s lack of access to quality health care, iParticipate is playing a key role in pushing for improvements to public- and private-sector providers, and also in empowering citizens to demand better service.

Improved Dissemination of Health Information

This advocacy is coupled with wider dissemination of information on health and other health-related issues to different communities using different media—radio, SMS, printed materials, e-resource center, e-library, e-discussion groups, Facebook pages, and web portals. These increased not only information availability, but also user’s access to relevant health governance information.

Increasing Citizen Engagement in Health Governance

The advocacy and dissemination activities were done alongside building the capacity of different stakeholders, more particularly journalists, local government officials, civil society organization leaders, and students, on the use of ICT for governance. These trainings increased their capacity to analyze and make use of government data for advocacy, while at the same time monitoring the quality of public health service delivery by government.
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Risks

Central to ICT-enabled information dissemination and open data monitoring initiatives is the capacity of these initiatives to actually make a difference in the lives of citizens. For example, data that highlights health spending and inconsistencies in prioritization, as well as those public reporting mechanisms on health governance, will only be useful for citizens if there are actual improvements in government spending and public health service delivery. If positive results are not obtained, citizens will get disillusioned and will likely discontinue availing themselves of these initiatives.

Also, as is the case with many health-focused open data initiatives, the primary risk involves personally identifiable information. While the focus of the government’s data provision and iParticipate’s data-driven analysis tools are not at all on sharing personal health information, continued vigilance and targeted data responsibility strategies will be essential to ensure that no potentially damaging personal information slips through the cracks.

Lessons Learned

Enablers

Cross-sector collaboration

Without access to resources and expertise from SPIDER, CIPESA’s implementation of iParticipate would have been significantly more challenging. While the funding provided by the Sweden-based international organization obviously played a major enabling role, the ability to plug into SPIDER’s international network of businesses, universities, NGOs and governments working to leverage ICT for development also helped to shape the approach and offerings of the initiative.

CIPESA’s reputation as a development organization

Additionally, CIPESA continues to be a driving force in Uganda’s desire to improve transparency and accountability in governance. Just as it was able to tap into an international network of expertise, CIPESA leveraged its own network of development actors, both at the national and sub-national level, to inform the project. Its reputation with donors, government agencies, civil society organizations and other stakeholders is an important element in
CIPESA’s ability to influence policy-making as well as government decision-making despite the limitations mentioned below.

**Barriers**

*Lack of demand-side capacity*

CIPESA experienced challenges in achieving desired results. First, driving citizen participation is affected by at least two significant barriers—low connectivity and low levels of awareness of ICT use among citizens. While progress has been made in efforts to train citizens in ICT use, the lack of consistent access (especially outside of resource centers) hampered efforts. Also, especially regarding efforts focused on health and budget information, many technical concepts require sophisticated knowledge to enable meaningful participation—highlighting the need for intermediaries who perform the task of making complex information understandable to citizens.

While journalists could have performed this intermediary or explanatory role, CIPESA seems to have found it a challenge to incentivize journalists to spend time learning and educating themselves on the relevant issues. Journalist participation was also limited by geography, as health service delivery generally remains a big problem outside the urban/semi-urban areas where most journalists are based. Citizen groups in these areas were also limited in their ability to participate, primarily by a lack of connectivity and capacity.

*Citizen media habits*

While CIPESA made use of ICT as a means to disseminate and collect information, a study\(^\text{222}\) it conducted in 2015 revealed that newspapers, radio, and television were in fact the most trusted sources of information by Ugandans. The same study indicated that very few Ugandans use ICT as a means to monitor and report on government services. This suggests that the means used by CIPESA to engage citizens with health governance data did not match with the manner in which citizens habitually acquire and share trusted information.

The survey did find that a growing number of people in the country are starting to use the Internet, and especially social networks like Facebook and Twitter, to discuss issues of national and local concern. However, citizen use of such networks was generally limited to information sharing, and not to actually raising concerns to accountable officials (most of whom do not in any

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case have social media accounts). The main limits on more widespread use of ICTs were illiteracy, and language and cost barriers.

**Availability of resources**

The capacity of CIPESA to proactively elevate health service delivery concerns to accountable government officials was also hampered by resource constraints. CIPSA tried to surmount fund shortages by using health service delivery reports received by one of its partners, Transparency International Uganda (TIU). But the organization was nonetheless constrained in its outreach and awareness-raising efforts. For example, while CIPESA succeeded in producing potentially useful health service delivery maps, it was often unable to disseminate these widely enough to reach their intended audiences. Funding constraints also affected CIPESA’s ability to follow up on adverse findings reported by citizens using its platform.

**Looking Forward**

CIPESA main goal is to increase the impact that iParticipate will be able to make in using ICT for health service delivery monitoring. Currently, it is trying to find new ways of addressing the challenges identified above through more creative and well-targeted outreach and communication efforts. For example, the previous SPIDER project that was the basis for iParticipate made extensive use of radio programs to increase debate and reaching out to public officials on key concerns of the communities. The radio program implemented with NUMEC was able to reach approximately 1.6 million listeners.

As mentioned above, and as concluded by CIPESA’s own research, a number of factors limit the potential of ICT as a tool in monitoring government performance and enforcing accountability. The most important of these factors include poor technological infrastructure, including slow internet speeds and irregular electricity; low levels of ICT capacity among citizens; higher trust and use of traditional media as sources of data and information; and the high cost of internet access. iParticipate’s future, and more generally the future of open data as a tool to achieve better health outcomes in Uganda, will be largely dependent on its ability to address and overcome (or at least mitigate) these challenges.

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223. Ibid.
Conclusion

Although iParticipate has had relatively little impact on citizen empowerment to date, it has leveraged a number of strategies that have yielded success in other contexts. The initiative’s diverse offerings are implemented with a clear understanding of the intended audience – including notably government officials – and efforts are consistently driven through existing intermediaries, like journalists. This focus on empowering intermediaries to act as enablers for greater citizen participation is one reason for optimism regarding the longer-term impacts of iParticipate – including if and when funding is no longer available. Relatedly, the project often seeks to meet its intended audience where they already are – such as at ICT training centers or on popular radio broadcasts – increasing reach and the likelihood that its message is being absorbed by the public. While iParticipate has not yet had a transformative impact on citizen participation in Ugandan health governance, its continued efforts to increase awareness and train potential users of open data have the potential to gradually improve health outcomes by bringing together government actors, intermediaries and citizens to work toward common ends.