



SMARTER CROWDSOURCING ZIKA

Smarter Crowdsourcing for Zika and Other Mosquito-Borne Diseases

A Handbook of Innovative Legal, Technical,
and Policy Proposals and a Guide to their
Implementation

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zika.smartercrowdsourcing.org



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Foreword

Problems such as Mosquito-Borne Diseases (MBDs) require innovative actions. Taking advantage of technologies, such as big data and insights from the behavioral sciences to solve problems in new ways is key. Yet policymakers everywhere are facing a crisis of agility – namely the ability to identify, implement and test innovations in response to new challenges quickly. Thus, to foster transformation in how we address health and social issues, we need, first, to work differently and open our institutions to new ideas.

It is in this spirit that the Inter-American Development Bank (IDB) in a joint effort with the The Governance Lab based at New York University (The GovLab), launched “Smarter Crowdsourcing for Zika,” an initiative to accelerate finding actionable solutions to the Zika epidemic by bringing together curated worldwide knowledge, expertise and policy-makers through online conferences.

This manual is the culmination of this initiative, which attracted experts from six continents to share their thinking with the governments of Panama, Colombia, Rio de Janeiro and Argentina, about new ways to combat MBDs. The following twenty proposals shed light on how to address the Zika virus in the region. What is unique in this effort is that we got and shared good ideas quickly but, most important, we turned them into implementable solutions.

Ultimately, Smarter Crowdsourcing is an experiment. We combined curation with crowdsourcing, brainstorming with research, shared experiences with innovation and built learning networks. We hope to have generated a momentum for the uptake of innovation in public health.

We invite you to make use of the innovations in policy and service delivery outlined here and welcome your feedback on the new approaches that are working in your community.

Ferdinando Regalia

*Division Chief, Social Protection and Health Division
Inter-American Development Bank*



Zika alone was estimated to have cost the region over \$3.5 billion in 2016, with the long-term costs still relatively unknown

Executive Summary

According to the World Health Organization, vector-borne diseases account for nearly a fifth of all known human infections and result in more than 1 million deaths each year. Mosquito-borne diseases (MBDs) cause the large majority of these deaths and together represent a huge portion of the global burden of infectious disease. In Latin America, MBDs such as dengue, chikungunya, and now Zika increasingly threaten public health and wellbeing and disrupt trade and economic productivity. Zika alone was estimated to have cost the region over \$3.5 billion in 2016, with the long-term costs still relatively unknown.¹

Public institutions at the local, national, and international level bear the responsibility of acting quickly and effectively to stop these epidemics. However, in the absence of a proven vaccine or cure for these diseases—and amidst shifting scientific understanding of emergent diseases like Zika—policymakers face a difficult challenge in managing complex MBD health emergencies.

Smarter Crowdsourcing provides public officials a way to discover the most effective and innovative actions by which to address complex issues such as Zika. Smarter Crowdsourcing combines the agility and diversity of crowdsourcing (also called open innovation) with

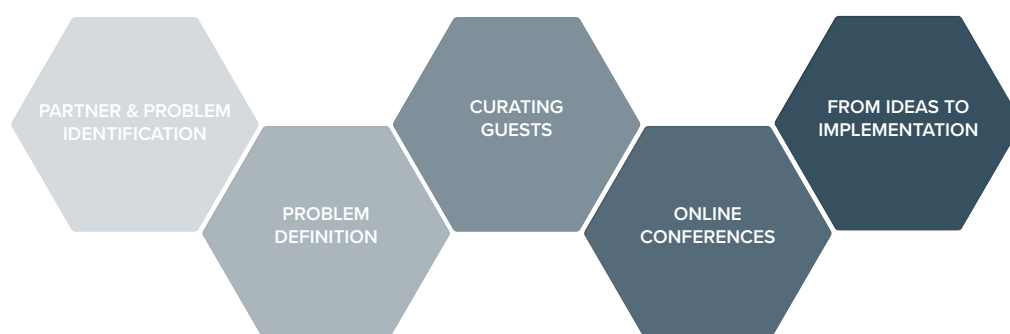
¹ World Bank Group. [The short-term economic costs of Zika in Latin America and the Caribbean](#). 2016.



curation to target those with relevant know-how and bring them together in a format designed to produce effective and implementable outcomes.

In line with the Smarter Crowdsourcing philosophy, the Governance Lab and the Inter-American Development Bank, in partnership with the governments of the City of Rio de Janeiro, Argentina, Colombia and Panama, hosted a series of online conferences between August and October 2016 involving those at a local and global level with relevant experience, skills, knowledge and, above all, creative ideas for how governments and the public can fight Zika.

FIGURE 1. SMARTER CROWDSOURCING METHODOLOGY



Each of these conferences focused on a different component of the problem, with the goal of identifying the most effective and innovative approaches to fighting Zika. The problems discussed in the conferences were:

- ▶ **Assessing public understanding of Zika:** What are the most effective ways to capture the public's understanding of mosquito borne diseases? How can governments use these findings to inform the design of campaigns to improve public awareness?
- ▶ **Behavior change:** What are the most effective ways for getting the public to change behavior to prevent mosquito breeding and mosquito bites and get proper access to healthcare?
- ▶ **Trash and standing water accumulation:** What can be done to eliminate uncollected waste and standing water where Aedes Aegypti mosquitoes breed?
- ▶ **Surveillance and data sharing:** How do we develop policies and practices for better epidemiological data collection and for sharing data with the appropriate authorities?



- ▶ **Long-term care:** How do policymakers provide affordable and ongoing support for families whose members are at risk for, or already suffer from, the chronic effects of Zika such as microcephaly?
- ▶ **Predictive analytics:** What are the innovative options to analyze available data from new technologies to predict and therefore prevent outbreaks?

Many ideas were discussed during each conference. After the conclusion of these conferences, participating governments prioritized those ideas they were most interested in pursuing.

The Smarter Crowdsourcing team subsequently conducted further interviews and research into these ideas, identifying their costs and benefits, the steps required for implementation, and the key strategic decisions that governments would need to make along the way. The team's findings have been combined into this Implementation Report, which consists of twenty initiatives selected for their importance and potential impact as well as their suitability for immediate implementation.

This Implementation Report is designed to enable public authorities to translate these new ideas into practical improvements in the way they deliver policies and services. The Report includes:

- ▶ **20 recommendations, summarized in a series of infographics.** Infographics include:
 - ▶ A list of the proposed recommendations
 - ▶ A taxonomy of the types of actions each recommendation entails (e.g., private-public partnerships, prizes, software platforms)
 - ▶ Resources and time required for implementation
 - ▶ Potential cost offsets
 - ▶ A list of specific experts best-positioned to help governments implement each recommendation
- ▶ **Detailed implementation guidance** for each intervention, organized into the six themes of the online conferences

Readers can use the executive summary and infographics to develop a general understanding of what this document proposes and then can reference the detailed guidance to learn more about those ideas they are most interested in.



Over 100 experts from 25 countries participated in the process of proposing ideas and developing them into implementable solutions. A full list of these experts, as well as their geographic distribution and organizational affiliations, is available on the [project website](#).

For more about Smarter Crowdsourcing for Zika:

[Website](#)

[Playbook](#)

[Introductory video](#)

[Assessing public awareness conference](#)

[Communication and Behavior Change conference](#)

[Trash and Standing Water conference](#)

[Information Collection/Data Governance conference](#)

[Long-Term Care conference](#)

[Predictive Analytics Conference](#)

The content of this document, including its recommendations, is the sole responsibility of The GovLab and does not represent the IDB's official position or view on this matter, nor an endorsement of any individual or firm to perform activities related to the recommendations.



A. Overview of Recommendations

Twenty recommendations in six issue areas

ISSUE AREA	RECOMMENDATION
1 Assessing understanding	1.1 Conduct an assessment of social media penetration to understand who can be reached by digital listening activities and how
	1.2 Convene an interagency committee to assess and prioritize demand for digital listening insights across government
	1.3 Appoint a Chief Analytics Officer to drive implementation of data-driven policies and projects such as digital listening and predictive analytics platforms
	1.4 Partner with research organizations, technology platform partners, and commercial analytics providers to develop the supply of desired digital listening insights
2 Behavior change	2.1 Create prize-backed challenges to promote engagement and innovation in Zika control at both the community and individual levels
	2.2 Compile peer-reviewed best practices in Zika / MBD public communications and present them in a way that is accessible for policymakers seeking actionable ideas
	2.3 Explore the use of “serious games” to raise awareness and change behavior by organizing hackathons and/or partnering with game designers to deploy effective platforms
3 Trash accumulation	3.1 Involve communities in locating and removing litter
	3.2 Use drones to identify and map areas with accumulated trash
	3.3 Commit to private-public partnerships (PPP's) with manufacturers to reduce trash accumulation
	3.4 Collect trash in hard-to-reach areas using adaptive vehicles
4 Surveillance and data sharing	4.1 Improve the speed and reliability of surveillance data by integrating flexible mobile technologies like SMS and smartphone app reporting into surveillance activities
	4.2 Collaborate with companies and universities to identify new sources of disease surveillance data
	4.3 Promote openness and participation in surveillance data collection, storage, sharing, and use by developing a data governance playbook for epidemic response and building broad commitment to use it
5 Long-term care	5.1 Use online support communities akin to Patients Like Me to provide patient-to-patient support
	5.2 Develop 2-way SMS-based support systems like Text4Baby to provide long-term medical care and support cost-effectively
6 Predictive analytics	6.1 Improve Zika response by building a predictive analytics platform
	6.2 Use prize-backed challenges to rapidly develop predictive models and leverage outside expertise
	6.3 Increase data analytics literacy among public health officials by training them in data science (through partnerships with research institutions, universities, and other training providers)
	6.4 Collaborate on creation of a Zika-related data portal that compiles national and other open datasets



B. Types of action proposed

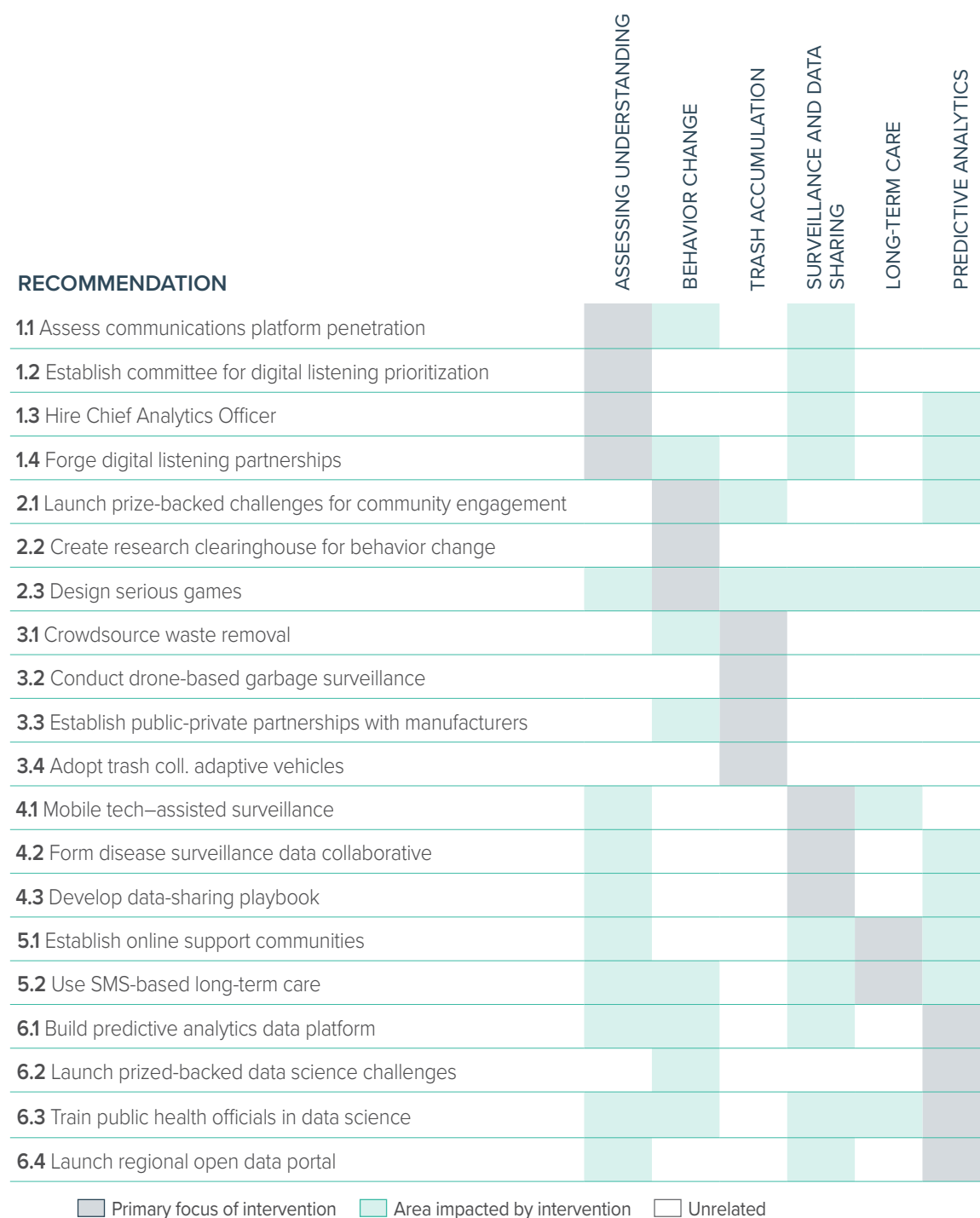
Recommendations involve eight broad types of action

ACTION TYPE	RECOMMENDATION	ISSUE AREA
Research-Related	2.2 Create research clearinghouse for behavior change	Behavior change
	1.1 Assess platform penetration	Assessing understanding
Analytic / data sharing platforms	6.1 Build predictive analytics data platform	Predictive analytics
	6.4 Launch regional open data portal	Predictive analytics
Software platforms	2.3 Design serious games	Behavior change
	4.1 Conduct mobile technology-assisted surveillance	Surveillance & data sharing
	5.1 Establish online support communities	Long-term Care
	5.2 Use SMS-based long-term care	Long-term Care
Hardware investments	3.2 Conduct drone-based garbage surveillance	Trash accumulation
	3.4 Adopt trash collection adaptive vehicles	Trash accumulation
Prizes and challenges	6.2 Launch prized-backed data science challenges	Predictive analytics
	2.1 Launch prize-backed challenges for community engagement	Behavior change
	3.1 Crowdsourcing waste removal	Trash accumulation
Public Private Partnerships	4.2 Form disease surveillance data collaborative	Surveillance & data sharing
	1.4 Forge digital listening partnerships	Assessing understanding
	3.3 Establish PPPs with manufacturers	Trash accumulation
Human Capital	6.3 Train public health officials in data science	Predictive analytics
	1.3 Hire Chief Analytics Officer	Assessing understanding
Governance	4.3 Develop data-sharing playbook	Surveillance & data sharing
	1.2 Establish committee for digital listening prioritization	Assessing understanding



C. Interrelationships between recommendations

Most recommendations have cross-cutting impacts





D. Resources and time (1/3)

All recommendations require low-to-moderate investment and completed in <18 months

NOTE: All costs in USD; are approximate and for comparison purposes

RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
1.1 Assess communications platform penetration			Primarily informal consultations, may require commissioned study if necessary information not readily available
1.2 Establish committee for digital listening prioritization			Minimal (aside from time of involved individuals, cost of meeting space, and coordination of meetings)
1.3 Hire Chief Analytics Officer			+ full time employee, with necessary institutional support to develop and execute Ministry-wide analytic programs
1.4 Forge digital listening partnerships			Resource requirements likely to vary depending on partnership model; however this will ideally involve hiring small full-time staff to manage partnerships / data and curate insights
RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
2.1 Launch prize-backed challenges for community engagement			Funding the prize, publicizing the initiative, generating relevant guidance materials for participants, and [potentially] compensating judges and technical advisors (although ideally this will be done pro-bono)
2.2 Create research clearinghouse for behavior change			Initial up-front investment in developing a user-friendly website; operation of the clearinghouse will require a small staff to identify, review, and publicize relevant literature
2.3 Design serious games			Resource requirements likely to vary depending on the ambition of the game. Simple features added to existing games can cost \$20k to \$60 (e.g., 30-second video), while more complex features may cost \$200-\$300k. Completely new games can cost \$500k to \$1M

AGGRESSIVE ESTIMATE

CONSERVATIVE ESTIMATE









- Significant Investment (e.g., \$500k + startup costs, full-time team, implementation of a major program)
- Moderate Investment (e.g., \$100k - \$500k startup, 1-2 full-time hires, implementation of a small program / pilot)
- Some Investment (e.g., \$10k - \$100k startup, 0-1 full-time hires)
- Low Investment (e.g., \$10k or less, uses existing employees)




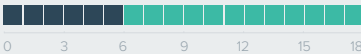




D. Resources and time (2/3)

All recommendations require low-to-moderate investment and completed in <18 months





NOTE: All costs in USD; are approximate and for comparison purposes

RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
3.1 Crowdsourcing waste removal			Crowdsourcing applications often free of charge; some funds needed to publicize the initiative, engage with the public, and store the data
3.2 Conduct drone-based garbage surveillance			Some expenditure needed to store and analyze the data; small investments needed to pay for drones, training of operators, and overall project management
3.3 Establish public-private partnerships with manufacturers			Minimal, other than time and expenses of health ministry staff involved in partnership; may require some investment if tax break required
3.4 Adopt trash coll. adaptive vehicles			Assumes initiative is launched in pilot neighborhoods; primary investments are in the vehicles (1-2 per community) and their operators

RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
4.1 Conduct mobile technology-assisted surveillance			Resource requirements will vary depending on the technology platform(s) selected for development. Assuming software adaptation from open-source projects, development staff can be seconded part-time from other software projects. Main costs will likely be in workforce training and investment in mobile devices such as smartphones
4.2 Form disease surveillance data collaborative			Main costs stem from the need to hire a chief data officer to liaise with private partners. Actual data costs may be minimal if shared as a form of corporate philanthropy
4.3 Develop data-sharing playbook			Initial playbook development costs are minimal and will only require stakeholder meetings and expert consultation. Long-term playbook strategy implementation costs will vary with the scope of commitments agreed upon in the playbook. Costs can be shared with private sector partners depending on ownership of individual action items

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-  Some Investment (e.g., \$10k - \$100k startup, 0-1 full-time hires)
-  Low Investment (e.g., \$10k or less, uses existing employees)



D. Resources and time (3/3)




All recommendations require low-to-moderate investment and completed in <18 months

NOTE: All costs in USD; are approximate and for comparison purposes

RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
5.1 Establish online support communities			Convening relevant experts and stakeholders to develop initial content (and regularly update and refine content), testing and refinement of messaging through focus groups or A/B testing
5.2 Use SMS-based long-term care			Convening relevant experts and stakeholders to develop initial content, purchase or adaptation of technological platform, bulk purchase (or donation) of messages from telecommunications providers
RECOMMENDATION	RESOURCES	TIME REQUIREMENT (months)	DETAIL ON RESOURCES REQUIREMENTS
6.1 Build predictive analytics data platform			Hiring or commissioning of experts to build the model, developing of user interfaces, as required. To manage the platform, chief data officer to partner with university or private organization and/or establish an in-house team
6.2 Launch prized-backed data science challenges			Funding the prize itself, publicizing the initiative, and generating relevant guidance materials for participants. Coordination of the challenge can be led by existing employees
6.3 Train public health officials in data science			Costs will vary depending on model(s) used, but may include funding travel and tuition for employees to attend training programs or the costs of developing local programs in collaboration with universities
6.4 Launch regional open data portal			Costs to government will vary depending on ultimate institutional owner. Primary investments would include front-end site development and back-end integration of the data. Subsequent operational costs would largely center around technical support to portal users and adaptations to incorporate new datasets / queries

AGGRESSIVE ESTIMATE





CONSERVATIVE ESTIMATE


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-  Moderate Investment (e.g., \$100k - \$500k startup, 1-2 full-time hires, implementation of a small program / pilot)
-  Some Investment (e.g., \$10k - \$100k startup, 0-1 full-time hires)
-  Low Investment (e.g., \$10k or less, uses existing employees)







E. Offset potential (1/2)

All recommendations have opportunity for cost offsets





RECOMMENDATION	RESOURCES	OFFSET POTENTIAL
1.1 Assess communications platform penetration		Already low to no cost. Can leverage existing research and expertise at universities, UN, World Bank, IDB, and other institutions
1.2 Establish committee for digital listening prioritization		Already low to no cost. Reduce time investment by getting expert advice ahead of time
1.3 Hire Chief Analytics Officer		The salary for this role could be offset by assigning her data-driven efficiency projects that save money
1.4 Forge digital listening partnerships		This can be low to no cost. Can save money by using existing research funds to support academics conducting digital listening

RECOMMENDATION	RESOURCES	DETAIL ON RESOURCES REQUIREMENTS
2.1 Launch prize-backed challenges for community engagement		The cost of a prize varies. Save money by using micro-prizes such as donated mobile phone minutes
2.2 Create research clearinghouse for behavioral change		This can be low to not cost. Save money by convening a wide array of stakeholders in universities and other institutions to crowdsource this project
2.3 Design serious games		Games can be expensive to design and build. The memo recommends strategies for adapting existing games and/or seeking philanthropic support for production

RECOMMENDATION	RESOURCES	DETAIL ON RESOURCES REQUIREMENTS
3.1 Crowdsource waste removal		This is low to no cost with only a small outlay for coordination and significant potential for savings in sanitation costs
3.2 Conduct drone-based garbage surveillance		This requires an investment in hardware. But money can be saved by sharing the use of surveillance drones designed for other purposes
3.3 Establish PPPs with manufacturers		The costs of container remediation are borne by the private sector
3.4 Adopt small trash collection vehicles		Cost of removing trash using alternative vehicles could be offset through use of those tax revenues used to pay for trash collection; this collection could also be done by the communities themselves, with communities earning revenues by selling recyclables to recycling companies

AGGRESSIVE ESTIMATE








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-  Moderate Investment (e.g., \$100k - \$500k startup, 1-2 full-time hires, implementation of a small program / pilot)
-  Some Investment (e.g., \$10k - \$100k startup, 0-1 full-time hires)
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E. Offset potential (2/2)

All recommendations have opportunity for cost offsets

RECOMMENDATION	RESOURCES	DETAIL ON RESOURCES REQUIREMENTS
4.1 Conduct mobile technology-assisted surveillance		mHealth technologies, including participatory digital surveillance and mobile-assisted case reporting, have the potential to expand surveillance at low cost compared to traditional methods. Investments in mobile devices and human resources can be offset by broad integration with other government activities like disaster response
4.2 Form disease surveillance data collaborative		Data collaboratives are, by definition, corporate data philanthropy
4.3 Develop data-sharing playbook		More open and participatory surveillance data can generate cost savings through faster and more accurate epidemic detection and modeling. In addition, insights generated from data sharing can lead to more efficient use of public health resources
RECOMMENDATION	RESOURCES	DETAIL ON RESOURCES REQUIREMENTS
5.1 Establish online support communities		Convening relevant experts and stakeholders to develop initial content (and regularly update and refine content), testing and refinement of messaging through focus groups or A/B testing
5.2 Use SMS-based long-term care		Text messages can be donated or purchased in bulk; open source platform like RapidPro can save software costs; long-term savings derive from reduced hospitalizations
RECOMMENDATION	RESOURCES	DETAIL ON RESOURCES REQUIREMENTS
6.1 Build predictive analytics data platform		Analytics platforms are designed to reduce medium to long-term costs, as the data they generate can help optimize resource deployment (e.g., preemptively sending health workers to where an outbreak is likely to occur can avoid the costs associated with an outbreak)
6.2 Launch prize-backed data science challenges		Prizes can be donated, and the challenge should be formulated to produce results that decrease costs. Challenges can also work with small prizes (or no prizes), provided the work is compelling enough and there is sufficient non-financial recognition of participants' contributions
6.3 Train public health officials in data science		More data science training can enable these officials to analyze their own agencies' work and identify cost savings
6.4 Launch regional open data portal		Money can be saved by using existing open source platforms and prioritizing datasets designed to generate insights that reduce costs

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-  Some Investment (e.g., \$10k - \$100k startup, 0-1 full-time hires)
-  Low Investment (e.g., \$10k or less, uses existing employees)



F. Additional potential contacts (1/2)

Experts are able to help with each intervention

For help with public sector innovation, see The Network of Innovators at www.networkofinnovators.org

ISSUE AREA	NAME OF CONTACT	ROLE / ORG
Assessing understanding	Josh Tucker	New York University
	Lee Rainie	Pew Research
	We Are Social UK	We Are Social UK
	Beth Simone Noveck	GovLab
	Amen Ra Mashariki	Chief Analytics Officer, New York City
	Jeff Chen	Chief Data Scientist, Department of Commerce
	Eugene Yi	MIT Media Lab
	Molly Jackman	Public Policy Research Manager, Facebook
Behavior change	David Broniatowski	Assistant Professor, George Washington University
	Jaykumar Menon	McGill University
	Patricio Fuentes and Reko Niimi	UNICEF Brazil Country Office
	Karen Lyons	Pew Trusts
	Jude Ower	CEO, Playmob
	Julián Ugarte, Luis E. Loria, Marina Spindler, and Matías Rojas	Socialab
	Sarah Cornish and Emily Treat	Games for Change
Trash accumulation	Jeff Kirschner	Litterati
	Daniel Lombrana	Crowdcrafting
	Joe Eyerman	RTI international
	Dr. Graham Alabaster	World Health Organization
	Dr. Graham Alabaster	World Health Organization



F. Additional potential contacts (2/2)

Experts are able to help with each intervention

For help with public sector innovation, see The Network of Innovators at www.networkofinnovators.org

ISSUE AREA	NAME OF CONTACT	ROLE / ORG
Surveillance and data sharing	Gordon Cressman	RTI International
	John Brownstein	Healthmap, Harvard Medical School
	Brian Lee	U.S. Centers for Disease Control Health Information Innovation Consortium
	Richard Benjamins	Director of External Positioning & Big Data for Social Good at LUCA: Data-Driven Decisions (Telefonica)
	Stefaan Verhulst	The Governance Lab
	Michael Johansson	U.S Centers for Disease Control
Long-term care	Anita McGahan	University of Toronto
	Alejandra Ruiz del Rio Prieto and Eduardo Clark	Prospera Digital (Presidencia de Mexico)
Predictive analytics	Lakshminarayanan Subramanian	Professor at Courant Institute, NYU
	Michael Johansson	Biologist at CDC
	Jesse Bell	North Carolina Institute for Climate Studies
	Gianluca Fontana	Centre for Health Policy, Institute of Global Health Innovation, Imperial College
	Daniel Ray	Chief Data Scientist, UK National Health Service
	Michael Johansson	Biologist at CDC



ISSUE AREA 1

Assessing Understanding

Successful containment of Zika and other mosquito-borne diseases (MBDs) will depend on the public having a basic understanding of these diseases, how they spread, and what can be done to avoid or treat them. Rising cell phone and social media use generate data that can be used to answer questions about public opinion and understanding. These techniques are known as “digital listening” or sentiment analysis.

This memo describes four practical recommendations – and the steps for implementing them – for Latin American governments wishing to incorporate digital listening into their efforts to combat Zika and other MBDs. The four recommendations are:

- ▶ Conduct an assessment of social media penetration to understand who can be reached by digital listening activities and how.
- ▶ Convene an interagency committee to assess and prioritize demand for digital listening insights across government.
- ▶ Appoint a Chief Analytics Officer to drive implementation of the digital listening agenda (and other data-driven policy projects).
- ▶ Partner with research organizations, technology platform partners, and commercial analytics providers to develop the supply of desired digital listening insights.



We also recommend that our government partners (with the help and coordination of an independent third party NGO or inter-governmental organization) convene their national health ministries, international organizations, leading academics, and technology companies to decide on a strategy to institutionalize a more coordinated MBD digital listening approach. We propose the creation of a Latin American Digital Listening Network for Health as one possible approach.

I. The challenge

Why digital listening: the need for better public awareness of Zika

Misunderstanding and a lack of public awareness severely limit the success of control efforts for Zika and other MBDs. Myths, rumors, and other types of misinformation put communities at increased risk of transmission and prohibit effective mobilization of the public in prevention efforts. Common misperceptions include the idea that the virus is not transmitted by mosquitoes, that the virus does not cause conditions like microcephaly,² and that methods like personal hygiene provide sufficient protection against infection.^{3,4} To design better health interventions for Zika and other MBDs, it is critical that policy-makers regularly evaluate what their constituents know and don't know about disease transmission, symptoms, and prevention.⁵

Currently, no gold standard method exists to quantify public knowledge relating to these diseases. Established practice involves a mix of qualitative and quantitative techniques, including phone surveys, household visits, structured interviews, focus group discussions, and community dialogues. Choice of methods inevitably involves tradeoffs in cost, speed, level of insight, and data generalizability. Telephone surveys, for instance, may reach a broad cross-section of the population rapidly and at low cost but must be painstakingly validated against actual behaviors.⁶ Focus group analysis, on the other hand, can uncover important underlying beliefs and attitudes but are costly, poorly generalizable, and often

² "Microcephaly is a birth defect where a baby's head is smaller than expected when compared to babies of the same sex and age. Babies with microcephaly often have smaller brains that might not have developed properly." ["Facts about Microcephaly,"](#) U.S. Centers for Disease Control.

³ ["Knowledge, attitude and practice on dengue, the vector and control in an urban community of the Northeast Region, Brazil"](#), dos Santos SL. et al, *Ciencia & saude coletiva* 6 Suppl :39-30, January 2011.

⁴ ["As Brazil Confronts Zika, Vaccine Rumors Shape Perceptions"](#), Worth K., Frontline PBS, February 2016

⁵ ["Knowledge, attitude and practice on dengue, the vector and control in an urban community of the Northeast Region, Brazil"](#), dos Santos SL. et al, *Ciencia & saude coletiva* 6 Suppl :39-30, January 2011.

⁶ Ibid.



do not provide easily actionable intelligence to policymakers.⁷ Overall, new strategies are needed to enable quick and actionable assessment of public awareness for health responders with limited resources.⁸

II. The opportunity

Sentiment analysis methods, first developed in universities, have come into widespread use as tools to help companies better understand their customers. Such social media-based digital listening techniques provide a new option for rapid, affordable, and detailed assessment of public awareness of MBDs in order to guide health crisis messaging and response. Given their large user base and wealth of real-time health information-sharing activity, social media platforms such as Twitter, Facebook, Whatsapp and others, represent an important untapped source of data at the population-level and about specific segments of the population. We describe how digital listening works with reference to specific examples of digital listening techniques with demonstrated success in the public health context.

1. TECHNIQUE

Network analysis of how public opinion is formed and influenced

Another approach is to explore more granular uses of social media to gain a better understanding of who knows what. There are new approaches that can be applied to understand who is saying what about MBDs and to identify the sources of both information and misinformation. This analysis can, in turn, help target public health messaging in ways that address the root causes of such misinformation.

HOW IT IS USED

- ▶ To identify how people share information on immunization campaigns, what events and underlying values drive public discussion, and which types of people are most influential in those conversations, as in [UN Global Pulse's study](#) tracking conversations related to immunization in India, Kenya, Nigeria, and Pakistan.
- ▶ To learn more about what people were saying on Twitter about diabetes and who was listening, as in this "[mixed-methods approach](#)." This study recommended that public health organizations focus more on building partnerships with influential disseminators of information and less on one-off campaigns.

⁷ Ibid.

⁸ "[Assessing public perception: issues and methods: issues and methods](#)", Dowler E. et al, Health Hazards and Public Debate Chapter 3, 2006.



2. TECHNIQUE

Early warning of trending misinformation on social media

Innovative data partnerships have used social media monitoring “dashboards” as an early warning system to identify real-time trends in misinformation-sharing relating to Zika and other diseases. These techniques have the potential to greatly increase the speed with which information campaigns can respond to misunderstanding.

HOW IT IS USED

- ▶ To evaluate Ebola misinformation propagated through Twitter in the United States, as in this [analysis by academics at Virginia Polytechnic Institute](#), finding that it may be possible to distinguish rumors from facts by looking at posts’ response ratios.
- ▶ To [track anti-vaccine sentiments](#) in Eastern Europe, as in this UNICEF study, identifying three underlying drivers of vaccine fears and recommending targeted public health messaging campaigns to address them.

3. TECHNIQUE

Analytics to assess and improve the effectiveness of outreach initiatives

Advertising agencies and marketing analytics firms frequently provide campaign effectiveness data to corporate clients, meaning tools already exist to address many questions relevant for Zika. As discussed during the conference, Facebook has been conducting research on how to surface information from aggregated facebook posts that can inform the messages governments and health organizations send. They would like to leverage these tools to provide information that will be useful and relevant.

HOW IT IS USED

- ▶ To [evaluate a social media campaign in Atlanta](#) aimed at reducing adolescent dating violence, finding the campaign effective but imprecisely targeted (e.g., only 3.5% of Facebook “likes” were from the target audience).
- ▶ To evaluate [tweets about Breast Cancer Awareness month in the United States](#), finding that such tweets typically neither generated the desired conversation nor promoted specific behaviors (the study also outlined potential strategies for better generating conversation, including by partnering with high-profile celebrities and focusing campaigns on specific actions, like fundraising).



4. TECHNIQUE

Targeted surveys and other two-way interactions

Both free and paid tools allow governments to have two-way interactions to better assess public health awareness. Governments, multilateral institutions, and nonprofits also continue to collaborate with the private sector and academia to develop custom tools

HOW IT IS USED

- ▶ To communicate with community members and conduct rapid polls, such as through UNICEF's Short Message Service (SMS) System, [RapidSMS](#).
- ▶ To share information on public health questions, as [through Facebook public health "bots"](#) (Universidad Carlos III de Madrid's is also piloting a project to deploy "bots" on various instant messenger applications).
- ▶ To engage in [risk communication during](#), which helped the US Center for Disease Control (CDC) to better adapt its communications to public concerns and to make the public feel more included in the outreach process (also see the CDC's social media best practices website).

In addition, social media and cellphone data can be used to track and target the spread of the disease, which will be covered in the brief on Predictive Analytics.

While digital listening can provide useful information, it is not without limitations. Perhaps most importantly, not everyone has access to the Internet—and, among those who do have access, not everyone uses social media regularly. In many Latin American countries, rural populations have limited access to technology, necessitating more conventional survey strategies like phone calls and home visits to gain insight into the views of these populations. These limitations mean that it is often best to view digital listening as a complement, rather than a substitute, to more conventional survey methods.⁹ However, there is evidence that digital listening can be especially useful in providing insight into the sentiments of young people in particular.

⁹ For an in-depth discussion, see [Understanding Vaccine Refusal: Why we Need Social Media Now](#), Dredze, M., Broniatowski, D. A., Smith, M. C., & Hilyard, K. M *American Journal of Preventive Medicine* 50(4), 550–552.



III. Actions governments can take to capture the opportunity

In order to take advantage of these innovations in government, we recommend four actions:

1. Assess Social Media Penetration and Digital Listening Capability

Conduct an assessment of social media penetration to understand who can be reached by digital listening activities and how.

The first step in implementing digital listening solutions should be assessment of in-country social media use in order to identify the most appropriate platforms of focus and the specific populations groups that may be reached.¹⁰ Penetration can be compared across platforms by users, engagement, and other metrics tracked by commercial media analytics firms. Country-level statistics are compiled by services like Statista and WeAreSocial and are publicly available. However, consultation with industry advertisers such as GlobalWebIndex, ComScore, and eMarketer is recommended to provide more granular insights and identify long-term tracking interests. If the social media user base is well understood, statistical stratification methods may improve insight generalization from non-representative digital listening sample populations. Company representatives, such as Molly Jackman at Facebook, as well as academics such as Deb Roy and his lab at MIT or David Broniatowski at George Washington University could provide expert advice in this area. Undertaking this assessment is a relatively low resource, rapid activity with very little downside except that such an assessment needs to be repeated on a regular basis as demographics and platforms change.

2. Articulate the Demand for Digital Listening Insights

Convene an interagency committee to assess and prioritize demand for digital listening insights across government.

To assess the highest-yield opportunities for inclusion of digital listening efforts into the public health agenda, health officials should create a mechanism, such as an inter-agency committee, for soliciting, coordinating and prioritizing research needs from across government. This body should work to determine key public awareness assessment needs on an ongoing basis and identify the most appropriate questions for

¹⁰ Key research questions will include assessing (1) availability of internet, (2) penetration of hardware enabling internet use (i.e., desktops, laptops, smartphones), and (3) population having social media accounts and rates of engagement.



digital listening research. Because a wide variety of policy and service delivery practices in public health (and beyond) could potentially benefit from the insights derived from social media listening, having an inter-agency would enable a government to speak in a coordinated fashion to its own data science team or to third party platform and analytics providers about their needs. The downside of such coordination is that it potentially slows down processes by having every agency within the Department of Health (or every official) undertake its own digital listening process. However, the resource commitment is relatively low and consistent with how most governments already coordinate their policy making activities.

3. Institutionalize the Digital Listening Agenda

Appoint a Chief Analytics Officer to drive implementation of the digital listening agenda and integrate digital listening technologies into public health programs.

To champion implementation of digital listening strategies within the health sector in both the short and long-term, the Ministry of Health should create a Chief Analytics Officer role, which reports to the Minister of Health. This official must have sufficient institutional support to ensure the prioritization of data initiatives throughout the Ministry.

Responsibilities would include:

- ▶ Oversee the Ministry of Health's digital listening research agenda
- ▶ Chair the body created in recommendation 2 to identify digital listening needs and priorities
- ▶ Pursue research and data-sharing partnerships with tech companies
- ▶ Develop long-term expertise and human resources for digital listening within the government
- ▶ Identify existing extra-governmental resources for digital listening
- ▶ Ensure integration of digital listening capabilities into health sector planning
- ▶ Liaise with foreign government counterparts to share insights and best practices
- ▶ Produce real-time reports on a variety of questions, using social media data to inform policymaking



If bureaucratic difficulties inhibit the Ministry's ability to create this position, this role could be seconded from industry or from a research institution or university (i.e., as an "Analytics Fellow") and supported by foundation or philanthropic funding, provided the fellow is given sufficient support by senior Ministry leadership. If the person is given an important charge, such as to develop a digital listening program in response to Zika, the role will be prestigious and eagerly sought after as a professional advancement.

The advantages to having a person with both policy and data science training in-house are myriad, especially if that person sits within the senior leadership team and has insight into the Department's core mission and priorities, and can be hired quickly and given a broad mandate. The challenge, of course, will be to find funding for such a role but the costs of the hire can either be funded externally or offset through cost savings arising from more targeted and efficient delivery of services enabled by the digital listening program.

4. Develop the Supply of Digital Listening Services

Partner with MIT Media Lab or other non-profit analytics organizations to generate insights.

The MIT Media Lab's Social Machines Lab headed by Professor Deb Roy, who also serves as Twitter's Chief Media Scientist, like other select universities around the world could serve as data warehouses and analytics providers, collecting and organizing data from social media platforms and other sources. Those potential partners may already have data sharing relationships with social media platforms that could be adapted for public health digital listening. These partners could then link social media data to other data-sets (either that they collect or that interested governments and companies provide) and conduct analyses to support digital listening, as defined in collaboration with interested governments. Such a partnership would involve governments providing clear research questions, supplying government sources of relevant open data, and collaborating on a plan for converting the analyses into actionable measures to improve public health. The MIT Media Lab is a data partner with Twitter and would integrate Twitter data. This partnership could also extend far beyond Zika, providing a useful model for digital listening on a multitude of public health issues.

When selecting partners, governments may find benefits in working with both local and international partners. In many cases, excellent researchers and universities are available locally and come with local knowledge and language skills. International partners,



meanwhile, may prove a useful complement to this local expertise, particularly when it comes to analytic capabilities and pre-arranged partnerships with social media platforms.

Alternatively, partner directly with technology platform providers.

Technology companies are also interested in building their digital listening capabilities for social good. There are a few potential models for how governments and NGOs can collaborate with companies to use private sector data.¹¹ Those include:

FIGURE 2 – POTENTIAL PARTNERSHIPS WITH TECHNOLOGY PLATFORM PROVIDERS

TYPE OF PARTNERSHIP	DESCRIPTION
Research partnerships	Corporations share data for research. This often entails using anonymized and aggregated samples of datasets. In the social impact context, it may entail the corporations conducting analyses in-house for public or social sector partners.
Prizes and challenges	Companies make data available to qualified applicants who compete to develop new apps or discover innovative uses for the data. Companies typically host these contests in an effort to incentivize a wide range of civic hackers, pro-bono data scientists and other expert users to find innovative solutions with the available data.
Trusted intermediaries	Companies share data with a limited number of known partners for data analysis, modeling, and other activities.
API's (Application program interfaces)	Companies allow developers to access data for data analytics, testing, or product development.

For more information on potential archetypes for data partnerships, see this [taxonomy of partnerships](#) and this overview of [suggested readings](#).

Three particular partnership models have the potential to significantly enhance Zika digital listening:

Facebook could partner with a multilateral or nonprofit organization like UNICEF or WHO to develop Zika dashboards that track: public awareness and understanding of the disease (at aggregate and community levels), key drivers of the conversation about Zika and how to best influence it, and the effectiveness of public engagement campaigns. Predictive

¹¹ <https://medium.com/internet-monitor-204-data-and-privacy/mapping-the-next-frontier-of-open-data-corporate-data-sharing-73b243878d2#.mq0ap2xhw>



analytics could also help governments to get ahead of the disease, identifying potential new outbreaks or emerging trends in public (mis)information. This support should be iterative and ongoing, to ensure that the tools developed can be adequately adapted to future developments related to Zika (e.g., discovery of new ways the disease transmits) and is adaptable for future public health crises. Note that Facebook typically works with nonprofits or multilateral institutions on public policy issues, rather than working directly with governments.

Twitter already provides most of its data to select partners through the “Firehose API” including to the MIT Media Lab, UN Global Pulse, Dataminr, Datasift, Gnip, Lithium, and Topsy. Some health-specific monitoring is also available through healthtweets.org (see [here](#) for a description). Governments can partner with one of those organizations to access and analyze the data.

Google is already partnering with UNICEF on Zika, with a range of initiatives underway. These include building a platform to map and anticipate outbreaks of the virus, adding information and health alerts to its search engine, and other support. Governments could consider working with UNICEF to ensure that these efforts address their needs or, to the extent that they do not, exploring other partnership models with Google.

Use free or commercial-off-the-shelf analytics tools.

Some free or off-the-shelf tools can also provide basic analytic capacity. These tools can be particularly useful for tracking the same types of metrics that corporate marketers may track, like social media references, engagement with campaigns or websites, etc. For an overview of fifteen free and paid facebook analytics tools, see: [here](#). For some other ideas and comparisons, see [here](#) and [here](#). Before commencing, however, it may be a useful starting point to first contact those groups which have conducted public health-specific digital listening studies, as outlined earlier in this document. In particular, some pre-developed health surveillance tools may be useful (or modifiable) in Zika efforts, especially HealthTweets.org, MappyHealth, crowdbreaks, and Sickweather.



IV. Action governments can take collectively to catalyze effective digital listening

Convene national health ministries, international organizations, leading academics, and technology companies to consider ways to institutionalize a more coordinated MBD digital listening approach. We recommend the creation of a Latin American Digital Listening Network for Health as one possible solution.

Right now, digital listening in the public health context often rests upon ad hoc partnerships (e.g., UNICEF's Zika partnership with Google) or individual academic studies, but these types of one-off partnerships are not sufficiently scalable or sustainable to address the threat of Zika, other MBDs, and whatever comes next. There is a clear need to adopt a new approach that is simultaneously institutionalized and agile: institutionalized to ensure efforts build off of one another, and agile to ensure that studies can be completed on the tight timelines that global health crises require.

The partner governments (with the assistance of an NGO or other third-party organization) could leverage their deep expertise and institutional relationships across Latin America to convene a team of executives in health ministries, international organizations, and technology companies as well as leading academics in public health, data analytics, and computer science to discuss ways to develop a more coordinated response to the challenges posed by MBD digital listening. Partners in such an effort could include:

- ▶ WHO and PAHO leadership in epidemic surveillance and response
- ▶ Senior analytics staff at health ministries
- ▶ IDB's health team and country leads
- ▶ Director of UN Global Pulse
- ▶ Public health leadership of the Economic Commission for Latin America (ECLAC)
- ▶ Prominent digital listening-focused academics (e.g., researchers at a research institution like the Gorgas Institute or Imperial College London's Center for Precision Medicine)
- ▶ Social-impact staff of technology companies (e.g., Molly Jackman at Facebook and Deb Roy at Twitter)



These conversations could drive the creation of a Latin American Digital Listening Network for Health, which could have the following functions, each of which addresses current gaps in the region's MBD response:

- ▶ Provide a trusted and centralized repository for digital listening data storage, mitigating the need for ad-hoc data sharing by multiple parties during each crisis
- ▶ Facilitate dialog among companies, governments and academics in digital listening, breaking down silos and better coordinating efforts
- ▶ Connect governments needing expertise with experts who can provide it, minimizing the time spent searching for the right people to talk with (which may never lead to the right expert)
- ▶ Offer agile digital listening tools and services, allowing governments to harness cutting edge capabilities in this growing field

A public health or technology-focused organization should eventually lead such an effort. This initiative could be a natural fit within the World Health Organization, UN Global Pulse, or the Economic Commission for Latin America (ECLAC). The GovLab stands ready to help with coordination and convening.



ISSUE AREA 2

Behavior Change

To protect the public from Zika and other mosquito-borne diseases (MBDs), governments must encourage citizens to change behaviors that leave their communities at risk of mosquito breeding and biting. However, communicating and achieving this necessary behavior change is a well known public health challenge. This memo makes three recommendations for how governments can use innovative approaches to improve communication with the public regarding MBDs and drive behavior changes necessary to mitigating their risk. These recommendations are focused on the priorities articulated by partner governments.

- ▶ Create prize-backed challenges to promote engagement and innovation in Zika control at both the community and individual levels
- ▶ Compile peer-reviewed best practices in Zika/MBD public communications and present them in a way that is accessible for policymakers seeking actionable ideas.
- ▶ Explore the use of “serious games” to raise awareness and change behavior by organizing hackathons and/or partnering with game designers to deploy effective platforms



I. The challenge

Why are new ways to communicate about Zika needed?

In public health crises, communication programs aim not only to provide the public with comprehensive information about the disease and its causes, but also to prompt people to take the necessary steps to reduce risk and engage in desirable health-protection behaviors.

Often, however, these communication strategies fall short for diverse reasons:

Failing to communicate exactly how behaviors must change - and the importance of doing it. Public communications plans must do more than just communicate how a disease spreads. They must also communicate the best approach to stemming that spread in a way that leads to changed behaviors.¹²

Letting uncertainty and incomplete information degrade public action. “In situations involving heightened risk perceptions and weak levels of scientific certainty, authorities struggle to explain what is not known as much as what is known.”¹³ It is critical that these uncertainties are clearly distinguished from those already-apparent best-practices used to fight the virus, and that the public is aware of such distinctions.¹⁴

Failing to instill enough urgency to overcome built-in inertia. People are constantly assessing the costs and benefits to their behaviors and are unlikely to change their habits unless they are presented with a clear case that the benefits of doing so outweigh the costs. Communications must therefore clearly outline not just what to do but also why it is important to do it now.^{15, 16}

¹² For example, in a study in Madeira Islands, residents understood the importance of vector-control measures but were invariably convinced that, by using insecticides or flyswatters, they were already taking efficient measures for aegypti-control. “[Impact of a dengue outbreak experience in the preventive perceptions of the community from a temperate region: Madeira Island, Portugal](#)”, Nazareth T. et al, PLoS Neglected Tropical Diseases, March 2015.

¹³ “[Uncertainty management: Communicating the Zika risk](#)”, Rainford J and Greenberg J, Policy Options, January 2016

¹⁴ A risk communication note developed by the WHO Department of Pandemic and Epidemic Diseases (Gamhewage et al.) takes Zika as an example, emphasizing that “the current fears about the spread of the Zika virus, its complications such as microcephaly, and the many factors still unknown to experts leave confusion and fear that cannot be assuaged by the traditional forms of risk communication that work for a familiar disease outbreak.” “[Zika virus infection: global update on epidemiology and potentially associated clinical manifestations](#)”, Garcia E. et al, WHO Weekly Epidemiological Record No. 7, February 2016.

¹⁵ A WHO report on social mobilization and communication relies on the understanding that “people perceive benefits and drawbacks to all behaviors,” and these often vary for different segments of the population. “[Planning Social Mobilization and Communication for Dengue fever prevention and control, A Step-by-Step Guide](#)”, Parks W. and Lloyd L, WHO Report, 2004.

¹⁶ Additionally, a study in Sao Paulo shows the need to eliminate standing water that harbored mosquito-



Inconsistent follow-through. Experts in communication for behavioral impact stress that continuous messaging is required to take people through the gradual stages of behavior change: “from initial awareness to becoming more informed, then convinced, deciding to take action, taking that action, repeating that action, and finally maintaining that action.”¹⁷ Many programs succeed in informing and convincing different segments of the population but do not lead to effective change in behavior over the long-term.¹⁸

These shortfalls can and must be addressed through future Zika-related communications, and this memo outlines several potential tools to aid in that effort.

II. The opportunity

As governments deal with more public health crises, they experiment with ways to better communicate with the public and change public behaviors. New technologies, particularly the ability through social media to reach younger populations and to carefully segment messaging to different audiences, have further added to governments’ communication arsenal. (A lengthier discussion of the application of social media for understanding what people know is the focus of [Implementation Memo](#)).

Suggestions at the online conference fell into five categories:

Serious Games: Use games and mobile apps to raise awareness of the diseases, especially among young people, and in some cases even help with data collection and vector elimination.¹⁹

Celebrity Public Service Announcements (PSA): The celebrity PSA has long been practiced but the suggestion was made to approach celebrity “YouTubers”—those with a large following on YouTube – to spread the word. Such YouTubers might be particularly

breeding sites was resisted by the very poor, who could not prioritize the enormous efforts it would take to eliminate waste from their poverty-ridden, polluted areas, and by the very rich, who did not want to sacrifice their potted plants and swimming pools.” [“Dengue control in Ribeirão Preto, São Paulo, Brazil”](#), Passos A. et al, *Cad. Saúde Pública* vol.4 suppl.2, 1998.

¹⁷ [“Planning Social Mobilization and Communication for Dengue fever prevention and control, A Step-by-Step Guide”](#), Parks W. and Lloyd L, WHO Report, 2004

¹⁸ Park and Lloyd note, for example, that “in areas where piped water supplies are available, traditional water storage practices often continue because of cultural preferences for collecting rainwater or socioeconomic reasons, including the inability to pay water rates.” *Ibid*

¹⁹ The term “serious games” refers to “digital game technologies that serve a purpose other than pure entertainment.” [“Game-Based Interventions in Public Health: Exploiting the Engaging Factor of Gameplay”](#), Sylvester Arnab, in N. Lee (ed.), *Encyclopedia of Computer Graphics and Games* (2015).



effective for reaching young, urban dwellers, and thus serve as a complement to more widely known celebrities.

- ▶ **Data Visualizations to Improve “Gist” Understanding:** Key visualizations to improve understanding of key messages.
- ▶ **Prize Backed Challenges** – Using prize-backed challenges as an incentive for behavior change.
- ▶ **What Works Learning** – Documenting what works through a repository of case studies from other communities.

For more details on the ideas outlined during the conference, see [here](#).

III. Actions governments can take to capture the opportunity

Create prize-backed challenges to promote engagement and innovation in Zika control at both the community and individual levels.

Prize-backed challenges are becoming an increasingly popular tool in the hands of governments and philanthropists to drive rapid innovation and investment in specific problem areas. Given the wide range of possible competition and prize formats, governments can design challenges to solve needs ranging from specific technology gaps to community-level behavior change.²⁰ These types of competitions have the advantage of paying for results instead of effort (as is too often the case in traditional research-support grants) and can serve as powerful levers to encourage private investment in undeveloped market areas.

We offer three options for implementing prize-backed challenges relevant to Zika and other MBD behavior change at the end of this section. By compiling existing literature, we also summarize in **Figure 3** the key steps that governments will need to take in order to set up a prize.

A number of resources are available to assist governments in designing and implementing such prize-backed challenges. Organizations like [NESTA](#) offer best practice guidelines based on the experience of previous competition organizers. Additionally, the White House has compiled a series of reports on the use of prize-backed challenges in the US

²⁰ See Kalil 2006 Brookings Institution report for overview of prize models. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=0...6.2795&rep=rep&type=pdf>



federal government [here](#); it also offers a toolkit with examples of different types of prize-backed challenges on its [community page for challenge organizers](#).

For specific expertise, the GovLab's networkofinnovators.org offers governments a way to connect with past challenge organizers worldwide. This may be useful for consulting on specific questions of design or implementation. Expert participants from the September 7 conference may also be able to offer additional advice: Prof. Jaykumar Menon of McGill University, for example, previously led global prize development at the X-Prize Foundation and helped review this section's recommendations.

FIGURE 3 - STEPS INVOLVED IN SETTING UP A PRIZE-BACKED CHALLENGE²¹

STEP	ACTIONS
1 Planning and Goal-Setting	<ul style="list-style-type: none">▶ Defining and articulating the problem to be addressed▶ Deciding whether a challenge or grand challenge is the best tool for the need▶ Researching problem, consulting experts on strategy and design▶ Setting specific prize objectives<ul style="list-style-type: none">▶ Deciding whether to use financial or non-financial incentives▶ Determining audience▶ Creating a timeline of implementation milestones▶ Determining ownership and copyright
2 Prize Design	<ul style="list-style-type: none">▶ Identifying potential stakeholders, participants, and innovators▶ Creating prize appropriate to audience<ul style="list-style-type: none">▶ Financial or non-financial resources▶ Prize value▶ Designing evaluation mechanism<ul style="list-style-type: none">▶ Assessment criteria▶ Judges▶ Setting competition rules<ul style="list-style-type: none">▶ Duration▶ Eligibility▶ Rights to new technologies▶ Assessing the potential costs

²¹ Adapted from challenge design guides by [NESTA](#) and [McKinsey](#).



STEP	ACTIONS
3 Implementation	<ul style="list-style-type: none">▶ Deciding on competition platform: online, new or existing▶ Funding a prize-backed challenge▶ Navigating governmental endorsement and privacy concerns▶ Engaging the target audience▶ Monitoring evaluation metrics
4 Impact	<ul style="list-style-type: none">▶ Developing winning entries into solutions

Overall resource requirements and development timeline will vary according to prize design. Prizes can incorporate financial and non-financial resources to fit budgetary needs and targeted audience. Although implementation can be undertaken by a single full-time employee, implementation can also be outsourced to private firms specializing in prize-backed challenge design and operation (Idea Crossing, InnoCentive, NineSigma, Spigot, BigCarrot.com, Socialab, etc). Implementation complexity and timeline will vary based on the prize design.

Below, we outline three ways in which governments can capture the opportunity presented by prize-backed challenges in order to better tackle MBDs. These three options are intended to drive community mobilization, individual behavior change, and technology development for MBDs, respectively.

Create a municipal “seal of excellence” prize to mobilize communities and inspire local ownership of the fight against Zika and other MBDs

Governments can create a prize awarded in the name of the head of state or equivalent authority to local communities making exemplary progress in vector control, case identification, and other criteria. Specific goals and evaluation metrics should be developed with health expert guidance to balance public health impact and participation feasibility. However, evaluation should be flexible enough to allow communities to try different strategies to achieve the target outcomes. Renewability of the seal of excellence may encourage sustained engagement beyond the initial challenge period. In the past, UNICEF has successfully used this type of prize to drive [village-level progress towards MDG targets in Brazil](#)²², and India has used a similar approach to focus on sanitation behav-

²² Patricio Fuentes and Reiko Niimi at the [UNICEF Brazil country office](#) led an impact evaluation of the municipal seal of approval program and may be able to advise implementation of similar initiatives.



iors.²³ Contacts from these programs, outlined in the footnotes, may be able to assist in designing similar interventions.

- ▶ **Advantages:** Engages municipal-level stakeholders in MBD prevention and control. Flexible to adapt to local needs and challenges. Encourages cooperation at the community scale.
- ▶ **Disadvantages:** May be difficult to monitor community-level progress, depending on evaluation criteria and assessment methods. Scaleup to national level may take many months.

Partner with telecom companies to develop a “mobile micro-incentive” to encourage simple learning and behavior-change actions in individual citizens

High cell phone penetration rates present an opportunity for governments to mass-distribute Zika informational materials, knowledge quizzes, and vector control challenges. By offering a “micro-prize” in the form of free talk time, data, or other mobile rewards for given behaviors, governments can incentivize simple actions like visiting an informational website, correctly answering questions about Zika transmission, sharing a message on social media, or making an individual commitment towards standing water elimination. These challenges can be deployed by SMS, WhatsApp, or other platforms for maximum reach. Requiring users to respond with a particular message or code to unlock the reward can enable a level of interactivity. To implement this option, governments should pursue partnerships with local network carriers towards designing a specific micro-prize. For example, the Mexican Presidency’s Prospera project (<https://www.gob.mx/prospera>) relies on the donation of free text messaging to deliver behavior change information in connection with maternal child health. Public-private partnerships on health messaging can offer a public relations boost to the telecom operator. At the same time, a small airtime or phone credit prize is likely to present negligible marginal costs to the network.

- ▶ **Advantages:** Broad population penetration. Rapid deployment.
- ▶ **Disadvantages:** Scalable to fit specific budget constraints (e.g., only the first 10,000 respondents receive a prize). Relies on effective telecom partnerships.

²³ See the [Nirmal Gram Puraskar challenge](#), which formed part of a strategy known as community-led total sanitation (CLTS).



Set up a technology innovation prize to develop new, high-impact risk communication and behavior change tools

This type of challenge, open to the general public, should focus on developing new tools that health officials can use in the field to communicate MBD health risk and drive behavior change at a local level. Governments can develop a centralized website to solicit challenge entries and judging. Past competitions, such as the USAID [grand challenge to combat Zika](#), have developed new educational programs and software tools to help officials understand which motivational “levers” are most effective in producing behavior change in specific communities.

- ▶ **Advantages:** Directs research toward priority knowledge gaps and technology needs. Draws from on global knowledge and talent.
- ▶ **Disadvantages:** Substantial prizes may be necessary recruit top-level innovators and solutions. Judging submissions may require high level of technical expertise.

Establish a What Works Clearinghouse at the national or international level that consolidates Zika/MBD risk communication and behavior change literature and identifies best interventions for policymaker action

When designing health interventions, policymakers often turn to the academic literature for evidence-based guidance. However, it can be difficult for policymakers to identify proven best strategies for Zika or other emergent MBDs for several reasons: the literature is limited in scope and quality, it is not easily accessible to policymakers in one location, it is rapidly evolving in light of scientific and public understanding and it may be literature from other fields that might need to be drawn upon. These factors present an important challenge to designing the communications and mass social mobilization programs necessary for effective vector control and MBD prevention efforts.

To solve this problem, governments should create a centralized knowledge clearinghouse for Zika and other MBDs to better assess the evidence base for available interventions. A clearinghouse is a database of peer-reviewed literature that helps policymakers learn what works when new implementing policies and services. Clearinghouses have been widely employed across several areas of governance to bridge the gap between academic research and government policy.



A knowledge clearinghouse created specifically around Zika and other MBDs can assist governments in implementing a “what works learning” approach to MBD interventions. Such a clearinghouse can expedite and institutionalize the type of *ad hoc* meta-analysis and systematic review traditionally conducted by academic researchers and organizations in other fields of medicine and public health but lacking in MBD risk communication and behavior change interventions. Specifically, we envision this clearinghouse serving several key functions:

- ▶ Creates a centralized and searchable repository of the latest academic literature. This gives policymakers access to the most up-to-date evidence in a “one-stop shop.”
- ▶ Assesses the effectiveness of available interventions. This assessment quickly demonstrates (for example, through a color-coded scale) whether or not an intervention has been proven effective. The assessment also provides an indication of the strength or quality of available evidence for each intervention (e.g., high, medium, or low).
- ▶ Organizes options for policymaker review and action. The clearinghouse categorizes interventions in a way that enables easy consideration by government stakeholders seeking solutions.
- ▶ Harmonizes research needs and objectives. The clearinghouse identifies knowledge gaps in the literature and assists in governmental research agenda-setting.

Governments have several options for implementing a clearinghouse. Below, we have included two possible options that differ in scope and resource requirements.

(a) Create a clearinghouse within the national government to share knowledge specifically on Zika/MBD risk communications and behavior change interventions.

Governments can create an intragovernmental clearinghouse that focuses specifically on identifying best practices in MBD risk communication and behavior change. Examples of this type of limited-scope, national-level clearinghouse model include the [What Works Clearinghouse](#) run by the U.S. Department of Education and the [Crime Solutions database](#) run by the U.S. Department of Justice.

- ▶ **Advantages:** A limited-scope clearinghouse can be quickly implemented within the government and scaled to meet specific policymaker needs. Technical experts necessary for setup can be seconded from the Ministry of Health. Once online, this type of clearinghouse requires few full-time personnel to maintain. A committee of volunteer experts can be recruited from leading academic institutions to assist in building the database and reviewing the literature.



- ▶ **Disadvantages:** It is unclear whether there will be sufficient high-quality literature on Zika that falls within this narrow scope of focus. In addition, the creation of clearinghouses at a national as opposed to international level, may result in duplication of effort. Housing the clearinghouse at a national level may also preclude the addition of valuable international expertise.

(b) Partner with other international stakeholders to create a regional coordinating clearinghouse for Zika/MBD knowledge with a broad scope of focus to include but not be limited to communication and behavior change interventions.

Governments can partner with each other and with international stakeholders to set up an international knowledge clearinghouse for Zika/MBD interventions. This clearinghouse should cover a broad range of Zika/MBD literature, with the specific scope of focus negotiated by participating stakeholders. Possible models for this type of clearinghouse include the [Results First Clearinghouse](#) run by the Pew Charitable Trusts, or the [Cochrane Database of Systematic Reviews](#). The Results First Clearinghouse aggregates information from multiple U.S. government agencies and national-level clearinghouses into one central library, while the Cochrane database employs teams of academic volunteers distributed internationally to review medical literature for intervention efficacy.

Possible contributors to this international clearinghouse might include several of the below initiatives already working to coordinate and compile Zika literature:

- ▶ The [Global Virus Network Zika Task Force](#) serves as a coordinating body for global scientific research on Zika. However, the task force does not currently have a focus on communications and behavior change interventions, nor does it provide a central repository for its published work.
- ▶ PAHO is currently maintaining a [comprehensive database](#) of global Zika-related research, including some research on risk communication interventions. With this database as a starting point, PAHO or WHO could help spearhead the creation of an international What Works Clearinghouse. WHO involvement could improve global research agenda-setting and communications activities currently defined within WHO [Strategic Response Plans](#).
- ▶ The U.S. National Academies of Sciences, Engineering, and Medicine (NASEM) has an interest in coordinating Zika research priorities within the American scientific community. Its past efforts have included [a workshop](#) to set research priorities aimed at stemming the transmission of Zika within the U.S.



- ▶ **Advantages:** An international clearinghouse avoids duplication of effort across national governments and can better benefit from the leadership and technical expertise of multinational institutions like WHO/PAHO. Additionally, a single global clearinghouse with a clear topical mandate will likely attract more literature and generate better insights than multiple clearinghouses of national scope. At the same time, the resource requirements of an international clearinghouse are unlikely to be significantly larger than those of a national-level clearinghouse.
- ▶ **Disadvantages:** Setting up a regional or global clearinghouse will likely take more time than setting up a national clearinghouse, since there is a need to recruit and coordinate with diverse international stakeholders.

Below, we have outlined a general roadmap of steps necessary to set up a clearinghouse for either implementation option. We recommend convening a broad stakeholder discussion to critically address these points.

1. Define clearinghouse scope of focus.
2. Identify sources of information the database will use.
3. Set inclusion criteria and evidentiary standards for the database.
4. Establish a classification system to organize information in the database for policymakers. This system should include mechanisms to display the efficacy of interventions, as well as a taxonomy of other information relevant to end-users (study geography, date, authorship, contact information, etc.)
5. Define a governance structure for the database.
6. Assign roles for contributing to and maintaining the database.
7. Develop an engagement strategy to encourage policymaker use of the library.
8. Explore a network of partnerships (academic, private, public) to further build the database and leverage its insights.

We anticipate that steps 7 and 8, outlined above, will represent critical enabling factors for clearinghouse success. Without a strong network of policymakers, researchers, civil society organizations, and community influencers to build and leverage the clearinghouse, the gathered data will not improve Zika risk communication and behavior change practic-



es. As such, governments should pay special attention to how clearinghouse data will be disseminated and utilized. To assist in this regard, [Paul Lussier's research group](#) at Yale University has extensive expertise in developing public-private stakeholder networks to leverage technical data for social behavior change. His group, as well as the other existing clearinghouse organizations mentioned throughout this section, may represent sources of guidance during the implementation process.

Explore the use of “serious” games to raise awareness and change behavior by organizing hackathons and/or partnering with game designers to deploy effective platforms

With smartphones now in the hands of much of the world's youth and phone-based gaming becoming an increasingly popular form of entertainment, serious games have become a common tool for public health practitioners seeking to educate the public. Although there is no single definition for “serious games,” the term is generally used to describe games that are used for purposes other than just entertainment (i.e., education).²⁴ At least in part due to their engaging (and often communal nature), serious games have proven to be effective tools in increasing the public's knowledge of health issues.²⁵

(a) As a first step, health ministry communications leadership, in concert with other public health officials, should conduct a strategic assessment of knowledge gaps by demographic - and game / smartphone usership among those demographics.

A serious game is only useful if it can get to the people it is intended to reach. An assessment of smartphone penetration and game use within that target population can best determine the platform to use and, based on that knowledge, the extent of that game's ambition.²⁶

24 “[Serious Games for Health](#),” Vorvika Wattanasoontorn et. al, *Entertainment Computing* 4 (2013) 23-247.

25 For a detailed review of existing studies (and a synthesis of several previous literature reviews), see “[Using a Serious Game to Promote Community-Based Awareness of Neglected Tropical Diseases](#),” Saturnino Luz et. al., *Entertainment Computing* 5 (2016): 43-55.

26 For example, if the target is young people in areas where smartphone penetration is low, then a mobile game is not a viable solution. In that case, governments may want to partner with schools to either create a desktop based game for use in the classroom or to develop another campaign that leverages gamification's power in generating engagement but best takes advantage of the technologies available (e.g., creation of a classroom activity that informs students about Zika in a fun way). In this scenario, students would likely only interact with the game during school hours. This means such a game would be best suited for generating awareness and some specific knowledge, but not necessarily useful for changing and tracking behaviors. On the contrary, if the target population does have smartphone access and frequently uses those phones to play games, possibilities exist to create games that go beyond just generating awareness to also change behaviors or mobilize collective action. Such games could be simple or complex, with the opportunity for multi-player and location-based functionalities, and the ability for governments to regularly update to



Likely, the Health Ministry and partner organizations will already have completed significant work to determine at-risk populations and to assess their knowledge of Zika, its effects, and how it can be stopped. As discussed in the August 3 Smarter Crowdsourcing Conference on Assessing Public Awareness ([link to memo](#)), this assessment should be done through a combination of traditional methods (e.g., door-to-door surveys) and digital listening (e.g., social media analytics). In order to design effective interventions, it is crucial that this assessment go beyond just whether the a given group knows about Zika, as governments also need to know *what they know*.

(b) Next, health ministry communications staff can determine the appropriate model for developing serious games for target demographics.

The following approaches to game development may prove particularly useful, although each comes with its own advantages and challenges. These approaches are outlined in the table below, with practical advice in the text beneath the table.

enhance gameplay or add new information.



FIGURE 4 - POTENTIAL STRATEGIES FOR DEVELOPING A SERIOUS GAME

APPROACH	DISCUSSION
Add new features into an existing game	<p>New features could include Zika-related videos, quizzes, and even entirely new “levels”</p> <p>Advantages include lower costs (can cost as little as a few thousand dollars), less development time (as fast as one month), and lower user acquisition costs (since the audience has already been captured by the main gaming platform)</p> <p>Disadvantages include diminished control over the end-product and a shorter shelf-life of the ultimate product (dependant on agreements with the developer of the main game)</p>
Develop a new game	
i) Use entirely new code	<p>Creating a new game from scratch would involve starting with the game’s educational objectives and its audience’s interests, then developing a storyline, and, ultimately, a complete game</p> <p>Advantages include maximal control over the ultimate product (including the ability to select the optimal mix of purely educational and purely entertainment-oriented content) and over how long the game lives</p> <p>Disadvantages include significantly longer development times (depending on the game’s complexity, likely at least a year) and costs (could be more than \$1 million), as well as higher difficulty and risk in acquiring users (it is often hard to predict whether a game will acquire the users its developers hope it will)</p>
ii) Host a development hackathon	<p>A hackathon could mobilize game developers, designers, and public health experts for an intense, several-day effort to build the initial prototype of a game and to generate buzz behind it prior to its launch</p> <p>Advantages include fast mobilization of expertise needed to develop an initial prototype and early buzz about the game</p> <p>Disadvantages include potential challenges coordinating participants and building a useful product in such a short period of time</p>
iii) Modify code from an existing game	<p>Code from existing games, particularly public health serious games, is often available for adaptation to new games</p> <p>Advantages include shortened development times and (ideally) the availability of data on how the game performed during its previous release</p> <p>Disadvantages may include challenges making games developed for other countries and other public health challenges address new, zika-related educational needs</p>



1.I) DETAIL: DEVELOP NEW FEATURES FOR EXISTING GAMES

Perhaps the fastest and least resource-intensive option is to build the game based on existing systems. This model can be useful because it requires significantly less development, as much of the game already exists, with only some features edited to repurpose for Zika. At the simplest level, this could even involve adding new features to existing games. Where those games are already popular, this could have the added benefit of immediately putting the desired messages in front of millions of users.

For example, the following games and developers could be particularly appealing potential partners:

- ▶ **Niantic (Pokemon Go):** Already the most downloaded game in history,²⁷ Pokemon Go's features as a location-based, augmented reality game are particularly useful for Zika control efforts. For example, one could imagine adding a Zika Pokemon at locations where there is standing water, which can be "captured" by removing the standing water.
- ▶ **Etermax (Trivia Crack):** This Argentinian studio has created Trivia Crack, a trivia quiz game played regularly by more than sixty percent of Argentines.²⁸ A feature that adds questions about Zika could quickly reach the majority of the country.

Other regional studios for potential partnership would include Uruguay's [IronHide Game Studio](#) (makers of [Kingdom Rush](#)) and [Yogome](#) of Mexico (a leading maker of multilingual games).

For more information about leading Latin American game developers, see [here](#).

1.II) DETAIL: DEVELOP A NEW GAME FROM SCRATCH

Although it can be done, developing an entirely new game is often a risky and costly endeavor. This would entail hiring a game development studio with experience in the target country and also involving public health experts and medical specialists in the development of the educational content.

Case studies of successful public health-related digital games demonstrate that the following characteristics can prove particularly appealing:

²⁷ <http://www.hitfix.com/the-dartboard/pokemon-go-already-most-popular-mobile-game-in-us-history>

²⁸ <http://www.forbes.com.mx/latam-suelo-fertil-para-la-industria-de-juegos-moviles/#gs.sDWn5i8>



Opportunities to make meaningful contributions to a cause

This can take a few forms. For example, [MalariaSpot](#) allows players to analyze actual images of blood smears and identify malaria parasites.²⁹

[Mosquito Alert](#), meanwhile, is a Spanish citizen-science platform for studying and controlling the spread of urban *Aedes* mosquitos. Through this app, users send potential sightings of urban *Aedes* or their breeding sites to experts for validation. They can also see a real-time map of reported sightings.

Interactions with other people within the game³⁰

In the context of vector-borne diseases, where collective effort is critical for stemming the spread of a disease, including evidence of that collective effort into gameplay can be particularly motivating. For example, [Dr. Luden's LSG](#) (Leishmaniasis Serious Game), developed to help address the spread of leishmaniasis in rural Peru, requires users to perform a variety of increasingly-difficult tasks, including eliminating the breeding grounds of the sandfly that spreads the disease. Players gain more points for performing tasks collaboratively, and the game's simulation model is designed so that one player's actions impact those of the people around him or her.

Measurable progress within the game

For example, in the United States [Healthseeker](#), a Facebook-based game, bridges intention and action through specific tasks and associated prizes. Players also interact in a variety of ways – by challenging one another to complete missions, sending virtual “kudos,” and interacting and sharing supportive messages on a virtual “refrigerator door.”

The game must then also be disseminated through media that the target audience frequents. In many cases, that may need to involve the support of influential figures on social media, many of whom are in fact from Latin America. For example, six of the twenty most-followed YouTube channels in the world are Spanish-language,³¹ while the

29 MalariaSpot users' diagnoses proved strikingly accurate, particularly when multiple users' analyses were combined. “[Crowdsourcing Malaria Parasite Quantification: An Online Game for Analyzing Images of Infected Thick Blood Smears](#),” Miguel Angel Luengo-Oroz et. al., *J Med Internet Res*. 2012 Nov-Dec; 4(6): e67.

30 Collaborative games are often viewed as more engaging and likely to be shared with friends. See, e.g., “[A Comparison Between an Individual and a Collaborative Versions of a Serious Game to Learn About Dengue Fever](#),” Diego Buchinger and Marcelo da Silva Hounsell, *Revista Informática na Educação: teoria e prática*, Porto Alegre, v. 8, n. , p. 67-84, jan./jun. 2015 (translated to English).

31 See <http://socialblade.com/youtube/top/00/mostsubscribed> for detailed statistics and https://en.wikipedia.org/wiki/List_of_the_most_subscribed_users_on_YouTube#cite_note-0- for a chart with nationalities.



top video maker on YouTube (with 49 million subscribers), although English speaking, largely focuses on game reviews in his videos.³² Partnerships with Facebook and Twitter for free or discounted ad space, as well as with Google for “sponsored search” placement could also increase awareness of the game.

2.I) DETAIL: DEVELOP A NEW GAME WITH DEVELOPMENT INITIATED DURING A HACKATHON

As a first priority, health ministries should identify game developers from in-country willing to be involved in planning and running the hackathon.

They may also seek partnerships with international game developers that have deep experience in leading collaborative efforts to build social impact-oriented serious games, including in Latin America. Several potential partners are identified at the end of the serious games section.

These three categories of participants are crucial to ensuring that the hackathon results in a useful end product:

- ▶ **Public health experts** are needed to highlight the key knowledge gaps for the game to fill and to develop the substantive messages that the game will convey.
- ▶ **Designers** with experience working with the target populations are needed to ensure that the game is built in a way that the audience can relate to.
- ▶ **Game developers**, meanwhile, can translate the ideas into a working game.

Other useful parties could include:

- ▶ **Social media companies** can provide expert developers as well as specialized knowledge on how to integrate any game with social media platforms.
- ▶ **Game development companies**, particularly those with viral games already on the market, could help to find creative ways to merge Zika-related subgames into their already-popular software (see Recommendation 2b of this memo).
- ▶ **Medical and scientific specialists** can provide more specific expertise on Zika and its transmission mechanisms. They could be particularly helpful in identifying opportunities for games to participate directly in fighting Zika.
- ▶ **Member of the target audience** can also help ensure that the end product is desirable to them.³³

³² <https://www.youtube.com/user/PewDiePie>

³³ For a detailed overview of a potential process for developing a community-oriented serious game, see Luz et. al



Depending on the complexity of the game, the size and sophistication of the assembled team, and the length of the hackathon, organizers will need to modulate their objectives as to the ultimate output of the hackathon. With a simpler game, a working prototype may be ready by the end of the hackathon. If it is more sophisticated, the development process could take six months or longer.

2.II) DETAIL: DEVELOP A NEW GAME, USING CODE FROM AN EXISTING GAME

In many cases, code from existing games can be licensed, often for free. To the extent that existing games can be modified for new purposes, this can significantly cut down on the time and resources required to make a game. Github and other websites offer comprehensive lists and links to open-source games, and the organizations listed at the end of this section can also help brainstorm existing platforms for new serious gaming ideas.

a. Health ministry communications staff can seek the support of social-impact oriented game developers to aid in both strategic planning and game development

Several social impact-oriented game developers are willing to support Latin American governments on the development of Zika-related serious games. Each of these organizations works internationally and has significant experience in Latin America – including the four countries represented by this conference.



ORGANIZATION

DETAIL



New York-based **Games for Change** “facilitates the creation and distribution of social impact games that serve as critical tools in humanitarian and educational efforts.” Games for Change offers paid services, of varying degrees of breadth and depth, including facilitating workshops, providing strategic advisory services, and running game development contests or hackathons and incubating the ultimate results. Sarah Cornish and Emily Treat are happy to work with interested organizations to define the ideal partnership, which they believe would likely start with a workshop during which they would help to better define the need for a serious game and help build a strategy to make the game.



Playmob provides the technical bridge between social impact organizations and game developers. They leverage existing partnerships with the developers of popular games (or build new partnerships) to build into those games new features for charitable causes. Although based in the UK, they have international offices and experience working with partners from various countries. Jude Ower, founder and CEO of Playmob, is available to help governments or nonprofits think through their Zika-related needs and/or connect them to the right people.

socialab

Socialab is a Chilean nonprofit with experience throughout Latin America (and formal presences in Argentina, Chile, Colombia, Mexico, and Uruguay). They offer a tested platform for initiating challenges to address big social issues. This can range from broad problems addressed to general audiences to more specific, technical challenges (including a Zika serious games hackathon). Julián Ugarte, Luis E. Loria, Marina Spindler, and Matías Rojas have all expressed a willingness to help interested governments brainstorm ideas and, potentially, to support Zika control efforts.³⁴

³⁴ For additional resources on how Socialab work, see this [background brochure](#), this [overview](#) of “challenges” as a development too, and this list of [key items to discuss](#) in an initial “diagnostic” call with Socialab.



ISSUE AREA 3

Trash Accumulation

Preventing Dengue, Zika, and Chikungunya requires eliminating trash and containers that can fill with standing water, which allow *Aedes* mosquitoes to breed with alarming rapidity. We propose four recommendations, discussed at greater length below, designed to facilitate and accelerate trash identification and removal. They are:

- ▶ Involve communities in locating and removing litter.
- ▶ Use drones to identify and map areas with accumulated trash.
- ▶ Commit to Public-Private Partnerships (PPP's) with manufacturers to reduce trash accumulation.
- ▶ Collect trash in hard-to-reach areas using adaptive vehicles.

I. The challenge

Mosquitoes breed with alarming rapidity wherever water collects. There are two main contributors to standing water in urban environments. The first is an over-accumulation of waste due to the inefficiency of trash collection, derelict land use conditions, and the absence of options for easy disposal of trash, particularly industrial trash such as tires and construction residue that cannot be easily picked up by standard garbage trucks. The second is water reservoirs, which inherently create breeding grounds for mosquitoes which can thrive in any amount of standing water.



Governments have been dealing with Dengue epidemics for years, and the impact of trash and standing water has long been known. Studies have shown that female Aedes mosquitoes prefer to lay eggs in water that collects or is stored in man-made containers, and require only a small amount of water to do so.³⁵ Programs to eliminate those breeding sites were created but are not fully effective.

II. The opportunity

During the conference the use of technology to locate and identify waste was mentioned by several experts as the best and most cost effective way to improve the work that is currently being done to remove breeding sites. Suggestions at the September 2 conference fell into five categories:

- ▶ **Locating Waste:** using technology, for instance mobile phones and satellite images, to locate trash accumulation and even the composition of it in order to take measures to remove it.
- ▶ **Financial Disincentives (Fines and taxes):** using financial disincentives to reduce waste, such as fines on those who accumulate trash on their property and don't take action to eliminate breeding sites.
- ▶ **Public-Private Partnership with Container Manufacturers:** the main components of the trash are usually composed of three or four different types of containers. There's a need to involve the private sector industries that produce those products, and work with them on ways to prevent them from becoming accumulated waste.
- ▶ **Citizen Collectors:** using informal collectors who commonly know where to find waste and can also help identify illegal dump sites.
- ▶ **Biological Control:** Although introducing fish or other natural predators that feed on the Aedes larvae in small streams and water deposits was discussed and recommended by some, there was no consensus among those present (nor in the literature) as to the large scale efficacy and concerns expressed regarding possible environmental impact.³⁶

For more details on the ideas outlined during the conference, see [here](#).

³⁵ "Zika, Mosquitoes, and Standing Water", Centers for Disease Control and Prevention- Public Health Matters Blog, March 2016.

³⁶ "Life history variation of invasive mosquitofish (*Gambusia holbrooki*) along a salinity gradient", Alcaraz C and Garcia-Berthou E, Biological Conservation, June 2007



III. Actions governments can take to capture the opportunity

Based on the priorities articulated by the participating governments, this memo focuses on online, offline and hybrid crowdsourcing strategies, the use of drones and adapted collection vehicles, and partnerships with private industry to reduce waste.

1. Adopt Crowdsourcing To Locate And Remove Waste

What is Crowdsourcing? Crowdsourcing was coined by Jeff Howe in 2006 to refer to an institution taking a function once performed by employees and outsourcing it to an undefined (and usually large) network of people in the form of an open call. Since Howe coined the term, many new forms of crowdsourcing have grown in prominence and come into widespread use in the public as well as the private sector.³⁷

What are the Types of Crowdsourcing? Crowdsourcing practices, like group work more generally, can be distinguished by where the crowdsourcing takes place – in physical space or online – as well as the type of task the group is asked to perform. Online crowdsourcing involves leveraging the Web, smartphones or other network technology to gain access to crowd contributions. Offline crowdsourcing, on the other hand, enables distributed volunteer problem-solvers to contribute toward a pre-defined objective in physical space. There is also a hybrid model, which depends upon the use of technology to coordinate activities in physical space.

We explore and recommend strategies for undertaking both online and offline crowdsourcing with different types of tasks in response to the Zika crisis.

Online Crowdsourcing. Online crowdsourcing focuses on assigning tasks to a distributed audience to perform online that cannot be done by a computer alone, such as classifying photos or sorting data. For example, Amnesty International's [Decoders Project](#) asks volunteers to assess satellite photographs taken in Darfur to identify instances of human rights abuses. There are currently 8,000 active participating volunteers mapping remote and vulnerable villages. Open Street Map involves "the crowd" in collecting and mapping geospatial information.^{38,39} During the Ebola crisis in West Africa,⁴⁰ this was particularly useful in aiding relief efforts.

37 "The GovLab Selected Readings on Crowdsourcing Data", The Governance Lab, December 2013

38 "Citizens as sensors: the world of volunteered geography", Goodchild MF, GeoJournal, August 2007.

39 "The Fundamentals of Human Factors Design for Volunteered Geographic Information", Parker, C.J, Springer, 2014.

40 "Battling Ebola in Sierra Leone", Young A and Verhulst SG, Open Data's Impact, January 2016



As government seeks to do more with less in the fight against Zika, looking to the success of online crowdsourcing initiatives could provide a blueprint for engaging citizens to help accomplish difficult, time-consuming objectives at little cost. For example, Galaxy Zoo leverages the crowd to analyze images of space and tag galaxy shapes accordingly. This type of work is too nuanced for a machine, but quite simple and straightforward for an attentive human being. Since female Aedes mosquitoes lay eggs in water that accumulates in man-made containers, volunteers with access to satellite imagery could help to quickly locate trash and target collection efforts. By loading satellite images onto a crowdsourcing website, the public can augment the work of government by helping to spot the trash.

Such a project could be set up on Crowdcrafting, the leading open source online crowdsourcing platform.⁴¹ Crowdcrafting is a free and open source tool for creating crowdsourcing projects.

To create one's own online and customized crowdsourcing effort on one's own website, PyBossa⁴² (made by the same company as Crowdcrafting) is an alternative. PyBossa runs crowdsourcing projects for the British Museum, CERN and the United Nations. Daniel Lombrana is the point of contact for both PyBossa and Crowdcrafting and can be reached at Daniel Lombrana Gonzalez <teleyinex@gmail.com>.

Another option would be to join forces with [Let's do It](#), a civic-led mass movement that provides technology and expertise to concerned citizens looking to map community waste and then organizes the World Waste day to clean it up in "one, massive cleanup day." According to the Let's do It website, [local chapters](#) are already active in Colombia and Argentina and will soon be active in Panama and Brazil.

Offline Crowdsourcing. While most of the paradigmatic examples of crowdsourcing for the public good implemented in recent years have relied on some form of technology to coordinate efforts by distributed groups, the tasks undertaken are often done in physical space. For example, it is possible to create an offline crowdsourcing effort to engage people in picking up trash in their communities.

Blended Crowdsourcing. Online and offline crowdsourcing can be combined to encourage people both to spot and document trash and standing water and to remediate the problem.

⁴¹ crowdcrafting.org

⁴² pybossa.com



The *Litterati*⁴³ project, for example, uses citizens as distributed sensors, photographing litter they encounter day to day. The app is one of many examples of ‘participatory sensing’ efforts – especially prevalent in the realm of disaster response – that are allowing citizens to crowdsource important data, often using smartphones, that would be either impossible or time-consuming for institutions to collect themselves. The steady growth of smartphones in Latin America allows for usage of these tools. If we look at numbers in Brazil, 90% of the population owns a cell phone and 57%⁴⁴ owns a smartphone. There are currently 244 million mobile devices (smartphones and tablets) in Brazil, which represent 1.2 devices per person.⁴⁵

Photographs submitted through Litterati have embedded metadata with detailed information on the litter identified, including geolocation, time, type of trash, composition and even the brands whose products are present. With that data it is possible to create a “litter fingerprint” for the specific area targeted and overlay it with other data (i.e., school and business locations, socioeconomic demographics) to design more effective and efficient plans to remove and prevent trash accumulation.

It is admittedly challenging to get people involved on a sustained basis, but with proper communication and education, it has been shown from previous experiences, such as “What’s on the Menu” from the New York Public Library,⁴⁶ that the public responds positively to well defined projects, especially those that will benefit their communities directly. Crowdsourcing projects don’t necessarily have to be long and continuous to be effective, as seen in a project in San Francisco where a small team documented the litter they found during a week in an effort to demonstrate how much the tobacco industry contributed to litter accumulation. As a result of this enhanced insight from one week of crowdsourcing, the city imposed a tax on cigarette consumers, with the revenue allocated to litter-removal interventions. But, obviously, investment needs to be made in making people aware of any crowdsourcing effort and encouraging their participation.

⁴³ The Litterati Project

⁴⁴ “57% da população brasileira usa smartphone, diz estudo”, Medeiros H, exame.com, 2016

⁴⁵ “Tecnologia de Informação”, Meirelles FS, 2016

⁴⁶ “Crowdsourcing and Community Engagement” Peaker A, Educause Review, October 2015



How to Design and Implement a Crowdsourcing Project

Whether offline, online or blended, there are clear and obvious benefits to addressing trash accumulation through crowdsourcing, including taking advantage of distributed manpower to clean up the trash more effectively but also to document and collect data about trash to enable additional policy interventions (such as partnering with private companies to reduce container production, explained later in the memo). Crowdsourcing also gets more members of a community engaged in and aware of an important issue.

Designing and implementing a crowdsourcing project that is well-positioned for success involves a number of important steps and considerations. The following roadmap was developed based on extensive research into the theory and practice of crowdsourcing and consultations with experts working in the space. These steps can be undertaken by a government official (or team) planning the crowdsourcing effort or outsourced to a vendor.

STRATEGY

Clearly define the problem the crowdsourcing effort is meant to address and how the effort coexists with related initiatives - For example, the goal might be to identify large items such as tires or electronics or illegal dumping of things like furniture or ineffective trash collection services or the spotting of trash in private lots that might not otherwise be visible

Create a detailed, overarching plan for the crowdsourcing initiative and define key milestones

DESIGN

Define the tasks the crowd will be asked to perform (e.g., photograph litter you encounter, tag trash in satellite images)

Design tutorials and guides to effectively explain the tasks and the details of how citizens should contribute

ENGAGEMENT

Identify and target the specific crowd that is best-positioned to provide useful input (e.g., people living in a particular area, individuals with specific skills or knowledge)

Decide on an incentive structure for catalyzing participation (i.e., a financial incentive or non-financial motivations like gamified leaderboards)

Build a sense of community among the participating crowd in order to keep them engaged



IMPLEMENTATION

Choose a platform (e.g., Litterati or Crowdcrafting) to use for implementing the crowdsourcing project

If existing platforms do not satisfy needs, access outside contractors and/or intermediaries to support the design and implementation of the desired crowdsourcing platform

Implement the project and create internal mechanisms for making use of the contributions of the crowd

Determine the institutional resources (e.g., team composition) required to implement a successful crowdsourcing initiative and design a team to support participants

Connect the efforts of the crowd to enable them to aggregate and build off each other's work

READINESS

Ensure that strategies are in place to generate high-quality and accurate data

Where applicable, determine the ownership and copyright of crowd contributions

Develop a strategy to navigate privacy concerns (e.g., a data responsibility framework)

Assess the potential time and resources required from the crowd in order for them to participate well

Create a strategy for mitigating any potential tensions regarding free speech and public record laws

IMPACT

Define criteria and metrics to measure the effectiveness of the crowdsourcing effort

Leverage reputation systems and other techniques to enable the crowd to evaluate crowd contributions (through voting, rating or peer-review)



2. Use Drones To Locate Waste

The issue: Areas of difficult accessibility and visibility for trash collection and sanitation teams, where trash can accumulate and become breeding sites, are a big problem in dense urban areas with irregular terrains. Because these are extensive areas, it would be impossible to inspect them manually in a time effective manner.

The proposition: Using an unmanned aerial vehicle (UAV), also known as a drone, to inspect and map areas for accumulated trash will help governments focus efforts to prevent MBDs. This is a complementary measure and drones will be used in hard to reach locations to spot where teams should be sent to remove trash.

A drone is an aircraft without a human pilot aboard. These may be operated with several levels of autonomy:

- ▶ remote controlled by a human operator
- ▶ controlled intermittently by a human and autonomously
- ▶ fully controlled by onboard computers

Low cost unmanned aircraft systems are emerging to democratize access to the aerial perspective for the common good. They can be equipped with cameras and other tools that will help governments and institutions easily and cost-effectively gather information that previously would have been impossible.

The use of this tool offers a cheaper solution for mapping areas with difficult accessibility. It allows for high resolution images and different angles, and technology advances allow it to be self controlled or controlled remotely (see Figures 5 and 6).⁴⁷

A project by RTI in Guatemala⁴⁸ helped local government to map areas with difficult accessibility and visibility for spots where mosquitoes could breed. Some of these locations provide coverage for breeding sites and are difficult to see with traditional methods.

⁴⁷ “Agricultural Drones” Anderson C, MIT Technology Review, May/June 2014

⁴⁸ “Drone Assisted Vector Intervention Data Tool (DAVID)”, RTI International, August 2016



FIGURE 5



FIGURE 6



The steps necessary to implement a drone project to locate waste accumulation are:

- ▶ **Selecting the technology:** As seen in previous projects, it is usually cheaper to acquire the drones locally. They can vary greatly in price according to local supply, so as a last resort they can be bought from international markets with better prices and imported. Some can also be modified and equipped to better suit the needs of the project.⁴⁹
- ▶ **Finding expertise to handle the drones:** even though most drones are easy to pilot and handle, conducting technical flights to map and search areas requires some level of expertise. A number of drone pilot courses are being created, but experts can also be found in engineering and technology schools or hired through private companies.⁵⁰
- ▶ **Defining the areas to be mapped:** even though using drones is a practical and fast way to map geographical areas, it still would require time to cover large territories, so ideally the areas to be searched should be defined previously with an accessibility parameter, meaning that areas that are more easily seen and covered in traditional ways should be less prioritized than areas with difficult access.
- ▶ **Analyzing the data:** after the images are collected, they must be processed. Recognizing waste in images can be done manually, but when a vast amount of photos is captured, it would be impossible to do so in a time efficient way, so image recognition softwares can be used.^{51 52}

⁴⁹ "How to buy a drone" UAV Coach, 2016

⁵⁰ HIRE UAV PRO

⁵¹ Immaga- Image Recognition Platform-as-a-service

⁵² Data Mapper- Professional Drone based Mapping and Analytics



- **Creating an open data portal:** making the data available can not only stimulate research to understand littering patterns but also engage the communities on littering prevention.

One possibility that drones provide in urban environments is spotting discarded objects left on rooftops by the population, where they are not removed by regular trash collection companies and create possible breeding sites very close to homes and difficult to be seen from street level. Drones can also place mosquito traps at different heights to check if they are infested.

Drones can also be equipped with lenses that filter the images and separate plastics and other materials, and allow them to be quantified and mapped and help identify the sources of trash. The Race for Water Foundation tested this approach with a specially developed drone used to assess the trash that is present on the shores, and to create an initial overview of the innovative technology's capabilities, in order to further explore unmapped territories during a sailing expedition that aimed to draw up the first global assessment of plastic pollution in the ocean.⁵³

Alternative approaches involve the use of satellite images on demand or hiring small planes to photograph the area, but those incur larger costs than using drones.

3. Commit To Public-Private Partnerships With Container Manufacturers To Reduce Trash Accumulation

In 2010 the organization for Economic Co-operation and Development (OECD) published the book [Extended Producer Responsibility – A Guidance Manual for Governments](#) in which it states: “Municipal waste has increased 22% per capita from 1980 to 1997. At the same time, the difficulty of siting new waste disposal facilities has increased. Faced with the increase of waste, many governments have reviewed available policy options and concluded that placing the responsibility for the post-consumer phase of certain goods on producers could provide a means to relieve certain environmental pressures, arising from post-consumer waste. Extended Producer Responsibility (EPR) is a policy approach under which producers accept significant responsibility – financial and/or physical – for the treatment or disposal of post-consumer products. Assigning such responsibility could provide incentives to prevent wastes at the source, promote product design for the environment and support the achievement of public recycling and materials management goals.”

⁵³ [Race For Water](#)



As mentioned in the conference by Graham Alabaster and Jeff Kirschner, the main components of trash in a certain region can be traced back to very few industries. Involving those industries in the waste collection process through public-private partnerships can reduce the burden on governments and effectively create less trash accumulation.

These public-private partnerships may take different forms. In Europe it has become common to create policies in which companies are responsible for taking back the byproducts of their industry from end users at the end of the product's useful life, or financing the creation of a collection and recycling infrastructure. The goal of these partnerships is to protect public health and the environment and they encourage manufacturers to:

- ▶ design products for reuse, recyclability, and materials reduction;
- ▶ change consumer behavior by incorporating waste management costs into the product's price, backed by data showing the impact of that product on litter;⁵⁴
- ▶ promote innovation in recycling technology.⁵⁵

They can be achieved by mandatory policies, negotiation with industries or even voluntarily through incentives.

After doing a recognition study of the main components of the waste that is causing accumulation of water in the targeted area, these programs can be focused to help promote the goal of removing the byproducts from the environment by creating incentives for companies to either redesign their products to avoid water accumulation after being discarded or to prevent them from being discarded (recycle/reuse).

The industry may also choose to delegate the responsibility to a third party which is paid by the producer for used-product management. That third party can be a community based program for example.

Creating community based collection programs that can generate income and prevent waste accumulation has been successful even without the disease prevention factor. A project by the WHO in Nairobi⁵⁶ organized a community group to work on recycling. It taught them to separate the products not only by type of material but also by brand. Organic waste was used for compost and non-organic materials were either sold back to

⁵⁴ "[San Francisco to double litter fee on cigarette sales](#)", Sabatini J, SF Examiner, December 2015

⁵⁵ "[Sustainable Consumption and the Law](#)", Salzman J, Environmental Law, 1997

⁵⁶ "[Project Evaluation Report- The Mukuru Recycling Centre](#)", Kwach H, June 2006



the companies that produce them, through partnerships, or even used to produce useful tools for the community (i.e., paper bricks). The decision on what to do with the product was based on the price of the material, which fluctuates with time.

4. Adopt A Strategy For The Collection Of Trash In Hard To Reach Areas

The issue: According to Rio de Janeiro government officials, one of the biggest challenges for waste collection in the city is reaching and removing trash from dense communities that are built on hill slopes with very narrow streets where regular collection trucks cannot reach and that creates an impediment for trash to be taken out of the community. Generally, the inhabitants of such communities eventually throw it onto the slopes or into the rivers, polluting the area and creating sanitation hazards.

While it is important to educate these communities on the matter, it is also necessary to provide them with capacity to help the government solve the problem.

The proposition: Graham Alabaster introduced us to the idea of a trash removal plan that relies on the use of small refuse collection vehicles which can gain access to the dense urban areas, as done before in a project in Homa Bay, Kenya.⁵⁷

The concept of the project is to create a microsystem of trash collection inside communities where regular trash collection systems do not reach.

Although the project relies on these small refuse collection vehicles, it is important to explain how the whole process must be created, since if the trash containers are not provided and explained to the community, the use of the small refuse collection vehicles would be ineffective.

Below are steps suggested by that project:

- ▶ Providing good trash **storage containers** to the population, to prevent open-air accumulation that allows the breeding and spreading of mosquitoes. They could be:
 - ▶ **Dustbins (primary):** mostly made of plastic or metal, with openings or holes on the sides. They are low cost, have a long life span, and are not susceptible to theft because they are stored indoors.
 - ▶ **Plastic and galvanized bins (secondary):** These waste receptacles vary in capacity between 7-250 litres. They can be made of plastic or galvanized

⁵⁷ Homa Bay Town Integrated Solid Waste Management Baseline Survey. UN-Habitat, Nairobi.



materials near construction sites since waste from construction can be too heavy and break plastic bins. These would be placed strategically by the municipality at different locations within the community at different intervals where people and local businesses could throw in their wastes.

- ▶ **Bulk Containers (Tertiary):** These are the largest communal storage facilities with load capacities between 7 and 10 tons. Such containers are mechanically lifted into large collecting vehicles. The fact that these are open storages of waste, unprotected against rain, insects and rodents causes a potential hazard and must be emptied frequently.

The criteria for the placement of refuse receptacles (secondary) in the community should be based on the level of waste generated in a given area and the accessibility and convenience to the householders in that area. In terms of location for bulk containers, the criteria should be the availability of space and accessibility for regular trash collection cars.

- ▶ Implementing a **collection process** that assures rapid removal of trash. The first step is aimed at removing trash from households and can involve two different approaches:
 - ▶ **Communal Collection:** community members are instructed to manually dispose of their home wastes at predetermined locations containing secondary storage receptacles described earlier and the small refuse collection vehicles will visit those sites at intervals to empty them and bring the trash to the bulk containers.
 - ▶ **Door-to-Door collection:** small refuse collection vehicles stop as close as possible to the entrance of houses, and the individual household containers are emptied directly into the vehicles that would then bring the trash to the bulk containers.

Once trash is moved to the bulk containers, the process is completed through:

- ▶ **Regular collection route:** regular municipal trash collection cars that work pre-established routes would stop at the locations of these tertiary containers and empty them regularly.
- ▶ Determining the best vehicles to be employed for the **transportation of wastes** from the collection sites to the place of final disposal. Important factors to take into consideration when selecting refuse collection vehicles for purchase or lease include financial (acquisition, operation and maintenance costs) and logistic (ease of entry and exit for personnel; materials-loading efficiency; loading capacity; nature of







wastes; housing density and configuration of streets; and the distance from the collection site. Options include the following:

- ▶ **Small adapted vehicles:** identify cheap locally available small trucks that could be adapted as refuse collection vehicles by attaching a hopper with separated compartments for waste and recyclables. They can be used to easily maneuver along narrow and steep roads in densely populated urban areas. These will serve two purposes: 1) routinely collect (and replace) the filled secondary bins throughout the community for transport to the bulk containers (tertiary); and 2) conduct door-to-door collection where appropriate on its route.
- ▶ **Wheelbarrows:** to be used for manual transport in areas so small that no vehicle can reach. They can be used to transfer wastes from households to secondary containers.
- ▶ **Garbage trucks:** regular trucks that collect trash in the city will remove and empty the bulk containers and take the trash to the final processing facilities.

The project can be either managed and run by the community and the revenue from selling the recyclables could help support it along with government incentives, or it could be structured and managed entirely by the responsible government agency.



Here are references to organizations mentioned throughout this memo that could be part of possible actions with Latin American governments to fight Zika:

ORGANIZATION	DETAIL
	<p>Litterati's mission: an app and online community that aims to create a litter-free world by crowdsourcing trash cleanup. The idea is simple: After identifying a piece of litter, users photograph and post it on the app, using hashtags to identify it and geolocation to map it. Geotags provide insight into problem areas, while keywords identify the most commonly found brands and products. This data will be used to work with companies and organizations to find more sustainable solutions.</p>
	<p>RTI International is an independent, nonprofit research institute dedicated to improving the human condition. Clients rely on us to answer questions that demand an objective and multidisciplinary approach—one that integrates expertise across the social and laboratory sciences, engineering, and international development. Combining scientific rigor and technical proficiency, we deliver reliable data, thorough analysis, innovative methods, novel technologies, and sustainable programs that help clients inform public policy and ground practice in evidence. We scale our approach to fit the demands of each project, delivering the power of a global leader and the passion of a local partner.</p>
	<p>Crowdcrafting is a web-based service that invites volunteers to contribute to scientific projects developed by citizens, professionals or institutions that need help to solve problems, analyze data or complete challenging tasks that can't be done by machines alone, but require human intelligence. The platform is 100% open source - that is its software is developed and distributed freely - and 100% open-science, making scientific research accessible to everyone. Crowdcrafting uses PyBossa software: an open source framework for crowdsourcing projects. Institutions, such as the British Museum, CERN and United Nations (UNITAR), are also PyBossa users.</p>
	<p>The WHO's goal is to build a better, healthier future for people all over the world. Working through offices in more than 50 countries, WHO staff work side by side with governments and other partners to ensure the highest attainable level of health for all people. Dr. Graham Alabaster, based in the main office in Geneva made himself available for any follow ups.</p>



ISSUE AREA 4

Surveillance and Data Sharing

Effective collection and dissemination of data among governments, clinicians, researchers and the public is essential to managing disease outbreaks. However, there are deficits in the accuracy and agility with which authorities collect and share data, especially in the context of new and poorly understood outbreaks like Zika. In order to improve the speed and comprehensiveness of disease surveillance data, this memo outlines recommendations for the use of both new technology and more open and participatory data collection practices.

We propose three recommendations discussed at greater length below. They are:

- ▶ Improve the speed and reliability of surveillance data by integrating flexible mobile technologies like SMS and smartphone app reporting into surveillance activities.
- ▶ Collaborate with companies and universities to identify new sources of disease surveillance data.
- ▶ Promote openness and participation in surveillance data collection, storage, sharing, and use by developing a data governance playbook for epidemic response and building broad commitment to use it.



I. The challenge

Governments require disease surveillance data that is robust, timely, and open in order to drive effective evidence-based public health response. Improved surveillance data benefits policymakers, researchers, clinicians, and patients alike through more accurate epidemic modeling, more efficient application of resources, and ultimately more cases averted. Unfortunately, international health crises like the Ebola epidemic and present Zika epidemic highlight continuing challenges in data collection, sharing and use. Persistent hurdles in data availability, quality, standardization, and timeliness limit critical research and decision-making abilities from the local to international levels. These challenges carry particular weight in the context of MBDs such as Zika, dengue, and chikungunya for which there is not yet an effective vaccine.

Challenges in epidemiological data collection arise from a number of factors within existing disease surveillance systems. These include:

- ▶ Regional variation in health resources and infrastructure for disease surveillance
- ▶ Lack of coordination among public and private health actors
- ▶ Jurisdictional decentralization within health systems
- ▶ Slow provider-based case reporting structures
- ▶ Lack of scientific knowledge about the characteristics of emerging diseases, including their long-term clinical symptoms and routes of transmission

After obtaining disease surveillance data, the additional challenge of data governance arises. Governments must consider how to share data responsibly among health authorities, researchers, patients, and the broader public so as to permit the data to be put to good use.⁵⁸ Key challenges in this area include:

- ▶ Regulating access to sensitive/identifying information within the health system
- ▶ Giving patients and communities secure access to their own information
- ▶ Balancing the interests of individual patients and the public during emergent health crises
- ▶ Developing frameworks for data sharing that protect patient privacy
- ▶ Making anonymized data more accessible, standardized, and interoperable to permit best use for the public interest

⁵⁸ “An Epidemic Of Disease Reporting,” Mariner W, Health Affairs Today, November 2008.



Problems in epidemic data collection and sharing prevent evidence-based decision-making at all levels of government. Shortcomings in surveillance data collection and sharing have been cited as an underlying factor in issues ranging from the resurgence of dengue and *Ae. aegypti* in Latin America⁵⁹ to poor containment of Ebola cases in West Africa in the 2014–2016 epidemic. Improved information gathering and dissemination practices will be a key to managing not only Zika and other MBDs at present but emerging health threats in the future.

II. The opportunity

During the conference, experts discussed a variety of ideas to improve information collection and data governance. A full summary of points discussed is available in the conference 4 takeaways document. Ideas fell into three broad categories: strengthening existing surveillance systems, developing new sources of data, and improving data openness and sharing during epidemics.

Strengthening existing surveillance systems – Ideas to strengthen existing surveillance structures centered around improved data transmission and case reporting from areas of low connectivity. Dr. Pia MacDonald from RTI International gave several examples of flexible techniques to improve data collection in areas of low internet connectivity and phone penetration. Hon. Tolbert Nyenswah shared how Liberia used smartphones during the Ebola crisis to accelerate case reporting, contact tracing, and lab diagnostic confirmation. Dr. Duane Gubler suggested better integration of community health workers within surveillance and reporting structures.

Developing new sources of data – Many experts suggested collecting data in new ways and from new sources. Proposed methods ranged from networked PCR machines and ovitraps to drones and crowdsourcing. Experts agreed that new attention should be devoted to developing information streams from private sources.

Improving data openness and sharing during epidemics – There was a great deal of discussion and debate, in particular, on the question of how data should be managed. Actionable suggestions focused on data standards, data centralization, and flexible data management protocols. Experts agreed that new data frameworks need to be adaptable to future health threats and priorities.

⁵⁹ See history of *Aedes aegypti* control in Brazil by [Braga and Valle](#).



III. Government actions to capture the opportunity

1. Improve the speed and reach of disease surveillance systems by integrating flexible mobile technologies like SMS and smartphone apps into surveillance activities: two ways to do this are through digital participatory surveillance and mobile device-assisted case reporting

For all the promise of predictive analytics and the use of algorithms to predict outbreaks, predictive analytics depend upon having access to enough data upon which to base a model. But current MBD surveillance systems are limited in both speed and reliability of case identification. These issues are often exacerbated by manual, paper-based reporting structures that make distributed information collection from geographically remote areas difficult. Recently, advances in mobile and wireless technology have led to the birth of a new wave of “mHealth” strategies enabling improved health service provisioning based on the proliferation of mobile connected devices. To capture this mHealth opportunity, governments should integrate flexible mobile technologies such as SMS and smartphone app reporting within the MBD surveillance agenda, improving the connectivity of community health resources and increasing speed and reliability in case reporting by directly engaging the public. Two ways to do this are by implementing digital participatory surveillance and by using smartphone apps to assist in case detection and reporting.

mHealth is a subdivision of the larger eHealth, or electronic Health, movement. mHealth covers mobile information and communication technologies ranging from SMS-based health reminders to telemedicine. Because of the near-ubiquity of mobile device penetration and wireless network coverage around the world, mHealth technologies have the capability to extend health system service provision and information gathering far beyond the reach of traditional infrastructure like clinics, roads, or even electrical grid.⁶⁰

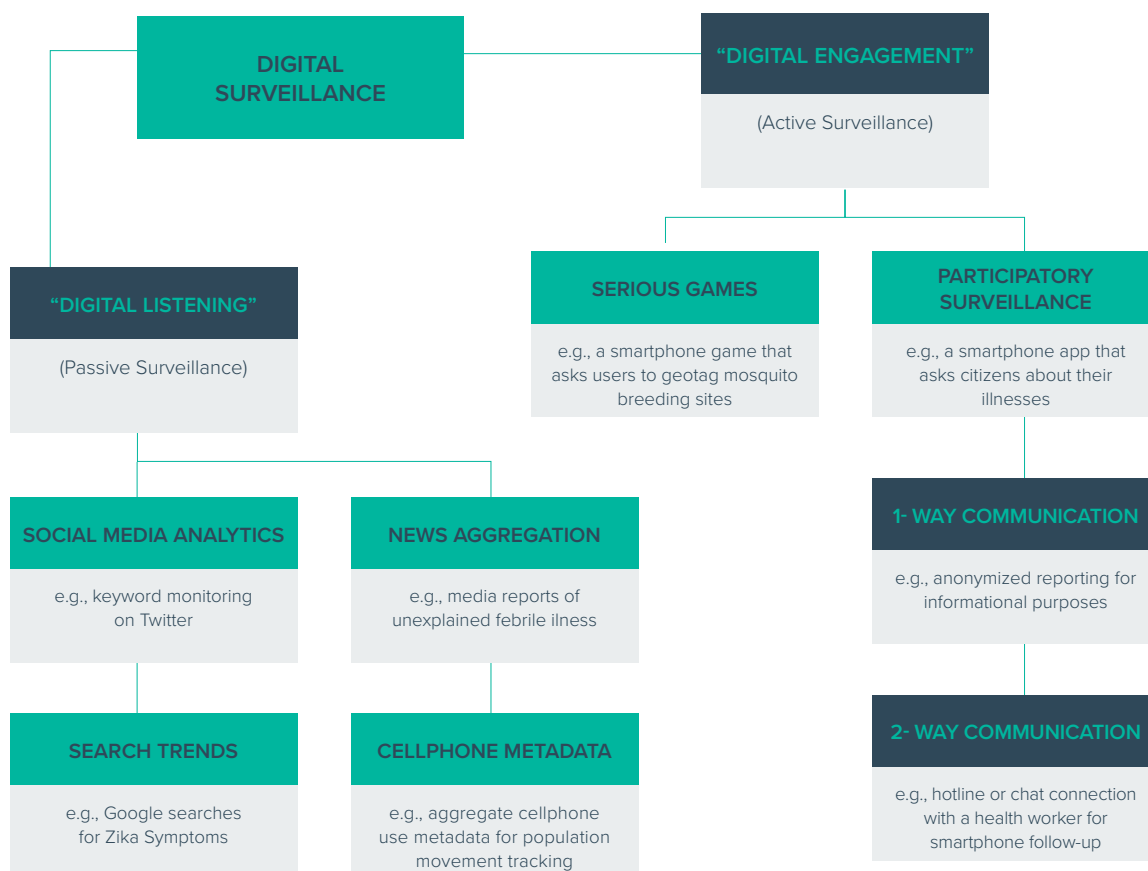
A variety of mHealth technologies are applicable to surveillance activities for Zika and other MBDs in order to improve case identification, confirmation, and reporting. These methods fall under the broad umbrella of digital surveillance, which serves as a novel supplement to traditional disease and vector surveillance methods. In **Figure 7** we provide a hierarchy of potential digital surveillance tools. Note that many mHealth technologies serve as platforms integrating multiple types of digital surveillance, including the use of social media analytics

⁶⁰ See the latest WHO [strategic report](#) on mHealth technologies for an overview of applications.



to understand what people do and do not understand about the disease as well as the use of mobile platforms to deliver public health messages to underserved populations.

FIGURE 7 - POTENTIAL DIGITAL SURVEILLANCE TOOLS⁶¹



Here we focus on two additional digital surveillance concepts: digital engagement (a form of participatory surveillance) and mobile technology-enabled case reporting (the use of mobile phone apps and messaging to assist health workers gathering epidemiological intelligence).

Adapt digital engagement and participatory surveillance tools to supplement Zika case-finding.

Participatory surveillance gathers epidemiological data by asking people to report their own health symptoms and observations. Whereas traditional surveillance systems rely on the reports of medical providers, participatory methods engage ordinary community

⁶¹ Adapted from Pagliari and Vijaykumar, 2016. [PLoS NTD](https://doi.org/10.1371/journal.pntd.0004788).



members in order to cast a broad net of detection. While participatory methods offer less specificity than traditional provider-based reporting, these participatory techniques have proven extremely useful as a complement to established surveillance.

Key advantages of participatory surveillance systems include the following: high sensitivity to emerging outbreaks, flexibility in case definition, near real-time identification of suspect cases, and relatively low barriers to scale-up over large populations. A growing body of literature on best practices and lessons learned is now available based on the experience of projects such as [Influenzanet](#), one of the largest participatory surveillance systems currently in operation. Over the past decade, Influenzanet has grown to track flu-like illnesses in European countries through the online reports of tens of thousands of volunteers.⁶²

There remains [untapped potential](#) in applying participatory surveillance to additional infectious diseases like Zika. Recent pilot projects have developed participatory surveillance tools for diseases, including dengue, and efforts are now underway to adapt these tools to other MBDs. These tools are not a substitute for highly specific diagnoses reported by trained clinical providers. However, participatory reporting has the potential to capture patterns in a broad range of symptoms that clinicians do not regularly monitor or report. This is particularly important in the context of diseases like Zika for which case definitions are evolving and for which the full range of long-term health effects is not known. Participatory surveillance of syndromic conditions can also potentially identify outbreaks of novel diseases by highlighting anomalies such as spikes in unexplained or unusual symptoms.

Governments should actively engage in developing and deploying participatory surveillance tools to serve as a supplementary source of Zika disease surveillance. Efforts should focus on developing these tools for mobile platforms, as increasing device penetration and cell coverage present an opportunity to reach the most users at the lowest possible cost.

To maximize data quality from participatory surveillance systems, governments can pursue several strategies. One approach would be to set up sentinel surveillance operations in several key areas covered by participatory surveillance. This would allow for the cross-validation of participatory surveillance insights. For example, trained health providers in sentinel sites could follow up on unexplained spikes in febrile illness identified from participatory reporting and distinguish through laboratory testing whether these cases might be due to Zika, dengue, chikungunya, or another disease. Another approach

62 See [additional details](#) on Influenzanet, as well as recent [lessons learned](#) and [performance assessment](#).



might be to incorporate health education materials within participatory reporting apps or websites such that laypersons can report more specific symptoms according to established case definitions.

One additional advantage of participatory reporting tools is that they may also be readily adapted to vector surveillance. Certain software platforms, such as the Kidenga app detailed below, already incorporate a mosquito vector surveillance component in addition to a disease surveillance component. While participatory vector surveillance is outside the scope of this recommendation, projects like [Mosquito Alert](#) provide a promising precedent for the use digital crowdsourcing to track and speciate disease vectors. Our memo regarding risk communication and behavior change details additional strategies to assist in vector surveillance.

Key Next Steps: Governments should first identify a technology platform for participatory surveillance. Adaptation of existing smartphone-based apps and SMS messaging systems will likely represent the fastest and most affordable option. However, platform selection may depend on local assessment of mobile device penetration, connectivity, and social media usage (see our memo on assessing understanding for detailed options on conducting such an assessment). Meanwhile, experts in participatory surveillance systems who may be able to assist in platform selection and development include Michael Johansson at CDC and John Brownstein (developer of [Healthmap](#)) at Harvard Medical School.

Existing tools that may be repurposed for Zika surveillance include the [Kidenga project](#) maintained by the University of Arizona. Kidenga is a smartphone app developed for dengue that solicits weekly participatory health and vector surveillance reports from individuals and offers educational resources on MBD prevention and care. Under a grant from the CDC Health Information Innovation Consortium, the Kidenga team is currently [expanding their software to cover other diseases, including Zika](#).⁶³ Several other existing tools may also serve as starting points for a new Zika/MBD surveillance platform, including: [DengueChat](#), [Flu Near You](#), [Salud Boricua](#), and [Dengue Na Web](#).

After a platform is selected for development and reporting, each government should establish a process for the integration of digital participatory surveillance data into its Ministry of Health's information and analytics systems. This process should include

⁶³ Brian Lee oversees this project at the CDC and can likely facilitate consultation with the developers.



considerations for making participatory surveillance data available alongside traditional data streams to decisionmakers at a local and regional level as well as at the national level.

The final phase of rollout is product marketing to end users and engagement of relevant communities. This precise engagement strategy will depend on the platform selected and the actions asked of end-users. Engagement strategies may require an educational component to instruct users in proper use of the tool. This can be integrated with health education resources within the platform as incentives to user adoption. Another strategy might be to allow communication with local health providers within the platform as an additional incentive to report symptoms.

Advantages: High sensitivity to emerging outbreaks; broad reach; flexible to changing case definitions; low cost compared to traditional surveillance methods; low barriers to scale-up; geographic resolution greater than that allowed by provider-based reporting; potential to also include vector surveillance

Disadvantages: Low specificity; high community buy-in and participation necessary for success; not a replacement for traditional surveillance methods; follow-up diagnostics required for insight validation

Key Enablers: A large and active participant base is key to developing timely insights from participatory surveillance. In addition, continuous calibration of digital surveillance tools against traditional, high-specificity surveillance data is necessary to validate and improve generated insights. In general, governments should be careful to overlay participatory surveillance data onto data obtained from traditional provider-based systems and to make decisions with consideration of both data streams. To avoid the missteps of previous crowdsourced digital surveillance projects such as Google Flu Trends, researchers should be careful to avoid the “big data hubris” assumption that digital tools can replace rather than supplement traditional methods.⁶⁴ Effective use of digital surveillance relies on transparency in software development and careful application of big data toward areas where traditional models are insufficient.

⁶⁴ For a postmortem analysis of Google Flu Trends and summary of key lessons learned, see [Lazer et al.](#)



Mobile technology-enabled case reporting.

mHealth approaches can improve Zika case reporting by placing mobile devices and technologies in the hands of community-based health workers to improve their connectivity and integration within surveillance structures. Mobile technologies—whether SMS or smartphone- or tablet-based—present an opportunity to accelerate case reporting speeds and improve the ease and reliability of reporting from remote areas. Moreover, technologies that incorporate 2-way communication allow for follow-up continued tasking and education of end-user healthcare workers. Such technologies enable surveillance task-sharing between traditional high-level providers and other health resources such as community health workers and ordinary laypeople.

Several mature open-source solutions already exist to enable faster and more robust surveillance reports from distributed low-level providers based on mobile technologies. The [Coconut Surveillance app](#), developed by RTI International, is a prime example. Coconut Surveillance runs on Android devices and has been used extensively to guide malaria surveillance and elimination at the district level in Zanzibar. The system integrates diverse features including offline data storage and syncing, case geotagging, and participatory SMS reporting. The system also provides prompts to end users to assist in active casefinding and collection of supplementary case information from medical providers. Coconut Surveillance was readily adapted to facilitate case identification and contact tracing during the 2014–2016 Ebola epidemic in West Africa, and the system may prove valuable for integrated MBD surveillance in Latin America.

Another potential tool is [MEDSINC](#), a system developed by faculty at the University of Vermont. MEDSINC is a phone-based integrated clinical assessment and surveillance tool for newborn/infant health designed to be used by both health professionals and laypersons alike. The tool is being piloted with partners including UNICEF, Save the Children, and PAHO. The system provides prompts to end users that [scale with knowledge and expertise](#), such that diagnostic tasks can be shifted away from high-level providers as appropriate. The system feeds GIS and diagnostic data into a central analytics interface for insight generation.

Our report on long-term care includes an extended discussion of SMS-based technologies and solutions capable of facilitating accelerated case identification and reporting, including the UNICEF [RapidPro](#) platform and associated initiatives like [U Report](#). See Memo 5 for an overview of key features and implementation factors.



Key Next Steps: Governments should conduct an analysis of which mobile technology platforms can best improve Zika case identification and reporting in the hands of community-based health workers. Experts in mobile information and communications technology platform development and implementation such as Gordon Cressman at RTI International can assist in this assessment. Critical considerations for selecting a platform include: flexibility to future health needs, ease of adaptation to Zika and other MBDs, integration into existing surveillance systems, and necessary workforce training burden.

Advantages: potentially much faster and more reliable than paper-based systems; flexible to emerging health reporting needs; able to integrate diverse data sources

Disadvantages: dependent on technological literacy among end-users; subject to wireless coverage and mobile handset penetration; software tools require validation against new diseases like Zika with differing clinical presentation and epidemiological characteristics from past applications

2. Develop new sources of disease surveillance information by building data collaboratives with academics and private companies

Developing evidence-based interventions for emergent diseases like Zika requires access to as much data as possible. With the proliferation of mobile apps, platforms, and sensors, new and valuable data on how people and societies behave is becoming increasingly abundant, but most of this data is privately held. To leverage such data for public benefit, governments are increasingly turning towards the use of data collaboratives.

The term data collaborative refers to a new form of public-private partnership model focused on the exchange of data and expertise among diverse actors to help solve public problems. These actors include private companies, research institutions, and government agencies.⁶⁵ Data collaboratives are essential vehicles for harnessing the vast stores of privately held data for public good. To explore new sources of disease surveillance information relevant to Zika and other MBDs, governments should accelerate the creation and use of data collaboratives in partnership with academic institutions and private companies.

⁶⁵ For more information on data collaboratives—including case studies, best practices, and lists of critical enablers—governments may consult the GovLab's [data collaboratives project](#) led by Stefaan Verhulst.



The key benefits of data collaboratives are as follows:

- ▶ Increased data and analytic capacity for evidence-based decision-making.
Data collaboratives have the potential to open up novel data streams and analytic abilities to governments for disease modeling, surveillance, and treatment.
- ▶ New platforms for information exchange and coordination.
Data collaboratives create new platforms for research and collaboration among data providers and users.
- ▶ Shared standards and frameworks to enable multi-sector participation.
Data collaboratives facilitate the emergence of standards and frameworks to make data interoperable and useful across sectors, actors, and purposes. Such interoperability creates synergistic effects benefitting data scientists, policymakers, and providers.

As noted in section 1 of this report, data collaboratives take on several forms, which include research partnerships, prizes and challenges, trusted intermediaries, and APIs (application program interfaces). A full description of these models is included in Appendix A.

As the amount of data held by private companies continues to rapidly increase, the establishment of data collaboratives will be an important tool to ensure that this data is used to its full potential. Below in **Figure 8**, we have outlined key incentives facilitating multi-sectoral cooperation around data collaboratives.

FIGURE 8 - INCENTIVES TO ESTABLISH DATA COLLABORATIVES

Public Sector Value of Shared Private Data	Private Sector Motivations to Share Data (6 R's Framework)
<ul style="list-style-type: none">▶ Situation monitoring and awareness▶ Improved governance through data-driven policymaking and service delivery▶ Enhanced problem-solving capacity▶ Better prediction and forecasting	<ul style="list-style-type: none">▶ Reciprocity▶ Research & Insights▶ Reputation & Public Relations▶ Revenue Generation▶ Regulatory Compliance▶ Responsibility and Corporate Philanthropy

In **Figure 9** below, we have included several existing successful models of data collaboratives with a focus on disease control and prevention.



FIGURE 9 - SUCCESSFUL PUBLIC HEALTH MODELS OF DATA COLLABORATIVES

CASE	PARTNERS	DATA SHARED	DETAILS
Harvard-Safaricom Malaria Surveillance	Safaricom, Harvard School of Public Health	Mobile phone use metadata	Safaricom, a large Kenyan mobile network provider, shared cellphone use metadata with the Harvard School of Public Health in order to study how population movement affects malaria distribution in Kenya. The collaborative published its findings in Science and identified hotspot areas driving transmission in surrounding regions.
InfoDengue	Twitter; Government of Rio de Janeiro, Brazil; academic researchers	Tweets, dengue case reports, meteorological data	Brazil's InfoDengue Project offers real-time analysis to almost 500 cities in Brazil. The system can predict new cases of Dengue transmission, to help Health Departments be more efficient in response planning. The project is a partnership between universities and the regional and local government in Rio.
Clinical Study Data Request Program	Academic researchers, 2 pharmaceutical companies	Clinical trials data	The Clinical Study Data Request Program collects anonymized clinical trial data from 2 different private companies. It then shares this data with participating researchers online to allow them to conduct new analyses of the available data.
Accelerating Medicines Partnership	10 biotech and pharmaceutical companies, US federal government, nonprofits	Proprietary drug design data	The Accelerating Medicines Partnership pools data from pharmaceutical companies, nonprofits, and government researchers in order to overcome industry fragmentation and improve innovation in drug design. The collaborative assists pharmaceutical companies in finding new drug targets and reduces wasteful repetition of testing done when companies work in information silos.

- **Key Next Steps:** Governments should convene relevant stakeholders to identify key data needs for Zika and other MBDs. This process should review successful data collaborative models and establish a plan for approaching potential private and academic data-sharing partners. Included in this process should be an analysis of key incentives for each party and how they can best be aligned as in **Figure 9** above.



Data collaboratives can leverage private sector data for diverse purposes within MBD surveillance and prediction modeling. One particularly valuable application is the use of private telecommunications data to understand human mobility and disease transmission. Human mobility plays an important role in the importation and domestic spread of MBDs. As such, “mobility characterization is key to predict[ing] the spatial and temporal risk of a human-transmitted infection.”⁶⁶ Below, we present a case study on potential data collaboratives making use of telecom mobility data.

⁶⁶ Oliver N, Matic A and Frias-Martinez E (2015) Mobile network data for public health: opportunities and challenges. *Front. Public Health* 3:89. Pg. 4 doi: 0.3389/fpubh.2015.0089



Case Study: Utilizing Telecom Mobility Data for Prediction Modeling

Ministries of Health routinely collect and analyze disease surveillance and demographic data for epidemiological purposes. However, additional types of data have the potential to improve disease analyses and predictive models. Human mobility data is one such type of data. Telecommunication companies routinely generate data valuable for mobility mapping from two sources: event-driven data collected whenever a cell phone user requests a billed service (e.g., SMS, phonecalls, internet) and network-driven data collected periodically by the signal tower(s) to which a phone is connected. Event-driven data, also referred to as Call Detail Records (CDRs), has successfully been used to analyze [malaria](#) and [Ebola](#) transmission and to measure the impact of containment activities by the Mexican government [against swine flu](#). Meanwhile, network-driven data has been successfully used to model traffic patterns and urban congestion. For an overview of mobility mapping opportunities, see [Oliver et al.](#)

A number of data-sharing projects are underway in this area. [UN Global Pulse](#) is a particularly active and successful partner in several data collaboratives and can offer valuable insight to governments when planning such a project. For example, UN Global Pulse is currently pursuing a partnership with Telefónica, one of the largest telecom providers in the world, to incorporate mobility data from Colombia into epidemiological models of the spread of mosquito borne diseases. UN Global Pulse will provide health, meteorological and social media data, while Telefonica will supply CDRs. As of mid-November 2016, the parties were negotiating terms of data exchange.

An alternative approach to securing mobility data is to engage 3rd parties. Real Impact Analytics, for example, is an organization that carries out mobile data analyses through its [Data for Good Initiative](#) with support from foundations and NGOs. The Swedish nonprofit [Flowminder](#) also works with governments and international nonprofits to analyze mobile and other data. They have worked in Peru on developing frameworks to simulate human movement to understand the transmission of infectious diseases like malaria.

An important component of leveraging all this private data effectively for public health purposes is building demand and technical capacity within the Ministry of Health. Our memo on predictive analytics provides detailed recommendations in this regard.

- ▶ **Advantages:** Mobile phone data provides a new source of mobility information that is high resolution and persistent over time. Using such data leverages the data science capabilities of private companies. Development of APIs for social good offers long-term data access.
- ▶ **Disadvantages:** Granularity of location data depends on cell tower placement and density. Mobility patterns will be more accurate in urban areas than in rural areas. Generalizability of insights depends on mobile device penetration and connectivity in local country. Future of existing corporate data philanthropy efforts is hard to predict.⁶⁷

⁶⁷ In the future, companies may start to charge for use of their data. Companies like Telefonica are in the process of monetizing the analysis of the data. They recently created a big data B2B unit, LUCA, through which they work with enterprises and governments. They have used their mobility data to help optimize tourism and transportation and have collaborated with humanitarian agencies in pilot studies.



3. Promote openness and participation in surveillance data collection, storage, sharing, and use by developing a data governance playbook for epidemic response and building broad commitment to it

Based on the challenges in data collection and sharing observed in the international response to Ebola and Zika within the past two years, leading global health actors have issued renewed commitments to making epidemic and surveillance data more open and accessible. The World Health Organization issued a [consensus statement](#) in September 2015 signalling broad international support for more open research and surveillance during public health emergencies. Following this statement, more than 30 leading international medical journals, research institutes, development agencies, and funding organizations signed a pledge this year to institute more open data policies for Zika and future health threats, including rules to make data freely available without negatively impacting publication prospects.

The Open Data and Open Science Movement

Big data technologies, built around open access, have the potential to transform health research. Health researchers already routinely collect, analyze, and publish large quantities of data, practices which will only accelerate in the future. Now, instead of producing and collecting data only from traditional sources (e.g., clinician, insurance or pharmacy records) researchers are also obtaining data directly from patients via the devices they carry and from providers such as mobile phone companies that are collectively yielding greater insight into the environment in which people live and the choices they make. Researchers are mashing up clinical data with new sources of information from social media, administrative agencies, and companies to obtain a better picture of health. In turn, researchers are sharing data with one another and with the public to “get more eyeballs” on problems and accelerate the pathway to cures. The more data is shared, the greater the potential benefits for research and for patients.

The open science movement, in particular, emphasizes this non-proprietary and participatory approach to data sharing. Rather than having those researchers who collect the information keep it to themselves, there is growing consensus that broader access and dissemination will open new avenues of investigation and replicability, improving the speed and quality of health research. Greater access to personal health data, through apps, wearables and electronic health records, also means that individual participants will play important new roles in data collection, use and governance.



Building on the tremendous momentum and international support around the global open data and open science movement, governments should develop a data governance playbook to outline key steps to improve openness in data collection, storage, sharing, and use during epidemic response. These playbook actions will be unique to individual governments as a result of their differing legal environments, unique disease surveillance structures, and local values and priorities. To accommodate these unique considerations, this section provides a high-level roadmap of key steps governments need to take in order to develop a data governance strategy for improving epidemic response. In addition, this section illustrates key data flows within national and international disease surveillance systems and leverage points suitable for improving openness and responsible sharing.⁶⁸

The data governance playbook for epidemic response serves several key functions:

- ▶ Defines common values and standards to govern how data is collected, stored, shared, and used in epidemic response
- ▶ Identifies key barriers to data openness, decentralization, participation, and responsible use—from the local to international level
- ▶ Determines appropriate leverage points and interventions necessary to overcome those barriers
- ▶ Develops a strategic plan to achieve improvements in partnership with key stakeholders
- ▶ **Key Next Steps:** In **Figure 10**, we have outlined an action roadmap for developing a data governance playbook for epidemic response. Governments should begin by convening key stakeholders in the epidemic data collection and dissemination community and using the systematic approach described below to develop a broad, multi-sector commitment to data openness and responsible use. The roadmap includes a step-by-step review of existing health data actors and policies, key weaknesses in the data collection system, opportunities to ensure more responsible use. In addition to the roadmap, we provide in this section several high-level frameworks to assist in considering openness and responsibility at each phase of the playbook development process.

⁶⁸ Digital strategy playbooks have successfully assisted government actors in diverse contexts. The US Department of Health & Human Services developed an extensive [Health IT Playbook](#) to identify strategies that could help providers implement improved electronic health record systems. Meanwhile, the US Digital Service created a [high-level digital playbook](#) to guide implementation of digital projects across the US federal government. At a local level, New York City developed a [playbook](#) of best strategies to improve its digital municipal services.



FIGURE 10 - ACTION ROADMAP FOR DEVELOPING A DATA GOVERNANCE PLAYBOOK

STEP	KEY QUESTION	ACTION ITEMS
1 Vision Development	What are the current challenges we face in surveillance data collection, storage, sharing, and use, and what is our vision for an improved system?	<ul style="list-style-type: none"> ▶ Identify, recruit, and engage relevant stakeholders ▶ Articulate the problem ▶ Define a vision for the future ▶ Set key objectives for the process ▶ Identify core values
2 Information Mapping	What are the key data flows within our surveillance system—who supplies information, and who needs it?	<ul style="list-style-type: none"> ▶ Map key information flows within the health system relevant to Zika/MBD surveillance. For each information flow, define the 1) source and recipient, 2) type and amount of data being exchanged 3) timing/frequency of exchange ▶ Assess current and future data needs in order to support long-term care, transmission reduction, or disease research priorities
3 Challenge Identification	What are the barriers to openness, decentralization, and participation at each stage of the data life cycle?	<ul style="list-style-type: none"> ▶ Identify key bottlenecks and barriers to data collection, sharing, and use: regulation, technical challenges, infrastructure, knowledge, etc
4 Strategic Planning	What actions and approaches will we use to overcome these barriers?	<ul style="list-style-type: none"> ▶ Evaluate potential points of intervention in order to improve data collection, sharing, utilization ▶ Perform targeted research to compare alternative approaches at each key decision point ▶ Create an action plan of priority interventions. For each item, define the 1) owner, 2) available resources, and 3) supporting stakeholders and expertise
Implementation Phase		
5 Monitoring & Evaluation	What impact has this project achieved, and how can operational research continue to improve its impact in the future?	<p>Set key M&E indicators (case report delay, patient satisfaction, international benchmark comparisons, etc)</p> <p>Define actors responsible for continuing M&E</p>



Roadmap implementation can be integrated into the portfolio of the Chief Data Officer or equivalent in the Ministry of Health. The CDO should serve as a champion of the initiative, helping secure stakeholder commitments and forward momentum. Development of data governance playbook strategies under the provided framework will likely take 3–5 months. Resource requirements for implementation will vary with scope of actions in the playbook.

To assist in playbook development, we have included in **Figure 11** a conceptualization of the data life cycle for epidemic surveillance data. This graphic provides a framework for identifying the key information flows and bottlenecks in the process of surveillance data collection, storage, analysis, and use, as formalized in steps 2 and 3 of the playbook action roadmap. This framework can be used to develop relevant chapters of the data governance playbook as appropriate.

FIGURE 11 - SURVEILLANCE DATA LIFE CYCLE



In **Figure 12**, we have outlined each phase of the data life cycle in additional detail, providing key opportunities and goals at each level as well as example actions that governments



can incorporate into their strategy playbooks. On the left, the chart lists an overarching opportunity or goal within each phase of data use. On the right, the chart provides an explanation of the key actions by which more governments can accelerate those goals. This figure can serve as a basis for populating the data governance playbook with recommendations for individual stakeholders.

FIGURE 12 - KEY OPPORTUNITIES FOR OPENNESS AND ENGAGEMENT IN SURVEILLANCE DATA LIFE CYCLE

COLLECTION	
Opportunities	Interventions & Leverage Points
Improve data quality	Standardize case definitions according to WHO/PAHO protocol. Develop a unified electronic reporting form. Strengthen workforce training and education, especially among maternal & child health providers. Implement data review and quality control protocols for missing/incomplete/incorrect/duplicate data.
Reduce delay in case reporting	Use mobile technologies like SMS and smartphone apps to improve connectivity of remote health actors.
Increase volume and timeliness of data	Explore supplementary sources of disease surveillance including digital listening and participatory data collection techniques.
SHARING	
Opportunities	Interventions & Leverage Points
Protect privacy	Review policies that govern and restrict the storage and sharing of health information. Improve knowledge of these regulations among relevant staff. Ensure relevant surveillance databases allow for case identification while also guaranteeing confidentiality. Develop contingency plans for breaches of confidentiality.
Coordinate data ownership and access across multiple regions and levels of government	Develop protocols for distributed data ownership and access that promote trust and mutual dependence between different government actors. Example models of distributed ownership include the CDC's Emerging Infections Program (EIP), where 10 centers of excellence across the US collect independent surveillance data but coordinate with each other and with CDC for pooled analysis. The International Society for Disease Surveillance "Distribute" project served as another example of decentralized surveillance, where community-based health providers directly submitted anonymous syndromic surveillance data for aggregate reporting.



SHARING

Opportunities

Interventions & Leverage Points

Improve availability and usability of data for researchers

Set up an online, open repository for national surveillance data that provides timely reports in machine-readable format. Our memo on predictive analytics includes a detailed recommendation for implementing such a portal.

Standardize data for interoperability

Report case definitions along with surveillance data to allow for international comparison of suspected, probable, and confirmed cases.

Ensure responsible use

Establish a code of conduct for research using public surveillance datasets.

ANALYSIS

Opportunities

Interventions & Leverage Points

Accelerate publication of scientific research

Require researchers funded by government grants to make data openly available as soon as possible. Encourage submission to journals that have [standing open data policies](#) or allow fast-track publication.

Ensure scientific rigor, Match supply of specialized expertise with demand

Publish open datasets to encourage participation of multiple research groups; use scientific peer-review as a system of checks-and-balances ensuring research quality.

Of course, more open and accessible data also entails additional data responsibilities. Successful data stewards regard these responsibilities not just as a policy but as a set of principles, values, and processes underlying all collection and use of data for public interest purposes. To assist governments in considering their own responsibilities in epidemic data collection and dissemination, we provide a [framework](#) adapted from the UN Office for the Coordination of Human Affairs (OCHA) in **Figure 13**. This 4-step framework provides a high-level assessment process that should be integrated and formalized as appropriate into the playbook.



FIGURE 13 - DATA RESPONSIBILITY FRAMEWORK, ADAPTED FROM UN OCHA⁶⁹

STEP	KEY QUESTIONS TO ASK
1 Identify the need and context	<ul style="list-style-type: none"> ▶ What are the public interest benefits of using the data? ▶ Why might the data be used inappropriately, and by whom? ▶ Who currently has access to the data?
2 Take inventory of the data and how it is stored	<ul style="list-style-type: none"> ▶ Where is the data, and how is it stored? ▶ Is data access monitoring and/or restricted? ▶ Who might be able to access the data in the future?
3 Pre-identify risks and harms	<ul style="list-style-type: none"> ▶ What are the potential harms of the data being released publicly? ▶ What might lead to a malicious data breach or accidental release? ▶ Can the data be combined with other data for additional harmful effect? (e.g., databases that can be combined to directly identify individuals) ▶ Is there a danger that the data may be wrongfully interpreted?
4 Develop Risk Mitigation Strategies	<ul style="list-style-type: none"> ▶ Create specific policies and strategies to govern how you handle data and respond to crisis scenarios (e.g., decision trees) ▶ Adopt technological solutions to safeguard data ▶ Develop an access control system ▶ Train personnel accordingly
MINIMUM STANDARDS	
<p>Data should be used for a specific public interest purpose, not just because it can be used</p> <p>Data-driven approaches should not be undertaken without the appropriate technical expertise</p> <p>Plans must be made in advance to mitigate risks and protect vulnerable populations</p> <p>Actors must identify and adhere to relevant ethical and legal rules</p>	
BEST PRACTICES	
<p>Make data responsibility a continuous process, not just a policy</p> <p>Set “bright line” rules in advance for when scenarios require shutdown of the project</p> <p>Be transparent in data practices and open to external review</p> <p>Implement checks and balances among stakeholders to ensure accountability</p>	

⁶⁹ See additional resources: [UN OCHA policy brief, Understanding Data Risk](#). Governments should consult framework authors Stefaan Verhulst (NYU GovLab), Nathaniel Raymond and Ziad Al Achkar (Harvard Humanitarian Initiative), and Jos Berens (Leiden University Centre for Innovation) for specific advice.



IV. EXHIBITS

APPENDIX A: TYPES OF DATA COLLABORATIVES

TYPE OF PARTNERSHIP	DESCRIPTION
Research partnerships	Corporations share data for research. This often entails using anonymized and aggregated samples of datasets. In the social impact context, it may entail the corporations conducting analyses in-house for public or social sector partners.
Prizes and challenges	Companies make data available to qualified applicants who compete to develop new apps or discover innovative uses for the data. Companies typically host these contests in an effort to incentivize a wide range of civic hackers, pro-bono data scientists and other expert users to find innovative solutions with the available data.
Trusted intermediaries	Companies share data with a limited number of known partners for data analysis, modeling, and other activities.
API's (Application program interfaces)	Companies allow developers to access data for data analytics, testing, or product development.

For more information on potential archetypes for data partnerships, see our memo on digital listening as well as our [taxonomy of partnerships](#) and [suggested readings](#).



ISSUE AREA 5

Long-Term Care

As scientists, health providers, and policymakers learn more about Zika's long-term effects, they will need to constantly adapt their strategies for providing long-term care. In the near term, governments can focus on building flexible platforms to facilitate long-term care, even as the specifics of that support remain in flux.

We propose the following two recommendations, which could be implemented separately or as part of one integrated platform:

- ▶ Use online support communities akin to [Patients Like Me](#) to provide patient-to-patient support
- ▶ Develop 2-way SMS-based support systems like [Text4Baby](#) to provide long-term medical care and support cost-effectively



I. The challenge

Not since the Rubella virus in the 1960s has the world witnessed a disease with as devastating effects on newborns as Zika. Although the medical community does not yet have a complete understanding of the long-term effects of Zika on children infected prior to birth, microcephaly has been confirmed in more than 1,500 babies born to Zika-infected mothers.⁷⁰ Microcephaly, which can lead to various developmental disorders, including intellectual disability, hearing loss, vision problems, and problems with moving and balance, will necessitate lifelong care.⁷¹ These babies will need constant follow-up with Neurologists, Ophthalmologists, Otolaryngologists, and Physical Therapists, among many other specialists. Guillain-Barré syndrome, another potential result of infection, can also cause long recovery times.⁷²

With much of the government response to-date focused on stemming the spread of Zika, comparatively less attention has been paid to this long-term public health challenge. For example, Brazil's National Health System (SUS) has not yet developed a full response to the long-term health care requirements created by Zika. The Ministry of Health's Protocol of Healthcare and Response to Microcephaly Occurrence Relating to the Zika Virus Infection downplayed the need for changes to prenatal care or childbirth routines and stated that "care of the newborn baby should continue to be provided by the primary care facility in the region which will also provide referrals to the necessary therapeutic specialists." However, waiting lines are significant, and there are not enough specialists to address all cases.

New ideas are needed both to strengthen the existing primary and specialized care systems and to build Zika-specific support networks and treatment infrastructure.

70 "Zika Virus and Birth Defects — Reviewing the Evidence for Causality", Rasmussen SA, The New England Journal of Medicine vol 374, May 2016.

71 "Facts about Microcephaly," U.S. Centers for Disease Control.

72 "Guillain-Barré Syndrome outbreak associated with Zika virus infection in French Polynesia: a case-control study," Van-Mai Cao-Loremau et. al, Lancet 2016; 387: 53-39.



II. The opportunity

As governments increasingly consider ways to provide the long-term care necessitated by Zika's spread, they can benefit from the models developed and lessons learned from other efforts to fight long-term medical conditions, including cancer, diabetes, and even alcoholism. Because many of the long-term effects of Zika are not yet fully understood, governments will likely need to take an iterative approach – developing new interventions and adapting old ones as they learn more.

Participants discussed a variety of challenges and solutions during the October 10 call, largely focused on five thematic areas:

- ▶ **Prevention methods:** stemming the spread of Zika through (1) sexual transmission and (2) in-utero infection. Additionally, various ideas to address mosquito-borne transmission were discussed during conferences two (“communications and behavioral change”) and three (“[trash and standing water](#)”)
- ▶ **Monitoring and diagnosis of complications:** intensifying surveillance to identify Zika complications in babies who are asymptomatic at birth; assessing the psychological needs of families of Zika-impacted babies
- ▶ **Support resources for pregnant women:** ensuring pregnant women have access to answers to their Zika-related questions, ways to communicate with medical professionals, connections to a support community of other expecting mothers, and psychological support
- ▶ **Long-term support systems for families:** ensuring medical care and support networks are available at every stage of long-term care, empowering families to address the disease from infection to birth (and beyond)
- ▶ **Community-oriented or state-level interventions:** adaptation or supplementation of existing medical care systems for Zika, including specialized Zika centers and telemedicine programs

For more detail on the ideas outlined during the conference, [see here](#).



III. Actions governments can take to capture the opportunity

At this stage, with study of the long-term effects of Zika still ongoing, governments should avoid developing solutions that are inflexible to what will inevitably prove an evolving set of needs. Instead, governments should move quickly to develop a flexible communications infrastructure that facilitates the timely dissemination of advice on long-term treatment to Zika patients, facilitates social and emotional support networks, and improves patient outcomes.

This memo outlines potential next steps for two promising long-term care platforms: (1) online support communities and (2) SMS-based support (e.g., RapidPro). These could be implemented as part of separate initiatives, or, even better, under the umbrella of one combined initiative.

Prior to launching either initiative, governments should first ensure that such initiatives will effectively reach their target groups, as per the telecommunications penetration assessment outlined in memo (“digital listening”). Should these assessments indicate insufficient cell phone penetration or literacy in the target groups, alternative solutions could include in-person community support groups, telephone hotlines, radio programs, or other initiatives.

Promote the development and use of online support communities akin to Patients Like Me to provide patient-to-patient support and patient-to-doctor support

Health care providers and health-oriented non-profits have developed a number of online communities over the past several years. These online communities can perform many functions, as outlined below:

FUNCTION*	DETAIL	EXAMPLES
Connecting patients with other patients	Sharing personal stories, progress on treatment, etc. with other patients - either through public “posts” or private messages	<ul style="list-style-type: none">▶ American Cancer Society, Cancer Survivors Network▶ American Diabetes Association, Support Community▶ MyCounterpane▶ Mamasenforma



FUNCTION*	DETAIL	EXAMPLES
Connecting with family, friends, and other supporters	Sharing updates on the healing process, coordinating help, receiving supportive messages, and educating family and friends on the disease	<ul style="list-style-type: none">▶ American Cancer Society, MyLifeLine.org▶ MaizApps.com (for autism)
Learning about the disease and treatment options	Providing users with professionally-reviewed information and advice, facilitating self-care, providing peace-of-mind, and identifying situations where a doctor's visit would be appropriate	<ul style="list-style-type: none">▶ American Cancer Society, I Can Cope▶ WebMD▶ Contigo (for breast cancer)
Connecting with health providers	Communicating directly with health providers regarding medical questions, appointment scheduling, prescription refills, etc.	<ul style="list-style-type: none">▶ MyChart▶ iDoctus
Gathering data from a distributed audience ("crowdsourcing")	Sharing data on conditions and the effectiveness of treatment with experts	<ul style="list-style-type: none">▶ Patients Like Me

* Not exhaustive; for a list of top Spanish-language health apps (including a range of community support apps), [see here](#)

Various academic studies have demonstrated the effectiveness of online support communities, particularly in patient empowerment, in encouraging physical activity,⁷³ and even in improving patients' perceptions of their health providers.⁷⁴

A Zika long-term-care-focused online support community could incorporate any or all of these features, either initially or in subsequent additions. The government has a role to play in ensuring that the right people come together to plan and govern this effort. Implementing this idea would require roughly the following steps:

73 Wilma Kuijpers et. al., A Systematic Review of Web-Based Interventions for Patient Empowerment and Physical Activity in Chronic Diseases: Relevance for Cancer Survivors, *J. Med. Internet Res.* 2013; 5(2).

74 Priya Nambisan, Evaluating Patient Experience in Online Health Communities: Implications for Health Care Organizations, *Health Care Mgt. Rev.*, 2011 36(2), 24-33.



STEP 1: IDENTIFY A LONG-TERM INSTITUTIONAL SPONSOR

- ▶ Because online support communities must “live” for a long time, they require constant management and editing to keep users engaged
- ▶ Identification of a long-term institutional sponsor with sufficient resources, expertise, and reach to run an online support community well is therefore a critical prerequisite
- ▶ The government need not be the institutional sponsor but any sponsor should have a reputation for independence and nonpartisanship and should have adequate funding to ensure reliable performance over time

STEP 2: DEVELOP A GOVERNANCE STRUCTURE

- ▶ Once an institutional owner has been identified, that owner can convene a broader set of critical stakeholders to agree on a governance structure to oversee both content creation and long-term management. Again, governments have a role to play here as convenors to ensure the independence and legitimacy of the effort
- ▶ Likely, these stakeholders would include health care professionals, health-oriented government bodies, non-profits, and NGO’s focused on Zika, technology platform providers, web developers, and others

STEP 3: ENGAGE THE PATIENTS AND PROVIDERS

- ▶ Subsequent engagement with the medical community and patients can help to identify what features the online support community should have as well as specific content
- ▶ Patient focus groups can also help to test the efficacy of various messages or prototypes prior to launch
- ▶ Finally, the tech and telecommunications communities should be enlisted to ensure that access to this platform is free and usable by all regardless of socio-economic status, literacy level, or ability to afford access to technology



STEP 4: BUILD THE TOOL

- ▶ Once all of the requirements have been developed, the actual online support community must be built
- ▶ Given the variety of online support communities, social media platforms, and mobile engagement platforms (see SMS recommendation below), technical development may prove to be a relatively small investment (i.e., ~\$25 k or less)

STEP 5: DISSEMINATE AND GENERATE SIGNUPS

- ▶ Publicizing the online support community can take place through a variety of platforms and with a range of partners
- ▶ Health care providers, insurance companies, and government agencies likely already have regular interactions with patients during which they can encourage sign-up (or even sign patients up during their visits). Alternatively, such entities may be able to spread the word by email or SMS

To maximize the number of prospective users who choose to sign up for the community, the sign-up page should generally be short, easy to understand, link to a privacy policy and terms of use, and provide a simple, clear value proposition. For some guidance on increasing sign-up rates, see [here](#) and [here](#)

STEP 6: MANAGE AND UPDATE THE ONLINE SUPPORT COMMUNITY

The institutional owner will need to devote manpower and financial resources in order to keep the site running and update content, as needed

At this point, there should be clear procedures already in place for updating content, pushing news to users, and changing features, with the governance board meeting regularly to review and update those procedures as needed

Develop two-way SMS-based support systems like Prospera to provide long-term medical care and support cost-effectively

Whereas online support communities require the user to have internet access and to either install an application or log in online, SMS-based programs can push information straight to users' phones. The potential reach of such programs may be greater, as they can be accessed by users without smartphones, do not require data connections, and can



disseminate information in a personalized way. Governments have a key role to play in building the coalition of research and public health partners needed to create the platform and telecommunications and media organizations needed to disseminate news of the services. Governments are also needed to ensure the independence, reliability, and non-commercial nature of the content.

In developing SMS-based support systems, governments can leverage two models already in place for maternal and infant health, while expanding those models to also include further stages in child development for Zika-impacted babies:



PROGRAM

DETAIL



Maternal health program in the U.S., developed through a collaboration between ZERO TO THREE (a non-profit dedicated to meeting the development needs of infants and toddlers), Grey Healthcare Group (a healthcare communications firm), CTIA Wireless Foundation (a foundation formed by U.S. wireless providers), and Voxavi, Inc. (a developer of mobile health technology platforms)

Mothers sign up via text message, after which they receive three messages per week on various topics related to their pregnancies

Program also provides urgent news updates to mothers and can remind mothers of upcoming medical appointments

Content developed in collaboration with various health organizations, consultation with the U.S. Centers for Disease Control, and focus groups with mothers from target demographics

In partnership with major cell phone carriers, text messages are free

Has had significant positive impact, with participants demonstrating greater knowledge in crucial topics related to their pregnancy, greater confidence in that knowledge,⁷⁵ and positive behavioral changes (e.g., lower alcohol consumption rates).⁷⁶ For an overview of the available data, see [here](#)



Prospera, the world's second-largest Conditional Cash Transfer (CCT) program, has partnered with UNICEF Mexico to implement Prospera Digital, an SMS-based program that channels personalized and timely information to pregnant Prospera beneficiaries⁷⁷

Prospera Digital sends text messages with important information to pregnant women, allows patients to evaluate the quality of health services, and alerts their medical providers of changes to their conditions (providing them with early warning of medical needs)

Utilizes UNICEF's open-source RapidPro interactive messaging platform and is free for users (initially through partnership with Mexico's telecommunications providers, now through a government contract for bulk rates)

Recently completed pilot phase, with positive initial feedback from participants

75 See, e.g., "Initial Outcomes from a 4-Week Follow-Up Study of the Text4Baby Program in the Military Women's Population: Randomized Control Trial," W. Douglas Evans et. al., J. Med. Internet Res. 2014: 6(5) e 131.

76 See, e.g., "Dose-Response Effects of the Text4baby Mobile Health Program: Randomized Control Trial," William Evans et. al., JMIR Mhealth Uhealth 2015; 3(1):e12.

77 This section is based off of online review of the Prospera Digital Initiative, as well as consultation with Alejandra Ruiz del Río and Eduardo Clark, two leaders of Prospera Digital.



These case studies indicate the following critical elements to a successful SMS-based support system:

Partnership with the platform provider, telecommunications companies, subject-matter experts, and health care providers

Platform provider: Develops the technological platform or modifies an existing one to match the program's needs. In this case, that would likely involve using UNICEF's RapidPro, which has already been used successfully in a variety of contexts and can be deployed as a hosted platform for ~\$10–\$20k per year⁷⁸

Telecommunications company: To provide SMS services at a free or discounted rate and to ensure reverse-billing so that citizens receive information free of charge

Subject-matter experts: To ensure that the information shared matches best-practice. Such experts could be leading academics on the given topics or a federal oversight agency, like the CDC

Health care providers: To provide key input on the information to be sent to patients as well as to identify ways that they can be included in the two-way communications scheme (e.g., by allowing patients to text doctors directly)

Content developed in partnership with subject matter experts and tested with community members

The following process was used, for instance, for Text4Baby:

Informal discussions with pregnant women and new moms to “gauge interest in the service, determine topics of importance, and explore the relevance and comprehension of sample messages”⁷⁹

Review of literature and medical guidelines in collaboration with the U.S. CDC to identify priority topics and content

Input and review by various national, state, and local organizations to validate content and ensure consistency with existing government programs

⁷⁸ Directional estimate provided by the Prospera Digital team, assuming ~5 million message per year. Note that there are a variety of technical schema, of varying levels of functionality and complexity. A major benefit of RapidPro is that it is far more user friendly than previous Short Message Peer to Peer (SMPP) platforms.

⁷⁹ For more information, see: www.text4baby.org/about/message-content



One-on-one cognitive testing in collaboration with the Health Literacy Team at the Emory University School of Medicine helped to refine messages

Prospera has also monitored user response rates to specific messages, contacting participants to better gauge their reactions to messages where response rates have varied⁸⁰

Finally, content should be carefully screened so that only the most effective messages are shared, and, where possible, it should be personalized (e.g., with reminders about upcoming doctor's appointments)

Initiative launched through a targeted outreach program

- ▶ Text4Baby uses the wide reach of its various federal, state, local, and non-profit partners to drive enrollment. It offers resources on its website for various entities to spread the word, partners with other non-profits and media organizations for enrollment initiatives, and has even run a state enrollment contest
- ▶ In Mexico, the Prospera Digital initiative already had regular contact with participants through its CCT program

Content updated regularly and partnerships created with research community to study impact

- ▶ Because medical complications and treatments are constantly evolving, the content will need to be regularly updated to reflect current knowledge. This will require both an annual review process of all messages and a much faster process to quickly push breaking news to users who need to know about it
- ▶ Additionally, outside evaluation will be key to studying the success of any such project

As a critical next step, governments and interested partners should form working groups consisting of the key players outlined in bullet 1 above. They should ensure commitment to implement bullets 2-4 and subsequently begin working to develop the content and build the platform.

⁸⁰ For instance, Prospera Digital has found that response rates decrease significantly postpartum. Interviews with participants revealed, however, that such decreases were due to mothers feeling too busy to reply, not due to their lack of interest in information provided by the program, which remained high.



ISSUE AREA 6

Predictive Analytics

The use of predictive analytics – using existing patterns and trends in data to forecast outcomes – can help governments improve their response to the Zika outbreak by detecting at risk communities and improving the health worker deployment, awareness campaigns and mosquito breeding containment. Based on the priorities articulated by partner governments, this memo makes four recommendations discussed at greater length below. They are:

- ▶ Governments should build a data analytics platform to improve Zika response.
- ▶ Governments can use challenges to rapidly develop predictive models and leverage outside expertise.
- ▶ Governments should increase data analytics capacity of public health officials in partnership with research institutions and universities.
- ▶ Governments should collaborate on the creation of a Zika-related data portal. Such a collaborative portal would point to national and other open datasets and could be co-located with the clearinghouse.



I. The challenge

Disease outbreaks are difficult events to anticipate and therefore to prevent with standard analytical models. For some diseases, like dengue, the factors involved in transmission are known,⁸¹ but the Zika virus has many forms of transmission and some are still not clear.⁸² For Mosquito Borne Diseases (MBDs), the movement of viraemic people is more causative in spreading the disease and creating new outbreaks than is the movement of mosquitoes.⁸³ Hence, especially in the absence of an effective vaccine, it is especially important to have cost-effective tools for tracking both.

II. The opportunity

Big Data refers to the wide-scale collection, aggregation, storage, analysis and use of data. Predictive analytics is the use of that data with statistical algorithms to identify the probability of future outcomes based on available data. Predictive analytics rely on capturing relationships between explanatory variables and the predicted variables from past occurrences, and exploiting them. The goal is to go beyond knowing what has happened to providing a best assessment of what will happen in the future.

Predictive models paired with appropriate data can help inform questions like: how many people will the outbreak potentially infect; how far and how quickly will the disease spread; what areas and people are at highest risk; and when are they most at risk. Predictive models have helped government agencies improve restaurant inspections or predict which buildings should be inspected to prevent fires.

Predictive models can help governments make better decisions about how to make use of limited resources to prevent and deal with outbreaks.⁸⁴ “A predictive model is a formula for estimating the unknown value of interest: the target. The formula could be math-

⁸¹ [Centers for Disease Control and Prevention, Dengue](#): Epidemiology

⁸² “How does Zika virus spread? What we know so far” Welch A, CBS News, February 2016

⁸³ “[Disease Surveillance and Outbreak Prevention and Control](#)” Dengue Haemorrhagic Fever: Diagnosis, Treatment, Prevention and Control-Chapter 6, WHO, 1997

⁸⁴ In Chicago, data on weather, demographic, previous testing and spraying locations was collected, then an algorithm was used to predict future West Nile virus presence in mosquitoes. With that information city health officials could direct insecticide spraying and other containment measures to the affected areas. In Pakistan, the Punjab government uses data from a public health hotline to forecast Dengue outbreaks 2-3 weeks ahead of time and identify locations to increase awareness or dispatch mosquito control teams.



emational, or it could be a logical statement such as a rule” or a mix of both.⁸⁵ It is built by using available data. The mathematical procedures identify the variables (attributes or features of the data) that are most informative or, in other words, that correlate with our target of interest and that “reduce our uncertainty in it.”⁸⁶ For example, by knowing, which neighborhoods are most likely to suffer from an outbreak within a given time period, awareness campaigns and vector reduction efforts can be targeted using this data, making government responses more efficient.

Whereas there is a great deal of potential for the application of new predictive models to improve the response to Zika, there always needs to be evaluation, testing and evolution of the models since we do not know what works.

At the online conference, experts made eight broad categories of suggestions for applying predictive analytics:

- ▶ **Open and share both data and metadata widely:** The more open institutions are about collecting and sharing data, the more agile, collaborative, and successful the modelling process can become. Across the board, experts issued a call for governments to open more data.
- ▶ **Be Creative in Finding New Data Sources Such as Government Hotline Data:** Data from phone calls in New York City and Pakistan has helped government agencies use risk-based approaches when allocating resources.
- ▶ **Get the public to collect and contribute data:** Citizen participation can be leveraged in data collection. When the community’s contribution is built on trust, data collection can be increased and improved, especially if the community can see a correlation to useful public services provided as a result.
- ▶ **Establish Public-Private Data Partnerships (data collaboratives) with private sector:** Data sources that illustrate human movement are especially valuable and those can be had from telephone companies. Data sources that illustrate behavior are also valuable and these can be gotten from search engine companies.

⁸⁵ Ibid, Pg. 45

⁸⁶ Provost, Foster, Fawcett, Tom. Data Science for Business. O’Reilly Media July 2013. Pg 44



- ▶ **Share variables developed by others:** Sharing algorithms and protocols will accelerate development of better localized models.
- ▶ **Incentivize and gamify engagement with the wider data-science community through prize-backed challenges:** Hackathons, data expeditions and challenges such as the Dengue forecasting challenge have helped activate volunteer data scientists to engage with forecasting mosquito borne diseases.

Identify drivers of Zika transmission at a global level: A study used environmental, socioeconomic, and mosquito abundance variables to track and predict the global potential distribution of Zika virus. The study also identified the major drivers of transmission based on 5 km spatial resolution.⁸⁷

Articulate the Demand: Before starting any predictive analytics process it is important to understand the questions and needs of the organization.

⁸⁷ Mapping the global geographic potential of Zika virus spread



III. Actions governments can take to capture the opportunity

Governments should build a data analytics platform to enable the creation of predictive models to improve Zika response

Before data analytics can be applied, data must first be made available and organized to enable the development of algorithms. There are six steps in the data mining process necessary to build a predictive analytics platform, shown in the figure below:

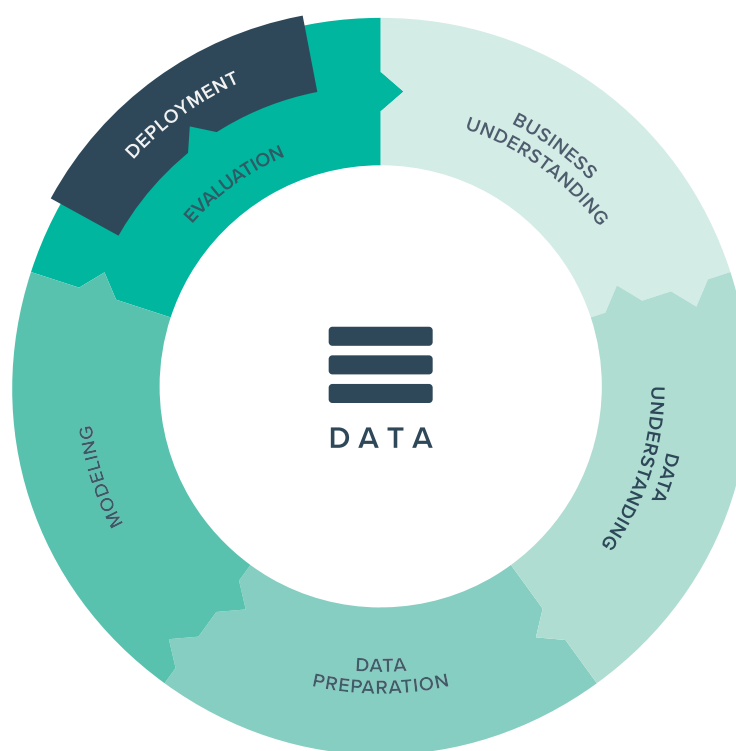


FIGURE 14: THE CRISP DATA MINING PROCESS⁸⁸

The process is not linear, and teams should expect to go back and forth between the different phases.

⁸⁸ Cross Industry Standard Process for Data Mining (CRISP-DM; Shearer, 2000). By Kenneth Jensen (Own work) [CC BY-SA 3.0 (<http://creativecommons.org/licenses/by-sa/3.0>)], via Wikimedia Commons



BUSINESS UNDERSTANDING

The first stage in developing a data analytics platform is to define and understand the problem that has to be solved and the questions to be answered. These questions need to be translated into a “target variable” which defines and describes in detail the variable that will be forecasted by the predictive model. The target variable is the output of the model.

In 2015, seven U.S. federal agencies partnered to host the Dengue Forecasting Challenge.⁸⁹ The goal of the contest was to forecast key metrics for historical dengue seasons in Iquitos, Peru, and San Juan, Puerto Rico. The target variables⁹⁰ were:

- ▶ **Timing of peak incidence**, defined as “the week when the highest incidence of dengue occurs during the transmission season.”
- ▶ **Maximum weekly incidence**, defined as “the number of dengue cases reported during the week when incidence peaks.”
- ▶ **Total number of dengue cases in a transmission season.**

These three targets would help health officials plan the allocation of resources, such as hospital staffing, and when to intensify preventive messaging. For example, knowing the total amount of cases helps for longer term planning regarding budget allocation.

Defining these questions is the first step in the process and can be best accomplished by joint analysis between the data science team and the public servants that are leading and implementing the process where the predictive model might be applied. The Chief Data Scientist of the U.S. Department of Commerce, Jeff Chen, recommends creating a process map of how decisions and resources flow in the organization, including people who are in each level of the organization and will make decisions and/or communicate to each other. What data do these people use? What data would be useful when making decisions?

This phase requires fluid communication and iteration between data scientists and decision makers, as modelers may be able to do one thing and decision makers may need something else, so they must work together to find overlap.

⁸⁹ [Dengue Forecasting Project](#), National Oceanic and Atmospheric Administration (NOAA)

⁹⁰ <https://predict.phiresearchlab.org/legacy/dengue/targets.html>



DATA UNDERSTANDING

This next stage involves identifying the available sources of data needed to forecast the target variables. For the Dengue Forecasting system in Pakistan, the Punjab Information Technology board used the following data:

- ▶ **Dengue cases detected by hospitals:** they had historical data but also near real time data, as hospitals reported dengue cases every day.
- ▶ **Climate data:** rainfall, temperature and humidity at the city level, from the Punjab meteorological department.
- ▶ **Public Hotline data:** volume of calls received that are categorized as a dengue symptoms inquiry call by the telephone operator. They include location of the caller.⁹¹ This variable is key for utilizing the data in a prediction model.
- ▶ **Awareness Data:** dengue awareness seminar (where the health hotline number is promoted) carried out by a government health worker and reported to the hotline.

In this phase, **the government agency should assess the risks and biases inherent in the data** in order to plan for and mitigate unintended consequences. For example, studies have shown that the rate of calling to 311 (incident reporting hotline) in the USA is higher in affluent neighborhoods.⁹²

In this phase it is important to identify if some data is unavailable but can be obtained by investing the necessary resources. For example, a simple reporting system might be set up so hospitals can send daily data about sick patients through a web form.

Companies might also have some relevant data that can be used in a predictive model, such as search engine query data. If there is data of interest in the private sector, a partnership could be set up to obtain that data, as explained in the Information Collection Implementation Memo. These public-private partnerships to use private sector data for solving public problems – called Data Collaboratives – are becoming more frequent. UN Global Pulse has a project with BBVA to analyze financial transaction data before and after natural disasters to analyze economic resilience. The insights from that data could be helpful for purposes such as designing the distribution of supplies or cash transfers.

91 N. Abdur Rehman, S. Kalyanaraman, T. Ahmad, F. Pervaiz, U. Saif, L. Subramanian, **Fine-grained dengue forecasting using telephone triage services**. Sci. Adv. 2, e150125 (2016). Pg 8

92 **Who Is Most Likely to Dial 3?**, Next City, April 2014. **When It Comes to 3, the Customer Isn't Always Right** Governing, January 2016.



This stage is iterative with the business understanding phase. For example, a desired target variable might have to be adapted due to the lack of data, by identifying suitable proxies for the missing data.

DATA PREPARATION

In this phase “the data are manipulated and converted into forms that yield better results.”⁹³ This can include normalizing values to make them comparable, removing missing values and converting data into different types.

MODELING

In this stage, mathematical techniques are used to find patterns in the data. In predictive analytics, the goal is to estimate an unknown value (our target). These methods are called supervised because they have a defined target. “The model describes a relationship between a set of selected variables (attributes or features) and a predefined variable called the target variable. The model estimates the value of the target variable as a function (possibly a probabilistic function) of the features.”⁹⁴

There are two main types of supervised statistical learning paradigms: classification and regression. Regression is used mainly when the target is numeric (eg. number of cases of Zika in a given week) and classification is used when the target is categorical (e.g., infected/not infected with Zika). Estimating the probability of a certain category is called class probability estimation. A model might produce a ranking of cases, for example, and then depending on the budget, one could establish a certain threshold and act upon all the cases above that threshold. In practice, many regression and classification techniques may yield similar (if not identical) predictions, due to considerable overlap between these two categories. Many contemporary “machine learning” approaches simultaneously embed both classification and regression-based techniques into the same underlying model, such as in the random forest algorithm, classification and regression trees (CART), or even in neural networks.

⁹³ Provost, Foster, Fawcett, Tom. Data Science for Business. O'Reilly Media July 2013. Pg 30

⁹⁴ Provost, Foster, Fawcett, Tom. Data Science for Business. O'Reilly Media July 2013. Pg 46



In addition to common statistical approaches, predictions may also arise out of ‘mechanistic’ models of the biological system.⁹⁵ Such techniques may be appealing in the context in which data needed for a more traditional statistical analysis are limited. In such a case, a researcher could make reasoned assumptions about the dynamics of a system, and simulate parameters from that structure without having full access to all the necessary data.^{96 97}

EVALUATION

The goal of this stage is to assess the results of the predictive models to see if they are valid and reliable. This process should involve domain experts and not just the data science team, as the results must be usable in practice. For example, during a data science challenge to develop models to improve the detection of health code violations by restaurants, the city of Boston evaluated models during 6 weeks by using the models to allocate hygiene inspections and comparing the results with the model forecasts.⁹⁸

This stage is critical because it can avoid building user interfaces for models that don’t work, saving valuable resources. For example, Jeff Chen, explains that building a model that produces a list of daily targets for a city requires a team of three: a product manager, an engineer and a data analyst. But turning that into a fully deployed web software, requires hiring two software engineers and a user experience tester. Hence – before investing these resources – it is key to ensure that the models work.

DEPLOYMENT

Deploying a predictive analytics model means using the results to guide some type of decision making. This might involve integrating the model into an existing system or building a user friendly platform to access the data. For example, fumigation teams could be deployed based on scores that assess an area’s risk of infection with mosquito borne diseases. Seasonal staffing plans might be designed on the basis of a forecast of infections.

95 Margevicius KJ, Generous N, Abeyta E, Althouse B, Burkom H, Castro L, et al. (2016) The Biosurveillance Analytics Resource Directory (BARD): Facilitating the Use of Epidemiological Models for Infectious Disease Surveillance. PLoS ONE (); e046600. doi:0.37/journal.pone.046600

96 Mechanistic biological modeling thrives, Ben O’Shaughnessy and Thomas D. Pollard (January 4, 2016) Science 35 (6270), 234-235. [doi:0.26/science.35.6270.234-c].

97 Systems biology (un)certainties. P. D. W. Kirk, A. C. Babbie and M. P. H. Stumpf (October 22, 2015) Science 350 (6259), 386-388. [doi: 0.26/science.aac9505]

98 [Keeping it Fresh: Predict Restaurant Inspections](#) DrivenData, 2015.



For data to be actionable in an operations context, the experts emphasized the need for data to be fine-grained (e.g., indicating location). According to Jeff Chen, the best data projects are those that produce a score that helps prioritize units among a group or indicate if an action should be taken or not.

ENABLERS FOR IMPLEMENTATION

Before implementing a predictive analytics platform, governments should hire a Chief Data Analytics officer to lead the process, as outlined in the Digital Listening Implementation Memo. This will greatly facilitate a partnership with a university, the selection of a vendor or the development of the model in house, alternatives discussed below.

PARTNERING WITH A UNIVERSITY OR RESEARCH ORGANIZATION

Academic and research organizations from Latin America and other parts of the world, such as the Courant Institute of Mathematical Sciences at NYU, the Scientific Computing Program of the Oswaldo Cruz Foundation, and the School of Applied Mathematics of the Getulio Vargas Foundation,⁹⁹ are partnering with governments to develop prediction or surveillance systems using Big Data.

According to Professor Lakshminarayanan Subramanian, that led the team at NYU that worked with the Punjab Information Technology Board (PITB) to develop the Dengue Forecasting system, the enablers for success in these types of projects are:

- ▶ A local government counterpart passionate to get things done, with access to resources and technical enough to understand the language.
- ▶ A “data ecosystem” with the following elements:
 - ▶ Phone hotline that captures data (calls) with location
 - ▶ User Driven social media (email, text, etc.)
 - ▶ Hospitals: they should provide data in a near real time basis.
 - ▶ Health worker app – to get trusted data on containment activity
 - ▶ Advertisement and education campaign that enables people to call/send data, and maintains information about the types of advertising and education done.
 - ▶ Fine-grained climate data is very useful (rainfall, temperature, humidity). Climate and location of people become proxies of mosquito breeding grounds.

⁹⁹ [InfoDengue: a nowcasting system for the surveillance of dengue fever transmission](#)



Staffing: 1 leading professor, 1-2 full time researchers and 1 software engineer at the university. A lab on the ground with 2 local researchers and 1 software engineer. 1 government counterpart and his team. The involvement of the professor was intensive, with daily 1 hour skype calls.

Timeline: Although the system can be bootstrapped with historical data of hospitals and weather, a full year of data is needed to account for seasonality before developing predictions. The project with Pakistan took two years.

Advantages: the organizations can provide data science expertise that the government agency doesn't have. Knowledge is disseminated through academic papers. Cost can be reduced by using graduate students such as PhD candidates as part of the team.

Disadvantages: In one-off partnerships to conduct predictive analytics experiments with academics, the incentives are (almost) always very different for each side. A government is unlikely to understand the details of a modeling approach and cannot assess the strengths and weaknesses of the models that are applied. A high degree of coordination is required to work with an external team and should ensure safeguards to make sure that there is full transparency with regard the algorithms that are developed.

HIRING A DATA SCIENCE COMPANY

This alternative involves carrying out a bidding process to contract an external provider. In-house data expertise is necessary to define the scope of the project, evaluate the proposals and manage the project. Foster Provost and Tom Fawcett offer a useful Proposal Evaluation Guide in their book "Data Science for Business."¹⁰⁰ It includes a series of key questions to ask for each of the six phases of the data mining process that proposals should cover. Other data experts from different government agencies could be included in the proposal evaluation process as well.

- ▶ **Advantages:** specialized expertise in data.
- ▶ **Disadvantages:** Cost and length of bidding process.

¹⁰⁰ Provost, Foster, Fawcett, Tom. Data Science for Business. O'Reilly Media July 2013. Appendix A



DEVELOPING A PREDICTIVE MODEL WITH AN IN-HOUSE TEAM

This would require hiring a Chief Data Analytics officer to lead the process, as outlined in [the Digital Listening Implementation Memo](#). A standard team includes a product manager, a data analyst and a software engineer.

- ▶ **Advantages:** There is no need to negotiate an agreement with an external organization. Building institutional knowledge and capacity for these projects.
- ▶ **Disadvantages:** If there is no in-house capability, developing it will be slow. Risk of mistakes if team is inexperienced.

Governments can use challenges to rapidly develop alternative predictive models and leverage outside expertise

As the implementation memo on communication and behavior change explained, prize-backed challenges are a useful tool to drive rapid innovation and investment in specific problem areas. Prize-backed challenges have also proven useful in the data science arena. They are already being used to advance predictive models in mosquito borne diseases, with and without monetary prizes as incentives.

In 2014, the U.S. Defense Advanced Research Projects Agency (DARPA) launched its Chikungunya virus challenge competition on the InnoCentive challenge platform to “seek methods to accurately forecast the spread of chikungunya virus in the Caribbean, and North, Central, and South America.”¹⁰¹ 38 teams from around the world participated for several awards totalling USD\$500,000.¹⁰²

In 2015, sixteen teams participated in the Dengue Forecasting Challenge, which was run without any additional budget or monetary prizes. Participation in a workshop at the White House, where the winner would present their research, as well as authoring a manuscript with the evaluation results were the incentives.¹⁰³ This paper with results is forthcoming.

The U.S. Centers for Disease Control and Prevention (CDC) run an Epidemic Prediction Initiative that holds yearly influenza prediction challenges with no monetary incentives.¹⁰⁴ The goal of the initiative is that forecasting is used not only for research but also for decision making. For example, “the goal of flu forecasting is to provide a more-timely

¹⁰¹ [DARPA Forecasting Chikungunya Challenge](#), Innocentive.

¹⁰² [CHIKV Challenge Announces Winners, Progress toward Forecasting the Spread of Infectious Diseases](#), Darpa, May 2015

¹⁰³ [Project Description: Dengue Forecasting Project](#), National Oceanic and Atmospheric Administration (NOAA)

¹⁰⁴ [Epidemic Prediction Initiative](#)



and forward-looking tool that health officials can use to target medical interventions, inform earlier public health actions, and allocate resources for communications, disease prevention and control.”¹⁰⁵ Participants are mostly researchers from universities that are incentivized by the availability of data and the possibility of advancing applied science. These incentives are also applicable in Latin America.

Using the framework already presented for how to run a prize-backed challenge, what follows is a specific description of the steps taken to institute the Dengue Forecasting Challenge.

¹⁰⁵ [FluSight 2016-17](#), Epidemic Prediction Initiative, CDC.



FIGURE 15 - STEPS INVOLVED IN SETTING UP A MOSQUITO-BORNE DISEASE PREDICTIVE CHALLENGE¹⁰⁶

STEP	ACTIONS
1 Planning and Goal-Setting	<ul style="list-style-type: none"> ▶ Defining and articulating the problem to be addressed: The idea for the challenge was born in an interagency group of the National Science and Technology Council (NSTC) in the White House, called the Pandemic Prediction and Forecasting Science and Technology Working Group. Its co-chair, Michael Johansson from the Centers for Disease Control and Prevention, explains that the goal was to push forecasting forward in a way that would be relevant to applied use. The National Oceanic and Atmospheric Administration Agency (NOAA) was a strong supporter of distributing paired climate data and assessing its value for forecasting. ▶ Deciding whether a challenge or grand challenge is the best tool for the need: The organizers believed a challenge would be an effective way of comparing different types of models. ▶ Researching problem, consulting experts on strategy and design: Nine months before the challenge, they convened a meeting in the White House with subject matter experts to get input for developing the project. ▶ Setting specific prize objectives <ul style="list-style-type: none"> ▶ The targets to forecast were: timing of peak incidence, maximum weekly incidence and the total number of cases in a transmission season, for Iquitos, Perú and San José, Puerto Rico. ▶ Deciding whether to use financial or non-financial incentives: they didn't have a budget so they used non-financial incentives, mainly visibility through a meeting at the White House and the authoring of a report. ▶ Determining audience: Researchers, scientists and companies working on the prediction of infectious diseases. ▶ Creating a timeline of implementation milestones: The challenge took four months but the planning phase lasted 8-9 months, with a total of 13 months. ▶ Challenge planning milestones: <ul style="list-style-type: none"> ▶ Writing project description ▶ Collecting and processing the data so it was easy to use ▶ Dengue data: weekly laboratory-confirmed and serotype-specific cases for each location. ▶ Climate data: Environmental data from weather stations, satellites, and climate models were also provided, on a daily time scale. ▶ Creating metadata descriptions ▶ Challenge execution milestones: <ul style="list-style-type: none"> ▶ Training data release for model development: June 5, 2015 ▶ Model description and training forecasts due: August 2, 2015 ▶ Testing data release for model evaluation: August 9, 2015 ▶ Testing forecasts due: September 2, 2015 ▶ Model and forecast evaluation workshop: mid to late September, 2015 ▶ Determining ownership and copyright: participating teams would own their own models and they only had to submit descriptions of them, so there were no copyright issues.

¹⁰⁶ Framework adapted from challenge design guides by [NESTA](#) and [McKinsey](#).



STEP	ACTIONS
2 Prize Design	<ul style="list-style-type: none">▶ Identifying potential stakeholders, participants, and innovators: The key stakeholders for organizing this challenge were already part of the Pandemic Prediction and Forecasting Science and Technology Working Group. There was a community of researchers working on forecasting epidemics that had been participating in previous challenges through the Epidemic Prediction Initiative and others.▶ Creating prize appropriate to audience: Johansson explains that one of the main challenges for researchers is availability of data, so that and the visibility provided by the White House were sufficient incentives for participants.▶ Designing evaluation mechanism<ul style="list-style-type: none">▶ Assessment criteria: Forecasts were quantitatively evaluated for each target using two metrics: relative Mean Absolute Error for Point forecasts and logarithmic scoring rule for probability distributions.¹⁰▶ Judges: an interagency panel evaluated the models.▶ Setting competition rules<ul style="list-style-type: none">▶ Duration: 4 months▶ Eligibility: there were no restrictions on who could participate.▶ Rights to new technologies: none were needed.▶ Assessing the potential costs: The challenge didn't have a specific budget, so no one could be hired to carry it out. The main human resources needed were:<ul style="list-style-type: none">▶ one liaison from the Office of Science and Technology at the White House to help in coordination.▶ one project manager from CDC. Dedication could be up to half of his time depending on the stage of the project.▶ three employees from NOAA: Data expert, website developer, and coordinator. Collecting the data was done with the help of the managers of the specific databases and it took the equivalent of one FTE for two weeks to a month.

107 Project Description: Dengue Forecasting Project, National Oceanic and Atmospheric Administration (NOAA)



STEP	ACTIONS
3 Implementation	<ul style="list-style-type: none">▶ Deciding on competition platform: online, new or existing: They looked at the existing platforms like Kaggle but finally decided against using them as they weren't set up to do what they wanted. NOAA set up a simple website with the content and data provided by the challenge organizers.▶ Funding a prize-backed challenge: Agencies were already committed through their work in the interagency committee, and mobilized their employees to carry out the coordination, data preparation and judging.▶ Navigating governmental endorsement and privacy concerns: The initiative was born in an interagency committee and enabled thanks to the commitment of the participant agencies and the support of the White House.▶ Engaging the target audience: Nine months before the launch of the project, the target audience was consulted informally during a meeting about Dengue in the White House. The Department of Defense, NOAA and OSTP did the outreach using tools such as the White House blog, a press release, and related mailing lists such as workshop participants and participants of the flu and chikungunya prediction challenges. This led to several companies participating that hadn't been part of the initial workshop. During the process, representatives from CDC and NOAA answered questions from participants.▶ Monitoring & evaluation metrics: key indicators are model prediction accuracy and number of participating teams.
4 Impact	<p>The challenge helped determine if certain approaches are better for modelling. Although none of the models were good at accomplishing what they wanted, the challenge helped understand what is not good and created a learning opportunity by allowing model comparisons. The organizers are working on a paper to make the learnings more broadly known and help advance the science.</p>

Michael Johansson, CDC biologist and organizer of the Dengue Forecasting Challenge, and Dr. Jesse Bell, from the North Carolina Institute for Climate Studies and the National Oceanographic and Atmospheric Agency, expressed their interest in collaborating with governments interested in hosting a predictive analytics challenge around Zika.

Governments should increase data analytics capacity of public health officials in partnership with research institutions and universities

Capacity limitations among public officials is one of the barriers for developing predictive analytics projects.¹⁰⁸ To carry out big data projects, public servants “will need the capabil-

¹⁰⁸ Tat-Kei Ho, Alfred, and McCall, Bo. Ten Actions to Implement Big Data Initiatives: A Study of 65 Cities. Using Technology Series, IBM Center for The Business of Government, 2016. Pg 27



ity to (1) manage and process large accumulations of unstructured, semistructured, and structured data; (2) analyze that data into meaningful insights for public operations; and (3) interpret that data in ways that support evidence-based decision making.”¹⁰⁹ According to the McKinsey Global Institute, talent with data analytic skills will face relevant shortages.¹¹⁰ This shortage will have a disparate impact in the public sector, “as private sector employers will pay more to attract skilled professionals in big data analytics.”¹¹¹

Data analytical capacity in public health officials covers a broad range of activities and abilities:

- ▶ Which questions can be asked given the available data, such as how to frame a question about cost savings in light of gaps in information
- ▶ How to elicit insights from data even without knowing what the questions are, such as seeing if patients affected by Zika cluster into different subgroups based on their characteristics
- ▶ How to translate insights into evidence-based operational improvements, such as using risk assessment models to deploy health workers during vector control activities
- ▶ How to collaborate with clinicians and researchers to devise more individualised and effective healthcare
- ▶ How to publish data responsibly for use by researchers and app makers while safeguarding personal privacy
- ▶ How to combine healthcare with demographic and environmental data about educational attainment or employment, for example, to assess impact of innovative services on specific populations
- ▶ How to make data visual and useful to citizens to inform their own decision-making and make patients more effective partners in care
- ▶ How to collect and make use of data contributed by patients and citizens scientists, who can contribute highly granular sources of new data

¹⁰⁹ Mergel, Ines; Rethemeyer, R. Karl and Isett, Kimberley. Big Data in Public Affairs Public Administration Review, Vol. 76, Iss. 6, pp. 7. © 2016 by The American Society for Public Administration. Pg 4 DOI: 10.1111/puar.12625.

¹¹⁰ McKinsey Global Institute (2011), Big Data: The Next Frontier for Innovation, Competition, and Productivity (www.mckinsey.com).

¹¹¹ Pandula Gamage (2016) New development: Leveraging ‘big data’ analytics in the public sector, Public Money & Management, 36:5, 385-390, DOI: 10.1080/09540962.2016.94087



- ▶ What the urgency and frequency are for analysing different kinds of data so that public agencies can plan for and respond to emergencies, such as extreme weather conditions, major accidents or unforeseen events or infectious disease outbreaks
- ▶ How to make the decisions about data governance, such as who should have access to which data and for what purposes

We are providing an initial taxonomy of data analytical expertise built by GovLab through its research about data for healthcare for the National Health Service in the UK and other organizations. It has two axes: types of data analytical skills (structured analysis, unstructured analysis, predictive, decision support, traceability, governance, implementation/communication/visualisation) and types of expertise (credentials, skills, experience using data). The taxonomy follows.

TYPES OF DATA ANALYTICAL SKILLS: DATA ANALYTICAL SKILLS FALL INTO THE FOLLOWING PRIMARY CATEGORIES:¹¹²

- ▶ *Structured analysis of patterns of care:* Analytical capabilities in healthcare can identify patterns of care and discover associations culled from massive healthcare records, thus providing a broader view for evidence-based clinical practice.
- ▶ *Unstructured data analytical capability:* Unstructured and semi-structured data in healthcare refer to information that can neither be stored in a traditional relational database nor fit into predefined data models. The ability to analyze unstructured data plays a pivotal role in the success of big data in healthcare settings because 80 percent of health data is unstructured.
- ▶ *Predictive capability:* Predictive capability is the ability to apply diverse methods from statistical analysis, modeling, machine learning, and data mining to both structured and unstructured data to determine future outcomes.¹¹³
- ▶ *Decision support capability:* Decision support capability aims to produce reports about daily healthcare services to aid managers' decisions and actions.
- ▶ *Traceability:* Traceability is the ability to track output data from all the system's

¹¹² See Yi Chuan Wang, et al., "Beyond a Technical Perspective: Understanding Big Data Capabilities in Health Care", 2015 48th Hawaii International Conference on System Sciences, accessed 30 March 2016, <https://pdfs.semanticscholar.org/b58/c0c484f3640f774240b6ba9cf08497a9d2.pdf>

¹¹³ Data Analytic Capabilities for Medicare Program Assessment, Center for Medicare and Medicaid Services, September 2014, accessed Dec 9 2016, <https://www.cms.gov/medicare-medicare-coordination/fraud-prevention/fraudabuseforprofs/downloads/data-analytic-assesstoolkit-09224.pdf>



IT components throughout the organisation's service units. Healthcare-related data such as activity and cost data, clinical data, pharmaceutical R&D data, patient behavior and sentiment data are commonly collected in real time or near real time from payers, healthcare services, pharmaceutical companies, consumers and stakeholders outside healthcare.

- ▶ **Data governance:** Data governance is the ability to manage overall availability, usability, integrity, and security of the data employed in an enterprise and to develop policies, platforms and procedures to enable data to be shared and algorithms to be used responsibly and effectively.
- ▶ **Implementation, Communication and Visualization:** To be of value to the enterprise, data analysis has to be translated into insights for managers. This requires a degree of clinical and institutional literacy as well as strong communications, design and visualization skills.

Types of expertise: As with other types of expertise, data analytic know-how in any of the previous topics comes in three different forms, which imply different strategies for searching for and uncovering this know-how

- ▶ **Credentials:** These signal technical knowledge gained through education and publication. Indicia are credentials issued by third party institutions such as universities or publishers. Data Science credentials include diplomas in computer science, statistics, economics, computation, social science, and informatics. These degrees and certificates can be useful, albeit incomplete, proxies of knowledge. Credentials can often be misleading, however, as degrees alone say little about actual skill and ability, or may indicate the possession of theoretical skills that fit poorly with current practice. Furthermore, many social science programs that were once qualitative have become heavily quantitative and might provide as much training in data analytics as a computer science degree. Many experts have published articles in peer-reviewed journals; others publish in magazines, but some of the best analysts do not publish at all.
- ▶ **Skills:** Skills are methods and tools developed and deepened through a combination of training and practice. Data science skills include the ability to use tools such as R, D3, Hadoop, Postgres, MapReduce, iPython for visualisation, natural language



processing, graph analytics for analysis, or parallel databases for data management. In addition to data management, analysis, storage and visualisation, skills in data governance, data ethics, and domain expertise are equally important and relevant. The list of tools within each domain is growing and changing.

- ▶ **Experience using data:** This includes agency-specific experience, heuristics or routines/methods. Experience using data can be of greater relevance to a manager than any degree or tool. The know-how developed by city officials about the health data provided to the InfoDengue project in Brazil, is as important as the specific database or visualisation they used.

This taxonomy can help identify the competencies needed when hiring employees to work in these areas, and when developing specific programs to train public servants in the health sector.

We recommend the following strategies when partnering with universities and research institutions to increase data analytics capacity of public health officials:

ALLOCATE FUNDS FROM CURRENT TRAINING BUDGETS TO FULLY OR PARTIALLY FUND EMPLOYEES TO ATTEND EXISTING DATA SCIENCE PROGRAMS OFFERED BY LOCAL OR INTERNATIONAL UNIVERSITIES

- ▶ The University of Maryland, the University of Chicago and New York University have developed a training program in applied data analytics, for those with a quantitative masters degree like statistics, economics or computer science or at least two years of experience in a “hands-on, data oriented field.”¹¹⁴
- ▶ In Panama and Bogota, the ADEN International Business School offers a program in business analytics and big data¹¹⁵.
- ▶ In Panama, Universidad Internacional de Ciencia y Tecnología has recently launched a PhD in Data Science.¹¹⁶
- ▶ In Argentina, the Instituto Tecnológico de Buenos Aires offers a Diploma in Big Data,¹¹⁷

¹¹⁴ [Training Program in applied Data Analytics](#), University of Maryland.

¹¹⁵ [Program Especializado en business analytics y big data](#), Aden International Business School

¹¹⁶ [Doctorado en data science](#), Universidad Internacional de Ciencia y Tecnología

¹¹⁷ [Diplomatura en big data](#), ITBA



and Universidad de Palermo offers an executive program in Big Data and Analytics.¹¹⁸

Advantages: Speed of training, as programs are available immediately and many last a year or less as they are executive training.

Disadvantages: Programs haven't been developed for health professionals and may not include exercises and examples in health.

DEVELOP A BID FOR A UNIVERSITY OR RESEARCH INSTITUTION TO DEVELOP A BESPOKE TRAINING PROGRAM

This option might be advantageous if there are many public employees that need training. The bid should require the academic institutions to design a program that should include practical examples and exercises from the health field. Additionally, students should develop a final team project addressing a problem that the government agency currently faces.

Costs can be reduced if part of the content is delivered online. For example, the GovLab has developed an online self-paced course on “Solving Public Problems with Data,” designed for public entrepreneurs—passionate and innovative people, inside and outside of government, who want to increase their capacity to use data and evidence to do good in the world. The free course, sponsored by the Laura and John Arnold Foundation, examines how data analytics can be used to improve decisionmaking and problem solving in the public sector. It launches in the first trimester of 2017.

Advantages: Content can be tailored to specific needs and volume/format can enable price discounts. Employees studying together can enable a sense of community and allow them to address the agency's current challenges.

Disadvantages: Length and bureaucracy of bidding process.

¹¹⁸ Big Data y Analytics, Universidad de Palermo



GOVERNMENTS SHOULD COLLABORATE ON THE CREATION OF A ZIKA-RELATED DATA PORTAL THAT POINTS TO NATIONAL AND OTHER OPEN DATASETS AND COULD BE CO-LOCATED WITH THE CLEARINGHOUSE

The more open institutions are about collecting and sharing data, the more agile, collaborative, and successful the modelling process can become. The experts participating in the Smarter Crowdsourcing – Zika project issued a call for governments to open more data. There are many benefits to this. Establishing routine practices data sharing can help prepare effectively for emergencies caused by epidemics¹¹⁹ and promote a data market where companies can take advantage of the information and big data technologies.¹²⁰ The availability of information with a regional scope could help jumpstart projects by researchers that are looking to build predictive models to improve Zika response.

The lack of a centralized repository of information has led to budding initiatives such as a Zika Data Guide¹²¹ from BuzzFeed News and a separate Zika Data Repository¹²² from the CDC. Michael Johansson from CDC led the efforts for this data repository and can provide technical expertise to governments wishing to engage in these efforts. In Appendix A, we include a description of this project that can help guide future endeavors.

A collaborative portal among governments directs efforts to addressing a problem that affects all. At a minimum, the portal would contain links to the data sets that governments have made public on their local websites and that are useful for building predictive models, such as hospital data, geographic data, temperature, rainfall, humidity, vector data, surveillance reports, etc. It doesn't have to necessarily house the data, but simply point to where it exists. Ideally, the portal would help overcome current challenges of lack of machine-readability and automatic updating in available datasets by providing the data in a raw spreadsheet form.

This is aligned with the WHO/PAHO recommendations within the Zika Strategic Response Plan that calls for shared platforms with “common repositories for data, research out-

119 Chretien J-P, Rivers CM, Johansson MA (2016) Make Data Sharing Routine to Prepare for Public Health Emergencies. PLoS Med 3(8): e00209. doi:[0.37/journal.pmed.00209](https://doi.org/10.1371/journal.pmed.00209)

120 J.M. Cavanillas et al. (eds.), New Horizons for a Data-Driven Economy, p99
DOI 0.007/978-3-39-2569-3_

121 [Data and pointers to data related to the 2015-16 zika outbreak](#), BuzzFeedNews, GitHub

122 [Data repository of publicly available zika data](#), CDCEPI, GitHub



comes and findings.”¹²³ In April 2016, they launched a database that gathers and makes searchable Zika related research.¹²⁴

This collaboration could generate opportunities for opening new types of information, as governments that have published open data in a certain field could help those that haven’t by advising them on how to do it. These could be published as an API (Application Program Interface) or uploaded into the portal if they aren’t available anywhere else or linked to it if they already exist in government websites.

Some of the key design criteria for the organization that should manage this portal are:

- ▶ A non-partisan, non-political trusted third party
- ▶ With secure infrastructure or the knowledge of how to procure it
- ▶ With experience publishing data
- ▶ With the ability to monitor the use of the data and improve based on user feedback

Alternatively, this portal could build on the CDC Zika Data Repository and be hosted by PAHO, as they already have a comprehensive website on Zika with information on a variety of issues both for the general public and health authorities.¹²⁵

An example of governments working collaboratively in health data began in 2014, involving the US and UK governments and centering around health data and information technology to “improve the quality and efficiency of the delivery of health care in both countries.”¹²⁶ It includes sharing quality indicators, opening health data and making it interoperable.

Below, we have outlined a general roadmap of steps necessary to set up a Zika-related data portal. We recommend convening a broad stakeholder discussion to critically address these points.

- ▶ Define data portal scope of focus.
- ▶ Identify sources of data the portal will use. The majority of this data is already public and being shared by governments in some way, albeit not easy for researchers to find and use.

¹²³ [Zika Strategic Response Plan](#), WHO/PAHO, July 2016 p.32

¹²⁴ [Zika Research Projects List](#), WHO/PAHO. [PAHO launches database that gathers worldwide Zika virus research](#), April 2016

¹²⁵ [PAHO portal on Zika](#)

¹²⁶ [US and UK working to strengthen use of health IT for better patient care](#) HHS Press Office, January 2014. [A U.S. & U.K Collaboration Around Health Data and IT](#), HHS Idea Lab, May 2015



- ▶ Establish metadata standards for open data sets linked to the portal.
- ▶ Describe the metadata for each set.¹²⁷
- ▶ Organize a central catalogue that makes data sets easily searchable.
- ▶ Define a governance structure for the portal.
- ▶ Assign roles for contributing to and maintaining the portal.
- ▶ Develop an engagement strategy to encourage use of the library by researchers, academics, the private sector and public employees, including a clear feedback loop.
- ▶ Use the feedback loop to constantly improve the portal.

The availability of open data can be further promoted by establishing policies where government funded research in these diseases require data sharing.¹²⁸ Institutions like The Gates Foundation, the US National Institutes of Health (NIH) and Wellcome Trust have embraced these policies in recent years.

In our implementation memo on Changing Behaviors, we also recommended the creation of a centralized What Works knowledge clearinghouse of peer reviewed literature relevant to designing Zika and other MBD interventions. The Zika Open Data portal could be co-located with the clearinghouse to establish synergies in governance, maintenance and communication.

127 See example of metadata at: http://dengueforecasting.noaa.gov/Training/dengue-metadata-iquitos_training.html

128 Chretien J-P, Rivers CM, Johansson MA (2016) Make Data Sharing Routine to Prepare for Public Health Emergencies. PLoS Med 3(8): e00209. doi:[10.1371/journal.pmed.00209](https://doi.org/10.1371/journal.pmed.00209)



IV. Exhibits

Appendix A - CDC GitHub Surveillance Data Repository Case Study

To enable health researchers to access country-level Zika surveillance data in a single location, the CDC established a free online GitHub data repository. The repository scrapes publicly available data from national surveillance reports and compiles them into machine-readable formats. The tool allows researchers to pull the latest data automatically from across the region. Over 100 researchers from around the world currently follow and engage with the repository. Michael Johansson led development at CDC and can provide technical expertise to governments wishing to develop similar projects.

Pros: Resource requirements to establish and maintain the repository were low: just a few person-hours per week to write the software and compile weekly reports. The project incurred no direct costs. Meanwhile, the project has allowed many new researchers to engage with the data to build better prediction models.

Cons: The data housed in the repository is dependent on what is published in national reports. As such, case definitions are not clearly interoperable between countries. In addition, errors may arise from countries publishing surveillance data in non-machine-readable formats like PDF files.



APPENDIX

Additional Project Materials

Conference 1

Assessing Public Awareness

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ [Problem Briefs \(English, Spanish, Portuguese\)](#)
- ▶ [Conference chat](#)
- ▶ [Conference Video: <https://vimeo.com/180933796> Password: zika1](#)
- ▶ [Conference Transcript](#)
- ▶ [Conference Takeaways \(English, Spanish, Portuguese\)](#)
- ▶ [Implementation Memo \(English\)](#)

Conference 2

Communication and Behavior Change

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ [Problem Briefs \(English, Spanish, Portuguese\)](#)
- ▶ [Country answers](#)
- ▶ [Conference Chat](#)
- ▶ [Conference Video: <https://vimeo.com/181856430> Password: zika1](#)
- ▶ [Conference Transcript](#)
- ▶ [Conference Takeaways \(English, Spanish, Portuguese\)](#)
- ▶ [Implementation Memo \(English\)](#)



Conference 3

Trash and Standing Water

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ Problem Briefs ([English](#), [Spanish](#), [Portuguese](#))
- ▶ [Country answers](#)
- ▶ [Conference Chat](#)
- ▶ Conference Video: <https://vimeo.com/183711205> Password: zika1
- ▶ [Conference Transcript](#)
- ▶ Conference Takeaways ([English](#), [Spanish](#), [Portuguese](#))
- ▶ Implementation Memo ([English](#))

Conference 4

Information Collection/Data Governance

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ Problem Briefs ([English](#), [Spanish](#), [Portuguese](#))
- ▶ [Country answers](#)
- ▶ [Conference Chat](#)
- ▶ Conference Video: <https://vimeo.com/184744582> Password: zika1
- ▶ [Conference Transcript](#)
- ▶ Conference Takeaways ([English](#), [Spanish](#), [Portuguese](#))



Conference 5

Long-term Care

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ [Problem Briefs \(English, Spanish, Portuguese\)](#)
- ▶ [Country answers](#)
- ▶ [Conference Chat](#)
- ▶ [Conference Video: <https://vimeo.com/188049314> Password: zika1](#)
- ▶ [Conference Transcript](#)
- ▶ [Conference Takeaways \(English, Spanish, Portuguese\)](#)
- ▶ [Implementation memo \(English\)](#)

Conference 6

Predictive Analytics

- ▶ [Confirmed Participants](#)
- ▶ [Supporter Bios](#)
- ▶ [Problem Briefs \(English, Spanish, Portuguese\)](#)
- ▶ [Country answers](#)
- ▶ [Conference Chat](#)
- ▶ [Conference video: <https://vimeo.com/189045850> Password: zika1](#)
- ▶ [Conference transcript](#)
- ▶ [Conference Takeaways \(English, Spanish, Portuguese\)](#)



APPENDIX 2

Comprehensive List of Supporters and Participants

EXPERT PARTICIPANTS AND SUPPORTERS									
#	Name	Country	Organization	Role	ISSUE AREA				
					(Check marks shading denotes issue areas individual was involved with or conferences attended)				
				Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
1	Nicolas Schweigmann	Argentina	Buenos Aires University	Director, Mosquito Study Group		✓			
2	Dr. Lynn Weekes	Australia	NPS Medicinewise	CEO	✓				
3	Fabro Steibel	Brazil	Institute for Technology and Society	Executive Director	✓				
4	Rafael Maciel de Freitas	Brazil	Instituto Oswaldo Cruz, Fiocruz	Public Health Researcher, Hematozoa Transmitters Laboratory		✓			
5	Flávio Coelho	Brazil	Getulio Vargas Foundation	Professor of Mathematical Epidemiology, Applied Mathematics School; Head, Mathematical Epidemiology Research Center			✓		
6	Oswaldo G. Cruz	Brazil	Fundação Oswaldo Cruz.	Epidemiologist			✓		✓
7	Joao Bosco Siqueira	Brazil	Federal University of Goias	Associate Professor, Institute Tropical Pathology and Public Health			✓		
8	Dirceu Greco	Brazil	Minas Gerais - Belo Horizonte	Federal University of MD, PhD, Professor, Infectious Diseases and Bioethics, School of Medicine				✓	
9	Rumi Chunara	USA	New York University	Associate Professor of Computer Science and Engineering and Public Health, College of Global Public Health and Polytechnic School of Engineering					✓
10	Pedro Alarcon	Spain	Telefonica	Senior Data Scientist					✓
11	Kristýna Tomšů	Brussels	Real Impact Analytics	Data Scientist					✓
12	Jaykumar Menon	Canada	McGill University	Professor of Practice, Institute for the Study of International Development		✓			



EXPERT PARTICIPANTS AND SUPPORTERS										
#	Name	Country	Organization	Role	ISSUE AREA					
					(Check marks shading denotes issue areas individual was involved with or conferences attended)					
					Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
13	Anita McGahan	Canada	University of Toronto	Rotman Chair in Management, Professor of Strategic Management					✓	✓
14	Esmily Yusmary Ruiz Varón	Colombia	Ministry of Health and Social Protection	Consultant, Communicable Diseases	✓					
15	María Lucía Mesa Rubio	Colombia	Ministry of Health and Social Protection	Advisor, Vice Minister			✓			
16	Ligia Moncada	Colombia	National University of Colombia	Professor, Public Health Department, School of Medicine		✓				
17	Juliana Quintero	Colombia	Fundación Santa Fe Bogotá	Associate Researcher, Centro de Estudios e Investigación en Salud - CEIS			✓			
18	Jón Ingi Bergsteinsson	Denmark	MEDEI ApS	CTO and Co-Founder			✓			
19	Abdallah M. Samy	Egypt	Ain Shams University	Assistant Professor						✓
20	Romain Lacombe	France	Plume Labs	CEO and Co Founder		✓				
21	Dr. Adriana Naim	Guatemala	RTI International	Health Programs Coordinator		✓	✓			
22	Jose Ignacio Mata	Honduras	Salud Mesoamérica 205	Expert in Communication for Behavioral Change	✓					
23	Carlos Urmeneta	Honduras	IDE	Honduras Country Director			✓			
24	Mario Mosquera	India	UNICEF India	Chief, Communication for Development	✓					
25	Dr Elad Yom- Tov	Israel	Microsoft Israel	Principal Researcher						✓
26	Tolbert Nyenswah	Liberia	Ministry of Health	Deputy Minister of Health for Disease Surveillance and Epidemic Control				✓		
27	Montserrat Narváez	Mexico	Curarse en Salud	Project Director	✓	✓		✓		



EXPERT PARTICIPANTS AND SUPPORTERS					ISSUE AREA <small>(Check marks shading denotes issue areas individual was involved with or conferences attended)</small>					
#	Name	Country	Organization	Role	Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
28	Emma Iriarte	Panama	Inter-American Development Bank	Executive Secretary, Salud Mesoamérica Initiative; Health Lead Specialist					✓	
29	Juan Pane	Paraguay	Centro de Desarrollo Sostenible	Chief Innovation Officer						✓
30	Prof Duane J. Gubler	Singapore	Duke-NUS Medical School	Professor Emeritus and Founding Director, Signature Research Program in Emerging Infectious Disease				✓		
31	Esteban Moro	Spain	Carlos III University of Madrid	Assistant Professor, Department of Mathematics, Carlos III University of Madrid, Spain; Visiting Professor, MIT Media Lab, USA	✓					
32	Frederic Bartumeus	Spain	MosquitoAlert, Catalan Institution for Research and Advanced Studies (ICREA);	Director/Research Professor				✓		✓
33	Richard Benjamins	Spain	Telefonica	Director External Positioning & Big Data for Social Good, LUCA Data-Driven Decisions						✓
34	Rafael Navajo	Spain	GMV	Global eHealth Business Development Manager						✓
35	Miguel Luengo Ortiz	Spain/USA	Malaria Spot/UN Global Pulse	Founder, Chief Data Scientist		✓				
36	Dr. Gaya36 Ganthewage	Switzerland	World Health Organization	Medical officer, Infectious Hazards Management, Health Emergency Programme	✓					
37	Aphaluck 37 Bhatiasevi	Switzerland	World Health Organization	Technical Officer, Risk Communication		✓				
38	Dr. Graham Alabaster	Switzerland	World Health Organization	Senior Technical expert, Public Health, Environmental and Social Determinants of Health (PHE) Unit			✓	✓		
39	Chiara Servili	Switzerland	World Health Organization	Department of Mental Health and Substance Abuse					✓	
40	Jonathan van Geuns	The Netherlands	Public Impact & Innovation Frontiers	Partner/innovation lead & Founder						✓
41	Juliet Bedford	UK	Anthologica	Director		✓				



EXPERT PARTICIPANTS AND SUPPORTERS					
#	Name	Country	Organization	Role	ISSUE AREA
					(Check marks shading denotes issue areas individual was involved with or conferences attended)
					Assessing und. Behavior change Trash accumulation Surveillance and data sharing Long-term care Predictive analytics
42	David Broniatowski	USA	The George Washington University	Assistant Professor, School of Engineering and Applied Science	✓
43	Huilong Ding	USA	North Carolina State University	Associate Professor of Technical Communication, Department of English	✓
44	John P. Elder	USA	San Diego State University	Distinguished Professor, Division of Health Promotion and Behavioral Science, Graduate School of Public Health	✓
45	Manuel García Herranz	USA	UNICEF	Lead Research Scientist, Office of Innovation	✓
46	Molly Jackman	USA	Facebook	Public Policy Research Manager	✓
47	Wendy Nilsen	USA	National Science Foundation	Program Director, Smart and Connected Health	✓
48	Brendan Nyhan	USA	Dartmouth College	Professor, Department of Government	✓
49	Dr. Rafael Obregon	USA	UNICEF	Chief of the Communication for Development Section	✓
50	Nancy Pendarvis Harris	USA	JSI	Vice President	✓
51	Mathias Pollock	USA	Population Services International (PSI)	Social and Behavior Change Technical Advisor	✓
52	Lee Rainie	USA	Pew Research Center	Director of Internet, Science and Technology Research	✓
53	Alex Rutherford	USA	UNICEF	Research Scientist, Innovation unit	✓
54	Dr. Magdalena Serpa	USA	PATH	Senior Program Officer, Maternal, Newborn, Child Health & Nutrition	✓
55	Joshua Tucker	USA	Social Media and Political Participation Lab (Smapp), NYU	Co-Director	✓
56	Allison Wolff	USA	Facebook		✓



EXPERT PARTICIPANTS AND SUPPORTERS										
#	Name	Country	Organization	Role	ISSUE AREA					
					(Check marks shading denotes issue areas individual was involved with or conferences attended)					
					Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
57	Brian Elbel	USA	NYU School of Medicine & NYU Wagner Graduate School of Public Service	Associate Professor of Population Health and Health Policy		✓				
58	Baruch Fischhoff	USA	Carnegie Mellon University	Howard Heinz University Professor, Department of Engineering and Public Policy, Institute for Politics and Strategy		✓				
59	Gabrielle Hunter	USA	Center for Communication Programs, Johns Hopkins University	Program Officer		✓				
60	Christopher Mast	USA	Merck	Executive Director & Area Lead for Infectious Disease		✓				
61	Carlos Scartascini	USA	Inter-American Development Bank	Research Economist		✓				
62	Joe Eyerman	USA	RTI Center for Security, Defense, and Safety	Director			✓			
63	Durland Fish	USA	Yale School of Public Health	Professor Emeritus of Epidemiology, Department of Epidemiology of Microbial Diseases			✓			
64	Nicholas E. Johnson	USA	Open Trash Lab	Founder			✓			
65	Jeff Kirschner	USA	Litterati	Founder and CEO			✓			
66	Dietmar Offenhuber	USA	Northeastern University	Assistant Professor of Public Policy and Urban Affairs			✓			
67	Michael Reynolds	USA	Earthship Biotechure	Principal Architect			✓			
68	Alfredo Rihm	USA	Inter-American Development Bank	Water and Sanitation Specialist			✓			
69	Sebastian Acevedo	USA	Inter-American Development Bank	Consultant on Open Government, Public Innovation and Data Analytics				✓		
70	Yaneer Bar-Yam	USA	MIT/New England Complex Systems Institute	Research Scientist/Professor and President				✓		
71	Michael A. Johansson	USA	CDC/Harvard TH Chan School of Public Health	Biologist, CDC Division of Vector Borne Diseases; Visiting Scientist				✓		✓



EXPERT PARTICIPANTS AND SUPPORTERS					ISSUE AREA			
#	Name	Country	Organization	Role	(Check marks shading denotes issue areas individual was involved with or conferences attended)			
					Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing
72	Dr. Pia MacDonald	USA	RTI International	Senior Director, Applied Public Health Research		✓		
73	Diana Patricia Rojas	USA	University of Florida	MD, PhDc, Center for Inference and Dynamics Infectious Diseases, Department of Epidemiology		✓		
74	Alfonso Rosales	USA	World Vision	Senior Maternal and Child Advisor/ZIKV LACRO regional response director		✓		
75	Lakshminarayan an Subramanian	USA	New York University	Associate Professor, Courant Institute of Mathematical Sciences		✓		
76	Bergen Cooper	USA	The Center for Health and Gender Equity	Senior Policy Research Associate		✓		
77	Karin Nielsen	USA	UCLA	MD, MPH, Professor of Clinical Pediatrics, Division of Infectious Diseases, David Geffen UCLA School of Medicine; Director Center for Brazilian Studies		✓		
78	George Saade	USA	UTMB	Professor of Obstetrics		✓		
79	Dr. Anne Wheeler	USA	RTI International	Public Health Analyst		✓		
80	Jeff Chen	USA	Department of Commerce	Chief Data Scientist				✓
81	Ivo D. Dinov	USA	University of Michigan	PhD, Associate Professor, Departments of Computational Medicine & Bioinformatics and Health Behavior and Biological Sciences; Director of the Statistics Online Computational Resource				✓
82	Kacey Ernst	USA	University of Arizona	PhD, MPH, Associate Professor Epidemiology and Biostatistics Department				✓
83	George Gemelas	USA	University	Ethics, Politics, & Economics, B.A. Yale University 208 On Yale Behalf of Professor Paul Lussier				✓
84	Andrew Hluff	USA	Michigan State University	Ph.D., Assistant Professor, College of Veterinary Medicine				✓
85	Ari Kahn	USA	University of Texas at Austin	Human Translational Genomics Coordinator, Texas Advanced Computing Center				✓



EXPERT PARTICIPANTS AND SUPPORTERS										
#	Name	Country	Organization	Role	ISSUE AREA					
					(Check marks shading denotes issue areas individual was involved with or conferences attended)					
					Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
86	Albert Ko	USA	Yale School of Public Health	Professor of Epidemiology (Microbial Diseases) and Medicine (Infectious Diseases); Department Chair - Epidemiology of Microbial Diseases	✓				✓	
87	Paul Lussier	USA	Yale School of Forestry & Environmental Studies	Lecturer		✓				
88	Jude Ower	UK	PlayMob	CEO		✓				
89	Sarah Cornish	USA	Games For Change (G4C)	Senior Director of Programs and Strategy		✓				
90	Emily Treat	USA	Games For Change (G4C)	VP of Lab Services		✓				
91	Luis Loria	Costa Rica	Socialab	Costa Rica Director / Founder		✓				
92	Marina Spindler	USA	Socialab	Member of Board of Directors		✓				
93	Matias Rojas	Chile	Socialab	Co-Founder		✓				
94	Gail Tilden	USA	Nintendo	VP Brand Management (retired)		✓				
95	Alejandra Ruiz del Rio Prieto	Mexico	Presidencia de la República Mexicana	Assistant Director of Strategic Projects		✓				
96	Eugene Yi	USA	MIT Media Lab	Laboratory for Social Machines		✓				
97	Maurício Barahona	UK	Imperial College London	Professor and Chair in Biomathematics		✓				
98	Sophia Yaliraki	UK	Imperial College London	Profesor of Theoretical Chemistry		✓				
99	Eduardo Clark	Mexico	Mexicana	Presidencia de la República						✓
100	Gordon Cressman	USA	RTI International	Senior Director, International ICT					✓	



COUNTRY REPRESENTATIVES						Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)				
#	Name	Country	Organization	Role	Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
1	Dr. Jorge San Juan	Argentina	Ministry of Health	National director of epidemiology	✓	✓	✓			
2	Dr. Raul Forlenza	Argentina	Ministry of Health	Epidemiology director	✓	✓	✓	✓		
3	Agustin Benassi	Argentina	Ministry of Modernization	National Directorate of Data and Public Information				✓		
4	Andrea Jalit	Argentina	Ministry of Health	Communication Services	✓	✓	✓			
5	Dra Alicia Mañana	Argentina	Ministry of Health	Ministry of Health: Epidemiology Directorate				✓	✓	
6	Dr.Christian Hertlein	Argentina	Ministry of Health	Epidemiology Directorate				✓		✓
7	Dr. Eugenio Mirkin	Argentina	Ministry of Health	Epidemiology Directorate	✓	✓	✓			
8	Dra Mariel Caparaelli	Argentina	Ministry of Health	National Directorate of Maternity, Childhood and Adolescence		✓			✓	
9	Dra. Teresa Varela	Argentina	Ministry of Health	Epidemiology Directorate	✓		✓	✓		
10	Florencia Guedes	Argentina	Ministry of Health	Communication Services	✓	✓	✓			
11	Gaston De Rochebouet	Argentina	Ministry of Modernization	National Directorate of Public Innovation	✓		✓	✓		✓
12	María Victoria Gazia	Argentina	Ministry of Health	Epidemiology Directorate		✓				
13	Martin Elias Costa	Argentina	Ministry of Modernization	National Directorate of Public Innovation				✓		✓



COUNTRY REPRESENTATIVES					Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)					
#	Name	Country	Organization	Role	Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
14	Tomas Dominguez Vidal	Argentina	Ministry of Modernization	National Directorate of Public Innovation	✓	✓	✓	✓	✓	✓
15	Malena Tenerlin	Argentina	Ministry of Modernization	National Directorate of Modernization	✓	✓	✓	✓	✓	✓
16	Aranzazu Echezarreta	Argentina	Ministry of Modernization	National Director of Public Innovation	✓	✓	✓	✓	✓	✓
17	Rudi Borrmann	Argentina	Ministry of Modernization	Undersecretary of Public Innovation and Open Government	✓	✓	✓	✓	✓	✓
18	Beatriz Loureiro Werneck	City of Rio de Janeiro	Secretary of Health	Rehabilitation Coordination					✓	
19	Betina Durovni	City of Rio de Janeiro	Secretary of Health	Primary Care and Health Surveillance Undersecretary					✓	
20	Cristina Boaretto	City of Rio de Janeiro	Secretary of Health	Health Promotion Superintendent	✓	✓	✓	✓	✓	
21	Cristina Lemos	City of Rio de Janeiro	Secretary of Health	Health Surveillance Superintendent				✓	✓	
22	Denise Jardim	City of Rio de Janeiro	Secretary of Health	Health Promotion Department				✓		
23	Elen Barreto	City of Rio de Janeiro	Secretary of Health	Health Promotion Department				✓		
24	Elenice Almeida	City of Rio de Janeiro	Secretary of Health	Women's Health Program					✓	
25	Jamile Costa	City of Rio de Janeiro	Secretary of Health	Child and Adolescent's Health Program					✓	
26	Maria Aparecida Duarte Vidon Blanc	City of Rio de Janeiro	Secretary of Health	Rehabilitation Coordination					✓	



COUNTRY REPRESENTATIVES						Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)				
#	Name	Country	Organization	Role	Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
27	Valeria Saraceni	City of Rio de Janeiro	Secretary of Health	Health Situation Analysis Coordination	✓	✓	✓	✓	✓	✓
28	Ana María Lara Salinas	Colombia	Ministry of Health and Social Protection	Cooperation and International relation Advisor	✓	✓	✓	✓	✓	✓
29	Andrea Avella	Colombia	Ministry of Health and Social Protection	Demography and Epidemiology Department				✓		
30	Claudia Cuellar	Colombia	Ministry of Health and Social Protection	Demography and Epidemiology Department				✓		
31	Diego Alberto Cuellar Ortiz	Colombia	Ministry of Health and Social Protection	Knowledge Management and Information Sources Group						✓
32	Dr. María Mercedes Muñoz	Colombia	Ministry of Health and Social Protection	Coordinator of the Public Health Surveillance Group	✓	✓	✓	✓		✓
33	Esmily Ruiz Varón	Colombia	Ministry of Health and Social Protection	Subdepartment of Communicable Diseases		✓				
34	Jairo Hernández Márquez	Colombia	Ministry of Health and Social Protection	Healthy Territories Group Coordinator	✓	✓	✓			
35	Julio Padilla	Colombia	Ministry of Health and Social Protection	Subdepartment of Communicable Diseases Specialist	✓	✓	✓			
36	Liliana Cuevas	Colombia	National Institute of Health	Specialist, Congenital Defects Surveillance					✓	
37	Marcela Mercado	Colombia	National Institute of Health	Department of Research in Public Health					✓	
38	Mónica Lucía Ramírez	Colombia	Ministry of Health and Social Protection	Subdepartment of Environmental Health Intern	✓	✓	✓			
39	Oscar Eduardo Pacheco	Colombia	National Institute of Health	Director of Surveillance				✓		



COUNTRY REPRESENTATIVES						Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)				
#	Name	Country	Organization	Role	Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing	Long-term care	Predictive analytics
40	Ricardo Amortegui Gonzalez	Colombia	Ministry of Health and Social Protection	Communications Group Coordinator	✓	✓	✓			
41	Dr. Israel Cedeño	Panama	Ministry of Health	International Epidemiological Surveillance Coordinator	✓	✓	✓	✓		✓
42	Dr. Juan Pascale	Panama	The Gorgas Memorial Institute for Health Studies	Deputy Director	✓	✓				
43	Dr. Lizbeth Cerezo	Panama	Ministry of Health	National Coordinator of Epidemiological Surveillance of Arboviruses and Malaria	✓	✓	✓	✓	✓	✓
44	Dr. Marcela Reyes	Panama	Ministry of Health	Department of Epidemiology				✓		
45	Dr. María Eugenia Barnett de Antinori	Panama	The Gorgas Memorial Institute for Health Studies	Global Health Security Project Coordinator	✓	✓				
46	Evidelia Saavedra	Panama	Ministry of Health	Promotion Department	✓	✓				
47	Gliz Checa	Panama	Ministry of Health	Promotion Department	✓	✓				
48	Joel Gonzalez	Panama	Ministry of Health	Communication Department	✓	✓				
49	Julio Rulloba	Panama	Presidency	Communications		✓				



INTER-AMERICAN DEVELOPMENT BANK PARTICIPANTS AND SUPPORTERS						
#	Name	Role	Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)			
			Assessing und.	Behavior change	Trash accumulation	Predictive analytics
1	Adela Barrio	Operations Associate	✓		✓	
2	Ana Rodriguez	Sector Manager for Institutional Capacity and Finance Sector	✓		✓	
3	Antonio Moneo	Learning & Knowledge Management Sr. Associate	✓		✓	
4	Diana Pinto	Health Lead Specialist	✓	✓	✓	✓
5	Diego Molano	Consultant, President's Office	✓		✓	
6	Ian Mac Arthur	Social Protection Lead Specialist	✓		✓	
7	Inés Vásquez	Sector Specialist	✓		✓	
8	Julie Katzman	Executive Vice President	✓		✓	
9	Kleber Machado	Water & Sanitation Lead Specialist	✓		✓	
10	Luiz Ros	Special Advisor for Innovation, President's Office	✓		✓	
11	Marcia Rocha	Health Sr. Specialist	✓		✓	
12	Mario Sanchez	Social Protection Lead Specialist	✓		✓	
13	Michelle Marshall	Consultant for Learning & Knowledge	✓		✓	
14	Miguel Porua	Modernization of State Lead Specialist	✓		✓	
15	Rafael Anta	Lead Specialist	✓	✓	✓	✓
16	Ralf Moreno	Project Manager	✓	✓	✓	✓



THE GOVERNANCE LAB PARTICIPANTS AND SUPPORTERS						
#	Name	Role	Issue area (Check marks shading denotes issue areas individual was involved with or conferences attended)			
			Assessing und.	Behavior change	Trash accumulation	Surveillance and data sharing
1	Professor Beth Simone Noveck	Director	✓	✓	✓	✓
2	María Hermosilla	Project Manager and Research Fellow	✓	✓	✓	✓
3	Dr. Rafael Ayoub	Health Research Advisor	✓	✓	✓	✓
4	Anirudh Dinesh	Graduate Research Assistant	✓	✓	✓	✓
5	Dinorah Cantu	Academy Coordinator	✓	✓	✓	✓
6	Jesse Marks	Graduate Research Assistant	✓	✓	✓	✓
7	Peter Suwondo	Graduate Research Assistant	✓	✓	✓	✓