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The politics of participatory epidemiology: Technologies, social media and influenza surveillance in the US

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Participatory epidemiology;
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Abstract
Background: Health surveillance is now being augmented and transformed by the use of "unofficial" knowledge or sources of information. This unofficial data largely comes from Internet-based systems which gather information from non-state actors through intelligence networks, Internet and media scrawling, metadata analysis (online drug sale reports, Google searches, online forums, etc.) and social media analysis.
Objectives: The main objective of this article is to explore the policy implications of such a revolution, an issue that has been surprisingly largely ignored by the literature in public policy. The research question underpinning this analysis is: what are the policy implications of the growing use of knowledge/data from Internet-based technologies for health surveillance in the US? The theoretical importance and challenges of these technologies for public policies conclude this paper.
Methods: Using influenza as a case study, this article conducts a review of the documented impacts, for public health policy, of the use of communication and Internet-based technologies for surveillance. To do so, we inventory different social media-based initiatives currently used for influenza and public health surveillance while evaluating their consequences/impacts for public health policy.
Conclusions: The main conclusion is that the way we access, produce and distribute data/information about influenza (through the use of communication and Internet-based technologies for surveillance) has a direct impact on the risk perception and, ultimately, on public health policies through an "overload" of data.
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1. Introduction: getting a flu shot at the gas station

Fueling my car on a crispy November morning in Southern Virginia, the screen on the gas pump reminded me not to forget to get my annual flu shot, which can be purchased directly across from the gas station. Getting the annual flu shot is the new normal in the United States (US) and across the Western world. To use the words of Briggs and Nichter [1], it has been "naturalized". It is even a matter of social responsibility and healthiness; something we have to be reminded of every year, even by a gas pump. This emotional and cultural experience with the annual flu shot was well articulated by President Barack Obama in 2009: "if I had the two people that are most important in my life, my two daughters, get it right away [the flu shot] then you need [...] to make sure your children get it as well." [2].

Why do we now recommend annual flu shots for everyone? Just 15 years ago, it was recommended only for children, the diseased or the elderly. Why vaccines over other prevention strategies? Why do we not find similar incentives, marketing strategies and policies for other leading causes of deaths in the US, which bypass by far the impacts of influenza in terms of mortality (56,979 deaths), [3] such as heart disease (611,105 deaths), cancer (584,881 deaths), chronic lower respiratory diseases (149,205 deaths), and accidents (unintentional injuries – 130,557 deaths)? It is also important to note that there is no clear-cut consensus about the scope, dangerousness and deadliness of flu in medical circles [4]. Part of the answer is to be found, we suggest, with a major revolution [5] occurring in the field of health surveillance: the fact that conventional health data (direct observations, registries, and clinical data) is now being augmented and transformed by the use of what Weir and Mykhalovskiy [6] called "unofficial" knowledge or sources of information of public health surveillance. This unofficial data largely comes from Internet-based systems gathering information from non-state actors through intelligence networks (CDC, IOM, GPHIN, DoD), Internet and media scrawling, metadata analysis (online drug sale reports, Google searches, online forums) and social media analysis [7]. The question explored here is the policy implications of such a revolution, a question that has been surprisingly largely ignored by the literature in social sciences.

This paper seeks to conduct an analysis on the impacts of communication and Internet-based technologies for surveillance on the public health policy field, using influenza as a case study. The research question underpinning this analysis is: *what are the policy implications of this growing use of knowledge/data from Internet-based technologies for health surveillance in the US?* The main argument developed in this paper is that the way we access, produce and distribute data/information about influenza (through the use of communication and Internet-based technologies for surveillance) has a direct impact on the risk perception and, ultimately, on public health policies. In order to support this argument, we first review the politics of influenza surveillance in the US. This is followed by an analysis of social media and crowdsourced based surveillance systems. The analysis then shifts to a review of problems faced by this type of surveillance. Theoretical and conceptual challenges for public policies conclude this paper.

2. Influenza surveillance in the US: the politics of "participatory" epidemiology

Influenza represents a puzzle for public health policy [8], as it is difficult to anticipate and prepare for potential outbreaks because of the different types of viruses involved as well as their changing nature which pressures vaccine production and access. This uncertainty has been documented for its impact on the governing mechanisms put forward to anticipate the impacts of influenza [4]. Obtaining valid and up-to-date data is thus presented in this narrative as primordial. In this context, influenza has been identified as a top national health priority in the US and globally [9,10], even if its health impacts are limited compared to other health issues [11]. Increasing the influenza vaccination rate is now one of the priorities of the US "Healthy People 2020" initiative. Influenza also usually appears in the top 10 leading causes of death in the US (in 2013, according to the CDC, influenza was ranked 8th with 56,979 deaths) [12]. Influenza is also portrayed as having severe health, social and economic consequences [13]. In this context, the CDC recommends that everyone get an annual flu shot: "All persons aged 6 months and older are recommended for annual vaccination, with rare exception." [14].

This ranking of influenza as a top health priority dates back at least to the early 2000s. In 2004 the Bush administration declared that influenza represented "a danger to our homeland" [15], which resulted by a radical increase in the annual budget allocated to this issue in the US, rising from around 50 to 100 million USD annually to 6 billion annually [16]. Dr. Margaret Chan, the WHO Director General since 2006, also acknowledged that "[f]or global health security, I share your deep concern about the looming threat of an influenza pandemic" [17]. Spending and funding opportunities for influenza were, until very recently, extremely limited at the global scale. The 2004-5 H5N1 outbreak provoked a radical shift in global health policies: more than 2 billion USD has been spent for this health issue globally for the 2004–2008 period [18]. Non-health actors were also rapidly involved. For example, the military was recognized as a key actor in influenza surveillance and data production [19], reinforcing the securitization of health [4] that followed the end of the Cold War, as well as the private sector, outside the specific health surveillance and technology sub field. The media also "frame" [20] influenza more frequently as an anti-vaccination problem or as a health issue with major economic consequences by reproducing "naming controversies (Mexican flu, swine flu, etc.) and reinforcing the normalization process of influenza as a key health priority.

The politics of influenza in the US is characterized in this context by a constant reference to, and mention of, data about influenza (especially the 56,979 annual deaths). This data is used to evaluate influenza impact on societies. Influenza data plays a key role in the policy and institutional apparatus around influenza in the US. Problematizing their origins, production and circulation appears to be highly

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