



# *L'importanza della trasparenza dei dati scientifici per la lotta ai patogeni*

*Ilaria Capua*

*OIE and FAO Reference Laboratory for Avian Influenza  
OIE Collaborating Center for Diseases at the Human Animal  
Interface*

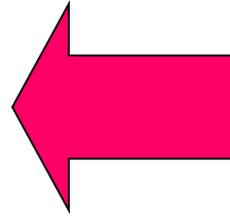
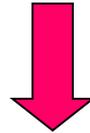
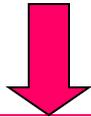
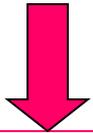
*Istituto Zooprofilattico Sperimentale delle Venezie  
Legnaro – Padova, Italy*





Contributo dell'Italia ad una gestione più trasparente dei dati di sorveglianza virologica a livello internazionale

Controversie sul “supervirus killer H5N1” sintetizzato in laboratorio – pubblicare o no la ricetta per farselo in casa?



HIV/AIDS, SARS,  
Rabies, BSE, West  
Nile, Influenza, Ebola





This is not going to stop

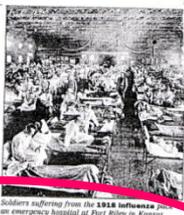




Technology, Management & Market

**Awaiting the Next Big One**  
The 20th century's flu pandemics

YEAR	COMMON NAME/TYPING	POSSIBLE SOURCE	DEATHS
1918	Spanish flu/H1N1	Pig or bird host of mutated H1N1 virus	40 million
1957	Asian flu/H2N2	Mixed infection of avian virus, human H2N1 and swine H2N2 strain in Asia	2 million
1968	Hong Kong flu/H2N2	Mixed infection of avian virus, swine H2N1	2 million



Soldiers suffering from the 1918 influenza pandemic in an emergency hospital at Fort Riley in Kansas.

**One WHO Expert on SARS Finds Flu More Frightening**  
Doctor Deems World Unprepared for Next Anticipated Pandemic That Could Cause Health Crisis

By GUYTON NAIK

**A**S AN EXPERT ON SARS, Klaus Stohr usually wears the same clothes as any doctor, and often juggling three phone calls at once. But his chief worry just now is SARS. It's the flu.

Not any flu, but a long-awaited influenza pandemic that could spark a massive influenza pandemic in public health. This sort of virus could circle the globe in less than six months, long before a vaccine is ready. Though antiviral drugs exist, not a single country has stockpiled them in anticipation of an outbreak. And there are glaring cracks in the flu pandemic surveillance systems of many countries, especially those in the developing world.



Klaus Stohr

"We're not prepared," says Dr. Stohr, the scientist who heads the World Health Organization's influenza program and is also leading the agency's fight against severe acute respiratory syndrome. Compared with the devastation of a flu pandemic, he adds, "SARS will be something to smile about."

Influenza is one of the oldest and most common diseases known to man. But a flu pandemic would be a lot harsher than the flu bug that sickens millions of people around the world and kills tens of thousands of them each year. Annual flu outbreaks occur when the structure of the flu virus undergoes small changes, permitting it to evade the immunity that people have acquired from previous infections or from vaccinations. But sometimes the surface proteins of a flu virus change substantially, and nobody has immunity against such a bug. It is also acquires the ability to spread from person to person, the stage is set for a lethal pandemic.

The damage can be catastrophic. The Spanish flu pandemic of 1918 killed more than 40 million people, while those of 1957 and 1968 together killed some four million. By comparison, SARS is a lot less infectious, and it has caused fewer than 700 reported deaths so far.

Global air travel and urban overcrowding increase the risk. The WHO projects that in developed countries alone the next pandemic could cause as many as 2.3 million hospitalizations and 600,000 deaths in less than two years. The toll in developing countries could be worse. Countries that belong to the WHO have recognized the danger only by developing a resolution underlining the need to improve flu surveillance and response.

Influenza pandemics have occurred historically at 20-year intervals. Since the last one occurred 80 years ago, the consensus is hard to avoid. We're due for one, not a matter of if, but when. It will happen in a pandemic form, either in Europe, as in 1918, or in Asia, as in 1957. The far side of the Pacific is the source of a flu pandemic that could spark a massive influenza pandemic in public health. This sort of virus could circle the globe in less than six months, long before a vaccine is ready. Though antiviral drugs exist, not a single country has stockpiled them in anticipation of an outbreak. And there are glaring cracks in the flu pandemic surveillance systems of many countries, especially those in the developing world.

Journal Link: WSJ.com subscribers can see an interactive graphic tracing the path of the infected people who fueled the SARS outbreak, in the Online Journal at WSJ.com/SARS.

**Le Monde**  
MARDI 3 FÉVRIER 2004



Grippe aviaire : l'épidémie devient extrêmement dangereuse

**Grippe aviaire : l'épidémie devient extrêmement dangereuse**  
« NOUS SOMMES bel et bien confrontés à une pandémie », a déclaré le directeur général de l'Organisation mondiale de la Santé (OMS) lors d'une conférence de presse mardi 2 février. Les experts de l'Organisation mondiale de la Santé (OMS) ont évoqué l'existence d'une possible transmission internationale du virus, celui de deux jeunes Vietnamiennes décédées après avoir été infectées par un poulet. Les pays asiatiques experts doivent se réunir, dit-il, à l'Institut Pasteur de Paris, afin de définir les actions d'urgence dans les dix pays d'Asie frappés par l'épidémie.

**Juppé fait face à son la droite critique le**

**CE, UN POSTE À VENISE ? SA NE, VOUS TENDRENT-ILS ?**  
Dans le même temps, plusieurs voix critiques contre les annonces de nomination de Juppé ont été entendues. Jacques Chirac a annoncé une mesure d'urgence. Le Monde, le président de l'Assemblée nationale, Bernard Luchaire, minimise l'importance des faits. Selon nos informations, une



Documento riservato della Casa Bianca pubblicato dal «New York Times»

**Virus, rapporto segreto Usa: milioni di morti, ospedali in tilt**  
L'influenza aviaria in Europa: duemila tacchini colpiti in Turchia

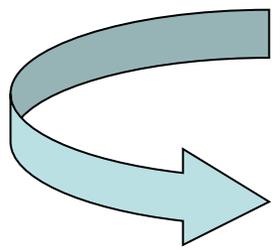
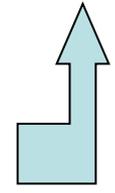
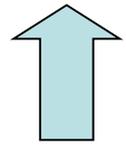


Gli esperti europei di influenza riuniti a Malta. Il nostro Paese deve aumentare le scorte di antivirali, pronto il piano di emergenza

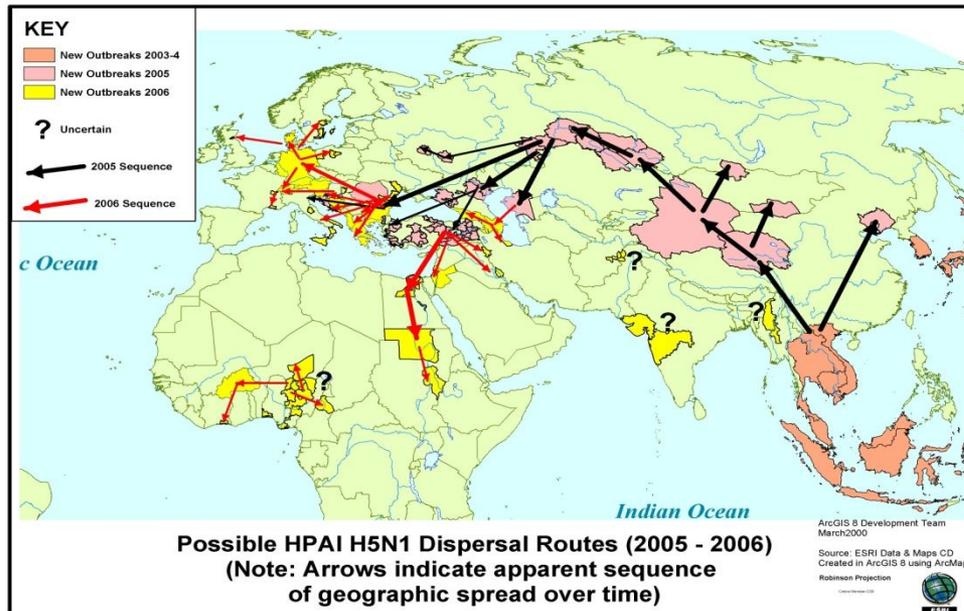
**«I virus dei polli colpirà 16 milioni di italiani»**

Crovare: epidemia inevitabile. Le previsioni: 150 mila vittime. Un commissario in ogni Asl





# January 2006: H5N1 reaches Africa







## AVIAN INFLUENZA

# As H5N1 Keeps Spreading, A Call to Release More Data

**PARIS**—An impassioned call by a prominent Italian influenza scientist has renewed the debate about how to balance global health against scientists' needs to publish and countries' demands for secrecy. On 16 February, Ilaria Capua, of the Istituto Zooprofilattico

tricky from the start. WHO, FAO, and OIE encourage countries to send virus samples to specialized reference labs that can confirm the outbreak and study the virus further. Some have been reluctant to do so because they worry about intellectual-property rights or not

**Showing her cards.** Ilaria Capua says she will submit H5N1 sequences from her lab to public databases immediately.

dozens of individual governments, Brown says.

Capua counters that just isolating and sequencing a virus that comes in the mail does not give researchers the right to sit on the data—especially not at a government lab. “Most of us are paid to protect human and animal health,” she says. “If publishing one more paper becomes more important, we have our priorities messed up.” Governments can often be persuaded to release the sequences, adds Capua, who repeated her call at an OIE meeting in Paris on Monday and also plans to submit it to ProMED, an e-mail list about emerging infectious diseases.

WHO agrees that in an ideal world, scientists would share their data widely and voluntarily, says Wenqing Zhang of the agency's Global Influenza Programme. But because that's not happening, the agency created a special secured section at the Influenza Sequence Database at Los Alamos National Laboratory in New Mexico in 2004. Currently, some 15 labs have passwords to access these data, says Zhang, including WHO's eight reference labs. The system is invaluable for WHO, she adds, as it helps the agency track the virus and adjust risk assessments if necessary.

Virologist Yi Guan of the University of

# THE WALL STREET JOURNAL

MONDAY, MARCH 13, 2006

## Scientist Rebels Against WHO Over Bird Flu

Scientists around the world, racing to discover how avian influenza is spreading and whether it is evolving toward a pandemic strain, face a dilemma: Should they share their interim findings widely, show them only to a select set of peers, or keep them to themselves until they can publish papers, often critical to their careers?

Now, a lone Italian researcher has cast a harsh spotlight on the WHO's system, suggesting that it places academic pride over public health - and snubbing it by posting prized bird-flu data in plain view.

Ilaria Capua, a 39-year-old Italian veterinarian working on avian influenza in a government lab, last month received a sample of the virus in the mail from Nigerian health authorities. The virus had just attacked birds in Nigeria, the first confirmed case of the disease in Africa. The sample was something of a prize, a chance to study a specimen and explore how it spread from its stronghold in Asia.

Within days of isolating the virus, Dr. Capua says, she got an offer from a senior scientist at the WHO in Geneva, whom she declined to name, to enter her finding in the closed system. She could submit the virus's genetic information, or sequence, to the database. In exchange, she would be given the password to the WHO's massive stash of data. A spokesman for the WHO confirmed that the offer was made.

Instead, Dr. Capua posted the gene sequence in a public database accessible on the Internet. She also sent a letter on Feb. 16 to around 50 of her colleagues urging them to do the same with their bird-flu samples.

"If I had agreed" to the WHO's request, she said in an interview, "it would have been another secret sequence."



Ilaria Capua

# The New York Times

EDITORIAL

## Secret Avian Flu Archive

Published: March 15, 2006

At a time when health authorities are racing to head off a possible avian flu pandemic, it is distressing to learn that the World Health Organization is operating a secret database that holds the virus's genetic information. A lone Italian scientist has challenged the system by refusing to send her own data to the password-protected archive. Instead, she released the information publicly and urged her colleagues to do the same. She is surely right. The limited-access archive should be opened or bypassed immediately to encourage research on this looming health menace.

The campaign by Ilaria Capua, an Italian veterinarian who works on avian influenza, was spotlighted in recent articles in the journal *Science* and *The Wall Street Journal*. The hidden data could be of immense value in determining how the virus is evolving and in developing effective vaccines or drugs. The possibility of breakthroughs can increase only if many more scientists can analyze the data.

washingtonpost.com

## Bird Flu Fears Ignite Debate on Scientists' Sharing of Data

By David Brown  
Washington Post Staff Writer  
Thursday, May 25, 2006; A20

The issue gained public attention in February when Ilaria Capua, a 40-year-old virologist at the Tri-Veneto Region Experimental Animal Health Care Institute in Italy, sequenced the first H5N1 sample from Africa, isolated from a chicken farm in northern Nigeria. Someone at WHO invited her to contribute it to the Los Alamos data, but she declined and instead filed it in GenBank.

# nature

## Action stations

The time for sitting on flu data is over.

Concern about the accessibility of data on flu strains remains an acute issue, which research administrators and political leaders should step forward and address.

Indonesia has become the hot spot of avian flu, with the virus spreading quickly in animal populations, and human cases occurring more often there than elsewhere. Yet from 51 reported human cases so far — 39 of them fatal — the genetic sequence of only one flu virus strain has been deposited in GenBank, the publicly accessible database for such information.

And last week in China, researchers belatedly published details of

EDITORIALS NATURE | Vol 441 | 29 June 2006

the appearance of human-to-human transmission. In the Sumatra event, the transmission did not spread beyond the family.

Yet scientists outside the WHO networks have no access to these data. The problem last year spurred the US National Institutes of Health (NIH) to create a consortium to sequence and make public thousands of flu strains from humans and birds.

**"H5N1 sequences should be promptly deposited in a publicly accessible database."**

Very quickly, this more open approach led to the useful discovery that viruses swap genes with each other more frequently than had been previously thought.

Some political leaders are drawing the appropriate conclusions. Dennis Kucinich (Democrat, Ohio) and Wayne Gilchrest (Republican, Maryland) are circulating a letter in the House of Representatives

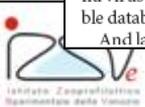
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CORRESPONDENCE

NATURE | Vol 440 | 30 March 2006

## Shared data are key to beating threat from flu

SIR — We fully support Ilaria Capua in her call for avian-influenza researchers to release data to the public, rather than store them in restricted databases, as reported in your Editorial "Dreams of flu data" (*Nature* 440, 255–256; 2006). Keeping sequences secret, whatever the motivation, slows down scientific progress and hinders efforts to protect public health. The influenza genome sequencing project ([www.niaid.nih.gov/dmid/genomes/mscs/influenza.htm](http://www.niaid.nih.gov/dmid/genomes/mscs/influenza.htm)) has, in the past year, sequenced more than 1,000 complete genomes of human influenza and released them to GenBank ([www.ncbi.nlm.nih.gov/genbank](http://www.ncbi.nlm.nih.gov/genbank)).





## RESOLUTION No. XXVI

### Sharing of avian influenza viral material and information in support of global avian influenza prevention and control

1. OIE Members reporting outbreaks of avian influenza should agree to **share animal avian influenza viral material and information** about avian influenza viruses through OFFLU with the international scientific community.
2. OIE Reference Laboratories must actively encourage sharing of material and data with the international scientific community, and as a minimum **deposit genetic data within 3 months of receiving an isolate into a public database** designated by the OFFLU Steering Committee, which will manage scientific relations with the WHO.
3. To enhance cooperation and transparency, the actions taken by countries must be recognised in subsequent publications and other benefits arising from the use of biological material or data that they have submitted to OIE Reference Laboratories.



# Avian flu: global sharing of virus samples

## Another joint FAO/OIE initiative

**1 August 2006, Rome** - OFFLU, the OIE/FAO joint network of expertise on avian influenza, will systematically make avian influenza virus sequences accessible to the entire scientific community. With this gesture OFFLU reiterates its call to the world's scientists, international organisations and countries for a global sharing of virus strains and sequences.

Since its launch in April 2005, OFFLU has been mainly working on promoting the key objectives "to exchange scientific data and biological materials (including virus strains) within the network, and to share such information with the wider scientific community". Under this new impetus, strains will be sent to the U.S. National Institutes of Health for sequencing and deposited in full transparency on the free-access database, GenBank.

On 14 March 2006, the Scientific Committee of OFFLU, made up of the world's leading veterinarian experts on avian influenza, revised its terms of reference to put new emphasis on the need for further collection, characterization and exchange of avian influenza viruses, and for the expansion of the genomic database for animal influenza viruses.

### Critical to surveillance and control efforts

Sharing virus strains, samples and sequences is a critical part of the global work on the surveillance and control of the highly pathogenic H5N1 virus, and supports the preparation of

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**World Health  
Organization**

**SIXTY-SECOND WORLD HEALTH ASSEMBLY**  
Provisional agenda item 12.1

**A62/5 Add.1**  
**18 May 2009**

# **Pandemic influenza preparedness: sharing of influenza viruses and access to vaccines and other benefits**

## **Outcome of the resumed Intergovernmental Meeting**

**Report by the Director-General**

### **5.2 Genetic sequence data**

5.2.1 Genetic sequence data, and analyses arising from that data, relating to H5N1 and other influenza viruses with human pandemic potential should be shared in a rapid, timely and systematic manner with the originating laboratory and among [WHO Network] laboratories. (*Consensus*)

5.2.2 Recognizing that greater transparency and access concerning influenza virus genetic sequence data is important to public health and there is a movement towards the use of public-domain or public-access databases such as Genbank and GISAID respectively; and (*Consensus*)



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## Media centre

# Landmark agreement improves global preparedness for influenza pandemics

News release

17 APRIL 2011 | GENEVA - After a week of negotiations continued through Friday night and into Saturday morning, an open-ended working-group meeting of Member States successfully agreed upon a framework to ensure that in a pandemic, influenza virus samples will be shared with partners who need the information to take steps to protect public health.

The working-group meeting was convened under the authority of the World Health Assembly and coordinated by WHO.

### A significant victory for public health

"This has been a long journey to come to this agreement, but the end result is a very significant victory for public health," says Dr Margaret Chan, Director-General of WHO. "It has reinforced my belief that global health in the 21st century hinges on bringing governments and key stakeholders like civil society and industry together to find solutions."

The legal regimes will address clear roles and responsibilities of WHO, national labs and vaccine and pharmaceutical manufacturers.





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participant MEDIA [www.contagion.it](http://www.contagion.it)

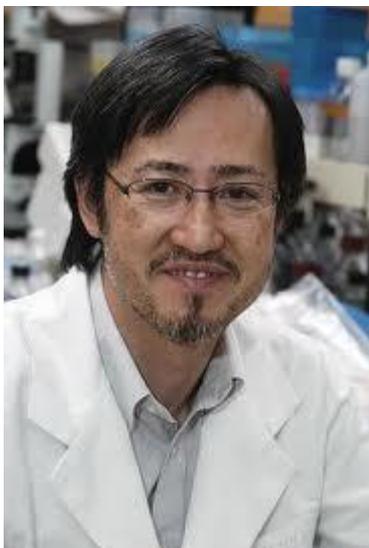


OXFORD SCIENTIFIC/PHOTOLIBRARY/GETTY



# The fight over flu

A proposal to restrict the planned publication of research on a potentially deadly avian influenza virus is causing a furore. Ten experts suggest ways to proceed.





**CENSORED**





Pause on Avian Flu Transmission Research

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