PANDEMIC INFLUENZA PREPAREDNESS PROGRAMME

Statistical Legacy Group

A report for the Chief Medical Officer

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List of Abbreviations

BBC	British Broadcasting Corporation
CCC	Civil Contingencies Committee
CMO	Chief Medical Officer
CMO-SLG	Chief Medical Officer's Statistical Legacy Group
DH	Department of Health
ECDC	European Centre for Disease Prevention and Control
FF100	First Few 100
FLU-CIN	Flu-Clinical Information Network
GP	General Practitioner
HPA	Health Protection Agency
HPS	Health Protection Scotland
ICNARC	Intensive Care National Audit and Research Centre
ILI	Influenza-like-illness
LSHTM	London School of Hygiene & Tropical Medicine
MHRA	Medicines and Healthcare products Regulatory Agency
NHS	National Health Service
NPFS	National Pandemic Flu Service
ONS	Office for National Statistics
PIPP	Pandemic Influenza Preparedness Programme
RCGP	Royal College of General Practitioners
RDPH	Regional Director of Public Health
RSS	Royal Statistical Society
SAGE	Scientific Advisory Group for Emergencies

SPI	Scientific Pandemic Influenza Advisory Committee
SPI-M	Scientific Pandemic Influenza Advisory Committee subgroup on Modelling
UCL	University College London
UK	United Kingdom
WHO	World Health Organization

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1. Purpose

The CMO's Statistical Legacy Group, whose terms of reference can be found in Annex one, was set up to produce a report for the Chief Medical Officer with recommendations for any improvements to the system for collection, analysis and presentation to the public of data in a future influenza pandemic. This report will be used to support the review of the *National Framework for responding to an influenza pandemic*.

2. Executive summary

In planning and preparing for an influenza pandemic, the Government's strategic objectives were, and remain, to support NHS preparedness and to reduce the impact of pandemic flu on the UK population.

The "***National Framework for responding to an influenza pandemic***" set out a 'defence in depth' approach to preparing for and responding to a pandemic. This is a strategy to protect the public by:

i. reducing the spread of the virus, supported by good hygiene advice, provision of face masks for health care and social workers and appropriate social distancing measures;

ii. minimising serious illness, supported by rapid access to antiviral and antibiotics medicines and healthcare; and

iii. avoiding deaths, supported by access to vaccines.

The aim of surveillance is to ensure that accurate, timely, and reliable information is provided to all partners involved in a response to a pandemic. It is also of significant benefit in informing the press and public during a pandemic.

Prior to the 2009 pandemic, a set of information requirements had been identified for pandemic surveillance. These were considered at the time to be the minimum data that would need to be collected and reported to those involved in managing the response. Steps had been taken by the Department of Health and its partners to ensure an adequate surveillance system would be in place to collect these data, bearing in mind the uncertainty surrounding the nature of any pandemic, its timing and the form of response required.

In the event, during the 2009 pandemic, data about the activity and impact of the H1N1 virus and the NHS and operational response were available from a wide range of systems. These included GP sentinel schemes, virological surveillance, NHS Direct, the National Pandemic Flu Service, the Flu-Clinical Information Network, the CMO's confidential investigation of swine flu deaths in England, and vaccination uptake data. In addition, the Department of Health received regular reports on NHS pressures including daily data on numbers of suspect H1N1 in-patients as well as pressures on bed capacity, critical care, ambulance services and others.

The principal source of up to date knowledge on the characteristics and progress of the pandemic came therefore from the surveillance systems listed above. However, the response was also informed by further analyses and modelling based on these surveillance data, which was intended to describe in more depth the impact and likely course of the pandemic.

Early on, analysis of spread in the population was challenging because the nature of disease caused by the H1N1 virus meant that only a small (but unknown) proportion of those people becoming infected contacted healthcare services. Since most surveillance (apart from the FF100 cases and their contacts, see annex two) was based on numbers of patients seeking healthcare, it was impossible to estimate with any accuracy numbers of people infected at any time. This was despite having estimates of how quickly the epidemic was evolving.

As well as making prediction of the trajectory and peak of the epidemic difficult, the lack of data on cases that were not apparent to health services (whether symptomatic or not) also complicated early assessment of disease severity. This in turn led to great uncertainty in projections of the likely eventual numbers of deaths and hospitalisations the pandemic would cause. It was only in early September 2009 that data from Southern hemisphere countries on the later phases of the pandemic allowed more reliable severity estimates to be made. At around the same time, preliminary serological data became available in the UK on the levels of background immunity in certain age groups and on the total infection attack rate (symptomatic and non-symptomatic) during the spring/summer wave of the pandemic.

Surveillance information therefore played an important role in supporting the response but also provided the basis for regular detailed briefings on the pandemic to the media and to the public. Throughout all stages of the pandemic, effective and regular communications with the media and public was critical. Important communication mechanisms included the Department of Health's public media campaigns, weekly Chief Medical Officer (CMO) briefings and HPA weekly reports.

The H1N1 pandemic of 2009 provided rare experience of collecting, interpreting, and presenting data during a time of widespread public health emergency. This has enabled the responsible organisations and external interested parties to consider the challenges involved in doing so and put forward recommendations for improvements. For example, the President of the Royal Statistical Society (RSS) wrote to CMO in July 2009 on the subject of pandemic reporting.

The Chief Medical Officer's Statistical Legacy Group was set up to document in a systematic way lessons from that experience, in particular to evaluate the strengths and weaknesses of the data collected, identify best practices in the use of those data to inform the response and in the communication of surveillance information to the public and external interested parties.

The CMO-SLG reviewed the data collection processes used during the H1N1 (2009) pandemic, specifically looking at the intended use of this information in terms of robustness (e.g. freedom from bias and precision). The group also reviewed how statistical information was communicated to the public during the pandemic, and to fellow professionals, and obtained additional expert views on this from science media representatives.

Overall, the group agreed that surveillance of the pandemic in the UK had been among the most comprehensive in the world. For example, the UK appears to be the only country that implemented WHO's recommendation to include the first few hundred cases in a formal epidemiological study. The group also concluded that all data streams actually collected during the H1N1 (2009) pandemic were useful to the response. However, their relative value varied at different periods of the pandemic.

The group considered that media coverage of the H1N1 (2009) pandemic had to a large degree been reasonable and balanced and that this was a sign that the overall approach to communicating surveillance data had been broadly effective. The communication of statistical data during a pandemic is always likely to be challenging but the regular and open briefings provided by the CMO had been especially welcomed by the media. The HPA technical briefings were also helpful and authoritative. The publication of planning assumptions was problematic because they were frequently misconstrued as predictions, despite repeated warnings. This illustrates how difficult it can be to be open and transparent without causing undue alarm.

Despite the overall success of the surveillance and communication programme, the group did identify specific areas for improving the collection and communication of statistical data during a future pandemic. Considering these, the **CMO-SLG recommends the following high-level enhancements:**

- **Preparedness plans should include the actual mechanisms/processes for data collection, harmonisation of data streams and definitions, and how surveillance responses will be calibrated to the apparent severity of a future pandemic;**

- **Community-based surveillance systems are needed to quantify time-specific (weekly or fortnightly) infection and/or illness rates in the community and to track changes in healthcare-seeking behaviour;**

- **The primary purpose of surveillance data is to assist with managing the response However, planning for future pandemics should include, as part of its communications planning, a strategy for ensuring that throughout any pandemic the collection of surveillance and other data is accompanied by transparent, orderly and proportionate release of those data on an equal footing to all. The principles and protocols of the Code of Practice for Official Statistics should be followed with any necessary exceptions to the detailed practices explained.**

- **Whilst the group recognised that the response itself should always take precedence and that there are inherent differences between health systems in the different UK nations, where possible, a UK approach to surveillance and communicating data to the public should be adopted.**

3. Surveillance background

The aim of the Pandemic Influenza Preparedness Programme (PIPP) is to ensure that the UK is well prepared to respond effectively to a pandemic, by employing a range of measures in advance of and during a pandemic to mitigate its impact on health and care services.

3.1 Strategy

The objective of surveillance is to ensure that during a pandemic, the necessary information will be available in a timely manner to:

i. allow early detection of pandemic influenza in the UK;

ii. determine the characteristics of the pandemic strain so as to inform national and local level decisions about the management of clinical and public health measures necessary to mitigate and manage the effects of the pandemic;

iii. provide accurate and timely assessment of the spread and clinical impact of the virus to inform the national co-ordination of the overall UK response to the pandemic;

iv. identify service pressures within the NHS and social care arising from the pandemic;

v. provide accurate and timely information to the public, interested professionals, and the media about the progress and health impact of the pandemic;

vi. enable clinical audit and research programmes to be undertaken to increase understanding of the nature of the pandemic and to inform plans for future ones;

vii. communicate relevant information needed in other countries and at a European and global level (ECDC and WHO).

Previous influenza pandemics, including H1N1 (2009), have varied widely in their characteristics and impact. They have also shown variation in their local timing and impact. Until a new pandemic virus emerges, pandemic planning necessarily uses data from past pandemics to anticipate the likely progression and impact of future pandemics, and to evaluate the potential effectiveness and utility of intervention options. It is therefore inevitable that generic plans for surveillance and response drawn up in the inter-pandemic period need refinement in real-time to account for the specific characteristics (such as severity, age and risk groups affected) of a new pandemic virus.

3.2 Coverage

The national surveillance arrangements are broadly aligned with reporting three different types of data that will address the key policy and public health questions needed to respond to a pandemic in the UK. These are:

3.2.1 Epidemiology (Activity, spread and clinical impact of the virus)

- What is the type and strain of the virus in the UK? How does it compare with other countries; has it changed in the UK; and is it susceptible to treatment?

- What impact is the pandemic having on the population - how fast is it spreading; how severe is it in terms of GP consultations, hospitalisations and fatalities; and what groups are most affected? Can we predict the trajectory of the pandemic, the extent and timing of peak healthcare demand and when the pandemic will end?

3.2.2 Clinical response measures (Distribution, safety and effectiveness)

- What are the clinical features and outcomes of the pandemic strain? Do we need to revise advice to clinicians on clinical management of patients with pandemic flu and its associated complications?

- How many antivirals and vaccines from our stockpile have been used and how many remain? Do we need to change our policy on distribution (antivirals and vaccines)?

- Are the antivirals, antibiotics and vaccines proving to be safe and effective?

3.2.3 Service capacity (Pressures on the health and social care services)

- Are our distribution arrangements for antivirals and vaccines working? Is there sufficient logistical capacity for effective and timely distribution to the public?

- How are the primary, secondary and social care services coping across the UK? Where and to what level are pressures developing?

Where possible pandemic influenza surveillance should be built on existing data collection mechanisms that are already in place to monitor the onset, magnitude and duration of seasonal influenza activity. Routine virological, clinical and epidemiological data on seasonal influenza are currently collated by the HPA, on a UK basis, and published weekly during the normal influenza season. In addition, the NHS has a well-established system in place for monitoring pressures on the health service, particularly in winter and when influenza is circulating. These web based data are collated by the Department of Health.

Some of this information will be needed for exchange with international bodies and neighbouring countries both in order to conform to international obligations and to aid in collective decision-making and coordination of measures.

3.3 H1N1 (2009) pandemic response

With the emergence of the novel H1N1 virus in April 2009, it became apparent that the world was on the verge of a pandemic. Over the next weeks and months, the UK's surveillance preparedness plans were put into action and work started on addressing gaps in the arrangements. The plans fell into two phases:

3.3.1 Assessment surveillance phase

At the onset of the H1N1 pandemic in the UK, there was little evidence about the severity and impact of the virus. The focus during the initial phase was therefore on treating affected individuals and on reducing the spread of the disease (to the extent that it could be achieved). In addition, a second priority was the collection of critical data to allow the epidemiological and clinical characteristics of the new pandemic virus to be assessed. Third, this phase saw the NHS prepare intensively for handling potential surges in primary care and hospital demand later in the year.

By late June 2009, sustained community transmission of pandemic H1N1 (2009) influenza virus was clearly underway. This initial epidemic peaked in late July, going into decline once school holidays started in England and Wales. Clinically, the infection appeared up to that time to cause a mild illness in most cases. Throughout the pandemic, infection rates were highest in children and young adults. A small subset of cases experienced more severe disease, especially in those with underlying risk factors.

There were similarities between the H1N1 (2009) pandemic and the "Asian" influenza pandemic of 1957. In the UK, the virus emerged in early summer; transmission was concentrated in children and young people; and illness caused by the virus generally was mild. Evidence from both 1957 and 2009 pandemics indicates that there may have been some protective immunity amongst older age groups.

The HPA led the "containment" phase response, supported by the NHS in running the Flu Response Centres. This response comprised:

- identifying and tracing close contacts of probable and confirmed cases, including those arriving from Mexico, and gathering and recording epidemiological data;
- giving post exposure prophylaxis to close contacts of probable and confirmed cases of H1N1 (2009) pandemic influenza. In primary schools, this was generally those children in the same class as the case and those in other classes who had spent an hour or more in the same room as the case when the individual was symptomatic. In practice, this may have meant all the classes in the same school year;
- advising on the closure of schools in the event of a probable or confirmed case in a school setting;
- making information available (e.g. on hand hygiene) at all ports of entry;
- putting in place enhanced surveillance arrangements.

Despite the use of the term 'containment', it was recognised from the outset that it would not be possible to "contain" the virus in the UK. Ministers decided that the containment phase, including prophylaxis of close contacts, should be continued by the HPA until one of three triggers (below) was reached:

- clear evidence of sustained community transmission;

- robust evidence that the disease was no worse than seasonal influenza infection;
- the number of cases was such that HPA operational resources, augmented by NHS support, were unable to meet the demand for confirmatory testing (estimated to be 3,000 cases, but later 10,000 cases).

The situation was reviewed on a daily basis, drawing on epidemiological and scientific advice from the HPA and the Scientific Advisory Group for Emergencies (SAGE), which superseded the Scientific Pandemic Influenza Advisory Committee (SPI) on 5 May 2010.

It became clear as the pandemic evolved that the extent of early spread in different areas of the UK was variable, with pressures on the health service (monitored using FluCon reporting and GP ILI consultation rates) showing substantial geographic heterogeneity, with notable early high-demand 'hotspots' in London and the West Midlands.

In the initial stages, this may have reflected different rates of "seeding" from imported cases of infection. Therefore, as the virus became more widespread there was an increased need for flexibility in the local and regional response. Pandemic monitoring of the spread, and therefore impact, of the virus helped in the decision making process to implement national policy (in particular the decision to switch on the National Pandemic Flu Service in England on 23rd July 2009).

3.3.2 Monitoring surveillance phase

In July 2009, in the light of the advice from SAGE and HPA, Ministers concluded that the UK had reached the point where:

- the virus was spreading in communities and would continue to spread, with the emergence of a number of clusters;
- much more was known about the nature and threat of the virus; and
- sufficient time had passed for the NHS to adapt its preparations (e.g. increasing hospital bed capacity if required).

On 2nd July, a national decision was made to move to a "treatment phase" in which the policy and public health strategy was to offer antivirals to all groups in the population for the treatment of suspected H1N1 (2009) if they met the clinical criteria. The UK had moved past the stage where swabbing patients to confirm diagnosis and tracing contacts was practical or effective.

The National Pandemic Flu Service (NPFS), which went live in England on 23rd July, provided an online and telephone self-assessment service. This enabled large numbers of people to be assessed for H1N1 (2009) symptomology and if appropriate authorised antiviral medicines, enabling GP time to be freed up to focus on those with more serious disease.

The H1N1 (2009) pandemic presented itself in the UK in two 'waves' one closely following the other. It is believed that the closure of schools for the summer holidays in late July led to a reduction in contact rates in children and thus an interruption of the first 'wave' at the beginning of the school holidays. Once schools returned in September, the rate of infections grew again until

the latter half of October when a decline in pandemic influenza activity occurred, possibly due to the start of half-term school holidays.

Since the end of the second wave in early January 2010, pandemic HIN1 (2009) has continued to circulate at low levels. This is as expected; following the pattern of previous pandemics there is likely to be a resurgence of the virus during the next seasonal flu period in the UK.

In light of the response to the H1N1 (2009) pandemic, the Chief Medical Officer established a Statistical Legacy Group to produce a report with recommendations for improvements to the system for collection, analysis and public presentation of data in a future influenza pandemic.

3.4 Chief Medical Officer's Statistical Legacy Group (CMO-SLG)

The pandemic has highlighted the challenges involved in collecting, interpreting and presenting data during a time of public health emergency when both the burden placed on the health system and the public appetite for information are great.

Therefore, CMO-SLG has:

- reviewed the data collection procedures instigated during the H1N1 (2009) influenza pandemic to consider what amendments may be required in a future influenza pandemic.
- reviewed best practice and identified lessons learned, considering the balance between data gathering and NHS reporting burdens.
- considered in what circumstances complex statistical data need to be communicated to the general public and media and how, where necessary, this is best done.

The group's conclusions are reflected in this report, which will be used to support the review of the *National Framework for responding to an influenza pandemic.*

4. Data collected during the H1N1 (2009) pandemic

This section reviews the surveillance data collected over the two phases/stages of the H1N1 (2009) pandemic in England and discusses their usefulness as well as any improvements that could be made for a future pandemic.

4.1 Data collected during the assessment surveillance phase

From 27th April 2009, when the first cases of H1N1 (2009) were detected in the UK, until 2nd July 2009, the HPA and DH implemented a series of pandemic specific surveillance systems with the objective of gathering information to build a clear understanding of the virus. The focus in this phase was on characterising the clinical, epidemiological, and virological features of the new disease.

This included the rapid implementation of the First Few 100 (FF100) system (explanations of the surveillance systems are given in annex two and three). Data collection for the FF100 system began in early May and included detailed demographic, exposure, clinical, treatment and outcome data for more than 300 cases of laboratory confirmed pandemic influenza and their close contacts. Information was obtained through interviews and medical record reviews. Virological swabbing was undertaken, when possible, for people with an influenza-like illness and blood samples for serological testing were sought from cases and their close contacts. More limited demographic and epidemiological information was gathered from confirmed cases in the HPA Fluzone system (a streamlined version of FF100) during the remainder of this phase. This included information on patients hospitalised with H1N1 (2009) and on the small number of people who died as a result of swine flu. This allowed preliminary case-severity estimates but uncertainty as to the proportion of cases being detected during this response phase plus the relatively low numbers of severe cases limited the conclusions that could be drawn The FF100 study was a demanding design to implement in practice and did not in the event provide the definitive information that had been hoped for on the epidemiology of the pandemic.

4.2 Data collected during the monitoring surveillance phase

The objective in this phase was to monitor the spread, activity, and impact of the virus across the UK. The HPA and the Department of Health already had established seasonal influenza surveillance systems. However, additional pandemic systems were required to monitor the spread e.g. with the introduction of NPFS and to monitor the impact of the pandemic, in particular, in terms of hospitalisation and death.

Monitoring of the clinical severity and impact of the pandemic virus during the treatment phase was undertaken through data on laboratory confirmed hospital admissions collected by the HPA/CMO through a web-based data collection tool and the CMO's Confidential Investigation of swine flu deaths in England. Additional detailed clinical information on hospitalised patients was available later from the Flu-Clinical Information Network (FLU-CIN) situation report.

Data on suspected swine flu deaths in hospitals were collected as part of the daily SitRep to feed into CMO's Confidential Investigation into swine flu mortality. In addition, excess all-cause mortality was monitored through daily deaths data from the General Register Office (GRO) and weekly death registrations from the Office for National Statistics (ONS). The ONS decided not to

publish (in the weekly deaths publication, which conforms already to National Statistics standards), information on number of deaths where H1N1 was mentioned on the death certificate because the figures would have been different from those provided by the CMO. In addition, numbers where H1N1 was mentioned might not have provided a comprehensive count, depending on recording practices.

The GRO data stream was specific for the pandemic and enabled age-specific estimates of excess mortality to be made. However, cases referred to the coroner, included as a part of the registration data, could be subjected to delays until the coroner has reached a verdict.

Virological surveillance of a subset of cases from which samples were acquired was essential for monitoring of circulating virus subtypes and to detect changes within a virus subtype that may have affected vaccine or antiviral efficacy. Antiviral resistance testing was carried out on samples of isolates of influenza sent to the HPA from primary and secondary care and from certain sub-groups such as immunosuppressed patients, and therefore they were able to detect any emergence of antiviral resistance.

In addition, monitoring the circulating influenza subtypes and their relative proportions was also important in determining the relative contribution of the pandemic virus to overall illness and mortality.

The RCGP/RMN virological primary care surveillance systems were able to provide both qualitative and quantitative information on the viral activity within the community. This also included monitoring the different subtypes of influenza, other viral respiratory pathogens, and any drift in the pandemic virus. A new virological surveillance system was initiated with self-swabbing of a sample of persons who had been issued antivirals through the NPFS system.

Using an established laboratory surveillance system, the antibiotic sensitivity of key bacterial pathogens (e.g. Streptococcus pneumoniae) which are responsible for possible secondary bacterial infections was monitored. This was used to advise clinicians on the most appropriate treatment regimes and enabled antibiotic resistance of likely secondary bacterial infections to be identified early.

Antiviral and vaccine safety surveillance was very important. The MHRA has the established passive yellow card reporting system, which provided an alerting mechanism for possible antiviral and vaccine associated adverse events. In addition, HPA established enhanced surveillance of Guillain-Barré syndrome with the Association of British Neurologists and the British Paediatric Surveillance Unit. This aimed to provide an estimate of increased risk of Guillain-Barré syndrome post-influenza infection.

With support from the HPA, vaccine uptake for both pandemic and seasonal influenza vaccine was monitored through the DH run Imm-Form website for those groups targeted for influenza vaccination. Specific collections of data concerning vaccine uptake were also undertaken in primary care and amongst health care workers in the secondary care sector. In-season estimates of pandemic influenza vaccine effectiveness were undertaken through follow-up in primary care of individuals with acute respiratory illness who were swabbed.

Monitoring of the operational pressures on the NHS was also an important element of the surveillance strategy. Several information systems were used to monitor operational pressure and

response in the NHS in England during the pandemic, both routine and those, such as FLU-CON and SOC-CON, which were developed for the pandemic.

During the monitoring phase, information from the various surveillance systems were fed into a mathematical model (developed by HPA Centre for Infections) to estimate the number of symptomatic H1N1 (2009) cases that occurred in the previous week. There was considerable uncertainty around these estimates, not least because it was difficult to determine the proportion of patients with symptomatic infection that were consulting either their GP or NPFS, though a limited amount of health-seeking behaviour data was collected from a web-based cohort study ('Flu-survey') run by the London School of Hygiene and Tropical Medicine. It should be noted that the UK was unique in placing such public emphasis on estimates of case numbers (though CDC also produced case number estimates using a Monte Carlo approach); following declaration of Phase 6 and the recommendation of WHO to move away from confirmatory testing, all other nations moved to reporting surveillance data streams directly (GP ILI rates, hospitalisations, deaths) rather than modelled estimates of symptomatic cases.

Information from H1N1 (2009) serological testing was helpful in allowing the total number of pandemic influenza infections in the population to be estimated, though such preliminary data (on the infection rates in the spring/summer wave) were only available in October 2009 and testing results on serological samples taken in the autumn only became available in late spring 2010. Serological testing for pandemic H1N1 antibodies made use of convenience samples of residual sera collected in hospitals throughout the pandemic

Annex two summarises the surveillance systems coordinated by the HPA and external partners during the H1N1 (2009) pandemic, and Annex three describes the surveillance systems coordinated by the Department of Health during the H1N1 (2009) pandemic.

4.3 Review of data collected

After reviewing the systems and mechanisms for data collections during the H1N1 (2009) pandemic, CMO-SLG examined three key questions:

4.3.1 What issues were identified concerning the data collected?

Consensus on the data collected for H1N1 (2009) was that they served their main purpose but improvements could be made to some surveillance systems in order to strengthen a future response. Discussion on the data collected during the H1N1 (2009) pandemic led the group to conclude:

Planning phase

The group recommended that the data collection process/mechanism should be included when planning future pandemic information requirements. In addition, it was suggested that mechanisms be available for refining the surveillance response depending on the severity and extent of any future pandemic.

The need for standard definitions was voiced, especially in relation to influenza related hospitalisations and deaths. Early on in the pandemic CMO recommended that the definition of a swine flu related death was one where the deceased had tested positive for H1N1 or "influenza"

was recorded on either part of the death certificate. In the future, the importance of agreeing a definition of 'pandemic-related death' in pandemic planning and obtaining support for this from the relevant parties should be noted.

Containment phase (Assessment surveillance)

The group acknowledged that some surveillance systems were put in place under the pressure of the response to a pandemic and over short timescales to meet the high demand for information. Members concluded that the HPA responded effectively to the high demand for information, but acknowledged that if time had allowed and as SPI had requested prior to April 2009, more detailed consideration of design of the data collections might have been beneficial, especially to obtain detailed information on transmission patterns.

The First Few Hundred (FF100) system was implemented for the first time during the 2009 pandemic. Although detailed assessment of early cases and their close contacts through a FF100 approach had been recommended by WHO, the UK was the only country to report attempting this. Much valuable information was obtained on the clinical and epidemiological features of pandemic influenza from FF100. Establishing such a system for the first time was a challenge and a review of the lessons learnt is being carried out by the HPA. External peer review of proposed study designs for future pandemics should also be considered.

In retrospect it is clear that the criteria (e.g. influenza-like-illness with fever, travel history to affected area or contact with known case) employed by HPA for testing people for H1N1 infection during the containment phase meant that only a small proportion of individuals with H1N1 infection were being detected. As the epidemic spread, a higher proportion of new cases arose from school-based clusters with no epidemiological linkage to prior cases or travel to affected countries, suggesting under-ascertainment of cases may have increased over time. Thus while the data collected on early cases was useful in giving early estimates of incubation periods, serial intervals and household attack rates, in retrospect it is possible that too much emphasis was placed on trying to interpret temporal trends in confirmed case numbers (e.g. in estimating epidemic growth rates) during this phase.

Treatment phase (Monitoring surveillance)

The group emphasised the importance of continuing the routine seasonal flu surveillance data streams, especially, Q-Surveillance data that cover approximately 40% of GP practices, and the Royal College of General Practitioners (RCGP) data stream that has an established baseline starting in the 1960s.

Members of CMO-SLG agreed that the four UK countries should attempt to identify consistent and interoperable mechanisms to report rates of clinical illness amongst GPs to enable UK-wide reporting. Linkage of virological and clinical surveillance in primary care should also be continued and enhanced.

It was acknowledged that there will always be variation in the practical implementation of the case definition of influenza-like-illness (ILI). Over the H1N1 (2009) pandemic, the definition of ILI was affected by the introduction of the National Pandemic Flu Service (NPFS), and the changes made to the READ codes in 2009. The nature of influenza is that its clinical impact varies amongst different population groups, and though the information collected is very useful to monitor

activity levels, the information tends to be less informative on monitoring change over time. Therefore, ideally, methods for assessing the magnitude of these impacts could be considered in advance.

The group concluded that some data collections worked very well during the last pandemic, in particular the solution associated with the NPFS system; the data obtained from the system met user requirements. The linkage of virological results to antiviral issuance was extremely important in better understanding the rate of positivity amongst those issued with antivirals.

However, the group recommended that the processes and mechanisms by which virological samples are collected should be reviewed so to ensure as far as possible that the samples collected each week are both more representative of the general population (unbiased) and sufficient in number to allow analyses to be stratified by age and region. Random or stratified random sampling methods would be preferable in achieving this goal, as quota type sampling can lead to uncontrolled and unquantifiable biases.

In addition to improving virological sampling, better-designed (in terms of sample numbers and sources thereof) and random sampling would also benefit serological surveillance in future pandemics. Serosurveillance provides critical data on background population immunity and community infection rates which is difficult to obtain from any other source and is critical for making real-time model-based projections of epidemic trajectory. Information on background immunity became available in August 2009 during the H1N1 (2009) pandemic, with reliable data on attack rates during the spring/summer wave becoming available in the late autumn. The members recognised that issues related to the development of tests and obtaining samples meant that delay was inevitable and that this work was carried out in England faster than in most other countries and was among the first such data to be reported globally. The group noted that while a large random sample of the population would provide the most statistically robust assessment of the serological status of the population, practical considerations meant that 'residual specimen' sampling had been used (although a second laboratory source had to be added in 2009 in recognition that sample numbers were insufficient to answer questions on immunity by age-group). While such a sampling approach did not provide a fully representative sample of the population, previous experience suggested that it provided a reasonable assessment of population serological status, although this is difficult to test without a comparison random sample.

CMO-SLG felt that uncertainty as to how a symptomatic influenza ‘case’ should be defined, together with the huge uncertainties involved in estimating incidence of symptomatic cases over time meant that the emphasis place on estimates of numbers of cases throughout the 2009 pandemic should be reassessed in planning for future pandemics unless more reliable community based sourced of data become available. The UK was unique in the world in placing such emphasis on reporting symptomatic case numbers after June 2009, and the HPA estimates have in retrospect proved to be underestimates of the true community burden of (albeit mild) respiratory disease caused by the pandemic.

In a milder pandemic, with more activity centred at community level, information from community based surveillance systems would be most beneficial, and might assist in reducing uncertainty on true incidence of infection and illness in the general population. During the 2009 pandemic, a regular telephone survey was undertaken by the Ipsos MORI Social Research Institute on behalf of the Department of Health to track the general public’s responses and attitudes during the

outbreak. In future, such respondents could be asked about their own experience of ILI in the past week; and which, if any, healthcare provider they contacted about it. The internet based 'flu survey' run by the London School of Hygiene & Tropical Medicine (LSHTM), for which participants signed-up to provide future weekly updates, provided valuable information on the proportion of people with ILI who were seeking primary care, and absenteeism levels. CMO-SLG were of the view that these systems should be enhanced to collect more community based surveillance data.

The group recognised that in some cases there may be scientific constraints preventing information being obtained quickly (for example in the time required to develop an assay). Action should be taken to prioritise and minimise such constraints.

Hospital data

Hospital data on cases admitted with influenza or its complications were essential for assessing disease severity and anticipating healthcare demand. Members agreed that more could be done to make the clinical criteria for virological testing consistent across the country in order to make reporting of hospitalisation and mortality as a result of influenza more consistent and complete overall. It was also noted that comprehensive, highly sensitive testing for pandemic flu in hospitals is not achievable, due to the volume of patients being admitted and the fact that many people admitted with flu-induced complications to pre-existing conditions (such as chronic obstructive pulmonary disease) are admitted many days after symptoms started and therefore at a point where virus may no longer be detectable. However, it was recognised that during the H1N1 (2009) pandemic the criteria for virological testing in hospitals were not consistent. This prevented an accurate regional picture of hospitalisation and mortality rates from being developed. Consideration should be given to how all, or a representative sample of patients admitted to hospital with influenza-like-illness might be tested in a future pandemic, particularly if severity (and therefore hospitalisation rates) is greater than seen in 2009. Moreover, use of such a sentinel system in seasonal epidemics would not only provide useful information in epidemic winters but also ensure more robust data are available in the next pandemic.

In terms of response management, the group considered that it was vital to have daily data on hospital activity, especially incident numbers of admissions and numbers in critical care. In addition to the daily situation reports, weekly information from the Intensive Care National Audit and Research Centre was available and very useful.

Mortality data

On mortality reporting, there was strong support from the group for having real-time pandemic related death data. However, in England there can be considerable delays in registration of deaths. Given the speed and short notice at which the CMO's office instigated the CMO's Confidential Death Investigation process, the group recognised that it provided valuable data for informing the public health response and in maintaining public confidence that DH/HPA had a good factual understanding of the emerging situation. The benefits were most obviously seen in the case of excess death reporting. However, CMO-SLG noted that the variation in criteria used for virological testing between hospitals (commented on in relation to hospitalisation data) mean that the number of deaths reported via the CMO's investigation is almost certainly an underestimate of true mortality in England and Wales; this made comparison of mortality rates between England and Scotland (which reported a substantially higher per-capita mortality) problematic.

The group noted that the low number of deaths during this pandemic meant that it was feasible for the CMO to investigate each reported death. However, in a more severe pandemic, a different approach to real-time monitoring of suspect and confirmed deaths occurring in NHS hospitals would be needed. The public health service, working with the NHS, would be the natural body to deliver such a system. However, as in the H1N1 (2009) pandemic, CMO-SLG felt that the leadership and support of the CMO would be essential to obtaining timely and comprehensive data on deaths during the next pandemic.

In a more severe pandemic, it would be even more important than in 2009 that factors that increase risk of death are rapidly identified, together with more general clinical investigations into severe disease and deaths. This work would need to be adequately resourced and have the appropriate authority. If numbers of deaths are large, consideration should be given to only undertaking detailed investigation of a representative sample of deaths, with a sampling scheme that controls for both laboratory and reporting biases. Various epidemiological approaches might also be adopted e.g. a case control study. Consideration should be given to record-linkage to enhance such data by identifying deaths occurring in a given period after a confirmed hospital admission with flu.

The group is aware that proposals are being considered for improving the process of death certification including the creation of a new role of medical examiner. There is also likely to be some national oversight of this process with the possibility of enhanced surveillance as result. These changes would seem likely to make the identification of pandemic-related deaths easier once implemented and the introduction of medical examiners would allow for the more reliable use of standard definitions.

In addition, CMO-SLG emphasised the additional value of the timely monitoring of population-wide excess age-specific mortality, using the systems developed in 2009 and previously. However, in 2009 the relatively small number of deaths caused by H1N1 was spread over the pandemic and thus these deaths were not detectable by excess mortality monitoring systems, given the intrinsic normal level of fluctuations in daily and weekly mortality. However, the group felt that excess mortality data would be invaluable in giving perhaps the most accurate picture of the mortality burden of a more severe future pandemic.

It was acknowledged that cases referred to the coroner may not be included in the registration data as these could be subjected to delays until the coroner has reached a verdict. In England, informants are required to register a death within five days. However, these provisions cease to have effect if the Coroner decides to hold an inquest. The relevant legislation[1] does allow for 'interim' registration while awaiting an inquest, but only in a situation where an inquest has been adjourned pending resolution of criminal charges or criminal proceedings. Therefore, the registrar would be unable to act on 'interim' instructions from a coroner in any other situation. An unpredictable number of deaths in a pandemic may be the subject of inquests and it would be useful for statistical purposes to register the fact of an individual's death while awaiting the result of any inquest. Resolving this limitation to the registration process would however require an amendment to the primary legislation but would have the added advantage of making the process in England more similar to that which currently exists in Scotland.

[1] *Births and Deaths Registration Act 1953 & Coroners Act 1988*

4.3.2 What additional data should have been collected?

The group acknowledged that a future pandemic is likely to have different characteristics from H1N1 (2009) and the information requirements may be considerably different. Also, as technology evolves, further information could be available (for example, development of immunological tests using saliva samples could open up new possibilities for data collection).

Community surveillance

Further community based surveillance would be beneficial in a future pandemic, to monitor ILI rates in the community, infection rates (if real-time serosurveillance becomes feasible) and the propensity of individuals to seek healthcare. This would – in combination with existing surveillance systems – provide a comprehensive picture of the community, primary and secondary care activity during a pandemic. However, community surveillance mechanisms should not, themselves, pose a transmission risk (e.g. by requiring people to congregate).

Information on over the counter (i.e. non-prescription) drugs might have been beneficial in 2009 in providing a proxy means of monitoring the community impact of the pandemic. However, consumer stockpiling at the beginning of a pandemic would need to be taken into account. Such information might be available through supermarket transaction databases.

4.3.3 What data should not, in retrospect, have been collected?

The group agreed that all data streams collected during the H1N1 (2009) pandemic were useful to the response but the robustness of some of the data streams could be improved by ideally operating more powerful and more representative sampling schemes. Their relative value varied at different periods of the pandemic. Some of the less used data streams during the H1N1 (2009) response may be more important in another pandemic. Therefore, there were no data streams that CMO-SLG considered should be discontinued.

CMO-SLG also identified some instances during the H1N1 (2009) pandemic when epidemiologists and mathematical modellers involved in the response were unaware of some established data streams. Therefore in a future pandemic it would be important to ensure that data users were made aware of all the available information sources, whilst ensuring that any use of data was in compliance with appropriate standards of data protection and information governance.

4.4 Summary of recommendations for future data collections

Whilst acknowledging that only finite time, budgets and personnel are available for pandemic planning and surveillance, the CMO-SLG recommends that:

I. **When future pandemic information requirements are finalised, the data collection mechanisms to be used should be specified as far as possible, although maintaining a degree of flexibility to take into account inherent uncertainties in the presentation of any future pandemic.**

II. **A mechanism be available for refining the surveillance response depending on the impact and severity of any future pandemic.**

III. **A standard definition for pandemic related deaths should be agreed.**

IV. **Sample based surveillance systems should be designed to collect samples that are representative, sufficient in number and unbiased as far as possible.**

V. **In a more severe pandemic, it would be especially important that investigation of deaths and underlying factors that increase risk of death are undertaken. Various analytical approaches could be used, including representative sampling and a case control study, to investigate deaths during the next pandemic.**

VI. **Government should consider amending legislation to ensure that all deaths that are subject to an Inquest are registered for statistical purposes while awaiting the verdict.**

VII. **Community based surveillance systems should be developed to quantify infection or illness rates in the community and allow changes in healthcare seeking behaviour over time to be tracked during a future pandemic.**

VIII. **Procedures are put in place to ensure that data users are made aware of all the available information sources in a pandemic.**

IX. **Priority should continue to be given to routine seasonal flu surveillance data streams, especially, Q-Surveillance data and the Royal College of General Practitioners (RCGP) data, in order to maintain established baselines, though the data from these systems may be impacted by pandemic interventions (i.e. NPFS).**

5. Communication of complex statistical data beyond those directly involved in managing the response

5.1 Introduction

The primary purpose of surveillance and complex statistical data is to help inform the response to the pandemic. However, these data will also be of great interest to the wider media, at risk groups and the general public.

The Statistical Legacy Group was tasked with considering the challenges of communicating complex statistical data to the general public and media, and how this is best done.

5.2 Approach to review

In reviewing how complex statistical data were communicated during the H1N1 (2009) pandemic, the Statistical Legacy Group sought evidence from science media representatives of the BBC, the Science Media Centre, and freelance journalism. They were asked about their views on general principles for communicating statistics, complexity and uncertainty, how complex statistical data were communicated during the pandemic and how this could be improved.

In addition, papers from the Behaviour and Communication sub-group of the Scientific Pandemic Influenza Advisory Committee on communicating risk and planning assumptions were considered[2]. The group also reviewed examples of how complex statistical data was communicated during the H1N1 (2009) pandemic.

5.3 Communication strategy for H1N1 (2009) pandemic

From planning phases and throughout the response to the H1N1 (2009) pandemic, the Department of Health's approach to public communications sought to be one of openness and transparency. The overarching objectives for the communication effort were to:

- Maintain public confidence in the government response
- Improve awareness and understanding of the disease (H1N1 influenza)
- Raise awareness of the National Pandemic Flu Service (NPFS)
- Position the NPFS as a route to treatment
- Promote good respiratory and hand hygiene (RHH) and other precautionary measures
- Encourage seasonal and swine flu vaccine take-up.

The Department of Health used a range of communication channels throughout the response. The pandemic had the potential to affect the entire population and so the use of mass media such as

[2] *Briefings from the SPI-B&C group: Planning Assumptions – Communication issues (October 2010) and Principles of Effective Communications (February 2010)*

TV, radio, and national press was crucial. In addition, communication to the public was directed through the NHS and targeted channels were also used to reach specific at-risk groups.

In preparing for a pandemic, the Department of Health had commissioned a series of research projects looking at communications and the likely public responses to an influenza pandemic. Findings from these projects were used to inform the development of their communications strategy, which was largely based around the WHO phases.

As the H1N1 (2009) pandemic emerged, plans had to be modified as the outbreak developed differently to that envisaged. The Department of Health communications team mobilised rapidly and worked closely with the Cabinet Office, the NHS, the Devolved Administrations, other Government departments, and the HPA to develop an updated and consistent set of plans and messages.

A public opinion tracker, set up in May 2009 by the Department of Health, indicated that the public had consistently high levels of satisfaction with the information received about swine flu.

During the H1N1 (2009) influenza pandemic complex statistical data were presented to the public in various ways, in particular through the planning assumptions, the CMO's regular media briefing (weekly from 2 July 2009 to 14 January 2010), and the weekly epidemiological situation reports published by the HPA on its website. In addition, the HPA made available papers on specific topics related to the H1N1 (2009) pandemic.

5.4 Key findings

Surveillance and management of the pandemic brought together, out of necessity, data of various kinds from a wide range of sources. It was not possible in the time available to take a co-ordinated and planned approach to dissemination. This meant that DH did not fully follow the principles and protocols of the Code of Practice for Official Statistics as communications channels evolved over time.

The group agrees that, in future pandemics, it should be possible to plan ahead on dissemination and ensure that key statistics of general interest to parliament, the public and the media are pre-announced and published in line with the Code to give transparent and equal access to all. Such arrangements should support, rather than replace, arrangements for briefing the specialist press such as those given by CMO. The group recognises that even with such planning it may not be appropriate to apply all the detailed practices of the Code to all the relevant data. For example, some data may be hard to understand and open to misinterpretation and the skilled staff that could provide the appropriate commentary and meta-data may need to focus on analysis directly supporting handling the epidemic. Such necessary exceptions should, however, be clearly explained.

The group also recognise that different considerations should apply to forecasts and planning assumptions. Publication of forecasts and planning assumptions may not always be appropriate and, when it is, would not normally be done within the same governance framework as the simple facts.

5.4.1 Feedback from Science Media Representatives

Despite the challenging nature of communicating statistical data, the media coverage was largely reasonable. There was an apparent lack of public alarm throughout the pandemic even when cases started to appear in the UK and DH's proactive approach to communications may have contributed to this.

However, this was not a universal view and some commentators outside of the UK had suggested that the UK's response was 'hysterical'. This may have reflected the fact that the pandemic hit the UK much earlier than the rest of Europe or that sections of the UK media were more assertive than their European counterparts.

From the outset, a good deal of information was available to journalists throughout the pandemic. The avoidance of a vacuum of up to date information was thought to have successfully limited the extent of speculative or frankly misinformed reporting.

The weekly press briefings provided by the CMO and the HPA technical briefings were beneficial and enabled complex issues to be discussed at length in advance. Throughout the H1N1 (2009) pandemic these briefings typically took place in the afternoon. The CMO-SLG recommends that these briefings be held in the morning to accommodate reporting deadlines and therefore maximise the impact of the material presented.

There were some considerable communication challenges during the H1N1 (2009) pandemic due to the paradoxical nature of some messages. For example, there was a need to balance general reassurance that the virus caused a mild illness with warnings to high-risk groups that infection could be serious.

In addition, considerable efforts were made to explain the term 'reasonable worst case scenario', when used in the planning assumptions, including that this was not a prediction. Nevertheless, the figures associated with the reasonable worst case were frequently misinterpreted as a prediction. The group agreed that the term 'reasonable worst case scenario' was probably not the most helpful, and recommended some work to develop more transparent terms for public messages.

Occasional examples of conflicting advice given during the pandemic by authorities, for example regarding the advisability of postponing pregnancy, were a concern when they occurred. Such lack of consistent messaging could easily have led to a more widespread erosion of public trust in the medical advice being given; and may, for example, have adversely affected the uptake of H1N1 vaccine by pregnant women.

5.4.2 Audience and recipients for complex statistical data

Although the primary purpose of surveillance data and resulting analyses is to help inform the response to the pandemic, this information is of interest to others including:

- Patients and potential patients who want to know how they and their families might be affected and what they need to do.

- Citizens, commentators and patients. These are not necessarily experts in science but are concerned with higher-level questions, such as “Is the government handling this properly?”

- Independent scientists with expertise in one or more aspects and an appetite for detailed data.

There are overlaps in the information requirements of these groups. Commentators play an important role as a communication channel with potential patients and the wider public and they rely on the independent scientists to complement the information they receive from government sources. A clear, transparent and consistent communication strategy, which addresses the needs of all three groups, is required to help build and maintain trust. The specific information requirements of the wider public and independent scientists are discussed in more detail below.

5.4.3 Public information requirements

A key concern for the public during a pandemic is the risk to themselves and those close to them. In essence, the public has a number of different levels of information requirement. Firstly, the public wants to know the probability that contracting pandemic influenza would be fatal for them or to their children. Secondly, whether they are likely to be hospitalised; and thirdly whether they will need to take time off work.

In addition, other valuable information requirements include the number of people hospitalised, critically ill and dying; and the level of pressure on GPs and A&E departments/units. Such information provides the media and public with a rough and ready way to assess the situation.

Throughout the H1N1 (2009) pandemic, the NHS Choices website had the basic information that the public needed. The group agreed that this information was accurate and well presented.

5.4.4 Scientific community’s information requirements

During a future pandemic, ‘independent experts’ will require access to accurate and timely information. It is understood that journalists will always seek input from “independent experts” in addition to those that are seen as “government approved”. Therefore, the availability of such information will help to ensure that consistent and accurate messages are conveyed.

Independent scientists would also like to know the quality and extent of the data being used, alongside its inherent strengths and weaknesses. The provision of such data enables more insights on the data to be made and facilitates wider analytical approaches including methodological advances.

During the H1N1 (2009) pandemic, some independent scientists felt that they were not able to determine the quality of published data, in particular from the First Few Hundred (FF100) database and the representativeness, timeliness and extent of virological data that were being used to estimate, weekly and by age-group, the proportion of those contacting their GP about ILI who actually had H1N1 (2009). Where raw data were provided to independent scientists there were sometimes inadequate “health warnings” highlighting the strengths and weakness of the data. This resulted in concern among some independent scientists.

However, the provision of raw data during a response (and responding to inevitable questions following their use by others) would consume scarce expert resources and could therefore undermine the effectiveness of the expert support to the response itself. The group therefore recommends that a balance needs to be struck between the agreed desirability of making data and metadata widely available during the pandemic and the resources required to do so in a timely manner.

Independent scientific advice and peer review is valuable during all stages of the response to a pandemic. This may be achieved most efficiently through sharing protocols, raw data, methods and commentary with previously agreed groups of independent scientists.

5.4.5 Presenting statistical data

The CMO-SLG explored with the science media representatives how statistical data should be presented to the public in a future pandemic. Several general conclusions were made:

- Communication is best done by trusted clinical or scientific professionals (e.g. senior HPA staff, the CMO or the government CSA) rather than politicians, with due attention to the need for those presenting complex data to understand the underlying complexities and to provide consistent messages in relation to other spokespersons.

- The *Code of Practice for Official Statistics*[3] should be used as assurance that the statistics have been produced and explained to high standards and that they serve the public good. A set of good reporting practices, as agreed by the CMO-SLG, is given in annex four.

- Pictures and diagrams, which properly convey uncertainty, should be utilised where possible to support and explain statistics.

- Comparison with other hazards should be made to contextualise the risk from pandemic influenza.

- The presumption should be that any data held should be communicated if it is reasonable to do so because delayed or unofficial disclosure may well damage public trust. In assessing reasonableness, the validity of the data and how comprehensible they are should be considered. Releasing large amounts of raw data may not be helpful for the general public, but might increase the confidence of more expert stakeholders (such as healthcare professionals or scientists). Data which are released should preferably be accompanied by (perhaps brief) interpretative text to put those data into context.

- A clear distinction should be made between reporting what has happened in the past and what might happen in the future. In particular, channels communicating these two issues should be separated.

- Official sources of information are likely to be perceived as valid and reliable, as long as they are seen to be open and transparent, and any underpinning scientific papers are, or will be, in the public domain.

[3] *Code of Practice for Official Statistics. January 2009, UK Statistics Authority.*

Differing reporting mechanisms across the four UK countries can on occasion lead to difficulties for those sections of the media that report the entire UK situation. It is recommended that the four CMOs should agree to present a core set of statistical data that are common to the four nations of the UK.

Although the media often seeks to provide unequivocal messages, the media representatives interviewed thought that the public would accept the uncertainty of the early stages of a pandemic. Lessons could be learned from weather forecasting; the public understands that we can be much more certain about the near future in comparison to the mid-term. One option would be to present a range of possible future scenarios along with their probabilities. However, in this pandemic, it was not possible to provide such a statement for a significant period, although in a more severe pandemic this might be possible more quickly.

5.4.6 Planning assumptions

Communicating NHS/DH planning assumptions during a future pandemic is an area that requires further thought. During the early stages of a future pandemic, when there is a relative lack of data it may be possible to use expert judgement to provide a narrative of what is likely to happen, without assigning spurious precision to these assessments. Once the required data are available, one would move to using quantitative outputs and models. It is important that it is clear to others when judgement is being exercised and broadly on what basis.

When communicating ranges in the planning assumptions it is recommended that more emphasis should be given to the 'central' or 'expected' value than the extreme ranges. A focus of the worse feasible case value is statistically undesirable since this is in fact one of the most unlikely actual outcomes.

A significant issue in 2009 was that revisions to planning assumptions took several weeks to be approved for pubic release, by which time they were sometimes already out of date (and inconsistent with the most current estimates of severity being generated by SPI-M for SAGE). Reducing these delays, revising the assumptions more frequently, and making the underpinning epidemiological analysis of severity publicly available, would greatly reduce the potential for extravagant media speculation and stories of the "Government says thousands could die" variety.

5.5 Summary of recommendations for future communications of statistical data in a pandemic

Whilst acknowledging that only finite time, budgets and personnel are available for pandemic planning and surveillance, the CMO-SLG recommends that:

i. **Priority for efficient use of scarce expert resource should always be given to supporting management of the response.**

ii. **Planning for future pandemics should include, as part of its communications planning, a strategy for ensuring that throughout any pandemic the collection of surveillance and other data is accompanied by transparent, orderly and proportionate release of those data on an equal footing to all. The principles and protocols of the Code of Practice for Official Statistics should be followed with any necessary exceptions to the detailed practices explained.**

iii. **Reporting mechanisms used to communicate complex statistical data are improved to highlight the quality, representativeness and extent of the data alongside its strengths and weaknesses. Any improvements should be balanced against likely increases in the burden on staff involved in managing the response.**

iv. **The Department of Health in collaboration with the Cabinet Office should undertake a review of the methods used to generate and communicate the planning assumptions during a future pandemic. It is recommended that expert judgement is used during the early stages of a future pandemic when key data are lacking to say what is likely or not likely. It is recommended that the communication of the planning assumptions is separated from general dissemination of factual data and that planning assumptions are refreshed more frequently and quickly as information becomes available.**

v. **The four CMOs should develop a core set of statistical data that are common to the four nations of the UK.**

vi. **Planning for future pandemics should include, as part of its communications planning, the continuation of regular media briefings given by the Chief Medical Officer or other trusted health professional. This avoids a vacuum of information and enables potential future issues to be anticipated and discussed in advance, preventing subsequent "scare stories."**

vii. **Planning for future pandemics should include, as part of its communications planning, the continuation of Code of Practice for Official Statistics - compliant weekly epidemiological situation reports, such as on HPA's website, to update the public and professionals and to enable complex issues to be discussed.**

6. Conclusions

The CMO-SLG reviewed the data collection procedures instigated during the H1N1 (2009) influenza pandemic with the aim of benefit in the response to a future influenza pandemic. Specifically to:

a) Highlight and record best practice
b) Identify lessons learned
c) Consider the balance between data gathering and NHS reporting burdens.

In addition, the CMO-SLG considered in what circumstances complex statistical data needs to be communicated to the general public and media and how, where necessary, this is best done.

Overall, the group agreed that surveillance of the pandemic in the UK had been among the most comprehensive in the world. For example, the UK appears to be the only country that implemented WHO's recommendation to include the first few hundred cases in a formal epidemiological study. The group also concluded that all data streams actually collected during the H1N1 (2009) pandemic were useful to the response. However, their relative value varied at different periods of the pandemic.

The group considered that media coverage of the H1N1 (2009) pandemic had, with few exceptions, been reasonable, balanced and well informed. This was a sign that the overall approach to communicating surveillance data had been broadly effective. The communication of statistical data during a pandemic is always likely to be challenging but the regular and open briefings provided by CMO had been especially welcomed by the media. The HPA technical briefings were also very helpful and authoritative. The publication of planning assumption statistics was a particular problem because they were frequently misconstrued as predictions, despite repeated warnings.

Despite the overall success of the surveillance and communication programme, the group did identify specific areas for improving the collection and communication of statistical data during a future pandemic. Specific recommendations are given in earlier chapters. The **CMO-SLG also recommends the following high-level enhancements:**

- **Preparedness plans should include the actual mechanisms/processes for data collection, harmonisation of data streams and definitions, and how surveillance responses will be calibrated to the apparent severity of a future pandemic;**

- **Community-based surveillance systems are needed to quantify time-specific (weekly or fortnightly) infection and/or illness rates in the community and to track changes in healthcare-seeking behaviour;**

- **The primary purpose of surveillance data is to assist with managing the response However, planning for future pandemics should include, as part of its communications planning, a strategy for ensuring that throughout any pandemic the collection of surveillance and other data is accompanied by transparent, orderly and proportionate release of those data on an equal footing to all. The principles and**

protocols of the Code of Practice for Official Statistics should be followed with any necessary exceptions to the detailed practices explained.

- **Whilst the group recognised that the response itself should always take precedence and that there are inherent differences between health systems in the different UK nations, where possible, a UK approach to surveillance and communicating data to the public should be adopted.**

7. Annex one – Terms of Reference

1. To review the data collection procedures instigated during the H1N1 (2009) influenza pandemic for the benefit of a future influenza pandemic.

2. Specifically to:

a) Highlight and record best practice
b) Identify lessons learned
c) Consider the balance between data gathering and NHS reporting burdens

3. To consider in what circumstances complex statistical data needs to be communicated to the general public and media and how, where necessary, this is best done.

4. To produce a report for the Chief Medical Officer with recommendations for improvements to the system for collection, analysis and public presentation of data in a future influenza pandemic. This report can be used to support the review of the National Framework for responding to an influenza pandemic.

8. Annex two – Outline of surveillance systems coordinated by HPA & external partners

Data source	Type	Information provided
First Few Hundred (FF100)	Enhanced surveillance of cases due to novel influenza virus and their close contacts. This includes collection of detailed demographic data, exposure, clinical, treatment and outcome data on cases and their close contacts.	Public health-based epidemiological analysis to determine key epidemiological, virological and clinical characteristics of a novel pandemic virus.
Health Protection Units	Routine investigation of outbreaks of acute respiratory illness by Health Protection Units (IRIS system of reporting)	Investigation of outbreaks brought to the attention of local HPUs early in the pandemic.
Outbreaks of respiratory illness	Ad hoc system of reporting to Respiratory Disease Department, CfI	Early investigation of outbreaks in schools, care homes etc.
Q surveillance	A primary care based syndromic surveillance system covering 22 million patients across England (and some in Wales and N. Ireland).	Q Surveillance provided daily and weekly reports on primary care consultations for flu-like illness and other related conditions. It gave an early indication of the rise in primary care consultations for flu-like illness and was sufficiently large to provide robust daily data by age group and region. It was possible to monitor the progress of the pandemic in different parts of the country to a similar level as the NPFS. Q Surveillance had the advantage of having historical data to interpret activity levels and, given that it included a clinical assessment, was less liable to be influenced by external sources, although a change in READ code was introduced during the pandemic. However, the number of consultations in England was affected by the NPFS system and historical comparisons were made more complex because of this. In addition laboratory confirmation information was not available nor coverage in Scotland.

The Royal College of General Practitioners (RCGP) primary care surveillance system	Includes patients of around 100 practices spread across England	Gave an early indication of a rise in primary care consultations for influenza-like illness and acute respiratory infections. Virological testing was available in a sub-set of around 50 practices providing confirmation of circulating viruses. Comparison data are available from the 1960s onwards, and has a longstanding, standardised baseline. RCGP information did monitor spread of influenza but it did not have the 'granularity' of the NFPS and Q surveillance systems. RCGP spotter practices enabled swabs to be taken from a sample of patients and positivity rates to be obtained. Information on vaccination status was gathered which allowed estimation of flu Vaccine Efficacy.
HPA RMN sentinel GP surveillance	Includes patients of around 60 practices spread across England	Samples from 50-60 GP practices provided positivity rates. Clinical information was gathered with samples including vaccination history, which allowed estimation of flu VE.
Medical Officers of Schools Association (MOSA) scheme	Boarding schools in the Medical Officers of Schools Association (MOSA) scheme send reports of various illnesses, including 'influenza-like illness, to the RDD CfI, each week during the school terms.	Up to 42 schools report covering a population of approximately 12,000 pupils with most of the schools located in the southern half of England.
The Regional Microbiology Network (RMN) sentinel GP scheme	Suspected cases investigated by the RMN network	Initially, the HPA RMN network investigated suspected cases and if confirmed H1N1 cases were followed up for outcome of infection, hospitalisation and underlying chronic conditions that may have be in risk factors for a severe outcome through primary care. Age matched non-confirmed suspected cases were followed up for comparison. These data were critically important for assessing hospitalisation rates by age group and risk group, and allowed for major changes in the clinical severity of H1N1 to be detected. This system was later a component of monitoring the effectiveness of H1N1 vaccine programme once introduced.
Hospitalisation	Web-based system of hospitalised cases of H1N1 in England	Initially, retrospective data was collected from NHS hospitals on confirmed H1N1 hospitalisations. Then all hospitals in England were asked to collect prospective data on confirmed H1N1 hospitalisations from late September. Hospital infection control teams were involved in collecting the information in a not dissimilar way to that collected for health care associated infections.
Excess Mortality	Excess deaths estimate	General registrar's office provided daily numbers of deaths from all causes stratified by age, gender and location. The Office for National Statistics (ONS) also provided the same data with additional information on the underlying cause of death, on a weekly basis. This was used to calculate the number of excess deaths. The thresholds

		were developed over a number of years and have demonstrated the impact of seasonal influenza and heat waves. This gave a timely indicator of increased mortality at national and sub-national levels by age group.
Flu Survey	Web-based survey run by LSHTM	Provided community behaviour information to estimate the proportion of people contacting primary care, and absenteeism levels.
MHRA Yellow Card	Enhanced Yellow Card System for collecting data on ADRs specifically related to pandemic countermeasures	ADR-type data was important to help inform policy around countermeasures management (specifically to provide advice to clinicians on patient management), but also for briefing ministers and the media /public.

9. Annex three – Outline of surveillance systems coordinated by DH

Health and Social Care Service capacity/resilience monitoring

Description of system

- FluCon and SocCon are reporting systems, which provide high-level summary data on the capacity and resilience of the health and social care service.
- FluCon reporting was developed to complement the Acute Trust pressures reports/SITREPs on a daily basis. FluCon is a pandemic-specific assessment of how the *whole* of the health care services (primary and secondary care) are coping during a pandemic. SocCon was established (based on FluCon) as a way of monitoring and reporting social care capacity issues during the pandemic and any other emergency.
- FluCon & SocCon were not intended to inform the micro-management of the NHS/Social Care Services. However, this assessment is useful in helping identify areas of the health/social service that require strategic co-ordination and support.

Data Purpose

- To provide a clearly communicated summary measure of how the primary and secondary health care services (FluCon) and adult's and children's social care services (SocCon) are coping during a pandemic, from local to national organisations.

Key policy areas

- **Health service management/resilience**
- **Social Care resilience**

Data specification

- The FluCon levels and criteria reflect different levels of business continuity decisions or actions taken in a pandemic to manage a 'surge' of patients (Pandemic flu: managing demand and capacity in health care organisations (surge))
- FluCon 0 is aligned with the pre-surge stage, whereas FluCon 1 – 3 represent increased demand for services and the effect on the provision of those services.
- The SocCon levels and criteria were based on the health (FluCon) reporting process and intended to reflect the management of 'demand' at the LA level.
- FluCon consists of a FluCon levels on a weekday basis for each (i) Primary Care Service (General Practices, Community Pharmacies, Out-of-hours and Other), (ii) Secondary Care Service, (iii) Ambulance Service broken down by (a) Country (b) SHA and (b) PCT/Trust.
- SocCon reports contain a SocCon level on a weekly basis for (i) adult's social care services, (ii) children's social care services, broken down by (a) GO, (b) LA.

Data collection and reporting

FluCon

- Each health organisation (i.e. PCT or Trust) self-assesses their service against the criteria (listed in the 'FluCon Assessment & Guidance') and reports the FluCon level, which best represents the management of patients demand at the local level on a weekday basis.
- Each individual PCT/Trust reports a FluCon level for all of the services in their area to the Lead PCT (if one exists, otherwise direct to the SHA) and then SHA.
- The SHA then reports the complete FluCon information for their region to DH
- DH consolidates all regional data returns into a National Weekday Summary report that is sent out to all DH/HPA and NHS partners. A weekly summary report is included in the DH/HPA SITREPs and sent back out to all partners.

SocCon

- Each local service provider self-assesses their service against the criteria (listed in the 'SocCon Assessment & Guidance') and reports the SocCon level, which best represents the management of patients demand at the local level on a weekly basis.
- Each individual LA reports a SocCon level for all of the services in their area to their Government Office
- The GO then reports the complete SocCon information to Cabinet Office. Cabinet Office then shares the data with DH.
- DH consolidates the raw data into a weekly summary report.

Validity & Consistency Issues

- *Subjectivity* – The data is self-assessed by health organisations/care providers.
- *Consistency* – Persons responsible for data reporting in each organisation may vary from day to day.
- *Exception reporting process* - Each SHA/GO is responsible for ensuring a complete regional picture is reported to DH. Therefore they may utilise an exception (i.e. change in levels only) reporting process.

Data storage and maintenance

- All SHA level reports received and all National Summary reports are archived on the DH server.
- On a weekly basis the FluCon data for the previous weekly period is reviewed and any unusual or repeating patterns of FluCon data emerging are queried with the SHA to ensure it is an accurate reflection of the pressures on the particular PCT/Trust.

Data access and information governance

- Data access only to DH. Reports shared with NHS partners.
- All FluCon and SocCon Reports are under 'Protect' status

Data provider agreements and/or contracts

- The FluCon system and data is owned by DH. The SocCon data is owned by DH for adult's and DFE for children's.
- For H1N1 (2009), Informal agreement in place with LA/SHAs to provide FluCon data to DH on a daily basis
- For H1N1 (2009), Informal agreement in place with CCS to receive raw SocCon data each week.

Operational management – triggers, issues etc

- For FluCon - DH are the owners and operate the collection and reporting process.
- For SocCon - Cabinet Office operate the data collection process and Cabinet Office and DH jointly operate the reporting process.

Dormancy or mobilisation of system

- Agreement to activate the FluCon reporting system would need to be reached between DH and NHS partners
- For SocCon agreement would need to be reached between DH, CCS, DFE and GO partners
- In dormancy no maintenance to the technical system is required.

Any other issues/future development

- There needs to be further agreement on whether the FluCon and SocCon reporting systems would be considered useful for another pandemic and/or emergency. Agreement would need to be reached with NHS and GO partners in order to mobilise these systems.

Acute Trust SITREPs

Description of system

- Traditionally during winter Acute Trusts are responsible for reporting a daily Situation Report (SITREPs) reporting any Winter Pressures.
- During the pandemic, the winter SITREPs reports were expanded to capture data on hospitalisation related to swine flu.
- As with the Winter SITREPs, the Swine Flu SITREPs focuses on reporting issues which impact on the operational capability of Trusts.

Data Purpose

- During a pandemic, it is anticipated that all acute trusts will have to carefully plan and effectively respond to increased service pressures.
- Therefore, it will be vital to obtain and communicate daily information on health care service operations and capacity from a local to a national level.

Key policy areas

- **Health service management/resilience**

Data specification

- The Swine Flu SITREPs contain valuable detailed information on suspect cases regarding:
  - (i) Total inpatients, (ii) new admissions (iii) co-morbidities or underlying conditions (iv) numbers in critical care (v) new admissions to critical care and (vi) deaths in connection with swine flu
  - Serious operational problems (i) A&E closures (ii) A&E diversions (iii) trolley waits (iv) urgent operations cancelled (v) unplanned reductions in elective work (vi) difficulties in ambulances queuing
  - Further comments/other issues
- Reports are received on a daily basis from each Acute Trust in England

Data collection and reporting

- Each acute trust reports their SITREP through the UNIFY2 system daily to their SHA.
- The SHAs then collate the reports and submit them to DH
- DH use this data to inform a number of reports.

Data storage and maintenance

- Data are stored in an Oracle database held as part of the Unify2 system.
- DH responsible for maintenance of Unify 2 system.

Data access and information governance

- Access is controlled by password, and all data only available to DH.
- Data can be extracted in excel or csv formats (among others).
- Summary data on swine flu hospitalisations were published each week by HPA.
- Requests for access to data should be made through DH

Data provider agreements and/or contracts

- The DH owns the Acute Trust SITREPs data.

Operational management – triggers, issues etc

- During a pandemic, DH operated the collection (through UNIFY 2). Reporting of the Acute Trust SITREPs data was controlled by DH.

Dormancy or mobilisation of system

- Unify2 has been designed to allow rapid creation of collection systems. Subject to content being agreed, a new collection can be designed and in the field within a week.
- The constraining factor in data collection is generally the ability of the service to report accurately, not the ability of the system to collect the data.
- If DH require the same collection in future, then Unify2 system can be reactivated.

Resilience and contingencies

- DH have back-ups of data
- Unify2 is tested and used regularly

Flu-Clinical Information Network

Description of system

- FLU-CIN's aim was to collect rapidly detailed knowledge of severe swine flu, its complications, the associated risk factors and the effectiveness of different methods of treatment in order to inform the revision of clinical management guidelines.
- Five sentinel centres were established in England. A further centre was set up in Scotland (funded by the Scottish Government Chief Medical Officer and Public Health Directorate). English data collectors also collected data from Wales and Northern Ireland. The University of Nottingham coordinated the data collection aspects of this project.

Data Purpose

- The main purpose of FLU-CIN is to provide the information required to support clinical management of patients admitted to hospital with complications arising from swine flu through the revision and dissemination of national patient management guidelines.
- There is no equivalent system for seasonal influenza.

Key policy areas

- **Clinical management of hospitalised patients**

Data specification

- A dataset was agreed by a strategy group including representatives of the British Infection Society, the British Thoracic Society and the Health Protection Agency, clinician members of the Scientific Advisory Group for Emergencies and of the Pandemic Influenza Clinical and Operational Group and the pandemic flu team's Consultant Clinical Advisers. The group took into consideration the work undertaken to develop a clinical information network in the preparedness phase by the Pandemic influenza Preparedness Programme. This had not been fully completed when swine flu emerged.

Data collection and reporting

- There are five sentinel centres involved in FLU-CIN in England:
  - Imperial College Healthcare NHS Trust
  - Nottingham University Hospitals NHS Trust
  - University Hospitals of Leicester NHS Trust
  - Sheffield Teaching Hospitals NHS Foundation Trust
  - The Liverpool group (Royal Liverpool University Hospital NHS Trust, Liverpool Women's Hospital NHS Foundation Trust and Royal Liverpool Children's NHS Foundation Trust).
- A sixth centre has been established in Scotland by NHS Quality Improvement Scotland (QIS).
- Each English centre was provided with funding to recruit two whole time equivalent nurses for six months on Agenda for Change pay scale 6 or 7 to collect data for the project. These nurses manually collect the relevant patient and treatment information from patient records and transmit this by courier (with appropriate protection for confidentiality) to the University of Nottingham, where it would be entered on to a secure Access database. The aim is to collect data on a sample of patients with confirmed H1N1 infection.
- The Ethics and Confidentiality Committee of the National Information Governance Board gave permission for the collection of patient-identifiable data for FLU-CIN (which would, amongst other things, enable repeat admissions to be identified). They also confirmed that there was no need to apply for section 251 approval. Initially, patient identifiable data was collected however this subsequently changed to pseudo-anonymised data.
- Data collection was expected to be focused on patients in the Sentinel Centres. However, whilst case numbers were low in these centres, data collectors would visit other hospitals with confirmed cases to collect data. The University of Nottingham coordinated this process.
- Analysts from the University of Nottingham would analyse the data and submit two page summary reports (in PDF format) to the Strategy Group for consideration on a regular basis (usually each fortnight). These reports would also be sent to the Scientific Advisory Group for Emergencies (SAGE) and the Pandemic Influenza Clinical & Operational advisory (PICO) group for information. Should the Strategy Group consider it necessary to propose an amendment to the clinical management guidelines, the proposed amendment would be put to the British

Infection Society, the British Thoracic Society and the Health Protection Agency as authors of the existing guidelines. With their views, the proposed amendment will be put to the Pandemic Influenza Clinical and Operational Group (or its clinical sub-group) and if endorsed published.

Data storage and maintenance

- Data collected is stored on an Access database held at the University of Nottingham.
- The University of Nottingham undertake a regular review of the database to identify any duplicates.
- Informal and random error checking is undertaken on the database on a regular basis. Illogical dates are investigated, critical missing dates sought, other basic missing data such as gender sought if this has not been recorded. In addition, FLU-CIN records of patients admitted with a respiratory complication of influenza have been reviewed by a clinician.
- A systematic data cleaning exercise is planned once data collection comes to and end, which will include further error checking.

Data access and information governance

- The University of Nottingham has sole access to the database. This will be handed over to the Department once the project has finished.
- Data is provided to stakeholders through summary reports provided on a fortnightly basis. In addition, analyses of the data are submitted for publication in peer-reviewed journals.
- A data access agreement has been put in place to enable access to the database by researchers. This can be found at:
- Clinical leads in the sentinel centres have been granted a period of exclusivity for access to the data for research purposes.

Data provider agreements and/or contracts

- The Department of Health own the data
- Memorandums of Understandings (MOUs) and Contracts have been put in place with the NHS Trusts and Foundation Trusts acting as Sentinel Centres and with the University of Nottingham acting as the 'hub' for the project.

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Operational management – triggers, issues etc

- The University of Nottingham coordinate this project on behalf of the Department of Health. They are responsible for entering the data collected on to an Access database and producing analyses and summary reports as requested by the Department.
- A Strategy Group has been established to oversee this project. The main aim of this group is to review the data collected and, if necessary, make recommendations on the revision of clinical management guidelines.
- An Operational Group has also been established to provide the necessary operational support to ensure successful day-to-day running of the sentinel surveillance scheme under the direction of the Strategy Group.
- Have agreed terms of reference.

Dormancy or mobilisation of system

- The operational management during this pandemic may not apply to future pandemics. Data collection for FLU-CIN ceased in min-January 2010. The Strategy Group has reviewed the dataset used during this pandemic and have submitted to the Department a proposed dataset that should be collected for future pandemics.
- The Department are reviewing the options of setting up a similar system for a future pandemic.

Resilience and contingencies

- A weekly back-up of the database is made. The back-up is stored on free standing hard disk that then goes in to a locked safe.

National Pandemic Flu Service (NPFS)

Description of system

- The UK acquired a stockpile of oseltamivir (Tamiflu) and Zanamivir (Relenza).
- The provision of antiviral treatment to symptomatic members of the public was agreed as being a key component of the programme's strategy to reduce illness and deaths during the pandemic.
- NHS Direct was commissioned by DH to develop a National Pandemic NPFS service which would:
  - Enable symptomatic (eligible) patients rapid access to antiviral medicines
  - Enable symptomatic (eligible) patients access to antivirals in a way that does not burden the healthcare system.

Data Purpose

- Collect information on the symptoms of pandemic influenza using a national clinical algorithm;
- To authorise antivirals as appropriate and detail unique reference numbers (which can be used to reconcile the patient with the authorisation at point of collection);
- Gather and report on data on the spread and impact of the virus across England and to;
- Provide integration with the DH stock management system to ensure stocks are monitored and distribution arrangements are maintained.

Key policy areas

- **Clinical response measures**
- **Health care resilience**

Data specification

- Daily information on verified contacts broken down by:
  - age
  - location (PCT, SHA, GOR Region and Country)
  - channel (Web, telephony)
- In addition to this an additional field was provided to specify web or call contact types
- NPFS was delivered through two public access channels of web and telephone.
- NPFS makes provisions for high levels of availability and business continuity to meet the demands.

Data Collection and reporting

- Responses to the clinical algorithm and the outcome of the assessment is recorded against in the NPFS database.
- Operational information on the NPFS is collected by the central system to monitor the service levels.
- DH were responsible for sharing this data with partners

Data storage and maintenance

- The system supplier maintain the full raw dataset from NPFS and a subset of that data (from specification) is sent to NHS-D who then provide a further processed set to DH.
- Internal data checks are carried out by DH before data is disseminated.

Data access and information governance

- System supplier and NHS-D host the full NPFS data set in secure environment.
- Access to NPFS data is made available to DH through NHS-D.
- DH also hosts a processed version of the data (to specification) and share this with stakeholders via the Immform web portal.

Data provider agreements and/or contracts

- DH own the full NPFS data set.

Operational management – triggers, issues etc

- During a Pandemic, the DH receive data in line with an agreed specification on a daily basis. The DH are then responsible for publishing this data to allow access for Modellers and other partners

Dormancy or mobilisation of system

- Data collection systems will be maintained and tested during dormancy.
- In dormancy, the DH antiviral database would be archived on a test/archive server.

Contingencies for data reporting

- The NPFS will undergo rigorous annual testing to stress test the technology and ensure all components function to agreed standards.
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Any other issues/future development

- Ensure all procedures are thoroughly document and tested to enable swift and efficient mobilisation of Surveillance systems in the event of a future Pandemic (this includes any operational 'triggers').

Antiviral Stock Management System (SMS)

Description of system

- A system that works alongside the NPFS for the efficient distribution of the national stockpile of antivirals. To keep the wastage to a minimum level.
- A system that ensures antiviral medicines are readily available for distribution at outlets.
- A system that provides information to the NPFS on antiviral availability at collection point level to aid the directing of patients.
- A system that provides surveillance reports (national/regional/PCT/SHA) on the issuance of stock.

Data purpose

- To manage the antiviral stockpile across England.
- To enable PCTs to use this system to order antivirals for their own Collection Points.
- Ordering replacement antivirals automatically for the Collection Points with low stock levels.
- To have traceability of the stock.
- To have an interface with the Antiviral National Distributor (AND) warehouse management system for data exchange on antivirals stock status, delivery information and new orders.
- To capture information on GP vouchers.

Key policy areas

- **Clinical response measures**
- **Health care resilience**

Data specification

- Daily information on antiviral distributions broken down by:
  - GP Voucher/ACP assessment
  - location (PCT Code, Antiviral Collection Point – ACP code)
  - Gender,
  - Age of patient
  - Product (Tamiflu, Relenza)
  - Dosage verification
- Information on undistributed stocks, stocks in transit and timely snapshots of stocktake data

Data Collection and reporting

- Data for deliveries and orders are collected automatically via the SMS system at distribution point level.
- Surveillance reports are extracted from the SMS on a daily basis and used to update the response

Data storage and maintenance

- Data is collected through entry of stock consumption at ACP level onto the SMS. Predefined daily reports available through SMS system.
- Accuracy of data is dependent on data entry at ACP level as the system assimilates reports in real time.

Data access and information governance

- The Stock Management System hosts the raw data (daily and cumulative) and pre-defined reports (current and historical).
- Access to the Stock Management System database to access data and reports is limited and password controlled
- Local level access is available for local planners to analyse activity in areas that they are responsible for, but not others.

Data provider agreements and/or contracts

- System and data owned by DH.

Operational management – triggers, issues etc

- The DH are responsible for maintaining the SMS portal

Dormancy or mobilisation of system

- Mobilising the system would involve the advised re-opening and co-ordination of regional ACPs and staff for the data collection process.
- In dormancy, the DH antiviral database is archived on a test/archive server.

Resilience and contingencies

- The SMS (as with NPFS) will undergo rigorous annual testing to stress test the technology and ensure all components function to agreed standards.

Mortality data: Death registration data/CMO deaths enquiry system

Description of system

- When a person dies, the attending doctor certifies the death (unless referred to a coroner for investigation) and then the informant must register the death with the General Registry Office (GRO).
- Death registration data is collected and processed by the GRO's for E&W, Scotland (Scot) and Northern Ireland (NI). The GRO's then pass this data onto the ONS, HPS and NISRA respectively for publishing as official statistics at a later date.
- During the pandemic death registration data was the main input for the HPA to help calculate excess deaths to the pandemic virus. However, it was also felt that more information on attributable causes of death and co-morbid conditions would help the DH monitor the severity of the pandemic.
- Therefore, the CMO confidential deaths enquiry system was implemented. Every hospital trust reported any deaths on a daily basis, through the DH Situation Report system. On receipt of a death report, the CMO's team contacted the responsible senior physician in the trust directly to gather further information. A parallel system was established for deaths occurring outside of hospital. Regional Directors of Public Health (RDPHs) were provided with a weekly list of deaths in their region known to DH, and asked to report any additional deaths that might not have been captured by the main reporting systems.

Data Purpose

- For pandemic purposes, mortality statistics are crucial to estimating (i) the impact of the pandemic (i.e. groups/geographical areas most at risk), (ii) calculating case fatality rates (modelled data) and also for (iii) informing ministers and health service planning and response.

Key policy areas

- **Epidemiology – clinical impact and severity monitoring**
- **Death systems management**

Data specification

Death registration data – GRO's and ONS

- Each of the GRO's (E&W, Scot and NI) provided daily death registration to the DH Surveillance team, broken down by: (i) Date of registration, (ii) Date of death, (iii) Age, (iv) location (registration district/council) and total counts.
- ONS also sent us a weekly mortality file of all death registrations in E&W for the past week, broken down by: (i) Date of death, (ii) Date of Registration, (iii) Age, (iv) Gender and (v) ICD-10 codes of death and (vi) location (registration PCT and resident PCT).

CMO confidential deaths enquiry

- Data was collected from Acute trusts (via the Acute Trust SITREPs) across England on a daily basis, broken down by: (i) age group, (ii) date of death, (iii) Hospital number, (iv) NHS number, (v) Medical Director name and (vi) contact details.
- On a weekly basis, data was collected via Primary Care Trusts on all deaths occurring in non-acute settings, broken down by: (i) name of GP practice, (ii) practice manager's email and contact details, (iii) date of death, (iv) NHS number
- Trusts were asked to report deaths *suspected* to be related to pandemic influenza
- It is important to note the CMO's definition of any death that may be attributable to swine flu:
    - Death caused by swine flu (PART 1 of death certificate)
    - Swine flu contributed to death (PART 2 of death certificate)

  AND/OR
    - Patient tested positive for swine flu.
- This definition was applied, to confirm or refute each suspected death reported

Data Collection and reporting

- Death registration relies on the informant (usually a relative) registering the death.

- Data on registered deaths is held by the GRO for E&W on a database system introduced in March 2007– Register On-Line (RON).
- ONS directly extract data from RON and store it on the M204 database in Titchfield.
- Northern Ireland Statistics and Research Agency (NISRA) have a live link to the GRO for NI central database system.
- The GRO for Scot/Health Protection Scotland (HPS) collates and report death data for Scotland.
- The confidential deaths enquiry system is owned by the CMO's office with data collected and maintained within that office. The CMO deaths enquiry system involves a weekly check of all the deaths reported to DH via the (i) Acute Trust SITREP route and (ii) Primary Care Trust reports of community deaths in their region. The data collected by this system is confidential because the data collected involves patient identifiable data streams.
- The CMO's team reconciled all the deaths reported in each region of England and the CMO announced the latest number of confirmed swine flu deaths in England as part of his briefing.

Data storage and maintenance

- During the pandemic, DH maintained a central database for data from GRO and ONS.
- The CMO's office is responsible for storing and maintaining the confidential death data.

Data access and information governance

- Daily data from the GROs and weekly data from ONS were made available to users.
- The CMO system data were strictly confidential between the CMO and selected DH colleagues until the aggregate numbers were released in the weekly CMO briefing.

Data provider agreements and/or contracts

- For the pandemic, the DH had an agreement with GRO E&W, GRO Scot and GRO NI to receive daily data direct from source – this was a documented informal agreement.
- The weekly detailed death data from ONS was contractually agreed and funded for by the DH.
- The CMO's team were responsible for the data confidentiality and provider agreements for their enquiry system.

Operational management – triggers, issues etc

- An informal agreement between the DH and each GRO for the provision of daily death registration data.

Dormancy or mobilisation of system

- DH have agreement from GROs to obtain daily registration data in a future pandemic.

Resilience and contingencies

- Data provision is entirely dependent on the separate data providers (i.e. from the GROs and ONS) to be able to send DH the data.

Any other issues/future development

- ONS currently provide weekly death data as an ongoing data stream. This enables DH/HPA to monitor excess deaths and create a baseline.
- DH have agreement from GRO to obtain the required data in the event of a future pandemic.

10. Annex four – Good reporting practice during a pandemic

The CMO-SLG recommends the following good practices should be used for reporting during a future pandemic.

1. Provide clear description when reporting rates, e.g. “rates are per million of population” or “per million infected”.

2. Report how samples were acquired – representatively according to a pre-defined sampling scheme, as a convenience sample, or by self-selection.

3. Provide the response-rate by those invited to take part – whether a pre-defined sampling scheme has been used or otherwise.

4. Reporting by age group is beneficial especially for influenza pandemics.

5. Provide numerator/denominator when reporting percentages or provide standard error.

6. Analyse reporting-delay distributions, such as the delay between the date when specimen was obtained and laboratory-result-date; and make clear the date by which results are being reported.

7. Be clear about definitions. For example, be explicit about whether hospitalisation refers to suspect or confirmed cases, and whether confirmation occurs routinely, atypically, or for a representative sample of hospitalisations.