Participatory Disease Surveillance in Latin America

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ABSTRACT
Participatory disease surveillance systems are dynamic, sensitive, and accurate. They also offer an opportunity to directly connect the public to public health. Implementing them in Latin America requires targeting multiple acute febrile illnesses, designing a system that is appropriate and scalable, and developing local strategies for encouraging participation.

Categories and Subject Descriptors
J.3 [**Computer Applications**]: Life and medical sciences, health and medical information systems

Keywords
Participatory surveillance, public health, acute febrile illness, dengue, influenza, Puerto Rico

1. INTRODUCTION
Participatory surveillance for influenza has proven to be timelier and more sensitive than traditional influenza surveillance systems [1-5]. At the same time, participatory surveillance is also useful for addressing common epidemiological challenges including identification of risk groups and evaluation of the effectiveness of interventions [6]. There are, however, a number of limitations for these systems: limited sample size (depending on the level of public engagement), biases in the sample (participants may represent a unique subset of the target population), and low specificity (it may be difficult or impossible to distinguish different diseases based on self-reported symptoms).

2. PUERTO RICO
In 2012, we launched SaludBoricua, an Internet-based participatory surveillance system for acute febrile illness (AFI) in Puerto Rico, where dengue, influenza, and other AFIs are common. Although SaludBoricua is still in its infancy, the system is providing valuable insight into how to engage the public. We have implemented several types of promotional materials and have conducted focus groups to evaluate their appeal as well as general interest in the system. We have also designed an evaluation component, not only to assess how well self-reported data compares to data captured through traditional surveillance mechanisms, but also to use the participatory system to better understand gaps in the traditional, healthcare-based surveillance systems. At the same time, we are using traditional, healthcare-based surveillance data to evaluate the ability of self-reported symptoms to differentiate distinct AFIs, principally dengue and influenza.

3. LATIN AMERICA
This work lays the foundation for AFI surveillance throughout the Americas. SaludBoricua is based on the Flu Near You participatory surveillance system for monitoring influenza activity throughout the United States and Canada. The current efforts with SaludBoricua will lay the technical foundation for expanding participatory surveillance in Latin America and develop models for engaging local partners and populations throughout the Americas.

4. ACKNOWLEDGMENTS
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5. REFERENCES
[1] Marquet, R.L., et al. 2006. Internet-based monitoring of influenza-like illness (ILI) in the general population of the Netherlands during the 2003-2004 influenza season. *BMC Public Health* 6, 242.

[2] van Noort, S.P., et al. 2007. Gripenet: an internet-based system to monitor influenza-like illness uniformly across Europe. *Euro surveillance*, 12(7), E5-6.

[3] Friesema, I.H., et al. 2009. Internet-based monitoring of influenza-like illness in the general population: experience of five influenza seasons in The Netherlands. *Vaccine*, 27(45), 6353-7.

[4] Paolotti, D., et al. 2010. Internet-based monitoring system for influenza-like illness: H1N1 surveillance in Italy. In

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ACM 978-1-4503-2038-2/13/05.

Proceedings of the 3rd International ICST Conference on Electronic Healthcare for the 21st century, Casablanca, 2010.

[5] Tilston, N.L., et al. 2010 Internet-based surveillance of Influenza-like-illness in the UK during the 2009 H1N1 influenza pandemic. *BMC Public Health*, 10, 650.

[6] Eames, K.T.D. et al. 2012. Rapid assessment of influenza vaccine effectiveness: analysis of an internet-based cohort. *Epidemiology and Infection*, 140(7), 1309-1315.