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Web-based participatory surveillance of infectious diseases: the Influenzanet participatory surveillance experience

D. Paolotti[1], A. Carnahan[2], V. Colizza[1,3,4], K. Eames[5], J. Edmunds[5], G. Gomes[6], C. Koppeschaar[7], M. Rehn[2], R. Smallenburg[7], C. Turbelin[3,4], S. Van Noort[6] and A. Vespignani[1,8,9]

1) *ISI Foundation, Turin, Italy,* 2) *Swedish Institute for Communicable Disease Control, Stockholm, Sweden,* 3) *UMR-S 707, Institut National de la Santé et de la Recherche Médicale,* 4) *UMR-S 707, Université Pierre et Marie Curie-Paris 6, Paris, France,* 5) *London School of Hygiene and Tropical Medicine, London, UK,* 6) *Instituto Gulbenkian de Ciência, Oeiras, Portugal,* 7) *Science in Action BV, Amsterdam, The Netherlands,* 8) *Laboratory for the Modeling of Biological and Socio-technical Systems, Northeastern University, Boston and* 9) *Institute for Quantitative Social Sciences at Harvard University, Cambridge, MA, USA*

Abstract

To overcome the limitations of the state-of-the-art influenza surveillance systems in Europe, we established in 2008 a European-wide consortium aimed at introducing an innovative information and communication technology approach for a web-based surveillance system across different European countries, called Influenzanet. The system, based on earlier efforts in The Netherlands and Portugal, works with the participation of the population in each country to collect real-time information on the distribution of influenza-like illness cases through web surveys administered to volunteers reporting their symptoms (or lack of symptoms) every week during the influenza season. Such a large European-wide web-based monitoring infrastructure is intended to rapidly identify public health emergencies, contribute to understanding global trends, inform data-driven forecast models to assess the impact on the population, optimize the allocation of resources, and help in devising mitigation and containment measures. In this article, we describe the scientific and technological issues faced during the development and deployment of a flexible and readily deployable web tool capable of coping with the requirements of different countries for data collection, during either a public health emergency or an ordinary influenza season. Even though the system is based on previous successful experience, the implementation in each new country represented a separate scientific challenge. Only after more than 5 years of development are the existing platforms based on a plug-and-play tool that can be promptly deployed in any country wishing to be part of the Influenzanet network, now composed of The Netherlands, Belgium, Portugal, Italy, the UK, France, Sweden, Spain, Ireland, and Denmark.

Keywords: Europe, infectious disease, influenza-like illness, Internet, participatory surveillance
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Corresponding author: D. Paolotti, ISI Foundation, via Alassio 11/c, 10126 Turin, Italy
E-mail: daniela.paolotti@isi.it

Introduction

Infectious diseases remain a serious medical burden all around the world, with 15 million deaths per year estimated to be directly related to infectious diseases [1]. The emergence of new diseases such as human immunodeficiency virus/AIDS and SARS, and the rise of the new influenza strains H1N1, H5N1, and H7N9, as well as other respiratory pathogens such as the novel coronavirus Middle East respiratory syndrome coronavirus, represent a few examples of the global problems facing public health and medical science researchers. Even though pathogens such as the SARS coronavirus and H5N1 had a limited impact in terms of mortality, their sudden appearance has shown how abruptly health emergencies on a global scale can arise.

In recent times, our ability to control epidemic outbreaks has been, to a high degree, facilitated not only by advances in modern science (new cures, new drugs, and cooperative infrastructures for disease control and surveillance), but also by the worldwide spread of new technologies such as computers and smartphones, which allow more than 2 billion persons worldwide to have access to the Internet. This

represents an unprecedented opportunity to collect and communicate health-related information in real time and with high geographical resolution, including individuals who do not have contact with the healthcare system. Real-time surveillance data are crucial for rapidly identifying public health emergencies, optimizing the allocation of resources to respond to them, and devising mitigation and containment measures.

Although existing disease surveillance systems (predominantly general practitioner (GP)-based but also involving laboratory-based reporting, mandatory notifications, etc.) have a fundamental role in monitoring and understanding the spread of communicable diseases, they also have several important limitations. One of the major issues is that, for diseases such as influenza-like illness (ILI), only an unknown proportion of all infected individuals see a doctor. In addition, consultations frequently occur with a considerable delay, taking place only when a complication has occurred or a doctor's certificate is required (for example, in Sweden such a certificate is not required until after 1 week of absence from work). Other issues concern: the time delay in data reporting and aggregation; the lack of information on the patterns of household transmission; the lack of uniform standards for clinical definitions, which may vary considerably between countries and even between reporters (European Influenza Surveillance Network). Furthermore, age-stratified rates of physician consultation may vary widely with different healthcare and health insurance systems. Healthcare-seeking behaviour can change unpredictably during an epidemic, making extrapolations of those statistics to the general population uncertain.

To overcome the above limitations in the existing infectious diseases surveillance systems, with a focus on ILI, we proposed an innovative information and communication technology approach based on Web2.0 tools. Starting from the pivotal and successful experiences with Internet-based monitoring systems in The Netherlands and Portugal [2–4], the Influenzanet consortium undertook the challenge of deploying an innovative real-time and interlinked surveillance system across multiple European countries.

Materials and Methods

The first successful example of using the web for public health purposes dates back to 2003, when, in The Netherlands and Belgium, a Dutch scientific communication project was initiated by the small company Science in Action. The purpose was to inform the general population about influenza by means of a self-reporting Internet platform in Dutch (http://www.degrotegriepmeting.nl), where volunteers in The Netherlands and Belgium (the Flemish part) could answer socio-demographic, medical and behavioural questions, and report their influenza-related symptoms each week. User participation was achieved through targeted communication and recruitment. A positive side effect of this project was the collection of almost real-time data about influenza, including from individuals who did not visit a doctor when ill. Knowledge of volunteers' postal codes allowed the real-time collection of data at the postal code level. Thanks to a vigorous communication campaign using both online and offline media, the project attracted 20 000 users during this first season.

The possibility of collecting such detailed data about influenza cases from such a wide audience attracted the interest of the Gulbenkian Institute of Science Epidemiology group in Portugal, who implemented their own platform in Portuguese, and deployed the system at the beginning of the 2005 influenza season (http://www.gripenet.pt). In Portugal, during the first 2 years of the project, approximately 5000 volunteers were attracted [3]. On the basis of this success, the computational epidemiology group of the ISI Foundation in Turin, Italy decided to deploy a similar platform during the winter of 2007, to carry out influenza surveillance with the aim of informing computational models for studying the spread of ILI on a large scale. Data collected by these four platforms have been evaluated [3,4] (Paolotti *et al*., 3rd International ICST Conference on Electronic Healthcare for the 21st Century, 2010, Abstract no. 30), and the estimated seasonal influenza incidence curves have been found to be in good agreement with those from the former European Influenza Surveillance Scheme.

Since 2009, the four Internet-based monitoring systems have formed the foundation of a European-wide network of platforms that became the key instrument for providing real-time disease incidence for the epidemic forecast infrastructure developed by the EU-funded research project EPIWORK (http://www.epiwork.eu). The proposed network of web platforms, called Influenzanet (http://www.influenzanet.eu), saw, for the first time, the collaboration of epidemiologists, public health practitioners and modellers with the aim of collecting epidemiological data in real time through the contributions of Internet volunteers self-selected from among the general population. The epidemiology teams devised reference standard questionnaires for different diseases to collect unified data across European countries (presented in the supporting information). ILI has been the focus in the early deployment of the system, but the final goal is to considerably enlarge the portfolio of diseases and health conditions monitored. In June 2009, the plans to export the platform to other European countries were accelerated by the unfolding of the H1N1 pandemic in the northern hemisphere. A web system very similar to the Italian platform was rapidly deployed