

# Case registry systems for pandemic influenza A(H1N1)pdm09 in Europe: are there lessons for the future?

J Whelan<sup>1,2</sup>, K Greenland<sup>1,2</sup>, M Rondy<sup>1,2</sup>, W van der Hoek (Wim.van.der.Hoek@rivm.nl)<sup>1</sup>, M Robert-Du Ry van Beest Holle<sup>1</sup>

1. Centre for Infectious Disease Control, National Institute for Public Health and Environment (RIVM), Bilthoven, the Netherlands
2. European Programme for Intervention Epidemiology Training (EPIET), European Centre for Disease Prevention and Control (ECDC), Stockholm, Sweden

## Citation style for this article:

Whelan J, Greenland K, Rondy M, van der Hoek W, Robert-Du Ry van Beest Holle M. Case registry systems for pandemic influenza A(H1N1)pdm09 in Europe: are there lessons for the future?. *Euro Surveill.* 2012;17(19):pii=20167. Available online: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=20167>

Article submitted on 28 July 2011/ published on 10 May 2012

Countries across Europe developed a range of database systems to register pandemic influenza A(H1N1)pdm09 cases. Anecdotal reports indicate that some systems were not as useful as expected. This was a cross-sectional, semi-structured survey of health professionals who collected and reported pandemic influenza A(H1N1)pdm09 cases in 23 countries within the 27 European Union (EU) Member States plus Norway. We describe here the experiences of using pandemic case register systems developed before and during the pandemic, whether the systems were used as intended and, what problems, if any, were encountered. We conducted the survey to identify improvements that could be made to future pandemic case registers at national and EU level. Despite many inter-country differences, 17 respondents felt that a standardised case register template incorporating a limited number of simple standard variables specified in advance and agreed between the World Health Organization and the European Centre for Disease Prevention and Control could be useful. Intra- and inter-country working groups could facilitate information exchange, clearer system objectives and improved interoperability between systems.

## Introduction

After the Single European Act of 1986, the European Commission pushed for better collaboration between national sentinel systems for infectious disease surveillance, establishing 'Eurosentinel' in 1989 [1]. This international sentinel network of general practitioners included surveillance of influenza-like-illness (ILI) and acute respiratory infection (ARI). Since then, ILI and ARI surveillance have become well established in Europe and many European Union (EU) Member States have developed sophisticated surveillance systems for influenza and other infectious diseases [2-4]. Since September 2008, national ILI/ARI data, virological data and other indicators from all 27 EU Member States plus Iceland and Norway have been reported on a weekly basis to the European Centre for Disease Prevention and Control (ECDC). The novel influenza A(H1N1)pdm09 pandemic of 2009 posed a range of new challenges,

however [5], and evaluations of pandemic preparedness and response are still ongoing at regional, national and multinational level. Many focus on the high-level strategic management aspects of the pandemic, while others look more specifically at vaccination and antiviral strategies, surveillance, communications and cross-sectoral working [6]. In this survey, we focus on the challenges encountered with both new and established pandemic influenza case registration systems by the professionals within public health institutions of EU Member States and Norway, who were charged with collecting, analysing and reporting on the 94,512 influenza A(H1N1)pdm09 cases in the first three months of the pandemic [7] (and many more thereafter).

The rationale for this study was the experience with case registration in the Netherlands, heretofore undescribed: at the onset of the pandemic, a newly developed data warehouse known as Pandora (Pandemic Research Application) was trialled as a pandemic case register. Pandora was originally developed in response to the avian influenza A(H7N7) outbreak that occurred in the Netherlands in 2003 [8]. It was designed to facilitate outbreak control and research through comprehensive data collection from clinical, laboratory, hospital, public health and agricultural sources and also to facilitate data linkage at an individual level. It was not fully operational at the onset of the influenza A(H1N1)pdm09 pandemic and the operating system failed when it was used as a real-time case registration system. It had to be abandoned in the early phase of the outbreak, but was later used successfully to record hospitalisation data during the pandemic and is now operational and on standby for avian influenza outbreaks, as originally intended.

Anecdotal reports indicate that in some other European countries, complex database systems were also developed to register influenza cases that were subsequently not used at all, not used immediately, or did not provide the necessary information during the pandemic. We hypothesised that countries using case registers that were well established pre-pandemic

were less likely to experience problems scaling them up than those that developed new systems. Our aim was to ascertain whether other countries successfully managed comprehensive data linkage within their pandemic case register and whether a single system could successfully meet the competing information needs of stakeholders. Our objectives were to describe – from the perspective of the system user – experiences of using pandemic case register systems developed before and during the pandemic, whether the systems were used as intended during the pandemic and what problems, if any, were encountered. The survey was conducted with a view to identifying improvements that could be made to future pandemic case registers at national and EU level.

## Methods

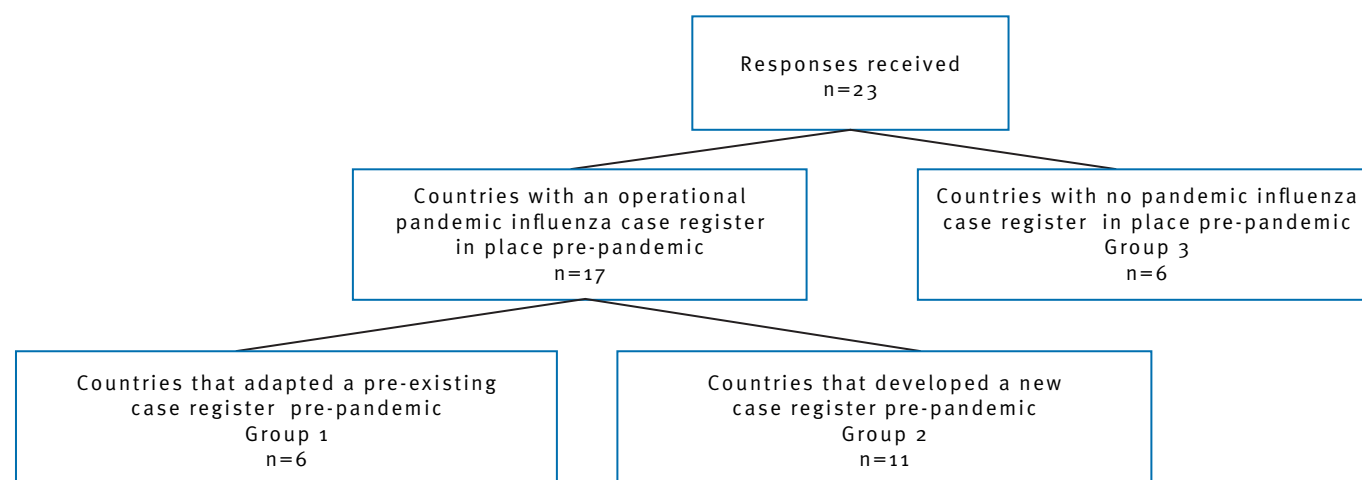
A cross-sectional survey was conducted in June and July 2010, which included 30 countries within 27 EU Member States (England, Wales, Scotland and Northern Ireland were approached separately) plus Norway. Fellows who were training with the European Programme for Intervention Epidemiology Training (EPIET), placed at national centres for surveillance and control of communicable diseases across the EU, identified one senior person in their institute with direct experience of the pandemic case registration system in that country. Following initial email contact, two follow-up reminder emails were sent, and if no response was received, the EPIET fellow recommended an alternative contact person. Respondents were guaranteed anonymity, unless the respondent gave permission for their country to be named.

The survey was conducted by electronic questionnaire using QuestBack software [9]. Questions, in English, related to the purpose and content of the case registration system (objectives, data sources, data collected and means of collection), professional groups involved (in developing the system and data collection, aggregation and reporting), necessary adaptations and ultimately a description of the systems used, problems encountered and lessons learnt. The questionnaire was first piloted with four senior, multilingual health professionals working in national public health institutes across Europe for whom English is not their first language. It was semi-structured and divided into two sections: (i) relating to the pandemic influenza case register in place before pandemic phase 4 was declared by the World Health Organization (WHO) on 27 April 2009 and before the first case of influenza A(H1N1)pdm09 was confirmed in their country (hereafter referred to as ‘pre-pandemic’) and (ii) relating to the pandemic influenza case register or other additional/supporting systems or software used after the first case was confirmed. Sections i and ii comprised 15 and 10 questions, respectively, and the questionnaire took approximately 10 minutes to complete. Response options were dichotomous (yes/no), Likert-type scales and open-text fields. Descriptive analysis was conducted on qualitative data.

Using the approach of Baker et al. [10], case register objectives were classified as control focused or strategy focused. They were considered control focused if they were necessary for the monitoring and management of healthcare systems and other services

## FIGURE

Flow chart of 23 respondent countries<sup>a</sup> in survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe and their status regarding having a pandemic influenza case register pre-pandemic<sup>b</sup>, June–July 2010



<sup>a</sup> Belgium, Bulgaria, Cyprus, England, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Norway, Poland, Romania, Scotland, Slovakia and Sweden.

<sup>b</sup> ‘Pre-pandemic’ refers to before pandemic phase 4 was declared by the World Health Organization on 27 April 2009 and before the first case of influenza A(H1N1)pdm09 was confirmed in their country.

internally within the country. Objectives were classed as strategy focused if they supported prevention strategies to reduce population health risk. Control-focused and strategy-focused objectives are, of course, not mutually exclusive and one can inform the other.

Univariable analysis (using Pearson chi-square test) was conducted using Stata 11.1. Probability of  $p \leq 0.05$  was considered statistically significant.

## Results

Of the 31 countries contacted, 23 responded to the questionnaire: Belgium, Bulgaria, Cyprus, England, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Norway, Poland, Romania, Scotland, Slovakia and Sweden. Six respondents were heads of department (at an epidemiology or surveillance of infectious diseases unit) nationally or at state level, seven were epidemiologists and four were public health doctors or medical officers. Nine described their principle role as one of coordination or management within their department, and about half of the respondents ( $n=12$ ) had a responsibility in relation to surveillance, data analysis and reporting. Only one respondent reported a role in making recommendations and one described a role in public relations.

A total of 17 responding countries reported having an operational pandemic influenza case registration system in place pre-pandemic, of which 11 developed a new system in advance and six adapted an existing register, including the seasonal influenza registration system ( $n=3$ ) and other infectious disease surveillance systems ( $n=2$ ). Six countries did not have a pandemic influenza case register prepared pre-pandemic (Figure). We divided responding countries into terciles based on per capita gross domestic product, but did not find any difference in countries' state of readiness whether they had a system in place pre-pandemic or not (data not shown).

### Countries with an operational pandemic influenza case register in place pre-pandemic ( $n=17$ )

Countries with a pandemic influenza case register in place pre-pandemic were divided into those that adapted an existing system ( $n=6$ , Group 1) and those that developed a new one ( $n=11$ , Group 2). All 17 of these countries reported that clear objectives were defined in advance (Table 1). All respondents reported at least one control-focused objective and one strategy-focused objective, but Group 1 countries were more likely than those in Group 2 to report 'to inform strategies to prevent/reduce mortality and morbidity' as an objective (Pearson chi-square statistic: 3.61;  $p=0.05$ ).

Involvement of experts in the development of the register was variable (Table 1) and no statistically significant

**TABLE 1**

Respondent countries with a pandemic influenza case register developed pre-pandemic<sup>a</sup> ( $n=17$ ): objectives and professional groups involved in its development, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

Objectives of case register and professional groups involved in its development	Number of respondent countries $n=17$
Objectives specified (answered by the 17 countries) <sup>b</sup>	
Control-focused objectives	
To count cases and track the number of cases occurring over time	16
To track cases geographically	15
To follow individual cases over time, documenting outcome (death, hospitalisation, etc.)	15
To conduct contact tracing	11
Strategy-focused objectives	
To inform strategies to prevent/reduce mortality and morbidity	13
To maintain virological surveillance	12
To record detailed information about all cases	11
To record detailed information about early cases only	9
Other <sup>c</sup>	3
No clear objectives specified	0
Professional groups involved in developing the register (answered by the 17 countries) <sup>b</sup>	
Epidemiologists	16
Information technology specialists (health-/public health-focused)	12
Health/public health specialists (e.g. physicians, nurses)	10
Laboratory experts (e.g. virologists)	8
Infectious disease doctors	8
Health service managers/planners	6
Information technology specialists (non-health related)	4
General practitioners	4
Other	0

<sup>a</sup> Pre-pandemic refers to before pandemic phase 4 was declared by the World Health Organization on 27 April 2009 and before the first case of influenza A(H1N1)pdm09 was confirmed in their country.

<sup>b</sup> Multiple answers were possible.

<sup>c</sup> Other objectives were: to collect symptoms, travel history, demographics and treatment provided, to record detailed information about fatal cases with influenza A(H1N1)pdm09, and to monitor antiviral therapies and vaccination status among cases and to estimate transmission parameters and effectiveness of interventions.

difference was found between the involvement of the various professional groups.

#### Data sources and data collection

Data sources used, means of data entry and state of readiness for use are reported by group in Table 2. There was no statistically significant difference between Groups 1 and 2 in the number or nature of data sources accessed or the means of data entry. Where data were entered manually, software used included EpiData (n=2), Microsoft Excel (n=2), Microsoft Access (n=2), dBase (n=1) and MySQL open source database [11] (n=2).

Four respondents in Group 1 provided details of their country's register (Box 1). Brief descriptions provided by respondents in Group 2 are in Box 2.

#### System readiness pre-pandemic

In five of the six respondent countries that adapted a pre-existing case register before the pandemic (Group 1), the systems were live and ready for use pre-pandemic. In countries where the system was not ready for use immediately on confirmation of the first case in the country, the system was ready within five days in one country, within 30 days in two countries (paper records were kept until the system was ready in one country) and within two months and six months for recording of cases and deaths, respectively in one country.

#### Necessary system modifications

Overall, 16 of the 17 countries with an operational pandemic influenza case register in place pre-pandemic reported that they used their new or adapted system during the pandemic (one country had to abandon their

**TABLE 2**

Development of case registers pre-pandemic<sup>a</sup> by 17 respondent countries (Groups 1 and 2) during the influenza pandemic, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010, June–July 2010

Development of case registers	Number of respondent countries n=17		
	Group 1 Adapted pre-existing case register before pandemic (n=6)	Group 2 Developed new case register before pandemic (n=11)	
Data sources used <sup>b</sup>			
Laboratory reports	6	10	
National notifiable infectious disease database	6	6	
Hospital admission information	5	7	
Regional case reports	3	6	
Sentinel network of physicians	4	4	
Other	0	2	
Means of data entry			
Entered automatically	1	3	
Entered manually	2	1	
A combination of both of the above	3	7	
State of readiness			
Was the system live and ready for use before the World Health Organization declared pandemic phase 4 (27 April 2009)?	Yes	5	2
	No	1	6
Was the system live and ready for use before the first influenza A(H1N1)pdm09 case was confirmed in your country?	Yes	5	8
	No	1	3
Modification of the register			
Was the case register modified at any point?	Yes	1	7
	No	5	3

<sup>a</sup> Pre-pandemic refers to before pandemic phase 4 was declared by the World Health Organization on 27 April 2009 and before the first case of influenza A(H1N1)pdm09 was confirmed in their country.

<sup>b</sup> Multiple answers were possible.



## Box 1

Overview of case registration systems, provided by four respondent countries in Group 1<sup>a</sup>, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

### Germany

In Germany, the multistate electronic reporting system for communicable diseases (SurvNet [12]) was used. This is a physically distributed, dynamic database used by all local health departments, state health departments and the Robert Koch Institute, the national agency for infectious disease epidemiology. The database is characterised by a number of highly standardised, core questions, but it incorporates responses to questions in free-text format in order to obtain additional information about risk factors, therapy, etc. from cases.

### Sweden

A detailed description of pandemic influenza A(H1N1)pdm09 surveillance in Sweden is available [13]. Briefly, a comprehensive regional/national system for communicable disease surveillance called SmiNet-2 has been developed [2]. This web-based system allows for reporting from physicians (via an online form) and laboratories (directly from the laboratory data system). Random, population-based reporting was also conducted in Stockholm via a telephone- or Internet-administered cohort study ('SickReport', described in detail elsewhere [3]), in which approximately 5,500 people participated during the pandemic. Surveillance of influenza-related web queries on a medical advice website [14] was conducted via an automated system that used statistical modelling to estimate the proportion of patients with influenza-like illness also described in detail elsewhere [15,16]). Other systems used in Sweden included aggregated voluntary laboratory reporting of the number of samples analysed for influenza virus infection and the proportion positive, voluntary reporting of severity of influenza illness from a register within intensive care departments called 'Intensive care of influenza cases in Sweden' (IRIS), reports of deaths from pathologists and the official death registry, and weekly reports on use of antivirals and vaccine coverage from the county medical officers (Smittskyddsläkarna) of the Swedish Institute for Communicable Disease Control (SMI).

### Ireland

In Ireland, the web-based 'Computerised Infectious Disease Reporting' (CIDR) information system was used [4]. This is a shared national information system for the regional health departments, the Ministry of Health, the Health Protection Surveillance Centre and other partners.

### Finland

In Finland, several surveillance systems were used [17]. These included the national infectious disease register, notifications of clusters of influenza (via doctors responsible for communicable disease control in healthcare districts); influenza-like or influenza-related illnesses reported by selected primary healthcare centres in all healthcare districts, case-based surveillance (including details of symptoms and recent travel), hospital surveillance (daily number of patients hospitalised and total number of inpatients in general wards and in intensive care units with confirmed or suspected Influenza A(H1N1)pdm09 infection), virological surveillance and mortality surveillance.

<sup>a</sup> Respondent countries that adapted a pre-existing case register before the influenza pandemic.

new system during the pandemic because it could not be adapted to the new situation in time). In Group 1 (countries that adapted a pre-existing case register before the pandemic), five of the six respondent countries were able to use their system effectively without modification. In Group 2 (countries that developed a new case register before the pandemic), seven of the 11 respondent countries had to modify the system after a variable number of cases were confirmed (mean: 418 cases; range: 1–1,200). Reasons for modifying or abandoning the system are in Box 3. There was no statistically significant difference between the professional groups involved in system development and successful implementation of the system.

Of the 17 countries with an operational pandemic influenza case register in place pre-pandemic, 12 reported using more than just the case register. Other systems used in tandem with the case register were Microsoft Excel (n=4, which one respondent reported was used to record the very earliest cases before switching

## Box 2

Overview of case registration systems, provided by five respondents in Group 2<sup>a</sup>, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

We collected individual data on everyone who was swabbed in our country during the pandemic. We had a separate database for those who required antivirals and those who took the influenza vaccine and also for our sentinel surveillance.

We connected our notification system with the (central and peripheral) laboratory systems, together with the questionnaires that were developed for studies among patients and contacts.

We had several systems for different purposes and times. The First Few 100 (FF100) database was for detailed follow-up of 392 cases and their contacts (this was an online Postgre SQL database [18]). Along side this, we had a less detailed national dataset (the 'Whiteboard') of all confirmed cases which occurred (e.g. all FF100 cases were on the Whiteboard but not vice versa), this was initially an Excel spreadsheet until an online SQL database could be built. This housed data until 1 July 2009 when we stopped our containment phase. Case data was also on another on-line system (which had been developed and rolled out to local health protection teams during the containment phase so ran in parallel to the Whiteboard for a while). This included discarded (negative) cases and was also used for case management locally.

Our case tracking system consisted of (a) notification of laboratory-confirmed severe cases who were hospitalised (b) laboratory reporting of influenza A(H1N1)pdm09 cases, (c) sentinel surveillance of influenza-like illness, including a clinical and a laboratory component.

Multiple sources for the first 200 cases: communicable disease web-based reporting system NAKIS. Laboratory reporting system, sentinel providers reporting system and hospital admission system were additional.

<sup>a</sup> Respondent countries that developed a new case register before the pandemic.

to the national case register database, and another reported using for cases of severe acute respiratory infections), Microsoft Access (n=2, which was reportedly used for collecting data on enhanced surveillance of pandemic cases in intensive care units, for monitoring all cause deaths, pneumonia and influenza deaths, and for monitoring sentinel general practice ILI and virological surveillance), Microsoft Word (n=1) and a paper-based system (n=3), which one country reported for a few weeks at the very outset of the pandemic in their country.

### Countries with no pandemic influenza case register pre-pandemic (n=6)

Six countries had no pandemic influenza case register in place before the first case of influenza A(H1N1)pdm09 was confirmed in their country. The systems

#### Box 3

Reasons for modifying or abandoning the case registration systems in place before the pandemic, provided by seven respondents in Groups 1 and 2<sup>a</sup>, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

*The system was too complex to use, users were not familiar enough with system.*

*The system crashed after the inclusion of around 20 suspect cases (so actually before the first confirmed case). Problem was that it had been tested for around 10 cases, that worked fine, but after 20 it technically shut down due to the overload of information. Too complex, too slow.*

*It was not flexible to changing demands.*

*At the beginning of the pandemic we developed a system for epidemiological investigation of every confirmed case. After the first 1,000 cases it was impossible to manage contact tracing of all confirmed cases and we adopted a more simple form to be filled in only for confirmed cases that were to be a fraction of ILI cases diagnosed by hospitals and GPs.*

*The continuation of enhanced surveillance of influenza A(H1N1)pdm09, including contact tracing around cases, would be inadvisable as case counts increased. Under such circumstances it was exceedingly difficult to maintain this practice, and its public health benefit was doubtful. On 15 July 2009 we moved to a mitigation phase, which was communicated as 'patient protection phase'. In this phase, contact tracing was discontinued and the recommendation for chemoprophylaxis of all close contacts was withdrawn. Surveillance shifted to: a) notification of laboratory-confirmed severe cases who were hospitalised, b) laboratory reporting of influenza A(H1N1)pdm09 cases, (c) sentinel surveillance of influenza-like illness, including a clinical and a laboratory component.*

*Modifications had to be made due to the gap of reporting demands of WHO and ECDC.*

*The necessity to include additional indicators.*

ECDC: European Centre for Disease Prevention and Control; GP: general practitioner; WHO: World Health Organization.

<sup>a</sup> Group 1: respondent countries that adapted a pre-existing case register before the influenza pandemic. Group 2: respondent countries that developed a new case register before the pandemic.

used instead included Microsoft Word (n=3), Microsoft SQL (n=1), a paper-based system (n=3), Microsoft Access (n=1) and Voozano [19] (n=1). Respondents' brief descriptions of the systems used are shown in Box 4.

### Suggestions for future pandemic case registers

Respondents were asked what they would change about the way cases were tracked when developing a system for a future pandemic. In countries where an existing national system was adapted (n=6) there were few suggestions for improvement, but one comment was 'Incorporate a contact tracing functionality for early cases in the containment phase'. In countries developed a new system pre-pandemic (n=11), comments predominantly related to simplification of the reporting forms and automatic data collection (Box 5).

### Usefulness of a standardised case register developed at EU level

Finally, respondents were asked if they would find it useful if a standardised case register template was developed at the European level for use in future pandemics. Of the 23 respondents, 17 thought that this could be useful, with one respondent noting that it would allow comparison of information between countries and evaluation at EU level, and another that if such a register was also compliant with WHO requirements, it could avoid double reporting. However, some respondents expressed reservations (Box 6).

### Discussion

In this paper, we describe the case registers developed before and during the influenza pandemic in European countries in order to support planning for case registry systems for future pandemics. Not surprisingly, countries that made use of a pre-existing, standardised national computerised surveillance tool that was pretested, live and ready for use before the pandemic reported relatively few problems and five of six such countries used their system without modification. In countries that started to develop a new system before the pandemic, five were live and ready for use by the time WHO declared a pandemic and a further five were ready by the time the first case was confirmed in their country.

All countries with an operational system in place pre-pandemic reported that the system was designed to meet a variety of control and strategic objectives, with a clear emphasis on national monitoring. Countries that developed a new system were less likely to report prevention or reduction of morbidity and mortality as a strategic objective than countries with a well-established surveillance system, although we were unable to investigate this further.

Even at national level, the process seems to have been complicated, with new systems incorporating data from multiple sources in multiple formats. Seven countries had to modify their system, mainly because it was

#### Box 4

Brief description of case registration system provided by four respondents in Group 3<sup>a</sup>, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

*We had no system - we could not succeed in developing a common tool ... The questionnaire was based on [that provided by] WHO (not adapted to the situation) and was too long. When it was ready it was no longer useful. Instead we used Excel and then relied on sentinel surveillance.*

*Primary health centres reported to the regional Public Health centres, which further reported to the national level.*

*Before the pandemic, we worked on a tracking system and were waiting for funds to set it up. It helped us to set up a system in few days. The database could then be shared by national and local representatives of the institute and with major partners. Therefore management of cases and analysis in real time could be done with the same tools.*

*We did not have a case tracking system during the pandemic. To register the cases we used the WHO form for case-based data collection. This form was filled in by hand and was sent back by fax from Ministry of Health.*

WHO: World Health Organization.

<sup>a</sup> Respondent countries with no pandemic influenza case register in place pre-pandemic.

too complex, difficult to manage, inflexible or system users were not familiar with it. In one country, the new system was abandoned due to its incapacity to handle large amounts of case data. In some countries where the recording systems had not been developed before the pandemic, attempts were made to develop a common tool, but time and financial pressures seem to have been a limiting factor.

Clear themes emerged as to how international monitoring and communication could be improved and 17 respondents agreed that a standardised case register template developed at European level would be useful. The respondents suggested firstly, use of a limited number of simple standard variables, specified in advance and agreed between WHO and ECDC (to ease data collection requirements) and secondly, a distributed or web-based data collection tool (to facilitate data transfer to WHO and ECDC and inter-country comparison).

The efficiency of electronic data transmission during the international severe acute respiratory syndrome (SARS) outbreak in 2003 has previously been described [20]. Krause et al. also advocate (and respondents in our survey largely agreed) that flexible, scalable systems, capable of coping with large quantities of data must be available to deal with new global epidemics as the characteristics of the disease, the organism and

#### Box 5

Suggestions for improving case registration systems in countries that experienced difficulty with their system during the influenza pandemic, provided by 15 respondents in Groups 2 and 3<sup>a</sup>, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

*Simplify the form at the beginning.*

*Develop a separate simpler system (fewer variables), different from the one we used.*

*Develop a much simpler system, because it's very likely that you have to adapt your system anyway. MS Access will probably be enough. Merging of datasets can be done as you go along, you don't have to prepare all this automatically in advance.*

*It will be useful to use [a] standardised case register template.*

*Standard variables with in-built validation rules, easier linkage between systems.*

*It would be better to have had a dedicated outbreak database already in existence. Setting up a database for use at such short notice was not ideal.*

*Making it automatically fed, not manually.*

*What would have helped if the information could have just been transported to WHO/ECDC data bases with just a click of a button.*

*We would use web based system only (not paper based).*

*We need to have the national legal basis in place beforehand. We would want to integrate a system for surveillance of serious cases, including hospital admissions and deaths.*

*I would design a standard tool for the whole country – I would not record cases in Excel again.*

*Reporting forms should be ready beforehand. Population based surveillance to get data must be more firmly established beforehand. A vaccination register for continuous follow up of efficacy and side-effects is a must.*

*In our small country our system worked efficiently enough for tracking the cases, just the computer-based data transfer would be simpler. There are plans to include the creation and introduction of computerised data flow system for influenza to the national influenza plan.*

*It would be better to have had a dedicated outbreak database already in existence. Setting up a database for use at such short notice was not ideal.*

*I would like to use a web based information system for tracking the cases.*

ECDC: European Centre for Disease Prevention and Control; MS: Microsoft; WHO: World Health Organization.

<sup>a</sup> Group 2: Countries that developed a new case register pre-pandemic. Group 3: countries with no pandemic influenza case register in place pre-pandemic.

the outbreak emerge. Not all respondents in our survey, however, were convinced that a common register would be easily implementable, pointing to the different requirements and capacities of countries' health-care systems locally and nationally, and at EU level, and the lack of data comparability between countries within existing systems.

There were a number of limitations in this study: firstly, the questionnaire was distributed in English, and there may have been issues with interpretation and response (although the questionnaire was pretested with a number of colleagues across Europe for whom English is not their first language). Secondly, it would have been useful to define direct and indirect costs related to staffing and resources required to operate and maintain different systems, but given the lack of any standard measure, we were unable to obtain this information. Finally, it remains unclear why countries internally experienced such surveillance difficulties. These could have been due to pressure on staff, as other essential services had to be maintained. Or there may have been excessive or unclear expectations by local or national managers and decision-makers, or it may reflect inherent deficiencies within the case-register system. Also, in relation to international monitoring and communication, although respondents clearly felt the process needed to be simplified, we did not ascertain what their expectations at the European level would be and why. These are clearly issues that warrant further investigation.

Overall, respondents saw the value of pre-pandemic planning and standardisation of data collection and data linkage at the national level at the very least. Given the wealth of experience gained in this pandemic, intra- as well as inter-country working groups could facilitate information exchange and improved interoperability between systems in the future. Also, given the requirement under the International Health Regulations (2005) [21] that countries report certain disease outbreaks and public health events to WHO, and given the partnership between EU Member States, European Economic Area (EEA)/European Free Trade Association (EFTA) countries and ECDC [22], clear objectives for monitoring of influenza at EU level with a minimum set of indicators should be agreed.

## Acknowledgements

We would like to thank the following: EPIET fellows from cohort 15 and 16 who facilitated this survey and the respondents who gave freely of their time; Nilva E. Egana and Sridhar R. Papagari Sangareddy (Public Health Informatics fellows at the United States Centers for Disease Control and Prevention) for their advice on questionnaire design and content; Biagio Pedalino and Ioannis Karagiannis for their critical appraisal of the survey; Marlies Mak who worked extensively on Pandora in RIVM.

## Box 6

Concerns expressed by eight respondents regarding development of a standardised case register at European Union level, survey on case registry systems for pandemic influenza A(H1N1)pdm09 in Europe, June–July 2010

### Four respondents thought it could be useful

*[It] depends on what it will contain. We don't need it but for EU standardisation we need case definitions and guidance as to data validation, to get comparable data.*

*Yes, potentially useful. However, it will need to be flexible to adapt rapidly and in a short space of time to the characteristics of the new emergent flu organism identified.*

*Yes but unfortunately, different administrative level authorities often demand more specific tools.*

*Yes, providing that it would be possible for us to adapt it.*

### Four respondents did not think it would be useful

*Probably not. We want the system to be integrated with our already existing systems.*

*Personal opinion: generally preferred, but in reality not feasible, and at the end: you would not gain comparable data because of the different health systems.*

*Not totally convinced.*

*Not necessary, each country should develop its own depending on its capacity and local conditions.*

EU: European Union.



## References

1. van Casteren V, Leurquin P. Eurosentinel: development of an international sentinel network of general practitioners. *Methods Inf Med.* 1992;31(2):147-52.
2. Rolfhamre P, Jansson A, Arneborn M, Ekdahl K. SmiNet-2: description of an internet-based surveillance system for communicable diseases in Sweden. *Euro Surveill.* 2006;11(5) *Euro Surveill.* 2006;11(5):pii=626. Available from: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=626>
3. Bexelius C, Merk H, Sandin S, Nyrén O, Kühlmann-Berenzon S, Linde A, et al. Interactive voice response and web-based questionnaires for population-based infectious disease reporting. *Eur J Epidemiol.* 2010;25(10):693-702.
4. Health Protection Surveillance Centre (HSPC). Computerised infectious disease reporting (CIDR). Dublin: HSPC. [Accessed 2 May 2012]. Available from: <http://www.hpsc.ie/hpsc/CIDR/>
5. Nicoll A, Ammon A, Amato Gauci A, Ciancio B, Zucs P, Devaux I, et al. Experience and lessons from surveillance and studies of the 2009 pandemic in Europe. *Public Health.* 2010;124(1):14-23.
6. European Centre for Disease Prevention and Control (ECDC). Pandemic 2009 evaluations. Stockholm: ECDC. [Accessed 2 May 2012]. Available from: [http://ecdc.europa.eu/en/healthtopics/pandemic\\_preparedness/pandemic\\_2009\\_evaluations/Pages/pandemic\\_2009\\_evaluations.aspx](http://ecdc.europa.eu/en/healthtopics/pandemic_preparedness/pandemic_2009_evaluations/Pages/pandemic_2009_evaluations.aspx)
7. World Health Organization. Pandemic (H1N1) 2009 - update 58. 6 July 2009. Available from: [http://www.who.int/csr/don/2009\\_07\\_06/en/index.html](http://www.who.int/csr/don/2009_07_06/en/index.html)
8. Koopmans M, Wilbrink B, Conyn M, Natrop G, van der Nat H, Vennema H, et al. Transmission of H7N7 avian influenza A virus to human beings during a large outbreak in commercial poultry farms in the Netherlands. *Lancet.* 2004;363(9409):587-93.
9. QuestBack. Oslo: QuestBack. [Accessed 2 May 2012]. Available from: <http://www1.questback.com/>
10. Baker MG, Easther S, Wilson N. A surveillance sector review applied to infectious diseases at a country level. *BMC Public Health.* 2010;10:332.
11. Oracle Corporation. MySQL 5.1 reference manual. Redwood City, CA: Oracle Corporation; 2010. [Accessed 7 May 2012]. Available from: <http://dev.mysql.com/doc/refman/5.1/en/>
12. Faensen D, Claus H, Benzler J, Ammon A, Pfoch T, Breuer T, et al. SurvNet@RKI--a multistate electronic reporting system for communicable diseases. *Euro Surveill.* 2006;11(4):pii=614. Available from: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=614>
13. The Swedish Institute for Communicable Disease Control (Smittskyddsinstitutet, SMI). 2011. The influenza A(H1N1)2009 pandemic in Sweden, 2009-2010. A report from the Swedish WHO National Influenza Centre. Solna: SMI; 2011. Article number: 2011-15-1 Available from: [http://www.smittskyddsinstitutet.se/upload/Publikationer/The-Influenza-A-H1N1-2009-Pandemic-in-Sweden-2009-2010\\_2011-15-1.pdf](http://www.smittskyddsinstitutet.se/upload/Publikationer/The-Influenza-A-H1N1-2009-Pandemic-in-Sweden-2009-2010_2011-15-1.pdf)
14. Stockholm County Council. Vårdguiden. Stockholm: Stockholm County Council. [Accessed 2 May 2012]. Available from: <http://www.vardguiden.se>
15. Hulth A, Rydevik G, Linde A. Web queries as a source for syndromic surveillance. *PLoS One.* 2009;4(2):e4378.
16. Hulth A, Rydevik G. Web query-based surveillance in Sweden during the influenza A(H1N1)2009 pandemic, April 2009 to February 2010. *Euro Surveill.* 2011;16(18):pii=19856. Available from: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19856>
17. Lyytikäinen O, Kuusi M, Snellman M, Virtanen MJ, Eskola J, Rönkkö E, et al. Surveillance of influenza in Finland during the 2009 pandemic, 10 May 2009 to 8 March 2010. *Euro Surveill.* 2011;16(27):pii=19908. Available from: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19908>
18. PostgreSQL Global Development Group. PostgreSQL 9.1.3 documentation. PostgreSQL Global Development Group; 2011. [Accessed 2 May 2012]. Available from: <http://www.postgresql.org/files/documentation/pdf/9.1/postgresql-9.1-US.pdf>
19. Epiconcept. Voozano. Paris: Epiconcept. [Accessed 4 May 2012]. Available from: <http://www2.voozano.net/>
20. Krause G, Benzler J, Porten K, Buchholz U, Claus H, Ammon A. [SARS surveillance--did it meet the demands made on the surveillance of new infectious diseases?]. *Gesundheitswesen.* 2003;65(12):715-8. German.
21. World Health Organization (WHO). International health regulations (2005). 2nd ed. Geneva: WHO; 2008. Available from: [http://whqlibdoc.who.int/publications/2008/9789241580410\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241580410_eng.pdf)
22. European Centre for Disease Prevention and Control. Partnerships. Stockholm: ECDC. [Accessed 2 May 2012]. Available from: <http://ecdc.europa.eu/en/aboutus/partnerships/pages/partnerships.aspx>