The challenges of global case reporting during pandemic A(H1N1) 2009
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Abstract During the 2009 A(H1N1) influenza pandemic, the World Health Organization (WHO) asked all Member States to provide case-based data on at least the first 100 laboratory-confirmed influenza cases to generate an early understanding of the pandemic and provide appropriate guidance to affected countries. In reviewing the pandemic surveillance strategy, we evaluated the utility of case-based data collection and the challenges in interpreting these data at the global level. To do this, we assessed compliance with the surveillance recommendation and data completeness of submitted case records and described the epidemiological characteristics of up to the first 110 reported cases from each country, aggregated into regions. From April 2009 to August 2011, WHO received over 18 000 case records from 84 countries. Data reached WHO at different time intervals, in different formats and without information on collection methods. Just over half of the 18 000 records gave the date of symptom onset, which made it difficult to assess whether the cases were among the earliest to be confirmed. Descriptive epidemiological analyses were limited to summarizing age, sex and hospitalization ratios. Centralized analysis of case-based data had little value in describing key features of the pandemic. Results were difficult to interpret and would have been misleading if viewed in isolation. A better approach would be to identify critical questions, standardize data elements and methods of investigation, and create efficient channels for communication between countries and the international public health community. Regular exchange of routine surveillance data will help to consolidate these essential channels of communication.

Introduction
Pandemic A(H1N1) 2009 illustrated the importance of several aspects of pandemic preparedness and response. One was the need for timely surveillance data to inform policy decisions about public health response and mitigation activities. Throughout the entire course of the pandemic there was a critical need for data to describe the clinical presentation and course of the illness, estimate the epidemiological parameters related to the spread of the virus and the clinical severity of infection, and assess the impact of the pandemic on healthcare systems. The sharing of these data with the international public health community by countries affected in the course of the pandemic made it possible for countries to learn about the behaviour of the virus and for the World Health Organization (WHO) to modify recommendations for surveillance and response.

From 2004 to 2007, WHO coordinated a series of global consultations to design a pandemic surveillance strategy.5–7 These consultations culminated in the publication of the Global surveillance during an influenza pandemic manual on the WHO web site on 28 April 2009.4 A comprehensive early assessment was an important part of the strategy designed to generate a preliminary understanding of the severity of the pandemic, identify the affected populations, and estimate hospitalization rates for the planning of health services. The guidelines described the data elements to be collected and shared with WHO as part of the early assessment. These included individual case reports containing clinical and demographic data on at least 100 of the earliest laboratory-confirmed cases and describing the methods that countries used to collect these data.

With the spread of influenza A(H1N1)pdm09, an adapted interim surveillance manual containing a link to the suggested data collection form was published on the WHO web site on 29 April 2009.4 Following the declaration of the pandemic, this guidance was updated on 10 July 2010 with a suggested form for the collection of data on at least the first 100 laboratory-confirmed cases. The form included data variables for: demographics; date of symptom onset and type of symptoms experienced; medical history, including vaccination and pre-exposure antiviral treatment; pneumonia and its complications; treatment, including hospitalization, admission to an intensive care unit and need for mechanical ventilation; and outcome (Fig. 1).6

In this paper, we examine whether case-based data reporting was useful in meeting the stated objectives of the comprehensive early assessment component of pandemic surveillance guidelines. We do so by evaluating the level of country participation, the resulting data quality and completeness of the data, and the challenges in analysing and interpreting such data at the global level. The results of this evaluation are intended to inform future pandemic surveillance recommendations.

Individual case-based data collection was only one part of the WHO pandemic surveillance strategy, which also included early case detection and investigation and the collection and dissemination of virological surveillance data and of other critical data from a wide variety of sources.7–11 These surveillance components are not evaluated in this paper.

Collecting and collating case-based data
From 29 April 2009 to August 2010, WHO International Health Regulations (IHR) contact points at each of the six WHO regional offices collaborated with the IHR National Focal Points to facilitate collection of paper and/or electronic case-based clinical and epidemiological data from early laboratory-confirmed cases. This information was sent to WHO headquarters in Geneva to produce the global case-based dataset. However, data reached WHO at different time intervals and in different formats. No countries reported exactly the
same variables and all reported them in slightly different formats.

Interim analyses of the global dataset were conducted in July 2009, February 2010, August 2010 and August 2011 – upon receipt of final submission of individual country case-based data. This paper assesses the final global dataset as of 31 August 2011. We assumed that case records represented only laboratory-confirmed cases, as specified in the surveillance recommendation.

The global case-based dataset

We examined the global case-based dataset from two perspectives. First we assessed the uptake of the recommendation to collect and submit case-based data and the degree of compliance by evaluating the total number of countries reporting and the total number of case records submitted from different geographic regions. We then examined the value of using a limited number of earlier case reports to identify population groups at risk of infection and severe disease. Since the original intent of the comprehensive assessment segment of pandemic surveillance was to use the first 100 or so cases from each country to characterize the pandemic, we summarized the epidemiological characteristics of up to 110 of the earliest cases, obtained only from case records that included the date of onset of illness. We did this to represent cases collected in conformity with the guidance. For example, if a country submitted 234 records, the first 110 by date of symptom onset were defined as “earlier cases”. Cases for which no date of onset was given were excluded from this evaluation.

The epidemiological characteristics we evaluated included age and sex distribution, hospitalization ratios, complications and illness outcome (Table 1). We also evaluated clinical features, defined by symptom fields (Table 2). These characteristics were assessed by region and globally.

Ethics

This was an observational global surveillance programme in which case data contained no personal identifiers. Countries voluntarily submitted the data to WHO. During development of surveillance guidelines, WHO sought legal and ethical advice on the collection of these data. Prior to submitting this paper for publication, WHO sought and received consent to publish these findings from all countries included in this analysis.

Uptake of recommendation

As of 6 July 2009, a total of 94 512 cases and 429 deaths attributed to pandemic influenza had been reported to WHO by 135 countries and overseas territories. By that time, WHO had received individual case data for 2774 of the reported cases from 43 of the 135 countries; 2139 (86%) of the cases were reported by 21 countries.

From April 2009 to August 2011, a total of 18 311 individual case reports of laboratory-confirmed influenza caused by the A(H1N1)pdm09 virus were received at WHO headquarters from 84 of its 193 Member States. The majority were submitted from January to March 2010, but the last case reports arrived in August 2011. The 84 countries represented all continents; however, European countries contributed 9177 (50%) of the case reports contained in the global dataset. One European country alone submitted 6002 case
records – 33% of the total case records received. The fewest reports came from northern Africa and the Middle East, which, combined, submitted 47 case records. Information on the methods used to identify and select the cases for data collection was not included in any of the reports.

### Inclusion of date of onset

Of the 18,311 case-based records available to WHO, 9,932 (54%) included the date of symptom onset and 3,710 cases met our definition for “earlier” cases (Table 1). Data from three countries were excluded because date of onset was missing. Date of onset for the earlier cases from 81 countries ranged from 28 March to 8 November 2009. The earliest cases were reported from countries in the Americas and Asia (Fig. 1).

For the epidemiological characteristics that we evaluated, data completeness ranged from 4% for illness outcome to 99% for age and sex (Table 1). Nine of the 17 symptom fields on the WHO case summary form (Appendix A, available at: http://www.who.int/csr/resources/publications/swineflu/caseformadapted20090508.pdf) were reported by all regions. Completeness of these symptom fields ranged from 51% (productive cough) to 75% (fever) (Table 2).

### Global age and sex distribution

The median age of early cases was relatively consistent regionally and globally. It was 23 years (interquartile range, IQR: 14–33) overall, and slightly lower in the Americas and sub-Saharan Africa (Table 1). There were slightly more males (53%) than females among the earlier cases.
Adequacy of data to assess severity

Of 3710 earlier case records, 2980 (80%) included hospitalization data; of which 1336 cases (45%) had been hospitalized. The Americas and Europe reported lower rates of hospitalization among earlier cases than countries in Asia, Northern Africa and the Middle East (Table 1). Of 28 cases in northern Africa and the Middle East with hospitalization data, 23 (82%) were hospitalized (Table 1). Information on the reason for the hospitalization was seldom provided in the explanatory notes accompanying the data.

Of 3495 earlier case records from the Americas, Asia, Europe, northern Africa and the Middle East, 1764 (50%) included information about pneumonia. Pneumonia had been diagnosed in 69 (4%) of these 1764 cases. Data on mechanical ventilation were complete for only 177 (13%) of the 1336 hospitalized cases, of which 53 (30%) received mechanical ventilation.

Symptoms and clinical outcomes

The most common signs and symptoms recorded in all regions were fever, cough and sore throat (Table 2). However, the regions reported symptoms in different ways, so the denominators for case reports with symptom information were different, which makes comparisons difficult. Only 445 (12%) case records included outcome data. Two deaths were reported among the earlier cases (both in the Americas) and 6 among subsequent cases (all in sub-Saharan Africa) (Table 1).

Discussion

When assessing a new infectious disease outbreak, it is of utmost importance – but enormously difficult – to quickly estimate its key characteristics, such as clinical severity, clinical presentation, the course of the illness and the risk factors associated with infection. All such information is critical for decision-making. Although it is encouraging that 84 of WHO’s 193 Member States shared case-based data, as recommended, reporting was less than timely and declined as the pandemic progressed. Of the 84 affected countries, a little over half had submitted case-based data by early July 2009. However, the conclusions that could be reached from analysis of the data were limited by the absence of information about data collection methods and degree of data completeness. WHO anticipated data reporting to vary somewhat, but substantial differences in data formatting hindered efficient processing. Furthermore, the large proportion of report forms with incomplete data limited the usefulness of the information derived. This was especially true for records that were missing the dates of onset, since the case-based component of the surveillance strategy relied on the assessment of the first few hundred cases.

Although WHO had previously published pandemic preparedness guidance in 1999 and revised it in 2005 and 2009, specific surveillance guidance for the collection of case-based data on earlier laboratory-confirmed cases was not included until 28 April 2009. As a result, countries may not have had enough time to incorporate WHO recommendations into their pandemic surveillance plans. Data collection and compilation in such a large-scale acute event is also challenging in itself. At the national and regional levels, limited laboratory capacity contributed to delays in case confirmation and subsequent reporting. At the global level, challenges included the creation of novel data management systems and data handling processes. This contributed to the delay in analysing and reporting aggregated results.

The key epidemiological characteristics observed in the early stages of the pandemic did not persist throughout, either globally or in the individual regions, nor were observations based on the earlier cases in individual countries the same as those based on the cases reported later. The global case-based data on hospitalization – a key indicator of the clinical severity of infection – illustrated some of the problems involved in interpreting aggregated data. The proportion of cases hospitalized in the Americas and Europe, which were the earliest areas to be affected, was substantially lower than that observed in Asia. Our ability to interpret the data centrally was limited by the lack of a defined system for reporting on (i) patient selection methods; (ii) the case definitions used, (iii) the type of investigation being conducted when a given case was detected; and (iv) the screening and surveillance policies in place at the time of case detection. As a result, we were unable to determine with certainty the reasons for the wide inter-regional disparity in the proportions of hospitalized cases. It is now known, however, that hospitalization policies and testing practices changed over time and varied markedly between regions. The threshold for hospitalization and testing was lower at the beginning of the pandemic and many Asian countries adopted a conservative approach to case management by hospitalizing the majority of cases that tested positive, regardless of clinical severity. Differences in the reported proportion of cases hospitalized over time could have been misinterpreted as an indication of changes in severity without the benefit of other information sources. The patient outcome data needed to generate estimates of deaths from infection with influenza H1N1pdm09 virus proved difficult to obtain in many countries and was therefore not usually submitted to WHO as part of the early case-based data reports.

The overall age and sex distributions and the frequency of the clinical signs observed in the dataset were consistent with later published observations. However, we observed minor differences in age from region to region. The reasons for this are still unclear. In some countries, surveillance practices that initially targeted returning travellers could have biased the median age of reported cases downward early in the course of the pandemic. Similarly, the investigation of large school outbreaks that occurred, in some cases, as the initial source of community transmission may have led to the identification of predominantly younger cases in later case reports, and national testing policies may have also been a factor. As with hospitalization data, the lack of information about how cases were selected limited our ability to interpret the data.

Despite the fact that our dataset represents the largest number of individual pandemic influenza case reports analysed to date, we were unable to fully evaluate the utility of the surveillance recommendations. We defined the first 110 case reports from each country as “earlier” cases to evaluate the usefulness of this approach in describing key characteristics of a new influenza pandemic. However, we had no information on when data actually became available for analysis, a datum that could have allowed more realistic assessment of the
usefulness of case-based data collection. We tried to overcome this limitation by comparing data from different regions. The Americas, for example, were affected earlier than Asia and much of sub-Saharan Africa. Other ways of analysing multinational data may yield more accurate representation of global trends. For example, we presented regionally aggregated data without adjusting for clustering of information within countries. However, even if we had statistically accounted for clustering, differences in transmission, laboratory capacity and reporting patterns between countries and regions would have probably still rendered us unable to draw firm conclusions from the analysis of regionally or globally aggregated data. In the end, the absence of local contextual information is what most hampered our ability to interpret the data. In contrast, the value of a globally aggregated, standardized, minimal case-based dataset has been demonstrated with less rapidly evolving events on a smaller scale, such as the avian influenza H5N1 epidemic. 

The global avian influenza case-based dataset has improved our understanding of this disease’s clinical features, risk factors and severity.

Conclusion

The influenza A(H1N1) 2009 pandemic clearly illustrated the challenges of identifying and promoting the appropriate tools for understanding a pandemic early in its course. It also provided an opportunity to evaluate the components of previously published pandemic surveillance strategies. Although the value of a globally aggregated, standardized, minimal case-based dataset has been demonstrated for events on a smaller scale, the value of this type of surveillance is less obvious during a large-scale event. However, health agencies in many countries did conduct case-based surveillance on early cases and, when these data were interpreted in their appropriate context by the countries themselves and the results were shared among WHO Member States through WHO network teleconferences and rapid publication, they provided valuable information that allowed countries subsequently affected to take preparatory steps.

Future guidelines will need to take account of the factors that hinder early reporting. Some might be, for example, pressures on national health systems caused by response activities; differences in health system infrastructure and information systems; reluctance on the part of health authorities to submit incomplete data early in an investigation; and investigators’ eagerness to publish early findings in peer-reviewed publications before their public dissemination. Accordingly, the challenge for WHO is the provision of timely information about acute public health risks of international concern so that countries still unaffected by a pandemic can make informed decisions about prevention and mitigation in the face of constraints to data access.

Improving the comparability and utility of global epidemiological data on influenza requires continued attention to building surveillance and laboratory capacity in all countries. To this end, the WHO Interim Global Epidemiological Surveillance Standards for Influenza (July 2012) offers a set of proposed surveillance objectives for a minimal, basic respiratory disease surveillance system. These objectives include the establishment by all countries of minimum standards for case reporting, data collection and analysis as part of inpatient and outpatient respiratory disease surveillance. The Interim Standards include guidance on how to establish sentinel surveillance for influenza-like illness and severe acute respiratory infection (SARI) and suggest minimum datasets and ways in which countries can share aggregated routine influenza surveillance data with WHO. In the setting of a pandemic or outbreak situation, rates of reporting of influenza-like illness, SARI, pneumonia, hospitalizations and SARI deaths at sentinel sites compared with historical data from sentinel systems would likely give the first indication of the severity of a pandemic as it unfolds. These data are likely to be more reliable than following the approach suggested by the IHR Review Committee, early estimations of severity should remain a key component of pandemic surveillance despite their complexity.

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Global case reporting during 2009 pandemic

Résumé
Les défis du signalancement des cas dans le monde pendant la pandémie de grippe à virus A(H1N1) de 2009

Pendant la pandémie de grippe à virus A(H1N1) de l’année 2009, l’Organisation mondiale de la Santé (OMS) a demandé à tous les États membres de fournir les données par cas au moins sur les 100 premiers cas de grippe confirmés en laboratoire afin d’obtenir une compréhension précoces de la pandémie et de fournir les directives appropriées aux pays touchés. En examinant la stratégie de surveillance de la pandémie, nous avons évalué l’utilité de la collecte des données par cas et les défis à relever dans l’interprétation de ces données au niveau mondial.

Pour ce faire, nous avons évalué le respect des recommandations en matière de surveillance et l’exhaustivité des données des hôpitaux, et nous avons décrit les caractéristiques épidémiologiques des 110 premiers cas signalés de chaque pays, regroupés en régions.

Sur la période allant d’avril 2009 à août 2011, l’OMS a reçu plus de 18 000 dossiers de cas fournis par 84 pays. Les données sont parvenues à l’OMS à différentes intervalles de temps, sous différents formats et sans informations sur les méthodes de collecte. À peine plus de la moitié des 18 000 dossiers a donné la date d’apparition des symptômes, ce qui ne permet pas d’évaluer si les cas reçus faisaient partie des premiers cas à être confirmés. Les analyses épidémiologiques descriptives se sont limitées à synthétiser les rapports d’âge, de masculinité et d’hospitalisation. L’analyse centralisée des données par cas n’a pas permis de déterminer l’âge et le sexe des patients, ni de recueillir d’autres informations sur les symptômes.

Les défis à relever pour assurer une collecte des données de manière précoces et exhaustive sont de taille et de nature importantes. Les défis à relever dans l’interprétation de ces données au niveau mondial sont nombreux, notamment en matière de surveillance des cas, de collecte des données et de mise en relation des données nationales et internationales.

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Los desafíos de la notificación de casos a nivel mundial durante la pandemia de A (H1N1) del año 2009

Durente la pandemia de gripe A (H1N1) del año 2009, la Organización Mundial de la salud (OMS) pidió a todos los Estados miembros que proporcionaran datos de hasta los primeros 100 casos de gripe confirmados en laboratorios con objeto de comprender con rapidez la pandemia y proporcionar orientación adecuada a los países afectados. Con objeto de examinar la estrategia de vigilancia de la pandemia, hemos evaluado la utilidad de la recogida de datos sobre casos y los desafíos que supuso la interpretación de esos datos a nivel internacional. Para ello, evaluamos el cumplimiento con las recomendaciones de vigilancia y la integridad de los datos de los registros enviados y describimos las características epidemiológicas de, como mucho, los 110 primeros casos de cada país, agrupados por regiones. Entre abril de 2009 y agosto de 2011, la OMS recibió más de 18 000 registros de casos de 84 países en intervalos de tiempo y formatos distintos, y sin información alguna sobre los métodos de recogida. Solo algo más de la mitad de los 18 000 registros indicaba la fecha de aparición de los síntomas, lo que dificultó evaluar si los casos se encontraban entre los primeros que se confirmaron. Los análisis epidemiológicos descriptivos se limitaron a resumir las proporciones por edad, sexo y hospitalización. Los análisis centralizados de datos sobre casos tuvieron poco valor en la descripción de las características fundamentales de la enfermedad. Fue difícil interpretar los resultados que, habría resultado engañosos si se hubieran observado de forma aislada. Un enfoque más apropiado permitiría identificar las cuestiones críticas, estandarizar los datos y los métodos de investigación, y crear canales de comunicación entre los países y la comunidad sanitaria internacional. El intercambio regular de datos de vigilancia rutinarios ayudará a consolidar dichos canales de comunicación fundamentales.

Resumen

Los desafíos de la notificación de casos a nivel mundial durante la pandemia de A (H1N1) del año 2009

Durante la pandemia de gripe A (H1N1) del año 2009, la Organización Mundial de la salud (OMS) pidió a todos los Estados miembros que proporcionaran datos de hasta los primeros 100 casos de gripe confirmados en laboratorios con objeto de comprender con rapidez la pandemia y proporcionar orientación adecuada a los países afectados. Con objeto de examinar la estrategia de vigilancia de la pandemia, hemos evaluado la utilidad de la recogida de datos sobre casos y los desafíos que supuso la interpretación de esos datos a nivel internacional. Para ello, evaluamos el cumplimiento con las recomendaciones de vigilancia y la integridad de los datos de los registros enviados y describimos las características epidemiológicas de, como mucho, los 110 primeros casos de cada país, agrupados por regiones. Entre abril de 2009 y agosto de 2011, la OMS recibió más de 18 000 registros de casos de 84 países en intervalos de tiempo y formatos distintos, y sin información alguna sobre los métodos de recogida. Solo algo más de la mitad de los 18 000 registros indicaba la fecha de aparición de los síntomas, lo que dificultó evaluar si los casos se encontraban entre los primeros que se confirmaron. Los análisis epidemiológicos descriptivos se limitaron a resumir las proporciones por edad, sexo y hospitalización. Los análisis centralizados de datos sobre casos tuvieron poco valor en la descripción de las características fundamentales de la enfermedad. Fue difícil interpretar los resultados que, habría resultado engañosos si se hubieran observado de forma aislada. Un enfoque más apropiado permitiría identificar las cuestiones críticas, estandarizar los datos y los métodos de investigación, y crear canales de comunicación entre los países y la comunidad sanitaria internacional. El intercambio regular de datos de vigilancia rutinarios ayudará a consolidar dichos canales de comunicación fundamentales.

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