Unlocking the Power of Citizen Data in Addressing Infectious Diseases

A scoping study to understand the opportunities of citizen data

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Appendix: List of Acronyms

- ATRAP – Action Towards Reducing Aquatic Snail-Borne Diseases
- CBS – Community-Based Surveillance
- CSID – Climate Sensitive Infectious Disease
- DOI – Digital Object Identifier
- DRC – Democratic Republic of the Congo
- ECLIPSE – Project title (used as a named initiative)
- FGDs – Focus Group Discussions
- FM – Frequency Modulation
- GHO – Global Health Observatory
- GSS – Ghana Statistical Service
- HIV – Human Immunodeficiency Virus
- ID – Infectious Diseases
- IFRC – International Federation of Red Cross and Red Crescent Societies
- IOA – International Organization for Action (as cited in reference)
- KIIs – Key Informant Interviews
- LIC – Low-Income Countries
- LMIC – Lower Middle-Income Countries
- NSOs – National Statistical Offices
- NTDs – Neglected Tropical Diseases
- SINAVE – Sistema Nacional de Vigilancia Epidemiológica
- SMS – Short Message Service
- TB – Tuberculosis
- UK – United Kingdom
- UMIC – Upper Middle-Income Countries
- UN – United Nations
- UNDP – United Nations Development Programme
- UNSD – United Nations Statistics Division
- VBD – Vector-Borne Diseases
- WADIM – Water-Associated Infectious Diseases in India: Digital Management Tools
- WHO – World Health Organization

Executive Summary

Citizen data offers opportunities to transform the way we monitor, prevent, and address infectious diseases. For instance, community-led reporting can track environmental shifts, mobility patterns, and early warning signs that formal surveillance may miss. The 2025 adoption of the UN-led Copenhagen Framework endorses citizen data's importance in embedding equity in development systems.

This scoping study aimed to explore the potential of the use of citizen data in the context of environmentally sensitive infectious diseases (ID), specifically cholera, schistosomiasis, leishmaniasis, and arboviruses including dengue and yellow fever. The study explored this potential of citizen data in Kenya, Malawi, Ghana, Vietnam, Colombia, and the Dominican Republic, combining a range of research methods to gain a clear picture of its use and effectiveness. This included:

- **Evidence generation:** stakeholder mapping, online surveys, key informant interviews, focus group discussions, and convenings (global, in-country, and with affected communities).
- **Analytical work:** examining a typology of applications of citizen data, exploring the readiness of key stakeholders to use citizen data for ID, understanding citizen data priorities, including governance, attitude and capacity barriers, and reviewing stakeholder groups key to the institutionalization of the use of citizen data in addressing ID.

In each country, the study focused on the most prominent disease(s) among those in focus. More detailed country reports can be found in the annex of this report.

The following represents the key findings:

1. **Most citizen data is produced for disease surveillance:** More than half of the applications of citizen data focus on producing data for disease surveillance, preparedness and/or response. There are far fewer examples (six out of the 35 examples mapped) that focus on resilience or capturing the lived experiences of citizens with the various illnesses.
2. Across the typology, we found **fewer examples where citizen data was produced to analyze patterns or to enrich other data sources** (eight out of the 35 examples mapped). This highlights a gap in the use of citizen data in infectious diseases that can be further tapped into.

3. **Fewer examples of citizen data in schistosomiasis and leishmaniasis:** We recognize that some of the diseases we focused on, e.g. dengue and cholera, already have significantly more research compared to neglected tropical diseases (NTDs) like schistosomiasis and leishmaniasis. This pattern is also observed in citizen data, with far fewer examples for the two NTDs. Because schistosomiasis and leishmaniasis disproportionately affect children—often in settings where routine surveillance and reporting are weakest—there is greater potential to establish complementary data sources such as citizen data to capture disease exposure, symptoms, and care-seeking at the community level. In this context, citizen data applied in an ethical and well-governed way can help address gaps in evidence and visibility, contributing to a more complete understanding of disease burden and inequities affecting children.
4. **Lack of open access to the data produced:** Organizations that produce citizen data often publicly share the analytics or summaries of the data and not the full datasets. While we agree that citizen data is produced for different purposes and may not always be made public, we argue that because citizen data is produced in an inclusive manner, the data should also be disseminated in an inclusive way and made publicly available for responsible use and re-use.
5. **We observed that most of the examples produce quantitative citizen data.** Qualitative data is important in complementing quantitative data, or data that governments already collect, as it helps to give more nuance to the data. The process of citizens producing qualitative data is also an opportunity to build-in action and influence behavior change.
6. **Low digital literacy and insufficient training on citizen data collection skills** among community members and non-governmental organizations limits the scaling up of citizen data. At the research and academic level, the most important skills are **design of citizen data initiatives, data informed decision-making, and community engagement.** At the government level, the most important skills are **data-informed decision-making and data re-use and sharing.**
7. Examples of where citizen data became embedded, replicated, or led to policy action were **characterized by the adoption of inclusive processes in the design and implementation of initiatives,** e.g. community leaders involved in the design of the collection process, community feedback sessions, and joint accountability mechanisms.
8. While some **doubts exist about the quality of citizen data** within government, research and academia, this is improving as National Statistical Offices take more responsibility in providing guidance on data quality.
9. **Data governance concerns persist around consent, data ownership, and community feedback mechanisms** when it comes to citizen data, especially in the health sector.
10. **The research and academic community could play a critical role in advancing citizen data for infectious diseases** by evolving methodologies to work with communities as equal research partners, working in multi-stakeholder groups to bring out the power of citizen data, and producing and translating knowledge as a public good.

11. To secure quick wins at the country level, **Kenya and Malawi are the most ready compared to the other countries** that were part of the study. These efforts should be laddered up to inform regional and global discussions on data, infectious diseases, and NTDs.

In response to these findings, and to align with the priorities of Wellcome and other funders in maximizing the use of citizen data for addressing infectious disease, funders could:

1. **Incentivize the establishment of citizen data governance frameworks** in research institutions to include privacy, consent, feedback loops, and promoting research equity.
2. **Encourage the sharing of citizen data to enable wider access and use.** The sharing of data openly should be in a responsible manner that safeguards the rights of communities.
3. **Support the development of guidance documents for producing quality citizen data,** effective engagement of citizens, and the continuous documentation of best practices in citizen data to aid in alleviating concerns on the quality of data.
4. **Provide funding to produce both qualitative and quantitative citizen data.** This could mean running a specific funding call on bringing citizen data into the knowledge base of specific disease areas, or applying citizen data in resilience-building plans for ID; and to advocate for its use in shaping policies.
5. **Convene the stakeholders mapped out in this study to identify research gaps** and determine which types of citizen data examples would be useful to address them. These research gaps could include disease and vector distribution; social determinants of infectious diseases; and the social and economic disease burden on households, in particular the impact on women.
6. **Support the strengthening of citizen data production skills among leishmaniasis and schistosomiasis stakeholders**, learning from the examples used in cholera and dengue. The strengthening of skills could take a capacity building approach of skills mapping and training; application of the skills to commissioned citizen data initiatives; and using the findings from the initiatives to inform policy.
7. **Develop, implement, and document use cases of citizen data** to better understand where citizen data is most useful. This could include better understanding of the resilience or coping mechanisms of communities to the various infectious diseases.
8. **Commission further research on citizen data** for topics like effectiveness of community-led disease surveillance; impact of citizen data in policymaking for infectious diseases; and reciprocity effects of citizen data initiatives, especially to the citizen scientists, etc.
9. **Designate an organization(s) with citizen data connections and expertise** to guide Wellcome teams in their uptake of these recommendations, by developing tools and holding discussions to ensure Wellcome's projects consider the potential for citizen data use.

Chapter 1: Background and Methodology

A continued burden of environmentally sensitive infectious diseases

Climate change and environmental degradation are reshaping how infectious diseases spread. As extreme weather intensifies and ecosystems shift, diseases once limited to certain regions are expanding their reach, putting millions more at risk while communities' ability to fight them is reduced. The statistics paint a stark picture: an estimated 4.7 billion people may face increased risk from vector-borne diseases like malaria and dengue by 2070,[1] while more than 1.3 billion people could be newly exposed to zika transmission by 2050.[2] In addition, there are over a billion people in the world whose lives are shortened or blighted by neglected tropical diseases (NTDs).[3]

In Kenya, six million people are affected by schistosomiasis, with 15 million more at risk.[4] In 2023, Kenya was among the top seven countries in the world representing 87 percent of global visceral leishmaniasis cases.[5] South America has seen a ten-fold rise in dengue cases over four decades, with Colombia reporting the most severe cases in the region.[6] Between December 2022 and July 2024, Malawi faced its deadliest cholera outbreak in history—worsened by drought, displacement, and malnutrition. In total, the country registered 59,376 cases and 1,772 cumulative deaths.[7]

These threats call for approaches that go beyond traditional surveillance, prevention, and response mechanisms. While data remains critical, current approaches often overlook a vital resource: the knowledge and lived experiences of the communities most affected by these diseases. Too often, those on the frontlines of climate-sensitive disease outbreaks remain largely invisible in data systems—an oversight that weakens prevention and response efforts. Communities affected by climate-sensitive infectious diseases possess invaluable insights about environmental changes, disease patterns, and local responses that could significantly enhance prevention and response efforts. Yet, this data and knowledge rarely reaches decision-makers in a systematic or actionable way.

Unlocking the power of citizen data

Citizen data represents a shift toward more inclusive and effective disease surveillance, prevention, and response. By engaging citizens and affected communities throughout the data value chain—from collection to analysis to use—it enables quicker, more nuanced responses to infectious disease threats.

According to the United Nations (UN)-led Copenhagen Framework,[8] citizen data is *data produced by and with sufficient engagement of citizens, communities, civil society* *organizations, and other actors at the design and/or collection stages of the data processes, with the aim to inform decision-making, responding to specific needs of a community, supplementing existing data from the National Statistical Systems at various levels, or filling data gaps*.

The Copenhagen Framework was approved by the UN Statistical Commission at the start of 2025 and acknowledges that there are many terms for citizen engagement in data—such as citizen science, community science, citizen data, crowdsourcing, volunteered geographic information, citizen observatories, citizen engagement in social innovation, community-based monitoring, participatory mapping, participatory action research, community-driven or community-generated data. The Copenhagen Framework uses "citizen data" as an inclusive, consistent term that encompasses different terms as long as the exercise meets the definition of citizen data.[i] Throughout this report, we use "citizen data" in alignment with the Copenhagen Framework's citizen data definition.

In the context of infectious diseases, citizen data has shown clear and valuable benefits. For instance, community-led reporting can track environmental shifts, mobility patterns, and early warning signs that formal surveillance may miss. Moreover, individual reporting mechanisms can highlight the impact of diseases on marginalized populations. This was evidenced by the work of the members of the Civil Society Collaborative on Inclusive COVID-19 Data, which used citizen data to shed light on the pandemic's effects on vulnerable groups often excluded from official statistics. This was data collected through insights from 37 studies, highlighting examples from 91 countries across Africa, the Americas, Asia, the Caribbean, Europe, and Oceania.[9] The increasing inclusion of citizen data in public health research, disease surveillance, and policymaking, combined with the urgent need for more comprehensive approaches to environmentally sensitive infectious-disease responses, presents an opportunity to transform health systems.

Scoping aims

Despite growing recognition of citizen data as a valuable tool for infectious disease prevention and response, it remains underutilized and not systematically integrated into decision-making processes. This limits its potential to strengthen surveillance, especially in settings where official data is delayed, incomplete, or excludes marginalized groups.

With increased momentum following the adoption of the Copenhagen Framework, there is a timely opportunity to leverage citizen data to inform public health strategies, particularly in the face of climate-sensitive disease threats. Yet practical guidance on how to realize this potential remains limited.

This scoping study sought to:

- Identify how and when citizen data can support more effective, equitable, and timely responses to infectious diseases.

- Clarify where citizen data is most relevant to Wellcome's Infectious Diseases strategic programmes priorities—including cholera, schistosomiasis, leishmaniasis, and climate-sensitive arboviruses (e.g. dengue and yellow fever)—while drawing insights from broader examples, such as malaria, HIV and COVID-19.
- Strengthen understanding of how citizen data can contribute to stronger, more inclusive systems across priority geographies.

Findings will inform future collaboration between Wellcome Trust and the Global Partnership for Sustainable Development Data (the Global Partnership), guide the development of Wellcome's Climate and Health Centres (Wellcome-funded research hubs focused on climate-related health risks), and support a growing evidence base for inclusive, climate-responsive health system.

Methodology

1. Research design

From July 2024 to June 2025, with funding from the Wellcome Trust, the Global Partnership, working with Strathmore University Hub for Natural Capital, undertook a scoping study to understand the opportunities of using citizen data to address environmentally sensitive infectious diseases. This scoping study focused specifically on cholera, schistosomiasis, leishmaniasis, and arboviruses including dengue and yellow fever—diseases impacting vulnerable populations across six countries in Africa, Asia, and Latin America. Fieldwork was conducted between September 2024 and May 2025 and focused on six guiding questions.

1. What are the types of applications where citizen data would help with prevention, preparedness, and response to environmentally sensitive infectious diseases?

2. What are the inclusive data processes and methods that would best support those applications?
3. Where are the gaps in the skills needed by civil society, the research community, National Statistical Offices (NSOs), and ministries to be able to institutionalize the use of inclusive data processes for infectious disease policymaking?
4. Which countries, where environmentally sensitive infectious diseases are critical, are most ‘ready’ for widespread use of citizen data methods and inclusive data processes?
5. Who are the stakeholder groups already connected to communities and well placed to coordinate these different methods?
6. Which organizations are well positioned to share relevant skills as training or fellowship providers?

To respond to the above six questions, the study used a mixed-methods approach combining global and in-country data collection. Desk research and stakeholder mapping were conducted both globally and within each study country to identify key actors, existing initiatives, and potential opportunities for integrating citizen data into health and climate systems. These were complemented by:

- **A global online survey** (n = 48 respondents) aimed at identifying gaps, priorities, and skills needed to use citizen data for infectious disease prevention and response. Respondents included civil society organizations, researchers, health practitioners, and representatives from National Statistical Offices around the world.
- **Key informant interviews (KIIs)** with 4–10 stakeholders per country, including civil society leaders, government officials, and public health experts, to gather in-depth perspectives on opportunities and barriers to institutionalizing citizen data at the country level.
- **Focus group discussions (FGDs)** were held at the global level to explore how inclusive methods and citizen data can strengthen trust and community participation in data processes. Two FGDs were conducted in total, bringing together 17 participants representing international organizations, civil society, public health institutions, academia and the research community. One discussion was dedicated specifically to the academic and research community to capture their perspectives and insights on inclusive and participatory data approaches.
- **In-country convenings** in each of the six countries (approximately 25-30 participants per convening) bringing together government, civil society, academia, and community groups. These sessions combined presentations, stakeholder dialogues, and group discussions for knowledge exchange and peer learning. Additionally, the study conducted community consultations in Malawi (n=26 community members), Kenya (n=34 community members), and Vietnam (n=10 community members) to capture community-led perspectives on the impacts of infectious diseases and the ways in which affected populations are driving local responses.

- Lastly, the study developed **six in-depth case studies** of successful citizen data initiatives. The case studies were a combination of examples of some of the infectious diseases in focus and those that have been led by communities and grassroots organizations that are not currently documented in formal literature. With this criteria, some of the case studies go beyond the countries and diseases in focus in this study, but still present relevant findings that are applicable. They were developed through a combination of desk research and interviews with the research team of the respective case study.

Each method added value to advancing inclusivity and equity in the study. For example, surveys captured broad insights into systemic barriers and skills needed across different actors; interviews provided deeper, context-specific perspectives and reflected the lived experiences of practitioners and policymakers; and focus group discussions created participatory spaces that amplified the voices of marginalized groups. Case studies brought out best practices from addressing other diseases and country contexts, as well as equity and inclusion practices worth replicating. Equity was intentionally embedded throughout the process through the use of local languages, translated tools, gender-balanced recruitment, facilitation approaches that prioritized community-based participation and dialogue, and the in-depth analysis of successful citizen data case studies.

This report is a synthesis of the findings from the study and is structured to respond to the six guiding questions. Chapter 3 draws conclusions and recommendations specifically addressed to Wellcome and other organizations.[ii]

2. Country selection

The Global Partnership and Wellcome began with an initial list of 12[iii] countries that were of shared strategic importance to their respective work. The countries were assessed through a structured readiness framework seeking to capture their diversity:

1. **The disease burden:** Countries were evaluated based on the prevalence of target diseases and environmental factors that accelerate transmission patterns to ensure a mix of each of the diseases in the final six countries.
2. **Citizen data readiness:** This was evaluated using the UN-led Copenhagen Framework key building blocks, including ongoing citizen data initiatives, civil society engagement, NSO interest, and existing multi-stakeholder collaborations. Priority was given to countries with ongoing work and interest in citizen data and to those with emerging interest in citizen data work.
3. **Economic diversity:** We ensured countries were a mix of Low-Income Countries (LIC), Lower Middle-Income Countries (LMIC), and Upper Middle-Income Countries (UMIC).
4. **Country governance factors:** We prioritized countries that have political stability, where organizational relationships with either the Global Partnership or Wellcome existed, and which we knew would be feasible to conduct research within the project timeframes. We

triangulated these factors by reviewing global indices like the Ibrahim Index of African Governance.

Based on this assessment, six countries were selected: Kenya, Malawi, Ghana, Vietnam, Colombia, and the Dominican Republic. This final selection reflects a deliberate mix of geographic representation, disease profiles, and citizen data maturity, capturing different stages of citizen data adoption and institutional integration.

- **Kenya** faces a significant burden of schistosomiasis; and accounts for 15 percent of global leishmaniasis cases.[10] Recent cholera outbreaks have demonstrated a concerning pattern change, with transmission now occurring during dry seasons, contrary to historical patterns.[11] Additionally, Kenya's National Bureau of Statistics has established a technical working committee on citizen data with published quality criteria, demonstrating strong institutional readiness.
- **Ghana** reported one of the highest numbers of dengue cases in 2024,[12] with transmission linked to climate change. The Ghana Statistical Service (GSS) prioritizes coordination across national statistical systems and actively trials citizen data platforms with various ministries, including ongoing climate adaptation work with the Ministry of Environment. GSS has also made significant strides by actively working with civil society on citizen data initiatives.
- **Malawi** continues to battle severe cholera outbreaks with nearly 60,000 cumulative cases from 2022-2024,[13] alongside a significant schistosomiasis burden. Like Kenya, Malawi has also observed shifts in cholera transmission patterns, with outbreaks during dry seasons. The National Statistical Office and civil society organizations are developing collaborative citizen data approaches, supported by political stability and existing partnerships.
- **Colombia** reported more than 290,000 dengue cases in 2024,[14] plus significant cutaneous leishmaniasis cases. Dengue epidemiology links closely to human behavior, environmental factors, vector dynamics, and viral characteristics. Colombia’s National Statistical Office actively participates in global conversations on citizen data and has adapted the Copenhagen Framework within its national statistical system.
- **The Dominican Republic** experienced cholera resurgence with 149 confirmed cases in 2024,[15] alongside 8,448 dengue cases.[16] The National Statistical Office has indicated a strong interest in citizen data approaches, supported by ongoing Global Partnership initiatives.
- **Vietnam** reported nearly 150,000 dengue cases with 36 deaths in 2023.[17] Vietnam's civil society organizations are working towards advancing citizen data approaches in the country, despite bureaucratic

Chapter 2: Findings

1. Typology of citizen data applications for infectious diseases

We mapped out 35 examples[iv] of citizen data initiatives that have been used for infectious diseases or for other health-related priorities. We obtained these examples through desk research and from recommendations by the stakeholders we interacted with. We then grouped these examples based on various characteristics. Most of the examples were led by non-government institutions (29 examples), and fewer (six examples) were led by government, particularly in Colombia—but with sufficient engagement of citizens. Other characteristics that were used to group the examples include: the purpose for which the data is produced; the infectious diseases focused on; the type of intervention, e.g. surveillance or response; the countries where these examples were implemented; and the technological readiness of the initiatives.

The sections below summarize some of the characteristics of the initiatives we mapped out.

Specific ID intervention that the initiative aimed to address	No. of examples from the mapping
Surveillance	23
Prevention	20
Preparedness	12
Response	9
Resilience / patient experience	7

**In the above table, some initiatives addressed more than one intervention.*

As indicated above, a majority of the examples aimed at producing data for disease surveillance and prevention. Some examples served more than one intervention, therefore an initiative could aim at capturing data for surveillance, preparedness, and response all together. There were far fewer examples that used citizen data to capture patient experiences or document the resilience of communities for infectious diseases.

In terms of diseases, the majority of examples from our mapping were for dengue fever, cholera, COVID-19, and malaria. We found one example of the use of citizen data for yellow fever in Brazil, and one for schistosomiasis in Uganda. There were some examples of the use of citizen data for leishmaniasis (one for cutaneous and two for visceral).

The use of technology in producing citizen data

Citizen data typically uses some form of technology to enable the production of the data. We assessed the examples using a technological readiness score to determine the replicability of the initiative. We gave a score of between 1 and 5. A score of 1 indicates a basic level of application of technology, mostly from a theoretical perspective, while a score of 5 indicates the approach is fully operational and has been (or can be) integrated into regular health data systems, and that the approach is widely used and has proven benefits in improving public health outcomes. Of the examples we mapped, there were none that scored 1 or 2. The majority scored 4, indicating that these could be replicated in different contexts. The examples that scored 5 in our observation demonstrate that the approach is easily replicated even in emergency contexts. Examples scored as 5 include: Ushahidi (used in various countries and topics even beyond ID), GroupMappers (Bangladesh), and the ATRAP Project (Uganda).

Technological readiness level score & description	No. of examples from the mapping
1 Basic principle observed: The initial concept of involving citizens in data generation is recognized, but practical applications are not yet developed. Mostly at the theoretical stage.	0
2 Technology concept formulated: The approach is conceptualized, outlining how citizens will be involved in the data generation process. Prototypes are developed but not yet tested in the field.	0
3 Proof of concept done experimentally: Small-scale trials or pilots demonstrate the potential benefits and challenges.	5
4 Technology validated in a relevant environment: The approach is implemented in a real-world setting, demonstrating its effectiveness. Feedback from participants is used to refine the system.	24
5 System complete and qualified: The approach is fully operational and maybe even integrated into regular health data systems. It is widely used and has proven benefits in improving public health outcomes.	6

Purpose for which the data is produced

These examples were also grouped into a five-category typology based on the purpose for which the citizen data is produced.[18]

Typology based on the purpose for which citizen data is produced

Define/ Consult	Collect	Enrich	Analyze	Disseminate
Citizens are engaged in defining issues, shaping data collection priorities, and influencing the design of solutions. This ensures that the data produced reflects community priorities and perspectives.	Citizens actively generate and collect data using tools such as mobile apps, SMS, surveys, and community-based monitoring.	Citizen data is combined with other datasets (e.g. administrative, satellite) to improve completeness, granularity, or relevance of the overall dataset.	Citizens or intermediaries interpret the data to generate insights, recognize patterns, and make meaning of findings relevant to community or public decision-making.	Insights and action plans are shared back with communities, policymakers, or the public through accessible and engaging platforms to spur action or feedback.

It is important to understand that citizen data is not always produced solely for one purpose, but rather it can serve more than one goal. In the table below, we further describe each of the objectives for which citizen data has been produced for infectious diseases. We include a few examples in each category.

Typology of citizen data applications and methods

Type of citizen data	Purpose for which the data is produced	Some examples from the mapping
DEFINE/ CONSULT	Communities are consulted while developing plans for disease preparedness or response. This enables them to speak out or provide feedback based on	U-report, led by UNICEF working with various organizations including youth organizations, has been used for cholera response in Mozambique. PhotoVoice Study with the Light Consortium in Malawi, where people

	their perspectives in order to improve future ID interventions.	with lived experiences of tuberculosis take photographs to document their lived experiences and the issues they face.
COLLECT	This is mostly used in **disease surveillance** either to report symptoms or to map out vectors. Data is collected using tech tools such as apps. The data is often quantitative.	Community Based Surveillance by the Red Cross/Red Crescent in Kenya to detect outbreaks of leishmaniasis. (See the full case study in annex). DengueChat, led by Social Apps Lab at the University of Berkeley, has been used in Brazil, Mexico, and Nicaragua.
ENRICH	Combining citizen data with other existing data on ID to draw patterns or to aid further analysis, e.g. disease modeling.	Water-Associated infectious Diseases in India: digital management tools (WADIM) jointly led by research institutes in the UK and in India.
ANALYZE	Citizens take part in drawing patterns from the data to inform a better understanding of the disease.	Malaria Spot Project in Spain is an interactive game that allows users to diagnose malaria by analyzing digital images of blood samples.
DISSEMINATE	Through interactive dissemination activities, data and further insights/ feedback are produced. Useful in informing behavior change or jointly developing action plans with citizens.	Mikado FM in Mali used radio shows during the COVID-19 pandemic to test knowledge, educate, and entertain listeners. The ECLIPSE project in Ethiopia, Brazil, and Sri Lanka used a combination of tools including community theatre and storytelling to inform behavior change for cutaneous leishmaniasis.

Finally, out of the 35 examples mapped, we developed five in-depth case studies. The case studies were developed through a mix of desk research and key informant interviews. They represent initiatives that were led by non-government actors or communities. These examples focus on specific infectious diseases such as leishmaniasis, schistosomiasis or HIV infections. As part of the in-depth analysis, we highlight the data governance processes of producing the data: how communities were involved in a way that promotes equity and reciprocity, as well as the impact of the initiatives on the communities and on policy. These case studies are included in the annex, and also highlighted in sections of this report.

From the mapping of the examples of citizen data initiatives, we make the following observations:

a) **Most citizen data is produced for disease surveillance:** More than half of the examples of citizen data focus on producing data for disease surveillance, preparedness and/or response. There are far fewer examples (six out of the 35 examples mapped) that focus on resilience or capturing the lived experiences of citizens with the various illnesses. Using citizen data to enrich resilience-building plans for ID could therefore be expanded considerably. One of the few examples we found was the PhotoVoice Project in Malawi, which captures the experiences of TB patients in order to improve access to TB treatment.

b) **Most citizen data is produced for the purpose of the 'collect' category:** While citizen data is produced for multiple purposes, there was a clear dominance of examples whose purpose included collecting data (25 out of the 35 examples mapped). This aligns with the fundamental reason for producing citizen data, which is to either fill an existing data gap or to produce data to complement existing data sources. For infectious diseases, there are significant areas where citizen data has the potential for closing key data gaps. Across the typology, we did find fewer examples where citizen data was produced to analyze patterns or to enrich other data sources (in eight out of the 35 examples mapped). This highlights a gap in the use of citizen data in infectious diseases that can be further tapped into.

c) **Collaborative partnerships in citizen-generated initiatives:** We observe that for a large number of citizen data examples, there is collaboration between academia, research institutions, and citizens in design and roll-out, e.g. the Water-Associated infectious Diseases in India: Digital management tools (WADIM) is a partnership between academic and research institutions in the UK and India. This demonstrates the value of collaborations in producing citizen data and in ensuring quality and rigor in the data produced.

d) **Fewer examples of citizen data in schistosomiasis and leishmaniasis:** We recognize that some of the diseases we focused on, e.g. dengue and cholera, already have significantly more research compared to NTDs like schistosomiasis and leishmaniasis. This pattern is also observed in citizen data, with far fewer examples for the two NTDs.[v] Because schistosomiasis and leishmaniasis disproportionately affect children—often in settings where routine surveillance and reporting are weakest—there is a greater potential to establish complementary data sources such as citizen data to capture disease exposure, symptoms, and care-seeking at the community level. In this context, citizen data applied in an ethical and well-governed way can help address gaps in evidence and visibility, contributing to a more complete understanding of disease burden and inequities affecting children. From the in-depth case studies (see annex for case studies on visceral leishmaniasis, cutaneous leishmaniasis, and schistosomiasis) there is an indication that citizen data has promising potential for NTDs.

e) **Lack of open access to the data produced:** Organizations that produce citizen data often publicly share the analytics or summaries of the data, and not the full datasets. While we agree that citizen data is produced for different purposes and may not always be made public, we argue that because citizen data is produced in an inclusive manner, the data should also be disseminated in this way and made publicly available—in a responsible manner—for use and re-use. The benefit of making citizen data available and shared responsibly, is that it enables other users including the government to use such data for decision-making, hence multiplying the value and benefits of the data. [vi] For modelers in the Climate Sensitive Infectious Disease (CSID) network, for example, the lack of access to citizen data becomes a barrier for them to use this data source in the modeling of ID. [vii]

f) While citizen data may be either quantitative (e.g. the number of community members reporting symptoms of leishmaniasis) or qualitative (e.g. opinions of young people following a cholera outbreak), **we observed that the majority of the examples produce quantitative data.** Qualitative data is important in complementing quantitative data, or data that governments already collect, as it helps to give more nuance to data. The process of citizens producing qualitative data is also an opportunity to build-in action and influence behavior change. This achieves both data and action. For example, in the DengueChat project which was deployed in Nicaragua, the communities were able to generate photographic data on mosquito breeding sites, through gaming concepts; teams of young people would then use the data to eliminate the breeding sites and earn badges in the process.[19]

2. What are the inclusive data processes and methods that would best support those applications?

To respond to this question, we refer to two main documents that aim to promote inclusion and equity in data: the Copenhagen Framework on Citizen Data and Wellcome's Equity Framework.

The third principle in the Copenhagen Framework promotes participation and inclusion: *All groups of interest should be involved, including those that are vulnerable and marginalized, and participation should be free, open, equitable, accessible, and transparent.*[20] Furthermore, participation should be meaningful and aim at fostering shared decision-making and recognizing the agency of participants.

Wellcome's Equity Framework[21] highlights that the research it supports aims to advance inclusive practices that broaden the range of people leading, participating in, and benefiting from science in order to drive equitable health outcomes. It does this by ensuring that the perspectives of people most affected by diseases inform Wellcome's work; integrating equity across research pathways; taking actions that redress power imbalances and inequality in global health systems; and championing evidence-informed policies and practices.

Across the examples of citizen data that we mapped and analyzed in detail, we observed practices of inclusion and equity that are worth emulating to enhance long-term effectiveness and action.

Practices of equity and inclusion

Early detection of diseases

Inclusive processes ensure citizens are engaged in the entire data value chain, from design to data analysis and use. Examples like the Kenya Red Cross community-based surveillance have promoted this approach by working with affected communities as volunteers to carry out surveillance in their locations. By deploying the community-based surveillance system in Tharaka Nithi County, the community volunteers were able to detect symptoms of visceral leishmaniasis at early stages, which triggered action by government and other stakeholders. It was through this inclusive surveillance mechanism that the Government of Kenya in 2021 categorized Tharaka Nithi County as an endemic county to visceral leishmaniasis.[22]

Reciprocal benefits for citizens and the research community

In Uganda, through the Action Towards Reducing Aquatic Snail-Borne Diseases (ATRAP) project, local citizens were actively engaged to monitor disease-carrying snails to generate risk maps that could inform effective, more targeted policy interventions. At the same time, the engaged citizens led awareness campaigns to help shift and mitigate risky water practices within their communities. ATRAP, together with the community leaders, established a network of 25 local residents, also called citizen scientists, to actively monitor 76 water-contact sites around Lake Albert. Each citizen scientist was allocated two to three sites nearest to their residence, and they collected snail data weekly for nearly three years (35 months). Equipped with smartphones, protective gear, scoop nets, and snail identification tools, they submitted geotagged data via the Kobo Toolbox. Once submitted, the ATRAP research team reviewed, quality assured and validated the data, provided regular feedback to the citizen scientists, created maps of snail distribution, and organized annual refresher training to provide upskilling and capacity development to ensure high-quality data collection.

The role of the citizen scientists went beyond data collection. These citizens led the development of contextually tailored schistosomiasis awareness campaigns that catered for the needs of their diverse communities to encourage behavior change. The preferred channels of communication included songs, football matches, church announcements, and other community-driven activities to share findings on snail distribution and encourage safer water practices. As a reciprocal effect, because the citizen scientists were engaged meaningfully throughout the project, they emerged as respected local health advocates—some were elected to leadership roles or recruited into other health initiatives, demonstrating a strong link between inclusive processes, knowledge translation, and community leadership.

In Bangladesh, GroupMappers was established in 2017 to bridge a significant gap that existed: there was not enough accurate and current information about where people actually live and therefore it was nearly impossible to track disease outbreaks or make sure healthcare provision reaches the people who need it most. GroupMappers' solution was simple but powerful: instead of relying on expensive traditional methods of mapping communities, they trained local volunteers to collect data using geospatial tools. GroupMappers built their approach around community involvement and accessible technology. Their volunteers are mostly young people who care about geography and public health, and they make it possible to run mapping projects that would otherwise cost far too much money.

The volunteer-based approach has also created a reciprocal effect for local people, particularly young adults. Participants of the project have developed skills in mapping technology, gained leadership experience, and become more engaged with public health issues in their communities. GroupMappers has built a culture of community-led mapping, with volunteers contributing to COVID-19 tracking, mosquito hotspot identification, and rabies vaccination planning, turning students into skilled public health mappers.

Influence on policy

In Ethiopia, Brazil, and Sri Lanka, as part of the ECLIPSE research partnerships for cutaneous leishmaniasis, members of the community played an active role in the research process. Their lived experiences on cutaneous leishmaniasis (CL) informed the research findings. They took part in innovative approaches to engage other members of their communities, for example through community theatre, storytelling, and photography. Members of the community were part of Community Advisory Groups (CAGs), which were used to review findings to ensure cultural alignment and accuracy. Selection of membership to the CAGs was done in a collaborative manner, following the community customs of seeking approval from the local leadership, and community members voting for whom they wanted to represent them in the CAGs.[23]

The findings from the ECLIPSE research informed the Ethiopian Ministry of Health and regional authorities to expand healthcare infrastructure for CL. Treatment for CL was now available in rural health facilities such as in Adishehu Primary Hospital, Hagere Selam Primary Hospital, and Adigrat General Hospital, which meant patients no longer needed to travel longer distances to access treatment, and with early detection, health facilities minimized referrals to higher level hospitals. There is also a 20-bed in-patient unit for treatment of severe CL at Hewo Hospital in Mekelle. Between November 2023 and July 2024, more than 500 people were treated in the new centres, with Hagere Selam Primary Hospital now the leading facility in the country treating CL.

Enhanced agency of communities

In the Community-led Monitoring (CLM) for HIV prevention project in South Africa, community monitors were selected in partnership with a Local AIDS Council Secretariat and civil society leaders to ensure local ownership and to address power dynamics. Priority was given to residents from the monitoring areas, typically with a Grade 10 to 12 education, fluent in local languages, and able to communicate in English. Monitors were paid monthly stipends as incentives, aligned with Department of Health rates, recognizing their time and expertise. All data collection and sharing practices were grounded in informed consent and ethical standards. While not all data from the initiative is public, due to the sensitivity of the data, community members retained ownership and decision-making power over how their data was used (ensuring it served their priorities rather than being extracted for external use).

The CLM initiative helped secure a dedicated budget line for community-led monitoring in South Africa's National Strategic Plan on HIV,[24] a significant milestone toward institutionalizing citizen data. For the first time, CLM was formally recognized and prioritized as a core component of the country's HIV response, with government resources allocated to support its implementation. This recognition elevated the role of communities from data collectors to key implementers and accountability actors within the national health system.

3. Barriers to institutionalizing citizen data for infectious diseases

A global view of barriers, capacity, and skills gaps

Effectively integrating citizen data into infectious disease policy frameworks requires diverse capacity and skills across stakeholder groups. While the initial focus of this research was on identifying capacity gaps, findings from the global survey and focus group discussions[viii] revealed a broader set of challenges including ethical concerns, attitudinal and institutional barriers. The following table summarizes these key barriers as they relate to the research and academic community, governments, and civil society organizations.

Summary of key barriers and gaps in capacity and skills

Stakeholder group	Attitudinal barriers	Skills gaps	Data governance and ethics	Institutional barriers
Research and academia community	Disconnect between traditional research and citizen/community-led data research, especially in how communities are treated as equal partners Skepticism on the quality and rigor of citizen data	Lack of practical training in inclusive, participatory, and citizen data methods Weak science communication and advocacy skills Difficulty engaging communities as equal research partners (e.g. balancing extracting	Limited knowledge of data governance and safeguarding protocols for citizen data in health Lack of standard ethical review processes and clarity on researcher obligations for citizen data related research/projects	Absence of cross-sector ethics boards or university policies for citizen data Lack of access to datasets from citizen data initiatives that can be reused

		information with providing incentives)		
Government including National Statistical Offices and Ministries of Health	Resistance to using non-traditional data (e.g. citizen data) Skepticism about reliability and usability of citizen data Difficulty in building trust with communities, which is critical for partnerships with affected populations	Limited experience in evaluating and using citizen data Weak data communication skills Inadequate training on integrating citizen data while preserving statistical integrity Difficulty in community engagement and trust-building	Concern around data privacy and protection, especially when sharing information across government	Lack of protocols for validating citizen data Weak multi-sector coordination with health, climate, and civil society stakeholders
Civil society	Persistent challenges in accessing and securing funding to produce citizen data and to advocate for its use in shaping policies	Limited technical skills in public health data collection, validation, and analysis that would be applied through citizen data initiatives	Limited understanding of privacy, consent, and data protection Risks when handling sensitive health data and working with vulnerable groups	Lack of quality control mechanisms to ensure data reliability and safety

At the community level	Perceptions that public health is solely the government’s responsibility, leading to limited community engagement in citizen data initiatives, as residents may not see themselves as having a role	Limited technical skills in citizen data collection Low awareness of diseases, especially NTDs like leishmaniasis, which may end up being under-reported	Limited understanding of privacy, consent, and their data rights	Lack of alignment between citizen data initiatives and existing governance structures

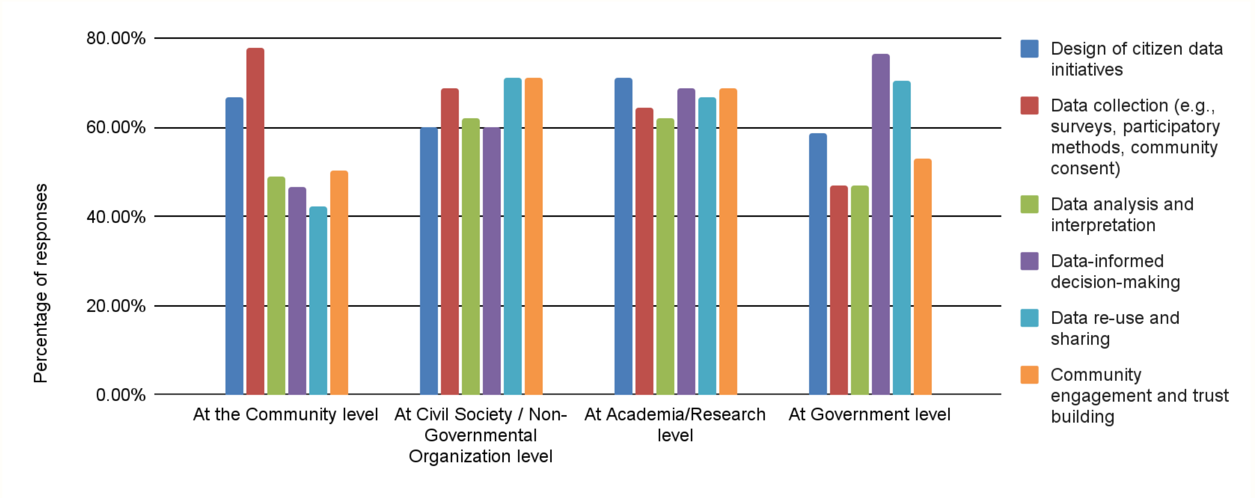
In the global survey, we asked respondents what skills and capacities are most needed for the various stakeholders to support the production and use of citizen data in infectious disease policymaking. The skills cut across the data value chain, from design and data collection to using data for decision-making and re-using data.

The findings highlight that:

- At the community level the most important skills are: the design of citizen data initiatives and participation in data collection activities.
- At the civil society/non-governmental level the most important skills are: community engagement and trust-building, data re-use and sharing, as well as data collection.
- At the research and academia level the most important skills are: design of citizen data initiatives, data-informed decision-making, and community engagement.
- At the government level the most important skills are: data-informed decision-making and data re-use and sharing.

Notably, from all the responses, community engagement appears among the top three skills that all stakeholders need to have. The findings highlight that among all the stakeholder types, our respondents agree that the research and academia community should have high levels of all of the skills required to support the production and use of citizen data to address infectious diseases.

Skills and capacities most needed for the various stakeholders to support the production and use of citizen data



A country-level view: contextualizing capacity and skills gaps

From the country research, five key themes on barriers and opportunities emerged consistently:

1. Institutional acceptance of citizen data

In countries where the National Statistical Offices have taken a proactive role in leading citizen data efforts, there is promising potential for the acceptance of the quality of citizen data. In Ghana, the Ghana Statistical Service has played a leadership role in citizen data initiatives. While there are concerns about data accuracy when non-professionals collect information, building strong relationships and documenting best practices can help to alleviate this.

In Kenya, while awareness of the role and value of citizen data is lower among ministries, state agencies and the health research community, there are much higher levels of awareness and engagement among civil society and the National Statistical Office (NSO). The Kenya National Bureau of Statistics (KNBS) has developed a quality criteria for accepting citizen data and has already used some datasets for reporting on the Sustainable Development Goals (SDGs).

Malawi's NSO is working to integrate citizen data into the country's data ecosystem, partnering with the UN and civil society to promote its use by developing a national citizen data toolkit to guide its application.

Since 2024, Colombia's NSO has taken a proactive approach, leading the national statistical system in integrating citizen data into official statistics. The organization has adapted the Copenhagen Framework on Citizen Data and developed a maturity model for evaluating citizen data initiatives. The existence of multi-stakeholder platforms like technical working groups to facilitate coordination and collaboration lend themselves as avenues to strengthen awareness, acceptance, and quality of citizen data.

In countries like the Dominican Republic and Vietnam, the acceptance of citizen data is further behind due to a limited backing by institutions such as the National Statistical Offices. The production of guidance documents for producing quality citizen data and the continuous documentation of best practices in citizen data could aid in alleviating concerns over the quality of the data.

2. Policy and governance frameworks for citizen data

Across all six countries, policy frameworks exist for the various diseases that were part of this study. Though not all of these frameworks are up-to-date or equal in terms of content and detail, they all generally prioritize the engagement of communities and working with civil society to advocate for better coordination in curbing these diseases. Countries like Kenya, Malawi, Ghana, and Colombia, for example, have master plans for the eradication of neglected tropical diseases (NTDs). These plans outline the importance of real-time data and engagement of non-state actors to enable the countries to achieve their aspirations for addressing these diseases. Such policy frameworks could be leveraged to enable more systematic roll-out of citizen data initiatives.

From a data governance perspective, Malawi exhibits gaps in data administration, with existing policies lacking clear guidance on data ownership, privacy protections, and ethical usage standards. Kenya's current data protection legislation inadequately addresses the specific confidentiality requirements for health-related citizen data, but the Ministry of Health has gone further to develop health-related data governance guidelines. Vietnam presents a unique case where centralized governance structures create restrictive barriers, leaving citizen data initiatives operating in an unofficial capacity due to rigid regulatory frameworks. In Colombia, Law 1581 of 2012 establishes general data protection principles but lacks clarity on the handling of sensitive health-related data when collected outside formal systems. While concerns persist around consent, data ownership, and community feedback mechanisms, our in-depth case studies have demonstrated that when done well, citizen data can be well governed.

3. Sustainability of citizen data and infrastructure

Financial sustainability poses ongoing challenges across implementing countries. For instance, Ghana's reliance on short-term, externally funded projects creates dependency relationships that limit long-term institutional capacity building. Malawi's heavy dependence on civil society organizations raises questions about program viability, particularly when combined with poor internet infrastructure and high costs for digital tools that hinder effective data integration.

4. Training and capacity building

Skills limitations significantly impact the effectiveness of citizen data. In Malawi, our respondents highlighted that high staff turnover rates and low digital literacy levels compromise both data quality and institutional memory. Kenya reveals inadequate feedback mechanisms for citizen data and insufficient training programs for key stakeholders, including members of the community. Ghana demonstrates a disconnect between academic research outputs and application into policymaking. In the Dominican Republic, communities and civil society also lack the skills on data management and digital literacy.

5. National cross-sectoral coordination

Overall, cross-sectoral collaboration for citizen data remains fragmented despite various efforts at coordination. In Colombia, the National Statistical Office has begun prioritizing citizen data and while the relationships with national ministries and other local implementing partners is currently weak, there is a common interest by stakeholders to strengthen these connections. The Dominican Republic demonstrates limited integration between citizen data initiatives and existing surveillance systems. Malawi's lack of dedicated citizen data frameworks results in fragmented data collection efforts and minimal cooperation between organizations, thereby reducing the overall effectiveness of the system, but again this is likely to improve over time as the National Statistical Office takes more interest in citizen data. In Vietnam, the high levels of bureaucracy in government limits the engagement with civil society organizations, however citizens have a general trust in government to take responsibility for producing real-time data on disease surveillance and alerts.

Across all six countries, these five themes point to a shared need for stronger investment in governance, skills, and coordination. While policy frameworks and institutional interest exist, they require sustained resources to translate into lasting systems change. Funders and development partners have a clear opportunity to strengthen national capacities by supporting long-term training programs, establishing cross-sector coordination mechanisms, and funding infrastructure for citizen data integration. By addressing these interconnected gaps, countries can better harness citizen data as a reliable, equitable, and sustainable tool for health surveillance and climate resilience.

4. Which countries, where environmentally sensitive infectious diseases are critical, are most 'ready' for widespread use of citizen data methods and inclusive data processes?

From the six countries, we found that widespread citizen data initiatives could be applied to infectious diseases that are prevalent in the country. There is also an opportunity to replicate, with contextual considerations, examples of citizen data initiatives that have been applied for that specific disease in other countries. From the six countries that we studied, Kenya and Malawi are quick wins for applying citizen data for infectious diseases at scale; Colombia and Ghana come second, while Vietnam and the Dominican Republic have a longer timeframe for the widespread use of citizen data for infectious diseases. It is important to ensure that country-level efforts ladder up to global and regional processes for infectious diseases in order to amplify the role of citizen data, but also to trigger further replication in other countries.

In terms of diseases, although we found one example of the use of citizen data for yellow fever in Brazil, our interactions with country stakeholders did not result in a particular interest in citizen data for yellow fever. As such, we do not include yellow fever as one of the diseases where citizen data would be most valuable in the table that follows.

The table below provides a summary of the priorities for each country for the expanded use of citizen data, drawing from the study findings.

Summary of country priorities for an expanded use of citizen data

Country	Disease where citizen data would be most valuable	Justifications from study findings	Types of citizen data that could be produced
Kenya	Leishmaniasis, schistosomiasis, cholera	● High prevalence of the diseases ● Advanced steps in institutionalizing citizen data with the National Statistical Office	● Collecting data on the capture and mapping of vectors ● Collecting data to understand patient

		- Presence of strong research and academia networks	experiences or how vulnerable populations are affected, e.g. children - Replicating citizen data approaches used in other contexts or diseases
Malawi	Schistosomiasis, cholera	- Presence of strong research and academia networks - Initial steps by the National Statistical Office to advance citizen data	- Collecting data on the capture and mapping of vectors - Collecting data to understand patient experiences or how vulnerable populations are affected, e.g. children - Replicating citizen data approaches used in other contexts or diseases
Colombia	Dengue fever, leishmaniasis	- The National Statistical Office and the National Health Institute are making proactive efforts to champion citizen data - The research and academia networks could benefit from establishing stronger relationships with government and affected communities	- Collecting data on the capture and mapping of vectors - Collecting data to understand patient experiences or how vulnerable populations are affected, e.g. children - Replicating citizen data approaches used in other contexts or diseases
Ghana	Dengue fever, cholera	- While there are strong efforts by the National Statistical Office to champion citizen data, there is a need to strengthen the relationships among research and academia - There are citizen data examples on dengue fever in other countries which could be replicated in Ghana	- Collecting data to understand patient experiences/resilience - Replicating citizen data approaches used in other contexts or diseases

Vietnam	Dengue fever	● The country has high levels of bureaucracy, which could hinder the institutionalizing of citizen data ● However, there are opportunities to further strengthen government-led infectious disease efforts to make them more inclusive	• Would require a longer timeframe for the widespread use of citizen data for infectious diseases
Dominican Republic	Dengue fever	● This is much less advanced in institutionalizing citizen data and as such would benefit from peer learnings on citizen data	• Would require a longer timeframe for the widespread use of citizen data for infectious diseases

5. Relevant stakeholder groups to advance citizen data

Strengthening citizen data for infectious diseases requires a clear understanding of which stakeholders are connected to communities and how they coordinate various citizen data methods. Based on desk research, consultations, country convenings, and focus group discussions, this section categorizes stakeholders by organizational type, disease focus, and their roles within inclusive data processes. Stakeholders are also grouped into three categories:

Capacity providers: These stakeholders bring technical expertise, financial resources, or policy influence to support citizen data systems. They assist grassroots actors through method design, infrastructure, and ethical standards. From our mapping, these include research and academic institutions and networks such as the Climate Sensitive Infectious Disease Network, KEMRI-Wellcome Trust, and Malawi Liverpool Wellcome Trust, which provide frameworks, methodologies, and validation for citizen data. Non-governmental organizations (e.g. Sightsavers, GroupMappers, International Treatment Preparedness Coalition (ITPC) Global, and Kenya Red Cross) offer training, tools, and direct interactions with grassroots organizations, while funders such as Wellcome Trust play a catalytic role by providing financial and technical support to advance inclusive data innovation. Global convenors (e.g. WHO EVIPNet) contribute to translating citizen data into policy insights. Government agencies also provide the legal and institutional frameworks needed to enable citizen data collection and use.

Capacity beneficiaries and implementers: These stakeholders are embedded in communities and directly implement citizen data. Their local relationships allow them to generate data that reflects lived realities and strengthens accountability between communities and institutions. Grassroots organizations mobilize citizens and inform local action by working with local governments and international organizations to embed citizen data in health systems. Examples include the Pakachere Institute for Health and Development in Malawi, which engages communities in monitoring disease prevention and service delivery.

Amplifiers of citizen data: These include multi-stakeholder networks and intergovernmental bodies that elevate citizen data visibility and influence. These amplifiers could also play a key role in developing guidelines and best practices for citizen data. Platforms like Uniting to Combat NTDs, redeLEISH, and Female Genital Schistosomiasis Integration Group (FIG) promote cross-country learning and uptake for NTDs, including dengue and leishmaniasis. The UN-led Collaborative on Citizen Data guides global adoption and funding while developing methodological guidelines for National Statistical Offices and other government institutions. Amplifiers thus provide the enabling environment for citizen data to be scaled and sustained.

A more detailed summary of the stakeholder mapping is outlined below. This classification helps identify where different stakeholders sit in the citizen data landscape and how they can be engaged more effectively—either by providing support, coordination, implementing approaches, or amplifying community efforts

Stakeholder landscape by organization type and disease focus

Organization type	Role in the citizen data ecosystem	Capacity role	Example actors	Primary disease or health focus
Grassroots/Civil society organizations	Community mobilization, data production, engaging local decision-making	Capacity beneficiaries and implementers	Pakachere Institute for Health and Development (Malawi), Health Rights Advocacy Forum (HERAF, Kenya), Social Enterprise Development Foundation (SEND, Ghana)	HIV infection, schistosomiasis, malaria, community health monitoring
Local and national governments	Formal coordination, resource allocation, policy integration	Capacity beneficiaries and implementers and amplifiers of citizen data	Ministries of Health, Environment, Local Health Authorities, National Statistical Offices	Multiple diseases based on national priorities
International and national NGOs	Program implementation, technical support, cross-border learning	Capacity providers	Sightsavers, Nala Foundation, Red Cross, Amref Health Africa, Cooperative for Assistance and Relief Everywhere (CARE), GroupMappers, International Treatment Preparedness Coalition Global (ITPC Global)	Cholera, NTDs, trachoma, schistosomiasis, HIV infections

Research and academic institutions	Methodological rigor, validation, reusing citizen data, ethical safeguards, funding citizen data initiatives	Capacity providers	Citizen Science Uganda Consortium, Climate Sensitive Infectious Disease Network (CSID Network), The KEMRI-Wellcome Trust Research Programme, The Malawi Liverpool Wellcome Research Programme, Oxford University Clinical Research Unit (OUCRU)	Infectious diseases, climate-health intersections
Partnerships and communities of practice	Knowledge sharing and evidence-informed policymaking, stakeholder coordination	Capacity providers and amplifiers	Dengue Alliance, redeLEISH Network, Uniting to Combat NTDs	Dengue, leishmaniasis, NTDs
Global and regional government networks	Regional coordination, technical assistance, standard setting	Amplifiers	Africa Centres for Disease Control and Prevention (Africa CDC), Africa Elimination of Cholera Epidemics Coordination Task Force (AECECT Task Force), World Health Organization (WHO), Evidence-informed Policy Network (EVIPNet), Pandemic Intelligence Hub	Cholera, pandemic preparedness, health security

The unique role the research and academic community could play in citizen data

Our study reveals that the research and academic community play a pivotal role in citizen data ecosystems. Focus group participants described how researchers are well-positioned to contribute across the data value chain—as producers, validators, and connectors between communities, institutions, and policymakers. This multifaceted role is seen as central to the credibility, coordination, and long-term sustainability of citizen data initiatives.

Respondents across the study highlighted that researchers and academic institutions are well-placed to support data quality and ethical rigor. They emphasized the value of academic involvement in structuring research questions, applying quality control and verification tools, and ensuring robust data protection practices. Additionally, the ability of researchers to foster trust through collaboration was frequently noted. Participants shared that engaging communities as genuine research partners and involving policymakers early in the process can help strengthen relationships, improve data relevance, and increase the likelihood of evidence being acted on.

Participants shared examples of partnerships with community leaders that made data collection more sustainable, cost-effective, and responsive to local realities. For instance, one participant described how training community leaders to collect data reduced the need for costly expert field visits while also promoting continuity and local ownership. Participants also emphasized the importance of researchers in communicating findings in a manner that is both accessible and relevant to policy actors. They noted that researchers can help frame citizen data as timely, locally grounded, and cost-effective—factors that catalyze data usability for decision-making.

Finally, researchers and academia were also recognized as having a unique role in institutionalizing citizen data approaches. Their credibility and long-term outlook enable them to secure funding, support cross-sectoral collaboration, and embed inclusive data practices within policy processes rather than limiting them to short-term or project-based efforts.

However, participants acknowledged that for research and academia to advance the citizen data agenda meaningfully, changes in approach across the data value chain are needed. They called for a stronger commitment to health and research equity, as well as deeper engagement with affected communities as equal research partners, either directly or through collaboration with grassroots organizations. Being equal partners means communities should be involved in shaping research priorities, participating in data collection and analysis, and contributing to the dissemination and use of findings. Participants also stressed the importance of researchers ensuring that research outputs are translated into clear, actionable policy messages that communities themselves can use to advocate for change and which they (research and communities) can use to engage the political class. Lastly, research and academia were encouraged to put citizen data to use to guide disease modeling or further research priorities.

Chapter 3: Conclusion and Recommendations

This study set out to understand the opportunities of using citizen data to address environmentally sensitive infectious diseases. A specific focus was on cholera, schistosomiasis, leishmaniasis, and arboviruses including dengue and yellow fever across six countries in Africa, Asia, and Latin America.

From the findings, we have created a set of recommendations for Wellcome and other funders, as well as for other actors (such as academia, NGOs, and governments).

Recommendations for Wellcome and other funders

Based on the conclusions from this scoping study, there is a real opportunity for citizen data to be used to address different infectious diseases, across the whole preparedness and response cycle.

To maximize the use of citizen data for addressing infectious disease, Wellcome and other funders could:

1. **Incentivize** the establishment of citizen data governance frameworks in research institutions to include privacy, consent, feedback loops, and promoting research equity.
2. **Encourage** open sharing of citizen data to enable wider access and use. The sharing of data openly should be in a responsible manner that safeguards the rights of communities.
3. **Support** the creation of guidance documents for producing quality citizen data, effective engagement of citizens, and the continuous documentation of best practices in citizen data to aid in alleviating concerns over the quality of data.
4. **Provide** funding to produce both qualitative and quantitative citizen data. This could mean running a specific funding call on bringing citizen data into the knowledge base of specific disease areas, or applying citizen data in resilience-building plans for ID, and to advocate for its use in shaping policies. Active collaboration between health researchers, CSOs, and community groups, and joint project ownership should be one of the requirements for funding.
5. **Convene** the stakeholders mapped out in this study—and others—to further identify research gaps and determine which types of citizen data examples would be useful to address them. The research gaps could include: disease and vector distribution, social determinants of infectious diseases, and social and economic disease burden on households, in particular the impact on women. These convenings could be at the country level for a set of diseases or for a specific disease in multiple countries.
6. **Support** the strengthening of citizen data production skills among leishmaniasis and schistosomiasis stakeholders, learning from the examples used in cholera and dengue. The strengthening of skills could encompass a capacity-building approach, including

skills mapping and training; application of the skills to commissioned citizen data initiatives; and using the findings from the initiatives to inform policy.

7. **Develop**, **implement** and **document** use cases of citizen data to better understand where citizen data is most useful. This could include better understanding of the resilience or coping mechanisms of communities to the various infectious diseases.
8. **Commission** further research on citizen data for topics like effectiveness of community-led disease surveillance; impact of citizen data in policymaking for infectious diseases; reciprocity effects of citizen data, etc.
9. **Designate** an organization(s) with citizen data connections and expertise to guide Wellcome teams in their uptake of these recommendations, by developing tools and holding discussions to ensure all Wellcome's projects consider the potential for citizen data use.

These opportunities are in line with Wellcome's equity principles of:

- **Prioritize** the perspectives of communities most affected by health challenges to inform what Wellcome does and how it does this;
- **Support** research that gives affected communities central importance from the outset; and
- **Provide** researchers with the tools and skills they need to engage with communities.

Recommendations for other actors including the research community, academia, NGOs, and government

1. **Design** research protocols and tools that meaningfully engage communities across the data value chain from priority-setting, data collection, analysis, and dissemination.
2. **Invest** in the technical and governance skills necessary for citizen data, such as skills in data collection, validation, and governance/ethical management of sensitive health data.
3. **Integrate** citizen data and inclusive data approaches into academic training and research design, with a focus on participatory and ethical practices.
4. **Develop** guidance documents for producing quality citizen data and the continuous documentation of best practices to aid in alleviating concerns on the quality of data.
5. **Strengthen** multi-stakeholder coordination at the government level through the use of existing, or establishing new, technical working groups to align efforts across government, academia, and civil society—ensuring citizen data is trusted and used.
6. **Leverage** existing policies and strategies such as NTD master plans to integrate citizen data into the implementation of these commitments.

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[i] In this paper, we refer to citizen data to acknowledge the advancement of the topic with the UN Statistical Commission. We do note that at the project inception, we used the term citizen-generated data. We keep the definition of the UN as the overarching definition of citizen data and citizen data as outlined in the Copenhagen Framework.

[ii] In addition to this report, the research team has produced six in-depth country reports and five in-depth case studies of citizen data used for infectious diseases that are included in the annexes. These are accompanied by elaborate spreadsheets that outline: the typology of citizen data examples (a subset of which is presented in this report) and the stakeholders that were mapped during the study.

[iii] Kenya, Uganda, Ghana, Malawi, Zambia, Senegal, Costa Rica, Colombia, the Dominican Republic, India, Vietnam, and Bangladesh.

[iv] This highlights the potential use of citizen data for infectious diseases. We prioritized examples that have been documented on the internet either as publications sharing their processes or impact or where the data is available online. We obtained these examples from a Google search and from recommendations from participants we interacted with during the study. We also aimed to include as many examples as possible from the six countries: Kenya, Malawi, Ghana, Vietnam, Colombia, and the Dominican Republic.

[v] There are more applications of citizen data in infectious diseases like COVID-19, cholera, dengue fever, malaria, and flu.

[vi] Group discussion on citizen data during the Climate Sensitive Infectious Disease (CSID) network virtual launch on 23 October, 2024. This limited access and sharing of citizen data points us to an important conversation around data governance, which is also highlighted in the latest version of the Copenhagen Framework that was presented to the UN Statistical Commission in 2025. Inclusive and well-functioning data governance systems need to be in place, which allow for citizens to have agency over their data and participate in decision-making.

[vii] Other barriers—though not fully interrogated—that limit the modelers from using citizen data could be the limited interactions between modelers and civil society or citizens, and therefore a missed opportunity to see civil society as potential users of models as well as producers of the data that modelers could use.

[viii] In total, we received input from 64 individuals across the survey and the focus group discussions. We hosted three focus group discussions: one with a mixed group of stakeholders; the second with research and academia; and the last with infectious disease modelers from the CSID Network.

Annex 1: In-Depth Country Reports

A Scoping Study on the Use of Citizen Data for Infectious Diseases in Kenya

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in Kenya to assess the potential for institutionalizing citizen data to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in Kenya, highlights notable use cases, and explores key challenges—including policy and institutional barriers—to collecting and utilizing citizen data. Additionally, it identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. While the broader study spans Africa (Kenya, Ghana, and Malawi), Asia (Vietnam), and Latin America (Colombia and the Dominican Republic), focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever, the Kenyan context specifically explored citizen data's application in addressing cholera, leishmaniasis, and schistosomiasis.

1.2. Disease burden and prevalence

Cholera remains a persistent health threat in urban slums and arid regions such as Nairobi, Tana River, and Garissa, as well as in refugee camps[1]. Women, children, the urban poor, and refugees are particularly vulnerable during these outbreaks and bear a disproportionate burden of the disease[2]. Between January 1 and April 2025, Kenya reported a total of 97 confirmed cholera cases and 6 deaths across multiple counties, with the case fatality rate declining from 7.2 percent to 6.2 percent over the period.[3,4] On the other hand, leishmaniasis, particularly its visceral form (VL), remains a major public health threat in Kenya, especially in arid, semi-arid, and remote rural regions where it is re-emerging due to climate change, population shifts, and social unrest.[5,6] As of April 2025, outbreaks were ongoing in Wajir, Turkana, West Pokot, and Marsabit counties, with 617 confirmed cases and 25 recorded deaths.[7] VL affects an estimated 1,600 people annually, causing over 170 deaths,[8] with young, malnourished children being the most vulnerable.[9] Left untreated, VL has a fatality rate over 95 percent[2], and treatment costs—around Kshs. 31,200 (USD $390) per case—far exceeding the average household's monthly income.[10] Equally, schistosomiasis[i] remains endemic in parts of Kenya, especially around Lake Victoria and the coast, affecting about 9.1 million people and putting another 17.5 million at risk.[11] It disproportionately affects school-aged children, leading to anemia, stunted growth, and cognitive impairment, which drive absenteeism, poor academic performance, and broader health, social, and economic burdens on families. Female genital schistosomiasis (FGS) affects about 4.7 percent of women of reproductive age, causing reproductive health issues and reduced hygiene-related quality of life.[12]

2. Methodology

In this study, we applied a qualitative scoping methodology to examine the landscape of citizen data for infectious disease prevention and response in Kenya. First, a comprehensive document review was conducted at the project's inception to map relevant policies, institutional frameworks, and key citizen data stakeholders. This review also identified disease hotspots for cholera, schistosomiasis, and both cutaneous and visceral leishmaniasis, informing the selection of locations for fieldwork and guiding the identification of participants for community consultations, key informant interviews (KIIs), and the national convening. The second phase involved a community consultation in Samburu County, which was purposely selected due to its status as a leishmaniasis-endemic region[5] and its ranking as the third poorest county in Kenya.[13] The community consultation engaged 34 participants, followed by a national convening with 25 representatives from government, CSOs, and academia. Participants from Mombasa, Kisumu, and Samburu represented communities affected by cholera, schistosomiasis, and leishmaniasis, respectively. Additionally, nine KIIs[ii] were conducted. Data from all engagements were thematically analyzed and presented using tables and narrative summaries.

3. Study findings

3.1. Policy and institutional framework

The study found that Kenya has strong policy and institutional frameworks for infectious disease surveillance, response, and data management (Table 1), offering a solid foundation for scaling citizen data and signalling a growing commitment to data-driven public health.

Table 1: Policy and institutional frameworks, responsible agencies, and integration relevance

Disease	Policy	Responsible agency	Relevance to integration of citizen data
Cholera, schistosomiasis, leishmaniasis, and other NTDs	Kenya National Multi-Sectoral Cholera Elimination Plan (NMCEP) 2022-2030[14]	MoH – Division of Disease Surveillance and Response (DDSR); and National Public	Enhance real-time detection; support targeted, evidence-based, and sustainable control of diseases.

		Health Institute (NPHI)	
	Kenya Cholera Management Guidelines – 2023 edition[15]	MoH – DDSR; and NPHI	
	Kenya National Master Plan for the Elimination of Neglected Tropical Diseases 2023-2027[16]	MoH – Division of Vector-borne and Neglected Tropical Diseases (Division of VBDs and NTDs) and NPHI	
	Kenya Strategic Plan for Control of Leishmaniasis 2021-2025[17]	MoH – Division of VBDs and NTDs and NPHI	
Other cross-cutting policy documents	Kenya Digital Health Act (No 15 of 2023)[18]	MoH – Division of Health Informatics (DHI)	Promote interoperable digital systems, real-time data use, and community engagement in health information and decision-making.
	Kenya Community Health Strategy 2020-2025[19]	MoH – Division of Community Health Services (CHS)	Promote community data use to guide targeted interventions and strengthen surveillance.
	Kenya Statistical Quality Assurance Framework (KeSQAF)[20]	Kenya National Bureau of Statistics (KNBS)	Provide a quality framework to validate and integrate citizen data into official statistics, ensuring its reliability and usability.

	Kenya Data Protection Act (No. 24 of 2019)[21]	MoH – DHI; and NPHI	Collect ethical citizen data while safeguarding privacy, building public trust, and supporting integration into health systems.
	Integrated Disease Surveillance and Response (IDSR)[22]	MoH – DDSR	Promote community-based surveillance and real-time reporting to enhance early detection, fill data gaps, and support timely outbreak response.
Notes: Kenya collaborates with the Global Task Force on Cholera Control (GTFCC) through its National Multi-Sectoral Cholera Elimination Plan (2022–2030), aligning with the Global Goal to reduce cholera deaths by 90 percent by 2030 and utilizing GTFCC tools like the Priority Areas for Multi-Sectoral Interventions (PAMI) approach for targeted interventions.[14]			

3.2 Citizen data stakeholders working in the country

The study identified four key stakeholder groups—state agencies, development and donor partners, civil society organisations, and academia—each with distinct roles in citizen data as shown in Table 2.

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders
State agencies: ● Establish and integrate citizen data frameworks into public health systems. ● Define data uses and guide research priorities. ● Act as collaborators and stewards alongside citizen data producers. ● Develop and enforce data quality standards. ● Become potential users of citizen data.	a) KNBS; b) NPHI; c) MoH (Divisions/Departments – VBDs and NTDs, CHS, DHI, DDSR); d) KEMRI (Neglected Diseases Research Division)

Research and academia ● Develop methodologies to produce citizen data. ● Apply these methodologies to their research. ● Build capacity through training programs for communities and non-governmental organizations. ● Educate future professionals on the ethical and effective use of citizen data	a) University of Nairobi; b) Maseno University; c) Strathmore University d) KEMRI-Wellcome Trust Research Programme. d) Africa Population and Health Research Center
Development partners and donors ● Support and advocate for the ethical and effective use of citizen data. ● Provide technical assistance and funding. ● Offer platforms the opportunity to amplify community voices in data-driven programs and policies.	a) UNICEF; b) WHO; c) USAID
CSOs ● Facilitate citizen data collection. ● Advocate for citizen data use in policy and program implementation. ● Research the effectiveness of citizen data to improve health and development outcomes.	a) SDG Kenya Forum[iii]; b) Kenya Health NGOs Network (HENNET); c) AMREF Health Africa; d) Kenya Red Cross Society; e) International Centre for Reproductive Health (ICHR)[23]; f) TWAWEZA[24]]; g) Care International
Notes: The Kenya Health Data Collaborative[25], led by WHO, unites the MoH, KNBS, UNICEF, and others to enhance coordination and support data-driven health decision-making. Complementary efforts by the KNBS Technical Working Group on citizen data, the Health TWG further advances collaborative citizen data initiatives in the country.	

3.3. Types and approaches of citizen data for infectious diseases

The study identified the main sources of citizen data for infectious disease as civil society-led, and community-led (Table 3). It is important to highlight that there are also government-owned systems that work closely with communities through innovations like mDharura,[26] eCHIS,[27] and the MOH led Community Scorecard.[28] While they remain as administrative data sources, these initiatives demonstrate good practices on inclusive data processes for infectious diseases, which could be further enhanced by integrating more citizen-centric approaches.

Table 3: Types and approaches of citizen data for infectious diseases[iv]

Tool	Description of the type of data	How citizens are involved
Community-based surveillance[29]	A mobile app by the Kenya Red Cross under the Community Epidemic and Pandemic Preparedness (CP3) program supports early detection, reporting, and response to human and animal health risks by collecting and analyzing community data using a One Health approach.	Surveillance and reporting through 150,000 volunteers
Community Baraza[v]	At the local level, individuals collect household health data and share it with community health promoters (CHPs). The issues that are highlighted are addressed through community dissemination forums, like health meetings and mother-to-mother groups, with support from local and county officials.	Reporting and dissemination

Box 1: eCBS data use case for leishmaniasis

Through eCBS, the first leishmaniasis case was flagged, despite the disease not being routinely tracked, after 15 alerts were raised in Tharaka Nithi. Of these, 11 cases were confirmed at a health facility, prompting the development of a coordinated response plan involving contact tracing, spatial and social behaviour analysis. This data use case was subsequently documented and published as a case study.[30]

3.4. Opportunities and challenges

1. Integration of citizen data into government systems and unlocking value: Leveraging citizen data provides a faster, cost-effective way to generate timely insights, especially during outbreaks when community collaboration is vital. Integrating citizen data into government systems—such as eCHIS, m-Dharura, and DHIS2—can enhance infectious disease surveillance and strengthen public health response.

> *Citizen data could be a more superior and cost-effective approach, producing results faster, especially when working with citizens to generate data and an outbreak occurs.*
> – Member of the National Task Force for Infectious Disease.

2. Awareness gaps: Despite collaborative platforms like the KNBS-led Health Data TWG, awareness and understanding of citizen data remain limited among state agencies and civil society organizations (CSOs).

3. Legal frameworks: Current data protection regulations fall short of addressing the heightened confidentiality requirements of health-related citizen data. Strengthened legal frameworks are urgently needed to safeguard personal health data, especially in the context of infectious disease surveillance.

> *There is a need to strengthen the personal data protection guidelines in the context of health and infectious diseases since health data is a lot more confidential.*
> – Respondent from Palladium Group.

4. *Capacity gaps:* Significant skills gaps in research design, data analysis, and community-based data collection exist at both national and sub-national levels. Strengthening capacity in citizen data is crucial, as local engagement improves data quality, fosters trust, and accelerates outbreak response.

> *Capacity for data analysis and management is inadequate at the national, county, and community levels.*
> – MoH Respondent.

Box 2: Highlight from Samburu community consultation

Community members prioritized tuberculosis, malaria, amoebiasis, pneumonia, and monkeypox, highlighting a broad disease burden that often overshadows NTDs. Awareness of leishmaniasis was notably low, known only by its symptoms and the local name *"Loriwo,"* indicating a critical gap in disease knowledge. Although no recent leishmaniasis cases were reported, underdiagnosis and low awareness likely contribute to its invisibility. Community health promoters (CHPs) reported at least one suspected infectious disease case weekly, mostly influenza and skin infections.

The community health promoters had reported an incidence of infectious diseases over the past one month. Influenza and skin diseases were the most frequently reported illnesses, *occurring weekly among the communities. The teams could not report a recent case of leishmaniasis among the communities.* – Respondent from the Community Consultation.

Citizens contribute to the data value chain through household and community surveillance, reporting suspected cases via phone calls, SMS messages, or word-of-mouth to CHPs, who record them in the eCHIS. Communities primarily access health data through Barazas and mother-to-mother groups. To strengthen citizen engagement, participants recommended expanding access to MoH toll-free lines and increasing transparency through platforms like e-CHALKBOARD—empowering communities to better detect and respond to neglected diseases such as leishmaniasis and schistosomiasis.

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[i] A parasitic disease that occurs in two forms—intestinal and urogenital—based on the infecting schistosoma species.

[ii] 9 KII Respondents: Kenya National Bureau of Statistics (KNBS), from MoH (Division of Diseases Surveillance and Response, Division of Neglected Tropical Diseases, Kenyatta National Hospital-National Surveillance Office, Kenya Medical Research Institute (KEMRI), Three from civil society organizations (Palladium Group Kenya, Bloomberg Data for Health Initiative, and Kenya Red Cross).

[iii] The SDG Kenya Forum is an umbrella network of civil society organizations, operating in Kenya, working in various sectors including health.

[iv] The types of data described align with a typology that categorizes citizen data initiatives based on their primary function: to define/consult, collect, enrich, analyze, or disseminate. These categories/types are highlighted in bold in Table 3.

[v] Comment from the national convening.

A Scoping Study on the Use of Citizen Data for Infectious Diseases in Ghana

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in Ghana to assess the potential for institutionalizing citizen data (citizen data) to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in Ghana, highlights notable use cases, and explores key challenges, including policy and institutional barriers to collecting and utilizing citizen data. Additionally, it identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. The broader study covers Kenya, Malawi, Ghana, Vietnam, Colombia, and the Dominican Republic, focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever. The Ghanaian context specifically explored citizen data's application in addressing dengue fever.

1.2. Disease burden and prevalence

Dengue fever, a mosquito-borne viral infection caused by the dengue virus serotypes DENV-1 to DENV-4, is an emerging public health threat in Ghana, particularly in dense urban and peri-urban areas with ideal mosquito breeding conditions.[1] Dengue cases in Ghana rose from 18 in 2023 to 54 confirmed cases by August 30, 2024,[2] and subsequently to more than 100 cases by the end of 2024.[3] In Greater Accra, serotypes 1, 2, and 3 have been identified among febrile patients, highlighting the risk of severe outbreaks due to co-circulation.[4] IgG seroprevalence ranges from 18.2 percent in the Western Region to 57.9 percent in the Upper East,[5] with higher rates in females, suggesting possible gender-related differences in exposure.[6] Evidence indicates significant underreporting, often due to misdiagnosis as malaria, with dengue exposure confirmed among malaria-positive children in urban centers—pointing to local transmission and wider undetected circulation.[7]

2. Methodology

The study applied a qualitative scoping methodology to examine the landscape of citizen data for infectious disease prevention and response in Ghana. First, a comprehensive document review was conducted at the project's inception to map relevant policies, institutional frameworks, and key citizen data stakeholders. This review informed the selection of participants for key informant interviews (KIIs) and the national convening. Seven KIIs[i] were conducted in the second phase with individuals from the National Statistical Office, Ministry of

Health, research, and civil society sectors. This was followed by a national convening with 28 representatives from government, civil society, and academia to gather broader insights. Data collected from these engagements were analyzed and thematically presented using tables and narrative summaries.

3. Study findings

3.1. Policy and institutional framework

Ghana has established a range of policy and institutional frameworks to guide the surveillance, detection, response, and data management of infectious diseases (Table 1), providing a strong foundation for the conceptualization and scaling of citizen data approaches. In response to the 2024 dengue outbreak, policy mechanisms were integrated with community-led data reporting. Collaboration between the Ghana Health Service and local health committees enabled rapid net distribution and targeted awareness campaigns in high-risk areas identified by communities [2].

Table 1: Policy and institutional frameworks, responsible agencies and integration relevance

Area of focus	Policy	Responsible agency	Relevance to the integration of citizen data
Disease Surveillance and Response, Dengue Fever, and NTDs.	The Ghana National Infection Prevention and Control (IPC) Strategy 2024[8]	MoH – Ghana Health Service (GHS)	Main policies for the prevention, reduction, and control of Healthcare-Associated Infections (HAIs) and Antimicrobial Resistance (AMR) in healthcare facilities in Ghana.
	WHO Dengue Fever Management Guidelines[9]	WHO, but implemented by GHS	
	National Public Health Emergency Response Centre (PHEC)[10,11]	GHS – Emergency Operations Centre (EOC) under the Public Health Division	Supports infectious disease surveillance through real-time data collection and response.

	Ghana Neglected Tropical Diseases – Master Plan 2021 – 2025[12]	Ghana Health Service (GHS) and other stakeholders.	Acknowledges the importance of working with civil society in advocacy for NTDs.
General data and statistics and data governance	Policy and Strategy on Digital Health 2023-2027[13]	MoH – GHS, Ministry of Communication and Digitalisation	It supports inclusive, interoperable data systems and citizen engagement, enabling integration of real-time citizen data to enhance health service delivery, responsiveness, and decision-making.
	Ghana Data Protection Act 2012[14]	Ministry of Communication and Digitalisation – Data Protection Commission (DPC)	Streamlines the collection and management of the protection of personal health data and the uptake of citizen data in Ghana.
	Ghana National Strategy for the Development of Statistics[15]	Ghana Statistical Service (GSS)	

3.2. Citizen data stakeholders working in the country

The study identified four key stakeholder groups—state agencies, development and donor partners, civil society organizations, and academia (Table 2).

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders
State agencies	a) Ghana MoH (Department of Digital Health and the Division of Community Health); b)

Provide official health statistics. Establish data frameworks. Integrate data into public health systems. Use data for targeted health interventions. Research data reliability and impact.	Ghana Health Services (GHS); c) National Public Health Institute; d) Ghana Statistical Service (GSS); e) Ministry of Communication and Digitalisation – Data Protection Commission (DPC)
Research and academia Develop methodologies to produce citizen data. Apply these methodologies to their research. Educate future professionals on ethical and effective citizen data production and use.	a) University of Ghana; b) Kwame Nkrumah University of Science and Technology (KNUST); c) The Noguchi Memorial Institute for Medical Research d) Africa Health Economics and Policy Association
Civil society organizations Advocate for ethical and effective citizen data use. Provide technical assistance and funding. Create platforms to integrate community voices into data-driven programs and policies.	a) Ghana NCD Alliance; b) Community Practice Pharmacists Association (CPPA), Ghana; c) Hope For Future Generations; d) Ghana Health NGOS Network (GHNGON), which includes AFENET Ghana, Amref Health Africa; e) World Vision Ghana; f) Jhpiego; g) Total Family Health Organisation
Donor and development partners Support national systems and health programs. Provide financial resources for health-related initiatives.	a) UNICEF; b) The Global Fund; c) Bloomberg Philanthropies (Data for Health Initiative); d) WHO

Offer funding and technical assistance for data systems and health monitoring. Strengthen capacity for data-driven decision-making. Facilitate the integration of citizen data into national health strategies.	

3.3. Types and approaches of citizen data for infectious diseases

The study identified citizen data approaches to infectious disease surveillance as outlined in Table 3. These are mostly led by civil society. Civil society organizations like World Vision engage communities in data collection and feedback. Coordinated integration of these approaches is crucial for inclusive data collection, greater impact, and stronger community engagement in disease surveillance.

While in many countries, citizen data efforts are driven by civil society and communities, the Ghana Statistical Service has stood out as a strong champion in stewarding citizen data with non-state actors. Some of the efforts of GSS are highlighted in Table 3. Although these examples do not relate to infectious diseases, it signifies the opportunities to work with GSS to champion citizen data in addressing infectious diseases.

> *In 2023, the Accra Metropolitan Assembly (AMA) partnered with NGOs using citizen data to identify areas with the worst sanitation challenges. Based on the data, the AMA prioritized waste collection in these neighborhoods. Local by-laws on open defecation were enforced more strictly in identified hotspots.*
> – Respondent from GSS.
>
> *We have initiated several projects that leverage citizen data for national development planning. These include our collaboration with UNDP to collect public service feedback via USSD and mobile platforms. Other initiatives such as 'Let's Talk' on gender-based violence and solid waste management in selected districts help integrate citizen voices into official statistics.*
> – Respondent from GSS.

Table 3: Types and approaches of citizen data for infectious diseases[ii]

Tool/approach	Description of the type of data	How citizens are involved
World Vision Ghana: Community Scorecard[16]	A social accountability tool that gathers service user feedback. This data is used to **enrich** other data sources to improve health services. It is implemented by World Vision Ghana in partnership with the MoH.	Community members provide feedback on health services, which is used to inform improvements.
GSS-led citizen data initiatives on various topics	Worked with non-state actors on citizen data initiatives to **collect** data on gender-based violence, marine litter[17], and waste management[18], and to provide feedback on the use of public funds[19] and public service delivery[20], therefore **enriching** existing data on these issues.	Collect data through various means including the development of mobile apps.

3.4. Opportunities and challenges

1. Acceptance of citizen data as a credible and reliable data source for disease surveillance: There have been great efforts by GSS to champion citizen data in various sectors; this however has not focused on infectious diseases. As such, stakeholders in the infectious disease space expressed concerns over the accuracy and consistency of data collected by non-professionals, potentially impacting decision-making and response. At the national convening, stakeholders from the MoH, local government, and CSOs stressed the need for improved coordination in using citizen data for disease surveillance.

> *The role of citizen data in early detection of outbreaks is critical, but we need to ensure that community data is reliable and acted upon swiftly.*
> - A participant at the National Convening.

The role of communities in data generation and use is often fragmented and under-supported, limiting the effectiveness of citizen data as a locally driven surveillance tool. Strengthening local involvement is essential to enhance health outcomes and the impact of community-generated data.

> *Engaging local communities directly in data collection not only improves the accuracy of information, but it also strengthens the local response mechanisms to health emergencies.*
> - Respondents from Total Family Health Organization.

> *If this data were collected and made available, we could see improved health response strategies, increased community empowerment in health matters, enhanced trust in health systems, and ultimately a reduction in disease-related morbidity and mortality.*
> - Respondents from the Ghana Non-Communicable Diseases Alliance

2. Strengthening capacity for citizen data: Insufficient funding and resources constrain the scope, quality, and sustainability of citizen data collection and analysis.

> *Many citizen data initiatives are heavily reliant on donor funding and tend to be short-term—once funding ends, the data collection activities usually come to a halt. Additionally, health-related citizen data is highly sensitive; without strong data protection protocols, there is a real fear among citizens that their personal information could be misused.*
> - A respondent from GSS

In addition, there remains limited technical capacity for data management and analysis, coupled with low awareness among stakeholders about citizen data's value for infectious diseases. This hinders its effective use in disease surveillance and response.

> *Capacity building and continuous training of community health workers has been crucial—not just in strengthening response systems during outbreaks, but also in empowering local communities to take ownership of their health outcomes.*
> - Representative, World Vision

3. Establishing standards and guidelines for citizen data to guide data integration and governance: While the Ghana Statistical Service has led several efforts on citizen data, stakeholders emphasized the absence of harmonized citizen data frameworks as a key challenge. Limited recognition of CSOs and private actors as data contributors, and the absence of clear methodological and legal standards were also highlighted as hindering effective collaboration. Ensuring privacy and ethical compliance, especially with sensitive health data, remains a key challenge due to weak regulatory and data protection frameworks.

> *Lack of harmonized citizen data frameworks, limited recognition of CSOs and private actors as data contributors, absence of clear methodological standards, and legal issues like data privacy, security, and lack of regulatory frameworks.*
> - National Chairman, Community Practice Pharmacists Association (CPPA), Ghana

In addition, integrating citizen data tools within existing national and sub-national health information systems is technically complex and requires policy support and infrastructure alignment.

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[i] **KII respondents**: Ghana Statistical Service, MoH (Military Hospital), Ghana Non-Communicable Diseases Alliance, World Vision Ghana, Community Practice Pharmacists Association (CPPA), Hope For Future Generations and the Total Family Health Organization-TFHO)

[ii] The types of data described align with a typology that categorizes citizen data initiatives based on their primary function: to define/consult, collect, enrich, analyze, or disseminate. These categories/types are highlighted in bold in Table 3.

A Scoping Study on the Use of Citizen Data for Infectious Diseases in Malawi

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in Malawi to assess the potential for institutionalizing citizen data (citizen data) to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in Malawi, highlights notable use cases, and explores key challenges—including policy and institutional barriers—to collecting and utilizing citizen data. It also identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. The broader study covers Kenya, Malawi, Ghana, Vietnam, Colombia and the Dominican Republic, focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever. In Malawi, the study specifically explored citizen data's application in addressing cholera and schistosomiasis.

1.2. Disease burden and prevalence

Cholera remains a major health threat in Malawi, with recent outbreaks underscoring the country's vulnerability to waterborne diseases.[1] As of March 2025, an ongoing outbreak since September 2024 has led to 298 cases and 14 deaths (A case fatality rate of 4.7 percent, well above the regional average of 1.5 percent).[2] The crisis is worsened by flooding from tropical cyclones, which damaged water and sanitation infrastructure.[3] Women in flood-prone and poorly serviced urban areas are disproportionately affected due to caregiving roles and increased exposure to unsafe water. Cholera poses a major financial burden in Malawi, with rural households spending about USD $14.34 per case—mainly on non-medical costs—an unsustainable expense for families living on under USD $2 a day.[4] Similarly, schistosomiasis[i] remains a prevalent neglected tropical disease in Malawi, putting over 50 percent of the population at risk and affecting an estimated 8.4 million people across all age groups.[5,6] Intestinal schistosomiasis has a 15 percent prevalence among adults with non-communicable diseases in Central and Southern Highlands, Likoma island and Lower Shire Valley, while urinary schistosomiasis is widespread with varied prevalence rates across regions.[7] The widespread prevalence of the disease significantly impacts economic productivity and elevates healthcare costs, with children bearing the greatest burden—over 25 percent of preschoolers are infected, leading to stunted growth, cognitive delays, and poor educational outcomes.[8]

2. Methodology

The study applied a qualitative scoping methodology to examine the landscape of citizen data for infectious disease prevention and response in Malawi. It began with a comprehensive document review to map relevant policies, institutional frameworks, and key citizen data stakeholders, while also identifying cholera hotspots to inform site selection and participant recruitment for community consultations, key informant interviews (KIIs), and the national convening. A national convening was then conducted in Lilongwe with stakeholders in disease surveillance and response at national and sub-national levels. The second phase involved a community consultation in Nsanje District, a region purposely selected for being recently affected by cholera, compounded by cyclone-related disruptions and ongoing cross-border health challenges with Mozambique.[9] The community consultation involved 26 community members, including local leaders, village health committees, and Health Surveillance Assistants. Lastly, five KIIs[ii] were conducted. Data collected from these engagements were analyzed and thematically presented using tables and narrative summaries.

3. Study findings

3.1. Policy and institutional framework

Malawi has a set of policies, laws, and institutional frameworks (Table 1) to support the effective use of data in the surveillance, detection, response, and management of infectious diseases. These structures, by and large, offer a good foundation for conceptualizing and scaling citizen data approaches and reflect Malawi's growing commitment to integrated, data-driven public health systems. However, this remains to be practically applied to citizen data efforts—at least at scale.

Table 1: Policy and institutional frameworks, responsible agencies and integration relevance

Area of focus	Policy	Responsible agency	Opportunities/relevance to integration of citizen data
General data and statistics governance and digital transformation	Malawi Access to Information Act (ATI Act) 2016[10]	Ministry of Information, Civic Education and Tourism	Enables transparency and public access to information, supporting open data use.
	Malawi Data Protection Act (2024)[11]	Malawi Communications Regulatory Authority (MACRA)	Provides legal safeguards for personal data in citizen data initiatives.

	Malawi Digital Economy Strategy (2021–2026)[12]	Ministry of Information and Digitalisation	Promotes digital infrastructure and systems for data-driven decision-making.
General infectious disease surveillance, cholera and NTDs	Malawi Integrated Disease Surveillance and Response (IDSR) Guidelines (2020)[13]	Public Health Institute of Malawi (PHIM)	Establishes a framework for integrating community-level disease reporting.
	Malawi Cholera Response Manual (2018)[14]	MoH	Guides cholera outbreak response, where citizen data can support early warning.
	Malawi Multi-Sectoral Cholera Control Plan (MMCCP) 2025-2030 [15]	MoH and stakeholders	Facilitates multi-sectoral engagement and data use in cholera control.
	Malawi Neglected Tropical Diseases – Master Plan 2023 – 2030[16]	MoH and stakeholders	Encourages advocacy with civil society to influence decision making on NTDs and in closing data gaps.

3.2. Citizen data stakeholders working in the country

There are four key stakeholder groups—government/state agencies, development and donor partners, civil society organizations, and academia—each with distinct roles in citizen data (Table 2). Malawi's infectious disease management framework is led by the MoH, with support from the Public Health Institute of Malawi (PHIM), the Department of Digital Health, and District Health Offices. Malawi has made significant strides in digital infrastructure, particularly with its digital ID system.[17] While government-led, citizen-data-specific policies and practices are limited, the National Statistical Office (NSO) is working to integrate citizen data into Malawi's data ecosystem, partnering with the UN and civil society to promote its use by developing a national citizen data toolkit to guide its application. The toolkit will be finalized later in 2025.[18]

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders
State agencies: Establish data frameworks. Integrate data into public health systems. Use data for targeted interventions. Research data reliability and impact.	a) MoH (Department of Digital Health and District Health Offices); b) PHIM; c) Malawi's National Statistical Office (NSO); d) Ministry of Information, Civic Education and Tourism; e) Malawi Communications Regulatory Authority (MACRA)
Development partners and donors Enhance inclusivity and accuracy of health data. Support more responsive public health interventions that are community centric.	a) UN Agencies (e.g. UNICEF, WHO, UNFPA); b) GIZ; c) FCDO
Research and academia Develop methodologies to produce citizen data. Apply these methodologies to their research.	a) University of Malawi; b) Mzuzu University; c) Malawi-Liverpool-Wellcome Trust Clinical Research Programme

Educate future professionals on ethical and effective citizen data use.	
CSOs Engage communities in data collection. Strengthen disease surveillance and emergency response. Support public health campaigns. Uphold community consent and data governance. Empower health workers in last-mile service delivery.	a) VillageReach; b) Lighthouse Trust; c) Malawi Red Cross Society; d) The Pakachere Institute for Health and Development Communication;[19] e) the Community Health Impact Coalition (CHIC)[20]

3.3. Types and approaches of citizen data for infectious diseases

Most citizen data initiatives were civil-society-led, as outlined in Table 3, with some emerging community-led efforts, signifying increased grassroots engagement in public health data. Government-owned systems that engage communities directly are also present, such as the Integrated Community Health Information System (iCHIS)[21]. These are examples of administrative data and not citizen data, but are a great demonstration of using inclusive data to address infectious diseases. These can be further enhanced by integrating more citizen-centric approaches.

Table 3: Types and approaches of citizen data for infectious diseases[iii]

Tool	Description of the type of data	How citizens are involved
CARE Community Scorecard[22]	CARE Malawi's participatory tool, initially for citizen feedback on public services. The feedback is useful to enrich other data sources to guide decision	Citizens contribute through focus groups, direct service feedback, and dialogues with providers.

	making. It was adapted to monitor the COVID-19 vaccine rollout.	
Citizen Voice and Action (CVA)[23]	A World Vision Malawi social accountability approach that empowers communities to engage the government and improve services. By enriching existing data, the data from social accountability has been used to advocate for more health workers in Phalombe.	Community members attend public forums, provide feedback, and hold local officials accountable for service improvements.
Photovoice Project[24,25]	A Lilongwe-based participatory project, backed by Our World International, that uses photography to highlight and disseminate information on community waste issues and solutions.	Citizens capture and present images to document challenges, discuss solutions in community meetings, and propose interventions.

3.4. Opportunities and challenges

While there are some promising examples from the scoping study in Malawi, citizen data for infectious disease efforts remains limited. In part, this could be because existing efforts are undocumented or rolled out on a small scale. Below, the opportunities and challenges of using citizen data to address infectious diseases in Malawi can be grouped into five major categories:

1. Policy and legal gaps: While there are policies in place, these have not been practically applied to guide the integration of citizen data. As such, there is unclear guidance on data ownership, privacy, and ethical use. Without legal protections, communities are often reluctant to engage, limiting the integration of citizen data into formal decision-making processes:

> *We lack a legal framework that defines how citizen data should be collected, stored, and used responsibly.*
> – KII from CSO providing technical assistance to MoH.

2. Coordination, collaboration and partnerships: Because Malawi lacks a dedicated citizen data framework for infectious diseases—or for data and statistics for that matter—there are challenges in collaboration and partnerships. Coordinated integration is key to inclusive data collection, impact, and community engagement. However, weak coordination, limited data-sharing, and funding competition hinder efficiency and lead to duplication.

> *Different organizations collect similar data, but there's no structured way to share or use it collectively.*
> – Comment from National Convening.

3. Skills and capacity gaps on data: Training gaps persist across government, civil society, and communities, with especially low data and digital literacy at the community level. Limited training of data collectors and high staff turnover undermine data accuracy and institutional memory.

> *Most community health workers collecting data receive minimal training on proper data management.*
> – Comment from National Convening.

4. Reporting and integration gaps: Although community networks aid in case detection, reporting is unstructured, due to the lack of standardized tools. Inconsistent data and the absence of validation frameworks limit citizen data integration into national systems. These challenges are compounded by poor internet access, high digital tool costs, and low digital literacy in rural areas, further restricting adoption and integration.

> *There's no uniform way to verify the accuracy of data collected by community members.*
> – Comment from National Convening.

> *Digital tools like iCHIS are promising, but connectivity issues remain a major challenge in remote areas.*
> – Comment from National Convening.

5. Sustainability: Financing for data systems and citizen data remains inadequate, with most community-level initiatives relying entirely on civil society support—raising significant concerns about their long-term sustainability.

Box 2: Highlight from the Nsanje District, Malawi community consultation

In Nsanje's Phokera area, the community highlighted the severe impact of cholera following the February 2024 cyclone, which damaged sanitation infrastructure and contaminated drinking water. Though the outbreak was largely contained, three new cases and one child fatality were recently reported.

Community members responded using home remedies like salt-water mixtures and contributed to citizen data by identifying symptoms and reporting them through Village Health Committees to Health Surveillance Assistants (HSA). Village leaders played a key role in mobilizing and facilitating health discussions, though these efforts lack systematic documentation to guide policy and programs.

CSOs, including the Red Cross, supported the response with guidance on using ORS, treating water, and early health-seeking behaviors. Cholera prevention messages were also shared via local radio stations like Zodiac, Times Radio, Gagasi FM, and Malawi Broadcasting Corporation.

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[i] A parasitic disease that occurs in two forms—intestinal and urogenital—based on the infecting *schistosoma* species

[ii] **5 KII respondents:** Malawi National Statistics Office; Partners in Health, Cooper Smith Malawi, Care Malawi, and the Leave No One Behind Coalition Malawi.

[iii] The types of data described align with a typology that categorizes citizen data initiatives based on their primary function: to Define/Consult, Collect, Enrich, Analyse, or Disseminate. These categories/types are highlighted in **bold** in Table 3.

A Scoping Study on the Use of Citizen Data for Infectious Diseases in Vietnam

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in Vietnam to assess the potential for institutionalizing citizen data to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in Vietnam, highlights notable use cases, and explores key challenges—including policy and institutional barriers—to collecting and utilizing citizen data. It also identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. The broader study covers Kenya, Malawi, Ghana, Vietnam, Colombia and the Dominican Republic, focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever. In Vietnam, the study specifically explored citizen data's application in addressing dengue fever.

1.2. Disease burden and prevalence

In Vietnam, dengue fever represents the most significant infectious disease threat, particularly concentrated in the southern regions such as Ho Chi Minh City and the Mekong Delta, where recurrent outbreaks strain local health systems and household finances. In the first four months of 2025, the country reported 24,900 dengue cases and three deaths, with Ho Chi Minh City alone accounting for 7,398 cases[1] —a 136 percent increase compared to the same period in 2024.[2] The Mekong Delta continues to bear the highest burden, accounting for approximately 70 percent of national cases and 80 percent of related deaths.[3] Early rainfall in 2025 heightened fears of an expanded outbreak, prompting health authorities to advocate for intensified mosquito control and public awareness efforts. Yet, factors like climate change, unplanned urbanization, and shifting rainfall patterns continue to complicate vector control and disease forecasting.[4] Economically, dengue imposes a substantial burden, especially on low-income families with children. A recent study estimated the median cost per pediatric dengue case at USD $1,859, with nearly 84 percent attributed to direct medical expenses and additional productivity losses, including caregiving time, averaging USD $275 per case.[5] These costs are primarily paid out-of-pocket, exacerbating financial vulnerability. Vietnam's Ministry of Health continues to emphasize early detection, prevention, and community involvement. Incorporating citizen data into national surveillance systems could strengthen early warning capabilities and improve outbreak response, particularly in high-risk areas.

2. Methodology

Fieldwork was primarily conducted in Ho Chi Minh City, reflecting the city's high dengue burden and accessibility to key health institutions. As a result, findings largely reflect perspectives from Ho Chi Minh City (HCMC) and may not be fully applicable to other regions of Vietnam. The study applied a qualitative scoping methodology to examine the landscape of citizen data for infectious disease prevention and response. The study began with a comprehensive document review to map relevant policies, institutional frameworks, and key citizen data stakeholders, while also guiding the selection of fieldwork sites and key informants. Subsequently, a community consultation meeting involving 10 participants from the private sector, civil society, and government was held at the Oxford University Clinical Research Unit (OUCRU), primarily involving individuals from Ho Chi Minh City (HCMC). This was complemented by a stakeholder convening with 16 professionals from the business management development, telemedicine and digital health, pharmaceuticals, advocacy, academic and research, public health, and healthcare sectors. The participants were also drawn largely from HCMC compared to other regions in Vietnam primarily due to logistical considerations. Similarly, most of the KII perspectives reflect experiences in HCMC and are not generalizable to all parts of Vietnam. Lastly, six KIIs[i] were conducted. Data collected from these engagements were analyzed and thematically presented using tables and narrative summaries.

3. Study findings

3.1. Policy and institutional framework

Vietnam has established a set of policies, laws, and institutional frameworks (Table 1) that support the use of data in the surveillance, detection, response, and management of infectious diseases, including vector-borne and neglected tropical diseases (NTDs). While the legal foundation for infectious disease reporting is robust, the integration of citizen data into these systems remains limited particularly in HCMC.

Table 1: Policy and institutional frameworks, responsible agencies and integration relevance

Area of Focus	Policy	Responsible agency	Opportunities/relevance to integration of citizen data
General infectious disease surveillance, vector-borne and NTDs	Law on Prevention and Control of Infectious Diseases (No. 03/2007/QH12) and	Local health stations and the Center for Disease Control (CDC)	Enforces citizens' reporting compliance, hence citizen data inclusion will enable timely information that supports early reporting, detection, and timely infectious disease surveillance system interventions.

	Circular No. 54/2015/TT-BY[6]		
	Dengue Fever Control Regulations Circular 54/2015/TT-BYT[7]	Hospitals and HCDC (Ho Chi Minh City Center for Disease Control)	Hospitals are required to report dengue cases to HCDC.
	Decree 117 (Administrative Penalties in Healthcare)[8]	All Health authorities	Penalties are issued to the people for not participating in vaccination programs for epidemic prevention; this establishes a legal framework for public health compliance and participation.
	National Strategy for Protection, Care, and Improvement of People's Health (Decision 89/QD-TTg, 2024)[9]	All Health authorities	Focuses on real-time disease control through early detection, monitoring, and data-driven interventions; focuses on maternal/child health in rural/ethnic minority localities.
General data and statistics governance and digital transformation	Decree 13/2023/ND-CP on Personal Data Protection[9,10]	Ministry of Public Security	Vietnam’s first comprehensive legal framework for data privacy, that defines how health data is utilized. An individual’s consent must be accented before processing except for dire emergencies, such as national disasters.

3.2 Citizen data stakeholders working in the country

There are five key stakeholder groups—government/state agencies, development and donor partners, academia and research institutions, civil society organizations, and local communities—each with distinct roles in citizen data (Table 2).

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders

State agencies: - Facilitate the establishment of community data networks. · Identify reporting hotspots. · Develop disease response toolkits through advanced analytical systems integration. · Forge inter-agency partnerships. · Establish legal frameworks that promote ethical citizen data adoption. · Promote reporting responsibilities through public health education and awareness campaigns.	a) Ho Chi Minh City Center for Disease Control (HCDC); b) Pasteur Institute (HCMC, Nha Trang); c) Hanoi Center for Disease Control; d) Ministry of Health; e) National Statistical Office (NSO); f) Ministry of Planning and Investment (MPI).
Development partners and donors · Fund collaborative surveillance projects. · Develop digital health solutions and data collection tools. · Offer technical support. · Fund initiatives and projects. · Develop global citizen data frameworks. · Launch collaborative citizen data initiatives.	a) Asian Development Bank (ADB); b) United Nations Statistics Division (UNSD);[11] c) Wellcome Trust
Academia and research institutions · Conduct research on infectious diseases and community data practices. · Build capacity for health professionals in surveillance and citizen data use. · Provide ethics guidance and support the validation of community data models. · Evaluate citizen data methodologies. · Assess citizen engagement approaches. · Integrate and galvanize citizen data science adoption.	a) The University of Medicine and Pharmacy; b) London School of Economics and Political Science (LSE);[12] c) Oxford University Clinical Research Unit (OUCRU)
Civil society organizations · Manage data collection within community networks. · Support marginalized groups. · Pilot citizen data toolkits. · Liaise with community networks. · Manage global citizen science events. · Offer thought leadership, insights, and lessons on citizen data.	a) Leave No one Behind (LNOB) Vietnam Coalition; b) Management and Sustainable Development Institute (MSD); c) International Civil Society Centre[13]

Local communities · Contribute to local level reporting. · Collect relevant health-related citizen data.	a) Neighborhood group leaders/community collaborators, e.g. retired doctors and village members; b) Local health stations; c) Community Health Workers; d) Citizens as informants; e) Schools; f) Community health collaborators

3.3 Types and approaches of citizen data for infectious diseases

The study identified two kinds of approaches to infectious disease surveillance, as outlined in Table 3: civil society-led and government-led initiatives. Community-level approaches aim to integrate citizen feedback, improve health reporting, and inform policy through advisory units, yet no fully community-led citizen data initiatives currently exist. Many stakeholders view existing government data systems as sufficient, reducing demand for separate citizen data efforts. While digital tools like apps and websites hold promise, barriers such as privacy concerns, limited public awareness, and weak technical infrastructure hinder their adoption. Although data flows from local facilities to the CDC are in place, there is a growing shift toward prioritizing timely, relevant data over incentive-based reporting. Inclusive digital citizen data platforms could bridge these gaps, enhancing citizen engagement and enabling faster, more responsive outbreak management.

Most citizen data initiatives in Vietnam are nascent but show potential in boosting disease surveillance. They highlight the necessity for integrated, user-friendly tools and robust community engagement. Challenges, mainly arising from insufficient resources like technical, staffing and funding shortages and stigma, necessitate policy support and public awareness campaigns. Upcoming efforts need to prioritize scalable pilots, cross-industry collaborations, and well-defined legal frameworks on data privacy.

Table 3: Types and approaches of citizen data for infectious diseases

Tool	Description of the type of data	How citizens are involved
Zoonotic Infections (VIZIONS)[14]	Photographic records of occupational exposures, zoonotic and perceived disease risks arising from livestock management and slaughter processes.	Farmers/food workers developed photo films of daily practices and narrations of disease transmission risks that were revised to develop stories that informed training materials and 30 films to initiate community dialogues.

e-Dengue App[15]	Locals use mobile apps and digital tools to report mosquito sightings, identify breeding sites, and share symptoms of dengue fever.	Citizens report mosquito sightings, locate potential breeding sites, and share information on dengue symptoms.
Programme Meso Vietnam[16]	Community-collected data from four communes on mosquito larval density, breeding site locations, and the distribution of Mesocyclops (crustaceans that prey on mosquito larvae) to assess vector control effects.	Trained local volunteers, termed 'collaborators', conduct monthly household larval surveys, record data, reintroduce Mesocyclops, share findings at commune meetings, lead community trainings, school workshops, clean-up drives, and participate in health promotion campaigns.
Wolbachia Community Engagement[17]	Socio-ecological data on community opinions, understanding, and acceptance of Wolbachia-based dengue control.	Residents in Khánh Hòa Province, through surveys, focus groups, and interviews, share concerns and preferences on consent processes, messaging, and local leadership engagement for Wolbachia mosquito trials.

Highlights from HCMC community consultation

Beyond dengue, community members identified several priority infectious diseases, including HIV/AIDS, COVID-19, influenza, mpox, measles, and hand-foot-and-mouth disease. Disease reporting was primarily driven by perceived severity; individuals were more likely to report illnesses deemed life-threatening or when prompted by public health announcements. Most citizens saw reporting as necessary primarily for accessing treatment at pharmacies or hospitals, while actual outbreak notifications were often viewed as the responsibility of health authorities. For instance: *Parents of school children and occupants in residential buildings are often reminded to report diseases to health authorities, but they choose not to, unless there is a serious outbreak going on in their neighbourhoods. – Community consultation participant, HCMC.*

Official disease detection relies on healthcare facilities as the first point of contact, with minimal direct citizen input. Bottom-up reporting approaches have had limited success and are typically activated only during major outbreaks. While the HCMC Center for Disease Control provides advanced public health updates, these communications often lack local relevance. In contrast, grassroots actors, such as local authorities and informal key opinion leaders, are seen as more responsive and have become critical sources of real-time citizen data.

To strengthen citizen data efforts, communities emphasized the importance of making data contributions meaningful and empowering. Key motivators include giving citizens control over their data, ensuring they see tangible benefits from participation, and involving skilled contributors to maintain technical data quality. Nonetheless, stigma surrounding infectious diseases and concerns about protecting others' privacy remain major barriers to community reporting and sustained citizen data engagement.

3.4 Opportunities and challenges

While there are some promising examples, citizen data for infectious disease efforts remain limited. In part this could be because existing efforts are undocumented or rolled out at a small scale. The limited visibility of citizen data may reflect its small scale or undocumented nature, as well as the HCMC context, where strong public health institutions like the Center for Disease Control (CDC) and Oxford University Clinical Research Unit (OUCRU) reduce perceived data gaps and the urgency for citizen data. Below, the opportunities and challenges of using citizen data to address infectious diseases in Vietnam can be grouped into seven major categories:

1. Data systems and integration: Surveillance remains siloed and centralized, lacking direct citizen-to-database pathways. Data is provincially confined, with limited real-time self-reporting or community alerts, creating blind spots in early detection.

> *There isn't any channel for citizens to report directly… no software system to collect data… only the province where a case is reported can download data. We can't access other provinces' information. We have a comprehensive information architecture… future systems will allow direct community input into the disease surveillance system.*
> – KII, public health official.
>
> *Vietnam's surveillance system is characterized by its centralized, government-led structure… reliant on routine reporting.*
> – Stakeholder meeting participant.

Further, electronic health records and unique health IDs present an appropriate and timely digitized pathway for integrating citizen data into national data ecosystems.

> *The consensus was that [citizen data] is needed… to improve the detection of outbreaks.*
> – Stakeholder meeting participant, HCMC.

> *Currently, efforts are underway to establish electronic health records and a unique health ID for each citizen.*
> – Stakeholder meeting participant, HCMC.

Legal and operational barriers: Scaling citizen data is hindered by the absence of integrated infrastructure, ambiguous legal frameworks, and rigid consent rules under Decree 13.

> *individuals have the responsibility to report but they must go to a healthcare facility.*
> – KII, HCMC CDC.

While citizens are legally required to report infectious diseases, citizen data lacks formal recognition and clear authority for government use. Its implementation is further obstructed by limited access to reporting tools, multiple layers of approval, and the Ministry of Health's dependence on People's Committees for public engagement.

> *The legal basis for using citizen data to inform government disease-control efforts is unclear.*
> – KII, public health official.
>
> *Citizens are legally obligated to report when they have an infectious disease. This is stipulated in the law. We just need to give them accessible tools. The Ministry of Health doesn't have authority over the public directly... it has to go through the People's Committees.*
> – KII, Lecturer in Public Health.
>
> *We must contact the ward chairman… then be accompanied by local authorities and neighborhood leaders to collect data.*
> – KII, dengue fever group.
>
> *Despite the presence of disease reporting laws, citizen data is not legally formalized.*
> – KII, dengue fever group.

> *The legal basis for using citizen data to inform government disease-control efforts is unclear.*
> – Stakeholder meeting participant.

Technological and analytical innovations: Citizen data initiatives are limited in scaling, which reduces data representativeness and predictive accuracy.

> *We require a large number of cases to make accurate predictions.*
> – KII, dengue virus group.

However, emerging technologies offer promising solutions with stakeholders emphasizing the potential of artificial intelligence (AI) and machine learning (ML) to strengthen citizen data analysis.

> *AI can accelerate citizen data processes and filter out inaccurate data,while ML can derive meaningful insights from large datasets.*
> – Stakeholder meeting participants, HCMC.

While WHO recommends using community-level indicators for citizen data surveillance, integrating citizen data into existing systems adds IT and operational burdens due to already extensive disease reporting.

> *WHO advises using community-level indicators for citizen data, not hospital diagnoses.*
> – KII, HCMC CDC.
>
> *Our current system already includes 40 diseases; integrating citizen data adds an IT burden.*
> – KII, Lecturer in Public Health.

Privacy, trust, and participation: Community understanding of citizen data remains limited, while privacy worries, lack of consent transparency, and perceived risks also limit participation.

> *To me, it seems relatively new… [but] I have actually worked with that type of data before.*
> – KII, dengue virus group.

> *People are unfamiliar with citizen data as a term but have used it in practice… [the] public doesn't yet see the benefits of reporting diseases; … People fear their personal info being compromised or misused.*
> – KII, HCMC CDC.

Fragmented coordination among health agencies, local authorities, and researchers continues to hinder the effectiveness of citizen data: Disjointed efforts can lead to inconsistent data collection and delays in public health responses.

> *The Ministry must work through People's Committees to reach citizens effectively... health projects require approval from multiple levels.*
> – KII, Lecturer in Public Health.
>
> *Even with hospital-based data, HCMC CDC can't access data from other provinces directly…There's no integration platform linking commune-level data directly into centralized systems.*
> – KII, HCMC CDC.

Strengthening collaborative mechanisms between stakeholders can ensure the collection of more representative data and enable timely, evidence-based interventions.

Emerging tools such as social media monitoring offer new avenues for disease surveillance through early detection of potential outbreaks:

> *Monitoring social media for potential outbreaks [allows] launch[ing] investigations accordingly.*
> – Participant at stakeholder meeting.

Integrating such innovations with traditional surveillance systems can significantly improve early warning capabilities.

> *Commune-level taskforces monitor social media and launch investigations.*
> – Participant at stakeholder meeting.
>
> *Local committees played key roles in past citizen data events—like plague surveillance using dead rats as signals.*
> – KII, Lecturer in Public Health.

Privacy concerns remain a key barrier to public participation in citizen data initiatives: Risks of stigmatization or breaches in confidentiality may discourage individuals from sharing health-related data.

> *People avoid sharing their phone numbers now because of how their data has been misused before. If people feel protected, they will voluntarily report. It's our job to explain the benefit.*
> – KII, HCMC CDC

Mitigating these risks through data aggregation and strong confidentiality safeguards is essential to protect individual rights while enabling responsive public health action.

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A Scoping Study on the Use of Citizen Data for Infectious Diseases in Colombia

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in the Republic of Colombia[1] to assess the potential for institutionalizing citizen data[2] to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in Colombia, highlights notable use cases, and explores key challenges, including policy and institutional barriers to collecting and utilizing citizen data. It also identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. The broader study covers Kenya, Malawi, Ghana, Vietnam, Colombia, and the Dominican Republic, focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever. In Colombia, the study specifically explored citizen data's application in addressing dengue fever and leishmaniasis.

1.2. Disease burden and prevalence

Dengue, malaria, and leishmaniasis remain among the most pressing vector-borne public health challenges in Colombia. In recent years, there has been a marked increase in the incidence, severity, and geographic spread of these diseases. Colombia experienced one of its worst dengue outbreaks in recent history in 2024.[i] By epidemiological week 15 of 2025, approximately 54,263 dengue cases had been reported, with around 2,780 new cases emerging each week.[ii] This spike has been driven by climate shifts, El Niño events, and the co-circulation of all four dengue virus serotypes, expanding mosquito habitats, and transmission periods.[3,4] Economically, dengue costs Colombia around USD $159.6 million annually. Ambulatory care and fatalities account for 75 percent of this, while indirect losses, mainly lost income due to illness or caregiving, total USD $92.8 million, disproportionately impacting low-income families.[5] On the other hand, leishmaniasis, particularly in its cutaneous form, continues to be endemic in rural and peri-urban regions of the country,[6] with cases reported in more than 30 departments.[7] As with dengue, efforts to control leishmaniasis are hindered by limitations in early detection, diagnostic infrastructure, and sustained vector control, especially in rural areas, regions affected by armed conflict, or those experiencing environmental degradation. The expansion of citizen data platforms and mobile disease reporting tools represents a new frontier for enhancing disease surveillance and response in under-served areas of Colombia.

2. Methodology

The study applied a qualitative scoping methodology to examine the landscape of citizen data for infectious disease prevention and response in Colombia. It was structured in three phases: document review, key informant interviews (KIIs), and a national multi-stakeholder convening. First, a document review was conducted at the onset of the study to map existing policies, institutional frameworks, and key actors involved in citizen data. This review also guided the selection of diseases based on their public health relevance and the availability of evidence on community participation in surveillance activities.

Subsequently, eight KIIs were conducted with representatives from government agencies, civil society organizations (CSOs), public health institutions, and research centres. Interviewees were purposively selected to capture a diverse range of perspectives on the generation, use, and governance of citizen data. In parallel, a national convening was held with the participation of 35 representatives from government, CSOs, and academia. During the event, government actors from Medellín and Bogotá shared experiences on current approaches to citizen data in disease surveillance and control, with practical examples from local health departments and community health initiatives.

The data collected from all activities were transcribed, thematically coded, anonymized, and analyzed. Key themes were identified and presented in the form of narrative summaries and supporting tables, providing both a descriptive and analytical view of the citizen data ecosystem in Colombia for infectious disease response.

3. Study findings

3.1. Policy and institutional framework

> *In Colombia, citizen data initiatives have been integrated into official systems. While there is no comprehensive study documenting how they are consolidated, progress has been made in community-based public health surveillance, which could be categorized as citizen data.*
> - KII, Data and Surveillance Expert, CSO

Colombia has developed a good foundation of policies and institutional frameworks for the surveillance and management of vector-borne diseases and neglected tropical diseases. Existing regulatory frameworks (Table 1) reflect a growing trend toward the adoption and integration of citizen data through community participation in disease surveillance and vector control.

Table 1: Policy and institutional frameworks, responsible agencies and integration relevance

Area of focus	Policy	Responsible agency	Opportunities/relevance to integration of citizen data

General infectious disease surveillance, vector-borne and NTDs	Integrated Management Strategy for Dengue Prevention and Control (IMS-Dengue)[8]	Ministry of Health and Social Protection (MSPS) (Ministerio de Salud y Protección Social), in collaboration with the Pan American Health Organization (PAHO)	Promotes multisectoral coordination and community-based interventions, offering a valuable opportunity to integrate citizen data into outbreak mapping and early detection efforts.
	National Plan for Control of Leishmaniasis (within the national Ten-Year Public Health Plan, 2022-2031)[9]	MSPS; Instituto Nacional de Salud (INS)	Recognizes the need for rural surveillance and intersectoral collaboration, highlighting the potential of citizen data to enhance case detection in hard-to-reach areas.
	National Public Health Surveillance System (SIVIGILA)[10]	INS	Colombia's core reporting system for infectious diseases can be enhanced through citizen data tools.
General data and statistics governance and digital transformation	Ten-Year Public Health Plan (PDSP) 2022–2031[9]	MSPS	The overall policy framework emphasizes equity, decentralization, and community participation.
	National Digital Health Strategy 2023-2026 (aligned with CONPES 3975)[11]	MSPS; Ministry of Information and Communication Technologies (MinTIC) and National Planning Department (Departamento Nacional de Planeación - DNP)	Digitize health information systems, providing the technical infrastructure for citizen data integration.

	Law 1581 of 2012 – Personal Data Protection Law[12]	Superintendence of Industry and Commerce (Superintendencia de Industria y Comercio - SIC)	Establishes data protection rules and critical use of citizen data.
General ecology, vector control, and disaster response	National Policy for the integral management of biodiversity and its ecosystemic services (PNGIBSE)[13]	Institute of Hydrology, Meteorology, and Environmental Studies (IDEAM)	Overall policy on the collection, analysis, and dissemination of scientific and technical information related to environment, hydrology, meteorology, and land use.
	Law 1523 of 2012 – National Policy for Disaster Risk Management[14]	Office of the President	Coordinate disaster response across different ministries, departments, and local governments

3.2. Citizen data stakeholders working in the country

Citizen data efforts in Colombia involve a broad ecosystem of actors spanning the public sector (national and territorial entities), civil society (including organized citizen groups), academia working on development issues, and the technology sector. Each category contributes uniquely to the generation, validation, use, and institutionalization of citizen data in the surveillance of infectious diseases, particularly those that are vector-borne (Table 2). Key institutions include Departamento Administrativo Nacional de Estadística (DANE), Colombia's National Statistical Office; Ministerio de Salud y Protección Social (MSPS), the Ministry of Health and Social Protection (national health policy leader); and Instituto Nacional de Salud (INS), the National Institute of Health, which oversees public health event surveillance. At the local level, departmental, district, and municipal health secretariats serve as operational arms. Direct citizen data actors comprise community action boards (juntas de acción comunal), community leaders, and volunteers. Instituto de Hidrología, Meteorología y Estudios Ambientales (IDEAM), the Institute of Hydrology, Meteorology, and Environmental Studies, provides climate data (temperature, precipitation, humidity) used in risk prevention, alongside public health indicators and epidemiological alerts. The other cross-sectoral efforts include SISPRO's (Sistema Integrado de Informacion de la Proteccion Social, the Integrated Social Protection Information System) digital infrastructure (which, while not designed specifically for citizen data, can support citizen data integration); territorial health planning units as emerging hubs for localized citizen data use; and open data initiatives by DANE and Departamento Nacional de Planeación (DNP), the National Planning Department, that offer pathways for official citizen data recognition.

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders
State agencies and local governments - Integrate data into public health surveillance systems, e.g. via SIVIGILA (Sistema Nacional de Vigilancia en Salud Pública, the National Public Health Surveillance System). - Set standards for health data quality and ethics. - Guide policy and research priorities. - Act as end-users of citizen data for decision-making and outbreak response. - Enable sub-national adoption of citizen data tools in departmental and municipal health structures. - Research data reliability and impact. - Identify local actors, centralizing information from community health monitors and managers, and carry out appropriate actions in the territory.	a) MSPS;[iii] b) INS; c) Departmental Health Secretariats (e.g. Antioquia, Valle del Cauca); d) National Administrative Department of Statistics (DANE);[iv] e) Departmental and District Health Secretariats (Secretarías Departamentales de Salud)[v] and Municipal Health Secretariats;[vi] f) IDEAM (Institute of Hydrology, Meteorology and Environmental Studies);[vii] g) Superintendence of Industry and Commerce (SIC);[viii] h) Ministry of Information and Communication Technologies (MinTIC)[ix]
Development partners and donors - Fund digital and community health surveillance.	a UN Agencies; b) Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ); c) USAID; d) World Bank Health Programs

- Advocate and provide technical assistance. - Integrate citizen data into national systems via pilots or scale-ups. - Support multi-sectoral platforms on development data.	
Academia and research institutions - Research and apply citizen data methodologies. - Develop analytical tools. - Educate future professionals on ethical and effective citizen data use. - Develop ethical frameworks for community data. - Serve as neutral validators for citizen data insights.	a) Universidad de los Andes; b) Universidad Nacional de Colombia; c) Fundación Instituto de Inmunología de Colombia (FIDIC); d) Universidad del Valle (Cali); e) PECET Research Group at the University of Antioquia; f) The Public Health Institute of the Pontifical Xavierian University; g) Other universities in the country
Civil society organizations (CSOs) - Facilitate grassroots and community surveillance. - Mobilize vulnerable populations (e.g. displaced, rural, or indigenous communities). - Advocate for citizen data use in local public health policy. - Bridge trust between citizens and government health agencies.	a) Juntas de accion comunal (community action boards); b) Comités de participación comunitaria (community participation committees); c) Juntas asesoras comunitarias en salud (AI overview community advisory boards in health); d) Lideres de salud (health leaders); e) Redes comunitarias de salud (community health networks) f) colaboradores comunitarios (community collaborators)

Private sector and technology providers - Provide mobile, digital, or geospatial infrastructure for citizen data platforms - Support data hosting and analytics tools - Co-develop citizen data solutions with health authorities and CSOs - Innovate around mHealth, WhatsApp reporting bots, and citizen dashboards	a) DANE Tech Innovation Hub; b) Datasketch; c) Movistar/Claro Colombia (mobile operators); d) SocialTIC; e) 1DOC3 (health chatbot startup)
Notes: The other cross-sectoral efforts include SISPRO (Sistema Integrado de Informacion de la Proteccion Social),[15] which, though not citizen data-specific, offers a digital foundation to integrate citizen data; territorial health planning units emerging as key nodes for localized data coordination; open government and open data initiatives by DANE and DNP[16] that provide pathways for citizen data to gain formal recognition; and civil society organizations, including community councils, indigenous reservations, and groups actively generating data through their own initiatives and resources.	

3.3. Types and approaches of citizen data for infectious diseases

> *The early warning system (rumor surveillance)[1] proposed by the National Institute of Health to complement syndromic surveillance involves collecting information from various media sources, including social media and community radio stations.*
>
> – KII, Data and Surveillance Expert, CSO.

The study identified the following approaches to infectious disease surveillance as outlined in Table 3 as collaborative government and civil society-led, community-led, government-facilitated and technology-based. These approaches differ in how data is generated, who owns and uses it, and the ways it informs public health decision-making. Most current efforts in Colombia fall under models led by institutions that work in collaboration with communities during implementation. These joint efforts help to establish coordinated actions on the ground and integrate citizen data within official systems, for instance, in the identification of confirmed malaria cases. Some tools and platforms, while primarily classified as administrative data systems, incorporate participatory elements and offer opportunities to expand citizen-centered data processes.

Table 3: Types and approaches of citizen data for infectious diseases[x]

Tool	Description of the type of data	How citizens are involved
RevCom: Community-Based Epidemiological Surveillance Network[17]	Led by the INS, the system combines early warnings, epidemiological and geospatial data, and community event reports. INS supports communities by identifying key actors, offering health training, and providing supplies as needed.	Trained community "watchers" from remote or Indigenous areas report health events and mobilize local response, while also linking communities with institutions for coordinated action.
ColVol Project[18]	Led by Colombia's Ministry of Health, INS, PAHO/WHO, and the Inter-American Development Bank (IDB), the initiative trains community collaborators in malaria diagnosis (microscopy and rapid tests), treatment delivery, and supplies them with tests, medications, and essential materials to carry out the strategy.	Trained volunteer collaborators in rural and remote areas diagnose, treat, and report malaria cases, supplying data for national surveillance. The strategy is driven by their activities within local territories.
Community-Based Epidemiological Surveillance (VEBC)[19]	Led by the Bogotá District Health Secretariat, the entity supports community networks and local actors in reporting issues via physical formats, provides training, and engages in community spaces to offer feedback on ongoing processes.	The community reports issues such as waste mismanagement, poor public services, and environmental risks, while organizing groups like COVECOM (Comité de Vigilancia Epidemiológica Comunitaria, the Community Epidemiological Surveillance Committee) to inform residents, assess local health conditions, and engage institutions in resolving problems.

Vector-Borne Disease Control and Prevention Program, including the Student Anti-Dengue Committees (CEA)[20,21]	Led by the Medellín Health Secretariat, the initiative engages communities through training in symptom self-reporting, identification of mosquito breeding sites, ovitrap monitoring, and entomological index surveys (LIE). It also supports Student CEA, groups of 10 students from grades 3 to 8, who are trained to promote awareness of vector-borne diseases in schools and families.	Citizens aid surveillance and vector control by reporting cases, monitoring breeding sites, and addressing risk factors. Students become peer educators, promoting dengue prevention locally and often continue these efforts beyond school.

Progress by DANE and INS in adoption of the Copenhagen Framework on Citizen Data

DANE is developing a citizen data Maturity Model to assess the capacity of civil society organizations (CSOs) to produce and use citizen data in areas such as the environment, citizen participation, diverse populations, and gender-based violence. So far, 150 CSOs with an interest in citizen data have been mapped, with 95 already implementing initiatives in these domains, such as *Registro Multidimensional Wayuu*, *Partera Vital*, and *App Diversa*. Key insights from this work highlight the need for clear and simple language, inclusive engagement of all civil society actors, and fostering active citizen participation and listening.

Progress by the INS: Colombia's Public Health Surveillance System, in operation for 17 years, is indicator-based, passive, and periodic, relying on standardized forms to monitor 107 notifiable conditions. These include communicable and non-communicable diseases, endo-epidemic illnesses, vaccine-preventable diseases, healthcare-associated infections, and conditions linked to environmental or sexual health risks. Priority diseases include leishmaniasis, malaria, dengue, Chagas, yellow fever, chikungunya, zika, and leprosy. Complementary strategies, such as event-based surveillance, through self-reporting, media monitoring, community input, AI, and alert systems, aim to detect public health "rumors" or emerging threats.

3.4. Challenges and opportunities

The study identified the following challenges and opportunities in utilizing citizen data for surveillance and response to infectious diseases in Colombia.

1. Legal and ethical safeguards for citizen data: Colombia's regulatory framework, Law 1581 of 2012, establishes the general principles for the protection of personal data. However, the framework has gaps regarding the handling of sensitive health-related data, when collected outside formal information systems. Concerns persist around informed consent, data ownership, and the existence of effective feedback mechanisms for the communities that generate or provide such data, highlighting the need for data protection and safeguarding frameworks that address the requirements of citizen data in disease surveillance.

All the regulations of the National Institute for Food and Drug Surveillance (INVIMA) are outdated and incompatible with citizen data principles. – KII, University of Antioquia.

2. **Digital infrastructure**: Although national platforms such as SIVIGILA (Sistema Nacional de Vigilancia en Salud Pública, the National Public Health Surveillance System) exist, there are connectivity challenges among the most vulnerable, rural communities and regions like the Amazon and the Pacific, which are further excluded by the lack of digital infrastructure including mobile and internet connectivity. This hampers the capacity of state and civil society to collect and share information within communities, underscoring the need for investment in last-mile digital infrastructure to reach Colombia's under-served populations.
3. **Interoperability of data systems:** Existing citizen data approaches that are civil society and community-led are being integrated into the legacy health and surveillance systems. However, the integration of information to guide actions in public health is a process that needs to be specified in the country. This reflects an opportunity for sustained investment in integrating legacy health systems with community-level citizen data, creating richer datasets to strengthen infectious disease surveillance and response.
4. **Limited capacity for citizen data use and analysis:** Significant gaps exist in the skills and infrastructure needed to manage and analyze citizen data, especially in rural and high-risk areas. Health, statistics, and information professionals often lack training in both quantitative and qualitative data methods, with disparities most acute in municipalities classified as categories three to six, which face severe fiscal and staffing constraints. These challenges are compounded by limited digital infrastructure and the absence of standardized tools for citizen data reporting. A systemic, multi-level approach is essential, building capacity from national to community levels in surveillance, data management, and qualitative analysis (e.g. thematic methods using NVivo, the qualitative data analysis software). Ensuring access to anonymized citizen data through open data portals would also enhance data use, knowledge sharing, and community-driven disease surveillance.

> *A significant weakness of most municipalities serving rural communities is that they are classified as sixth category (i.e. with the lowest administrative and fiscal capacity). As a result, the burden falls on the departmental level, which lacks the resources to consolidate, validate, and analyze the data in a timely manner, or to formulate an appropriate response.*
> - KII, Data and Surveillance Expert, CSO.

5. **The need for climate data in disease surveillance and response:** Despite progress in disease surveillance, the integration of health data with weather, climate, and environmental information remains limited, hindering effective response to environmentally sensitive diseases like dengue and zika. Investing in the linkage of these data systems offers a pathway to improved understanding, preparedness, and response, highlighting the need for stronger coordination across health, technology, and environmental sectors.

Climate monitoring data should be integrated into the early warning system.
- KII, Data and Surveillance Expert, CSO.

6. **Inadequate digital and participatory frameworks for citizen data:** Despite advances in open data platforms like SIVIGILA and Datos Abiertos, there is a gap in frameworks to enable meaningful citizen participation. Tools such as Reporta Bogotá, ColVol, and participatory forums (e.g. health councils or *cabildos de salud*) remain limited in reach, often excluding rural and vulnerable communities. Enhancing participation through low-tech digital solutions, like SMS and call centers, and leveraging local networks presents a clear opportunity to bridge citizen data gaps and scale community-driven surveillance in under-served areas.
7. **Limited integration of sectors:** Despite the growing interest in participatory health governance, information on the role of citizen data in surveillance remains limited among key actors involved in prevention and control efforts in human, environmental, and animal health, including local health departments and academic institutions. This presents a timely opportunity to adapt the Copenhagen Framework on Citizen Data and institutionalize citizen data in health surveillance by ensuring data quality, partnerships between the NSO and civil society organizations, and aligning policies to recognize citizen data alongside official statistics.

Another challenge is ensuring feedback: those who report need to feel that their input has an impact. If they do not see results, they may become demotivated. Showing them, for example, that a reported event led to concrete medical attention helps strengthen their sense of ownership in the strategy.
- KII civil society organization

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[i] This 2025 study, funded by the Global Partnership for Sustainable Development Data, was conducted by Strathmore University's Natural Capital Hub (SNCH) for national multi-stakeholder convenings in strategic partnership with the National Administrative Department of Statistics (DANE). It explored the potential to institutionalize citizen data to enhance policymaking in the prevention of and response to environmentally sensitive infectious diseases. "Citizen data refers to data originating from initiatives in which citizens participate at different stages of the data value chain, guided by key principles that promote inclusive, responsible, professional, and ethical production and use, regardless of whether the data is integrated into official statistics. Key aspects include the sufficient and meaningful participation of

citizens to the greatest extent possible, and participation occurs throughout the entire value chain." *(Copenhagen Framework V 1.0, United Nations Statistics Division)*

[ii] In Colombia, the term *Citizen Data* is commonly used to refer to *citizen generated data*. For consistency, this report will use citizen data throughout.

[iii] The Ministry initiated a proposal for community-based surveillance; however, the responsibility for its implementation was delegated to the INS.

[iv] DANE is currently developing quality assurance protocols and has collaborated with civil society and UN agencies on pilot projects. By adopting and adapting the Copenhagen Framework, DANE has mapped citizen data initiatives and is working on policy development, thereby contributing to better practices both nationally and globally.

[v] Local government health departments are responsible for public health planning, coordination, supervision, and oversight of the General System of Social Security in Health, as well as health promotion and disease prevention. In Colombia's 32 departments and six districts, these entities coordinate the Community-Based Surveillance Network (ReVCom) in partnership with municipal health secretariats.

[vi] In Colombia's decentralized health system, municipal authorities are tasked with upholding the right to health by designing, implementing, and evaluating local health policies, plans, and programs. Their responsibilities include health promotion, disease prevention, and public health risk control. With 1,122 municipalities, each operates within a defined scope. Municipal health entities also lead the operationalization of ReVCom by identifying local actors, consolidating data from community health monitors and managers, and coordinating appropriate territorial actions.

[vii] The institute, aligned with national environmental policy, centralizes key environmental data while fostering transparency, citizen participation, and institutional coordination. Its focus includes air and water quality, deforestation, climate change, and related services. To improve decision-making, it integrates citizen data, illustrated by its work with academia on the Enandes project in Cauca, where eight community agroclimatic roundtables incorporated local climate knowledge. These initiatives both enhance evidence-based decisions and empower communities as active participants in environmental management.

[viii] It sets data protection regulations for critical national use by both organizations and individuals and implements policies from the Ministry of Health and Social Protection (MSPS), including the central reporting system that incorporates ReVcom (the Community-Based Epidemiological Surveillance Network).

[ix] Design, adopt, and promote policies, plans, programs, and projects in the ICT sector.

[x] The types of data described align with a typology that categorizes citizen data initiatives based on their primary function: to define/consult, collect, enrich, analyze, or disseminate. These categories/types are highlighted in bold in Table 3.

A Scoping Study on the Use of Citizen Data for Infectious Diseases in the Dominican Republic

1. Country context

1.1. Introduction

This country report presents the findings from a scoping study conducted in the Dominican Republic (DR) to assess the potential for institutionalizing citizen data to support better policies for infectious disease prevention and response. In particular, it examines the current citizen data tools and approaches used for infectious diseases in DR, highlights notable use cases, and explores key challenges, including policy and institutional barriers to collecting and utilizing citizen data. It also identifies opportunities for scaling the integration of citizen data into the country's infectious disease response. The broader study covers Kenya, Malawi, Ghana, Vietnam, Colombia, and the DR, focusing on cholera, schistosomiasis, leishmaniasis, and arboviruses like dengue and yellow fever. In DR, the study specifically explored citizen data's application in addressing dengue fever and cholera.

1.2. Disease burden and prevalence

Dengue fever and cholera are two of the DR's most pressing climate-sensitive infectious diseases, both of which have seen increased incidence due to environmental and urban vulnerabilities. Between 2023 and 2025, the DR experienced a sharp decline in dengue incidence, with suspected cases dropping from more than 18,000 to just 48 by epidemiological week 16 in 2025, one of the lowest rates in the Americas.[1,2]. This turnaround follows a severe outbreak driven by DENV-3 (one of four distinct serotypes of the dengue virus), which disproportionately impacted children and strained health systems in Santo Domingo, Distrito Nacional, and Santiago.[2] Cholera re-emerged in the DR in 2022, following cross-border transmission from Haiti.[3] By early 2024, more than 1,600 suspected cases had been reported nationally, concentrated in high-risk urban communities such as La Zurza, San Cristóbal, and Dajabón.[4] These cases were primarily linked to inadequate water and sanitation systems and poor waste management in informal settlements.[3]

2. Methodology

The study applied a qualitative scoping methodology using a review of relevant documents, key informant interviews (KIIs), and a national multi-stakeholder convening to examine the landscape of citizen data for infectious disease prevention and response. The documents review mapped relevant policies, institutional frameworks, and citizen data stakeholders, while identifying dengue fever and leishmaniasis as priority diseases based on public health importance and evidence of community surveillance. Five KIIs[i] were then conducted with purposely selected representatives to capture diverse perspectives on citizen data generation and governance. In parallel, a national convening in Santo Domingo brought together 32[ii] participants who shared experiences with community-based surveillance and citizen data integration into formal systems. Data collected from these engagements were analyzed and thematically presented using tables and narrative summaries.

3. Study findings

3.1 Policy and institutional framework

DR has made strides in setting policies, laws, and institutional frameworks (Table 1) to support the effective use of data in the surveillance, detection, response, and management of infectious diseases, vector-borne and neglected tropical diseases (NTDs). Though not explicitly referencing citizen data, existing policies in the DR support decentralized data, community engagement, and digital health, offering a good foundation for citizen data integration. However, large-scale implementation remains limited.

Table 1: Policy and institutional frameworks, responsible agencies and integration relevance

Area of focus	Policy	Responsible agency	Opportunities/relevance to integration of citizen data
General infectious disease surveillance, vector-borne and NTDs	Integrated Strategy for Arbovirus Control (Estrategia Integrada para el Control de Arbovirus)[5]	Ministry of Public Health (MSP)–Department of Epidemiology	Emphasizes intersectoral coordination, community participation, and early detection, creating a clear entry point for integrating citizen data into vector surveillance and risk communication efforts.
	National Plan for Cholera Prevention and Control (Plan Nacional de Prevención y Control del Cólera)[6]	MSP–Environmental Health and Epidemiology Divisions	Emphasizes the need for community-level water, sanitation, and hygiene (WASH) data, where citizen data can enhance local outbreak alerts and enable rapid WASH response mapping.
General data and statistics governance and digital transformation	National Health Surveillance System (Sistema Nacional de Vigilancia Epidemiológica–SINAVE)[7]	General Directorate of Epidemiology (DIGEPI)	Serves as the national platform for disease notification and holds potential for integrating bottom-up reporting via digital citizen data tools.

	Ten-Year National Health Plan PLANDES (Plan Decenal de Salud 2021–2030)[8]	MSP–Planning Unit	Encourages decentralization and community-based health planning where citizen data can be integrated.
	National Digital Health Strategy 2024-2028 (Estrategia Nacional de Salud Digital, 2022)[9]	MSP; Ministry of the Presidency (DIGITAL República Dominicana)	Promotes the adoption of digital health tools, interoperability, and citizen engagement, key technical enablers for implementing citizen data systems.
	General Law on Protection of Personal Data (Law 172-13)[10]	Dominican Institute of Telecommunications (INDOTEL)	A legal foundation is essential for the ethical integration of citizen data, ensuring safeguards around consent, privacy, and data ownership; *however, reforms may be needed to strengthen protections specific to health data.*

3.2 Citizen data stakeholders working in the country

There are four key stakeholder groups: government/state agencies, development and donor partners, academia and research institutions, and civil society organizations, each with distinct roles in citizen data (Table 2). Additionally, the other cross-sectoral efforts include initiatives like the Sistema Nacional de Información en Salud (SINIS), which offers a platform for integrating citizen data, and the Open Government Partnership programs led by the Dirección General de Ética e Integridad Gubernamental (DGEIG), which promote participatory data practices, under the leadership of the MSP. Furthermore, the National Digital Agenda 2030 supports public innovation labs and hackathons, creating opportunities for citizen engagement in data-driven public health solutions. Community promoters also use citizen data approaches for additional surveillance.

> *The community promoters are enabled to identify malaria outbreak cases using a rapid test after training by CECOVEZ and MISPAS. Using a form, they assess the affected person, check for fever, and if the test is positive, administer the appropriate dose. If the patient is at risk, they are referred to the MISPAS offices in the community through the completion of a form.*
> – KII, IREM

Table 2: Stakeholders and their roles

Stakeholder categories and their roles	Stakeholders

State agencies · Lead national disease surveillance via Sistema Nacional de Vigilancia Epidemiológica (SINAVE) and Sistema Nacional de Información en Salud (SINIS). · Set national health data standards and policies. · Coordinate regional and municipal health structures. · Are key users and validators of health-related citizen data. · Support data-driven decision-making during outbreaks.	a) Ministerio de Salud Pública (Ministry of Public Health, MSP); b) General Directorate of Epidemiology (Dirección General de Epidemiología, DIGEPI) c) National Health Service (Servicio Nacional de Salud, SNS); d) National Statistics Office (Oficina Nacional de Estadística, ONE)
Development partners and donors · Fund and support health surveillance and digital data projects. · Pilot citizen data integration into formal systems. · Strengthen institutional capacity for community-health engagement. · Support multisectoral coordination around open data and transparency.	a) UN Agencies (e.g. UNICEF, PAHO/WHO); b) USAID; c) Centres for Disease Control and Prevention (CDC)
Academia and research institutions · Research infectious diseases and community data practices. · Develop analytics tools, dashboards, and digital visualizations · Build the capacity of health professionals in surveillance and citizen data use. · Provide ethics guidance and help validate community data models.	a) Universidad Autónoma de Santo Domingo (UASD); b) Instituto Tecnológico de Santo Domingo (INTEC); c) Pontificia Universidad Católica Madre y Maestra (PUCMM)
CSOs · Facilitate grassroots citizen data collection in under-served communities. · Support citizen involvement in early warning and health monitoring. · Mobilize marginalized populations (e.g. migrants, rural poor, women). · Advocate for citizen data integration into public health responses.	a) Participación ciudadana (citizen participation); b) Fundación Plenitud (Plenitude Foundation); c) Red Dominicana de Personas Viviendo con VIH/SIDA (Dominican Network of People Living with HIV/AIDS, REDOVIH); d) Centro de Orientación e Investigación Integral (Comprehensive Guidance and Research Center, COIN)

3.3 Types and approaches of citizen data for infectious diseases

The study identified two infectious disease surveillance approaches: civil society-led, and charity/foundation-led, each differing in data generation, ownership, use, and impact on public health decision-making. The citizen data initiatives are primarily leveraging community health workers and digital tools and there are growing examples of integration with national systems such as the Sistema Nacional de Vigilancia Epidemiológica (National Health Surveillance System, SINAVE). Some government-managed tools also incorporate participatory elements, presenting opportunities to expand citizen data systems. Moreover, citizen data approaches have been applied to other diseases like leptospirosis and dengue, often leveraging radio and media for community engagement.

> *There are various approaches that have been used in preventing leptospirosis in sugarcane and rice-growing areas, highlighting the importance of avoiding contamination and promoting preventive medicine.*
> – KII, Academia
>
> *We also have approaches that include radio and media like the Ganémosle al Dengue that features announcements made by health personnel, in which precautionary measures are recommended at the community level.*
> – KII, Regional Malaria Elimination Initiative Project (IREM)

Table 3: Types and approaches of citizen data for infectious diseases

Tool	Description of the type of data	How citizens are involved
Participación ciudadana (citizen participation in health monitoring)[11]	Information on public health service quality and disease outbreaks is increasingly being used to **hold authorities accountable** and **drive improvements** in healthcare delivery.	Citizens report on health service delivery and disease symptoms via community meetings.
AIME (Artificial Intelligence in Medical Epidemiology)[12]	Tech-enabled citizen sensing, developed by Rainier Mallol, leverages predictive analytics that combine citizen-reported data with environmental factors. Using AI models, it **forecasts** disease outbreaks, supporting timely interventions and public health preparedness.	Citizens contribute data through mobile apps and social media platforms.

Community-based use of OVitrap data for vector surveillance in the DR

In San José de Ocoa, OVItraps are used to monitor mosquito eggs with strong community involvement. Residents identify trap sites, collect samples, and report data, fostering local ownership and awareness. This participatory approach supports real-time mosquito surveillance and informs predictive models for dengue outbreaks. Universities work with communities to analyze the data, aiding preventive health strategies. Due to its success, the model will expand to at least five provinces in 2025, supporting a national shift from curative to preventive public health approaches

A good example of citizen data data is in the use of "Ovitraps" in San Jose De Ocoa, which allows for the detection of mosquito egg quantities in specific areas of a community and, based on that data, generates information of decision-making. Communities are involved in the placement and documentation of the Traps.

– KII, Academia.

Citizens learn how to read and interpret OVITRAP data, their reports become crucial in addressing environmental issues that have gained prominence. This kind of 'reporting' is often shared on social media, which helps feed into the 'rumor' software, which represents a 'reporting of a citizen's concern.

– KII, civil society organization (Plenitude Foundation).

3.4 Opportunities and challenges

Although promising examples exist, citizen data use in infectious disease management remains limited, likely due to under-documentation or small-scale implementation. Nonetheless, the opportunities and challenges in addressing infectious diseases in the DR fall into five main categories:

1. Integrating citizen data into surveillance systems: Citizen data provides a cost-effective, flexible tool for infectious disease surveillance in the DR, enabling timely, community-driven insights. In high-risk border provinces like Dajabón and Elías Piña, community health workers and residents play a key role in the early detection of and response to outbreaks such as cholera and malaria. Integrating citizen data into national surveillance platforms such as the SINAVE can deepen community engagement while helping to close persistent data gaps in disease monitoring.[13]

It should be integrated into a dashboard reporting to the Directorate of Epidemiology through SINAVE and ultimately support the design and redesign of public policies.

– KII, IREM

2. Building on the digital and participatory foundations for citizen data integration: Open data efforts like the *Portal de Datos Abiertos de Salud Pública (Public Health Open Data Portal)* promote transparency and broaden access to health information, while community platforms such as *veedurías ciudadanas (citizen oversight committees)* and *cabildos de salud (health councils)* enable citizen participation in health planning and oversight [14]. Pilot programs using SMS and mobile apps, though limited, show citizen data's potential to enhance surveillance.
3. Skills and capacity gaps on data: Disparities in data management and digital literacy at the municipal and community level remain a key challenge. Many local health teams lack training to analyze or validate community-generated data, and standardized reporting tools are still lacking.

> *WHO definitions and standards can be used, and criteria should be unified to improve standards, making it possible to share data and thus derive greater benefit.*
> – KII, academia

> *We are familiar with EWARS (Early Warning Alert and Response System), which combines epidemiological surveillance methods in a given location. The system combines ovitraps, mandatory notification, rumors, field surveys, and finally, cross-analysis with climate variables.*
> – KII, civil society

Legal and ethical safeguards: While Law No. 172-13 outlines general personal data protections, it lacks specific guidance for handling sensitive health data collected through citizen data. Key issues, such as consent, data ownership, and community feedback, remain unclear. The absence of a designated agency to oversee data protection creates overlap and ambiguity in enforcing safeguards.

> *There are legal challenges relating to the protection of health data, as existing data protection guidelines are more focused on financial data.*
> – KII, MISPAS

Infrastructure and interoperability: Although platforms like SINAVE exist, they offer limited pathways for integrating citizen data. Technical barriers, such as poor mobile coverage in rural areas, and budgetary constraints hinder real-time data flows and the integration of multiple data sources.

> *We do not yet have a methodology for integrating into the Main surveillance data system. This methodology should define how the data is collected and retrieved through creation of protocols and guidelines for community surveillance.*
> – Discussions from the National Convening

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[ii] National Convening attendants were drawn mainly from ONE (7), MISPAS (3), Linea 911 (1), CONAVIHSIDA (2), ADR (1), Fundación Plenitud (2), UASD (4), OPS / PAHO (1) ,Universidad INTEC (1), UNFPA (1) and SNS (1)

Annex 2: In-Depth Citizen Data Case Studies

Case Study 1: Using Citizen Data for Schistosomiasis Surveillance and Prevention in Uganda and the DRC

This case study has been collaboratively developed and validated by the ATRAP project team from the Royal Museum for Central Africa (RMCA) in Belgium, Mbarara University of Science and Technology (MUST) in Uganda and the University of Kinshasa (UNIKIN) in the Democratic Republic of Congo (DRC). The insights, impact, and information shared in this case study reflect the work and research carried out under the framework of the ATRAP project implemented in Uganda and DRC.

This case study represents a citizen data initiative that was led by an academic institution which engaged citizens directly.

Context and background

The Action Towards Reducing Aquatic Snail-Borne Diseases (ATRAP) initiative addresses the growing concerns of neglected tropical and vector-borne diseases like schistosomiasis in hard-to-reach areas of Uganda and the Democratic Republic of Congo (DRC).

According to the World Health Organization, more than 250 million people require preventative treatment for schistosomiasis, with 90 percent located in Sub-Saharan Africa. As a result, the WHO 2021-2030 strategy has heavily emphasized the need for schistosomiasis surveillance and prevention. However, for schistosomiasis prevention and control to work, the transmission cycle needs to be broken. This means that, apart from mass drug administration, targeted snail control and changes in community behaviour, such as stopping risky and unsanitary water practices, are needed.

However, there is a lack of trained snail experts and hence a lack of snail distribution data to design effective snail control strategies. Moreover, to induce sustainable behaviour change, active community involvement is key. The ATRAP initiative was created to help close this gap by actively engaging local residents to collect and share data on disease-transmitting snails and risky water practices with the broader community, making it easier to target interventions where they're needed most. In addition, bottom-up awareness campaigns were designed by the citizen scientists and their respective communities.

Description of the citizen data Initiative

Developed by researchers from the Royal Museum for Central Africa (RMCA) in Belgium, Mbarara University of Science and Technology (MUST) in Uganda and the University of Kinshasa (UNIKIN) in DRC and supported by the Belgian Development Cooperation, ATRAP was designed to put communities at the heart of data collection and dissemination. While ATRAP researchers oversee the initiative, locally trained citizens embedded in Uganda and DRC communities have led the ongoing work on the ground.

ATRAP's primary goal is to close significant gaps in schistosomiasis surveillance and prevention through active community involvement. The initiative employed the citizen science approach to respond to three key challenges: a lack of detailed data on snail populations in endemic areas, WHO's 2030 roadmap calling for greater community involvement in the control of neglected tropical diseases (NTDs) for sustained behaviour change, and the logistical difficulties of expert-led monitoring in remote regions. In response, ATRAP actively engaged local citizens to monitor disease-carrying snails to generate risk maps that could inform effective, more targeted policy interventions. At the same time, the engaged citizens led awareness campaigns to help shift and mitigate risky water practices within their communities.

For example, in Uganda, ATRAP, together with the community leaders, established a network of 25 local residents, also called citizen scientists, to actively monitor 76 water-contact sites around Lake Albert. Each citizen scientist was allocated two to three sites nearest to their residence, and they collected snail data weekly for 35 months. Equipped with smartphones, protective gear, scoop nets, and snail identification tools, they submitted geotagged data via the Kobo Toolbox. Once submitted, the research team (consisting of PhD students) reviewed, quality assured and validated the data, provided regular feedback to the citizen scientists, created maps of snail distribution and organized annual refresher trainings to provide upskilling and capacity development to ensure high-quality data.

The role of the citizen scientists went beyond data collection. They led the development of contextually tailored schistosomiasis awareness campaigns that catered for the needs of their diverse communities to induce behavior change. The preferred channels of communication included songs and drama, football matches, church announcements, and other community-driven activities to share findings on snail distribution and encourage safer water practices.

Data practices

Equity: Local researchers (citizen scientists) were recruited in collaboration with community leaders. The selection of the citizen scientists was done in collaboration with local leaders and was guided by a criterion: minimum age of 18, possession of a national ID, basic literacy skills, prior volunteer experience, and gender balance. The role of the local leaders in the selection process was to ensure that the citizen scientists were people that were trusted and respected in the community. The citizen scientists received financial compensation for their costs of transportation and internet connectivity.

Training and equipment: The citizen scientists were provided with theoretical and field-based training on schistosomiasis and snail hosts, including safety protocols, annually. They were provided with smartphones, scoop nets, protective gear and snail identification keys to enable data collection.

Type of data: The citizen scientists would scoop up snails every week and submit geotagged photos and counts of snails at designated water-contact sites for analysis and verification, as well as reporting on risky water practices.

Data quality: Data uploaded by the citizens into cloud-based submissions (via Kobo Toolbox) was verified semi-automatically. Files with reporting errors, like the wrong geolocation, would be flagged immediately. Advanced comparison between citizen and expert-generated data showed that both datasets agreed in identifying potential transmission hotspots.

Analysis and dissemination: The project researchers analyzed the data and shared results like maps of snail distribution and infection rates back with the broader communities through local dissemination events. The citizen scientists and village chiefs used these results to communicate risks and promote local water-behaviour change. A policy brief was shared with policymakers through a participatory stakeholder meeting.

Data governance: Data was curated and openly shared using the Global Biodiversity Information Facility (GBIF) platform. While there was no formal data governance structure, participants understood how data would be used and were involved in validation and communication. Trust was maintained through transparency and reciprocity between ATRAP researchers and communities. The citizen scientists also participated in peer review sessions during the annual refresher training.

Impact of the initiative

1. Change in the community

The ATRAP initiative led to significant changes within the participating communities, notably through increased health awareness and local ownership of schistosomiasis prevention. Communities became more informed about the disease and took charge of awareness campaigns, developing educational materials in local languages and conducting door-to-door outreach, collectively reaching more than 25,000 people in Uganda. These efforts contributed to visible behavioral shifts, with a decline in risky practices such as swimming in snail-infested waters. This was also evidenced in ATRAP community surveys, where the respondents who believed it is essential to avoid contaminated water rose from 73 percent to 91 percent. This citizen-led intervention also inspired the creation of local bylaws, including forming water committees, mapping boreholes, and installing signage to discourage open defecation.

Additionally, the citizen scientists emerged as respected local health advocates; some were elected to leadership roles or recruited into other health initiatives, demonstrating a strong link between knowledge translation and community leadership.

Involving the community members in snail monitoring also proved cost-effective, with citizen-led sampling costing 7.6 times less than expert-led efforts while offering much more than affordable and timely data collection (e.g. community empowerment and access to new data and informed intervention and decision-making). Finally, a ripple effect was also observed as family members of the citizen scientists also got involved in the snail sampling process, further expanding the initiative's knowledge exchange and reach.

2. Change in policy

The ATRAP initiative spurred growing interest and engagement from local government actors, marking an important step toward institutional recognition of citizen data. Community-led data collection improved local understanding of schistosomiasis risks and prompted district leaders to explore partnerships with development actors for further action. While full integration into national health systems is still evolving, ATRAP has reached more than 30 leaders at different levels of governance in Uganda and DRC through sharing newsletters on the initiative’s progress and organizing stakeholder meetings annually. Meanwhile, participatory workshops have united the citizen scientists, local NGOs, and local and national administrators to discuss outcomes and to co-design sustainable policy recommendations. In both countries, a policy brief was presented and discussed with the leaders during the final closing meetings.

One key step in ATRAP was assessing how much policymakers trust citizen data. Their responses fell into three categories: low trust, conditional trust, and high trust. About half expressed high trust, seeing citizen data as credible, frontline data sources. A third were cautiously supportive, dependent on proper training and oversight. A smaller group remained skeptical, viewing citizen data as applicable for early warning but not direct decision-making.

In response, the ATRAP team co-developed a Pathway of Trust in citizen data, a framework based on recommendations from policy actors to enhance the reliability and legitimacy of citizen data. This framework identifies key strategies to implement in a citizen data project lifecycle:

- Start: Build trust through elaborate community entry strategies to co-design and contextualize approaches that serve the project and community needs;
- Implement: Ensure data quality and credibility via training, supervision, and involvement of local leaders for support;
- Sustain: Promote transparency by sharing data, beyond simple dissemination, and protocols with policymakers to build long-term credibility.

Cross-cutting strategies like involving non-elected local leaders in oversight were also emphasized to reduce political bias and strengthen legitimacy. These efforts are paving the way for a more structured and sustainable use of citizen data in health policy in Uganda and DRC.

Challenges and opportunities from the initiative

The ATRAP initiative faced several challenges, including achieving gender balance in both countries. Also in DRC, gender-related norms challenged the participation of women and thus required adaptations like co-participation with spouses. Gatekeeping issues also emerged, as relying on single community leaders for participant selection led to bias in the nominated community members. Additionally, the absence of formal policy frameworks limited the integration of citizen data into local government systems.

Despite these hurdles, the project unlocked key opportunities. ATRAP built strong community networks of trained local residents ('local snail experts'), creating a foundation for future health and environmental efforts. Beyond biological data, the initiative captured valuable behavioral insights, helping tailor local awareness and behavior change strategies.

What's next

ATRAP has entered its second phase with a strong focus on action, using insights from phase one and findings from community surveys to design targeted interventions. This next phase responds directly to community and stakeholder priorities, such as the demand for safe water access and affordable snail control methods.

Key activities include the development of an AI-assisted mobile app to enhance accurate data collection; developing low-cost, plant-based snail control solutions like molluscicidal soap; testing rapid diagnostic tools to detect active disease transmission, and constructing an artificial wetland near the lake shores for water filtration.

In the second phase, ATRAP also aims to institutionalize the role of community members as local health monitors, embedding citizen data into ongoing public health efforts. Sustained success, however, will require flexible, long-term funding, policy frameworks that support the use of citizen data, and strong coordination across initiatives to avoid silos, duplication, and community fatigue.

Looking beyond the use of citizen data in addressing schistosomiasis, the ATRAP model has inspired another project in Chad: the ParaSahel project on interventions to tackle water-borne parasitic diseases. Some of the ATRAP research team members are closely involved in the ParaSahel project. The research team has also contributed to further publications on the promising potential of using citizen data in addressing Vector-Borne diseases in Africa.

Case study 2: Using Citizen Data through Community Surveillance to Detect and Respond to Visceral Leishmaniasis in Kenya

This case study has been collaboratively developed with a team from the Kenya Red Cross Society (KRCS), namely Hazael Kipyego and Paul Olale. The insights, impact, and information shared in this case study reflect the work and research carried out by KRCS and partners in Kenya. This case study represents a citizen data initiative that was led by members of a community, having received guidance and support on producing citizen data.

Tharaka Nithi is a county in the eastern part of Kenya with a population of approximately 400,000. The county's health profile indicates that in 2023, illnesses such as intestinal worms, amoebiasis, and non-communicable diseases were the main causes of morbidity for people over the age of five years.[1] Before 2021, there had been very minimal cases of outbreaks of visceral leishmaniasis in the county, and the government therefore did not count it as an endemic county for the disease.[2] However, after the Kenya Red Cross' early detection of the disease in 2021, through community-based surveillance, the county is now classified as endemic for visceral leishmaniasis.

Context and background

The Kenya Red Cross Society (KRCS) was founded in 1965 and officially acknowledged by the Kenyan Government as a voluntary aid society working alongside public authorities but maintaining its independence. As the sole National Red Cross Society in Kenya, the KRCS operates in alignment with the Fundamental Principles of the Red Cross and Red Crescent movement and operates as a humanitarian organization. The core structure of the KRCS encompasses the use of volunteers to enable the organization to deliver humanitarian action in time. Volunteers are drawn from diverse backgrounds, provided they adhere to the Society's values and principles.

As part of its role in humanitarian response, the KRCS also works to ensure disaster preparedness is a priority. Between 2018 and 2025, the KRCS has been part of the Community Epidemic and Pandemic Preparedness Programme (CP3). This initiative supports communities to be the first line of defense against epidemics and pandemics. Communities are trained on epidemic preparedness and response in communities (EPIC) and community-based surveillance (CBS) in order to prevent, detect, report, and respond to disease threats. CP3 was rolled out in six counties in Kenya: Tharaka Nithi, Narok, Bomet, West Pokot, Kakamega, and Baringo counties. CP3 takes a One Health approach because human-animal interaction poses significant public health risks due to zoonotic diseases, with substantial socio-economic consequences.[3]

Application of the CBS model to detect leishmaniasis in Tharaka Nithi County

In 2021, the skills that KRCS volunteers had gained through CBS were used in Tharaka Nithi County to detect an outbreak of visceral leishmaniasis. The robustness and sensitivity of the CBS system enabled a volunteer to detect an unusual illness through the ‘cluster of unusual illness classification’ in the CBS module.

The KRCS volunteer alerted their supervisor to an unusual health event in the county, with the patient exhibiting a distended abdomen and fever. Subsequently, 15 alerts were raised through CBS, samples were collected from the individuals and tested using an rK39 Rapid Diagnostic Test (RDT). Of these, 11 samples tested positive for leishmaniasis. This subsequently triggered a response plan in collaboration with the Ministry of Health (MoH), through the Neglected Tropical Diseases Unit. A total of 1,121 suspected cases were identified. A clinical assessment of the suspected cases was carried out in four health facilities, which had healthcare workers trained in visceral leishmaniasis management. 700 of these were sent for confirmatory PCR testing at the Kenya Medical Research Institute referral lab, while 421 were tested using rK39 by local MOH officials in collaboration with Médecins Sans Frontières (MSF). 94 of the 1,121 suspected cases tested positive. 46 (49 percent) of the positive cases were managed as inpatients at Marimanti Level 4 Hospital, while 48 (51 percent) were managed as outpatients.

In addition to detection, care, and treatment, the intervention triggered social behavior change interventions on disease prevention. This allowed the communities to appreciate imminent dangers of the disease in their community and to take precautions.

The use of multiple data sources and working with multiple stakeholders truly brought out the benefit of citizen data

The experience of using CBS to detect an outbreak of leishmaniasis highlighted the value of citizen data as an additional source of data to guide decision-making on responding to an outbreak of an infectious disease. As well-documented by the Kenya Red Cross, data from the CBS was meaningful when used alongside other data sources such as environmental risk data, social and behavior change data, as well as clinical and laboratory data. In addition to multiple data sources, the response to the disease outbreak also took a multi-stakeholder approach drawing action from government and non-government actors.

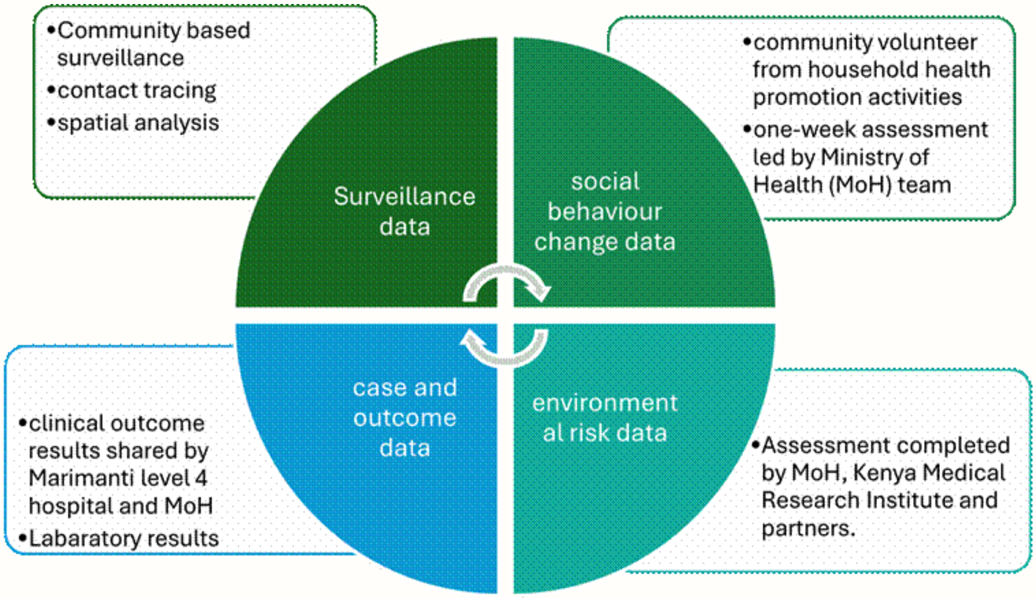

Figure 1: Using multiple data sources to improve response mechanisms to visceral leishmaniasis in Kenya[4]
Source: Reconstructed by author based on IOA Field Exchange 2022 report

Data processes for CBS and lessons learned

Data production and management process with CBS[5]

CBS data is generated with community members at the center. The system works through two groups: community volunteers who are selected by the community, and community health promoters (CHPs) who support government health promotion. The volunteers and promoters are trained on how to identify and report the alert signs and symptoms of potential health risks in their community. Members of the community are then encouraged to report incidents of health risks to the volunteers and promoters. The volunteers are also taught to protect the privacy of people they care for and to work in an ethically sound manner.

The community volunteers are grouped into teams and assigned a supervisor who will oversee their work and receive their alerts for quality assurance and for potential escalation to local authorities. Supervisors verify that each alert raised corresponds to a community case definition to establish if it meets the threshold for a reportable disease warranting further investigation with confirmatory laboratory testing.

True alerts are then escalated to human or animal health actors, and early action measures are taken.

To ensure affordability, the CBS model in Kenya uses a text-based SMS system. With a short USSD code the volunteers can dial in, which in turn activates leading questions for what they need to report on. Once reported, this goes to the supervisor for data verification. The CBS system is quite robust for detecting both diseases that are prevalent in a specific community and diseases that are not prevalent.

To truly put communities at the center of CBS, significant effort and investment are channeled into community sensitization and education on the conditions and symptoms that volunteers should look out for, guided by the community case definitions of the disease. This is done at the household level but also through group information sessions with the communities. This process, which comes before data collection, is important for empowering communities to understand health challenges and the right communication channels for reporting diseases.

Closing the loop on CBS

CBS relies on there being a mechanism in place with government and local authorities to ensure that alerts coming from the community are investigated and responded to. The relevant Ministry of Health, Ministry of Agriculture, National Centre for Disease Control, and the Red Cross or Red Crescent Society must all agree and work together to implement CBS.

CHPs and volunteers are trained to provide a first-level community response (such as community-level epidemic control measures and first aid) so they can assist while local authorities mount their response.

While it may not always be possible for government to adhere to the ‘7-1-7 strategy’[6] to respond to a disease outbreak, CBS has been encouraging communities to be part of the response e.g. through contributing financially by paying for their own vaccines in the case of Anthrax outbreaks.[7] In other situations, the KRCS has encouraged the private sector to provide subsidized vaccines and treatment.

Again, to truly demonstrate a community-centered approach, the CBS model encourages feedback to the community members after the data collection. These feedback meetings enable the communities to understand what was reported and the action that was taken. This further builds trust between community members and the community volunteers.

Lessons learned from using CBS to detect diseases

1. Data from CBS is reused for other interventions

As much as the data is first produced for CBS, over time the KRCS has observed that this data can be re-used for various interventions. For example, in Bomet county, the KRCS has been partnering with the organization Dig Deep Africa and the county government to use the data from CBS to guide interventions on water and sanitation hygiene (WASH) in the county. In addition, data from CBS has informed the work of the Vétérinaires Sans Frontières (VSF) in intervening on access to vaccines and rolling out animal vaccination in the country[8] .

2. The CBS system is robust enough to detect neglected diseases

With proper training of community volunteers on the CBS system, particularly in locations that are endemic for diseases like leishmaniasis, there is potential to further detect and respond to these NTDs much faster and in a cost-effective manner. The demonstrated example of detecting leishmaniasis in Tharaka Nithi county (see Case Study 1) demonstrates that the transmission of climate-sensitive infectious diseases should be monitored both in hotspots and locations perceived not to be hotspots, and robust systems like CBS can support this.

3. An empowered community is priceless in preventing and responding to infectious diseases

As demonstrated in various locations in Kenya where CBS has been rolled out, in communities that have taken the responsibility of taking action, there are positive results in addressing outbreaks of infectious diseases. The example of communities bearing the costs of responding to a disease outbreak in Narok county, for example, demonstrates the results of an empowered community. As reported by KRCS officials, in locations that have no CBS in place, such as refugee camps and some counties like Kisumu and Migori, that are currently experiencing cholera outbreaks, there remains late detection and response to disease outbreaks and often re-occurrence of vaccine preventable illnesses.

Looking ahead

The KRCS has institutionalized the CBS model as an approach that they use and maintain as part of their operations. It has currently expanded the model into the refugee camps of Dadaab and Kalobeyei and is working with partners to deploy CBS in additional counties. As reported by the Kenya Red Cross officials, with funds permitting, the CBS platform is quite robust so that citizens and communities can produce the data themselves, given sufficient training, guidance, and data management.

Looking to the future, there are plans to integrate the data from the CBS into the existing government data systems, such as the Electronic Community Health Information System (eCHIS), m-Dharura, Kenya Animal Biosurveillance Systems and others to inform the government's weekly situation reports on disease outbreaks. The KRCS prides itself on the depth and robustness of the data already produced through CBS; as such, they are keen to tap into the growing technological advancement and using AI to develop predictive models and analytics to support decision-making.

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Case Study 3: Community-led Monitoring for HIV Prevention in South Africa

This case study was collaboratively developed by the International Treatment Preparedness Coalition (ITPC) and the Networking HIV and AIDS Community of Southern Africa (NACOSA), and reflects the work, insights, and impact generated by communities, especially those most affected by HIV in Gauteng Province, South Africa.

This case study represents a citizen data initiative that was led by a civil society organization, in collaboration with local community-led organizations, which engaged people affected by HIV directly. While HIV sits outside the primary disease focus of this scoping study, it was included as a strong example of good practice in citizen data and community-led monitoring. This inclusion was agreed with Wellcome to ensure the case studies capture broader health-sector examples that illustrate effective, scalable citizen data practices.

Context and background

Around the world, communities are generating their own data to challenge inequities, influence decisions, and improve the services they rely on. In some healthcare contexts, this has taken shape through community-led monitoring (CLM), an approach that puts those most impacted by healthcare decisions at the center of data collection and use.

Rather than being passive recipients of care, CLM empowers communities to speak out about the challenges they face in the health system and to actively participate in designing monitoring frameworks to track those issues. Community members then receive training and data collection tools to track the availability, accessibility, affordability, and quality of public health services in real time. Using their lived experience alongside data-driven insights, they identify trends and gaps and work directly with health authorities to co-create solutions.

Building on this foundation, the International Treatment Preparedness Coalition (ITPC) has developed a comprehensive CLM model structured around four pillars: education, evidence, engagement, and advocacy. The model begins by equipping communities with knowledge about their health rights, what quality care entails, and data collection methods. Community members then collect both quantitative and qualitative data to generate insights. These findings are shared in local forums, such as Community Consultative Groups, where communities and duty-bearers come together to problem-solve. The final step, advocacy, is then used to push for improvements in services, policy, and funding.

ITPC began applying the comprehensive CLM model to HIV programming in 11 countries in West Africa in February 2017 and later adapted it to monitor disruptions in HIV services, including during COVID-19. What started as a rapid response has since evolved into a broader platform for community-led monitoring and prevention, now used across diverse contexts and disease areas across more than 20 countries.

Description of the initiative

The Citizen Science initiative was developed by ITPC using its established CLM model and implemented in South Africa, in partnership with Networking HIV and AIDS Community of Southern Africa, NACOSA. The goal was to generate timely, community-driven evidence to identify gaps in HIV prevention services, particularly around pre-exposure prophylaxis (PrEP) access, and to drive responsive action at both facility and district levels.

ITPC initiated the project as part of its broader mission to advance treatment access and to center community voices in health accountability. NACOSA led on-the-ground implementation, leveraging its experience in HIV service delivery and long-standing relationships with public health officials. NACOSA partnered with two local community organizations—one led by women living with HIV and another led by LGBTQI people—for data collection. Together, they aimed to strengthen community participation in health governance and supporting communities to generate data that could inform more inclusive and equitable service delivery.

The initiative kicked off in November 2020 and spent the first four months securing buy-in from the Department of Health, the Local Municipality, and Local AIDS Councils. Data collection started in March 2021 and wrapped up in October 2024. Over this period, the project trained 58 community monitors—40 of whom were people living with HIV, young people, sex workers, men who have sex with men, and trans* and gender diverse people—to collect data across 18 monitored sites, including 15 government facilities and three community facilities, covering each sub-district in the West Rand. The initiative used a mixed-methods approach, blending surveys, facility service tracking, and interviews with community members to generate both statistical insights and real-life experiences that shaped the analysis.

By 2023, the team had gathered a robust dataset from health facilities and communities in South Africa. When disaggregated by age and gender, the data revealed a troubling trend: young women aged 20–24 years had some of the lowest rates of pre-exposure prophylaxis (PrEP) uptake, despite having the highest rate of new HIV infections. This prompted the team to act quickly, using the evidence to inform targeted outreach and to redesign services to better reach and support young women and girls.

In response, NACOSA convened feedback sessions with communities and clinics, shared findings with health managers, and co-developed interventions such as youth-friendly clinic spaces, school-based outreach, and tailored health education campaigns. These local solutions were then linked to broader advocacy and planning efforts, ensuring that insights from community-generated data shaped district-level decision-making and contributed to more inclusive HIV prevention strategies.

Data practices

- Training and equipment: Community monitors were selected in partnership with a Local AIDS Council Secretariat and civil society leaders to ensure local ownership and to address power dynamics. Priority was given to residents from the monitoring areas, typically with a Grade 10 to 12 education, fluent in local languages and able to communicate in English. Monitors were paid monthly stipends aligned with Department of Health rates, recognizing their time and expertise. Monitors began with a three-day training that covered the program's goals, data collection tools, key indicators, and interviewing techniques. Accommodation was provided for those travelling from remote areas. To maintain quality and adapt to emerging needs, they undertook quarterly refresher sessions to reinforce skills and introduce new tools and techniques. In addition, field researchers underwent regular training (approximately every six months) in both quantitative and qualitative research methods, including the use of various tools and conducting key informant interviews. They also received Adherence Support training to strengthen clinic-based capacity. In response to gaps in gender-based violence service access, researchers completed WHO's LIVES training and participated in advocacy training, alongside Civil Society Forum leaders, to advance identified CLM initiatives. This layered approach ensured that monitors were not just data collectors, but empowered community researchers equipped with the skills to generate evidence, advocate for change, and lead the process in their own communities.

- Type of data: A mixed-methods approach was used, combining surveys, facility observations, and interviews to capture both quantitative data, such as service availability, and qualitative insights through personal stories and testimonials, particularly from young women and girls across the 18 sites. This enabled a deeper understanding of service gaps, surpassing what routine facility reporting alone could reveal.
- Data quality and validation: Data was verified weekly through community-based project staff, along with oversight by NACOSA and ITPC staff, which helped ensure data reliability. A peer learning approach was also introduced, where field monitors were taught how to review each other's work while onsite and provide immediate support or troubleshooting when needed, rather than waiting for the scheduled verification day. This approach built confidence and strengthened team participation.
- Analysis and use: Data was used in real-time to inform health facility feedback sessions and guide district-level planning. Age and gender-disaggregated analysis helped target interventions more effectively for young women and girls.
- Dissemination: The findings were shared publicly through open-access platforms, including Gates Open Research and on the ITPC website, to demonstrate their impact on young women and girls in the area. Most granular data remains confidential to protect the privacy of patients and participants.
- Data governance: All data collection and sharing practices were grounded in informed consent and ethical standards. While not all data is public, community members retained ownership and decision-making power over how their data was used (ensuring it served their priorities rather than being extracted for external use).

Impact of the initiative

1. Change in the community

The initiative increased awareness, improved health literacy, and built trust between communities and clinics. Armed with local data, citizens advocated for better access and helped shape services for young women and girls. As a result, in monitored sites, the number of young women and girls remaining on PrEP rose from 3,527 in January 2023 to 5,266 by December 2023, with 2,520 new initiations that year. Importantly, this growth was not a one-off spike—it was sustained over the year, suggesting that the changes were effective and relevant to those most in need.

One young community monitor shared: *"We used to feel invisible. Now, when we speak, they listen—and they act. Girls in our area are finally getting the support they need to stay protected."*

Beyond numbers, the initiative restored agency among communities and reinforced the idea that health equity starts with listening to those most affected.

2. Change in policy

The CLM initiative helped secure a milestone achievement in South Africa's National Strategic Plan (NSP) on HIV, TB and STIs 2023–2028.[i] For the first time, a national resource needs estimate for community-led monitoring was produced and included in the Plan's costing. This formal recognition of CLM as a core component of the country's HIV response is key for resource mobilization efforts and elevated the role of communities from data collectors to key implementers and accountability actors within the national health system.

Beyond the national level, CLM also influenced service delivery planning at health facility and district levels, demonstrating that disaggregated, community-based data can fill critical gaps in official reporting and surface the needs of groups often left behind, such as adolescent girls and young women.

Challenges and opportunities

CLM initially faced skepticism from some health providers who questioned the rigor and reliability of citizen data. These doubts subsided as citizen monitors consistently produced credible evidence and worked in close collaboration with clinics to address service delivery challenges.

Although the institutionalization of CLM in South Africa's National Strategic Plan on HIV, TB, and STIs offers a pathway for continuity through domestic funding, resource mobilization and sustainability remain a concern. Global health funding cuts threaten the long-term viability of community-led models, and replication is more challenging in sectors or regions lacking a robust civil society base.

Additionally, data privacy, ethical considerations, and safeguarding remain important and universal barriers, particularly when sharing sensitive insights externally. To mitigate these risks, individuals' identities and health facility names are anonymized in all public dissemination, and ITPC is in the process of acquiring clearance from an Institutional Review Board to further assure government stakeholders of its ethical data practices. At the same time, some governments are beginning to show greater openness to accessing community data more fluidly and in real time, reflecting confidence in both its credibility and the unique insights it provides beyond traditional health systems. On the community side, CLM actors are also becoming more adept at key processes such as ethical approvals, data cleaning and processing, and security protocols. This progress is helping to strike a balance between maintaining strong privacy safeguards and ensuring that data can be shared in ways that meaningfully influence high-level government decision-making.

Despite the challenges mentioned above, the model has unlocked new opportunities. ITPC is now exploring early warning systems to detect service gaps in real time and is developing public-facing dashboards to increase transparency and accountability. Plans are also underway to integrate CLM into broader capacity development initiatives and to support local clinic committees in strengthening community participation and oversight. There is also growing interest in adapting the CLM model to other health areas and regions—such as maternal health in Malawi or tuberculosis services in Eastern Europe—where community engagement remains limited but urgently needed. These efforts demonstrate the model's flexibility and its potential to strengthen equity-driven accountability across diverse health systems.

Another key opportunity is the application of CLM approaches to the early detection and response to infectious disease outbreaks, such as COVID-19 and Monkeypox. For example, during the COVID-19 pandemic, ITPC adapted its Community Treatment Observatory model into a rapid, short-term Community-Led Monitoring & Advocacy initiative in five countries. The initiative assessed access to HIV and/or TB care, treatment, and related human rights issues using "COVID-19-sensitive" indicators tailored to each national context. This initiative demonstrated how communities can be equipped to identify emerging health threats such as localized surges in fever, respiratory symptoms, or medicine shortages, and enable faster public health responses, especially in under-served or high-risk areas where formal surveillance is weak.

Beyond health, CLM methodologies can be applied to the ecological and environmental sector, enabling communities to monitor issues like air and water quality, land degradation, or the effects of climate change, and to influence environmental policy and accountability.

Finally, there is an opportunity to document and demonstrate the value for money of CLM methodologies which could further unlock funding to citizen data initiatives and address the sustainability concerns for public health funding.[ii]

What's next

In response to shifting donor landscapes in 2025, ITPC and NACOSA are now using the same approach of community-led monitoring to understand the impact of recent USAID, Global Fund and other bilateral funding cuts on health services in Malawi and South Africa. These funding cuts pose a serious threat to the sustainability of community-led approaches, particularly those that rely on local participation, real-time data, and grassroots accountability mechanisms. The findings from this research-Sounding the Alarm- will help inform advocacy and action on equitable health financing and the continued need for community-led monitoring mechanisms.

The organizations will use the results to engage with policymakers, donors, and partners to underscore the importance of protecting and scaling up community-led monitoring as a core part of resilient, people-centered health systems.

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[i] Goal 3: Build resilient systems for HIV, TB, and sexually transmitted infections (STIs) that are integrated into systems for health, social protection, and pandemic response.

[ii] The ITPC team estimates that on average it costs USD $9,500 per site per year to carry out a CLM activity to include: community-led monitoring—recruiting and training community monitors, data collection and analysis, feedback loops with clinics, stakeholder engagement, and coordination.

Case Study 4: Local Volunteers using Geospatial Data for Public Health and Infectious Disease Surveillance in Bangladesh

This case study explores the work of GroupMappers, a volunteer-driven initiative established in 2017 to support public health and infectious disease mapping in Bangladesh. GroupMappers was founded in 2017 by Prof. Richard Maude, Dr. Ipsita Sinha, and Sazid Ibna Zaman, driven by one key question: How can geospatial data help solve persistent challenges in malaria elimination? It began with funding support from the Wellcome Trust, as a collaborative initiative between the Mahidol Oxford Tropical Medicine Research Unit and the Communicable Disease Control (CDC) division of the Directorate General of Health Services (DGHS) in Bangladesh. Since then, it has evolved into a volunteer-powered network applying crowdsourced mapping, remote sensing, and spatial analytics to support malaria elimination, rabies control, dengue surveillance, and the COVID-19 response.

This case study highlights a non-government organization which produces data through volunteers. This case study was developed with contribution from one of the founders of GroupMappers, Mr. Sazid Zaman.

Context and background

Bangladesh has struggled with a fundamental problem: not enough accurate and current information about where people actually live. This is especially true in rural and remote areas, where community and settlement sizes remain largely unknown to health planners. Without this basic information, it's nearly impossible to track disease outbreaks or make sure healthcare provision reaches the people who need it most. A key challenge for the Ministry of Health and Family Welfare (MoHFW) and non-governmental organizations (NGOs) in conducting effective disease surveillance is precisely this lack of geographic information, including detailed, up-to-date maps and data on population distribution, that is essential for planning and response.

Additionally, the traditional approach of using paper maps and expensive GPS equipment simply wasn't working. It was too slow, too costly, and couldn't be expanded to cover the entire country. Other challenges include lack of technical capacity in collection and use of geographic data and the absence of a data-sharing culture. Health officials found themselves trying to plan services and respond to outbreaks without knowing exactly where communities were located or how many people lived there.

This gap caught the attention of researchers at the Mahidol Oxford Tropical Medicine Research Unit (MORU) and officials at Bangladesh's Directorate General of Health Services (DGHS). In 2017, they launched GroupMappers as a solution. The idea was simple but powerful: instead of relying on traditional methods of mapping, they would work with local volunteers who would be trained by GroupMappers to collect data using geospatial technology. Volunteers are mostly young people who live in the communities.

Description of the initiative

GroupMappers initially started as a pilot project with the aim of finding a way to collect and identify settlement location data and village names in Bangladesh. The pilot sought for a solution that was both affordable and scalable, and aimed to make this information freely available online for anyone working in public health, disaster response, or development. The pilot finalized the methods for mapping communities and villages by testing and refining different approaches over multiple phases. The project uses a collaborative approach that brings together groups of volunteers for field data collection and crowdsourcing activities. In the initial phase of the project, GroupMappers engaged volunteers representing a cross section of the community to digitize clustered settlements as polygons, and dispersed settlements as points using Google Earth Pro, covering a 3,500 km² area. This effort was later expanded to an additional 12,500 km² in the remote, hard-to-reach, and malaria-prone Chattogram Hill Tracts in South Eastern Bangladesh. These polygons were then exported as Keyhole Markup Language (KML) files and reviewed by a validation team at MORU, which checked the data against quality criteria and either approved or flagged datasets for revision. To name each settlement, GroupMappers initially engaged local student volunteers using smartphones and Google Maps, but this approach proved ineffective. They then shifted to using large, printed maps and involved multipurpose health volunteers and health staff to identify and name villages and communities. The hard copy maps had limitations, such as poor print quality and low visibility, and many participants lacked familiarity with all village locations, hindering the process. Finally, the team decided to use a mobile application and involve local government authorities, as each village in Bangladesh typically falls under their jurisdiction.

The final process of producing the data followed several key steps. Volunteers first mapped the locations by digitizing building structures on satellite images using QGIS (Quantum Geographic Information System), an open source platform for visualizing geospatial data and creating maps) dividing areas into grid squares and applying standardized methods and rules to maintain consistency. In addition, they digitized other key features such as the road network, hydrographic network, waterbodies, and points of interest to facilitate mapping activities. Following this, volunteers were assigned to visit the study areas and collaborate with local authorities to update the operational village lists, group buildings under appropriate village or community names, and gather additional information, e.g. population, ethnicity, and mobile network access. They used QGIS Cloud to confirm names and verify details of the relevant communities. To validate the data, volunteers used printed maps to cross-check their work with local government authorities after completing each area, along with verifying village coordinates recorded during field visits using the QField app.

This open-source GIS technology, combined with a mobile-friendly GIS approach, replaced the outdated system of bulky paper maps and costly GPS units. Additionally, the app is designed to be intuitive, function offline, and capture text, numbers, and photos all in one place, making it far easier to reach and document communities that had never been properly mapped before.

Beyond data collection, GroupMappers placed a strong emphasis on building local skills and fostering engagement. They offered opportunities for volunteers to get involved in writing newsletters, leading training sessions, and participating in other activities aligned with their interests. This helped cultivate a local community that understood both mapping techniques and public health priorities. So far, GroupMappers has a total of more than 50 active volunteers, in addition to 20 core experts and 19 members of staff. Jointly, the organization's projects have mapped locations like Dhaka City, South East Bangladesh, where malaria is prevalent and other projects have undertaken country-wide surveys.

Data practices

- Training and equipment: The mapping initiative was launched by a team from MORU and DGHS with strong geospatial expertise and diverse backgrounds. The current core team includes 20 members who train volunteers to use simple, accessible tools like Google Earth for digital mapping and mobile apps for field data collection, intentionally avoiding the need for costly GPS devices or complex setups. GroupMappers leads structured training programs that range from one-day training as well as re-training sessions to build practical skills in geospatial mapping, data collection, and open-source tools such as QGIS, OpenStreetMap, KoboToolbox, and QField. These sessions equip students and youth groups to contribute meaningfully to disaster preparedness, public health, and climate resilience through accurate and actionable mapping.

- **Selection of volunteers:** Volunteers are recruited through university outreach, open calls on social media, and community-based workshops. The organization conducts outreach to university students through a Campus Ambassador program; it also carries out targeted GIS and mobile data collection training in various locations across the country.
- **Type of data**: Groupmappers' data is primarily geospatial data. This includes digitized settlement boundaries, GPS coordinates, as well as the use of a variety of methods to gather information, including key informant interviews, participatory rural appraisals, and surveys using tools such as ODK, Kobo Toolbox, and SMS. Contextual information such as population estimates, ethnicity, mobile network availability, and infrastructure features (e.g. road networks, water bodies, points of interest) is also gathered to enhance spatial analysis. For disease surveillance, specific data points include locations of confirmed malaria and dengue cases, mosquito breeding sites, and vaccination coverage areas (e.g. for rabies).
- **Data quality and validation**: GroupMappers ensures data quality through a multi-stage validation process. First, all digital maps are reviewed by a technical team against defined criteria before field deployment. During fieldwork, volunteers verify village names, GPS coordinates, and other details directly with local residents and authorities. Data is further cross-checked using printed maps, mobile apps like QField, and satellite imagery. This layered approach, combining remote sensing, local knowledge, and field verification ensures the accuracy, consistency, and reliability of the final datasets.
- **Analysis and use**: The collected data supported various types of spatial analysis. This included accessibility modeling, disease risk mapping, and resource allocation planning. Teams could also analyze how accessible different areas were, predict patterns across unmapped areas, overlay different types of information, and use statistics to identify trends. The Bangladesh Government used this analysis to improve disease surveillance for malaria, rabies, and dengue.
- **Dissemination**: To make the data as useful as possible, GroupMappers focused on creating interactive web maps and visualizations. They built web-based mapping applications and combined data from multiple sources. A key priority was making all of this information freely available online for anyone to use while balancing with strong data governance frameworks.
- **Data governance**: GroupMappers' approach to data governance ensures that data is collected, managed, and shared responsibly. Clear data-sharing protocols and privacy safeguards are in place to protect sensitive information while enabling effective use by health programs, government agencies, and partners. Due to its linkages with MORU and working with the Ministry of Health, GroupMappers also adheres to the data governance guidelines set by these institutions and increasingly evolves its approaches to meet the needs of its community.

Application of the GroupMappers approach to various health priorities

GroupMappers has deployed its skills and technologies to various health priorities in Bangladesh, including dengue, malaria, rabies, and filariasis.

Table: Summary of GroupMappers' dengue mapping projects with approaches to involve communities in the data production process.

Project title	Year	Key activities and results
Dengue Risk Zoning	2019	Mapped 2,059 patient cases across 22 hospitals; conducted mosquito density analysis, and identified high-risk zones. This supported outbreak planning and volunteer GIS training.
Dengue Household Survey	2019	Surveyed 182 homes using Kobo Toolbox in high-risk drone-identified areas. Located 40 affected households; validated spatial dengue spread

Source: GroupMappers website

Table: Summary of GroupMappers' Malaria Mapping Projects

Project title	Year	Key activities and results
Expanding village mapping to others areas in Bandarban district in South Eastern Bangladesh	2023	Mapping 2,108 villages (Para/Mahalla/Camp) including 1,136 Tribal Paras, 845 Bengali Paras, 127 Mixed Paras, 18 Farms and 80 Camps in Alikadam Bandarban Sadar, Lama Naikhongchhari, Rowangchhari Upazila (sub-district) in Bandarban district.
Applying diagnostic network optimization analysis using OptiDx to inform the introduction of G6PD testing into	2023	Supporting National Malaria Elimination Program (NMEP) in Bangladesh to model an evidence-based strategy for introducing the G6PD diagnosis that best uses available resources to ensure optimal access to testing by P. vivax patients. Using optiDx, it shows the coverage and

Bangladesh for improved malaria treatment.		cost of potential scenarios for introducing the G6PD test.
Piloting village-level malaria data collection and surveillance towards elimination	2023	2,120 individual pieces of malaria surveillance data were collected for 644 villages in real time in Lama Upazila of Bandarban. This was fed into the Malaria API Tracker system (see below), with the data flow and dashboard optimized to ensure smooth functioning, usability, and to prepare for future scale-up.
Introducing Malaria API Tracker and an interactive platform for visualizing and updating village maps	2022	Designing and implementing a geospatial dashboard—Malaria API Tracker—to enable the collection, visualization, and analysis of malaria Annual Parasite Incidence (API) data at the Upazila and village level, based on the newly updated map covering 644 villages in Lama Upazila.

Table: Groupmappers' foundational institutional infrastructure

Project title	Year	Key activities and results
Settlement identification and community or village mapping in South East Bangladesh	2017-2019	In South Eastern Bangladesh, Groupmappers identified settlements using Google Earth, collected village names, updated maps, and validated the information with local authorities. As a result, they mapped approximately 43,000 clustered settlements as polygons and 142,000 dispersed settlements as points, covering 16,000 square kilometers including 592 villages across 759 square kilometers in Lama Upazila.
Strengthening geo-referenced health management information system	2025	In 2025, Bangladesh hosted the Global Fund's first flagship project on climate change and health. Under this project, village mapping was expanded across 12 sub-districts in Bandarban, Chattogram, Cox's Bazar, Khagrachhari, and Rangamati. Using an upgraded data collection

		system and a new mobile app, programs can now collect village-level data on malaria and other climate-sensitive diseases. The data feeds into a geospatial monitoring dashboard via API, enabling real-time checks and automatic anomaly detection to support timely field-level validation.

Impact of the initiative

1. Change in the community

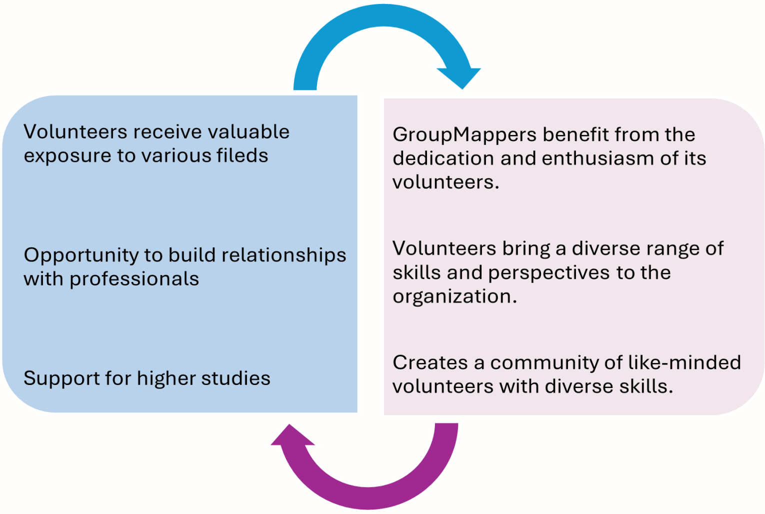
Before GroupMappers, many communities in Bangladesh, especially in remote areas, were missing from official maps, making it hard for health programs to track diseases or plan services. GroupMappers changed this by training local volunteers to map these areas using free tools like Google Earth and QGIS. Instead of relying on costly equipment, students and youth mapped more than 43,000 clustered and 142,000 dispersed settlements across 16,000+ km², helping turn missing data into meaningful action.

GroupMappers did more than map communities; it empowered youth with practical GIS and mapping skills. Through training and outreach, volunteers learned to use digital tools, engage with local authorities, and lead data collection efforts. This built a culture of community-led mapping, with volunteers contributing to COVID-19 tracking, mosquito hotspot identification, and rabies vaccination planning, turning students into skilled public health mappers.

GroupMappers' data has reshaped health responses. Its maps powered the Malaria API Tracker, helping the government track more than 2,100 cases in Lama Upazila. Beyond malaria, the organization supported COVID-19 risk mapping, creating 10,000+ maps, and using drones and surveys to identify dengue hotspots, guiding targeted control efforts. They also improved rabies and soil-transmitted helminth (STH) surveillance, training more than 25,000 data collectors and mapping millions of vaccination records.

GroupMappers brought a major shift in how data is shared and used in public health. In a setting where open data was uncommon, the organization promoted transparency through public dashboards, open-source maps, and easy-to-use visual tools. The data collected wasn't just for experts, it was made accessible to local health workers, NGOs, researchers, and communities. By blending local knowledge with digital tools like satellite imagery and mobile apps, they produced high-quality, community-verified data. This participatory approach strengthened trust between people and institutions, turning data into action and supporting more inclusive, effective public health responses.

The volunteer-based approach has also created new opportunities for local people, particularly young adults. Participants have developed skills in mapping technology, gained leadership experience, and become more engaged with public health issues in their communities. This has built a foundation of local expertise that can support future mapping and health initiatives.



Volunteers receive valuable exposure to various fileds

Opportunity to build relationships with professionals

Support for higher studies

GroupMappers benefit from the dedication and enthusiasm of its volunteers.

Volunteers bring a diverse range of skills and perspectives to the organization.

Creates a community of like-minded volunteers with diverse skills.

Source: Adapted from GroupMappers' visualization of its [volunteer model](), which showcases the synergistic partnership with volunteers.

2. Change in policy

The Bangladesh Government has directly incorporated GroupMappers’ data into its infectious disease surveillance systems. Health officials now use the community maps to identify hotspot villages for malaria, intestinal worms, rabies, and dengue, and to develop response plans at the district level.

Making this data widely accessible has also supported policy development beyond health. Local planners use the information for community development projects, and disaster preparedness officials rely on it to understand where vulnerable populations are located.

Challenges and opportunities

GroupMappers encountered several significant obstacles while developing these methods. Initially, volunteers used paper maps. The team quickly learned that printing high-quality paper maps was expensive and often impractical, especially for remote areas. Additionally, identifying landmarks using only paper maps proved difficult and unreliable. The team addressed these challenges by using geospatial technology that was straightforward to use and worked without internet connectivity. This dramatically reduced costs while improving the quality and consistency of collected data.

The team also had to work around the fact that Bangladesh lacked a common platform for sharing location data. Different organizations often collected similar information but couldn't easily share or combine their datasets. GroupMappers responded by building integrated systems that are open to the public. This emphasis on open data has enabled the creation of a foundation for more coordinated, data-driven public health action.

What's next

GroupMappers has changed how health systems connect with communities, proving that local people, with the right tools and training, can shape health decisions. GroupMappers scaled its efforts by supporting Bangladesh’s 2025 Global Fund climate and health project, expanding village mapping to 12 climate-sensitive sub-districts. With upgraded mobile tools, real-time dashboards, and integration of climate data, the team aims to enhance early warning systems and guide faster, smarter responses to disease threats. This next phase will continue empowering local volunteers and health workers to generate actionable data, ensuring that communities remain at the heart of public health planning in the face of growing climate challenges.

GroupMappers has shown how volunteer-driven, technology-enabled approaches can fill critical information gaps, build local capacity, and ultimately help ensure that health services reach the communities that need them most.

Case Study 5: Using Citizen Data to Address Dengue Fever with DengueChat

This case study has been collaboratively developed with the contribution of the University of California, Berkeley (UC Berkeley) and the Sustainable Sciences Institute (SSI). The insights, impact and information shared in this case study reflect the work and research carried out by SSI, UC Berkeley, research partners, and community members in Nicaragua.

This case study highlights a non-governmental organization, which works with community volunteers to produce citizen data. The case study was developed following an online group interview with the DengueChat team, namely: Maria Josefina Coloma, Harold Suazo, and James Holston.

Context and background

Dengue fever, transmitted by the Aedes aegypti mosquito, is a major health threat in Latin America. The mosquito thrives in environments characterized by rapid urbanization, inadequate water management, and climate variability. Existing surveillance systems often lack the ability to provide timely and detailed data at the household and community levels, making early detection of outbreaks and preventive action challenging for governments.

Recognizing this challenge, the Sustainable Sciences Institute (SSI), in collaboration with the University of California, Berkeley (UC Berkeley), and local partners in Nicaragua, Brazil, and Ecuador, set out to address the gap. Their efforts were built on evidence from the landmark Camino Verde ('Green Way') trial, which demonstrated the power of community mobilization to reduce mosquito indices and dengue transmission through the Socialization of Evidence for Participatory Action (SEPA) approach.[i]

Building on this foundation and the momentum of community engagement, the partners created DengueChat, a citizen data initiative that combines community mobilization with digital technology, producing actionable insights for both communities and policymakers. The first iteration began in Brazil in 2011 as a simple SMS-based tool, and this was later refined and piloted in Nicaragua. The pilot in Nicaragua demonstrated that citizen data can produce valid entomological data and effectively mobilize neighborhoods. The initiative later expanded to Paraguay and Iquitos, Peru, where it was scaled using implementation science strategies to larger urban settings.

Description of the initiative

Recurring dengue outbreaks in Nicaragua, Brazil, and Ecuador highlighted the limitations of top-down surveillance and vector control. DengueChat was developed to close this gap. The DengueChat platform empowers communities to generate and use their own data on disease surveillance and vector control. It connects households, volunteer *brigadistas*[ii], researchers, and health authorities in a shared system for collecting, analyzing, and responding to information about mosquito breeding sites, dengue symptoms, and prevention practices. The initiative reflects principles of community-based participatory research as outlined in broader scholarship on inclusive approaches to knowledge production[iii].

DengueChat closes the surveillance data gap by:

- Generating more timely and actionable data at the neighborhood level.
- Empowering citizens to become active agents of dengue prevention.
- Providing complementary citizen data to inform official decision-making.

The Sustainable Sciences Institute and the University of California, Berkeley led the initiative in collaboration with local non-governmental organizations (NGOs), health ministries, and community brigadistas. Brigadistas played a central role by receiving training in vector surveillance, data collection, and community mobilization. Although many brigadistas volunteered, the program aimed to maintain their involvement by integrating activities into community governance structures. A significant proportion of brigadistas were women, which promoted gender equity and strengthened community trust.

Additionally, Nicaragua's long history of neighborhood brigades made it possible to recruit and organize volunteers effectively. In the pilot, young people were particularly drawn to participate due to the appeal of using technology, and in later expansions, university outreach was utilized to mobilize new brigades. All brigadistas worked voluntarily and facilitators received phones or tablets to support data entry. Many participants later pursued further education, with some going on to become biologists or data specialists, demonstrating how the project created new pathways for professional development. Other brigadistas used their experience to document their work on their personal social media channels.

How the initiative worked

The design process for DengueChat began as a participatory effort. Communities co-created the platform to ensure usability and relevance. Organizers formed brigadas (community brigades) of brigadistas who collected data and mobilized neighbors. Brigadistas conducted household surveys, monitored mosquito breeding sites, and reported suspected dengue cases. They uploaded data to the DengueChat platform, where the system analyzed and visualized it. Teams then shared results with communities through meetings and with authorities through reports and dashboards.

This iterative feedback loop reinforced trust, strengthened accountability, and improved local responses. Pilot implementations were conducted in Nicaragua, Brazil, and Ecuador, each receiving significant academic and governmental support. One distinctive innovation was the real-time visualization of results: brigadistas could immediately see graphs, maps, and risk indices based on their work, providing them with a tangible sense of return on their effort. Pedagogy was central, too. Volunteers carried mosquito larvae and pupae in small containers into households, vividly demonstrating the mosquito life cycle and highlighting where simple interventions could disrupt it. With this emphasis on 'citizen entomology,' community-generated data clearly met the same scientific standards as professional entomology.

Data practices

- Types of data: Household survey data, mosquito larval indices, suspected case reports, community narratives, and entomological indices such as the House Index, Container Index, and Breteau Index. A complementary 'greenhouse' metric tracked homes free of breeding sites for a sustained period, providing communities with a visible marker of success.

- Data quality: To ensure data quality, standardized training on data collection for brigadistas was implemented, supplemented by supervision from researchers and triangulation with official entomological surveys. Importantly, professional entomologists confirmed that community data matched official surveys, validating its scientific rigour.

- Analysis and dissemination: The project utilized interactive dashboards, community assemblies, and peer-reviewed publications to disseminate its findings. Furthermore, historical tracking allowed neighbourhoods to identify recurring hotspot households or areas and direct interventions more strategically.

- **Data governance:** Local ownership of data was prioritized, supported by ethical oversight from academic partners. Communities were consulted to ensure their data use aligned with local priorities. Volunteers and residents had access to both visualizations and raw indices, reinforcing transparency and trust.
- **Public engagement:** Support was fostered through video resources and knowledge-sharing tools that raised awareness. Monthly 'socialization events' brought neighbors together to discuss findings, stage creative performances, and celebrate progress, blending technical feedback with cultural exchange.

Impact of the initiative

1. Change in the community

DengueChat increased public awareness regarding dengue transmission and prevention. Brigadistas coordinated neighborhood clean-up activities, engaged families in mosquito vector control, and demonstrated specific preventive measures. Data visualizations and dashboards supplied households with measurable evidence of intervention effectiveness, which enhanced trust in the intervention process and its outcomes.

The project contributed significantly to the development of skills and empowerment among participants. Brigadistas reported increased confidence in public speaking, and many adolescents and women assumed new leadership positions within their communities. Several participants characterized the experience as transformative, which motivated some to pursue higher education or, for women, to exit harmful relationships.[iv] Following the conclusion of pilot funding, certain communities continued DengueChat practices autonomously. These communities subsequently reported lower dengue incidence rates compared to those that discontinued the intervention.

2. Change in policy

Findings generated by DengueChat were integrated into local dengue control strategies. Ministries of Health recognized the citizen data as a valuable supplement to official surveillance systems. In international public health forums, the initiative has been referenced with other community-led monitoring programs as evidence that citizen data can enhance health system performance and accountability.

In Nicaragua, community health workers and brigadistas presented their findings directly to the Ministry of Health. This process contributed to the legitimization of citizen data and prompted authorities to implement community-led mobilization strategies in national dengue prevention campaigns. Subsequent large-scale breeding site removal initiatives were based on these community-driven approaches and findings. Over time, this recognition influenced international organizations, leading to the inclusion of community mobilization as a formal component of the World Health Organization's integrated vector management strategy.

Challenges and opportunities

1. Challenges

Sustainability presented a persistent challenge. The model’s reliance on volunteer brigadistas increased the risk of burnout and inequity over time. Much of the initiative relied on intrinsic motivation, but unresolved issues about compensation and long-term support persisted. Integration barriers also emerged. Citizen data formats were often incompatible with government health information systems, which limited adoption. Rural infrastructure limitations hindered real-time data reporting, requiring alternative methods such as paper forms and offline uploads. Ongoing training and supervision were necessary to maintain data quality and ensure the accuracy of entomological indices and survey results.

2. Opportunities

Despite these challenges, DengueChat generated substantial opportunities for innovation and expansion. The model demonstrated adaptability to other vector-borne diseases, including zika and chikungunya, and provided insights relevant to emerging outbreaks such as COVID-19. By enabling communities to produce rigorous data, the initiative facilitated the development of stronger One Health linkages that integrate human, animal, and environmental data streams. Policy mainstreaming represents another opportunity, as embedding citizen data within national surveillance frameworks can ensure that community perspectives inform decision-making processes. Finally, the platform’s utility extended beyond vector control. For example, brigadistas identified waste management as a significant factor in mosquito breeding, indicating that DengueChat’s digital and social infrastructure could be leveraged to mobilize communities around broader public health and environmental challenges.

What’s next

Looking ahead, DengueChat provides a robust model for scaling citizen data initiatives, offering a powerful foundation for participatory public health surveillance. The next phase should focus on institutionalization within government health systems, financial support and equity for brigadistas, and technological upgrades to enable real-time analytics and predictive modeling. With appropriate investment, the model can significantly enhance disease surveillance and empower communities to address diverse health challenges and geographies.

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[i] Camino Verde – for the prevention of dengue (n.d.) 'Pilot Study in Managua (2004-2007)'. Available at: https://caminoverde.ciet.org/camino-verde-trial/sepa-2/nicaragua/

[ii] Brigadistas are community members who lead the work on a volunteer basis.

[iii] Suazo Laguna, H.A. (2024) 'An Autobiographical perspective on community-based participatory research: An approach for more inclusive research in Nicaragua'. *Springer, Cham.* Available at: https://doi.org/10.1007/978-3-031-53793-6_17

[iv] As reported in a key informant interview with the DengueChat team.