# WP3 Prototype Online Course for Primary Care Staff

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

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| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| V3 | Draft | 22/5/2014 | ZADIG | Third draft |
| Vf | Final | 24/6/2014 | ZADIG | Final draft |

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# EXECUTIVE SUMMARY

Based on the results of D2.4 Study of feasibility of an online course for primary care staff, an online prototype has been developed.

The interactive e-learning course is to help healthcare professionals to get acquainted with the TELL ME issues of transparent communication in epidemics, before a new pandemic would occur. It provides reliable information based on TELL ME research, scientific publications and authoritative sources (WHO, ECDC, CDC). The contents of the course focus on preventative measures, from hygiene to vaccination, training health professional to convey this information to the public, according to counseling principles and improving their communication skills. The risk of discrimination and stigmatization linked to infectious outbreaks has also been emphasized, as this is one of TELL ME project peculiarity.

The main target of this course are healthcare professionals,  notably GPs, but also nurses, midwives, health assistants, et cetera, since one of the main lessons learnt from the experience of 2009 A (H1N1) pandemic is their crucial role in such cases. In fact, they often have strict relationship with patients and high levels of credibility and trust from the public. In the analysis made by TELL ME project in D2.3 (Report on Health Care Professional Communication Requirements) interviewed GPs felt that, when in 2009-2010 patients were alarmed by media communication on the pandemic, they did not have enough information and tools in order to handle people's doubts and give them reliable information, especially about vaccination.

This interactive online course allows therefore healthcare professionals to prove themselves in daily situations, after studying three documents in which all requested information is included:

- Dossier 1 – Epidemics and pandemics: what health professionals need to know
- Dossier 2 – Talking about prevention in case of pandemics: information and strategies for healthcare professionals
- Dossier 3 – Stigmatisation and discrimination: a guide for healthcare workers

It is mandatory to read all of the three sources before tackling the interactive activities.

The course can be done in several sessions, by logging on at different times.

It is divided in 6 case histories, each divided in steps with multiple-choice questions with only one correct answer.

At the end of each step one gets his/her score; the step is passed is at least 80% of correct answer has been done. Each case history is a prerequisite to the next.

When a case history is passed, an explanation of right answers is given. At this point, it is possible to return to course's activities summary or proceed to the next case with the navigation menu.

At the end of each case, a forum for discussion is open.

A certificate can be achieved when all case histories have been passed.

Case history 1

# Is everything clear?

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

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## INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

## 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

### 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is "an epidemic outbreak". A broad definition given by many epidemiologists for epidemic is "more disease than is anticipated by previous experience", whilst a more precise one is "a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension", and is to be distinguished by an outbreak, which is "an epidemic confined to a defined short time and place". Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when "there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time". This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase “enormous numbers of deaths and illness” had been removed and the revised web page simply read as follows: “An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity.” Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

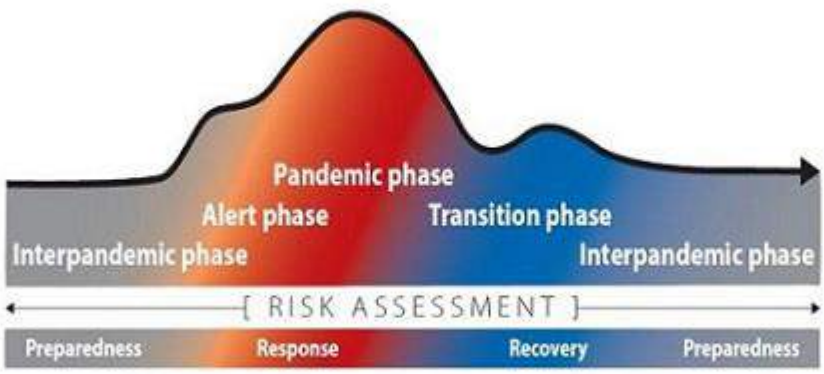
WHO argues that this phrase had little bearing on policy responses, it was “never part of the formal definition of a pandemic” and was never sent to Member States, but simply appeared in “a document on WHO’s website for some months”. In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO’s pandemic preparedness guidelines are only “pandemic phase” definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States “had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event”. This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

# 2. Main epidemics

## 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use.  Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

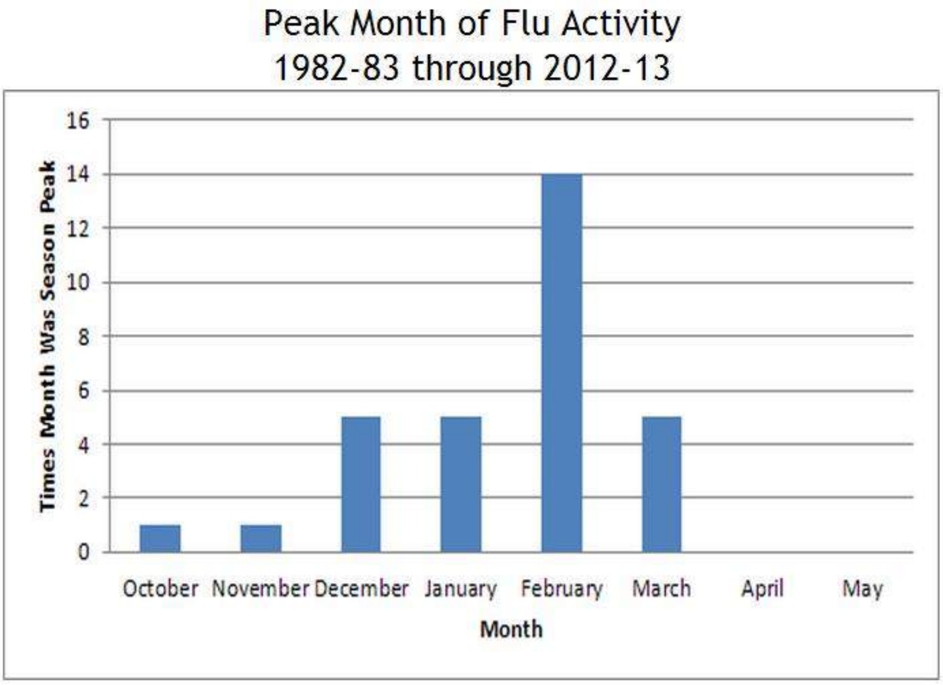
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




*During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.*

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the "low but real risk" group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name “swine flu” was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC's early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions. WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Case history 1 – Is everything clear?

**Topic:** Communication
**Target:** professionals, general population

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass the case history it's needed to answer correctly to 80% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Extrasources:**

- ECDC video – The influenza season is here, protect yourself and those you care about
- ECDC video – A new season, a different influenza?
- ECDC video – ECDC helps Europe respond to a new health threat
- ECDC surveillance:
    - Epidemiological data
    - Weekly Influenza Surveillance Overview (WISO)
    - European Influenza Surveillance Network (EISN)
    - The European Surveillance System (TESSy)

**Step 1**

A workshop on influenza is going to end. The speaker is showing his last slides, which are about the burden of the disease, and says: “Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a mild disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation”.
Two doctors in the audience comment with each other: “My dear George, he’s definitely right, but it’s so difficult to translate these data into messages for our patients”.
“That’s true. People undervalue the burden of this disease. And, well, after 2009 A(H1N1), with all that alarm about the so-called pandemic that’s become even worse”.

**On which basis did WHO declare a pandemic in 2009?**

- because of the novelty of the infectious agent and of its simultaneous geographic spreading
- because of the high number of deaths in a short time

- because of a higher number of cases than expected
- because of the enormous numbers of deaths and illness and of the widespread geographic spreading

**Step 2**

“You’re right, everyone was talking about pandemic, but nobody was even able to explain well which was the real risk, how the virus could be transmitted, and so on” confirms his colleague. “That was the information to give”.
“I must confess, Thomas, that a proper explanation of how a contagion spreads in both pandemic and epidemic cases is still extremely useful”.

**Which of the followings is true about the transmissibility of flu viruses?**

- avian influenza viruses transmit easily to animals other than birds, including humans
- seasonal influenza viruses can infect only humans
- swine influenza viruses can be caught eating pork
- H1N1 transmits as any other flu virus

**Step 3**

“Another thing that people don’t know, and that should be told, is that diseases do not catch us unaware, but that European authorities have set efficient surveillance and monitoring systems” ponders George.
“Yes, sometimes it looks like Europe wakes up in the morning just to find a huge army of viruses pushing on its eastern boundaries, like barbaric marauders”.
“Did you see the news citing ECDC, EISN, WISO or TESSy?”.
“No way, only the news of the death of a Chinese farmer in his nineties who was working in a poultry flock and who maybe did not even infected anybody else in his family”.

**What do EISN, WISO or TESSy stand for and which role do they have in influenza and influenza-like illnesses management?**

- EISN (European Influenza Surveillance Network), coordinated by ECDC, combines epidemiological and virological surveillance of influenza
- ECDC (European Centre for Disease Prevention and Control), coordinated by EISN, has research centers and hospitals dedicated to infectious diseases all over European countries
- TESSy (European Safety System) is a system aimed at analyzing the immunization coverag
- WISO (Worldwide Influenza Surveillance Overview) prevents flu patients from moving from one European country to another, in order to limit spread of the disease

**Step 4**

Meanwhile, the speaker goes on: “Anyway, the burden from influenza is not only about its lethality. Also the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases which result in time off work, losses to production and pressure and costs on the health and social care services”.
“Yes but, after the great fear of 2009, now everybody’s quiet, thinking that the problem cannot happen again every winter” says Thomas.
“That’s the consequence of crying wolf...”.
“I’m not surprised that many of my patients – even those at risk who would mostly benefit from a vaccine – when I talk about that clearly think: ‘we have been fooled once, that won’t happen again’”.
“Good luck when explaining drift and shift” says George, shaking his head.

**How should it be correctly explained to a patient the definition of drift or shift?**

- (●) antigenic drift is a minor change in the virus genome that happens continually over time and produces a new virus strain that may not be recognized by the body’s immune system
- ( ) antigenic drift is a major change in the virus genome that happens continually over time and produces a new virus strain that may not be recognized by the body’s immune system
- ( ) antigenic drift is a major change in the virus genome resulting in a new virus subtype, as it occurred in the spring of 2009 in the case of the swine flu
- ( ) antigenic shift is a minor change in the virus genome resulting in a new virus subtype, as it occurred in the spring of 2009 in the case of the swine flu

**Step 5**

Thomas adds: “No, they don’t take us seriously about this issue. They continue to think that it is a marketing strategy aimed to sell more vaccines”.
“Sure, but why this line of reasoning works for vaccines and then, when it comes to antiviral drugs, people go and stock them at the first sneeze?”.
“Even before that. Waiting for the first sneeze could be too late” jokes the doctor.

**Which is true about prophylaxis with antiviral drugs?**

- (●) as a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes
- ( ) as a general rule, WHO recommends the use of antiviral drugs for prophylactic purposes
- ( ) people at higher risk for influenza complications are candidates for prophylaxis, even they have been vaccinated
- ( ) healthcare professional are candidates for prophylaxis if they have been exposed to an infected

patients, even if they have been vaccinated

INVIA RISPOSTE

**Conclusion**

“If you think that a vaccine costs much less than some antiviral drugs...”.
Thomas is a bit disconsolate: “I’ve been a physician for many years and I’ve always tried to send proper messages to my patients. That’s why I can’t really understand these reactions”.
“There should be a large-scale effort, maybe at a European level, developed by healthcare professionals and experts in communication. Am I asking too much?”.

Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 1

## Summary

## Step 1

*Dossier 1 - Epidemics and pandemics - General guidelines*

**1.2. Pandemic**

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001). This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

## Step 2

*Dossier 1 - Epidemics and pandemics - General guidelines*

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the fluvirus but have no symptoms. During this time, those persons may still spread the virus to others.

[…]

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

[…]

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the New England Journal of Medicine claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name “swine flu” was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic.

[…]

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

[…]

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases.

[…]

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

## Step 3

*Dossier 1 - Epidemics and pandemics - General guidelines*

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## Step 4

*Dossier 1 - Epidemics and pandemics - General guidelines*

Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as antigenic drift, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called antigenic shift. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

## Step 5

*Dossier 1 - Epidemics and pandemics - General guidelines*

For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

[…]

*Dossier 2 - Talking about prevention*

**2.3. Prophylaxis with antiviral drugs in flu**

As a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes in flu. For people who have had exposure to an infected person and are at a higher risk of developing severe or complicated illness, an alternative option is close monitoring for symptoms, followed by prompt early antiviral treatment should symptoms develop.

According to the last Cochrane review, in fact (Jefferson et al, 2014), oseltamivir and zanamivir reduced the risk of symptomatic influenza but oseltamivir increased the risk of psychiatric adverse events in the combined on- and off-treatment periods and of headaches, nausea, vomiting and renal events during the treatment. The balance between benefits and harms should accordingly be considered when prescribing these drugs after a household member or other close contact has developed influenza, and it is rarely advantageous for healthy people.

Candidates for prophylaxis with antiviral drugs are rather family or other close contacts of a person with a suspected or confirmed case who are at higher risk for influenza serious complications but have not been vaccinated against the influenza virus strains circulating at the time of exposure (Harper et al., 2009; CDC, 2009).

Healthcare professionals should always keep in mind that cases of resistance to antiviral drugs have been reported (Inoue et al., 2009), and that persons who receive an antiviral medication for chemoprophylaxis might still get infected and be potentially able to transmit influenza virus, even if clinical illness is prevented (Lee et al., 2009; Khazeni et al., 2009).

## Case history 2

# A flu lesson

SEVENTH FRAMEWORK PROGRAMME

tellme

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

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# INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

# 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

## 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is “an epidemic outbreak”. A broad definition given by many epidemiologists for epidemic is “more disease than is anticipated by previous experience”, whilst a more precise one is “a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension”, and is to be distinguished by an outbreak, which is “an epidemic confined to a defined short time and place”. Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when “there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time”. This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase “enormous numbers of deaths and illness” had been removed and the revised web page simply read as follows: “An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity.” Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

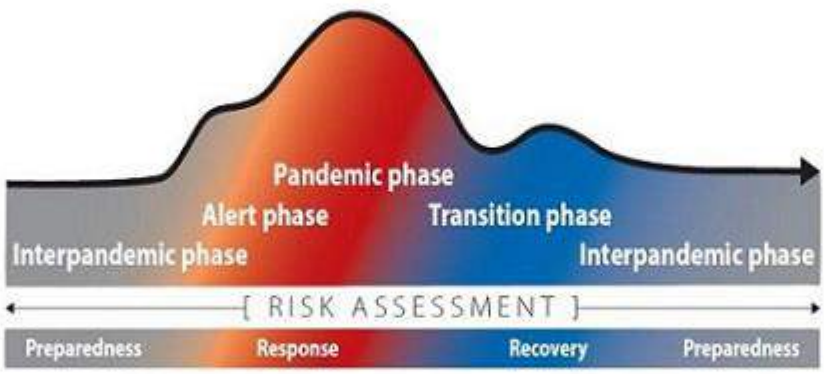
WHO argues that this phrase had little bearing on policy responses, it was “never part of the formal definition of a pandemic” and was never sent to Member States, but simply appeared in “a document on WHO’s website for some months”. In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO’s pandemic preparedness guidelines are only “pandemic phase” definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States “had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event”. This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

# 2. Main epidemics

## 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use. Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

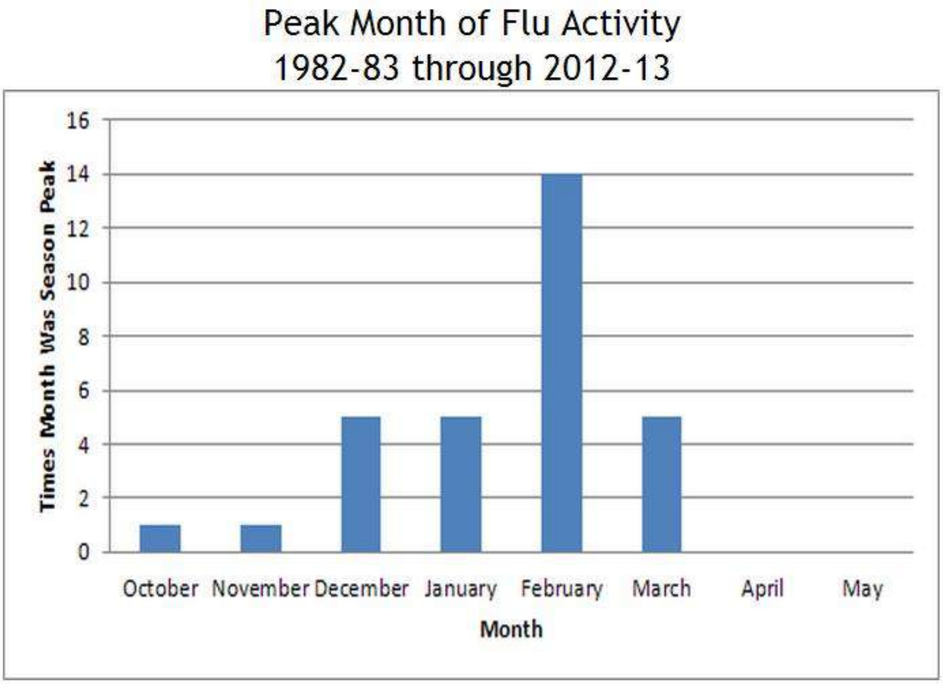
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




**During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.*

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the “low but real risk” group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name "swine flu" was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC's early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions.  WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Talking about prevention in case of pandemics: information and strategies for healthcare professionals

WP3 Prototype Online Course for Primary Care Staff
DOSSIER 2

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Talking about prevention in case of pandemics: information and strategies for healthcare professionals

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| **Vn** | **Status** | **Date** | **Organisation / Person responsible** | **Reason for Change** |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |

## Table of Contents

## INTRODUCTION

Prevention is essential in order to contain infectious outbreaks and, amongst preventive strategies, communication constitutes one of the key elements: it allows educating and informing citizens about healthy practices, raising awareness about diseases, involving patients and avoiding the diffusion of misinformation.

Healthcare workers constitute the interface between institutions and citizens, and this implies that they have a crucial role in preventive activities. They possess high accessibility by the population and have high credibility in the public's view. Patients often put greater trust in their general practitioners (GPs) than in governmental communication, meaning that they serve as example in attitude to health prevention and that they could perform further personalized communications. Knowing how to properly talk about prevention is thus crucial for healthcare professionals. This dossier will focus on the communication approaches that they should adopt in order to properly promote preventive measures in case of pandemics.

The chapter 1 of this dossier will summarize **some communication clues** to be kept in mind when talking with people regarding infectious risk and preventive measures, in order to avoid a top-down communication that could be either useless or counterproductive.

The chapter 2 will tackle the **main preventive measures** and describe the main issues associated to them. Particular attention will be given to anti-vaccine movements, in order to provide an effective framework of this reality and to identify key elements that could be useful to improve healthcare workers communication efforts.

The chapter 3 will go further into the concept of **urban myth** and analyse the most diffuse myths regarding preventive measures. Knowing in advance the rhetoric elements behind such modern legends may help health professionals to better hinder them.

The chapter 4 will present the **factors that mainly influence people's decision about vaccines**, dividing them into the most relevant subgroups that have been recognized. Identifying the characteristics of an interlocutor and targeting a message based on them is a key point in risk communication, especially for healthcare workers, who daily interact with citizens.

## 1. Talking to the public

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as "just another reassurance" and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

## 1.1 Perception of risk

According to Peter Sandman's theory, perception of risk by people does not depend only on the effective hazard, but also, and even more, by the outrage linked to it (Sandman, 1999). This depends on the danger being domestic or exotic, coerced or voluntary, chronic or acute, and so on. The studies on factors influencing risk perception highlight that this is basically related to emotional factors to such an extent that a series of components corresponding to the "perceived offence" (outrage), more than the real hazard that is the cause of the hazard itself, contribute to determine the perceived risk.

Healthcare professional, as well as institutions, must receive and "actively listen" people worries and be aware of offence "determinants" characterizing the perceived risk, so as to have greater opportunities to understand the origin of perception and be able to deal with it (Sjoberg, 1999).

They need to understand the main worries of the population involved, especially as far as the weakest categories are concerned, such as, for example, children and pregnant women. People, in fact, tend to base their risk assessment not on the count of possible number of dead, injured people or socio-economic damage, but on the perceived presence of specific characteristics of risk situations and on some perceived properties of risk source, such as, for example, the familiarity with risk, individual control, comprehension, effects on children, effects on future generations, personal engagement, uncertainty of scientific data, voluntary exposure, trust in Institutions (Lambert, 2003).

Communication must therefore follow the participatory model based on the interactive exchange assessment among all the parties (Leiss, 1987), concerning the attention to the emotional component of individual and collective perception (Slovic, 1987), as well as the understanding of social and personal issues, that is crucial to make scientific data a useful knowledge for citizen.

## 1.2 Listening is the first condition

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is "distant" from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the "focal issue", the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness.

Listening represents the first step in the professional relationship; it is based on empathy and on the other's point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other's shoes, thus entering his reference scheme and trying to see the "world" with the other's eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time "as if" you were the other, but without forgetting that it is just "as if". If there is no "as if" condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to "see the world with the eyes of the other person" so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction  not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one's own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one's own values and perceptions for embracing the one of the other person "as if" were one's own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

## 1.3 The empathic listening

Listening can be activated through the development of bidirectional communicative channels able to facilitate information flows and useful exchange so as to understand the patient's informative needs, his/her worries and for supporting the choices that justify the use of either some interventions or the others.

Interpersonal relationship generally represents the most effective way to implement the bidirectional exchange, so as to listen and deepen risk perception level, personal experience, information acquired, poor areas and to create the basis for a relationship of trust and cooperation.

Within the interpersonal context, it is possible to use a specific method called empathic mirroring which, through adequate communicative techniques, can ease the listening, thus favoring the focusing on the point of view of the other and on risk perception (Giampaoli S, 2005). Crucial techniques of empathic mirroring are

as follows: reformulation, clarification, ability in questions, use of first person messages (“I think that”, “According to me”).

“Reformulation” is a technique consisting in repeating what the other has just said, using the same words or rephrasing in a more concise way using other terms, without adding other concepts to the content. In this way, the operator may obtain a positive result from the other person, who knows of having been listened. One can wait the moment in which the other person has finished a sentence for intervening and resuming what has just been said: “You’re telling me that…”, “You mean that…”, “In other words…”, “Therefore, according to you…”, “You think that…”.

The person recognizing himself in the reformulation is sure of having been listened and understood, and is therefore confident to further express himself and cooperate. He is also facilitated to stay focused on the issue and on how he faces it.

“Clarification” facilitates the self-understanding underlying, through oral communication, the emotions associated to content. This is clear both at oral and non-oral communication. “I can see in your eyes that you’re worried”; “From your words I can feel you’re uncertain about what I’m saying”.

The “survey capability” is the ability in how to make questions, choosing the most adequate type based on interviews stages. “Open ended questions” have to be preferred in the initial stage of the interview; they allow for a wider chance of answer, tend to extend and deepen the relationship, encourage opinions and thoughts exposition (how, what he would like, could, may deepen, what he thinks).

“Closed ended questions” are defined, they force to a sole specific answer, often stress an answer, limit the communication and make it more focused, demand only objectives facts and sometimes may seem restrictive and obstructing (when?, where?, who?). Questions starting with “why” can be perceived by the person as accusingly, and should be avoided.

The use of first-person messages (“I think that”, “According to me”) make it easy to distinguish between what concerns the expert operator and what concerns the person, thus allowing to avoid conflicts and favoring a non-judging mood and an autonomous decision-making process.

## 1.4 Listening to communicate uncertainty

The empathic listening may favor the “uncertainty communication”, key process especially when, such as in an emerging outbreak, a crisis occurs while information are often incomplete and sometimes contrasting.

“Uncertainty communication” corresponds to processes communication and not to the outcomes, that is to the supported description of choices made or that will be made and the explanation underlying some decisions more than others. Declaring and supporting the uncertainty, it is possible to shorten the distance between a risk scientific-probabilistic assessment and a subjective personal assessment determined by the perception of risk, which increases when the emotional level increases.

The communication on uncertainty comes from the need of Institutions to communicate. Therefore, it demands a strategy and planning of communicative process, favored by the integrated participation and collaboration of institutions and systems involved at regional and national level. In fact, due to the fact that communication of uncertainty entails the choice of arguments and hypothesis that may explain, in a transparent way, to citizens, the reason for certain decisions more than others, it is crucial that the choice is

shared among figures and organizations involved in the communication process. Sharing creates the conditions for the formulation of homogeneous, understandable messages, able to make people understanding the reason behind certain choices, the consequences that they could entail, the reasons for which, at the moment, it is preferred to follow certain paths more than others. It is important that people understand and are informed even in an uncertain way, declaring “what is known and what is unknown”. The same is true at an individual level.

When people receive detailed explanations on hypothesis and/or paths chosen because considered, at the current level of knowledge, most likely or adequate, they have the chance to assess the situation with a greater serenity and “competence” and to arrange the choices within their life context. At the time of the emergency, they will be more likely to be collaborative, willing to face difficult situations.

Moreover, when people understand and take part in the choices, they feel respected and trust Institutions and professionals that listen and understand worries of individuals and community and are responsible for a comprehensible information. If, on the other hand, they feel “manipulated”, mislead, they lose trust and it is more likely that they will respond with denial and panic or ignore the provisions in a situation of maximum emergency.

Sometimes Institutions and experts avoid to explain complex issues and tend to reassure “Don’t worry, be calm, everything is under control”; they prefer “not to say”, but “it is not possible to communicate” because even the silence is a communication form. An information must always be given, reporting what has been done, what has been doing, what it is intended to do; transparency is basically the best choice.

## 1.5 Dealing with new media

Since many people use to look for information on the Internet, healthcare workers should pay attention to such a reality for two reasons: on the one hand, knowing the kind of information that flows through the net could be useful to forestall some possible criticism. On the other hand, social media and Facebook groups may constitute extremely valuable tools to keep patients up to date with advices and to promptly hinder false or ambiguous knowledge they could have found on the web.

Internet or social media use is not a remit of younger generations. According to some reports up to 476 million Europeans, of all age ranges, use the web. This accounts for approximately 65 per cent of the population, and the number continues to rise (IAB Europe, 2012). Estimates for the time an average European Internet user spends online is 27.6 hours per month, which exceeds the global mean of 24.5 hours. (comScore, 2012).

Kata (2012) highlights the fact that people nowadays are likely to search online for health information, and the anti-vaccination movement has taken advantage of this milieu to disseminate its messages.

“In the past when someone became ill, he or she would immediately go see a doctor. Nowadays people often turn first to the Internet and use the gathered information to formulate their thoughts. According to a health survey, a growing number of patients currently make their own judgements about what treatment and medicine they would like to have prescribed by a doctor. A literature review on health information-seeking behaviour on the web shows that, according to different articles and studies reviewed, interest in the Internet as a communication tool for health-related information is growing rapidly. This review also cites a WHO eHealth cross-country survey of seven countries which showed that 71% of Internet users surveyed had used the Internet for health purposes. The Internet, forums and social networking tools have allowed anti-

vaccination advocacy groups to have a broader reach than ever before. While years ago, vaccine-related rumours would have been restricted to certain countries, online tools allow these to spread more quickly and to different countries, as experts highlight" (ECDC, 2012).

As defined by Betsch (2010), Web 2.0 or social media is "Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, eg. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (eg static health portals), Web 2.0 enables two-way and multi-way communication."

Broadly speaking, social media is then a multi-way information sharing and communications tool, where users can converse and interact with each other irrespective of differences in geographical location or social background. The difference between social media (or Web 2.0 as it is sometimes known) and previous Internet platforms is that it is characterised by user-generated content. Within social media, users are more than just consumers of information, as the design of such platforms encourages them to share and contribute information to the network. McNab suggests that: "Until recently the predominant communication model was "one" authority to "many" – i.e. a health institution, the ministry of health or a journalist communicating to the public. Social media has changed the monologue to a dialogue, where anyone with ICT access can be a content creator and communicator." (McNab, 2009)

In recent years, there has been a shift towards social media being used not just as a platform to connect with friends and family but as the first place where users find out about breaking news stories. (Ofcom, 2011)

51 per cent of 18-24 year olds with a social networking profile agreed with the statement that they often find out about breaking news stories via social networking sites. 43 per cent of UK women agreed with this statement, whilst 27 per cent of men agreed. (Ofcom, 2011) Despite the overriding popularity of profile-based social networks such as Facebook, 'microblogging' sites such as Twitter (reaches one in ten Internet users worldwide) and Sina Weibo (337m users in China) uniquely encourage users to interact without being limited to interpersonal relations among friends. This form of concise, informal, rapid and open communication has led to microblogging sites to become fora where members discuss major world events and issues in real time. (comScore, 2011) According to a study by the Oxford Internet Institute, the average U.K. user now considers the Internet as their most important source for information. (2011) Notably, the study also found that *confidence* in the reliability of information found on the Internet has also increased, as users tend to trust the Internet as much as other forms of media. (2011) This may be explained by users' growing confidence in their ability to sift through and validate information on the Internet. Information from other media sources cannot be validated so immediately—for comparison, a second newspaper must be bought, or a different radio or TV programme must be waited for, yet with social media news or opinion can be cross referenced rapidly by drawing upon information posted by fellow users.

### 1.5.1. Benefit of Social Media

In contrast to traditional Web sites, which only allow communication of information to the public, social media allow not only the ability to provide information to the public, but also for the public to share information with the source. Users can create and disseminate information themselves, thus becoming more involved. An example of this interaction is demonstrated by a statement shared by the Centers for Disease Control and Prevention (CDC) on their Facebook page regarding vaccination on July 5, 2012: *"When was your*

*last tetanus shot? Tetanus vaccines can prevent this disease in children, teens and adults. Without the vaccine, you can get tetanus ("lockjaw") just by getting cuts, especially puncture wounds, that become infected with the bacteria."* This statement received 100 "likes" and elicited both supportive statements such as "Mine was only a couple years ago, but it's good to know what it helps prevent. I've had this done twice already" as well as dissenting statements with links to other information. Social media also allows individuals to provide public support for organizations, individuals, and causes by "liking" on Facebook or "following" on Twitter.

It also enables the sharing of information with a large audience. A link shared by an organization, individual, or cause, can be "shared" or "retweeted" to an individual's friends or followers, which can, in turn, lead to even greater shares or retweets. In this day and age, "going viral" is one of the fastest ways to facilitate the spread of information.

One major advantage of social media is that it can share "real-time" information regarding a public health crisis or other emergency scenario. For example, not only could a user receive information from an organization (eg, CDC), a public figure, but also their friends and associates. Because the individual self-selects the source of their own information, they are able to determine the sources that they most trust (CDC vs. NVIC), or alternatively like or know (eg, friend or celebrity). Such sources are likely to shape beliefs, attitudes, and behaviors. While this is great for sharing information, it can also be challenging, since people will be getting their information from the same types of places, which may not be reputable. They may also receive conflicting information, which can lead to mistrust and confusion. From this point of view, the "health blogger" or the "concerned mother" are sometimes as important as a GP in spreading good or bad information. Furthermore, individuals can easily receive information from "friends" or "followers." Simply sharing or tweeting "Should I vaccinate my child?" could provide an array of responses – both positive and negative – which could potentially influence an individual's decision making process.

### 1.5.2. Challenges of social media

It is relatively easy for messages to get distorted or used out of context. For example, for each "retweet" or "share," the original message can potentially be modified or added to by the user. While the initial source of information (eg, website) will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. Because of this, misinformation can rapidly spread amongst social media sources, leading to such sources as Snopes (www.snopes.com), a well-known resource for validating and debunking "social media legends." Frighteningly, social media users can "share" or "retweet" misinformation just as quickly and easily as accurate information. Two-way communication, while listed as a strength of social media, can also be used negatively to further perpetuate misinformation.

While social media avenues are great for getting information out quickly, they are not always well-suited to sharing complex or substantial amounts of information. Most social media outlets only allow limited lengths of communication. For example, "tweets" are limited to less than 140 characters, which often precludes sufficient evidence or explanation being provided.

While we are still trying to tackle with web 2.0, the experts say that web 3.0 is coming: more powerful software and machines are supposed to make the leap to a new "semantic" web, able to gice a meaning to the information gathered online, making the Internet less of a catalog and more of a guide — and even provide the foundation for systems that can reason in a human fashion (Markoff J, 2006).

## 2. Preventive measures

### 2.1. Non pharmacological measures

Most healthcare-associated infections are preventable through a number of personal measures that people may take to reduce their risk of being infected (Cowling et al., 2008; Jefferson et al., 2008). Amongst the most basic of these measures, there is a good hand hygiene, which means cleaning hands at the right times and in the right way. This should be do frequently, not too quickly – at least 20 seconds each time – and thoroughly with soap and water, especially after coughing or sneezing.

Another important practice is the so-called "social distancing", which means to avoid close contact with sick people. This can be done maintaining a distance of at least one metre from someone with symptoms of a disease and avoiding unnecessarily visit to people who are sick. When distance cannot be maintained, for instance in crowded situations, it is recommended to reduce the time of close contact with people who might be ill and the time in these situations to the extent possible.

Another simple rule to be followed is to avoid touching eyes, nose and mouth after a contact with surface that could be contaminated, while there is no evidence that wearing facemasks outside of healthcare settings during a pandemic offers effective protection or reduces transmission. This is why ECDC does not recommend their routine use.

Healthcare workers must remind the importance of these measures within a family or a group where one person has been infected. This means that patients should be encouraged to prevent other people from being exposed to their own potentially infectious nasal and oral discharge. They should cover their mouth and nose using tissues when coughing or sneezing; or cough or sneeze into an arm rather than their hands. In addition, tissues should be thrown in the bin after use. Since the importance of such a simple gesture may be sometimes underestimated, doctors should always stress its crucial role for prevention of infectious diseases. This is particularly true in healthcare facilities, since these places are the most exposed to pathogens.

### 2.2. Vaccination

### 2.2.1 Vaccination against flu

Vaccination is the most effective form of prevention from influenza, even if it cannot give a 100% protection from the disease. "Cross-immunity following infection by one strain or vaccination with a specific type or subtype often does not protect completely against subsequent variants of the same type or subtype. The extent to which influenza A(H3N2), A(H1N1), and B viruses circulate may vary by season. In addition, as the antigenic properties of these viruses might change due to continuous evolution of these viruses under immune pressure (antigenic drift), the virus strains of A(H3N2), A(H1N1) and B included in the vaccine have to be reviewed by the WHO annually and possibly changed. Also new vaccines may have to be made when variants of the virus emerge through a major change called an antigenic shift.

Most of the acquired protection against influenza comes from antibodies in the blood. Some additional protection comes from cell-based immunity and IgA antibodies produced on mucous membranes, like those of the respiratory tract. After the first (primary) infection, or vaccination, virus-neutralising antibodies to the haemagglutinin and neuraminidase appear in the blood in about one to two weeks and rise to a peak in about four weeks. Antibodies inhibit haemagglutination, agglutination of red blood cells due to multiple red blood cells bound by one virus, and so this is referred as haemagglutination inhibition (HAI). HAI correlates fairly well with virus neutralisation. Hence often the levels of these specific antibodies are used as a proxy for the presumed level of protection, with higher titres of more than 1:40 or 1:80 (in the older person) taken to indicate immunity.

After a second or further infection, or repeat vaccination, the antibodies appear and rise more quickly. The antibodies usually persist for months or years, although in people with weaker immune systems, like the elderly and those with chronic illness, they decline more quickly and vaccination is less effective. Another problem with influenza vaccination is that antibodies to one type or subtype of influenza do not necessarily give protection to other influenza virus types or subtypes (so called cross protection). Equally, they do not give full protection against subsequent drift variants of the same type or subtype. That is why seasonal influenza vaccines contain a mix of influenza virus types and subtypes and the composition has to be reviewed each year by the WHO" (ECDC official website, Factsheet for health professional).

#### 2.2.1.1. Influenza vaccines

In Europe, three main types of vaccines are currently available. They are all inactivated, with some of them adjuvanted:

- split virus vaccines consisting of disrupted virus particles
- subunit vaccines consisting only of the two main antigens, haemagglutinin and neuraminidase
- whole inactivated virus vaccines

In 2011, a live attenuated influenza vaccine that has been used in USA since 2002 was approved in Europe too for children (2-17 years of age).

#### 2.2.1.2. Vaccination strategies

In Europe, vaccination is usually recommended to reduce the risk of people at greater risk of complications from becoming infected (selective vaccination), more than to stop the spread of the disease, as in other countries is done, targeting schoolchildren. VENICE surveys of the EU/EEA countries sponsored by ECDC found that all reporting countries were recommending annual vaccination to the two largest groups which are highlighted by the European Union Health Council (Council of the EU 2009) and WHO (WHO 2002):

1. older people above a nationally defined age (usually 65 years and older);
2. all people over six months of age with chronic medical conditions: notably chronic heart or lung diseases, metabolic or renal disease, or immunodeficiencies.

Many countries emphasise the importance of annual vaccination of people in residential care for the elderly and disabled and there is excellent evidence that supports immunising those that care for them. Few EU countries recommend vaccination of children or offering vaccines to pregnant women, in this following a different strategy from policy in the United States (CDC 2010).

"In addition to the risk groups there are also other groups for who immunisation is often recommended – these are referred to as target groups. The most important of these are healthcare staff who are expected to prevent their infecting their patients with influenza-by-influenza vaccination as well as the other non-pharmaceutical measures. The vaccination will also protect the staff but its prime purpose is to prevent iatrogenic spread. Hence, all countries in Europe recommend that all healthcare staff should be immunized against influenza. This is especially important for patients at higher risk of infection and disease, where immunization is less likely to be effective. There is strong evidence that this protection works" (ECDC official website, Factsheet for health professional).

Influenza vaccines are licensed not only for those in the risk group. They can protect also well children, adolescents and younger adults. Almost all can choose to get vaccinated or to vaccinate their children so to protect weaker relatives, reduce the impact of the disease on daily life and limit its socio-economic consequences.

### 2.2.1.3. Vaccine efficacy and effectiveness

"Estimates of vaccine efficacy and effectiveness – or the extent to which vaccines protect in optimal circumstances (efficacy) and in practice (effectiveness) – vary according to the match between vaccine and the circulating viral strain and by age group and clinical category. Generally, the vaccines work less well in the elderly and those with chronic ill health. In trials, inactivated influenza vaccines have consistently been shown to prevent laboratory-confirmed illness in between 70% and 90% of healthy adults. The results are somewhat less in field effectiveness studies. The reduction in hospitalisations and deaths is less dramatic but still significant. Trial data cannot help here as hospitalisations, pneumonia and deaths are too uncommon to be revealed by trial data that also usually exclude those most at risk. Instead, observational data have to be used. These data are more subject to bias. However, modern epidemiological studies can compensate for these biases and when this is done, positive effects are consistently observed, although there are minority opinions that disagree" (ECDC official website, Factsheet for health professional).

### 2.2.1.4. Contraindications to vaccination

"As most viruses used for influenza vaccines are grown in eggs, egg-based vaccines should not be used for individuals with a definite history of serious allergic reactions to egg products" (ECDC official website, Factsheet for health professional). Live virus vaccines, not used in Europe, are contraindicated for pregnant women and immunocompromised patients.

### 2.2.1.5. Giving vaccines

“Most inactivated influenza vaccines are injected into the muscle in the outer upper arm. A single injection annually is sufficient except for previously unvaccinated preschool children with medical conditions for whom WHO recommends two doses at least one month apart” (ECDC official website, Factsheet for health professional).

### 2.2.1.6. Reactions to vaccines

“The three groups of inactivated influenza vaccine show minor differences in the mild reactions that sometimes follow vaccination. In trials, when whole virus vaccines are used, between one in five and one in six of those vaccinated experience local reactions in the arm, lasting for one or two days. Short-term reactions such as mild fever, malaise and muscle pains are reported in a much smaller proportion in the first few hours following vaccination. In contrast, trials of the split and subunit vaccines show even fewer reduced systemic reactions. There have been no strong temporal associations of the current vaccines with more severe reactions. Anaphylaxis is very rare but does occur as with all vaccines. More severe adverse events have been reported but they are extremely rare. One that has been reported historically with a particular vaccine in the 1970s is Guillain-Barré syndrome. With the modern influenza vaccines the seeming causative risk is either found to be very rare (0.8 per million doses) or there is no link found at all and more association is found with influenza infection than vaccination (Centers for Disease Prevention and Control 2010)” (ECDC official website, Factsheet for health professional).

### 2.2.1.7. Controversies about vaccines

Vaccines represent one of the best tools against infectious diseases but, at the same time, they are also one of the most controversial. The role played by healthcare professionals in supporting vaccine uptake is crucial for many reasons and is recognized by a huge literature. Recommendation from a healthcare professional is one of the strongest influence on vaccine acceptance.

In terms of communication, a healthcare professional that promotes vaccine uptake but does not undergo vaccination send a contradictory message to patients, which may lead to concerns and distrust towards vaccination. In fact, one of the main general strategies to increase the uptake of a vaccine in a population consists in health professionals becoming more actively involved in this issue of vaccination acceptance. They should not only to pass along the message, but also “to be” such message. But this does not substitute correct information and empowerment of the patient.

Before going into details, a distinction between mandatory and compulsory vaccination must be made. Compulsory vaccination allows the enforcement of a legal requirement to vaccinate; it has been often used in the past, especially with smallpox, and it was also one of the main reasons behind the rise of the first anti-vaccine movement.

A vaccination is mandatory when an individual can refuse it but such a choice entails a penalty, usually the denial of a social activity such as attending school or working in a hospital. Vaccine

mandates have tended to elicit strong negative reactions from subsets of the population, and, over time, the concerns of these groups have led to the allowance of medical, religious and philosophical exemptions to vaccine mandates, eroding their effectiveness. However, mandatory vaccination programme also allowed to improve vaccine uptake in many instances, conferring significant benefit to the public, or population good.

An important issue is the dilemma of mandating influenza vaccination for healthcare workers, which starts to be adopted somewhere, if one wants to keep on working on a premise. On the one hand, the ethical physician imperatives of non-maleficence (do no harm) and beneficence (act in the patient's best interest) certainly support mandated vaccination for healthcare workers; being vaccinated allows them avoiding the spread of a disease amongst patients and being ready to intervene in case of emergencies. On the other hand, the ethical principles of respect for an individual's rights and autonomy constitute a compelling counter-argument.

While philosophically and politically based vaccine opposition can be difficult to change, vaccine resistance based on personal and societal health decisions and risk analysis is believed to be less rigid and more open to influence. Within this second group of vaccine-resistant citizens, trusted health professionals can improve vaccine acceptance:

- through personal example;
- by unequivocal vaccination recommendations based on scientific evidence;
- by accurate and clearly explained information with a preparedness to counter common misconceptions and cognitive errors;
- using effective timing strategies to take advantage of heightened vaccine acceptance in various settings and emotional states.

An American study identified three main groups with regard to vaccine uptake (Nowak, 2005):

1) individuals who routinely receive the influenza vaccine – this group is more accepting of vaccines and includes a majority of over 65 elderly;
2) individuals who sometimes receive an annual immunization – these individuals, who comprise the largest population segment, make an active decision based on various inputs such as perceived risk of disease versus risk of exposure and perceived severity of disease;
3) those who do not get and do not intend to get the influenza vaccine – this group tends to feel that the vaccine is ineffective, unwarranted, or even dangerous.

This classification may be helpful for health professionals, since it would help to better target their communication based on the "kind" of patient they are facing. Since they are directed to healthy people, vaccines must be, and are tested to be, even safer than any other drug. Anyway, like for any other drug, the possibility of side effects cannot be completely excluded, but it is always estimated to be very lower than the disease they are intended to prevent. Unfortunately, on the media

occasional side effects are always emphasized, while benefits of vaccination tend to be undervalued, so it is sometimes hard to discriminate between serious results and misinformation, particularly for citizens, who thus need the help of professionals to filter all the information they receive.

A good example is represented by the concerns raised by 2009 pandemic influenza vaccines, feared to provoke Guillain-Barré syndrome (GBS), an acute polyneuropathy affecting the peripheral nervous system. The association between influenza vaccines – precisely a swine flu based human influenza vaccine – and GBS traced back to an outbreak in 1976 in USA when mass vaccination was performed and several cases of this kind of transient paralysis were recorded. Following the 2009 influenza pandemic vaccination campaigns, no evidence has been found of an association between GBS and flu vaccines (Dieleman et al., 2011).

On the other hand, in September 2010, Sweden and Finland noted that a number of children had developed narcolepsy, seemingly in association with having received the AS03-adjuvanted influenza pandemic vaccine used in those countries (Pandemrix). An increased risk of narcolepsy in children and adolescents after vaccination with Pandemrix was demonstrated by monitoring systems (VAESCO and ECDC, 2012; Miller et al., 2013). Monitoring systems and transparency about their results are of paramount importance to rebuild the trust in health authorities somehow hindered by 2009-2010 pandemic.

### 2.2.2. Anti-vaccination movement

Skepticism and myths regarding vaccines are quite widespread and constitute a serious issue for public health. For instance, the controversy about the combined measles, mumps and rubella (MMR) vaccine – which was reported by a fraudulent research paper (Wakefield et al., 1998) to provoke autism in children – led to a drop in vaccination compliance in UK, which in turns caused a rise of mumps and measles cases. In 2008, for the first time in 14 years, measles was declared endemic in the UK (Asaria and MacMahon, 2006). It is thus crucial, for GPs, to know motivations and dynamics of these movements, and the reasons that may push people to distrust vaccines or even consider them dangerous.

#### 2.2.2.1. Origins and history

Opposition to vaccination exists since the first vaccines were tested, in the mid-1700s. The first kind of objection to vaccination was based on religious belief; for instance, some people believed that, since diseases were sent by God, protection from them meant to challenge the divine will. When, at the beginning of the XIX century, vaccination became widespread in the United Kingdom through the work of Edward Jenner, political arguments were raised in addition to religious ones. In fact, the introduction of Vaccination Acts, which made vaccination mandatory even for infants, was considered a limitation to the right to autonomy and personal freedom.

Meanwhile, the American President Thomas Jefferson became interested in vaccines and promoted their use and distribution throughout the States of the Union. The resistance to vaccination in the US grew and, in 1879, William Tebb, a British anti-vaccine activist, founded the Anti-Vaccination Society of America, followed

by the New England Anti-Compulsory Vaccination League in 1882 and by the Anti-Vaccination League of New York City in 1885. Such an opposition spread, obtaining the attention of both wealthy and political supporters.

During the course of the last century, poorly explained public health campaigns – like the one carried out in Brazil at the beginning of 1900, which led to the Vaccine Revolt – and some incidents – like the one occurred in 1955, when more than 100,000 doses of polio vaccine were prepared with a live polio virus instead of the inactive one – fuelled the anti-vaccination movements across the world.

More recently, new and stronger forms of opposition emerged. Some have political basis, like the theory of the "Western plot", which circulated in China during the SARS outbreak in 2003, and led to growing suspicion and mistrust for vaccines in many other South-East Asian countries. Or the campaign against Western health professional vaccinating in countries like Afghanistan.

Some other are of cultural origin. Nowadays, the increasing "medicalization" of Western societies and the spread of pseudoscientific claims allowed those who refused vaccination to find more reasons to resist vaccination, aside from religious, moral or philosophical objections. Some believe that vaccine-preventable diseases do not constitute a serious health risk, that diseases like polio were defeated only by sanitation whilst others fear that vaccines are only promoted for profit of Big Pharma companies.

#### 2.2.2.2. Strategies

More than 200 years of history allowed the anti-vaccination movements to develop effective strategies, and to generate and diffuse rumours, conspiracy theories and myths concerning the related vaccine, which proved to be stubbornly resistant in time. Mainstream media, as well as the Internet, played a central role in the diffusion of these myths, especially since people have started becoming more skeptical and actively engaged in search of what they think are reliable sources of information to support their decision for choosing to vaccinate or not. There are four main rhetoric strategies used by anti-vaccination, which healthcare professionals should be aware of (Kata, 2012):

- skewing the science, which consist in the denigration and rejection of scientific studies that do not support anti-vaccine positions, usually claiming that they have been paid by pharmaceutical industries, and in the endorsement of poorly-conducted studies that promote anti-vaccine agendas;
- shifting hypotheses, based on the continual proposition of new theories about the harm caused by vaccines and on moving targets when evidence fails to support such ideas;
- censoring, i.e. suppressing critics and dissenting opinions;
- attacking the opposition, both with personal insults and filing legal actions.

#### 2.2.2.3. Countering false arguments

Strategies used by anti-vaccination activists may also be applied by people who got in contact with activists' messages and have been influenced by them. All these approaches are usually based on a strong polarization of the issue ("right versus wrong") and it is thus very important to not being perceived as an "enemy", meaning someone that could be paid by pharmaceutical companies or trust their claims. GPs need to be

perceived as trustworthy, in order to break this kind of opposition. Personal relationships, credibility, high level of trust are key elements to face anti-vaccination claims.

Trust is not something that can be built at the moment but needs to be pursued way before the appearance of a medical issue. For instance, resistance to vaccination is not a problem to be faced only at the beginning of the flu season, but need to be addressed in advance, by building empathetic relationships, knowing people's experiences, values and beliefs, and sharing their preoccupations.

Health care providers should work with vaccine resistant caregivers, avoiding strategies that will alienate them. It is better to aim for incremental success if full vaccination cannot be persuaded and it is also recommended to acknowledge concerns and be prepared to address them using accurate information. Most of all, vaccine resistant patients must not be abandoned; it is important to continue to provide care, and take advantage of every opportunity to further educate about the benefits of vaccination. It is also useful to utilize the same communication outlets as vaccine opponents and try to avoid the use of difficult-to-interpret statistics such as relative risks and probabilities that involve very large or small numbers. Monitoring common Internet search engine results for key terms is a good practice to remain updated on the kind of information circulating on the web.

## 2.3. Prophylaxis with antiviral drugs in flu

As a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes in flu. For people who have had exposure to an infected person and are at a higher risk of developing severe or complicated illness, an alternative option is close monitoring for symptoms, followed by prompt early antiviral treatment should symptoms develop.

According to the last Cochrane review, in fact (Jefferson et al, 2014), oseltamivir and zanamivir reduced the risk of symptomatic influenza but oseltamivir increased the risk of psychiatric adverse events in the combined on- and off-treatment periods and of headaches, nausea, vomiting and renal events during the treatment. The balance between benefits and harms should accordingly be considered when prescribing these drugs after a household member or other close contact has developed influenza, and it is rarely advantageous for healthy people.

Candidates for prophylaxis with antiviral drugs are rather family or other close contacts of a person with a suspected or confirmed case who are at higher risk for influenza serious complications but have not been vaccinated against the influenza virus strains circulating at the time of exposure (Harper et al., 2009; CDC, 2009).

Healthcare professionals should always keep in mind that cases of resistance to antiviral drugs have been reported (Inoue et al., 2009), and that persons who receive an antiviral medication for chemoprophylaxis might still get infected and be potentially able to transmit influenza virus, even if clinical illness is prevented (Lee et al., 2009; Khazeni et al., 2009).

## 3. Urban myths about preventive measures

Apocryphal and second-hand stories that emerge spontaneously in the community and can rarely be traced to a single point of origin, may give rise to what are called urban myths (or contemporary legends). These manifestations of modern folklore, or folk narratives, exist in various other forms such as rumours, riddles, gossip, children's rhymes and life-cycle rituals, and may concern any aspect of life.

In the context of epidemiology and medicine, there are several modern myths that can evoke feelings of uncertainty, anxiety, panic and fear among the general public, occasionally giving rise to conspiracy theories. GPs must be aware not only of the existence of such myths, but also of the rhetoric and narrative ways by which they break forth, in order to counter their negative effects on the citizens.

### 3.1. General features of urban myths

Urban legends are often attributed to a friend of a friend or presented claiming some kind of "insider knowledge" that people are inclined to accept as true. However, one of their main characteristic, especially with reference to infectious diseases and vaccination, is the absence of verification (or scientific support). They usually emerge spontaneously, most commonly transmitted by word of mouth (verbal) and chain letters or emails (written), the print media, new social media and other online sources, as well as more indirectly through visual arts, such as theatre, films, photography and painting. Also, they tend to be disseminated very quickly, especially through the Internet, whose great penetration allows them to reach a wide audience on a global scale.

Urban legends can be perceived as the product of a shared feeling, a set of emotions or stereotypes. It is widely accepted that, during times of crisis, people are prompted to search for meanings or points of reference to connect with past experiences. This is fertile ground for urban myths and legends to be born and spread among the members of a community. It is important to note that the content of such narratives carries substantial significance for the people, and this is what motivates communities to preserve and propagate these stories.

In general, urban myths and legends usually refer to:

- concerns or worries of people that need to be communicated and shared with the community for protection;
- the need to give meaning and explain some dramatic event in order to be better prepared against potential new threats;
- the need to provide an insightful social commentary on the cultural or economic context of society;
- the support to the social mechanism of building trust towards the other, by sharing everyday stories.

### 3.2. Myths about vaccines and preventive measures

- A disease can be transmitted from the vaccine.
- The vaccines are dangerous / more dangerous than the virus.

- Squalene, ingredient of the flu vaccine used as a booster, caused the Gulf War Syndrome.
- A mercury metabolite of thimerosal, ingredient of the flu vaccine used as a preservative, is a poisonous substance responsible for autism and other developmental disorders.
- Flu vaccines cause the Guillain-Barré Syndrome.
- Vaccines actually weaken the immune system, making people less able to withstand viruses on their own.
- The main pharmaceutical companies (generally referred to as "Big Pharma") promote vaccines only to increase their own profit.
- The governments secretly use vaccines for several infamous purposes, such as tracking citizens, experimental warfare and even mind-control techniques.
- If someone is vaccinated against seasonal flu each year, there is no need then to be vaccinated for other kind of flu, like the swine one.

### 3.3. Examples of myths about alternatives to vaccines

- To protect themselves from flu it is enough that someone just eats organic food, takes vitamins, washes hands and drinks plenty of liquids.
- Facemasks alone can protect from the pandemics.
- Bringing a child in contact with patients affected by the flu is the better option for building a natural immunity to the virus.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.

## 4. Compliance with vaccination

Compliance with vaccination depends on many positive or negative factors: desire for self-protection, desire to avoid infecting patients, desire to avoid infecting family members, perceived safety of the vaccine, perceived efficacy of the vaccine, perceived seriousness of the disease, perceived risk of the disease, perceived seriousness of complications from the disease, access to the vaccine, cost of the vaccine, fear that the vaccine could cause disease.

Different persons may be influenced by these factors in different ways; it is thus important to stress that "public" is not a single entity. Different people require different kinds of communication, based on their individual concerns and beliefs, as well as health, familiar and/or socio-cultural conditions. These sub-groups of population display differences in terms of compliance to vaccination that may be extremely variable. The next chapter will focus on each of these categories, highlighting factors that most influence their compliance

(or refusal) of vaccination. Such knowledge should be used by healthcare professionals to properly target their communication, "tailoring" it based on the person they are facing each time.

### 4.1. Opinion leaders

Opinion leaders do not constitute a real sub-group and may be found in any of them. However, they are a relevant component of risk communication (Katz and Lazarsfield, 1955). They are trustworthy members of a given social network and this can be true for a community but also for a family, where one person could be more in charge of medical decision, including vaccination, or has the ability to engage and convince other members of the group. Also, they serve as an alternative source of information (other than the media) and as a source of interpretation for people seeking clarification. It is thus crucial to identify opinion leaders within groups or families, in order to mediate preventive messages through them. Each GP who knows his own community could identify the most prominent opinion leaders in it, going from families to social, political and religious leaders.

### 4.2. Elderlies

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. is the number of visits the person pays to a physician during the year. One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians. Clearly, this information is of great importance for healthcare workers, since it highlights the relevance of their role and how much they are trusted by this sub-group. It is thus crucial, for them, to maintain such trust, always keeping in mind that major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine.

### 4.3. Chronically ill

Compliance rates of the chronically ill with influenza vaccine in the U.S. are greater than those of healthy people and have been increasing over the years. In contrast, compliance rates among the chronically ill in Europe are relatively low. It is also important to note that there is a wide difference in the compliance rates of groups of people with different chronic diseases and in each group there are differences in the compliance rates in different age groups.

For this category, as it happens with the elderlies, the main factors affecting compliance are the number of physician visits and the acceptance of their advice as positive factors, and the fear of side effects and disbelief in the vaccine effectiveness as negative factors.

### 4.4. Pregnant women

By most experts, pregnant women are considered at increased risk for complications of flu. However, few pregnant women are actually vaccinated in Europe, mainly because of a lack of knowledge of the importance of the vaccine, and especially because of concerns for effects of the vaccine on foetal and maternal health,

despite several studies showing the opposite (for instance, Legge et al., 2014). Again, as for previous categories, another factor found to influence vaccine uptake by pregnant women is their healthcare provider recommendation.

## 4.5. Children

Young children are often the targets of vaccination campaigns because preventing diffusion of a virus in this age group is one of the best ways to contain the spread of a disease.

Studies carried out in the US by the CDC revealed that the compliance of chronically ill children with the vaccine is greater than that of healthy children and that the percentage of children getting one dose of the vaccine is greater than the percentage of fully vaccinated children. In Europe, things are different. The rates of children's influenza vaccination should always be related to their parents' health behaviour.

Amongst the factors that were found to have a positive effect on vaccination rates of children there are the child's influenza vaccination in the previous year, the child's uninterrupted health insurance coverage, and even the mother's unmarried status. On the contrary, factors that were found to have a negative effect on vaccination rates of children include using a family doctor rather than a paediatrician for well-child visits, parents belief that the vaccine was unneeded or that their child was getting too many shots, and parents having a hard time obtaining the vaccine (CDC, 2004a, 2004b, 2011). There is also evidence that a proportion of parents of under-vaccinated children (children who have some but not all of the recommended vaccines) are not resistant to vaccination; rather, they often have issues with vaccine accessibility related to economic, social, and in some regions, geographical barriers.

## 4.6. Healthcare workers

Among the target groups, those of GPs is the one with more positive factors associated with compliance for vaccination: self-protection, the desire to avoid infecting patients, the desire to protect family members, the perceived efficacy and safety of the vaccine, as well as the perceived seriousness and risk of diseases, including the complications they may lead to. Access to vaccine and their cost are also included within the positive factors.

However, the fear of side effects of that vaccine could cause disease can be found even amongst healthcare workers, together with a feeling of invulnerability, and being too young and in good health to risk. All these factors have a negative effect on compliance towards vaccines.

Taken together, these observations reveal that health professionals, when compared to the other sub-groups, tend to have more altruistic reasons for being vaccinated but also tend to underestimate the importance of getting a vaccine, especially when young and healthy. Such behaviour should be avoided, since it could represent a bad example for their patients and, being them more likely to be exposed to pathogens, might also facilitate the spread of an infectious disease.

### 4.7. Socio-cultural differences

Obstacles for the acceptance of vaccines may also be caused by socio-cultural differences. For instance, highly qualified people had lower trust in vaccines (as reported mainly in Hungary). In the UK, African and Asians patients were found to be difficult groups to persuade, whilst Romanian and Hungarian general practitioners thought the same in the case of the Roma minority, even if Hungarian ones perceived two extremities regarding Roma minority: low trust in administration and in doctors, but a tendency towards getting scared easily and thus coming to doctor for help.

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# Case history 2 – A flu lesson

**Topic:** prevention by personal protective measures
**Target:** pediatric population

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass the case history it's needed to answer correctly to 80% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Extrasources:**

- ECDC - 5 ways to stop the spread of flu

### Step 1

In a foggy fall morning, students of a lower secondary school are attending their daily class.
“Good morning, everybody” says the science teacher, timely going into the classroom.
“Good morning, professor Henry” reply the still drowsy students.
“Today’s lesson will be a bit different from usual, but I’m pretty sure that you’ll find it so interesting that you’ll quickly get awake, even if it’s Monday”.
Such a presentation, together with the presence of an unknown person, catches the students’ attention. The stranger is a young woman and the professor introduces her as soon as she gets into the classroom.
“Doctor Anne is from Local Health Authorities and will stay with us during our science class. At first, she will explain you some things and after that, you’ll be allowed to ask some questions. This special class is due to the fact that our school joined a national educational program about flu”.
“And how to avoid it, obviously” says the doctor with a smile. “We think that taking care of our own health since we are young is really important. That’s why we chose to come here to talk with you”.

**Which of the followings is true about teenagers exposed to the types of flu that epidemically affected European people, i.e. seasonal and H1N1 flu?**

- teenagers were more susceptible than elderly during H1N1 pandemic
- teenagers were a category at risk of more severe complications than young children during pandemic H1N1 influenza
- teenagers are a category at risk for seasonal influenza
- teenagers are not at risk for any form of influenza

**Step 2**

The doctor goes on with her talk: “I’m going to ask you one question, but stay assured that I’m not going to give you a mark for that. Apart from getting a shot, who knows which is the first and easiest thing you can do by yourself in order to avoid catching a flu?”.
Many students raise their hands and many answers come: “aspirin”, “those medicines called antibiotics, you ignorant!”, “not catching cold”, “taking vitamins”, “not going to school”, “even to the cinema, then”.
Both the professor and the doctor smile, then Anne replies, in order to give the correct answer.

**Apart from vaccination, which is the best way to prevent flu in young and healthy population?**

- ○ prophylaxis with antiviral drugs
- ○ closing schools
- ● washing hands regularly and thoroughly with soap and water
- ○ washing hands regularly and thoroughly with alcohol-based sanitizers

**Step 3**

“I’m sorry, but nobody got the right answer”.
There is a sudden exchange of astonished gazes among the students.
“You couldn’t imagine that, uh? Washing your hands. I’m sure is something that all of you love to do even before your mother tells you about” says the doctor. Somebody laughs from the last benches.
The professor steps-in: “But it doesn’t end here. Some other simple things can protect you from the flu. Who among you noted the leaflet by ECDC [Extrasource: 5 ways to stop the spread of flu], which has been posted in the last very days in many places within the school and on all the toilets’ doors?”.
Nobody answers.
The doctor takes inspiration from what the professor just said and says: “If somebody had gone through it carefully, he would know that, it is also useful to… come on, try to get it”.
The students are involved by such an unusual lesson class and raise their hands to offer their answers.

**Which among the following measures helps to reduce contagion in seasonal flu?**

- ○ “Covering nose and mouth when sneezing or coughing”
- ● “Closing schools at the peak of the outbreak”
- ○ “Avoiding staying out in cold weather”
- ○ “Not practicing sports in open air in winter time”

**Step 4**

“Very good, you’re definitely improving” says the doctor. “Clearly, many of you have read the leaflet; however, I will leave you a copy of it because it is very important that you bring home what you just learned today. As I said, your answers were correct and I’m going to explain you why. Flu, or influenza, is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. And now, I’m also going to tell you why one of the answers I heard was wrong. Wearing a mask when you are in the street is not useful”.
“My father works in a hospital and uses it” objects a girl.
“Well, that’s different”.
Another hand is raised: “I have a very young brother, he’s just two months old. My mother fears that, if I get sick, I will infect him”.
“Well, in that case, you should stay away from him”.
“Away?”.
“Yes, you should avoid close contact if you’re sick...”.

**Which distance shall the doctor recommend?**

- (●) maintaining a distance of at least one meter
- ( ) maintaining a distance of at least 50 centimeters
- ( ) staying in another room
- ( ) not sleeping in the same room

**Step 5**

“However, you should know that keeping off somebody who’s already sick is a good thing to do, but doesn’t guarantee to be safe from getting flu. Influenza virus is already present in the droplets a few days before a person begins to manifest the first symptoms of sickness”.
“How many days before?” ask another student.

**How long does flu incubation last?**

- ( ) 7-15 days, on average 10 days
- ( ) few hours
- (●) 1-4 days, on average 2 days
- ( ) about a week

INVIA RISPOSTE

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**Conclusion**

“If you have some other questions about flu or about something on the leaflet that didn’t sound clear to you…” suggests the professor.
The class clams up, until a boy from the last bench says: “This leaflet is quite good, in fact there is a point that I really like”.
“Which one?” asks the doctor.
“Stay at home when you are ill!” answers the student laughing.

Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 2

## Summary

## Step 1

*Dossier 1 - Epidemics and pandemics - General guidelines*

**2.1.2. Categories at risk**

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

[…]

**2.3.2. Categories at risk**

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10% than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

## Step 2

*Dossier 1 - Epidemics and pandemics - General guidelines*

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

[…]

*Dossier 2 - Talking about prevention*

**2. Preventive measures**

**2.1. Non pharmacological measures**

Most healthcare-associated infections are preventable through a number of personal measures that people may take to reduce their risk of being infected (Cowling et al., 2008; Jefferson et al., 2008). Amongst the most basic of these measures, there is a good hand hygiene, which means cleaning hands at the right times and in the right way. This should be do frequently, not too quickly – at least 20 seconds each time – and thoroughly with soap and water, especially after coughing or sneezing.

## Step 3

*Dossier 1 - Epidemics and pandemics - General guidelines*

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

[…]

*Dossier 2 - Talking about prevention*

Another simple rule to be followed is to avoid touching eyes, nose and mouth after a contact with surface that could be contaminated, while there is no evidence that wearing facemasks outside of healthcare settings during a pandemic offers effective protection or reduces transmission. This is why ECDC does not recommend their routine use.

Healthcare workers must remind the importance of these measures within a family or a group where one person has been infected. This means that patients should be encouraged to prevent other people from being exposed to their own potentially infectious nasal and oral discharge. They should cover their mouth and nose using tissues when coughing or sneezing; or cough or sneeze into an arm rather than their hands. In addition, tissues should be thrown in the bin after use. Since the importance of such a simple gesture may be sometimes underestimated, doctors should always stress its crucial role for prevention of infectious diseases. This is particularly true in healthcare facilities, since these places are the most exposed to pathogens.

## Step 4

*Dossier 2 - Talking about prevention*

Another important practice is the so-called “social distancing”, which means to avoid close contact with sick people. This can be done maintaining a distance of at least one metre from someone with symptoms of a disease and avoiding unnecessarily visit to people who are sick. When distance cannot be maintained, for instance in crowded situations, it is recommended to reduce the time of close contact with people who might be ill and the time in these situations to the extent possible.

## Step 5

*Dossier 1 - Epidemics and pandemics - General guidelines*

People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two.

Case history 3

# All you need is vaccine

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

## Table of contents

## INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

## 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

### 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is “an epidemic outbreak”. A broad definition given by many epidemiologists for epidemic is “more disease than is anticipated by previous experience”, whilst a more precise one is “a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension”, and is to be distinguished by an outbreak, which is “an epidemic confined to a defined short time and place”. Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when “there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time”. This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase “enormous numbers of deaths and illness” had been removed and the revised web page simply read as follows: “An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity.” Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

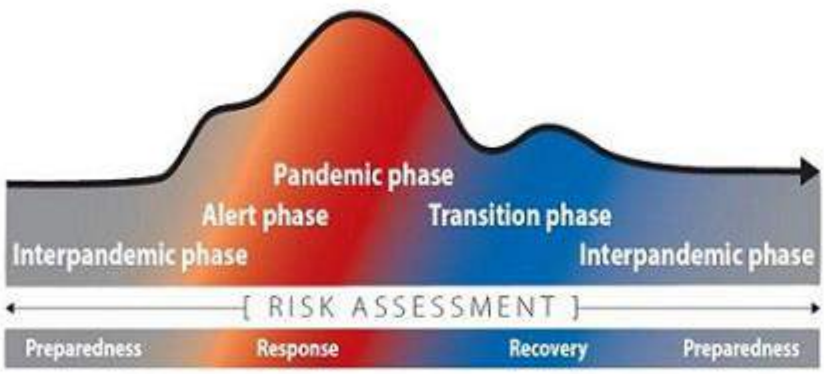
WHO argues that this phrase had little bearing on policy responses, it was “never part of the formal definition of a pandemic” and was never sent to Member States, but simply appeared in “a document on WHO’s website for some months”. In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO’s pandemic preparedness guidelines are only “pandemic phase” definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States “had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event”. This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

# 2. Main epidemics

## 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use. Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

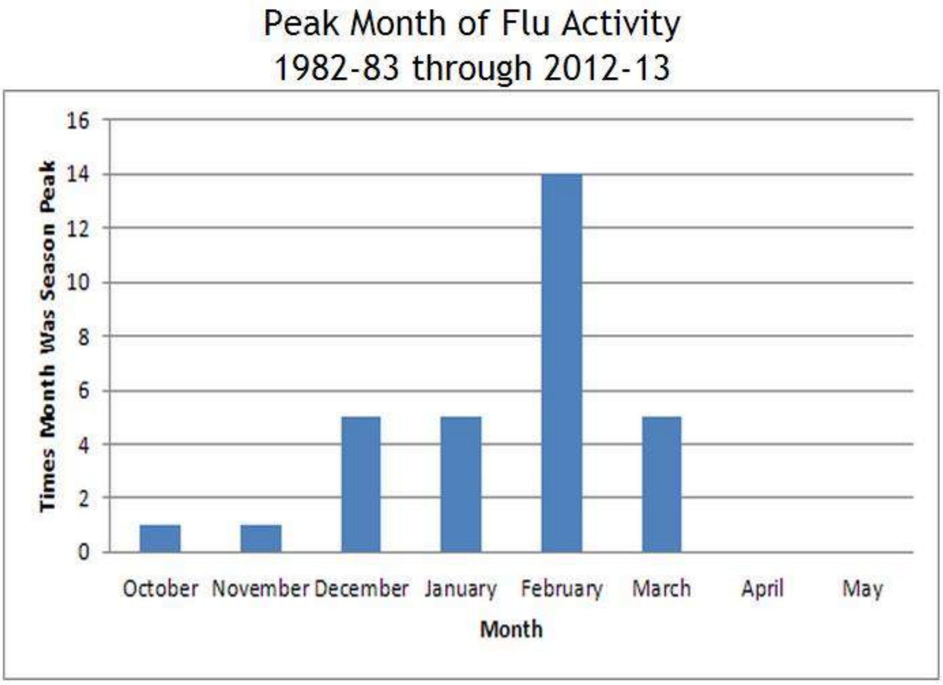
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




**During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.*

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the "low but real risk" group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name "swine flu" was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC's early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions.  WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Talking about prevention in case of pandemics: information and strategies for healthcare professionals

WP3 Prototype Online Course for Primary Care Staff
DOSSIER 2

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Talking about prevention in case of pandemics: information and strategies for healthcare professionals

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |

## Table of Contents

## INTRODUCTION

Prevention is essential in order to contain infectious outbreaks and, amongst preventive strategies, communication constitutes one of the key elements: it allows educating and informing citizens about healthy practices, raising awareness about diseases, involving patients and avoiding the diffusion of misinformation.

Healthcare workers constitute the interface between institutions and citizens, and this implies that they have a crucial role in preventive activities. They possess high accessibility by the population and have high credibility in the public's view. Patients often put greater trust in their general practitioners (GPs) than in governmental communication, meaning that they serve as example in attitude to health prevention and that they could perform further personalized communications. Knowing how to properly talk about prevention is thus crucial for healthcare professionals. This dossier will focus on the communication approaches that they should adopt in order to properly promote preventive measures in case of pandemics.

The chapter 1 of this dossier will summarize **some communication clues** to be kept in mind when talking with people regarding infectious risk and preventive measures, in order to avoid a top-down communication that could be either useless or counterproductive.

The chapter 2 will tackle the **main preventive measures** and describe the main issues associated to them. Particular attention will be given to anti-vaccine movements, in order to provide an effective framework of this reality and to identify key elements that could be useful to improve healthcare workers communication efforts.

The chapter 3 will go further into the concept of **urban myth** and analyse the most diffuse myths regarding preventive measures. Knowing in advance the rhetoric elements behind such modern legends may help health professionals to better hinder them.

The chapter 4 will present the **factors that mainly influence people's decision about vaccines**, dividing them into the most relevant subgroups that have been recognized. Identifying the characteristics of an interlocutor and targeting a message based on them is a key point in risk communication, especially for healthcare workers, who daily interact with citizens.

## 1. Talking to the public

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as "just another reassurance" and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

## 1.1 Perception of risk

According to Peter Sandman's theory, perception of risk by people does not depend only on the effective hazard, but also, and even more, by the outrage linked to it (Sandman, 1999). This depends on the danger being domestic or exotic, coerced or voluntary, chronic or acute, and so on. The studies on factors influencing risk perception highlight that this is basically related to emotional factors to such an extent that a series of components corresponding to the "perceived offence" (outrage), more than the real hazard that is the cause of the hazard itself, contribute to determine the perceived risk.

Healthcare professional, as well as institutions, must receive and "actively listen" people worries and be aware of offence "determinants" characterizing the perceived risk, so as to have greater opportunities to understand the origin of perception and be able to deal with it (Sjoberg, 1999).

They need to understand the main worries of the population involved, especially as far as the weakest categories are concerned, such as, for example, children and pregnant women. People, in fact, tend to base their risk assessment not on the count of possible number of dead, injured people or socio-economic damage, but on the perceived presence of specific characteristics of risk situations and on some perceived properties of risk source, such as, for example, the familiarity with risk, individual control, comprehension, effects on children, effects on future generations, personal engagement, uncertainty of scientific data, voluntary exposure, trust in Institutions (Lambert, 2003).

Communication must therefore follow the participatory model based on the interactive exchange assessment among all the parties (Leiss, 1987), concerning the attention to the emotional component of individual and collective perception (Slovic, 1987), as well as the understanding of social and personal issues, that is crucial to make scientific data a useful knowledge for citizen.

## 1.2 Listening is the first condition

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is "distant" from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the "focal issue", the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness.

Listening represents the first step in the professional relationship; it is based on empathy and on the other's point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other's shoes, thus entering his reference scheme and trying to see the "world" with the other's eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time "as if" you were the other, but without forgetting that it is just "as if". If there is no "as if" condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to "see the world with the eyes of the other person" so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction  not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one's own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one's own values and perceptions for embracing the one of the other person "as if" were one's own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

## 1.3 The empathic listening

Listening can be activated through the development of bidirectional communicative channels able to facilitate information flows and useful exchange so as to understand the patient's informative needs, his/her worries and for supporting the choices that justify the use of either some interventions or the others.

Interpersonal relationship generally represents the most effective way to implement the bidirectional exchange, so as to listen and deepen risk perception level, personal experience, information acquired, poor areas and to create the basis for a relationship of trust and cooperation.

Within the interpersonal context, it is possible to use a specific method called empathic mirroring which, through adequate communicative techniques, can ease the listening, thus favoring the focusing on the point of view of the other and on risk perception (Giampaoli S, 2005). Crucial techniques of empathic mirroring are

as follows: reformulation, clarification, ability in questions, use of first person messages (“I think that”, “According to me”).

“Reformulation” is a technique consisting in repeating what the other has just said, using the same words or rephrasing in a more concise way using other terms, without adding other concepts to the content. In this way, the operator may obtain a positive result from the other person, who knows of having been listened. One can wait the moment in which the other person has finished a sentence for intervening and resuming what has just been said: “You’re telling me that…”, “You mean that…”, “In other words…”, “Therefore, according to you…”, “You think that…”.

The person recognizing himself in the reformulation is sure of having been listened and understood, and is therefore confident to further express himself and cooperate. He is also facilitated to stay focused on the issue and on how he faces it.

“Clarification” facilitates the self-understanding underlying, through oral communication, the emotions associated to content. This is clear both at oral and non-oral communication. “I can see in your eyes that you’re worried”; “From your words I can feel you’re uncertain about what I’m saying”.

The “survey capability” is the ability in how to make questions, choosing the most adequate type based on interviews stages. “Open ended questions” have to be preferred in the initial stage of the interview; they allow for a wider chance of answer, tend to extend and deepen the relationship, encourage opinions and thoughts exposition (how, what he would like, could, may deepen, what he thinks).

“Closed ended questions” are defined, they force to a sole specific answer, often stress an answer, limit the communication and make it more focused, demand only objectives facts and sometimes may seem restrictive and obstructing (when?, where?, who?). Questions starting with “why” can be perceived by the person as accusingly, and should be avoided.

The use of first-person messages (“I think that”, “According to me”) make it easy to distinguish between what concerns the expert operator and what concerns the person, thus allowing to avoid conflicts and favoring a non-judging mood and an autonomous decision-making process.

## 1.4 Listening to communicate uncertainty

The empathic listening may favor the “uncertainty communication”, key process especially when, such as in an emerging outbreak, a crisis occurs while information are often incomplete and sometimes contrasting.

“Uncertainty communication” corresponds to processes communication and not to the outcomes, that is to the supported description of choices made or that will be made and the explanation underlying some decisions more than others. Declaring and supporting the uncertainty, it is possible to shorten the distance between a risk scientific-probabilistic assessment and a subjective personal assessment determined by the perception of risk, which increases when the emotional level increases.

The communication on uncertainty comes from the need of Institutions to communicate. Therefore, it demands a strategy and planning of communicative process, favored by the integrated participation and collaboration of institutions and systems involved at regional and national level. In fact, due to the fact that communication of uncertainty entails the choice of arguments and hypothesis that may explain, in a transparent way, to citizens, the reason for certain decisions more than others, it is crucial that the choice is

shared among figures and organizations involved in the communication process. Sharing creates the conditions for the formulation of homogeneous, understandable messages, able to make people understanding the reason behind certain choices, the consequences that they could entail, the reasons for which, at the moment, it is preferred to follow certain paths more than others. It is important that people understand and are informed even in an uncertain way, declaring “what is known and what is unknown”. The same is true at an individual level.

When people receive detailed explanations on hypothesis and/or paths chosen because considered, at the current level of knowledge, most likely or adequate, they have the chance to assess the situation with a greater serenity and “competence” and to arrange the choices within their life context. At the time of the emergency, they will be more likely to be collaborative, willing to face difficult situations.

Moreover, when people understand and take part in the choices, they feel respected and trust Institutions and professionals that listen and understand worries of individuals and community and are responsible for a comprehensible information. If, on the other hand, they feel “manipulated”, mislead, they lose trust and it is more likely that they will respond with denial and panic or ignore the provisions in a situation of maximum emergency.

Sometimes Institutions and experts avoid to explain complex issues and tend to reassure “Don’t worry, be calm, everything is under control”; they prefer “not to say”, but “it is not possible to communicate” because even the silence is a communication form. An information must always be given, reporting what has been done, what has been doing, what it is intended to do; transparency is basically the best choice.

## 1.5 Dealing with new media

Since many people use to look for information on the Internet, healthcare workers should pay attention to such a reality for two reasons: on the one hand, knowing the kind of information that flows through the net could be useful to forestall some possible criticism. On the other hand, social media and Facebook groups may constitute extremely valuable tools to keep patients up to date with advices and to promptly hinder false or ambiguous knowledge they could have found on the web.

Internet or social media use is not a remit of younger generations. According to some reports up to 476 million Europeans, of all age ranges, use the web. This accounts for approximately 65 per cent of the population, and the number continues to rise (IAB Europe, 2012). Estimates for the time an average European Internet user spends online is 27.6 hours per month, which exceeds the global mean of 24.5 hours. (comScore, 2012).

Kata (2012) highlights the fact that people nowadays are likely to search online for health information, and the anti-vaccination movement has taken advantage of this milieu to disseminate its messages.

“In the past when someone became ill, he or she would immediately go see a doctor. Nowadays people often turn first to the Internet and use the gathered information to formulate their thoughts. According to a health survey, a growing number of patients currently make their own judgements about what treatment and medicine they would like to have prescribed by a doctor. A literature review on health information-seeking behaviour on the web shows that, according to different articles and studies reviewed, interest in the Internet as a communication tool for health-related information is growing rapidly. This review also cites a WHO eHealth cross-country survey of seven countries which showed that 71% of Internet users surveyed had used the Internet for health purposes. The Internet, forums and social networking tools have allowed anti-

vaccination advocacy groups to have a broader reach than ever before. While years ago, vaccine-related rumours would have been restricted to certain countries, online tools allow these to spread more quickly and to different countries, as experts highlight" (ECDC, 2012).

As defined by Betsch (2010), Web 2.0 or social media is "Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, eg. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (eg static health portals), Web 2.0 enables two-way and multi-way communication."

Broadly speaking, social media is then a multi-way information sharing and communications tool, where users can converse and interact with each other irrespective of differences in geographical location or social background. The difference between social media (or Web 2.0 as it is sometimes known) and previous Internet platforms is that it is characterised by user-generated content. Within social media, users are more than just consumers of information, as the design of such platforms encourages them to share and contribute information to the network. McNab suggests that: "Until recently the predominant communication model was "one" authority to "many" – i.e. a health institution, the ministry of health or a journalist communicating to the public. Social media has changed the monologue to a dialogue, where anyone with ICT access can be a content creator and communicator." (McNab, 2009)

In recent years, there has been a shift towards social media being used not just as a platform to connect with friends and family but as the first place where users find out about breaking news stories. (Ofcom, 2011)

51 per cent of 18-24 year olds with a social networking profile agreed with the statement that they often find out about breaking news stories via social networking sites. 43 per cent of UK women agreed with this statement, whilst 27 per cent of men agreed. (Ofcom, 2011) Despite the overriding popularity of profile-based social networks such as Facebook, 'microblogging' sites such as Twitter (reaches one in ten Internet users worldwide) and Sina Weibo (337m users in China) uniquely encourage users to interact without being limited to interpersonal relations among friends. This form of concise, informal, rapid and open communication has led to microblogging sites to become fora where members discuss major world events and issues in real time. (comScore, 2011) According to a study by the Oxford Internet Institute, the average U.K. user now considers the Internet as their most important source for information. (2011) Notably, the study also found that *confidence* in the reliability of information found on the Internet has also increased, as users tend to trust the Internet as much as other forms of media. (2011) This may be explained by users' growing confidence in their ability to sift through and validate information on the Internet. Information from other media sources cannot be validated so immediately—for comparison, a second newspaper must be bought, or a different radio or TV programme must be waited for, yet with social media news or opinion can be cross referenced rapidly by drawing upon information posted by fellow users.

### 1.5.1. Benefit of Social Media

In contrast to traditional Web sites, which only allow communication of information to the public, social media allow not only the ability to provide information to the public, but also for the public to share information with the source. Users can create and disseminate information themselves, thus becoming more involved. An example of this interaction is demonstrated by a statement shared by the Centers for Disease Control and Prevention (CDC) on their Facebook page regarding vaccination on July 5, 2012: *"When was your*

*last tetanus shot? Tetanus vaccines can prevent this disease in children, teens and adults. Without the vaccine, you can get tetanus ("lockjaw") just by getting cuts, especially puncture wounds, that become infected with the bacteria."* This statement received 100 "likes" and elicited both supportive statements such as "Mine was only a couple years ago, but it's good to know what it helps prevent. I've had this done twice already" as well as dissenting statements with links to other information. Social media also allows individuals to provide public support for organizations, individuals, and causes by "liking" on Facebook or "following" on Twitter.

It also enables the sharing of information with a large audience. A link shared by an organization, individual, or cause, can be "shared" or "retweeted" to an individual's friends or followers, which can, in turn, lead to even greater shares or retweets. In this day and age, "going viral" is one of the fastest ways to facilitate the spread of information.

One major advantage of social media is that it can share "real-time" information regarding a public health crisis or other emergency scenario. For example, not only could a user receive information from an organization (eg, CDC), a public figure, but also their friends and associates. Because the individual self-selects the source of their own information, they are able to determine the sources that they most trust (CDC vs. NVIC), or alternatively like or know (eg, friend or celebrity). Such sources are likely to shape beliefs, attitudes, and behaviors. While this is great for sharing information, it can also be challenging, since people will be getting their information from the same types of places, which may not be reputable. They may also receive conflicting information, which can lead to mistrust and confusion. From this point of view, the "health blogger" or the "concerned mother" are sometimes as important as a GP in spreading good or bad information. Furthermore, individuals can easily receive information from "friends" or "followers." Simply sharing or tweeting "Should I vaccinate my child?" could provide an array of responses – both positive and negative – which could potentially influence an individual's decision making process.

### 1.5.2. Challenges of social media

It is relatively easy for messages to get distorted or used out of context. For example, for each "retweet" or "share," the original message can potentially be modified or added to by the user. While the initial source of information (eg, website) will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. Because of this, misinformation can rapidly spread amongst social media sources, leading to such sources as Snopes (www.snopes.com), a well-known resource for validating and debunking "social media legends." Frighteningly, social media users can "share" or "retweet" misinformation just as quickly and easily as accurate information. Two-way communication, while listed as a strength of social media, can also be used negatively to further perpetuate misinformation.

While social media avenues are great for getting information out quickly, they are not always well-suited to sharing complex or substantial amounts of information. Most social media outlets only allow limited lengths of communication. For example, "tweets" are limited to less than 140 characters, which often precludes sufficient evidence or explanation being provided.

While we are still trying to tackle with web 2.0, the experts say that web 3.0 is coming: more powerful software and machines are supposed to make the leap to a new "semantic" web, able to gice a meaning to the information gathered online, making the Internet less of a catalog and more of a guide — and even provide the foundation for systems that can reason in a human fashion (Markoff J, 2006).

## 2. Preventive measures

### 2.1. Non pharmacological measures

Most healthcare-associated infections are preventable through a number of personal measures that people may take to reduce their risk of being infected (Cowling et al., 2008; Jefferson et al., 2008). Amongst the most basic of these measures, there is a good hand hygiene, which means cleaning hands at the right times and in the right way. This should be do frequently, not too quickly – at least 20 seconds each time – and thoroughly with soap and water, especially after coughing or sneezing.

Another important practice is the so-called "social distancing", which means to avoid close contact with sick people. This can be done maintaining a distance of at least one metre from someone with symptoms of a disease and avoiding unnecessarily visit to people who are sick. When distance cannot be maintained, for instance in crowded situations, it is recommended to reduce the time of close contact with people who might be ill and the time in these situations to the extent possible.

Another simple rule to be followed is to avoid touching eyes, nose and mouth after a contact with surface that could be contaminated, while there is no evidence that wearing facemasks outside of healthcare settings during a pandemic offers effective protection or reduces transmission. This is why ECDC does not recommend their routine use.

Healthcare workers must remind the importance of these measures within a family or a group where one person has been infected. This means that patients should be encouraged to prevent other people from being exposed to their own potentially infectious nasal and oral discharge. They should cover their mouth and nose using tissues when coughing or sneezing; or cough or sneeze into an arm rather than their hands. In addition, tissues should be thrown in the bin after use. Since the importance of such a simple gesture may be sometimes underestimated, doctors should always stress its crucial role for prevention of infectious diseases. This is particularly true in healthcare facilities, since these places are the most exposed to pathogens.

### 2.2. Vaccination

#### 2.2.1 Vaccination against flu

Vaccination is the most effective form of prevention from influenza, even if it cannot give a 100% protection from the disease. "Cross-immunity following infection by one strain or vaccination with a specific type or subtype often does not protect completely against subsequent variants of the same type or subtype. The extent to which influenza A(H3N2), A(H1N1), and B viruses circulate may vary by season. In addition, as the antigenic properties of these viruses might change due to continuous evolution of these viruses under immune pressure (antigenic drift), the virus strains of A(H3N2), A(H1N1) and B included in the vaccine have to be reviewed by the WHO annually and possibly changed. Also new vaccines may have to be made when variants of the virus emerge through a major change called an antigenic shift.

Most of the acquired protection against influenza comes from antibodies in the blood. Some additional protection comes from cell-based immunity and IgA antibodies produced on mucous membranes, like those of the respiratory tract. After the first (primary) infection, or vaccination, virus-neutralising antibodies to the haemagglutinin and neuraminidase appear in the blood in about one to two weeks and rise to a peak in about four weeks. Antibodies inhibit haemagglutination, agglutination of red blood cells due to multiple red blood cells bound by one virus, and so this is referred as haemagglutination inhibition (HAI). HAI correlates fairly well with virus neutralisation. Hence often the levels of these specific antibodies are used as a proxy for the presumed level of protection, with higher titres of more than 1:40 or 1:80 (in the older person) taken to indicate immunity.

After a second or further infection, or repeat vaccination, the antibodies appear and rise more quickly. The antibodies usually persist for months or years, although in people with weaker immune systems, like the elderly and those with chronic illness, they decline more quickly and vaccination is less effective. Another problem with influenza vaccination is that antibodies to one type or subtype of influenza do not necessarily give protection to other influenza virus types or subtypes (so called cross protection). Equally, they do not give full protection against subsequent drift variants of the same type or subtype. That is why seasonal influenza vaccines contain a mix of influenza virus types and subtypes and the composition has to be reviewed each year by the WHO" (ECDC official website, Factsheet for health professional).

#### 2.2.1.1. Influenza vaccines

In Europe, three main types of vaccines are currently available. They are all inactivated, with some of them adjuvanted:

- split virus vaccines consisting of disrupted virus particles
- subunit vaccines consisting only of the two main antigens, haemagglutinin and neuraminidase
- whole inactivated virus vaccines

In 2011, a live attenuated influenza vaccine that has been used in USA since 2002 was approved in Europe too for children (2-17 years of age).

#### 2.2.1.2. Vaccination strategies

In Europe, vaccination is usually recommended to reduce the risk of people at greater risk of complications from becoming infected (selective vaccination), more than to stop the spread of the disease, as in other countries is done, targeting schoolchildren. VENICE surveys of the EU/EEA countries sponsored by ECDC found that all reporting countries were recommending annual vaccination to the two largest groups which are highlighted by the European Union Health Council (Council of the EU 2009) and WHO (WHO 2002):

1. older people above a nationally defined age (usually 65 years and older);
2. all people over six months of age with chronic medical conditions: notably chronic heart or lung diseases, metabolic or renal disease, or immunodeficiencies.

Many countries emphasise the importance of annual vaccination of people in residential care for the elderly and disabled and there is excellent evidence that supports immunising those that care for them. Few EU countries recommend vaccination of children or offering vaccines to pregnant women, in this following a different strategy from policy in the United States (CDC 2010).

“In addition to the risk groups there are also other groups for who immunisation is often recommended – these are referred to as target groups. The most important of these are healthcare staff who are expected to prevent their infecting their patients with influenza-by-influenza vaccination as well as the other non-pharmaceutical measures. The vaccination will also protect the staff but its prime purpose is to prevent iatrogenic spread. Hence, all countries in Europe recommend that all healthcare staff should be immunized against influenza. This is especially important for patients at higher risk of infection and disease, where immunization is less likely to be effective. There is strong evidence that this protection works” (ECDC official website, Factsheet for health professional).

Influenza vaccines are licensed not only for those in the risk group. They can protect also well children, adolescents and younger adults. Almost all can choose to get vaccinated or to vaccinate their children so to protect weaker relatives, reduce the impact of the disease on daily life and limit its socio-economic consequences.

### 2.2.1.3. Vaccine efficacy and effectiveness

“Estimates of vaccine efficacy and effectiveness – or the extent to which vaccines protect in optimal circumstances (efficacy) and in practice (effectiveness) – vary according to the match between vaccine and the circulating viral strain and by age group and clinical category. Generally, the vaccines work less well in the elderly and those with chronic ill health. In trials, inactivated influenza vaccines have consistently been shown to prevent laboratory-confirmed illness in between 70% and 90% of healthy adults. The results are somewhat less in field effectiveness studies. The reduction in hospitalisations and deaths is less dramatic but still significant. Trial data cannot help here as hospitalisations, pneumonia and deaths are too uncommon to be revealed by trial data that also usually exclude those most at risk. Instead, observational data have to be used. These data are more subject to bias. However, modern epidemiological studies can compensate for these biases and when this is done, positive effects are consistently observed, although there are minority opinions that disagree” (ECDC official website, Factsheet for health professional).

### 2.2.1.4. Contraindications to vaccination

“As most viruses used for influenza vaccines are grown in eggs, egg-based vaccines should not be used for individuals with a definite history of serious allergic reactions to egg products” (ECDC official website, Factsheet for health professional). Live virus vaccines, not used in Europe, are contraindicated for pregnant women and immunocompromised patients.

### 2.2.1.5. Giving vaccines

"Most inactivated influenza vaccines are injected into the muscle in the outer upper arm. A single injection annually is sufficient except for previously unvaccinated preschool children with medical conditions for whom WHO recommends two doses at least one month apart" (ECDC official website, Factsheet for health professional).

### 2.2.1.6. Reactions to vaccines

"The three groups of inactivated influenza vaccine show minor differences in the mild reactions that sometimes follow vaccination. In trials, when whole virus vaccines are used, between one in five and one in six of those vaccinated experience local reactions in the arm, lasting for one or two days. Short-term reactions such as mild fever, malaise and muscle pains are reported in a much smaller proportion in the first few hours following vaccination. In contrast, trials of the split and subunit vaccines show even fewer reduced systemic reactions. There have been no strong temporal associations of the current vaccines with more severe reactions. Anaphylaxis is very rare but does occur as with all vaccines. More severe adverse events have been reported but they are extremely rare. One that has been reported historically with a particular vaccine in the 1970s is Guillain-Barré syndrome. With the modern influenza vaccines the seeming causative risk is either found to be very rare (0.8 per million doses) or there is no link found at all and more association is found with influenza infection than vaccination (Centers for Disease Prevention and Control 2010)" (ECDC official website, Factsheet for health professional).

### 2.2.1.7. Controversies about vaccines

Vaccines represent one of the best tools against infectious diseases but, at the same time, they are also one of the most controversial. The role played by healthcare professionals in supporting vaccine uptake is crucial for many reasons and is recognized by a huge literature. Recommendation from a healthcare professional is one of the strongest influence on vaccine acceptance.

In terms of communication, a healthcare professional that promotes vaccine uptake but does not undergo vaccination send a contradictory message to patients, which may lead to concerns and distrust towards vaccination. In fact, one of the main general strategies to increase the uptake of a vaccine in a population consists in health professionals becoming more actively involved in this issue of vaccination acceptance. They should not only to pass along the message, but also "to be" such message. But this does not substitute correct information and empowerment of the patient.

Before going into details, a distinction between mandatory and compulsory vaccination must be made. Compulsory vaccination allows the enforcement of a legal requirement to vaccinate; it has been often used in the past, especially with smallpox, and it was also one of the main reasons behind the rise of the first anti-vaccine movement.

A vaccination is mandatory when an individual can refuse it but such a choice entails a penalty, usually the denial of a social activity such as attending school or working in a hospital. Vaccine

mandates have tended to elicit strong negative reactions from subsets of the population, and, over time, the concerns of these groups have led to the allowance of medical, religious and philosophical exemptions to vaccine mandates, eroding their effectiveness. However, mandatory vaccination programme also allowed to improve vaccine uptake in many instances, conferring significant benefit to the public, or population good.

An important issue is the dilemma of mandating influenza vaccination for healthcare workers, which starts to be adopted somewhere, if one wants to keep on working on a premise. On the one hand, the ethical physician imperatives of non-maleficence (do no harm) and beneficence (act in the patient's best interest) certainly support mandated vaccination for healthcare workers; being vaccinated allows them avoiding the spread of a disease amongst patients and being ready to intervene in case of emergencies. On the other hand, the ethical principles of respect for an individual's rights and autonomy constitute a compelling counter-argument.

While philosophically and politically based vaccine opposition can be difficult to change, vaccine resistance based on personal and societal health decisions and risk analysis is believed to be less rigid and more open to influence. Within this second group of vaccine-resistant citizens, trusted health professionals can improve vaccine acceptance:

- through personal example;
- by unequivocal vaccination recommendations based on scientific evidence;
- by accurate and clearly explained information with a preparedness to counter common misconceptions and cognitive errors;
- using effective timing strategies to take advantage of heightened vaccine acceptance in various settings and emotional states.

An American study identified three main groups with regard to vaccine uptake (Nowak, 2005):

1) individuals who routinely receive the influenza vaccine – this group is more accepting of vaccines and includes a majority of over 65 elderly;
2) individuals who sometimes receive an annual immunization – these individuals, who comprise the largest population segment, make an active decision based on various inputs such as perceived risk of disease versus risk of exposure and perceived severity of disease;
3) those who do not get and do not intend to get the influenza vaccine – this group tends to feel that the vaccine is ineffective, unwarranted, or even dangerous.

This classification may be helpful for health professionals, since it would help to better target their communication based on the "kind" of patient they are facing. Since they are directed to healthy people, vaccines must be, and are tested to be, even safer than any other drug. Anyway, like for any other drug, the possibility of side effects cannot be completely excluded, but it is always estimated to be very lower than the disease they are intended to prevent. Unfortunately, on the media

occasional side effects are always emphasized, while benefits of vaccination tend to be undervalued, so it is sometimes hard to discriminate between serious results and misinformation, particularly for citizens, who thus need the help of professionals to filter all the information they receive.

A good example is represented by the concerns raised by 2009 pandemic influenza vaccines, feared to provoke Guillain-Barré syndrome (GBS), an acute polyneuropathy affecting the peripheral nervous system. The association between influenza vaccines – precisely a swine flu based human influenza vaccine – and GBS traced back to an outbreak in 1976 in USA when mass vaccination was performed and several cases of this kind of transient paralysis were recorded. Following the 2009 influenza pandemic vaccination campaigns, no evidence has been found of an association between GBS and flu vaccines (Dieleman et al., 2011).

On the other hand, in September 2010, Sweden and Finland noted that a number of children had developed narcolepsy, seemingly in association with having received the AS03-adjuvanted influenza pandemic vaccine used in those countries (Pandemrix). An increased risk of narcolepsy in children and adolescents after vaccination with Pandemrix was demonstrated by monitoring systems (VAESCO and ECDC, 2012; Miller et al., 2013). Monitoring systems and transparency about their results are of paramount importance to rebuild the trust in health authorities somehow hindered by 2009-2010 pandemic.

### 2.2.2. Anti-vaccination movement

Skepticism and myths regarding vaccines are quite widespread and constitute a serious issue for public health. For instance, the controversy about the combined measles, mumps and rubella (MMR) vaccine – which was reported by a fraudulent research paper (Wakefield et al., 1998) to provoke autism in children – led to a drop in vaccination compliance in UK, which in turns caused a rise of mumps and measles cases. In 2008, for the first time in 14 years, measles was declared endemic in the UK (Asaria and MacMahon, 2006). It is thus crucial, for GPs, to know motivations and dynamics of these movements, and the reasons that may push people to distrust vaccines or even consider them dangerous.

#### 2.2.2.1. Origins and history

Opposition to vaccination exists since the first vaccines were tested, in the mid-1700s. The first kind of objection to vaccination was based on religious belief; for instance, some people believed that, since diseases were sent by God, protection from them meant to challenge the divine will. When, at the beginning of the XIX century, vaccination became widespread in the United Kingdom through the work of Edward Jenner, political arguments were raised in addition to religious ones. In fact, the introduction of Vaccination Acts, which made vaccination mandatory even for infants, was considered a limitation to the right to autonomy and personal freedom.

Meanwhile, the American President Thomas Jefferson became interested in vaccines and promoted their use and distribution throughout the States of the Union. The resistance to vaccination in the US grew and, in 1879, William Tebb, a British anti-vaccine activist, founded the Anti-Vaccination Society of America, followed

by the New England Anti-Compulsory Vaccination League in 1882 and by the Anti-Vaccination League of New York City in 1885. Such an opposition spread, obtaining the attention of both wealthy and political supporters.

During the course of the last century, poorly explained public health campaigns – like the one carried out in Brazil at the beginning of 1900, which led to the Vaccine Revolt – and some incidents – like the one occurred in 1955, when more than 100,000 doses of polio vaccine were prepared with a live polio virus instead of the inactive one – fuelled the anti-vaccination movements across the world.

More recently, new and stronger forms of opposition emerged. Some have political basis, like the theory of the "Western plot", which circulated in China during the SARS outbreak in 2003, and led to growing suspicion and mistrust for vaccines in many other South-East Asian countries. Or the campaign against Western health professional vaccinating in countries like Afghanistan.

Some other are of cultural origin. Nowadays, the increasing "medicalization" of Western societies and the spread of pseudoscientific claims allowed those who refused vaccination to find more reasons to resist vaccination, aside from religious, moral or philosophical objections. Some believe that vaccine-preventable diseases do not constitute a serious health risk, that diseases like polio were defeated only by sanitation whilst others fear that vaccines are only promoted for profit of Big Pharma companies.

### 2.2.2.2. Strategies

More than 200 years of history allowed the anti-vaccination movements to develop effective strategies, and to generate and diffuse rumours, conspiracy theories and myths concerning the related vaccine, which proved to be stubbornly resistant in time. Mainstream media, as well as the Internet, played a central role in the diffusion of these myths, especially since people have started becoming more skeptical and actively engaged in search of what they think are reliable sources of information to support their decision for choosing to vaccinate or not. There are four main rhetoric strategies used by anti-vaccination, which healthcare professionals should be aware of (Kata, 2012):

- skewing the science, which consist in the denigration and rejection of scientific studies that do not support anti-vaccine positions, usually claiming that they have been paid by pharmaceutical industries, and in the endorsement of poorly-conducted studies that promote anti-vaccine agendas;
- shifting hypotheses, based on the continual proposition of new theories about the harm caused by vaccines and on moving targets when evidence fails to support such ideas;
- censoring, i.e. suppressing critics and dissenting opinions;
- attacking the opposition, both with personal insults and filing legal actions.

### 2.2.2.3. Countering false arguments

Strategies used by anti-vaccination activists may also be applied by people who got in contact with activists' messages and have been influenced by them. All these approaches are usually based on a strong polarization of the issue ("right versus wrong") and it is thus very important to not being perceived as an "enemy", meaning someone that could be paid by pharmaceutical companies or trust their claims. GPs need to be

perceived as trustworthy, in order to break this kind of opposition. Personal relationships, credibility, high level of trust are key elements to face anti-vaccination claims.

Trust is not something that can be built at the moment but needs to be pursued way before the appearance of a medical issue. For instance, resistance to vaccination is not a problem to be faced only at the beginning of the flu season, but need to be addressed in advance, by building empathetic relationships, knowing people's experiences, values and beliefs, and sharing their preoccupations.

Health care providers should work with vaccine resistant caregivers, avoiding strategies that will alienate them. It is better to aim for incremental success if full vaccination cannot be persuaded and it is also recommended to acknowledge concerns and be prepared to address them using accurate information. Most of all, vaccine resistant patients must not be abandoned; it is important to continue to provide care, and take advantage of every opportunity to further educate about the benefits of vaccination. It is also useful to utilize the same communication outlets as vaccine opponents and try to avoid the use of difficult-to-interpret statistics such as relative risks and probabilities that involve very large or small numbers. Monitoring common Internet search engine results for key terms is a good practice to remain updated on the kind of information circulating on the web.

## 2.3. Prophylaxis with antiviral drugs in flu

As a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes in flu. For people who have had exposure to an infected person and are at a higher risk of developing severe or complicated illness, an alternative option is close monitoring for symptoms, followed by prompt early antiviral treatment should symptoms develop.

According to the last Cochrane review, in fact (Jefferson et al, 2014), oseltamivir and zanamivir reduced the risk of symptomatic influenza but oseltamivir increased the risk of psychiatric adverse events in the combined on- and off-treatment periods and of headaches, nausea, vomiting and renal events during the treatment. The balance between benefits and harms should accordingly be considered when prescribing these drugs after a household member or other close contact has developed influenza, and it is rarely advantageous for healthy people.

Candidates for prophylaxis with antiviral drugs are rather family or other close contacts of a person with a suspected or confirmed case who are at higher risk for influenza serious complications but have not been vaccinated against the influenza virus strains circulating at the time of exposure (Harper et al., 2009; CDC, 2009).

Healthcare professionals should always keep in mind that cases of resistance to antiviral drugs have been reported (Inoue et al., 2009), and that persons who receive an antiviral medication for chemoprophylaxis might still get infected and be potentially able to transmit influenza virus, even if clinical illness is prevented (Lee et al., 2009; Khazeni et al., 2009).

## 3. Urban myths about preventive measures

Apocryphal and second-hand stories that emerge spontaneously in the community and can rarely be traced to a single point of origin, may give rise to what are called urban myths (or contemporary legends). These manifestations of modern folklore, or folk narratives, exist in various other forms such as rumours, riddles, gossip, children's rhymes and life-cycle rituals, and may concern any aspect of life.

In the context of epidemiology and medicine, there are several modern myths that can evoke feelings of uncertainty, anxiety, panic and fear among the general public, occasionally giving rise to conspiracy theories. GPs must be aware not only of the existence of such myths, but also of the rhetoric and narrative ways by which they break forth, in order to counter their negative effects on the citizens.

### 3.1. General features of urban myths

Urban legends are often attributed to a friend of a friend or presented claiming some kind of "insider knowledge" that people are inclined to accept as true. However, one of their main characteristic, especially with reference to infectious diseases and vaccination, is the absence of verification (or scientific support). They usually emerge spontaneously, most commonly transmitted by word of mouth (verbal) and chain letters or emails (written), the print media, new social media and other online sources, as well as more indirectly through visual arts, such as theatre, films, photography and painting. Also, they tend to be disseminated very quickly, especially through the Internet, whose great penetration allows them to reach a wide audience on a global scale.

Urban legends can be perceived as the product of a shared feeling, a set of emotions or stereotypes. It is widely accepted that, during times of crisis, people are prompted to search for meanings or points of reference to connect with past experiences. This is fertile ground for urban myths and legends to be born and spread among the members of a community. It is important to note that the content of such narratives carries substantial significance for the people, and this is what motivates communities to preserve and propagate these stories.

In general, urban myths and legends usually refer to:

- concerns or worries of people that need to be communicated and shared with the community for protection;
- the need to give meaning and explain some dramatic event in order to be better prepared against potential new threats;
- the need to provide an insightful social commentary on the cultural or economic context of society;
- the support to the social mechanism of building trust towards the other, by sharing everyday stories.

### 3.2. Myths about vaccines and preventive measures

- A disease can be transmitted from the vaccine.
- The vaccines are dangerous / more dangerous than the virus.

- Squalene, ingredient of the flu vaccine used as a booster, caused the Gulf War Syndrome.
- A mercury metabolite of thimerosal, ingredient of the flu vaccine used as a preservative, is a poisonous substance responsible for autism and other developmental disorders.
- Flu vaccines cause the Guillain-Barré Syndrome.
- Vaccines actually weaken the immune system, making people less able to withstand viruses on their own.
- The main pharmaceutical companies (generally referred to as "Big Pharma") promote vaccines only to increase their own profit.
- The governments secretly use vaccines for several infamous purposes, such as tracking citizens, experimental warfare and even mind-control techniques.
- If someone is vaccinated against seasonal flu each year, there is no need then to be vaccinated for other kind of flu, like the swine one.

### 3.3. Examples of myths about alternatives to vaccines

- To protect themselves from flu it is enough that someone just eats organic food, takes vitamins, washes hands and drinks plenty of liquids.
- Facemasks alone can protect from the pandemics.
- Bringing a child in contact with patients affected by the flu is the better option for building a natural immunity to the virus.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.

## 4. Compliance with vaccination

Compliance with vaccination depends on many positive or negative factors: desire for self-protection, desire to avoid infecting patients, desire to avoid infecting family members, perceived safety of the vaccine, perceived efficacy of the vaccine, perceived seriousness of the disease, perceived risk of the disease, perceived seriousness of complications from the disease, access to the vaccine, cost of the vaccine, fear that the vaccine could cause disease.

Different persons may be influenced by these factors in different ways; it is thus important to stress that "public" is not a single entity. Different people require different kinds of communication, based on their individual concerns and beliefs, as well as health, familiar and/or socio-cultural conditions. These sub-groups of population display differences in terms of compliance to vaccination that may be extremely variable. The next chapter will focus on each of these categories, highlighting factors that most influence their compliance

(or refusal) of vaccination. Such knowledge should be used by healthcare professionals to properly target their communication, "tailoring" it based on the person they are facing each time.

### 4.1. Opinion leaders

Opinion leaders do not constitute a real sub-group and may be found in any of them. However, they are a relevant component of risk communication (Katz and Lazarsfield, 1955). They are trustworthy members of a given social network and this can be true for a community but also for a family, where one person could be more in charge of medical decision, including vaccination, or has the ability to engage and convince other members of the group. Also, they serve as an alternative source of information (other than the media) and as a source of interpretation for people seeking clarification. It is thus crucial to identify opinion leaders within groups or families, in order to mediate preventive messages through them. Each GP who knows his own community could identify the most prominent opinion leaders in it, going from families to social, political and religious leaders.

### 4.2. Elderlies

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. is the number of visits the person pays to a physician during the year. One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians. Clearly, this information is of great importance for healthcare workers, since it highlights the relevance of their role and how much they are trusted by this sub-group. It is thus crucial, for them, to maintain such trust, always keeping in mind that major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine.

### 4.3. Chronically ill

Compliance rates of the chronically ill with influenza vaccine in the U.S. are greater than those of healthy people and have been increasing over the years. In contrast, compliance rates among the chronically ill in Europe are relatively low. It is also important to note that there is a wide difference in the compliance rates of groups of people with different chronic diseases and in each group there are differences in the compliance rates in different age groups.

For this category, as it happens with the elderlies, the main factors affecting compliance are the number of physician visits and the acceptance of their advice as positive factors, and the fear of side effects and disbelief in the vaccine effectiveness as negative factors.

### 4.4. Pregnant women

By most experts, pregnant women are considered at increased risk for complications of flu. However, few pregnant women are actually vaccinated in Europe, mainly because of a lack of knowledge of the importance of the vaccine, and especially because of concerns for effects of the vaccine on foetal and maternal health,

despite several studies showing the opposite (for instance, Legge et al., 2014). Again, as for previous categories, another factor found to influence vaccine uptake by pregnant women is their healthcare provider recommendation.

## 4.5. Children

Young children are often the targets of vaccination campaigns because preventing diffusion of a virus in this age group is one of the best ways to contain the spread of a disease.

Studies carried out in the US by the CDC revealed that the compliance of chronically ill children with the vaccine is greater than that of healthy children and that the percentage of children getting one dose of the vaccine is greater than the percentage of fully vaccinated children. In Europe, things are different. The rates of children's influenza vaccination should always be related to their parents' health behaviour.

Amongst the factors that were found to have a positive effect on vaccination rates of children there are the child’s influenza vaccination in the previous year, the child’s uninterrupted health insurance coverage, and even the mother’s unmarried status. On the contrary, factors that were found to have a negative effect on vaccination rates of children include using a family doctor rather than a paediatrician for well-child visits, parents belief that the vaccine was unneeded or that their child was getting too many shots, and parents having a hard time obtaining the vaccine (CDC, 2004a, 2004b, 2011). There is also evidence that a proportion of parents of under-vaccinated children (children who have some but not all of the recommended vaccines) are not resistant to vaccination; rather, they often have issues with vaccine accessibility related to economic, social, and in some regions, geographical barriers.

## 4.6. Healthcare workers

Among the target groups, those of GPs is the one with more positive factors associated with compliance for vaccination: self-protection, the desire to avoid infecting patients, the desire to protect family members, the perceived efficacy and safety of the vaccine, as well as the perceived seriousness and risk of diseases, including the complications they may lead to. Access to vaccine and their cost are also included within the positive factors.

However, the fear of side effects of that vaccine could cause disease can be found even amongst healthcare workers, together with a feeling of invulnerability, and being too young and in good health to risk. All these factors have a negative effect on compliance towards vaccines.

Taken together, these observations reveal that health professionals, when compared to the other sub-groups, tend to have more altruistic reasons for being vaccinated but also tend to underestimate the importance of getting a vaccine, especially when young and healthy. Such behaviour should be avoided, since it could represent a bad example for their patients and, being them more likely to be exposed to pathogens, might also facilitate the spread of an infectious disease.

### 4.7. Socio-cultural differences

Obstacles for the acceptance of vaccines may also be caused by socio-cultural differences. For instance, highly qualified people had lower trust in vaccines (as reported mainly in Hungary). In the UK, African and Asians patients were found to be difficult groups to persuade, whilst Romanian and Hungarian general practitioners thought the same in the case of the Roma minority, even if Hungarian ones perceived two extremities regarding Roma minority: low trust in administration and in doctors, but a tendency towards getting scared easily and thus coming to doctor for help.

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# Case history 3 – All you need is vaccine

**Topic:** prevention with vaccine, prophylaxis with
**Target:** adults (elderly, subgroup at risk, pregnant women)

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass the case history it's needed to answer correctly to 80% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Extrasources:**

- ECDC – Vaccine schedules in the EU/EEA countries (comparison)
- ECDC – WHO Recommendation on influenza virus vaccines for the Northern Hemisphere 2013-2014 season
- ECDC – What you need to know about the flu
- ECDC – The flu. Are you sure you use the right measure to protect yourself? Get vaccinated
- ECDC – An area of controversy – immunising pregnant women against seasonal influenza
- ECDC – Influenza. Protect your patients. Protect yourself. Get vaccinated

**Step 1**

Susanne, a 59 years old long-time diabetic – but not insulin-dependent – and overweight woman, together with her husband John, 66 years old and with well controlled mild hypertension, is going to see her physician at the clinic. They have an appointment for getting the flu vaccine.

**As far as flu complications are concerned, they both are to be considered at risk because of**

- ( ) their age
- (•) his age, her health status
- ( ) her age, his health status
- ( ) their health status

**Step 2**

“We are even in advance, but I prefer to be among the first ones to arrive, to avoid those queues that wear me out” says John to his wife while parking the car.
“My dear, you have the luck of being as fit as a fiddle. With all my ailments, I resigned myself to sit in a waiting room”.
“Well, henceforth I will train my patience too, at least regarding the flu vaccine. When I came to take the prescriptions for your medicines, the doctor was so convincing: he recommended me to get it, from this year, even if I feel so healthy and strong”.

**The main factor effecting compliance rates with influenza vaccine among the elderly as John is:**

- his doctor’s advice
- his age
- the fear of severe complications of the disease
- the desire for self-protection, in order not to interfere with daily life

**Step 3**

The clinic has just got into activity. Suzanne and John are the first to get in.
“Good morning madam. The doctor is not arrived yet” says the nurse, who knows Suzanne. “I was surprised you were not already come, this year”.
“Yes, I usually come in October but it’s never the right day for my husband; he always has too many things to do. I hope you won’t tell us that, now that we are in December, it’s too late in the winter to get vaccinated...”.

**Which kind of answer should the nurse give to Susanne?**

- “there is no an ideal time to receive the vaccine, it depends on the peak occurrence that changes year on year”
- “actually, early December is a little bit late for your husband since he has never been immunized”
- “the ideal time is mid-fall, but December is still a good moment, since the peak usually occurs in February”
- “actually, early December is a little bit late, the protective effect could be lessened, since the peak usually occurs in February”

**Step 4**

“Fortunately, if I had lost the right moment I wouldn’t forgive you” says Suzanne to John, realizing that they could be vaccinated at the moment. “With our daughter pregnant, is even more important not to bring home some diseases. Speaking of this, what do you suggest us?”.

**Which recommendation should the nurse provide for Suzanne and John’s daughter?**

- flu vaccination of the pregnant daughter
- prophylaxis with antiviral drugs
- vaccination of all the family members, except the pregnant woman
- only non pharmacological measures since vaccination is unsafe in pregnancy

**Step 5**

“At which month is she?” asks the nurse while applying the vaccination to the Suzanne’s upper arm.
“She’s going into the fifth month”.
“That’s good”.
“But I thought that, for a pregnant woman, the vaccine is more dangerous than the disease itself. Isn’t that true?” asks John, a little worried by the possible answer. “All in all, if our daughter eats healthy, takes vitamins and does not get too much fatigued, maybe she won’t get the flu even if she is not vaccinated”.
“I understand your worries. Since I work as a nurse, even since I began to study, I always got vaccinated, even when I was pregnant”.

**The nurse has chosen an example based on her personal experience: is it a correct behavior?**

- yes, because her message will be more effective if “she is” the message
- yes, because John needs to be reassured
- no, because personal experience is not evidence-based
- no, because even if appealing, this approach doesn’t empower the public as a correct information and involvement would

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**Conclusion**

“Okay, we will talk about that with our daughter and advise her to talk with her doctor before she decides. May I tell her to come here at the clinic to have some information?”.
“For sure, it’s her right to be properly informed”.

Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 3

## Summary

## Step 1

*Dossier 1 - Epidemics and pandemics - General guidelines*

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

[…]

*Dossier 2 - Talking about prevention*

In Europe, vaccination is usually recommended to reduce the risk of people at greater risk of complications from becoming infected (selective vaccination), more than to stop the spread of the disease, as in other countries is done, targeting schoolchildren. VENICE surveys of the EU/EEA countries sponsored by ECDC found that all reporting countries were recommending annual vaccination to the two largest groups which are highlighted by the European Union Health Council (Council of the EU 2009) and WHO (WHO 2002):

1. older people above a nationally defined age (usually 65 years and older);
2. all people over six months of age with chronic medical conditions: notably chronic heart or lung diseases, metabolic or renal disease, or immunodeficiencies.

## Step 2

*Dossier 2 - Talking about prevention*

**4. Compliance with vaccination**

Compliance with vaccination depends on many positive or negative factors: desire for self-protection, desire to avoid infecting patients, desire to avoid infecting family members, perceived safety of the vaccine, perceived efficacy of the vaccine, perceived seriousness of the disease, perceived risk of the disease, perceived seriousness of complications from the disease, access to the vaccine, cost of the vaccine, fear that the vaccine could cause disease.

Different persons may be influenced by these factors in different ways; it is thus important to stress that “public” is not a single entity. Different people require different kinds of communication, based on their individual concerns and beliefs, as well as health, familiar and/or socio-cultural conditions. These sub-groups of population display differences in terms of compliance to vaccination that may be extremely variable.

[…]

*Dossier 2 - Talking about prevention*

**4.2. Elderlies**

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. is the number of visits the person pays to a physician during the year. One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians. Clearly, this information is of great importance for healthcare workers, since it highlights the relevance of their role and how much they are trusted by this sub-group. It is thus crucial, for them, to maintain such trust, always keeping in mind that major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine.

## Step 3

*Dossier 1 - Epidemics and pandemics - General guidelines*

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles.

[…]

*Dossier 2 - Talking about prevention*

Most of the acquired protection against influenza comes from antibodies in the blood. Some additional protection comes from cell-based immunity and IgA antibodies produced on mucous membranes, like those of the respiratory tract. After the first (primary) infection, or vaccination, virus-neutralising antibodies to the haemagglutinin and neuraminidase appear in the blood in about one to two weeks and rise to a peak in about four weeks.

## Step 4

*Dossier 1 - Epidemics and pandemics - General guidelines*

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

[…]

*Dossier 2 - Talking about prevention*

Few EU countries recommend vaccination of children or offering vaccines to pregnant women, in this following a different strategy from policy in the United States (CDC 2010).

[…]

**4.4. Pregnant women**

By most experts, pregnant women are considered at increased risk for complications of flu. However, few pregnant women are actually vaccinated in Europe, mainly because of a lack of knowledge of the importance of the vaccine, and especially because of concerns for effects of the vaccine on foetal and maternal health, despite several studies showing the opposite (for instance, Legge et al., 2014). Again, as for previous categories, another factor found to influence vaccine uptake by pregnant women is their healthcare provider recommendation.

## Step 5

*Dossier 2 - Talking about prevention*

**1. Talking to the public**

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as "just another reassurance" and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

[…]

Healthcare professional, as well as institutions, must receive and "actively listen" people worries and be aware of offence "determinants" characterizing the perceived risk, so as to have greater opportunities to understand the origin of perception and be able to deal with it (Sjoberg, 1999).

They need to understand the main worries of the population involved, especially as far as the weakest categories are concerned, such as, for example, children and pregnant women. People, in fact, tend to base their risk assessment not on the count of possible number of dead, injured people or socio-economic damage, but on the perceived presence of specific characteristics of risk situations and on some perceived properties of risk source, such as, for example, the familiarity with risk, individual control, comprehension, effects on children, effects on future generations, personal engagement, uncertainty of scientific data, voluntary exposure, trust in Institutions (Lambert, 2003).

[…]

It is possible to listen by putting oneself in the other's shoes, thus entering his reference scheme and trying to see the "world" with the other's eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time "as if" you were the other, but without forgetting that it is just "as if". If there is no "as if" condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to "see the world with the eyes of the other person" so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one's own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one's own values and perceptions for embracing the one of the other person "as if" were one's own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

[…]

**2.2.1.7. Controversies about vaccines**

Vaccines represent one of the best tools against infectious diseases but, at the same time, they are also one of the most controversial. The role played by healthcare professionals in supporting vaccine uptake is crucial for many reasons and is recognized by a huge literature. Recommendation from a healthcare professional is one of the strongest influence on vaccine acceptance.

In terms of communication, a healthcare professional that promotes vaccine uptake but does not undergo vaccination send a contradictory message to patients, which may lead to concerns and distrust towards vaccination. In fact, one of the main general strategies to increase the uptake of a vaccine in a population consists in health professionals becoming more actively involved in this issue of vaccination acceptance. They should not only to pass along the message, but also "to be" such message. But this does not substitute correct information and empowerment of the patient.

## Case history 4

# Why we do not recognize the real enemy

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 "Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks" |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

<u>History of changes:</u>

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

## Table of contents

# INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

# 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

## 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is “an epidemic outbreak”. A broad definition given by many epidemiologists for epidemic is “more disease than is anticipated by previous experience”, whilst a more precise one is “a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension”, and is to be distinguished by an outbreak, which is “an epidemic confined to a defined short time and place”. Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when “there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time”. This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase “enormous numbers of deaths and illness” had been removed and the revised web page simply read as follows: “An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity.” Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

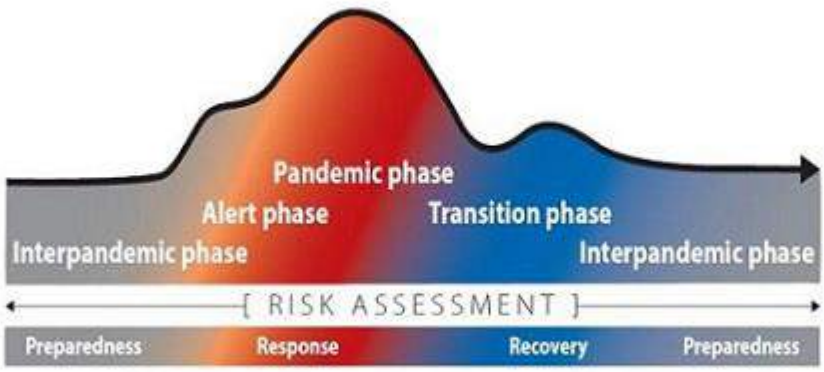
WHO argues that this phrase had little bearing on policy responses, it was “never part of the formal definition of a pandemic” and was never sent to Member States, but simply appeared in “a document on WHO’s website for some months”. In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO’s pandemic preparedness guidelines are only “pandemic phase” definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States “had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event”. This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

## 2. Main epidemics

### 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use.  Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

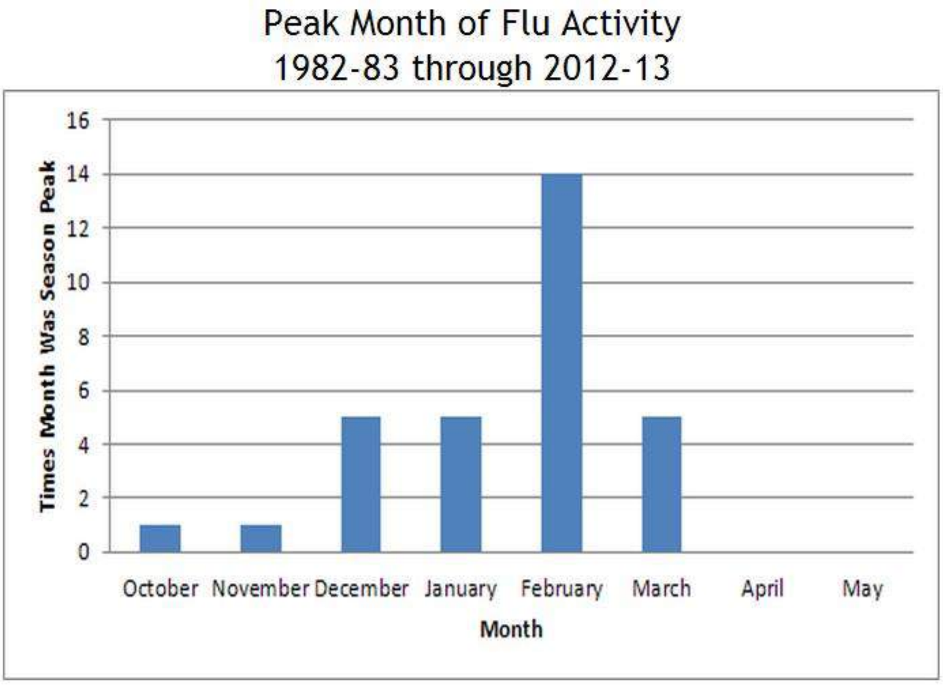
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




**During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.*

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the "low but real risk" group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name “swine flu” was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC’s early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions. WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Talking about prevention in case of pandemics: information and strategies for healthcare professionals

WP3 Prototype Online Course for Primary Care Staff
DOSSIER 2

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Talking about prevention in case of pandemics: information and strategies for healthcare professionals

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |

## Table of Contents

## INTRODUCTION

Prevention is essential in order to contain infectious outbreaks and, amongst preventive strategies, communication constitutes one of the key elements: it allows educating and informing citizens about healthy practices, raising awareness about diseases, involving patients and avoiding the diffusion of misinformation.

Healthcare workers constitute the interface between institutions and citizens, and this implies that they have a crucial role in preventive activities. They possess high accessibility by the population and have high credibility in the public's view. Patients often put greater trust in their general practitioners (GPs) than in governmental communication, meaning that they serve as example in attitude to health prevention and that they could perform further personalized communications. Knowing how to properly talk about prevention is thus crucial for healthcare professionals. This dossier will focus on the communication approaches that they should adopt in order to properly promote preventive measures in case of pandemics.

The chapter 1 of this dossier will summarize **some communication clues** to be kept in mind when talking with people regarding infectious risk and preventive measures, in order to avoid a top-down communication that could be either useless or counterproductive.

The chapter 2 will tackle the **main preventive measures** and describe the main issues associated to them. Particular attention will be given to anti-vaccine movements, in order to provide an effective framework of this reality and to identify key elements that could be useful to improve healthcare workers communication efforts.

The chapter 3 will go further into the concept of **urban myth** and analyse the most diffuse myths regarding preventive measures. Knowing in advance the rhetoric elements behind such modern legends may help health professionals to better hinder them.

The chapter 4 will present the **factors that mainly influence people's decision about vaccines**, dividing them into the most relevant subgroups that have been recognized. Identifying the characteristics of an interlocutor and targeting a message based on them is a key point in risk communication, especially for healthcare workers, who daily interact with citizens.

## 1. Talking to the public

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as "just another reassurance" and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

## 1.1 Perception of risk

According to Peter Sandman's theory, perception of risk by people does not depend only on the effective hazard, but also, and even more, by the outrage linked to it (Sandman, 1999). This depends on the danger being domestic or exotic, coerced or voluntary, chronic or acute, and so on. The studies on factors influencing risk perception highlight that this is basically related to emotional factors to such an extent that a series of components corresponding to the "perceived offence" (outrage), more than the real hazard that is the cause of the hazard itself, contribute to determine the perceived risk.

Healthcare professional, as well as institutions, must receive and "actively listen" people worries and be aware of offence "determinants" characterizing the perceived risk, so as to have greater opportunities to understand the origin of perception and be able to deal with it (Sjoberg, 1999).

They need to understand the main worries of the population involved, especially as far as the weakest categories are concerned, such as, for example, children and pregnant women. People, in fact, tend to base their risk assessment not on the count of possible number of dead, injured people or socio-economic damage, but on the perceived presence of specific characteristics of risk situations and on some perceived properties of risk source, such as, for example, the familiarity with risk, individual control, comprehension, effects on children, effects on future generations, personal engagement, uncertainty of scientific data, voluntary exposure, trust in Institutions (Lambert, 2003).

Communication must therefore follow the participatory model based on the interactive exchange assessment among all the parties (Leiss, 1987), concerning the attention to the emotional component of individual and collective perception (Slovic, 1987), as well as the understanding of social and personal issues, that is crucial to make scientific data a useful knowledge for citizen.

## 1.2 Listening is the first condition

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is "distant" from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the "focal issue", the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness.

Listening represents the first step in the professional relationship; it is based on empathy and on the other's point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other's shoes, thus entering his reference scheme and trying to see the "world" with the other's eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time "as if" you were the other, but without forgetting that it is just "as if". If there is no "as if" condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to "see the world with the eyes of the other person" so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction  not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one's own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one's own values and perceptions for embracing the one of the other person "as if" were one's own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

## 1.3 The empathic listening

Listening can be activated through the development of bidirectional communicative channels able to facilitate information flows and useful exchange so as to understand the patient's informative needs, his/her worries and for supporting the choices that justify the use of either some interventions or the others.

Interpersonal relationship generally represents the most effective way to implement the bidirectional exchange, so as to listen and deepen risk perception level, personal experience, information acquired, poor areas and to create the basis for a relationship of trust and cooperation.

Within the interpersonal context, it is possible to use a specific method called empathic mirroring which, through adequate communicative techniques, can ease the listening, thus favoring the focusing on the point of view of the other and on risk perception (Giampaoli S, 2005). Crucial techniques of empathic mirroring are

as follows: reformulation, clarification, ability in questions, use of first person messages ("I think that", "According to me").

"Reformulation" is a technique consisting in repeating what the other has just said, using the same words or rephrasing in a more concise way using other terms, without adding other concepts to the content. In this way, the operator may obtain a positive result from the other person, who knows of having been listened. One can wait the moment in which the other person has finished a sentence for intervening and resuming what has just been said: "You're telling me that…", "You mean that…", "In other words…", "Therefore, according to you…", "You think that…".

The person recognizing himself in the reformulation is sure of having been listened and understood, and is therefore confident to further express himself and cooperate. He is also facilitated to stay focused on the issue and on how he faces it.

"Clarification" facilitates the self-understanding underlying, through oral communication, the emotions associated to content. This is clear both at oral and non-oral communication. "I can see in your eyes that you're worried"; "From your words I can feel you're uncertain about what I'm saying".

The "survey capability" is the ability in how to make questions, choosing the most adequate type based on interviews stages. "Open ended questions" have to be preferred in the initial stage of the interview; they allow for a wider chance of answer, tend to extend and deepen the relationship, encourage opinions and thoughts exposition (how, what he would like, could, may deepen, what he thinks).

"Closed ended questions" are defined, they force to a sole specific answer, often stress an answer, limit the communication and make it more focused, demand only objectives facts and sometimes may seem restrictive and obstructing (when?, where?, who?). Questions starting with "why" can be perceived by the person as accusingly, and should be avoided.

The use of first-person messages ("I think that", "According to me") make it easy to distinguish between what concerns the expert operator and what concerns the person, thus allowing to avoid conflicts and favoring a non-judging mood and an autonomous decision-making process.

## 1.4 Listening to communicate uncertainty

The empathic listening may favor the "uncertainty communication", key process especially when, such as in an emerging outbreak, a crisis occurs while information are often incomplete and sometimes contrasting.

"Uncertainty communication" corresponds to processes communication and not to the outcomes, that is to the supported description of choices made or that will be made and the explanation underlying some decisions more than others. Declaring and supporting the uncertainty, it is possible to shorten the distance between a risk scientific-probabilistic assessment and a subjective personal assessment determined by the perception of risk, which increases when the emotional level increases.

The communication on uncertainty comes from the need of Institutions to communicate. Therefore, it demands a strategy and planning of communicative process, favored by the integrated participation and collaboration of institutions and systems involved at regional and national level. In fact, due to the fact that communication of uncertainty entails the choice of arguments and hypothesis that may explain, in a transparent way, to citizens, the reason for certain decisions more than others, it is crucial that the choice is

shared among figures and organizations involved in the communication process. Sharing creates the conditions for the formulation of homogeneous, understandable messages, able to make people understanding the reason behind certain choices, the consequences that they could entail, the reasons for which, at the moment, it is preferred to follow certain paths more than others. It is important that people understand and are informed even in an uncertain way, declaring "what is known and what is unknown". The same is true at an individual level.

When people receive detailed explanations on hypothesis and/or paths chosen because considered, at the current level of knowledge, most likely or adequate, they have the chance to assess the situation with a greater serenity and "competence" and to arrange the choices within their life context. At the time of the emergency, they will be more likely to be collaborative, willing to face difficult situations.

Moreover, when people understand and take part in the choices, they feel respected and trust Institutions and professionals that listen and understand worries of individuals and community and are responsible for a comprehensible information. If, on the other hand, they feel "manipulated", mislead, they lose trust and it is more likely that they will respond with denial and panic or ignore the provisions in a situation of maximum emergency.

Sometimes Institutions and experts avoid to explain complex issues and tend to reassure "Don't worry, be calm, everything is under control"; they prefer "not to say", but "it is not possible to communicate" because even the silence is a communication form. An information must always be given, reporting what has been done, what has been doing, what it is intended to do; transparency is basically the best choice.

## 1.5 Dealing with new media

Since many people use to look for information on the Internet, healthcare workers should pay attention to such a reality for two reasons: on the one hand, knowing the kind of information that flows through the net could be useful to forestall some possible criticism. On the other hand, social media and Facebook groups may constitute extremely valuable tools to keep patients up to date with advices and to promptly hinder false or ambiguous knowledge they could have found on the web.

Internet or social media use is not a remit of younger generations. According to some reports up to 476 million Europeans, of all age ranges, use the web. This accounts for approximately 65 per cent of the population, and the number continues to rise (IAB Europe, 2012). Estimates for the time an average European Internet user spends online is 27.6 hours per month, which exceeds the global mean of 24.5 hours. (comScore, 2012).

Kata (2012) highlights the fact that people nowadays are likely to search online for health information, and the anti-vaccination movement has taken advantage of this milieu to disseminate its messages.

"In the past when someone became ill, he or she would immediately go see a doctor. Nowadays people often turn first to the Internet and use the gathered information to formulate their thoughts. According to a health survey, a growing number of patients currently make their own judgements about what treatment and medicine they would like to have prescribed by a doctor. A literature review on health information-seeking behaviour on the web shows that, according to different articles and studies reviewed, interest in the Internet as a communication tool for health-related information is growing rapidly. This review also cites a WHO eHealth cross-country survey of seven countries which showed that 71% of Internet users surveyed had used the Internet for health purposes. The Internet, forums and social networking tools have allowed anti-

vaccination advocacy groups to have a broader reach than ever before. While years ago, vaccine-related rumours would have been restricted to certain countries, online tools allow these to spread more quickly and to different countries, as experts highlight" (ECDC, 2012).

As defined by Betsch (2010), Web 2.0 or social media is "Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, eg. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (eg static health portals), Web 2.0 enables two-way and multi-way communication."

Broadly speaking, social media is then a multi-way information sharing and communications tool, where users can converse and interact with each other irrespective of differences in geographical location or social background. The difference between social media (or Web 2.0 as it is sometimes known) and previous Internet platforms is that it is characterised by user-generated content. Within social media, users are more than just consumers of information, as the design of such platforms encourages them to share and contribute information to the network. McNab suggests that: "Until recently the predominant communication model was "one" authority to "many" – i.e. a health institution, the ministry of health or a journalist communicating to the public. Social media has changed the monologue to a dialogue, where anyone with ICT access can be a content creator and communicator." (McNab, 2009)

In recent years, there has been a shift towards social media being used not just as a platform to connect with friends and family but as the first place where users find out about breaking news stories. (Ofcom, 2011)

51 per cent of 18-24 year olds with a social networking profile agreed with the statement that they often find out about breaking news stories via social networking sites. 43 per cent of UK women agreed with this statement, whilst 27 per cent of men agreed. (Ofcom, 2011) Despite the overriding popularity of profile-based social networks such as Facebook, 'microblogging' sites such as Twitter (reaches one in ten Internet users worldwide) and Sina Weibo (337m users in China) uniquely encourage users to interact without being limited to interpersonal relations among friends. This form of concise, informal, rapid and open communication has led to microblogging sites to become fora where members discuss major world events and issues in real time. (comScore, 2011) According to a study by the Oxford Internet Institute, the average U.K. user now considers the Internet as their most important source for information. (2011) Notably, the study also found that *confidence* in the reliability of information found on the Internet has also increased, as users tend to trust the Internet as much as other forms of media. (2011) This may be explained by users' growing confidence in their ability to sift through and validate information on the Internet. Information from other media sources cannot be validated so immediately—for comparison, a second newspaper must be bought, or a different radio or TV programme must be waited for, yet with social media news or opinion can be cross referenced rapidly by drawing upon information posted by fellow users.

### 1.5.1. Benefit of Social Media

In contrast to traditional Web sites, which only allow communication of information to the public, social media allow not only the ability to provide information to the public, but also for the public to share information with the source. Users can create and disseminate information themselves, thus becoming more involved. An example of this interaction is demonstrated by a statement shared by the Centers for Disease Control and Prevention (CDC) on their Facebook page regarding vaccination on July 5, 2012: *"When was your*

*last tetanus shot? Tetanus vaccines can prevent this disease in children, teens and adults. Without the vaccine, you can get tetanus ("lockjaw") just by getting cuts, especially puncture wounds, that become infected with the bacteria."* This statement received 100 "likes" and elicited both supportive statements such as "Mine was only a couple years ago, but it's good to know what it helps prevent. I've had this done twice already" as well as dissenting statements with links to other information. Social media also allows individuals to provide public support for organizations, individuals, and causes by "liking" on Facebook or "following" on Twitter.

It also enables the sharing of information with a large audience. A link shared by an organization, individual, or cause, can be "shared" or "retweeted" to an individual's friends or followers, which can, in turn, lead to even greater shares or retweets. In this day and age, "going viral" is one of the fastest ways to facilitate the spread of information.

One major advantage of social media is that it can share "real-time" information regarding a public health crisis or other emergency scenario. For example, not only could a user receive information from an organization (eg, CDC), a public figure, but also their friends and associates. Because the individual self-selects the source of their own information, they are able to determine the sources that they most trust (CDC vs. NVIC), or alternatively like or know (eg, friend or celebrity). Such sources are likely to shape beliefs, attitudes, and behaviors. While this is great for sharing information, it can also be challenging, since people will be getting their information from the same types of places, which may not be reputable. They may also receive conflicting information, which can lead to mistrust and confusion. From this point of view, the "health blogger" or the "concerned mother" are sometimes as important as a GP in spreading good or bad information. Furthermore, individuals can easily receive information from "friends" or "followers." Simply sharing or tweeting "Should I vaccinate my child?" could provide an array of responses – both positive and negative – which could potentially influence an individual's decision making process.

### 1.5.2. Challenges of social media

It is relatively easy for messages to get distorted or used out of context. For example, for each "retweet" or "share," the original message can potentially be modified or added to by the user. While the initial source of information (eg, website) will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. Because of this, misinformation can rapidly spread amongst social media sources, leading to such sources as Snopes (www.snopes.com), a well-known resource for validating and debunking "social media legends." Frighteningly, social media users can "share" or "retweet" misinformation just as quickly and easily as accurate information. Two-way communication, while listed as a strength of social media, can also be used negatively to further perpetuate misinformation.

While social media avenues are great for getting information out quickly, they are not always well-suited to sharing complex or substantial amounts of information. Most social media outlets only allow limited lengths of communication. For example, "tweets" are limited to less than 140 characters, which often precludes sufficient evidence or explanation being provided.

While we are still trying to tackle with web 2.0, the experts say that web 3.0 is coming: more powerful software and machines are supposed to make the leap to a new "semantic" web, able to gice a meaning to the information gathered online, making the Internet less of a catalog and more of a guide — and even provide the foundation for systems that can reason in a human fashion (Markoff J, 2006).

# 2. Preventive measures

## 2.1. Non pharmacological measures

Most healthcare-associated infections are preventable through a number of personal measures that people may take to reduce their risk of being infected (Cowling et al., 2008; Jefferson et al., 2008). Amongst the most basic of these measures, there is a good hand hygiene, which means cleaning hands at the right times and in the right way. This should be do frequently, not too quickly – at least 20 seconds each time – and thoroughly with soap and water, especially after coughing or sneezing.

Another important practice is the so-called "social distancing", which means to avoid close contact with sick people. This can be done maintaining a distance of at least one metre from someone with symptoms of a disease and avoiding unnecessarily visit to people who are sick. When distance cannot be maintained, for instance in crowded situations, it is recommended to reduce the time of close contact with people who might be ill and the time in these situations to the extent possible.

Another simple rule to be followed is to avoid touching eyes, nose and mouth after a contact with surface that could be contaminated, while there is no evidence that wearing facemasks outside of healthcare settings during a pandemic offers effective protection or reduces transmission. This is why ECDC does not recommend their routine use.

Healthcare workers must remind the importance of these measures within a family or a group where one person has been infected. This means that patients should be encouraged to prevent other people from being exposed to their own potentially infectious nasal and oral discharge. They should cover their mouth and nose using tissues when coughing or sneezing; or cough or sneeze into an arm rather than their hands. In addition, tissues should be thrown in the bin after use. Since the importance of such a simple gesture may be sometimes underestimated, doctors should always stress its crucial role for prevention of infectious diseases. This is particularly true in healthcare facilities, since these places are the most exposed to pathogens.

## 2.2. Vaccination

### 2.2.1 Vaccination against flu

Vaccination is the most effective form of prevention from influenza, even if it cannot give a 100% protection from the disease. "Cross-immunity following infection by one strain or vaccination with a specific type or subtype often does not protect completely against subsequent variants of the same type or subtype. The extent to which influenza A(H3N2), A(H1N1), and B viruses circulate may vary by season. In addition, as the antigenic properties of these viruses might change due to continuous evolution of these viruses under immune pressure (antigenic drift), the virus strains of A(H3N2), A(H1N1) and B included in the vaccine have to be reviewed by the WHO annually and possibly changed. Also new vaccines may have to be made when variants of the virus emerge through a major change called an antigenic shift.

Most of the acquired protection against influenza comes from antibodies in the blood. Some additional protection comes from cell-based immunity and IgA antibodies produced on mucous membranes, like those of the respiratory tract. After the first (primary) infection, or vaccination, virus-neutralising antibodies to the haemagglutinin and neuraminidase appear in the blood in about one to two weeks and rise to a peak in about four weeks. Antibodies inhibit haemagglutination, agglutination of red blood cells due to multiple red blood cells bound by one virus, and so this is referred as haemagglutination inhibition (HAI). HAI correlates fairly well with virus neutralisation. Hence often the levels of these specific antibodies are used as a proxy for the presumed level of protection, with higher titres of more than 1:40 or 1:80 (in the older person) taken to indicate immunity.

After a second or further infection, or repeat vaccination, the antibodies appear and rise more quickly. The antibodies usually persist for months or years, although in people with weaker immune systems, like the elderly and those with chronic illness, they decline more quickly and vaccination is less effective. Another problem with influenza vaccination is that antibodies to one type or subtype of influenza do not necessarily give protection to other influenza virus types or subtypes (so called cross protection). Equally, they do not give full protection against subsequent drift variants of the same type or subtype. That is why seasonal influenza vaccines contain a mix of influenza virus types and subtypes and the composition has to be reviewed each year by the WHO” (ECDC official website, Factsheet for health professional).

#### 2.2.1.1. Influenza vaccines

In Europe, three main types of vaccines are currently available. They are all inactivated, with some of them adjuvanted:

- split virus vaccines consisting of disrupted virus particles
- subunit vaccines consisting only of the two main antigens, haemagglutinin and neuraminidase
- whole inactivated virus vaccines

In 2011, a live attenuated influenza vaccine that has been used in USA since 2002 was approved in Europe too for children (2-17 years of age).

#### 2.2.1.2. Vaccination strategies

In Europe, vaccination is usually recommended to reduce the risk of people at greater risk of complications from becoming infected (selective vaccination), more than to stop the spread of the disease, as in other countries is done, targeting schoolchildren. VENICE surveys of the EU/EEA countries sponsored by ECDC found that all reporting countries were recommending annual vaccination to the two largest groups which are highlighted by the European Union Health Council (Council of the EU 2009) and WHO (WHO 2002):

1. older people above a nationally defined age (usually 65 years and older);
2. all people over six months of age with chronic medical conditions: notably chronic heart or lung diseases, metabolic or renal disease, or immunodeficiencies.

Many countries emphasise the importance of annual vaccination of people in residential care for the elderly and disabled and there is excellent evidence that supports immunising those that care for them. Few EU countries recommend vaccination of children or offering vaccines to pregnant women, in this following a different strategy from policy in the United States (CDC 2010).

"In addition to the risk groups there are also other groups for who immunisation is often recommended – these are referred to as target groups. The most important of these are healthcare staff who are expected to prevent their infecting their patients with influenza-by-influenza vaccination as well as the other non-pharmaceutical measures. The vaccination will also protect the staff but its prime purpose is to prevent iatrogenic spread. Hence, all countries in Europe recommend that all healthcare staff should be immunized against influenza. This is especially important for patients at higher risk of infection and disease, where immunization is less likely to be effective. There is strong evidence that this protection works" (ECDC official website, Factsheet for health professional).

Influenza vaccines are licensed not only for those in the risk group. They can protect also well children, adolescents and younger adults. Almost all can choose to get vaccinated or to vaccinate their children so to protect weaker relatives, reduce the impact of the disease on daily life and limit its socio-economic consequences.

### 2.2.1.3. Vaccine efficacy and effectiveness

"Estimates of vaccine efficacy and effectiveness – or the extent to which vaccines protect in optimal circumstances (efficacy) and in practice (effectiveness) – vary according to the match between vaccine and the circulating viral strain and by age group and clinical category. Generally, the vaccines work less well in the elderly and those with chronic ill health. In trials, inactivated influenza vaccines have consistently been shown to prevent laboratory-confirmed illness in between 70% and 90% of healthy adults. The results are somewhat less in field effectiveness studies. The reduction in hospitalisations and deaths is less dramatic but still significant. Trial data cannot help here as hospitalisations, pneumonia and deaths are too uncommon to be revealed by trial data that also usually exclude those most at risk. Instead, observational data have to be used. These data are more subject to bias. However, modern epidemiological studies can compensate for these biases and when this is done, positive effects are consistently observed, although there are minority opinions that disagree" (ECDC official website, Factsheet for health professional).

### 2.2.1.4. Contraindications to vaccination

"As most viruses used for influenza vaccines are grown in eggs, egg-based vaccines should not be used for individuals with a definite history of serious allergic reactions to egg products" (ECDC official website, Factsheet for health professional). Live virus vaccines, not used in Europe, are contraindicated for pregnant women and immunocompromised patients.

### 2.2.1.5. Giving vaccines

"Most inactivated influenza vaccines are injected into the muscle in the outer upper arm. A single injection annually is sufficient except for previously unvaccinated preschool children with medical conditions for whom WHO recommends two doses at least one month apart" (ECDC official website, Factsheet for health professional).

### 2.2.1.6. Reactions to vaccines

"The three groups of inactivated influenza vaccine show minor differences in the mild reactions that sometimes follow vaccination. In trials, when whole virus vaccines are used, between one in five and one in six of those vaccinated experience local reactions in the arm, lasting for one or two days. Short-term reactions such as mild fever, malaise and muscle pains are reported in a much smaller proportion in the first few hours following vaccination. In contrast, trials of the split and subunit vaccines show even fewer reduced systemic reactions. There have been no strong temporal associations of the current vaccines with more severe reactions. Anaphylaxis is very rare but does occur as with all vaccines. More severe adverse events have been reported but they are extremely rare. One that has been reported historically with a particular vaccine in the 1970s is Guillain-Barré syndrome. With the modern influenza vaccines the seeming causative risk is either found to be very rare (0.8 per million doses) or there is no link found at all and more association is found with influenza infection than vaccination (Centers for Disease Prevention and Control 2010)" (ECDC official website, Factsheet for health professional).

### 2.2.1.7. Controversies about vaccines

Vaccines represent one of the best tools against infectious diseases but, at the same time, they are also one of the most controversial. The role played by healthcare professionals in supporting vaccine uptake is crucial for many reasons and is recognized by a huge literature. Recommendation from a healthcare professional is one of the strongest influence on vaccine acceptance.

In terms of communication, a healthcare professional that promotes vaccine uptake but does not undergo vaccination send a contradictory message to patients, which may lead to concerns and distrust towards vaccination. In fact, one of the main general strategies to increase the uptake of a vaccine in a population consists in health professionals becoming more actively involved in this issue of vaccination acceptance. They should not only to pass along the message, but also "to be" such message. But this does not substitute correct information and empowerment of the patient.

Before going into details, a distinction between mandatory and compulsory vaccination must be made. Compulsory vaccination allows the enforcement of a legal requirement to vaccinate; it has been often used in the past, especially with smallpox, and it was also one of the main reasons behind the rise of the first anti-vaccine movement.

A vaccination is mandatory when an individual can refuse it but such a choice entails a penalty, usually the denial of a social activity such as attending school or working in a hospital. Vaccine

mandates have tended to elicit strong negative reactions from subsets of the population, and, over time, the concerns of these groups have led to the allowance of medical, religious and philosophical exemptions to vaccine mandates, eroding their effectiveness. However, mandatory vaccination programme also allowed to improve vaccine uptake in many instances, conferring significant benefit to the public, or population good.

An important issue is the dilemma of mandating influenza vaccination for healthcare workers, which starts to be adopted somewhere, if one wants to keep on working on a premise. On the one hand, the ethical physician imperatives of non-maleficence (do no harm) and beneficence (act in the patient's best interest) certainly support mandated vaccination for healthcare workers; being vaccinated allows them avoiding the spread of a disease amongst patients and being ready to intervene in case of emergencies. On the other hand, the ethical principles of respect for an individual's rights and autonomy constitute a compelling counter-argument.

While philosophically and politically based vaccine opposition can be difficult to change, vaccine resistance based on personal and societal health decisions and risk analysis is believed to be less rigid and more open to influence. Within this second group of vaccine-resistant citizens, trusted health professionals can improve vaccine acceptance:

- through personal example;
- by unequivocal vaccination recommendations based on scientific evidence;
- by accurate and clearly explained information with a preparedness to counter common misconceptions and cognitive errors;
- using effective timing strategies to take advantage of heightened vaccine acceptance in various settings and emotional states.

An American study identified three main groups with regard to vaccine uptake (Nowak, 2005):

1) individuals who routinely receive the influenza vaccine – this group is more accepting of vaccines and includes a majority of over 65 elderly;
2) individuals who sometimes receive an annual immunization – these individuals, who comprise the largest population segment, make an active decision based on various inputs such as perceived risk of disease versus risk of exposure and perceived severity of disease;
3) those who do not get and do not intend to get the influenza vaccine – this group tends to feel that the vaccine is ineffective, unwarranted, or even dangerous.

This classification may be helpful for health professionals, since it would help to better target their communication based on the "kind" of patient they are facing. Since they are directed to healthy people, vaccines must be, and are tested to be, even safer than any other drug. Anyway, like for any other drug, the possibility of side effects cannot be completely excluded, but it is always estimated to be very lower than the disease they are intended to prevent. Unfortunately, on the media

occasional side effects are always emphasized, while benefits of vaccination tend to be undervalued, so it is sometimes hard to discriminate between serious results and misinformation, particularly for citizens, who thus need the help of professionals to filter all the information they receive.

A good example is represented by the concerns raised by 2009 pandemic influenza vaccines, feared to provoke Guillain-Barré syndrome (GBS), an acute polyneuropathy affecting the peripheral nervous system. The association between influenza vaccines – precisely a swine flu based human influenza vaccine – and GBS traced back to an outbreak in 1976 in USA when mass vaccination was performed and several cases of this kind of transient paralysis were recorded. Following the 2009 influenza pandemic vaccination campaigns, no evidence has been found of an association between GBS and flu vaccines (Dieleman et al., 2011).

On the other hand, in September 2010, Sweden and Finland noted that a number of children had developed narcolepsy, seemingly in association with having received the AS03-adjuvanted influenza pandemic vaccine used in those countries (Pandemrix). An increased risk of narcolepsy in children and adolescents after vaccination with Pandemrix was demonstrated by monitoring systems (VAESCO and ECDC, 2012; Miller et al., 2013). Monitoring systems and transparency about their results are of paramount importance to rebuild the trust in health authorities somehow hindered by 2009-2010 pandemic.

### 2.2.2. Anti-vaccination movement

Skepticism and myths regarding vaccines are quite widespread and constitute a serious issue for public health. For instance, the controversy about the combined measles, mumps and rubella (MMR) vaccine – which was reported by a fraudulent research paper (Wakefield et al., 1998) to provoke autism in children – led to a drop in vaccination compliance in UK, which in turns caused a rise of mumps and measles cases. In 2008, for the first time in 14 years, measles was declared endemic in the UK (Asaria and MacMahon, 2006). It is thus crucial, for GPs, to know motivations and dynamics of these movements, and the reasons that may push people to distrust vaccines or even consider them dangerous.

#### 2.2.2.1. Origins and history

Opposition to vaccination exists since the first vaccines were tested, in the mid-1700s. The first kind of objection to vaccination was based on religious belief; for instance, some people believed that, since diseases were sent by God, protection from them meant to challenge the divine will. When, at the beginning of the XIX century, vaccination became widespread in the United Kingdom through the work of Edward Jenner, political arguments were raised in addition to religious ones. In fact, the introduction of Vaccination Acts, which made vaccination mandatory even for infants, was considered a limitation to the right to autonomy and personal freedom.

Meanwhile, the American President Thomas Jefferson became interested in vaccines and promoted their use and distribution throughout the States of the Union. The resistance to vaccination in the US grew and, in 1879, William Tebb, a British anti-vaccine activist, founded the Anti-Vaccination Society of America, followed

by the New England Anti-Compulsory Vaccination League in 1882 and by the Anti-Vaccination League of New York City in 1885. Such an opposition spread, obtaining the attention of both wealthy and political supporters.

During the course of the last century, poorly explained public health campaigns – like the one carried out in Brazil at the beginning of 1900, which led to the Vaccine Revolt – and some incidents – like the one occurred in 1955, when more than 100,000 doses of polio vaccine were prepared with a live polio virus instead of the inactive one – fuelled the anti-vaccination movements across the world.

More recently, new and stronger forms of opposition emerged. Some have political basis, like the theory of the "Western plot", which circulated in China during the SARS outbreak in 2003, and led to growing suspicion and mistrust for vaccines in many other South-East Asian countries. Or the campaign against Western health professional vaccinating in countries like Afghanistan.

Some other are of cultural origin. Nowadays, the increasing "medicalization" of Western societies and the spread of pseudoscientific claims allowed those who refused vaccination to find more reasons to resist vaccination, aside from religious, moral or philosophical objections. Some believe that vaccine-preventable diseases do not constitute a serious health risk, that diseases like polio were defeated only by sanitation whilst others fear that vaccines are only promoted for profit of Big Pharma companies.

### 2.2.2.2. Strategies

More than 200 years of history allowed the anti-vaccination movements to develop effective strategies, and to generate and diffuse rumours, conspiracy theories and myths concerning the related vaccine, which proved to be stubbornly resistant in time. Mainstream media, as well as the Internet, played a central role in the diffusion of these myths, especially since people have started becoming more skeptical and actively engaged in search of what they think are reliable sources of information to support their decision for choosing to vaccinate or not. There are four main rhetoric strategies used by anti-vaccination, which healthcare professionals should be aware of (Kata, 2012):

- skewing the science, which consist in the denigration and rejection of scientific studies that do not support anti-vaccine positions, usually claiming that they have been paid by pharmaceutical industries, and in the endorsement of poorly-conducted studies that promote anti-vaccine agendas;
- shifting hypotheses, based on the continual proposition of new theories about the harm caused by vaccines and on moving targets when evidence fails to support such ideas;
- censoring, i.e. suppressing critics and dissenting opinions;
- attacking the opposition, both with personal insults and filing legal actions.

### 2.2.2.3. Countering false arguments

Strategies used by anti-vaccination activists may also be applied by people who got in contact with activists' messages and have been influenced by them. All these approaches are usually based on a strong polarization of the issue ("right versus wrong") and it is thus very important to not being perceived as an "enemy", meaning someone that could be paid by pharmaceutical companies or trust their claims. GPs need to be

perceived as trustworthy, in order to break this kind of opposition. Personal relationships, credibility, high level of trust are key elements to face anti-vaccination claims.

Trust is not something that can be built at the moment but needs to be pursued way before the appearance of a medical issue. For instance, resistance to vaccination is not a problem to be faced only at the beginning of the flu season, but need to be addressed in advance, by building empathetic relationships, knowing people's experiences, values and beliefs, and sharing their preoccupations.

Health care providers should work with vaccine resistant caregivers, avoiding strategies that will alienate them. It is better to aim for incremental success if full vaccination cannot be persuaded and it is also recommended to acknowledge concerns and be prepared to address them using accurate information. Most of all, vaccine resistant patients must not be abandoned; it is important to continue to provide care, and take advantage of every opportunity to further educate about the benefits of vaccination. It is also useful to utilize the same communication outlets as vaccine opponents and try to avoid the use of difficult-to-interpret statistics such as relative risks and probabilities that involve very large or small numbers. Monitoring common Internet search engine results for key terms is a good practice to remain updated on the kind of information circulating on the web.

## 2.3. Prophylaxis with antiviral drugs in flu

As a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes in flu. For people who have had exposure to an infected person and are at a higher risk of developing severe or complicated illness, an alternative option is close monitoring for symptoms, followed by prompt early antiviral treatment should symptoms develop.

According to the last Cochrane review, in fact (Jefferson et al, 2014), oseltamivir and zanamivir reduced the risk of symptomatic influenza but oseltamivir increased the risk of psychiatric adverse events in the combined on- and off-treatment periods and of headaches, nausea, vomiting and renal events during the treatment. The balance between benefits and harms should accordingly be considered when prescribing these drugs after a household member or other close contact has developed influenza, and it is rarely advantageous for healthy people.

Candidates for prophylaxis with antiviral drugs are rather family or other close contacts of a person with a suspected or confirmed case who are at higher risk for influenza serious complications but have not been vaccinated against the influenza virus strains circulating at the time of exposure (Harper et al., 2009; CDC, 2009).

Healthcare professionals should always keep in mind that cases of resistance to antiviral drugs have been reported (Inoue et al., 2009), and that persons who receive an antiviral medication for chemoprophylaxis might still get infected and be potentially able to transmit influenza virus, even if clinical illness is prevented (Lee et al., 2009; Khazeni et al., 2009).

## 3. Urban myths about preventive measures

Apocryphal and second-hand stories that emerge spontaneously in the community and can rarely be traced to a single point of origin, may give rise to what are called urban myths (or contemporary legends). These manifestations of modern folklore, or folk narratives, exist in various other forms such as rumours, riddles, gossip, children's rhymes and life-cycle rituals, and may concern any aspect of life.

In the context of epidemiology and medicine, there are several modern myths that can evoke feelings of uncertainty, anxiety, panic and fear among the general public, occasionally giving rise to conspiracy theories. GPs must be aware not only of the existence of such myths, but also of the rhetoric and narrative ways by which they break forth, in order to counter their negative effects on the citizens.

### 3.1. General features of urban myths

Urban legends are often attributed to a friend of a friend or presented claiming some kind of "insider knowledge" that people are inclined to accept as true. However, one of their main characteristic, especially with reference to infectious diseases and vaccination, is the absence of verification (or scientific support). They usually emerge spontaneously, most commonly transmitted by word of mouth (verbal) and chain letters or emails (written), the print media, new social media and other online sources, as well as more indirectly through visual arts, such as theatre, films, photography and painting. Also, they tend to be disseminated very quickly, especially through the Internet, whose great penetration allows them to reach a wide audience on a global scale.

Urban legends can be perceived as the product of a shared feeling, a set of emotions or stereotypes. It is widely accepted that, during times of crisis, people are prompted to search for meanings or points of reference to connect with past experiences. This is fertile ground for urban myths and legends to be born and spread among the members of a community. It is important to note that the content of such narratives carries substantial significance for the people, and this is what motivates communities to preserve and propagate these stories.

In general, urban myths and legends usually refer to:

- concerns or worries of people that need to be communicated and shared with the community for protection;
- the need to give meaning and explain some dramatic event in order to be better prepared against potential new threats;
- the need to provide an insightful social commentary on the cultural or economic context of society;
- the support to the social mechanism of building trust towards the other, by sharing everyday stories.

### 3.2. Myths about vaccines and preventive measures

- A disease can be transmitted from the vaccine.
- The vaccines are dangerous / more dangerous than the virus.

- Squalene, ingredient of the flu vaccine used as a booster, caused the Gulf War Syndrome.
- A mercury metabolite of thimerosal, ingredient of the flu vaccine used as a preservative, is a poisonous substance responsible for autism and other developmental disorders.
- Flu vaccines cause the Guillain-Barré Syndrome.
- Vaccines actually weaken the immune system, making people less able to withstand viruses on their own.
- The main pharmaceutical companies (generally referred to as “Big Pharma”) promote vaccines only to increase their own profit.
- The governments secretly use vaccines for several infamous purposes, such as tracking citizens, experimental warfare and even mind-control techniques.
- If someone is vaccinated against seasonal flu each year, there is no need then to be vaccinated for other kind of flu, like the swine one.

### 3.3. Examples of myths about alternatives to vaccines

- To protect themselves from flu it is enough that someone just eats organic food, takes vitamins, washes hands and drinks plenty of liquids.
- Facemasks alone can protect from the pandemics.
- Bringing a child in contact with patients affected by the flu is the better option for building a natural immunity to the virus.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.

## 4. Compliance with vaccination

Compliance with vaccination depends on many positive or negative factors: desire for self-protection, desire to avoid infecting patients, desire to avoid infecting family members, perceived safety of the vaccine, perceived efficacy of the vaccine, perceived seriousness of the disease, perceived risk of the disease, perceived seriousness of complications from the disease, access to the vaccine, cost of the vaccine, fear that the vaccine could cause disease.

Different persons may be influenced by these factors in different ways; it is thus important to stress that “public” is not a single entity. Different people require different kinds of communication, based on their individual concerns and beliefs, as well as health, familiar and/or socio-cultural conditions. These sub-groups of population display differences in terms of compliance to vaccination that may be extremely variable. The next chapter will focus on each of these categories, highlighting factors that most influence their compliance

(or refusal) of vaccination. Such knowledge should be used by healthcare professionals to properly target their communication, "tailoring" it based on the person they are facing each time.

## 4.1. Opinion leaders

Opinion leaders do not constitute a real sub-group and may be found in any of them. However, they are a relevant component of risk communication (Katz and Lazarsfield, 1955). They are trustworthy members of a given social network and this can be true for a community but also for a family, where one person could be more in charge of medical decision, including vaccination, or has the ability to engage and convince other members of the group. Also, they serve as an alternative source of information (other than the media) and as a source of interpretation for people seeking clarification. It is thus crucial to identify opinion leaders within groups or families, in order to mediate preventive messages through them. Each GP who knows his own community could identify the most prominent opinion leaders in it, going from families to social, political and religious leaders.

## 4.2. Elderlies

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. is the number of visits the person pays to a physician during the year. One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians. Clearly, this information is of great importance for healthcare workers, since it highlights the relevance of their role and how much they are trusted by this sub-group. It is thus crucial, for them, to maintain such trust, always keeping in mind that major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine.

## 4.3. Chronically ill

Compliance rates of the chronically ill with influenza vaccine in the U.S. are greater than those of healthy people and have been increasing over the years. In contrast, compliance rates among the chronically ill in Europe are relatively low. It is also important to note that there is a wide difference in the compliance rates of groups of people with different chronic diseases and in each group there are differences in the compliance rates in different age groups.

For this category, as it happens with the elderlies, the main factors affecting compliance are the number of physician visits and the acceptance of their advice as positive factors, and the fear of side effects and disbelief in the vaccine effectiveness as negative factors.

## 4.4. Pregnant women

By most experts, pregnant women are considered at increased risk for complications of flu. However, few pregnant women are actually vaccinated in Europe, mainly because of a lack of knowledge of the importance of the vaccine, and especially because of concerns for effects of the vaccine on foetal and maternal health,

despite several studies showing the opposite (for instance, Legge et al., 2014). Again, as for previous categories, another factor found to influence vaccine uptake by pregnant women is their healthcare provider recommendation.

### 4.5. Children

Young children are often the targets of vaccination campaigns because preventing diffusion of a virus in this age group is one of the best ways to contain the spread of a disease.

Studies carried out in the US by the CDC revealed that the compliance of chronically ill children with the vaccine is greater than that of healthy children and that the percentage of children getting one dose of the vaccine is greater than the percentage of fully vaccinated children. In Europe, things are different. The rates of children's influenza vaccination should always be related to their parents' health behaviour.

Amongst the factors that were found to have a positive effect on vaccination rates of children there are the child's influenza vaccination in the previous year, the child's uninterrupted health insurance coverage, and even the mother's unmarried status. On the contrary, factors that were found to have a negative effect on vaccination rates of children include using a family doctor rather than a paediatrician for well-child visits, parents belief that the vaccine was unneeded or that their child was getting too many shots, and parents having a hard time obtaining the vaccine (CDC, 2004a, 2004b, 2011). There is also evidence that a proportion of parents of under-vaccinated children (children who have some but not all of the recommended vaccines) are not resistant to vaccination; rather, they often have issues with vaccine accessibility related to economic, social, and in some regions, geographical barriers.

### 4.6. Healthcare workers

Among the target groups, those of GPs is the one with more positive factors associated with compliance for vaccination: self-protection, the desire to avoid infecting patients, the desire to protect family members, the perceived efficacy and safety of the vaccine, as well as the perceived seriousness and risk of diseases, including the complications they may lead to. Access to vaccine and their cost are also included within the positive factors.

However, the fear of side effects of that vaccine could cause disease can be found even amongst healthcare workers, together with a feeling of invulnerability, and being too young and in good health to risk. All these factors have a negative effect on compliance towards vaccines.

Taken together, these observations reveal that health professionals, when compared to the other sub-groups, tend to have more altruistic reasons for being vaccinated but also tend to underestimate the importance of getting a vaccine, especially when young and healthy. Such behaviour should be avoided, since it could represent a bad example for their patients and, being them more likely to be exposed to pathogens, might also facilitate the spread of an infectious disease.

## 4.7. Socio-cultural differences

Obstacles for the acceptance of vaccines may also be caused by socio-cultural differences. For instance, highly qualified people had lower trust in vaccines (as reported mainly in Hungary). In the UK, African and Asians patients were found to be difficult groups to persuade, whilst Romanian and Hungarian general practitioners thought the same in the case of the Roma minority, even if Hungarian ones perceived two extremities regarding Roma minority: low trust in administration and in doctors, but a tendency towards getting scared easily and thus coming to doctor for help.

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# Case history 4 – Why we do not recognize the real enemy

**Topic:** Prevention (vaccine)
**Target:** At risk population, vaccine resistant patients

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass the case history it's needed to answer correctly to 80% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Extrasources:**

- ECDC – Vaccine schedules in the EU/EEA countries (comparison)
- ECDC – Influenza risk groups (EU Council Recommendation of December 2009)
- ECDC – Influenza risk groups (2011 review)
- ECDC – Influenza vaccination

**Step 1**

Lionel is 17 years old and is a talented soccer player. His left shot does not forgive and he has been top-goal scorer for the last two seasons of the junior championship. His parents are very happy for his successes on the field, less for those in the classroom.
"I understand that soccer takes so much time and I don't expect you to be the top of the class, but neither I accept that every year you risk to be flunked" uses to say his mother. "Son, nothing's certain in life. If you don't make it big with the soccer, a piece of paper may always be useful".
"Don't worry, I know my way and nothing is going to stop me" replies Lionel. However, there is something that could stop him, even on the field: a serious form of asthma, with exacerbations in the spring and a higher sensitivity to infections during the colder months. Such a problem already cost him two recoveries. Thus, since he began to play seriously, he is under a constant medical control.
"Hi Lionel, how did it go last Sunday?" asks him the specialist in respiratory diseases before subjecting him to the spirometry planned for the early fall.
"Two sneaky goals. I could have scored another one but the defender knocked me down and I didn't get the penalty kick. However, we managed to win".
"Is the championship going to be difficult?".
"Yes, it is".
"I can wonder that. That's the reason why you cannot allow asthma to kick you down. I want to come back to an issue where I know there is some disagreement between you and your family".
Lionel's mother, who is present during the visit, suddenly freeze since she knows that even this year the doctor is going to talk about vaccines. But the doctor is ready to face the situation in the proper way.

**Which kind of approach should be adopted by the specialist?**

- by-passing the mother, focus on the kid's main interest for performance in football
- acceptation of patient's and/or his family's position and discontinuation of assistance
- acceptation of family's position without any further effort to change it, because anyone's opinion needs to be respected
- empathic listening to the mother's concerns, before trying to convince her to vaccinate her son

**Step 2**

While the doctor is explaining that his asthma put Lionel at risk of serious complications in case flu, the boy answers: "You're right and this year is definitely not affordable for me. There are at least two strong teams to beat and I can't risk being sick". The mother reacts: "Can you see that? You're still a child with no reason. In order to be able to kick a ball you are ready to take a medicine – and I'm not sure that calling it medicine is right – which could further weaken your defenses".
The physician does not openly express his opposition to the woman's arguments: "Madam, we already discussed that, but I take the liberty to say it again. By definition, a vaccine stimulate the organism's defenses..." and he then begins to argue against the mother's objections, trying hard to keep calm and not-assertive.
As a result, Lionel's mother concludes: "Anyway, we all know that vaccines contain dangerous substances that threatens health".

**Which mistakes in communication did the doctor in this case?**

- he said something not true, since asthma isn't such a risk factor for flu
- he put the relationship at risk, by-passing the mother and talking directly to her son
- he should have overtly said the mother was wrong
- he shouldn't have talked to the boy at all, because of his young age

**Step 3**

The doctor remembers what he has learned in a counselling course. "Listening, first". And so he lets the woman talk about all her concerns, trying to understand her. Only after that, he calmly explains her where she is wrong, showing understanding for her worries, but reassuring her with scientific evidences.
Lionel, who was expecting an intense and bothered answer from the physician, listens carefully to his words. However, his mother continues: "And what do you say about those persons who, following flu vaccination, were no more able to move their legs? And what about those kids that suddenly fall asleep with no chance to wake up? I don't want Lionel to suffer from such adversities".

**Which of the followings messages has to be passed in an answer reporting objectively the negative outcomes of influenza vaccines?**

- [x] Guillain-Barré syndrome is not more frequent with flu vaccines than with influenza, while their relation to narcolepsy has been confirmed in few cases, only with a particular kind of pandemic vaccine for H1N1 flu, only in two Scandinavian countries
- [ ] no association has been found between narcolepsy and flu vaccines, while their relation to Guillain-Barré syndrome has been confirmed and is strictly monitored by the regulatory Agencies
- [ ] no association has been found between either Guillain-Barré syndrome or narcolepsy and flu vaccines
- [ ] a relation to either Guillain-Barré syndrome and narcolepsy has been confirmed and is strictly monitored by the regulatory Agencies

**Step 4**

The doctor quietly explains which relationship exists between flu vaccines, Guillain-Barré syndrome and narcolepsy. Then concludes: “Anyway, everything is strictly monitored by the regulatory Agencies”. “Sure, you doctors always repeat the same stuff. You all agree with that. Those interests behind vaccines may demonstrate everything and its contrary!”.

**Which strategy used to deny and doubt vaccine effectiveness is most apparent in Lionel’s mother idea?**

- [x] skewing the science
- [ ] shifting hypotheses
- [ ] censoring opinions
- [ ] attacking the opposition

**Step 5**

“But, mum, who will take my place if I get sick? And what if I remain sick long enough to allow somebody else to take my place as a regular?” protests the boy. His mother is going to burst out again but the doctor intervenes: “Honestly, I did my best to show the situation as it is. And, honestly, I have to say, Lionel, that such motivations like missing a few matches or losing your regular spot in the team, are quite weak. Next year, when you’ll have to take this decision by yourself, it would be better if your choice will be more adult and reasoned”.
The boy nods.
“However, right now the decision is mine” cuts short the mother. “No vaccine for him”.
The doctor ends the visit and let both the kid and his mother to move into the room were the spirometry will be performed.
Two months later, the doctor received a phone call from Lionel’s mother: “Doctor, last Sunday my son played the entire match under the rain. Now, it’s been two days that he has shivers and high fever”.
“How much high, madam?”.
“Never below 38 and a half degrees. Several teammates of his are in the very same situation, according to

their mothers. But he's breathing badly, really badly. Do you think it could be something serious?".
"It's difficult to guess by phone. The easiest hypothesis is that he got the flu but, since his lungs are frail, it's better to watch out. Today I am at the hospital and I'm available, thus you can come and bring him whenever you want".
Lionel's mother replies: "I still believe that some rest and some homeopathic restoratives would be enough but, since my son insists and says he's feeling bad, I'll bring him to the hospital".
Indeed, Lionel got a serious form of flu, complicated by a heavy asthma exacerbation and a bacterial infection. "I know you won't agree, Madam, but we need to give him some medicines".
"But Lionel is already taking fever reducers and his medicines for asthma, at the maximum dose, as you told him for emergency cases".

**Which drugs are recommended to treat Lionel acute?**

- only antiviral drugs
- only antibiotics
- antiviral drugs plus antibiotics
- high dose antipyretics

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**Conclusion**

Lionel's father, who reached them at the hospital, understands the gravity of the situation and wins his wife's resistance about pharmacological therapy. "Mum, you have no idea what it means to not get any air even if you are breathing with the mask" says the kid when released from the hospital. "Doctor, next year I want to take the flu vaccine. I don't want to be in such a situation again". And at this point, also the mother agrees.

Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 4

## Summary

## Step 1

*Dossier 2 - Talking about prevention*

**1. Talking to the public**

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as “just another reassurance” and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

[…]

**1.2 Listening is the first condition**

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is “distant” from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the “focal issue”, the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness. Listening represents the first step in the professional relationship; it is based on empathy and on the other’s point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other’s shoes, thus entering his reference scheme and trying to see the “world” with the other’s eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time “as if” you were the other, but without forgetting that it is just “as if”. If there is no “as if” condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to “see the world with the eyes of the other person” so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one’s own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one’s own values and perceptions for embracing the one of the other person “as if” were one’s own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

[…]

### 1.3 The empathic listening

Listening can be activated through the development of bidirectional communicative channels able to facilitate information flows and useful exchange so as to understand the patient’s informative needs, his/her worries and for supporting the choices that justify the use of either some interventions or the others.

Interpersonal relationship generally represents the most effective way to implement the bidirectional exchange, so as to listen and deepen risk perception level, personal experience, information acquired, poor areas and to create the basis for a relationship of trust and cooperation.

Within the interpersonal context, it is possible to use a specific method called empathic mirroring which, through adequate communicative techniques, can ease the listening, thus favoring the focusing on the point of view of the other and on risk perception (Giampaoli S, 2005). Crucial techniques of empathic mirroring are as follows: reformulation, clarification, ability in questions, use of first person messages (“I think that”, “According to me”).

“Reformulation” is a technique consisting in repeating what the other has just said, using the same words or rephrasing in a more concise way using other terms, without adding other concepts to the content. In this way, the operator may obtain a positive result from the other person, who knows of having been listened.

One can wait the moment in which the other person has finished a sentence for intervening and resuming what has just been said: “You’re telling me that…”, “You mean that…”, “In other words…”, “Therefore, according to you…”, “You think that…”.

The person recognizing himself in the reformulation is sure of having been listened and understood, and is therefore confident to further express himself and cooperate. He is also facilitated to stay focused on the issue and on how he faces it.

“Clarification” facilitates the self-understanding underlying, through oral communication, the emotions associated to content. This is clear both at oral and non-oral communication. “I can see in your eyes that you’re worried”; “From your words I can feel you’re uncertain about what I’m saying”.

The “survey capability” is the ability in how to make questions, choosing the most adequate type based on interviews stages. “Open ended questions” have to be preferred in the initial stage of the interview; they allow for a wider chance of answer, tend to extend and deepen the relationship, encourage opinions and thoughts exposition (how, what he would like, could, may deepen, what he thinks).

“Closed ended questions” are defined, they force to a sole specific answer, often stress an answer, limit the communication and make it more focused, demand only objectives facts and sometimes may seem restrictive and obstructing (when?, where?, who?). Questions starting with “why” can be perceived by the person as accusingly, and should be avoided.

The use of first-person messages (“I think that”, “According to me”) make it easy to distinguish between what concerns the expert operator and what concerns the person, thus allowing to avoid conflicts and favoring a non-judging mood and an autonomous decision-making process.

## Step 2

*Dossier 2 - Talking about prevention*

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## Step 3

*Dossier 2 - Talking about prevention*

**2.2.1.6. Reactions to vaccines**

"The three groups of inactivated influenza vaccine show minor differences in the mild reactions that sometimes follow vaccination. In trials, when whole virus vaccines are used, between one in five and one in six of those vaccinated experience local reactions in the arm, lasting for one or two days. Short-term reactions such as mild fever, malaise and muscle pains are reported in a much smaller proportion in the first few hours following vaccination. In contrast, trials of the split and subunit vaccines show even fewer reduced systemic reactions. There have been no strong temporal associations of the current vaccines with more severe reactions. Anaphylaxis is very rare but does occur as with all vaccines. More severe adverse events have been reported but they are extremely rare. One that has been reported historically with a particular vaccine in the 1970s is Guillain-Barré syndrome. With the modern influenza vaccines the seeming causative risk is either found to be very rare (0.8 per million doses) or there is no link found at all and more association is found with influenza infection than vaccination (Centers for Disease Prevention and Control 2010)" (ECDC official website, Factsheet for health professional).

[…]

Since they are directed to healthy people, vaccines must be, and are tested to be, even safer than any other drug. Anyway, like for any other drug, the possibility of side effects cannot be completely excluded, but it is always estimated to be very lower than the disease they are intended to prevent. Unfortunately, on the media occasional side effects are always emphasized, while benefits of vaccination tend to be undervalued, so it is sometimes hard to discriminate between serious results and misinformation, particularly for citizens, who thus need the help of professionals to filter all the information they receive.

A good example is represented by the concerns raised by 2009 pandemic influenza vaccines, feared to provoke Guillain-Barré syndrome (GBS), an acute polyneuropathy affecting the peripheral nervous system. The association between influenza vaccines – precisely a swine flu based human influenza vaccine – and GBS traced back to an outbreak in 1976 in USA when mass vaccination was performed and several cases of this kind of transient paralysis were recorded. Following the 2009 influenza pandemic vaccination campaigns, no evidence has been found of an association between GBS and flu vaccines (Dieleman et al., 2011).

On the other hand, in September 2010, Sweden and Finland noted that a number of children had developed narcolepsy, seemingly in association with having received the AS03-adjuvanted influenza pandemic vaccine used in those countries (Pandemrix). An increased risk of narcolepsy in children and adolescents after vaccination with Pandemrix was demonstrated by monitoring systems (VAESCO and ECDC, 2012; Miller et al., 2013). Monitoring systems and transparency about their results are of paramount importance to rebuild the trust in health authorities somehow hindered by 2009-2010 pandemic.

## Step 4

*Dossier 2 - Talking about prevention*

**2.2.2.2. Strategies**

More than 200 years of history allowed the anti-vaccination movements to develop effective strategies, and to generate and diffuse rumours, conspiracy theories and myths concerning the related vaccine, which proved to be stubbornly resistant in time. Mainstream media, as well as the Internet, played a central role in the diffusion of these myths, especially since people have started becoming more skeptical and actively engaged in search of what they think are reliable sources of information to support their decision for choosing to vaccinate or not. There are four main rhetoric strategies used by anti-vaccination, which healthcare professionals should be aware of (Kata, 2012):

- skewing the science, which consist in the denigration and rejection of scientific studies that do not support anti-vaccine positions, usually claiming that they have been paid by pharmaceutical industries, and in the endorsement of poorly-conducted studies that promote anti-vaccine agendas;

- shifting hypotheses, based on the continual proposition of new theories about the harm caused by vaccines and on moving targets when evidence fails to support such ideas;
- censoring, i.e. suppressing critics and dissenting opinions;
- attacking the opposition, both with personal insults and filing legal actions.

## Step 5

*Dossier 1 - Epidemics and pandemics - General guidelines*

**2.1.3. Treatment**

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use.  Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

Case history 5

# Don’t judge a book by the cover

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| **Vn** | **Status** | **Date** | **Organisation / Person responsible** | **Reason for Change** |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

## Table of contents

# INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

# 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

## 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is “an epidemic outbreak”. A broad definition given by many epidemiologists for epidemic is “more disease than is anticipated by previous experience”, whilst a more precise one is “a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension”, and is to be distinguished by an outbreak, which is “an epidemic confined to a defined short time and place”. Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when “there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time”. This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase “enormous numbers of deaths and illness” had been removed and the revised web page simply read as follows: “An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity.” Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

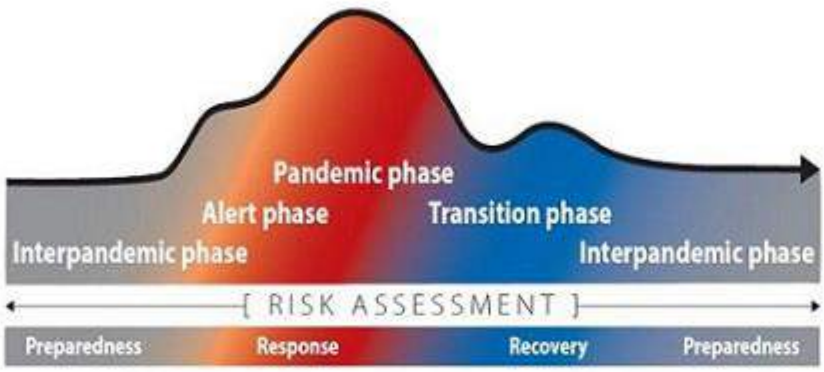
WHO argues that this phrase had little bearing on policy responses, it was “never part of the formal definition of a pandemic” and was never sent to Member States, but simply appeared in “a document on WHO’s website for some months”. In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO’s pandemic preparedness guidelines are only “pandemic phase” definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States “had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event”. This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

# 2. Main epidemics

## 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use. Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

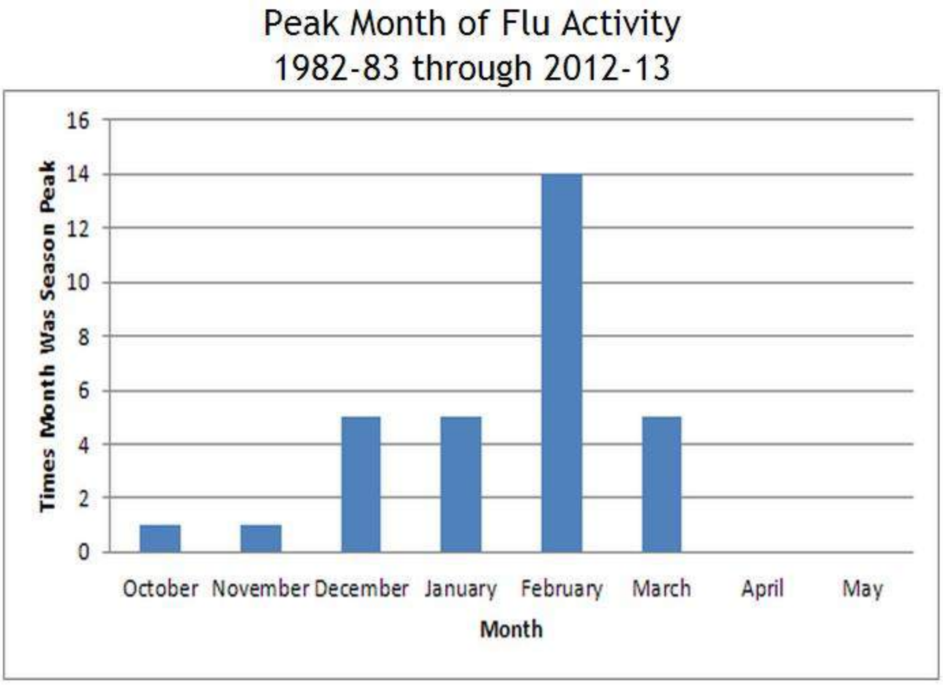
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




**During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.*

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the "low but real risk" group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name “swine flu” was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC's early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions. WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Talking about prevention in case of pandemics: information and strategies for healthcare professionals

WP3 Prototype Online Course for Primary Care Staff
DOSSIER 2

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Talking about prevention in case of pandemics: information and strategies for healthcare professionals

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| **Vn** | **Status** | **Date** | **Organisation / Person responsible** | **Reason for Change** |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |

## Table of Contents

## INTRODUCTION

Prevention is essential in order to contain infectious outbreaks and, amongst preventive strategies, communication constitutes one of the key elements: it allows educating and informing citizens about healthy practices, raising awareness about diseases, involving patients and avoiding the diffusion of misinformation.

Healthcare workers constitute the interface between institutions and citizens, and this implies that they have a crucial role in preventive activities. They possess high accessibility by the population and have high credibility in the public's view. Patients often put greater trust in their general practitioners (GPs) than in governmental communication, meaning that they serve as example in attitude to health prevention and that they could perform further personalized communications. Knowing how to properly talk about prevention is thus crucial for healthcare professionals. This dossier will focus on the communication approaches that they should adopt in order to properly promote preventive measures in case of pandemics.

The chapter 1 of this dossier will summarize **some communication clues** to be kept in mind when talking with people regarding infectious risk and preventive measures, in order to avoid a top-down communication that could be either useless or counterproductive.

The chapter 2 will tackle the **main preventive measures** and describe the main issues associated to them. Particular attention will be given to anti-vaccine movements, in order to provide an effective framework of this reality and to identify key elements that could be useful to improve healthcare workers communication efforts.

The chapter 3 will go further into the concept of **urban myth** and analyse the most diffuse myths regarding preventive measures. Knowing in advance the rhetoric elements behind such modern legends may help health professionals to better hinder them.

The chapter 4 will present the **factors that mainly influence people's decision about vaccines**, dividing them into the most relevant subgroups that have been recognized. Identifying the characteristics of an interlocutor and targeting a message based on them is a key point in risk communication, especially for healthcare workers, who daily interact with citizens.

## 1. Talking to the public

Healthcare workers need to be informed and updated about existing preventive measures and their efficacy, depending on the context. They should therefore be able to explain, in a simple and rigorous way, what people should do to protect themselves from potential exposure to infectious agents. Explanations and advices should not be perceived as "just another reassurance" and they work better when they involve practical instructions.

The communication flow should not be one-directional: as suggested by TELL ME project framework model for public health communication, citizens do not constitute a passive public but public sphere is in the centre of the model. It is important, then, for health professionals, to be listening to them, since they may express concerns and beliefs that need to be considered.

## 1.1 Perception of risk

According to Peter Sandman's theory, perception of risk by people does not depend only on the effective hazard, but also, and even more, by the outrage linked to it (Sandman, 1999). This depends on the danger being domestic or exotic, coerced or voluntary, chronic or acute, and so on. The studies on factors influencing risk perception highlight that this is basically related to emotional factors to such an extent that a series of components corresponding to the "perceived offence" (outrage), more than the real hazard that is the cause of the hazard itself, contribute to determine the perceived risk.

Healthcare professional, as well as institutions, must receive and "actively listen" people worries and be aware of offence "determinants" characterizing the perceived risk, so as to have greater opportunities to understand the origin of perception and be able to deal with it (Sjoberg, 1999).

They need to understand the main worries of the population involved, especially as far as the weakest categories are concerned, such as, for example, children and pregnant women. People, in fact, tend to base their risk assessment not on the count of possible number of dead, injured people or socio-economic damage, but on the perceived presence of specific characteristics of risk situations and on some perceived properties of risk source, such as, for example, the familiarity with risk, individual control, comprehension, effects on children, effects on future generations, personal engagement, uncertainty of scientific data, voluntary exposure, trust in Institutions (Lambert, 2003).

Communication must therefore follow the participatory model based on the interactive exchange assessment among all the parties (Leiss, 1987), concerning the attention to the emotional component of individual and collective perception (Slovic, 1987), as well as the understanding of social and personal issues, that is crucial to make scientific data a useful knowledge for citizen.

## 1.2 Listening is the first condition

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is "distant" from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the "focal issue", the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness.

Listening represents the first step in the professional relationship; it is based on empathy and on the other's point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other's shoes, thus entering his reference scheme and trying to see the "world" with the other's eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time "as if" you were the other, but without forgetting that it is just "as if". If there is no "as if" condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to "see the world with the eyes of the other person" so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one's own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one's own values and perceptions for embracing the one of the other person "as if" were one's own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

## 1.3 The empathic listening

Listening can be activated through the development of bidirectional communicative channels able to facilitate information flows and useful exchange so as to understand the patient's informative needs, his/her worries and for supporting the choices that justify the use of either some interventions or the others.

Interpersonal relationship generally represents the most effective way to implement the bidirectional exchange, so as to listen and deepen risk perception level, personal experience, information acquired, poor areas and to create the basis for a relationship of trust and cooperation.

Within the interpersonal context, it is possible to use a specific method called empathic mirroring which, through adequate communicative techniques, can ease the listening, thus favoring the focusing on the point of view of the other and on risk perception (Giampaoli S, 2005). Crucial techniques of empathic mirroring are

as follows: reformulation, clarification, ability in questions, use of first person messages ("I think that", "According to me").

"Reformulation" is a technique consisting in repeating what the other has just said, using the same words or rephrasing in a more concise way using other terms, without adding other concepts to the content. In this way, the operator may obtain a positive result from the other person, who knows of having been listened. One can wait the moment in which the other person has finished a sentence for intervening and resuming what has just been said: "You're telling me that…", "You mean that…", "In other words…", "Therefore, according to you…", "You think that…".

The person recognizing himself in the reformulation is sure of having been listened and understood, and is therefore confident to further express himself and cooperate. He is also facilitated to stay focused on the issue and on how he faces it.

"Clarification" facilitates the self-understanding underlying, through oral communication, the emotions associated to content. This is clear both at oral and non-oral communication. "I can see in your eyes that you're worried"; "From your words I can feel you're uncertain about what I'm saying".

The "survey capability" is the ability in how to make questions, choosing the most adequate type based on interviews stages. "Open ended questions" have to be preferred in the initial stage of the interview; they allow for a wider chance of answer, tend to extend and deepen the relationship, encourage opinions and thoughts exposition (how, what he would like, could, may deepen, what he thinks).

"Closed ended questions" are defined, they force to a sole specific answer, often stress an answer, limit the communication and make it more focused, demand only objectives facts and sometimes may seem restrictive and obstructing (when?, where?, who?). Questions starting with "why" can be perceived by the person as accusingly, and should be avoided.

The use of first-person messages ("I think that", "According to me") make it easy to distinguish between what concerns the expert operator and what concerns the person, thus allowing to avoid conflicts and favoring a non-judging mood and an autonomous decision-making process.

## 1.4 Listening to communicate uncertainty

The empathic listening may favor the "uncertainty communication", key process especially when, such as in an emerging outbreak, a crisis occurs while information are often incomplete and sometimes contrasting.

"Uncertainty communication" corresponds to processes communication and not to the outcomes, that is to the supported description of choices made or that will be made and the explanation underlying some decisions more than others. Declaring and supporting the uncertainty, it is possible to shorten the distance between a risk scientific-probabilistic assessment and a subjective personal assessment determined by the perception of risk, which increases when the emotional level increases.

The communication on uncertainty comes from the need of Institutions to communicate. Therefore, it demands a strategy and planning of communicative process, favored by the integrated participation and collaboration of institutions and systems involved at regional and national level. In fact, due to the fact that communication of uncertainty entails the choice of arguments and hypothesis that may explain, in a transparent way, to citizens, the reason for certain decisions more than others, it is crucial that the choice is

shared among figures and organizations involved in the communication process. Sharing creates the conditions for the formulation of homogeneous, understandable messages, able to make people understanding the reason behind certain choices, the consequences that they could entail, the reasons for which, at the moment, it is preferred to follow certain paths more than others. It is important that people understand and are informed even in an uncertain way, declaring “what is known and what is unknown”. The same is true at an individual level.

When people receive detailed explanations on hypothesis and/or paths chosen because considered, at the current level of knowledge, most likely or adequate, they have the chance to assess the situation with a greater serenity and “competence” and to arrange the choices within their life context. At the time of the emergency, they will be more likely to be collaborative, willing to face difficult situations.

Moreover, when people understand and take part in the choices, they feel respected and trust Institutions and professionals that listen and understand worries of individuals and community and are responsible for a comprehensible information. If, on the other hand, they feel “manipulated”, mislead, they lose trust and it is more likely that they will respond with denial and panic or ignore the provisions in a situation of maximum emergency.

Sometimes Institutions and experts avoid to explain complex issues and tend to reassure “Don’t worry, be calm, everything is under control”; they prefer “not to say”, but “it is not possible to communicate” because even the silence is a communication form. An information must always be given, reporting what has been done, what has been doing, what it is intended to do; transparency is basically the best choice.

## 1.5 Dealing with new media

Since many people use to look for information on the Internet, healthcare workers should pay attention to such a reality for two reasons: on the one hand, knowing the kind of information that flows through the net could be useful to forestall some possible criticism. On the other hand, social media and Facebook groups may constitute extremely valuable tools to keep patients up to date with advices and to promptly hinder false or ambiguous knowledge they could have found on the web.

Internet or social media use is not a remit of younger generations. According to some reports up to 476 million Europeans, of all age ranges, use the web. This accounts for approximately 65 per cent of the population, and the number continues to rise (IAB Europe, 2012). Estimates for the time an average European Internet user spends online is 27.6 hours per month, which exceeds the global mean of 24.5 hours. (comScore, 2012).

Kata (2012) highlights the fact that people nowadays are likely to search online for health information, and the anti-vaccination movement has taken advantage of this milieu to disseminate its messages.

“In the past when someone became ill, he or she would immediately go see a doctor. Nowadays people often turn first to the Internet and use the gathered information to formulate their thoughts. According to a health survey, a growing number of patients currently make their own judgements about what treatment and medicine they would like to have prescribed by a doctor. A literature review on health information-seeking behaviour on the web shows that, according to different articles and studies reviewed, interest in the Internet as a communication tool for health-related information is growing rapidly. This review also cites a WHO eHealth cross-country survey of seven countries which showed that 71% of Internet users surveyed had used the Internet for health purposes. The Internet, forums and social networking tools have allowed anti-

vaccination advocacy groups to have a broader reach than ever before. While years ago, vaccine-related rumours would have been restricted to certain countries, online tools allow these to spread more quickly and to different countries, as experts highlight" (ECDC, 2012).

As defined by Betsch (2010), Web 2.0 or social media is "Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, eg. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (eg static health portals), Web 2.0 enables two-way and multi-way communication."

Broadly speaking, social media is then a multi-way information sharing and communications tool, where users can converse and interact with each other irrespective of differences in geographical location or social background. The difference between social media (or Web 2.0 as it is sometimes known) and previous Internet platforms is that it is characterised by user-generated content. Within social media, users are more than just consumers of information, as the design of such platforms encourages them to share and contribute information to the network. McNab suggests that: "Until recently the predominant communication model was "one" authority to "many" – i.e. a health institution, the ministry of health or a journalist communicating to the public. Social media has changed the monologue to a dialogue, where anyone with ICT access can be a content creator and communicator." (McNab, 2009)

In recent years, there has been a shift towards social media being used not just as a platform to connect with friends and family but as the first place where users find out about breaking news stories. (Ofcom, 2011)

51 per cent of 18-24 year olds with a social networking profile agreed with the statement that they often find out about breaking news stories via social networking sites. 43 per cent of UK women agreed with this statement, whilst 27 per cent of men agreed. (Ofcom, 2011) Despite the overriding popularity of profile-based social networks such as Facebook, 'microblogging' sites such as Twitter (reaches one in ten Internet users worldwide) and Sina Weibo (337m users in China) uniquely encourage users to interact without being limited to interpersonal relations among friends. This form of concise, informal, rapid and open communication has led to microblogging sites to become fora where members discuss major world events and issues in real time. (comScore, 2011) According to a study by the Oxford Internet Institute, the average U.K. user now considers the Internet as their most important source for information. (2011) Notably, the study also found that *confidence* in the reliability of information found on the Internet has also increased, as users tend to trust the Internet as much as other forms of media. (2011) This may be explained by users' growing confidence in their ability to sift through and validate information on the Internet. Information from other media sources cannot be validated so immediately—for comparison, a second newspaper must be bought, or a different radio or TV programme must be waited for, yet with social media news or opinion can be cross referenced rapidly by drawing upon information posted by fellow users.

### 1.5.1. Benefit of Social Media

In contrast to traditional Web sites, which only allow communication of information to the public, social media allow not only the ability to provide information to the public, but also for the public to share information with the source. Users can create and disseminate information themselves, thus becoming more involved. An example of this interaction is demonstrated by a statement shared by the Centers for Disease Control and Prevention (CDC) on their Facebook page regarding vaccination on July 5, 2012: *"When was your*

*last tetanus shot? Tetanus vaccines can prevent this disease in children, teens and adults. Without the vaccine, you can get tetanus ("lockjaw") just by getting cuts, especially puncture wounds, that become infected with the bacteria."* This statement received 100 "likes" and elicited both supportive statements such as "Mine was only a couple years ago, but it's good to know what it helps prevent. I've had this done twice already" as well as dissenting statements with links to other information. Social media also allows individuals to provide public support for organizations, individuals, and causes by "liking" on Facebook or "following" on Twitter.

It also enables the sharing of information with a large audience. A link shared by an organization, individual, or cause, can be "shared" or "retweeted" to an individual's friends or followers, which can, in turn, lead to even greater shares or retweets. In this day and age, "going viral" is one of the fastest ways to facilitate the spread of information.

One major advantage of social media is that it can share "real-time" information regarding a public health crisis or other emergency scenario. For example, not only could a user receive information from an organization (eg, CDC), a public figure, but also their friends and associates. Because the individual self-selects the source of their own information, they are able to determine the sources that they most trust (CDC vs. NVIC), or alternatively like or know (eg, friend or celebrity). Such sources are likely to shape beliefs, attitudes, and behaviors. While this is great for sharing information, it can also be challenging, since people will be getting their information from the same types of places, which may not be reputable. They may also receive conflicting information, which can lead to mistrust and confusion. From this point of view, the "health blogger" or the "concerned mother" are sometimes as important as a GP in spreading good or bad information. Furthermore, individuals can easily receive information from "friends" or "followers." Simply sharing or tweeting "Should I vaccinate my child?" could provide an array of responses – both positive and negative – which could potentially influence an individual's decision making process.

### 1.5.2. Challenges of social media

It is relatively easy for messages to get distorted or used out of context. For example, for each "retweet" or "share," the original message can potentially be modified or added to by the user. While the initial source of information (eg, website) will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. Because of this, misinformation can rapidly spread amongst social media sources, leading to such sources as Snopes (www.snopes.com), a well-known resource for validating and debunking "social media legends." Frighteningly, social media users can "share" or "retweet" misinformation just as quickly and easily as accurate information. Two-way communication, while listed as a strength of social media, can also be used negatively to further perpetuate misinformation.

While social media avenues are great for getting information out quickly, they are not always well-suited to sharing complex or substantial amounts of information. Most social media outlets only allow limited lengths of communication. For example, "tweets" are limited to less than 140 characters, which often precludes sufficient evidence or explanation being provided.

While we are still trying to tackle with web 2.0, the experts say that web 3.0 is coming: more powerful software and machines are supposed to make the leap to a new "semantic" web, able to gice a meaning to the information gathered online, making the Internet less of a catalog and more of a guide — and even provide the foundation for systems that can reason in a human fashion (Markoff J, 2006).

## 2. Preventive measures

### 2.1. Non pharmacological measures

Most healthcare-associated infections are preventable through a number of personal measures that people may take to reduce their risk of being infected (Cowling et al., 2008; Jefferson et al., 2008). Amongst the most basic of these measures, there is a good hand hygiene, which means cleaning hands at the right times and in the right way. This should be do frequently, not too quickly – at least 20 seconds each time – and thoroughly with soap and water, especially after coughing or sneezing.

Another important practice is the so-called “social distancing”, which means to avoid close contact with sick people. This can be done maintaining a distance of at least one metre from someone with symptoms of a disease and avoiding unnecessarily visit to people who are sick. When distance cannot be maintained, for instance in crowded situations, it is recommended to reduce the time of close contact with people who might be ill and the time in these situations to the extent possible.

Another simple rule to be followed is to avoid touching eyes, nose and mouth after a contact with surface that could be contaminated, while there is no evidence that wearing facemasks outside of healthcare settings during a pandemic offers effective protection or reduces transmission. This is why ECDC does not recommend their routine use.

Healthcare workers must remind the importance of these measures within a family or a group where one person has been infected. This means that patients should be encouraged to prevent other people from being exposed to their own potentially infectious nasal and oral discharge. They should cover their mouth and nose using tissues when coughing or sneezing; or cough or sneeze into an arm rather than their hands. In addition, tissues should be thrown in the bin after use. Since the importance of such a simple gesture may be sometimes underestimated, doctors should always stress its crucial role for prevention of infectious diseases. This is particularly true in healthcare facilities, since these places are the most exposed to pathogens.

### 2.2. Vaccination

### 2.2.1 Vaccination against flu

Vaccination is the most effective form of prevention from influenza, even if it cannot give a 100% protection from the disease. “Cross-immunity following infection by one strain or vaccination with a specific type or subtype often does not protect completely against subsequent variants of the same type or subtype. The extent to which influenza A(H3N2), A(H1N1), and B viruses circulate may vary by season. In addition, as the antigenic properties of these viruses might change due to continuous evolution of these viruses under immune pressure (antigenic drift), the virus strains of A(H3N2), A(H1N1) and B included in the vaccine have to be reviewed by the WHO annually and possibly changed. Also new vaccines may have to be made when variants of the virus emerge through a major change called an antigenic shift.

Most of the acquired protection against influenza comes from antibodies in the blood. Some additional protection comes from cell-based immunity and IgA antibodies produced on mucous membranes, like those of the respiratory tract. After the first (primary) infection, or vaccination, virus-neutralising antibodies to the haemagglutinin and neuraminidase appear in the blood in about one to two weeks and rise to a peak in about four weeks. Antibodies inhibit haemagglutination, agglutination of red blood cells due to multiple red blood cells bound by one virus, and so this is referred as haemagglutination inhibition (HAI). HAI correlates fairly well with virus neutralisation. Hence often the levels of these specific antibodies are used as a proxy for the presumed level of protection, with higher titres of more than 1:40 or 1:80 (in the older person) taken to indicate immunity.

After a second or further infection, or repeat vaccination, the antibodies appear and rise more quickly. The antibodies usually persist for months or years, although in people with weaker immune systems, like the elderly and those with chronic illness, they decline more quickly and vaccination is less effective. Another problem with influenza vaccination is that antibodies to one type or subtype of influenza do not necessarily give protection to other influenza virus types or subtypes (so called cross protection). Equally, they do not give full protection against subsequent drift variants of the same type or subtype. That is why seasonal influenza vaccines contain a mix of influenza virus types and subtypes and the composition has to be reviewed each year by the WHO" (ECDC official website, Factsheet for health professional).

#### 2.2.1.1. Influenza vaccines

In Europe, three main types of vaccines are currently available. They are all inactivated, with some of them adjuvanted:

- split virus vaccines consisting of disrupted virus particles
- subunit vaccines consisting only of the two main antigens, haemagglutinin and neuraminidase
- whole inactivated virus vaccines

In 2011, a live attenuated influenza vaccine that has been used in USA since 2002 was approved in Europe too for children (2-17 years of age).

#### 2.2.1.2. Vaccination strategies

In Europe, vaccination is usually recommended to reduce the risk of people at greater risk of complications from becoming infected (selective vaccination), more than to stop the spread of the disease, as in other countries is done, targeting schoolchildren. VENICE surveys of the EU/EEA countries sponsored by ECDC found that all reporting countries were recommending annual vaccination to the two largest groups which are highlighted by the European Union Health Council (Council of the EU 2009) and WHO (WHO 2002):

1. older people above a nationally defined age (usually 65 years and older);
2. all people over six months of age with chronic medical conditions: notably chronic heart or lung diseases, metabolic or renal disease, or immunodeficiencies.

Many countries emphasise the importance of annual vaccination of people in residential care for the elderly and disabled and there is excellent evidence that supports immunising those that care for them. Few EU countries recommend vaccination of children or offering vaccines to pregnant women, in this following a different strategy from policy in the United States (CDC 2010).

"In addition to the risk groups there are also other groups for who immunisation is often recommended – these are referred to as target groups. The most important of these are healthcare staff who are expected to prevent their infecting their patients with influenza-by-influenza vaccination as well as the other non-pharmaceutical measures. The vaccination will also protect the staff but its prime purpose is to prevent iatrogenic spread. Hence, all countries in Europe recommend that all healthcare staff should be immunized against influenza. This is especially important for patients at higher risk of infection and disease, where immunization is less likely to be effective. There is strong evidence that this protection works" (ECDC official website, Factsheet for health professional).

Influenza vaccines are licensed not only for those in the risk group. They can protect also well children, adolescents and younger adults. Almost all can choose to get vaccinated or to vaccinate their children so to protect weaker relatives, reduce the impact of the disease on daily life and limit its socio-economic consequences.

### 2.2.1.3. Vaccine efficacy and effectiveness

"Estimates of vaccine efficacy and effectiveness – or the extent to which vaccines protect in optimal circumstances (efficacy) and in practice (effectiveness) – vary according to the match between vaccine and the circulating viral strain and by age group and clinical category. Generally, the vaccines work less well in the elderly and those with chronic ill health. In trials, inactivated influenza vaccines have consistently been shown to prevent laboratory-confirmed illness in between 70% and 90% of healthy adults. The results are somewhat less in field effectiveness studies. The reduction in hospitalisations and deaths is less dramatic but still significant. Trial data cannot help here as hospitalisations, pneumonia and deaths are too uncommon to be revealed by trial data that also usually exclude those most at risk. Instead, observational data have to be used. These data are more subject to bias. However, modern epidemiological studies can compensate for these biases and when this is done, positive effects are consistently observed, although there are minority opinions that disagree" (ECDC official website, Factsheet for health professional).

### 2.2.1.4. Contraindications to vaccination

"As most viruses used for influenza vaccines are grown in eggs, egg-based vaccines should not be used for individuals with a definite history of serious allergic reactions to egg products" (ECDC official website, Factsheet for health professional). Live virus vaccines, not used in Europe, are contraindicated for pregnant women and immunocompromised patients.

### 2.2.1.5. Giving vaccines

"Most inactivated influenza vaccines are injected into the muscle in the outer upper arm. A single injection annually is sufficient except for previously unvaccinated preschool children with medical conditions for whom WHO recommends two doses at least one month apart" (ECDC official website, Factsheet for health professional).

### 2.2.1.6. Reactions to vaccines

"The three groups of inactivated influenza vaccine show minor differences in the mild reactions that sometimes follow vaccination. In trials, when whole virus vaccines are used, between one in five and one in six of those vaccinated experience local reactions in the arm, lasting for one or two days. Short-term reactions such as mild fever, malaise and muscle pains are reported in a much smaller proportion in the first few hours following vaccination. In contrast, trials of the split and subunit vaccines show even fewer reduced systemic reactions. There have been no strong temporal associations of the current vaccines with more severe reactions. Anaphylaxis is very rare but does occur as with all vaccines. More severe adverse events have been reported but they are extremely rare. One that has been reported historically with a particular vaccine in the 1970s is Guillain-Barré syndrome. With the modern influenza vaccines the seeming causative risk is either found to be very rare (0.8 per million doses) or there is no link found at all and more association is found with influenza infection than vaccination (Centers for Disease Prevention and Control 2010)" (ECDC official website, Factsheet for health professional).

### 2.2.1.7. Controversies about vaccines

Vaccines represent one of the best tools against infectious diseases but, at the same time, they are also one of the most controversial. The role played by healthcare professionals in supporting vaccine uptake is crucial for many reasons and is recognized by a huge literature. Recommendation from a healthcare professional is one of the strongest influence on vaccine acceptance.

In terms of communication, a healthcare professional that promotes vaccine uptake but does not undergo vaccination send a contradictory message to patients, which may lead to concerns and distrust towards vaccination. In fact, one of the main general strategies to increase the uptake of a vaccine in a population consists in health professionals becoming more actively involved in this issue of vaccination acceptance. They should not only to pass along the message, but also "to be" such message. But this does not substitute correct information and empowerment of the patient.

Before going into details, a distinction between mandatory and compulsory vaccination must be made. Compulsory vaccination allows the enforcement of a legal requirement to vaccinate; it has been often used in the past, especially with smallpox, and it was also one of the main reasons behind the rise of the first anti-vaccine movement.

A vaccination is mandatory when an individual can refuse it but such a choice entails a penalty, usually the denial of a social activity such as attending school or working in a hospital. Vaccine

mandates have tended to elicit strong negative reactions from subsets of the population, and, over time, the concerns of these groups have led to the allowance of medical, religious and philosophical exemptions to vaccine mandates, eroding their effectiveness. However, mandatory vaccination programme also allowed to improve vaccine uptake in many instances, conferring significant benefit to the public, or population good.

An important issue is the dilemma of mandating influenza vaccination for healthcare workers, which starts to be adopted somewhere, if one wants to keep on working on a premise. On the one hand, the ethical physician imperatives of non-maleficence (do no harm) and beneficence (act in the patient's best interest) certainly support mandated vaccination for healthcare workers; being vaccinated allows them avoiding the spread of a disease amongst patients and being ready to intervene in case of emergencies. On the other hand, the ethical principles of respect for an individual's rights and autonomy constitute a compelling counter-argument.

While philosophically and politically based vaccine opposition can be difficult to change, vaccine resistance based on personal and societal health decisions and risk analysis is believed to be less rigid and more open to influence. Within this second group of vaccine-resistant citizens, trusted health professionals can improve vaccine acceptance:

- through personal example;
- by unequivocal vaccination recommendations based on scientific evidence;
- by accurate and clearly explained information with a preparedness to counter common misconceptions and cognitive errors;
- using effective timing strategies to take advantage of heightened vaccine acceptance in various settings and emotional states.

An American study identified three main groups with regard to vaccine uptake (Nowak, 2005):

1) individuals who routinely receive the influenza vaccine – this group is more accepting of vaccines and includes a majority of over 65 elderly;
2) individuals who sometimes receive an annual immunization – these individuals, who comprise the largest population segment, make an active decision based on various inputs such as perceived risk of disease versus risk of exposure and perceived severity of disease;
3) those who do not get and do not intend to get the influenza vaccine – this group tends to feel that the vaccine is ineffective, unwarranted, or even dangerous.

This classification may be helpful for health professionals, since it would help to better target their communication based on the "kind" of patient they are facing. Since they are directed to healthy people, vaccines must be, and are tested to be, even safer than any other drug. Anyway, like for any other drug, the possibility of side effects cannot be completely excluded, but it is always estimated to be very lower than the disease they are intended to prevent. Unfortunately, on the media

occasional side effects are always emphasized, while benefits of vaccination tend to be undervalued, so it is sometimes hard to discriminate between serious results and misinformation, particularly for citizens, who thus need the help of professionals to filter all the information they receive.

A good example is represented by the concerns raised by 2009 pandemic influenza vaccines, feared to provoke Guillain-Barré syndrome (GBS), an acute polyneuropathy affecting the peripheral nervous system. The association between influenza vaccines – precisely a swine flu based human influenza vaccine – and GBS traced back to an outbreak in 1976 in USA when mass vaccination was performed and several cases of this kind of transient paralysis were recorded. Following the 2009 influenza pandemic vaccination campaigns, no evidence has been found of an association between GBS and flu vaccines (Dieleman et al., 2011).

On the other hand, in September 2010, Sweden and Finland noted that a number of children had developed narcolepsy, seemingly in association with having received the AS03-adjuvanted influenza pandemic vaccine used in those countries (Pandemrix). An increased risk of narcolepsy in children and adolescents after vaccination with Pandemrix was demonstrated by monitoring systems (VAESCO and ECDC, 2012; Miller et al., 2013). Monitoring systems and transparency about their results are of paramount importance to rebuild the trust in health authorities somehow hindered by 2009-2010 pandemic.

### 2.2.2. Anti-vaccination movement

Skepticism and myths regarding vaccines are quite widespread and constitute a serious issue for public health. For instance, the controversy about the combined measles, mumps and rubella (MMR) vaccine – which was reported by a fraudulent research paper (Wakefield et al., 1998) to provoke autism in children – led to a drop in vaccination compliance in UK, which in turns caused a rise of mumps and measles cases. In 2008, for the first time in 14 years, measles was declared endemic in the UK (Asaria and MacMahon, 2006). It is thus crucial, for GPs, to know motivations and dynamics of these movements, and the reasons that may push people to distrust vaccines or even consider them dangerous.

#### 2.2.2.1. Origins and history

Opposition to vaccination exists since the first vaccines were tested, in the mid-1700s. The first kind of objection to vaccination was based on religious belief; for instance, some people believed that, since diseases were sent by God, protection from them meant to challenge the divine will. When, at the beginning of the XIX century, vaccination became widespread in the United Kingdom through the work of Edward Jenner, political arguments were raised in addition to religious ones. In fact, the introduction of Vaccination Acts, which made vaccination mandatory even for infants, was considered a limitation to the right to autonomy and personal freedom.

Meanwhile, the American President Thomas Jefferson became interested in vaccines and promoted their use and distribution throughout the States of the Union. The resistance to vaccination in the US grew and, in 1879, William Tebb, a British anti-vaccine activist, founded the Anti-Vaccination Society of America, followed

by the New England Anti-Compulsory Vaccination League in 1882 and by the Anti-Vaccination League of New York City in 1885. Such an opposition spread, obtaining the attention of both wealthy and political supporters.

During the course of the last century, poorly explained public health campaigns – like the one carried out in Brazil at the beginning of 1900, which led to the Vaccine Revolt – and some incidents – like the one occurred in 1955, when more than 100,000 doses of polio vaccine were prepared with a live polio virus instead of the inactive one – fuelled the anti-vaccination movements across the world.

More recently, new and stronger forms of opposition emerged. Some have political basis, like the theory of the "Western plot", which circulated in China during the SARS outbreak in 2003, and led to growing suspicion and mistrust for vaccines in many other South-East Asian countries. Or the campaign against Western health professional vaccinating in countries like Afghanistan.

Some other are of cultural origin. Nowadays, the increasing "medicalization" of Western societies and the spread of pseudoscientific claims allowed those who refused vaccination to find more reasons to resist vaccination, aside from religious, moral or philosophical objections. Some believe that vaccine-preventable diseases do not constitute a serious health risk, that diseases like polio were defeated only by sanitation whilst others fear that vaccines are only promoted for profit of Big Pharma companies.

### 2.2.2.2. Strategies

More than 200 years of history allowed the anti-vaccination movements to develop effective strategies, and to generate and diffuse rumours, conspiracy theories and myths concerning the related vaccine, which proved to be stubbornly resistant in time. Mainstream media, as well as the Internet, played a central role in the diffusion of these myths, especially since people have started becoming more skeptical and actively engaged in search of what they think are reliable sources of information to support their decision for choosing to vaccinate or not. There are four main rhetoric strategies used by anti-vaccination, which healthcare professionals should be aware of (Kata, 2012):

- skewing the science, which consist in the denigration and rejection of scientific studies that do not support anti-vaccine positions, usually claiming that they have been paid by pharmaceutical industries, and in the endorsement of poorly-conducted studies that promote anti-vaccine agendas;
- shifting hypotheses, based on the continual proposition of new theories about the harm caused by vaccines and on moving targets when evidence fails to support such ideas;
- censoring, i.e. suppressing critics and dissenting opinions;
- attacking the opposition, both with personal insults and filing legal actions.

### 2.2.2.3. Countering false arguments

Strategies used by anti-vaccination activists may also be applied by people who got in contact with activists' messages and have been influenced by them. All these approaches are usually based on a strong polarization of the issue ("right versus wrong") and it is thus very important to not being perceived as an "enemy", meaning someone that could be paid by pharmaceutical companies or trust their claims. GPs need to be

perceived as trustworthy, in order to break this kind of opposition. Personal relationships, credibility, high level of trust are key elements to face anti-vaccination claims.

Trust is not something that can be built at the moment but needs to be pursued way before the appearance of a medical issue. For instance, resistance to vaccination is not a problem to be faced only at the beginning of the flu season, but need to be addressed in advance, by building empathetic relationships, knowing people's experiences, values and beliefs, and sharing their preoccupations.

Health care providers should work with vaccine resistant caregivers, avoiding strategies that will alienate them. It is better to aim for incremental success if full vaccination cannot be persuaded and it is also recommended to acknowledge concerns and be prepared to address them using accurate information. Most of all, vaccine resistant patients must not be abandoned; it is important to continue to provide care, and take advantage of every opportunity to further educate about the benefits of vaccination. It is also useful to utilize the same communication outlets as vaccine opponents and try to avoid the use of difficult-to-interpret statistics such as relative risks and probabilities that involve very large or small numbers. Monitoring common Internet search engine results for key terms is a good practice to remain updated on the kind of information circulating on the web.

## 2.3. Prophylaxis with antiviral drugs in flu

As a general rule, WHO does not recommend the use of antiviral drugs for prophylactic purposes in flu. For people who have had exposure to an infected person and are at a higher risk of developing severe or complicated illness, an alternative option is close monitoring for symptoms, followed by prompt early antiviral treatment should symptoms develop.

According to the last Cochrane review, in fact (Jefferson et al, 2014), oseltamivir and zanamivir reduced the risk of symptomatic influenza but oseltamivir increased the risk of psychiatric adverse events in the combined on- and off-treatment periods and of headaches, nausea, vomiting and renal events during the treatment. The balance between benefits and harms should accordingly be considered when prescribing these drugs after a household member or other close contact has developed influenza, and it is rarely advantageous for healthy people.

Candidates for prophylaxis with antiviral drugs are rather family or other close contacts of a person with a suspected or confirmed case who are at higher risk for influenza serious complications but have not been vaccinated against the influenza virus strains circulating at the time of exposure (Harper et al., 2009; CDC, 2009).

Healthcare professionals should always keep in mind that cases of resistance to antiviral drugs have been reported (Inoue et al., 2009), and that persons who receive an antiviral medication for chemoprophylaxis might still get infected and be potentially able to transmit influenza virus, even if clinical illness is prevented (Lee et al., 2009; Khazeni et al., 2009).

## 3. Urban myths about preventive measures

Apocryphal and second-hand stories that emerge spontaneously in the community and can rarely be traced to a single point of origin, may give rise to what are called urban myths (or contemporary legends). These manifestations of modern folklore, or folk narratives, exist in various other forms such as rumours, riddles, gossip, children's rhymes and life-cycle rituals, and may concern any aspect of life.

In the context of epidemiology and medicine, there are several modern myths that can evoke feelings of uncertainty, anxiety, panic and fear among the general public, occasionally giving rise to conspiracy theories. GPs must be aware not only of the existence of such myths, but also of the rhetoric and narrative ways by which they break forth, in order to counter their negative effects on the citizens.

### 3.1. General features of urban myths

Urban legends are often attributed to a friend of a friend or presented claiming some kind of "insider knowledge" that people are inclined to accept as true. However, one of their main characteristic, especially with reference to infectious diseases and vaccination, is the absence of verification (or scientific support). They usually emerge spontaneously, most commonly transmitted by word of mouth (verbal) and chain letters or emails (written), the print media, new social media and other online sources, as well as more indirectly through visual arts, such as theatre, films, photography and painting. Also, they tend to be disseminated very quickly, especially through the Internet, whose great penetration allows them to reach a wide audience on a global scale.

Urban legends can be perceived as the product of a shared feeling, a set of emotions or stereotypes. It is widely accepted that, during times of crisis, people are prompted to search for meanings or points of reference to connect with past experiences. This is fertile ground for urban myths and legends to be born and spread among the members of a community. It is important to note that the content of such narratives carries substantial significance for the people, and this is what motivates communities to preserve and propagate these stories.

In general, urban myths and legends usually refer to:

- concerns or worries of people that need to be communicated and shared with the community for protection;
- the need to give meaning and explain some dramatic event in order to be better prepared against potential new threats;
- the need to provide an insightful social commentary on the cultural or economic context of society;
- the support to the social mechanism of building trust towards the other, by sharing everyday stories.

### 3.2. Myths about vaccines and preventive measures

- A disease can be transmitted from the vaccine.
- The vaccines are dangerous / more dangerous than the virus.

- Squalene, ingredient of the flu vaccine used as a booster, caused the Gulf War Syndrome.
- A mercury metabolite of thimerosal, ingredient of the flu vaccine used as a preservative, is a poisonous substance responsible for autism and other developmental disorders.
- Flu vaccines cause the Guillain-Barré Syndrome.
- Vaccines actually weaken the immune system, making people less able to withstand viruses on their own.
- The main pharmaceutical companies (generally referred to as "Big Pharma") promote vaccines only to increase their own profit.
- The governments secretly use vaccines for several infamous purposes, such as tracking citizens, experimental warfare and even mind-control techniques.
- If someone is vaccinated against seasonal flu each year, there is no need then to be vaccinated for other kind of flu, like the swine one.

### 3.3. Examples of myths about alternatives to vaccines

- To protect themselves from flu it is enough that someone just eats organic food, takes vitamins, washes hands and drinks plenty of liquids.
- Facemasks alone can protect from the pandemics.
- Bringing a child in contact with patients affected by the flu is the better option for building a natural immunity to the virus.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.

## 4. Compliance with vaccination

Compliance with vaccination depends on many positive or negative factors: desire for self-protection, desire to avoid infecting patients, desire to avoid infecting family members, perceived safety of the vaccine, perceived efficacy of the vaccine, perceived seriousness of the disease, perceived risk of the disease, perceived seriousness of complications from the disease, access to the vaccine, cost of the vaccine, fear that the vaccine could cause disease.

Different persons may be influenced by these factors in different ways; it is thus important to stress that "public" is not a single entity. Different people require different kinds of communication, based on their individual concerns and beliefs, as well as health, familiar and/or socio-cultural conditions. These sub-groups of population display differences in terms of compliance to vaccination that may be extremely variable. The next chapter will focus on each of these categories, highlighting factors that most influence their compliance

(or refusal) of vaccination. Such knowledge should be used by healthcare professionals to properly target their communication, "tailoring" it based on the person they are facing each time.

## 4.1. Opinion leaders

Opinion leaders do not constitute a real sub-group and may be found in any of them. However, they are a relevant component of risk communication (Katz and Lazarsfield, 1955). They are trustworthy members of a given social network and this can be true for a community but also for a family, where one person could be more in charge of medical decision, including vaccination, or has the ability to engage and convince other members of the group. Also, they serve as an alternative source of information (other than the media) and as a source of interpretation for people seeking clarification. It is thus crucial to identify opinion leaders within groups or families, in order to mediate preventive messages through them. Each GP who knows his own community could identify the most prominent opinion leaders in it, going from families to social, political and religious leaders.

## 4.2. Elderlies

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. is the number of visits the person pays to a physician during the year. One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians. Clearly, this information is of great importance for healthcare workers, since it highlights the relevance of their role and how much they are trusted by this sub-group. It is thus crucial, for them, to maintain such trust, always keeping in mind that major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine.

## 4.3. Chronically ill

Compliance rates of the chronically ill with influenza vaccine in the U.S. are greater than those of healthy people and have been increasing over the years. In contrast, compliance rates among the chronically ill in Europe are relatively low. It is also important to note that there is a wide difference in the compliance rates of groups of people with different chronic diseases and in each group there are differences in the compliance rates in different age groups.

For this category, as it happens with the elderlies, the main factors affecting compliance are the number of physician visits and the acceptance of their advice as positive factors, and the fear of side effects and disbelief in the vaccine effectiveness as negative factors.

## 4.4. Pregnant women

By most experts, pregnant women are considered at increased risk for complications of flu. However, few pregnant women are actually vaccinated in Europe, mainly because of a lack of knowledge of the importance of the vaccine, and especially because of concerns for effects of the vaccine on foetal and maternal health,

despite several studies showing the opposite (for instance, Legge et al., 2014). Again, as for previous categories, another factor found to influence vaccine uptake by pregnant women is their healthcare provider recommendation.

## 4.5. Children

Young children are often the targets of vaccination campaigns because preventing diffusion of a virus in this age group is one of the best ways to contain the spread of a disease.

Studies carried out in the US by the CDC revealed that the compliance of chronically ill children with the vaccine is greater than that of healthy children and that the percentage of children getting one dose of the vaccine is greater than the percentage of fully vaccinated children. In Europe, things are different. The rates of children's influenza vaccination should always be related to their parents' health behaviour.

Amongst the factors that were found to have a positive effect on vaccination rates of children there are the child’s influenza vaccination in the previous year, the child’s uninterrupted health insurance coverage, and even the mother’s unmarried status. On the contrary, factors that were found to have a negative effect on vaccination rates of children include using a family doctor rather than a paediatrician for well-child visits, parents belief that the vaccine was unneeded or that their child was getting too many shots, and parents having a hard time obtaining the vaccine (CDC, 2004a, 2004b, 2011). There is also evidence that a proportion of parents of under-vaccinated children (children who have some but not all of the recommended vaccines) are not resistant to vaccination; rather, they often have issues with vaccine accessibility related to economic, social, and in some regions, geographical barriers.

## 4.6. Healthcare workers

Among the target groups, those of GPs is the one with more positive factors associated with compliance for vaccination: self-protection, the desire to avoid infecting patients, the desire to protect family members, the perceived efficacy and safety of the vaccine, as well as the perceived seriousness and risk of diseases, including the complications they may lead to. Access to vaccine and their cost are also included within the positive factors.

However, the fear of side effects of that vaccine could cause disease can be found even amongst healthcare workers, together with a feeling of invulnerability, and being too young and in good health to risk. All these factors have a negative effect on compliance towards vaccines.

Taken together, these observations reveal that health professionals, when compared to the other sub-groups, tend to have more altruistic reasons for being vaccinated but also tend to underestimate the importance of getting a vaccine, especially when young and healthy. Such behaviour should be avoided, since it could represent a bad example for their patients and, being them more likely to be exposed to pathogens, might also facilitate the spread of an infectious disease.

### 4.7. Socio-cultural differences

Obstacles for the acceptance of vaccines may also be caused by socio-cultural differences. For instance, highly qualified people had lower trust in vaccines (as reported mainly in Hungary). In the UK, African and Asians patients were found to be difficult groups to persuade, whilst Romanian and Hungarian general practitioners thought the same in the case of the Roma minority, even if Hungarian ones perceived two extremities regarding Roma minority: low trust in administration and in doctors, but a tendency towards getting scared easily and thus coming to doctor for help.

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# Stigmatisation and discrimination: a guide for healthcare workers

WP3 Prototype Online Course for Primary Care Staff

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Stigmatisation and discrimination: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| **Vn** | **Status** | **Date** | **Organisation / Person responsible** | **Reason for Change** |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

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# INTRODUCTION

Being at the interface between institutions and citizens, healthcare workers play a fundamental role within public health. They represent the first line of intervention during an infectious disease outbreak and must be involved in preparedness and emergency plans from health authorities. This also implies that they should be aware of the importance of an effective risk communication in case of an epidemic and the best approaches to be followed, in order to properly manage it. Amongst the many relevant issues of risk communication during infectious disease outbreaks, there are those concerning stigmatisation and, in general, all violation of human rights, which constitute a serious problem for healthcare.

At first, it is important, for healthcare workers, to know why stigmatisation represents a serious issue for public health. Thus, the first section of this dossier will go further into the concept of stigmatisation and describe its negative consequences in terms of health, both in general and in the specific context of an epidemic or pandemic. The second chapter will provide useful information and advices to deal with stigmatisation-related issues within the doctor–patient relationship, while the third part of this dossier will examine the categories most at risk of suffering for stigmatisation. The fourth chapter will explain what differentiates human rights from medical ethics, and show their application in case of an epidemic.

## 1. The concept of stigmatisation

Since Greek times, a stigma was a mark or sign that indicated the individual who had it was of inferior moral quality, such as a slave, a criminal, a prisoner of war (Jones, 1987). Despite the different meaning given to the term by Christianity, related to the virtuous wounds of Christ (Ganzevoort, 2008), modern day use of the word seems to have returned to the original purpose: identifying individuals as not belonging to the normal social class of persons, thus indicating that they merit a higher level of concern than individuals considered normal (Hsin Yang et al, 2007). Stigmatised individuals can perceive themselves of being thought of in such way with psychological harms that can influence behaviour.

Individuals suspected to be carrying infectious disease are at risk of stigmatisation. Differential treatment of individuals in the healthcare process can cause or worsen an already pre-existing situation of stigmatisation than results because of the individual being part of a minority group. Such groups can range from the classic examples that are prone to stigmatising and discriminatory behaviour (e.g. racial, religious, sexual orientation, age) to more specific groups that only arise in specific healthcare contexts.

### 1.1. Negative Effects of Stigmatisation

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. Such behaviour often results from the negative self-judgment that these individuals have made as a result of their stigmatisation and could lead them not to seek help (Courtwright, 2009). For instance, an individual with a particular diagnosis – like HIV or hepatitis – could be scared by the expected social reaction that is likely to result from his condition and could thus feel a need to hide such condition from not only the public but also health care professionals.

In addition, during the context of an epidemic, marginalised groups that are already the source of stigmatisation (HIV again being a prominent example), may often be more at risk of contracting the condition itself, thus reinforcing the stigmatisation that such groups feel by both the epidemic and the healthcare response to it. It is thus clear that stigmatisation has many possible ways to bring about negative outcomes, which can be classified into both direct and indirect effects.

### 1.1.1 Direct Effects on Health

There is evidence that individuals who perceive themselves to be lower in the social order often undergo a chronic physiological stress response. Furthermore, stress has been shown to be more prevalent in more unequal societies. This response is associated with an increase in the production of stress hormones that, in the long term, can lead to a condition of chronic stress, which has been linked to negative health effects like poorer level of cardiovascular health (Marmot, 2004). The relationship between social positioning and health problems has also been recently used to explain why more equal societies do better (Wilkinson & Pickett 2010).

Another possible negative of such chronic stigmatisation is depression (Deacon, 2006), which is harmful in itself but which can also increase the likelihood of substance abuse and other harmful behaviours, including the refusal to follow health prevention measures that can lead to an increased risk to contract a disease, which would in turns strengthen the stigmatisation.

### 1.1.2. Indirect Effects on Health

In addition to the direct stress response, stigmatisation may also trigger a range of indirect negative effects that can be attributed to the notion of self-loathing or lack of individual self-worth (Courtwright, 2009). This alters individual behaviour so as make in several ways that can bring about negative consequences.

One of the main issues is the reduced desire to seek healthcare when needed, typical of group whose members, in attempting to obtain healthcare, are the subject of stigmatisation as a result of their membership of the group itself (Gornik, 2000). For instance, black or other groups with a perceived lower socio economic status are slower to seek treatment than their white counterparts, mainly because they feel they are to be judged more responsible for the condition through irresponsible behaviour than the white peers (Chesney, 1999). It is thus important not to exacerbate pre-existing stigmatisation and to always keep in mind that individuals who are stigmatised may have an increased aversion to using medical services.

Individuals that are the subject of stigmatisation often suffer a lesser motivation to secure important resources in social life. Among these resources, together with education or employment opportunities, there is also healthcare (Courtwright, 2009). It has been demonstrated that lower levels of education and lower incomes have a clear association with lower levels of personal health, which in turns result in disparities in personal health levels between stigmatised and non-stigmatised groups (Courtwright, 2009). Medical authorities should, during the context of an epidemic, aim in so far as is possible not to further worsen such problems.

## 1.2. Stigmatisation during epidemic/pandemic situations

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

The existence of such individuals and their susceptibility to stigmatisation must be taken into account when planning public health responses to epidemic situations. Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. In addition, these consequences could endure even after the epidemic has disappeared.

During a pandemic, as it may be obvious, the group of individuals that will experience the most stigmatisation issues are those who become infected. The stigmatisation of other groups (other than those who are infected) in an epidemic situation is based on assumptions that, because of their various characteristics, they are at increased risk of infection and therefore pose a threat. Individuals who are actually infected obviously pose a greater 'threat' than those who may be infected and so will be subject to a higher level of stigmatisation. Individuals who become infected therefore suffer from two conditions, the disease itself and the stigmatisation that comes with infection.

The SARS outbreak provided a recent example of the potential stigmatisation issues that individuals can face, even after their deaths (Kleinman & Lee, 2005). In China, instances of stigmatisation and discrimination included refusal by some funeral homes to handle the bodies of SARS victims, reluctance of certain medical and paramedical staff to care for SARS patients, discrimination of health professionals, e.g. refusing a service in the barber shop, forcing of employees to take annual leave as they had recently been to the hospital or to parts of mainland China hit by SARS.

# 2. Dealing with stigmatisation

There are two important ways for public institutions and health professionals to act in order to protect individual ability for self-respect and therefore to guard against stigmatisation (Rawls, 1971). First, individuals should be treated equally, irrelevant of any social group they belong to. This is of great importance for healthcare professionals, since they represent the first line of interaction with patients and should therefore act in order to ensure that all minorities and groups in society receive equal protection and treatment in response to epidemic threats. However, stigmatisation can also manifest as private behaviour that prevent individuals in stigmatised groups from using public services to the same extent as individuals in non-stigmatised groups.

An effective method that has been proposed to minimize such sources of stigmatisation was the establishment of independent associations that represent groups prone to stigmatisation, which are able to provide a secure space for stigmatised individuals to associate with other such individuals (Rawls, 1999). Healthcare workers should be aware of the existence of such groups and should foster communication with them, in order to encourage individuals to maintain "self-respect", thus being more likely to continue to seek access to the required public goods such as public healthcare. Such an approach has shown itself to be very efficacious in the reduction of stigmatisation for those individuals who are HIV positive. The engagement of such groups could be optimised not only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue in the planning of a response to a potential epidemic.

Communication strategies aimed to tackle risks of stigmatisation should not be targeted only at those persons belonging to minority groups; it is of great importance to remind all the people that the risks of contracting the infectious agent in question from individuals from the minority group is not usually higher than from someone in the general population.

## 2.1. Being ready and being trustworthy

It is very important to note that all the strategies and approaches that can be adopted to deal with stigmatisation require a good level of trust, which is not something that can be built at the moment but needs to be pursued way before the beginning of an epidemic. This is true at all levels of the healthcare hierarchy and particularly for healthcare workers, since they are those who daily and directly interact with patients.

It is thus important for a healthcare worker to be perceived as trustworthy; during an emergence, such perception will make people, even those at risk of stigmatisation, more likely to ask him for medical help and advice. In fact, the response of medical professionals can be important in the decision of stigmatised individuals to seek medical attention. Individuals are less likely to seek treatments from individuals that hold stigmatising views. This is an important factor that may help in explaining why, even in societies that create systems of equal access to healthcare, one does not always see the same levels of utilisation for the various groups that make up that society.

Stigmatisation in the context of epidemics may result from being part of a minority group, having some kind of “special” connection with the disease due to geographic, ethnic or working reasons, or having particular lifestyles. Healthcare professionals should be aware of these elements when dealing with their patients, in order to be able to identify potential stigmatisation issues in advance and to face them properly. Knowing people’s experiences, values and beliefs, and sharing their preoccupations, are two fundamental points on which to build a trust-based relationship, which in turns plays a key role in an effective risk communication, particularly when dealing with stigmatisation.

Healthcare professionals should also report in advance every possible case of stigmatisation they are aware of, in order to help health measures planning and to increase the surveillance level of potential cases.

## 2.2. Social Contact

Social contact plays a key role in every aspect of the doctor–patient relationship. Communication is characterized by two aspects: the content and the way by which it is delivered. A message is not only made of spoken or written words but also of non-verbal elements, such as expressions, gestures, tone of the voice, et cetera. An effective communication with patients should not be considered as a one-way transmission of information by the healthcare professional. The impact of such information on the patient and its awareness should always be taken into account and this may be done through listening, empathy, interaction and feedback. Such an approach helps the doctor to know the patient's history, which is one of the best ways to notice in advance those elements that could lead to stigmatisation.

Social contact is associated not only with individual happiness and contentment but also with human health. Research has shown a clear link between level of social support available to individuals and morbidity and mortality (Uchino et al, 1996). Social contact can also provide an important coping mechanism for those who feel stigmatised. In recent decades, this is a topic that has received a considerable amount of attention from researchers (Reblin & Uchino, 2008). Social isolation has been indicated as an increased risk factor for most types of mortality. Additionally, in recent years research has highlighted that individual health is not only improved by receiving support but by the ability of individuals to bestow care on others.

## 2.3. Personal privacy

Another aspect that every healthcare professional should always keep in mind is the importance of personal privacy as a tool against stigmatisation. Individuals should be allowed to seek care in a manner that will not unnecessarily compromise their personal privacy. In some cases this may mean not adding too much information regarding their condition to the record in order to assuage individual fears – whether rational or not – that the presence of their condition on their record will be used in a negative fashion by future employers or insurers.

The availability of anonymous testing and even treatment would likely mean that an increased number of individuals would feel less restricted by potential stigmatisation and seek treatment for their condition. In order to take advantage of the benefits that an anonymous environment would offer it would not be enough to have anonymous testing procedures in place, but such procedures would have to be actively publicised and disseminated so that individuals were aware of them (Herek et al, 2003).

## 2.4. Facing misinformation

In the early stages of an outbreak of an infectious disease it seems that individuals make use of the little information they have in order to protect themselves as much as possible. This will likely include, for instance, finding information on the possible geographical origins of the infectious agent in question. In an age where non-official sources of information are numerous and, to a certain extent, uncontrollable, individuals will always have access to a wealth of information even if no officially sanctioned information is yet available.

The Internet and social media has the potential to provide both reliable and unreliable information during an epidemic. During a vacuum in terms of official information, such facilities can spread rumour and conjecture widely and almost instantly. In the absence of official information, human instinct tends to take over with a likely result that assumptions will be made as to what constitutes a danger in terms of infection.

Healthcare professionals must be aware of the main rumours and conjectures that are circulating, in order to be able to better debunk them, thus decreasing the risk of stigmatisation they may provoke. They should also report any case of misinformation to medical authorities, allowing them to act by targeting the release of more accurate information designed to dispel any harmful unfounded rumours that may be circulating.

## 3. Categories at risk

Some categories of individuals are more likely than others to suffer stigmatization during the context of an epidemic. These include:

- pre-stigmatised groups e.g. the poor, homeless, immigrants, the old, individuals with conditions that result in a reduced immunity, ethnic minorities;
- individuals that become infected;
- individuals associated with the perceived origin of the outbreak in question;
- individuals that are to be vaccinated;
- medical Professionals.

### 3.1. The “origin issue”

Epidemics of infectious diseases have often been linked in popular perception to groups of individuals that have a particular origin. A good example for that is what happened in 2009, during the H1N1 pandemic: Mexico was perceived as being the origin of the new virus and this caused the outbreak to be called the Mexican flu in many states because it was thought to have first originated there (Gallagher, 2009). Information on the possible origin of an infectious agent is often the source of fear and anxiety and this came out clearly in 2009: for instance, there have been ships refusing to dock in Mexican ports, even in areas where there had been no incidence of infection, but which were willing to dock in US areas where infections had actually occurred. H1N1 fears led Haitian officials to turn back a Mexican ship carrying humanitarian food aid (CNN, 2009). Also, the identification of Mexico as ground zero of the emerging pandemic led to Mexican individuals experiencing numerous problems around the world and even in their own country, like unnecessary quarantine procedures or, in the US, the case of conservative media personalities who blamed Mexican immigrants for spreading the disease across the border, continuing their scapegoating of immigrants (Allison T, 2009).

There are plenty of similar examples in epidemiology: the great influenza pandemic at the end of the First World War, which was mistakenly given Spanish origins by many (Barry, 2004); an outbreak of hantavirus in the southern US, which was attributed to native Americans and dubbed the Navajo disease (Pearson et al, 2004); the Chinese community around the world being the source of negative attention in 2003 due to the SARS outbreak (Xinyu Jiang et al, 2006).

The problem of the disease origin is not merely a geographic one. The H1N1 influenza virus was, in addition to being popularly known as the “Mexican flu”, also named the “swine flu”. This resulted not only in negative outcomes for humans but also for pigs and the related livestock sector. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also triggered fear of those individuals such as pig farmers who worked in close proximity these animals. These reactions caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This led to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a one-time event. As a consequence, pigs presented no running health risks to humans despite the name "swine flu" being commonly used.

This is why it is therefore necessary for health authorities to be very careful when attributing origins to outbreaks of an infectious disease; references such as "Mexican flu" or "swine flu" should be avoided in favour of a more technical language. Unfortunately, it seems like such a cautious approach still need to be recognized by health authorities, as demonstrated by the recent case of the new SARS, quickly renamed Middle East Respiratory Syndrome (MERS) due to the location of its first cases. Healthcare workers should always keep in mind the importance of the "origin issue" and be ready to face it when dealing with patients, especially when the first ones to mistake are health authorities, as in the case of MERS.

### 3.2. Vaccination

Vaccination is one the most effective methods of combatting outbreaks of infectious disease (Ehreth, 2003) but it may also constitute a possible cause of stigmatisation. One of the irrational fears that many individuals often have about vaccines is that there is a risk that they will become infected with the virus contained in the vaccine. This may give rise to the fear of becoming infected and thus stigmatised as a consequence of vaccination.

Also, there are cases where certain lifestyle behaviours may be associated with an increased risk of infection. Thus, accepting a vaccination could represent a signal to others indicating that an individual is devoted to stigmatised activities. For instance, HIV vaccine trials have encountered difficulties recruiting individuals since many feared to be stigmatised as being sexually promiscuous or as intravenous drug users (Nyblade et al, 2003). This could also result from vaccination campaign targeted to some minorities that are considered at risk for lifestyle or health reasons (e.g. those who are elderly or obese) and that may suffer for stigmatisation as a consequence.

These are some significant examples of how the use of an effective medical instrument may lead to some negative effects. Healthcare workers should be ready to inform people belonging to these groups in order to prevent them from avoidance behaviours that could result in increased health risks, both for themselves and for the others.

### 3.3. Medical professionals

Medical professionals are not immune to stigmatisation. The large amounts of time they spend with individuals that are suspected of being infected or are indeed actually infected, can make them prone to stigmatisation issues and this is a problem, both for them and for their relationship with patients. For instance, general practitioners who worked with SARS patients in China reported higher levels of anxiety and social dysfunction (Verma et al, 2004). Stigma of this type flows from the fact that such workers are perceived as being at a higher risk of infection. Healthcare workers may also face the threat of quarantine under certain circumstances. In the SARS crisis in Canada, healthcare workers accounted for almost a quarter of total infected cases (Flood & Williams 2003). Such a stigmatisation may also come from colleagues who have not had the same contact with infected individual and can be long-term, even after the disease in question has disappeared. In addition, healthcare workers involved in the treatment of individuals during the early stages of an outbreak can feel blamed by other colleagues for allowing the infection to proliferate (Mitchel et al, 2002). Negative media reports and new stories over the performance and behaviour of healthcare workers can add to this sense of stigmatisation and stress.

## 4. Medical Ethics and Human Rights

It is somewhat universally accepted that public health information campaigns should be examined from an ethical or moral perspective, but there are disagreement over which approach to use. Contemporary medical ethics represents a collaboration between different theoretical schools of ethical philosophy (Peel, 2005). There are four principles that have been claimed to represent a combination of the various moral theories accepted throughout the world (Beauchamp & Childress, 1994):

- respect for autonomy;
- non-malfeasance;
- beneficence;
- justice.

Medical ethics have been used by physicians and those providing health interventions for centuries, if not millennia, to decide upon the moral acceptability of possible treatments.

There are advantages to the use of principals in medical practice. They provide a concise and coherent set of principles that doctors can use when making decisions. The system is easily taught to trainee medical professionals and does not require an advanced prior training in ethical or legal issues. The simplicity of the principals allow them to act as ethical trigger points in situations where individual medical professionals are required to make quick decision in urgent circumstances (Faunce, 2005).

This is in contrast to human rights, which, to a certain extent, represents a more complex discipline that is usually the domain of experts in the field. Human rights are designed to provide fundamental protections for individuals that allow them to have as equal as possible a level of participation in society and are therefore also applicable with regards to the provision of healthcare, which in most societies the state is seen as having an important responsibility in regulating. The principles found within Human Rights have been used increasingly by legal systems in the past decades to regulate healthcare provision. For instance, the Australian National University Medical School now teaches its students that human rights will, in the course of their careers, become more important in professional regulation than medical ethics (Faunce, 2005).

One key practical difference between the two systems is that one (human rights) focuses on the relationship between the state and its citizens and the other (medical ethics) is more concerned with a person to person relationship (i.e. between the physician and his or her patient). This results in an emphasis shift from trusting that the doctor always knew what was best for his patient to a situation where individuals were to be regarded as the best arbiter or what exactly was in their own best interests.

The increasingly high level of education and the ability to access types of information, including medical ones, has led to a change in the patient-physician relationship. The result of these developments was that many patients felt able to conduct their own research into their conditions and, where necessary, question or even refuse their physician's desired course of treatment.

Another factor that should be recognised is that the practice of medicine has changed considerably throughout the ages: in times gone by, physicians would act largely alone whilst modern medicine is organised on a greater scale and often by the state (Rastegar, 2004). On such a scale, systems of human rights are often better placed to adjudicate disputes than systems of medical ethics which are better adapted to dealing with dilemmas involving one or a few individuals. Also, human rights principals are also recognised as carrying more legal force. Healthcare workers represent the junction point between health institutions and patients, a position that requires them to know human rights and how to deal, in order to better manage every kind of situations they could deal with.

## 4.1. Human rights relevance to outbreaks of infectious diseases

The primary international sources of human rights are the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Each of these contains principles that may be pertinent during the course of an epidemic. It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies from being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality.

Strategies designed to tackle outbreaks of infectious disease often curtail individual freedoms. Prominent examples of such rights or freedoms can include the right of privacy of the individual, the right to bodily integrity and also the right to physical liberty. Poverty and communicable diseases also often have a close correlation (Dute, 2004). State organisations that engage in public health campaigns usually have good intentions – most notably the limitation of the spread of dangerous infectious diseases. Unfortunately, however, this aim is often pursued without adequate attention to the problems such public health campaigns can cause. The HIV/AIDS epidemic has shown that the potential exercise of public health powers and in particular powers of a compulsory nature have the potential to impact upon human rights, most notably individual liberty, physical integrity and privacy (Dute, 2004).

The human rights that are applicable during epidemic situations vary, from very precise duties to other more general principles that will inevitably apply in such contexts. The most important principles to consider are:

- the Right to life, which concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war);
- the Right to health, which is a social and economic right that foresees a duty upon states to provide healthcare for individuals in need of such services. This right has been used by groups of individuals, most notably in the developing world, to secure access to vital healthcare services such as vaccinations or antiretroviral therapy;
- the Right to freedom from inhuman or degrading treatment, which provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice the right has been closely linked to the concept of informed consent;

- the Right to liberty and security of person, which can be significantly engaged during a serious epidemic. In fact, such a right envisages freedom for individuals from arbitrary detention and there is obvious scope for conflict with such a right with techniques such as quarantine, which have been employed for many years during epidemics.
- the Right to a private and family life, which, in the context of healthcare it has been linked to both positive – a state can be required to act where such action is likely to protect an individual's private or family life – and negative - obligation upon states to desist from acts that may prevent individuals from realising this aim – duties;
- the Right to freedom against discrimination, which may can only be engaged in conjunction with another right and applied to a range of groups such as race, ethnicity and religion and, as been more recently accepted to those who have a different health status. It states that individuals cannot be denied their rights under the convention because they belong to one of the groups in question.

However, whilst human rights principals are useful protecting the fundamental rights of individuals in the context of an epidemic they are not able to completely prevent stigmatization during an epidemic. This is because the self-loathing needed for stigmatisation to exist can arise even where the state has itself done nothing to foster such a feeling. This is due to the fact that stigmatization can occur without discrimination and sometimes even when discrimination is prevented. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

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# Case history 5a – Don’t judge a book by the cover

**Topic:** Stigmatization

**Instructions for case history:**
- select an answer for each question and click on "submit answers" button;
- to overcome this case history it's needed to answer correctly to 100% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is overcome, click on "exit activity" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Target:** General population (adults)

**Step 1**

Spring 2013. A Chinese girl, apparently in her twenties, gets on a crowded subway. She has a cumbersome luggage and it will not be easy for her to bring it within such a throng. Curiously, however, she does not even need to push or ask for some space since she suddenly finds herself surrounded by emptiness. Lucas, a male nurse who is going to work, looks at that scene and thinks: “Here we are again with these fears. Nothing has changed...”.

**What does Lucas likely mean by that?**

- he refers to the outbreaks of avian flu in 2003 and 2013 and to their impact on stigmatisation of people perceived as related to the geographic origin of the disease
- he refers to the negative attention on the Chinese community around the world due to the frequently recurrent SARS outbreaks
- he refers to decennial cyclical regime of Mers outbreaks and to their impact on stigmatisation of people perceived as related to the geographic origin of the disease
- he refers to the fact that people coming from abroad or travelling around the world are the potential carriers of H5N1 viruses

**Step 2**

“… things are exactly as they were ten years ago. News report about some new disease on the other side of the world abroad and then it’s enough for a person to be just less rosy than usual and have slanting eyes to be feared as a plague-spreader. No ways to make these persons understand that a girl like her doesn’t have anything to do with it”.

**How can he rule out the possibility of potential transmission of avian viruses in the described circumstances?**

- ○ the girl seems at the moment healthy
- ○ spring is not the typical season when avian influenza occurs
- ● neither cases of H7N9 infection nor the new H7N9 virus have yet been detected, in people or birds, outside of China and Taiwan
- ○ avian influenza is acquired only following the ingestion of infected poultry meat

**Step 3**

The girl has just smiled shyly to thank who makes room for her, with a very eastern wave of the head, but she could not get any reaction. She keeps her eyes low and looks noticeably uncomfortable.
“Look at that” thinks Lucas, full of disdain. “I wonder how she feels now. Even not considering the everyday stress, I guess that if she will get sick, she won’t go to the doctor, fearing to be discriminated. If I was at her place, I would be already depressed. Such a shame”.

**Which can be major negative effects of stigmatization during pandemic/epidemic situations?**

- ○ increased access to healthcare by stigmatized individuals
- ○ medication misuse or overuse
- ○ unhealthy preventive behaviours
- ● stress, depression and reduced access to healthcare

INVIA RISPOSTE

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**Conclusion**

Suddenly, Lucas makes a decision and leaves his seat to offer it to the girl: “Miss, would you like to seat? Such a luggage is larger than you”.
“Oh, thank you, thank you very much” replies the girl.
Then Lucas, in a louder voice, in order to be heard by everybody around them, says: “Are you coming from somewhere far away with such a luggage?”.
“No, I’m leaving. I’ve been living here since I was born and this is the first time I go abroad” answers the young woman in a perfect local language.

Click on "exit activity" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Case history 5b – Don’t judge a book by the cover

**Topic:** Stigmatization

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass this case history it's needed to answer correctly to 100% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Target:** General population (adults)

**Step 1**

“Good morning madam, yes, yes you did right by calling me. I have not started to visit yet. Tell me”. Dottor Cox has just answered the phone with the speakerphone, while he is driving to his studio.
“Excuse me? Could you please just repeat? It seems that the line is not working well...”.
On the other side of the phone, Mary is telling her misfortunes almost without breathing.
“I understood that you’re not feeling well, ok, but I was saying that the phone is not working well...”.
After a few seconds, the connection gets better. “Oh, well, now I hear you clear. You’ve just said you are not feeling good, haven’t you?”.
Mary is that kind of patient who does not need to be asked by the doctor: “Not exactly, doctor, it’s more appropriate to say that I’m feeling quite bad. Cough, shivers, fever, burning eyes, even some nausea. It’s one week now, since that damned evening I went to that Middle East restaurant. I should have known that environment was clearly at risk!”.
“Excuse me, madam, what do you exactly mean?”
“What? Everybody can understand it, even without being a doctor: I just got that terrible disease, coming from Arabic countries, what’s its name?”.
“Do you mean MERS? Are you joking? Everything may happen but this seems quite a fancy interpretation of what is happening to you. However, if it’s a week you feel that bad, you could have called me before”.
“I just came back from one week in the mountains, I was skiing. Yes, because all this mess happened when I was away”.

**In the previous dialogue:**

- the lady misunderstood the news about a new virus because of her low level of education
- media are accused of hyping racism
- the doctor shows good communication skills

- the lady was misled by the stigmatizing naming of a disease

**Step 2**

"I understand" replies doctor Cox. "But now you're back".
"Yes, but I would prefer not to go to the clinic, because I know there are so many foreigners among your patients, you risk too. If I hadn't got the new disease at the restaurant, I could catch it in your studio...".

**From which potential threat does Mary feel menaced?**

- going out in the crowd to reach the doctor's office since a pandemic is on
- meeting both the doctor and his patients in the studio, since some of them come from countries where there is an outbreak now
- meeting the doctor, as, visiting so many people, he could be infected
- getting in touch with other patients in the doctor's office, whose levels of education are so low they are supposed not to follow preventive measures

**Step 3**

"What should we do, doctor?"
"What should we do? As you put it, it's not that easy to find a solution. But we certainly need to clarify some big misunderstanding. Madam, I'll call you back from my studio. I have a compelling visit and then I will commit to your case".
"Don't forget, doctor, I'll be waiting for your call in suspense".
Doctor Cox reaches his studio where he performs the urgent visit. After that, before calling Mary back to debunk all her false beliefs, he thinks whether he tackled his "difficult" patient in the best way. Then he gathers all his mental energy, his patience and everything he learned in the e-course of the TELL ME project, and calls the anxious lady.

**Why should the doctor think he did mistakes in his phone call with Mary?**

- he shouldn't have let Mary self-diagnose because in this way he lost his preminent role
- he should not have used a top-down approach, underestimating her concerns at the risk of jeopardizing their relationship
- he should have offered to visit her at home
- he should have been more resolute and prevent her from saying nonsense

INVIA RISPOSTE

**Conclusion**

At the end of the phone call the doctor mumbles: “Well, I interrupted Mary saying ‘Do you mean MERS?’ … Then I told her: ‘If it’s a week you feel that bad, you could have called me before’, not a good proof of empathic communication, indeed” admits to himself.

Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 5

## Summary

# Cartoon 1

## Step 1

*Dossier 1 - Epidemics and pandemics - General guidelines*

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

[…]

**2.2.4. Epidemiology**

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

[…]

*Dossier 3 - Stigmatisation and Discrimination*

**1.2. Stigmatisation during epidemic/pandemic situations**

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

The existence of such individuals and their susceptibility to stigmatisation must be taken into account when planning public health responses to epidemic situations. Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. In addition, these consequences could endure even after the epidemic has disappeared.

During a pandemic, as it may be obvious, the group of individuals that will experience the most stigmatisation issues are those who become infected. The stigmatisation of other groups (other than those who are infected) in an epidemic situation is based on assumptions that, because of their various characteristics, they are at increased risk of infection and therefore pose a threat. Individuals who are actually infected obviously pose a greater 'threat' than those who may be infected and so will be subject to a higher level of stigmatisation. Individuals who become infected therefore suffer from two conditions, the disease itself and the stigmatisation that comes with infection.

The SARS outbreak provided a recent example of the potential stigmatisation issues that individuals can face, even after their deaths (Kleinman & Lee, 2005). In China, instances of stigmatisation and discrimination included refusal by some funeral homes to handle the bodies of SARS victims, reluctance of certain medical and paramedical staff to care for SARS patients, discrimination of health professionals, e.g. refusing a service in the barber shop, forcing of employees to take annual leave as they had recently been to the hospital or to parts of mainland China hit by SARS.

[…]

There are plenty of similar examples in epidemiology: the great influenza pandemic at the end of the First World War, which was mistakenly given Spanish origins by many (Barry, 2004); an outbreak of hantavirus in the southern US, which was attributed to native Americans and dubbed the Navajo disease (Pearson et al, 2004); the Chinese community around the world being the source of negative attention in 2003 due to the SARS outbreak (Xinyu Jiang et al, 2006).

## Step 2

*Dossier 1 - Epidemics and pandemics - General guidelines*

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

[…]

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

## Step 3

*Dossier 3 - Stigmatisation and Discrimination*

**1.1. Negative Effects of Stigmatisation**

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. Such behaviour often results from the negative self-judgment that these individuals have made as a result of their stigmatisation and could lead them not to seek help (Courtwright, 2009).

[…]

**1.1.2. Indirect Effects on Health**

In addition to the direct stress response, stigmatisation may also trigger a range of indirect negative effects that can be attributed to the notion of self-loathing or lack of individual self-worth (Courtwright, 2009). This alters individual behaviour so as make in several ways that can bring about negative consequences.

One of the main issues is the reduced desire to seek healthcare when needed, typical of group whose members, in attempting to obtain healthcare, are the subject of stigmatisation as a result of their membership of the group itself (Gornik, 2000). For instance, black or other groups with a perceived lower socio economic status are slower to seek treatment than their white counterparts, mainly because they feel they are to be judged more responsible for the condition through irresponsible behaviour than the white peers (Chesney, 1999). It is thus important not to exacerbate pre-existing stigmatisation and to always keep in mind that individuals who are stigmatised may have an increased aversion to using medical services.

Individuals that are the subject of stigmatisation often suffer a lesser motivation to secure important resources in social life. Among these resources, together with education or employment opportunities, there is also healthcare (Courtwright, 2009). It has been demonstrated that lower levels of education and lower incomes have a clear association with lower levels of personal health, which in turns result in disparities in personal health levels between stigmatised and non-stigmatised groups (Courtwright, 2009). Medical authorities should, during the context of an epidemic, aim in so far as is possible not to further worsen such problems.

# Cartoon 2

## Step 1

*Dossier 3 - Stigmatisation and Discrimination*

**2.4. Facing misinformation**

In the early stages of an outbreak of an infectious disease it seems that individuals make use of the little information they have in order to protect themselves as much as possible. This will likely include, for instance, finding information on the possible geographical origins of the infectious agent in question. In an age where non-official sources of information are numerous and, to a certain extent, uncontrollable, individuals will always have access to a wealth of information even if no officially sanctioned information is yet available.

The Internet and social media has the potential to provide both reliable and unreliable information during an epidemic. During a vacuum in terms of official information, such facilities can spread rumour and conjecture widely and almost instantly. In the absence of official information, human instinct tends to take over with a likely result that assumptions will be made as to what constitutes a danger in terms of infection.

Healthcare professionals must be aware of the main rumours and conjectures that are circulating, in order to be able to better debunk them, thus decreasing the risk of stigmatisation they may provoke. They should also report any case of misinformation to medical authorities, allowing them to act by targeting the release of more accurate information designed to dispel any harmful unfounded rumours that may be circulating.

[…]

**1.2. Stigmatisation during epidemic/pandemic situations**

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

[…]

The problem of the disease origin is not merely a geographic one. The H1N1 influenza virus was, in addition to being popularly known as the “Mexican flu”, also named the “swine flu”. This resulted not only in negative outcomes for humans but also for pigs and the related livestock sector. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also triggered fear of those individuals such as pig farmers who worked in close proximity these animals. These reactions caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This led to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a one-time event. As a consequence, pigs presented no running health risks to humans despite the name “swine flu” being commonly used.

This is why it is therefore necessary for health authorities to be very careful when attributing origins to outbreaks of an infectious disease; references such as “Mexican flu” or “swine flu” should be avoided in favour of a more technical language. Unfortunately, it seems like such a cautious approach still need to be recognized by health authorities, as demonstrated by the recent case of the new SARS, quickly renamed Middle East Respiratory Syndrome (MERS) due to the location of its first cases. Healthcare workers should always keep in mind the importance of the “origin issue” and be ready to face it when dealing with patients, especially when the first ones to mistake are health authorities, as in the case of MERS.

## Step 2

*Dossier 3 - Stigmatisation and Discrimination*

**3. Categories at risk**

Some categories of individuals are more likely than others to suffer stigmatization during the context of an epidemic. These include:

- pre-stigmatised groups e.g. the poor, homeless, immigrants, the old, individuals with conditions that result in a reduced immunity, ethnic minorities;
- individuals that become infected;
- individuals associated with the perceived origin of the outbreak in question;
- individuals that are to be vaccinated;
- medical Professionals.

[…]

**1.2. Stigmatisation during epidemic/pandemic situations**

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

[…]

Healthcare workers should always keep in mind the importance of the “origin issue” and be ready to face it when dealing with patients, especially when the first ones to mistake are health authorities, as in the case of MERS.

## Step 3

*Dossier 2 - Talking about prevention*

**1.2 Listening is the first condition**

Listening, along with empathy, skills and experience, honesty and frankness, dedication and engagement, represents one of the key factors on which reliability and trust rely on (Covello, 1992).

More than 50% of communication reliability depends on the way in which people perceive the person who is in charge of communication. If people perceive empathy, listening and attention for their worries, their way of living and feeling the risk, they will be more willing to listen and trust. If, on the contrary, the person in charge of communication is not reliable because he/she is “distant” from people and exclusively focused on his/her own information objectives, the trust level will be reduced and at the same time the emotional components of perception prevail on the cognitive one. Therefore the communication content, even if adequate and scientifically sound, will not be perceived by people because passed through a relational process without empathy, not so focused on the identification of real informative needs of target, on its sensitivity and perception.

In those cases there is often the transformation of the communicative process in a conflict among contrasting positions where emotional reactions, sometimes even in a disordered way, prevail and the “focal issue”, the topic, the situation object of the communicative exchange may be missed.

Listening and empathy are communicative competences. This means that they are skills that can be learned by specific training so that the operator can use them in his professional relationship in order to enhance communication effectiveness.

Listening represents the first step in the professional relationship; it is based on empathy and on the other’s point of view acceptance, on the creation of a positive relationship and of a non-judging mood. It is needed to show interest and attention to speaker's needs, to create a relationship of trust and cooperation, premise for a future coalition.

It is possible to listen by putting oneself in the other’s shoes, thus entering his reference scheme and trying to see the “world” with the other’s eyes so as to understand the information from a rational and emotional point of view (thoughts, experience, emotions, significance) to understand his requests and needs. To listen through empathy means, therefore, to open up to the other person, follow and deeply understand his worries and emotions, assuming the same point of view. This means to live for some time “as if” you were the other, but without forgetting that it is just “as if”. If there is no “as if” condition, then it is no more possible to talk of empathy but of identification.

Being empathetic does not mean confusing the two points of view, even because often these two do not agree. This rather means to recognize what belongs to oneself (what I would do, think, decide, feel in the same situation) and being able, at the same time, to suffocate his/her own point of view to “see the world with the eyes of the other person” so as to recognize and accept, without judgments and interpretations, what the other perceives, thinks, feels or decides and does in the same situation. Empathy is supported by distinction not confusion.

In the professional relationship between healthcare workers and public, empathy contributes to maintain the roles separated. In fact, only through this distinction it is possible to recognize one’s own sensitivity and face emotional reactions of public, thus avoiding defensive behaviors that are often the reason for conflicts and symmetrical escalations. Just through distinction, it is possible to keep, in a transparent way, the appropriate distance from the public, to take part emotionally but without burning oneself. If one perceives transparency, that is a correlation among emotions showed and those really felt, he opens up himself, otherwise he will not.

Therefore, to communicate in an empathic way means being congruent with what one thinks and feels and what is expressed through oral and non-oral communication. This means to be able not to judge, leaving for some time one’s own values and perceptions for embracing the one of the other person “as if” were one’s own world. It means avoiding directedness, suggestions, interpretation. But this is not enough, because to listen in an empathic way also means being able to give back this recognition and comprehension.

## Case history 6

# Fear of whispering people

SEVENTH FRAMEWORK PROGRAMME

tellme

# Epidemics and pandemics: what health professionals need to know

WP3 Prototype Online Course for Primary Care Staff

DOSSIER 1

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Dealing with human rights: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
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# INTRODUCTION

Epidemics and pandemics represent serious threats to human life and health, and require great efforts in order to prevent them to inflict such damage. However, facing these problems is far from being easy, due to many factors, from their unpredictability to the high level of national and international cooperation that is necessary to establish when dealing with them.

Healthcare workers represent the first line of intervention and the first level of interaction between healthcare institutions and citizens. For these reasons, they should know as much information as possible – epidemiology, modes of transmission, symptoms, diagnosis, prevention, treatments and so on – about the infectious diseases that are circulating at the moment.

Prevention, in particular, is quite a relevant theme that also brings several issues, mainly because of the criticism that surrounds vaccines. Given this, a full dossier has been entirely dedicated to prevention. Such a dossier contains both technical information about preventive measures and advices about how to properly communicate them to the public. This is the reason why there is no reference to prevention in the following chapters.

# 1. Definitions

First, it is necessary to clarify a definition in order to avoid confusion and misunderstanding. The difference between epidemic and pandemic is highly important because of the different kinds of approach they require and the feelings they evoke in the citizens.

## 1.1. Epidemic

The term epidemic is often associated with outbreak and many epidemiologists use both terms interchangeably, sometime even together, that is “an epidemic outbreak”. A broad definition given by many epidemiologists for epidemic is “more disease than is anticipated by previous experience”, whilst a more precise one is “a number of cases (infectious or not) greater than the expected in a defined place and time of any dimension”, and is to be distinguished by an outbreak, which is “an epidemic confined to a defined short time and place”. Such a distinction, however, is less meaningful to the general public, since epidemic is more likely to imply a crisis (Green et al., 2002). According to the US Centers for Disease Control and Prevention (CDC), an epidemic (or an outbreak) exists when “there are more cases of a particular disease than expected in a given area, or among a specific group of people, over a particular period of time”. This may be due to the recurrence or emergence of a new microorganism within a given population or to the emergence of an agent with a genetic mutation.

At irregular intervals, an influenza A virus emerges which is different from the current human seasonal influenza viruses and can not only infect humans but can also cause disease in some of them and crucially is capable of efficient human to human transmission. The virus has to be novel enough to prevail over the seasonal A viruses, and because of its novelty there can be little specific immunity among humans, except for older people who may have met a similar virus in the past. This new virus can then spread rapidly from

human to human all over the world. Because of the lack of human immunity, the virus causes a variable amount of severe disease and deaths: this is an influenza pandemic (ECDC). As immunity increases among humans, and the pandemic virus changes, the pandemic strain becomes part of (and may dominate) the mix of seasonal influenza A viruses, perhaps changing some of the characteristics of seasonal influenza. Influenza pandemics vary, and in order to mitigate or even prevent some of their most concerning impacts there is a need for specific and general preparedness.

## 1.2. Pandemic

There have been controversies over the precise definition of what a pandemic is, especially following the 2009 H1N1 swine flu pandemic, with several experts claiming that there has been an excess of alarmism from healthcare authorities. A pandemic is said to occur when a new infectious agent, or a reemerging one, spreads across multiple continents, or even worldwide. This is the reason why, for instance, cancer, which is not infectious, is not considered pandemic even though is responsible for many deaths, nor is malaria, that spreads through continents but isn't new, nor are very severe diseases like those caused by Ebola virus, self-limiting because of their own lethality. According to the classical epidemiological definition, a pandemic is defined as "an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people" (Last JM, 2001).

This says nothing about population immunity, virology or disease severity. But by this definition, pandemics could be said to occur annually in each of the temperate Southern and Northern hemispheres, given that seasonal epidemics cross international boundaries and affect a large number of people. However, seasonal epidemics are not considered pandemics. A true influenza pandemic occurs when almost simultaneous transmission takes place worldwide. In the case of pandemic influenza A(H1N1), widespread transmission was documented in both hemispheres between April and September 2009, period that was out of season in the Northern hemisphere. (Kelly, 2011). Case fatality ratio ranged from 0.01 to 0.03% (Donaldson, 2009, Bandaranayake 2010, McVernon 2011), that is much lower than feared, similar to those normally seen in the case of seasonal influenza (Wilson 2009). However, the number of deaths was higher in younger people, as it happened in previous influenza pandemics (Kelly, 2011).

A debate is still ongoing whether H1N1 influenza should have been labelled a "pandemic" at all. The Council of Europe voiced serious concerns that the declaration of a pandemic became possible only after WHO changed its definition of pandemic influenza, few weeks before it also expressed misgivings over WHO's decision to withhold publication of the names of its H1N1 advisory Emergency Committee (Council of Europe, 2010). "At stake in this debate are the public trust in health officials and our collective capacity to respond effectively to future disease threats. Understanding this controversy entails acknowledging that both parties are partially correct, and to resolve it we must re-evaluate how emerging threats should be defined in a world where the simple act of labelling a disease has enormous social, economic and political implications", Peter Doshi wrote on the Bullettin of WHO (Doshi, 2011).

The controversy raised by the fact that since 2003, the top of the WHO Pandemic Preparedness homepage has contained the following statement: "An influenza pandemic occurs when a new influenza virus appears against which the human population has no immunity, resulting in several simultaneous epidemics worldwide with enormous numbers of deaths and illness". However, on 4 May 2009, scarcely one month before the H1N1 pandemic was declared, the web page was altered in response to a query

from a CNN reporter. The phrase "enormous numbers of deaths and illness" had been removed and the revised web page simply read as follows: "An influenza pandemic may occur when a new influenza virus appears against which the human population has no immunity." Months later, the Council of Europe would cite this alteration as evidence that WHO changed its definition of pandemic influenza to enable it to declare a pandemic without having to demonstrate the intensity of the disease caused by the H1N1 virus. WHO, however, denied having changed any definitions (WHO press conference, 2010).

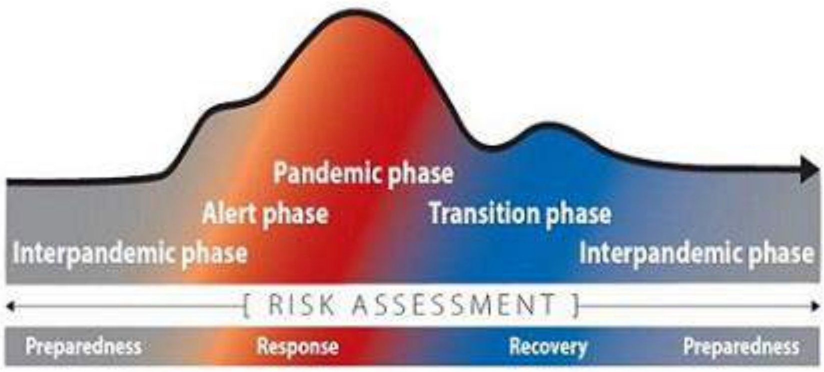
WHO argues that this phrase had little bearing on policy responses, it was "never part of the formal definition of a pandemic" and was never sent to Member States, but simply appeared in "a document on WHO's website for some months". In actuality, was displayed at the top of the WHO Pandemic Preparedness home page for over six years and is consistent with the descriptions of pandemic influenza put forth in various WHO policy documents over the years. While it unambiguously describes disease severity and certainly reflects general assumptions about pandemic influenza, it is unrelated to the criteria WHO applied to declare H1N1 influenza a pandemic. In fact, a formal definition of pandemic influenza has never been formulated. What we have from WHO's pandemic preparedness guidelines are only "pandemic phase" definitions.


*2009: WHO Pandemic influenza preparedness and response*

WHO declared a pandemic on 11 June 2009, after determining that the novel reassortant H1N1 virus was causing community-level outbreaks in at least two WHO regions, in keeping with the definition of pandemic phase 6. The declaration of phase 6 reflected wider global dissemination of H1N1, not disease severity. This point has received widespread attention and criticism. A new WHO 2013 interim guidance document (WHO, 2013), taking account of lessons learnt from the influenza A(H1N1) 2009 pandemic and of other relevant developments, updates and replaces the previous WHO guidance document (WHO, 2009), but it does not give yet a clear and formal definition of pandemics.

It admits that in 2009 Member States "had prepared for a pandemic of high severity and appeared unable to adapt their national and subnational responses adequately to a more moderate event". This document

aligns more closely with the disaster risk management structures already in place in many countries and underscores the need for appropriate and timely risk assessment for evidence-based decision-making at national, subnational and local levels. It introduces a risk-based approach to pandemic influenza risk management and encourages Member States to develop flexible plans, based on national risk assessment, taking account of the global risk assessment conducted by WHO.




*2013: Pandemic Influenza Risk Management WHO Interim Guidance*

Breaking this down further sensibly becomes an international, national, sub-national and local response to the outbreak at whatever level the pandemic presents itself. This approach is very similar to the latest thinking on what is seen as the best way to tackle climate change, which is a disaster risk management approach to climate change adaptation that is now further maturing into the convergence of "disaster risk reduction and climate change adaptation". There are some key principles in crisis management that may be relevant here:

- organizations are reluctant to take responsibility for the making of decisions for other organizations. In other words the WHO may declare a pandemic, but how governments respond is their own responsibility;
- "delegation of responsibility" is important in order to achieve a timely and an appropriate response (i.e. in relation to the local impact of the crisis);
- responsibility in a crisis lies where it does in 'peace time'. Of course there will be some aspects of that responsibility which will change because of the crisis but essentially responsibility rests where it is.

In response to lessons learnt from the influenza A(H1N1) 2009 pandemic, a revised approach to global phases is introduced in this guidance. The phases, which are based on virological, epidemiological and clinical data, are to be used for describing the spread of a new influenza subtype, taking account of the disease it causes, around the world. The global phases have been clearly uncoupled from risk management decisions and actions at the country level. Thus, Member States are encouraged as far as possible to use national risk assessments to inform management decisions for the benefit of their country's specific situation and needs.

Therefore, if the WHO identify an influenza outbreak and report the facts as known at the time, the responsibility for responding in an appropriate way lies with national governments. Of course, a

coordinated response between nations will help and the WHO should seek to facilitate this. The declaration that the influenza outbreak is a pandemic is almost academic at the beginning of the outbreak but may become more important and much clearer later as the influenza spreads. The fact is initially that an outbreak has occurred, is being monitored and governments and organizations need to take notice and respond appropriately. The WHO can of course give guidance on what is an appropriate response.

Anyway, a new definition of pandemic is needed, taking into account not only the spread of a new infection, but also its burden. This can depend on severity, in term of victims, but also on socio-economical costs, not to be undervalued in case of a widespread infection, even if less severe than expected.

## 2. Main epidemics

### 2.1. Seasonal influenza

### 2.1.1. Clinical information

Influenza is caused by RNA viruses from the *Orthomyxoviridae family*, which have a worldwide distribution and can infect birds and mammals, among which humans. They are usually classified into three broad types: A, B and C, according to differences in the antigenic properties of their external coat. Influenza A viruses, clinically the most threatening, are further divided into subtypes based on two proteins on the external coat, hemagglutinin (HA) (H1–H16) and neuraminidase(NA) (N1–N9). Type B viruses are usually responsible for less severe diseases, whereas type C viruses do not usually cause significant human disease. Each season, human influenza is caused by variable mixes of influenza A plus B viruses. Like other RNA viruses, the genome of influenza viruses is subject to a significant spontaneous mutation rate; in addition, their genome consists of eight separate segments. Thus, that re-assortment of the genome segments results in considerable antigenic variability, particularly of the HA and NA of the influenza A viruses.

Gradual changes in the level and type of human viruses in seasonal influenza is the result of what is known as *antigenic drift*, the continuous change of the viral HA and NA due to the high mutation rate of the genome and the fact that RNA viruses lack the proof-reading ability of DNA polymerases. This means also that influenza can quickly evolve to evade the human immune responses that follow natural infection or immunization. Pandemics are the result of larger changes sometime called *antigenic shift*. These are large genetic changes, for example through inclusion in the virus of HA and NA subtypes from avian or swine origin by reassortment. These reassortments are not rare but only very occasionally lead to a viable, transmissible influenza A virus for which many or most humans lack immune protection. That is then a pandemic strain.

Influenza is an acute infection that spreads easily from person to person. It is transmitted by droplets that get into the air when an infected person coughs or sneezes, but also through hand contact. For these reasons, the first line of defense is constituted by healthy habits such as covering their mouth and nose with a tissue when coughing, and washing their hands regularly. People could be able to pass the flu to someone else before they even know they are sick, as well as during the sickness. Some people can be infected with the flu virus but have no symptoms. During this time, those persons may still spread the virus to others.

Incubation usually lasts for 1-4 days, with an average of two. Symptoms are not specific and may be easily confused with those due to other respiratory affections, especially the common cold, which are not as severe as influenza and are called influenza-like illnesses. Typical of flu is the coexistence of sudden high fever (over

38°C), chills, cough (usually dry), headache, muscle and joint pain, weakness, sore throat, runny nose and malaise. In children, influenza may also produce gastrointestinal symptoms like nausea and vomiting. The presence of these symptoms in the season is usually enough to diagnosis influenza, but when a confirm is needed an antigen detection test, which is done by swabbing nose and throat, and then sending a sample to the laboratory for testing, can be done. The results of these tests can be available rapidly, and can help decide if specific treatment is appropriate.

### 2.1.2. Categories at risk

Influenza may cause some people to suffer from complications like pneumonia, bronchitis, sinus and ear infections, dehydration, and aggravation of pre-existent diseases. There are some categories that are more likely to incur into such complications, depending on age and health status. ECDC considers at risk people with:

- metabolic diseases (e.g. diabetes);
- chronic lung conditions (e.g. chronic bronchitis);
- cardiovascular disease (e.g. coronary artery disease);
- chronic kidney diseases (e.g. chronic renal failure);
- chronic neurological conditions and physical handicap (e.g. cerebral palsy);
- conditions and treatments that suppress the immune function (e.g. people receiving chemotherapy).

In some countries, it is considered that children and pregnant women are also in risk groups. While that was certainly the case in some countries in the 2009 pandemic, it is not clear if is the case in European Countries for seasonal influenza (ECDC, 2007b), although small children up to four years old were the most affected age group for mild disease during the 2011-2012 season (ECDC, 2013).

### 2.1.3. Treatment

NSAIDs and antipyretics can be used to keep fever under control and to mitigate the general discomfort that afflicts the patient. On the other hand, the use of antivirals in seasonal flu is controversial, since they could be useful in shortening the duration of the illness, but there are few evidences of their efficacy in reducing complications, hospitalization or death (Jefferson T et al, 2014a, b, c).

They can also have side effects, so they are not usually recommended in otherwise healthy adults with ordinary influenza. For people in a risk group, the most important way of preventing the serious complications of flu is to be vaccinated and take general precautions, but antivirals can also be considered, even if European countries have different policies about their use.  Currently two drugs are mostly recommended for this use: oseltamivir (whose trade name is Tamiflu) and zanamivir (Relenza).

Amantadine and other drugs of the same class should not be used any more as all circulating influenza viruses are resistant to them. Zanamivir and oseltamivir belong to neuraminidase inhibitor family, drugs that attack the flu virus replication cycle and prevent its spreading within the body.

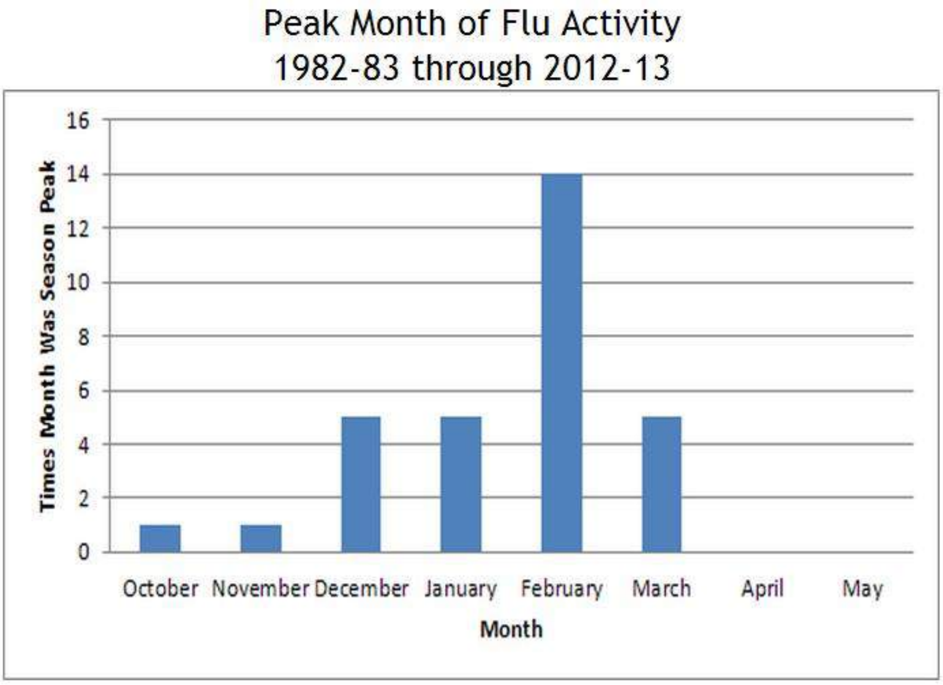
Oral oseltamivir or inhaled zanamivir (to be preferred in severely immunosuppressed patients) can so only be recommended when the flu is circulating or in laboratory-confirmed cases at high risk of complications, such as the elderly or those with underlying conditions like asthma or heart diseases, or in the general population when the illness gets complicated, requiring hospital admission and/or with symptoms and signs of lower respiratory tract infection (hypoxaemia, dyspnoea, lung infiltrate), central nervous system involvement and/or a significant exacerbation of an underlying medical condition.

Anyway, it is important to stress that the efficacy of these drugs in reducing the risks of serious complications is still under scrutiny and in any case they can only be effective if they are taken early in the illness. The earlier the better. After 48 hours from the onset, drugs are not thought to help much at all: given within 12 hours of the illness starting the benefit seems to be greater than if they are not given for 24 hours, which in turn is better than 48 hours. For people at high risk of complicated influenza who have had contact with cases of the disease chemoprophylaxis could also be considered.

### 2.1.4. Epidemiology

Influenza spreads around the world in seasonal waves of epidemics and, despite being perceived as a soft disease, represents a serious public health problem that causes severe illnesses and deaths for higher risk populations. It is estimated that, in Europe, excess deaths due to influenza are from 8 deaths per 100,000 population in milder season to 44 per 100,000 in more severe, non-pandemic, ones. Applying figures from the US CDC to the EU population as a whole (around 500 million in 2010) would result in around 38,500 premature deaths each year, but with considerable season-to-season variation. The burden from influenza anyway is not only about its lethality. In addition, the socio-economic impact cannot be forgotten, since the disease produces large numbers of mild to moderate cases that result in time off work, losses to production and pressure and costs on the health and social care services.

In temperate regions, annual epidemics begin in autumn with peak during winter. Cold temperature facilitates the spread of influenza: cold air becomes drier and dehydrates mucus, thus preventing the body from effectively expelling virus particles. In addition, cold environments allow viruses to survive longer and to be more easily transmitted via aerosol. The annual recurrence of called flu seasons allows influenza activity to be sometimes predicted and tracked even if the exact timing and duration of flu seasons may vary. On the average, the peak flu activity in the Northern hemisphere in the last thirty years occurred in February, as shown in the following table from CDC website.




*During 2008-2009, flu activity peaked twice because of the 2009 H1N1 pandemic. Activity in the United States peaked once in in February due to seasonal influenza activity and then again in the Spring (June), with the first wave of 2009 H1N1 viruses A second, larger peak of 2009 H1N1 activity occurred in October, the peak of the 2009-2010 season.

Usually, in almost all reporting countries, the most affected age group for mild disease is that of small children up to four years old, whilst the bigger group for hospitalized influenza cases is that of the elderly. (ECDC, 2013).

These data are collected each season through a constant monitoring of influenza and influenza-like illnesses conducted by several national and international institutions through extended networks of epidemiologic surveillance, which keep track of the number, localization and age distribution of new cases. In parallel, an intense activity of virological surveillance allows researchers to characterize the different virus strains circulating, thus updating the composition of the vaccine to be developed for the following flu season.

In Europe ECDC gathers and analyzes data coming from the European Influenza Surveillance Network (EISN) on a weekly basis and issues a weekly report, called Weekly Influenza Surveillance Overview (WISO). EISN consists of contact points for influenza surveillance (epidemiological and virological) nominated by the Competent Bodies for surveillance of the Member States.

The European Surveillance System (TESSy) aims to contribute to reducing the burden of disease associated with influenza in Europe, and include collection and exchange of timely information on influenza activity, contribution to the annual determination of the influenza vaccine content, provision of relevant information about influenza to health professionals and the general public and contribution to European influenza pandemic preparedness activities.

## 2.2. Avian flu

### 2.2.1. Clinical information

Among influenza viruses, type A are the most common in nature. They are generally hosted by wild aquatic birds, but can occasionally transmit to other animals, including humans. Avian influenza A viruses usually do not infect humans but rare cases of human infection with avian influenza A viruses have been reported, usually following direct or close contact with infected poultry.

Since 1996, a particular strain of bird flu known as A(H5N1) has emerged. First identified in Southern China and Hong Kong, it may have been around for longer than that elsewhere in the Far East. The A(H5N1) viruses kill a high proportion of poultry that they infect. They also infect a surprisingly wide range of birds and animals, have persisted over time, and spread to poultry in a number of countries with poor infection control in poultry flocks.

A(H5N1) occasionally infects humans in contact with infected poultry. Because it causes severe disease in humans, it has to be taken seriously by European public health and animal health authorities. Though occasionally present in European wild birds, A(H5N1) viruses have never become established in poultry in Europe because of high levels of biosafety. An outbreak of human infections with a new avian influenza A (H7N9) virus was reported in China by the World Health Organization on April 1, 2013. Chinese authorities promptly acted and closed live bird markets in order to control the spread of the disease. H7N9 influenza seems to be less deadly than H5N1, but its pandemic potential is considered concerning by experts.

Signs and symptoms may vary, depending on which avian influenza A virus is responsible for the infection. If the infection is low pathogenic the patient will show symptoms characteristic for influenza-like illness – thus including cough, fever, sore throat – and typically conjunctivitis, but in some cases also lower respiratory disease like pneumonia, which would require hospitalization. Symptoms associated with highly pathogenic avian flu virus are much wider and include all those reported for low pathogenic infections, but also severe respiratory illness, multi-organ disease, sometimes accompanied by nausea, abdominal pain, diarrhea, vomiting. Cases of neurologic changes, like altered mental status or seizures, have also been reported. Avian influenza A virus infection in humans can only be diagnosed through laboratory testing, usually by collecting a swab from the nose or throat of the sick person at the beginning of the illness and analyze it in a laboratory with a molecular approach or by trying to grow the virus.

Avian viruses do not transmit efficiently from person to person. Some cases of limited, non-sustained human-to-human transmission have been reported for H5N1 virus and some evidence points to limited person-to-person spread in rare circumstances also for the most recent H7N9 that spread in China. In any cases, healthcare personnel caring for patients with suspected or confirmed influenza A virus infection should wear recommended personal protective equipment and follow recommended infection control measures (standard, droplet, contact, and airborne precautions).

### 2.2.2. Categories at risk

Persons more at risk of being infected are those that work and/or live in close contact with poultry. In these circumstances, children may be at higher risk than adults and this could be due more to their rash behavior rather than their constitutional susceptibility. The European Centre for Disease Prevention and Control

(ECDC) included these persons in the “low but real risk” group. A second category is the one that comprehend those at theoretical risk of being exposed to the virus: healthcare workers, veterinarian, some ornithologists and hunters. Standard hygienic precaution to protect against other kinds of infections from birds – such as campylobacter and salmonella – should also be sufficient to protect against avian viruses such as H5N1 and H7N9. The majority of H5N1 cases have occurred among children and adults younger than 40 years old. Mortality has been highest in people aged 10-19 years old and young adults. As for H7N9, a prevalence of older males among infected patients was found by researchers but the reasons behind this unusual distribution are still unknown.

### 2.2.3. Chemoprophylaxis and Treatment

For avian flu, CDC and WHO currently recommend oseltamivir or zanamivir, two of four prescription antiviral medications currently licensed for use. Analysis on H5N1 circulating viruses suggested that most viruses are susceptible to these antivirals but also revealed some evidence of resistance to oseltamivir being identified in viruses isolated from some human cases.

The WHO reported that, according to laboratory tests, H7N9 viruses are sensitive to antiviral neuraminidase inhibitors (oseltamivir and zanamivir) but there is little experience with the use of these drugs for the treatment of H7N9 infection. Anyway, CDC recommended the use of oseltamivir or inhaled zanamivir chemoprophylaxis, especially for those considered at high-risk of exposure, which means household or close family member contacts of a confirmed or probable case. CDC also recommended treatments with a neuraminidase inhibitor medication for symptomatic close contacts. Healthcare workers that had close contacts with a confirmed or probable case, maybe during bronchoscopy or intubation, or handling inadequately screened/sealed body fluids without use of recommended personal protective equipment, are considered at a moderate risk of exposure, which correlates with an unknown risk of transmission; for these cases, antiviral chemoprophylaxis could be considered. Administration of chemoprophylaxis should begin as soon as possible after first exposure to the confirmed or probable case.

An adjuvanted vaccine against influenza A (H5N1) virus has been recently approved by the US Food and Drug Administration (FDA). It will be added to the US national stockpile as a second vaccine option but will not be available for commercial use or purchase. A vaccine against H7N9 is being tested in clinical trials.

### 2.2.4. Epidemiology

The most highly pathogenic strain known of avian influenza virus is H5N1, which spread throughout Asia and caused more than 600 sporadic cases of human infection in 15 countries since November 2003, with an estimated mortality rate of approximately 60%. The quick diffusion of H5N1 from Asia to Europe was probably due more to intense poultry trades than to bird migrations.

In 2012, no outbreak of highly pathogenic avian influenza (HPAI) in poultry or wild birds was reported in Europe while epidemics were reported in Africa, Australia, North America, the Middle East and especially in Asia, where the majority of outbreaks emerged, the subtype H5N1 being mainly responsible for these (ECDC, 2013).

H7N9 Chinese epidemic is being constantly monitored by the WHO in order to identify every possible sign of diffusion outside China or mutations that could provide the virus with the capability to spread from human to human. As far as February 2014, no cases of sustained human-to-human transmission have been confirmed, while many patients report a recent history of exposure to live poultry, which are suspected to be a main reservoir for the virus (Xian Qi, 2013).

H7N9 followed a similar seasonal pattern to H5N1 bird flu, with a second wave of infections in autumn and winter following its onset in spring 2013. As far as 20 February 2014 the total toll of infections was up to 361, with 112 deaths. At the same time, no cases of H7N9 infection have been reported, and the new H7N9 virus has not been detected, in people or birds outside of China and Taiwan. In January 2014, Canada has reported the first case of human infection with avian influenza A (H5N1) virus ever detected in the Americas, in a traveler who had recently returned from China. It is important to note that an avian flu pandemic may occur concurrently with the seasonal flu, thus increasing the chance of complications due to the combination of the two diseases.

## 2.3. A(H1N1) flu

### 2.3.1. Clinical information

In April 2009, a new strain of influenza A virus, belonging to the subtype H1N1, was identified. The virus was generated by a triple reassortment of bird, swine and human flu viruses, and showed a strict homology with swine flu viruses that, in the past, proved to be pathogenic for humans. It was unrelated to the human seasonal H1N1 viruses that have been in general circulation among people since 1977. Compared to seasonal influenza, H1N1 influenza had a higher frequency of pulmonary complications, including serious forms of viral pneumonia, which are harder to treat than bacterial pneumonias usually associated with seasonal influenza, often leading to ARDS.

Ways of contagion are pretty much the same as seasonal flu but there have been contrasting observations regarding contagiousness: the World Health Organization (WHO) reported that the H1N1 virus was probably more contagious compared to the seasonal one, while an article on the *New England Journal of Medicine* claimed the opposite about its transmissibility in households, compared to similar outbreaks in the past (Cauchemez S et al., 2009).

It is important to note that eating pork meat did not constitute a possible source of infection The name “swine flu” was due to the similarity between the combination of genes found in the new strain and that from some other swine-origin H1N1 influenza viruses, even if misconceptions were common on this point in populations at the time of pandemic. A correct diagnosis of H1N1 swine flu infection may only be obtained through testing of a nasopharyngeal, nasal or oropharyngeal tissue swab from the patient. Since 2010, a test based on molecular biology technique with 96% accuracy has been available.

### 2.3.2. Categories at risk

H1N1 influenza displayed a characteristic feature in terms of age sensitiveness, since adults, particularly those over 60, had some degree of immunity. According to CDC, 75% of patients were younger than 20, 10%

than 2 and only 10% were older than 40 years. In addition to chronic diseases, like for seasonal flu, pregnancy and obesity were considered strong risk factors for complications that required hospitalization.

### 2.3.3. Treatment

Antibodies to the seasonal H1N1 virus did not protect against the pandemic H1N1 swine flu virus circulating in 2009. The virus developed resistance to amantadine and rimantadine, while some rare variants also showed resistance to oseltamivir (Uyeki, 2014). Most patients recovered within one week, so antiviral treatments had to be used only when strictly necessary, as judged by the doctor, especially in case of hypoxia, hypotensive shock or sensory alterations. Also, prophylactic treatment with oseltamivir or zanamivir had to be considered for higher risk individuals that had been exposed to a patient with influenza (WHO, 2010).

Use of antivirals was supposed to significantly reduce the risk of pneumonia but some of these findings have been contested by an analysis carried out by the Cochrane Collaboration (Jefferson T, 2014a, b, c), which found no clear evidence that these drugs prevented lower respiratory tract infections or other complications of influenza. Antibiotics could become necessary in case of bacterial infections that may come together with H1N1 influenza. Vaccines for H1N1 swine flu are available.

### 2.3.4. Epidemiology

The initial warning of the 2009 pandemic came in the United States Centers for Disease Control and Prevention (CDC Atlanta) bulletin on 21 April 2009, with the description of two children in southern California (USA), who got a febrile respiratory illness provoked by a novel swine flu virus, without having had any known contact with pigs (ECDC, 2010, MMWR, 2009). Later, it emerged that the same virus had already caused epidemics in Mexico unusually late in their influenza season (in early March 2009), but only when cases of severe influenza appeared in seemingly healthy people in Mexico City, the virus was isolated.

Further studies in Canada and the USA showed that the Mexican and Californian viruses were indistinguishable: at this time, this virus already met the WHO criteria for a pandemic strain, well past WHO pandemic Phase 4 and probably beyond any possibility of successful containment.

On 25 April 2009, on the advice of an Emergency Committee convened under the International Health Regulations (IHR) 2005, the Director-General of WHO, Margaret Chan, declared that a Public Health Emergency of International Concern was underway. Within a few days, the same pandemic virus had been reported outside of the Americas and the transmission in New York City was increasing. The same Director General, again acting on the advice from the WHO Emergency Committee (IHR), declared then Pandemic Phase 5 on 29 April 2009. Since there are no qualitative differences between Phases 5 and 6, this implied that the pandemic was unstoppable and uncontainable, even though a number of more formally planned actions (such as switching to production of a pandemic strain vaccine) would not start until Phase 6. The initial reports on the new influenza A virus suggested that there were a significant number of severe respiratory illnesses and deaths in Mexico including among young, previously healthy, persons. This had prompted the Mexican authorities to take extreme measures early on, closing schools and banning public gatherings. Once more detailed reports from the USA were available it became clearer that the new virus was, in fact, not causing much severe disease as was reflected in ECDC’s early risk assessment.

There was a considerable delay before pandemic Phase 6 was formally declared on 11 June 2009, as even though it was quite clear that the epidemiological criteria for this phase had been reached, there had been pleas by some countries at the World Health Assembly in May for delay and more reflection. This meant that by the time Phase 6 was actually declared, the ECDC estimated that 74 countries worldwide (26 of which were EU/EEA countries) had already reported over 27 000 cases of influenza A(H1N1), including 141 deaths. With the declaration of Phase 6, a number of actions were automatically triggered at the country level, so many authorities needed to rapidly adjust their pandemic plans designed to deal with a more severe pandemic.

WHO declaration of Phase 6 in June 2009 raised many criticisms as the organization was accused of having been influenced by vaccine manufacturers to create alarmism. These accuses did not come only from those groups that constantly fight against vaccines, but also from medical journals and government officials. This provoked a raise of mistrust and suspicions, which in turn led to a diffuse sense of false alarm and in a loss of trust towards public health institutions. WHO declared the formal end of the pandemic on 10 August 2010, with an estimated global number of victims of 18.500 deaths, not so many in comparison with a common flu season.

This figure anyway referred only to laboratory-confirmed cases, which were a minority, especially in developing countries. Further studies increased this burden. A paper published on the *Lancet Infectious Diseases* in 2012 raised the estimated number of deaths to more than 284.000 (Dawood F, 2012). About 25-30% of official deaths were in previously healthy people under 65 years of age, so even if milder than expected, the pandemic provoked a small but real risk of severe disease and death from in all healthy adults and children. As mentioned previously, there was a higher than expected rate of ARDS.

When the vaccines were made available, they were greeted with variable enthusiasm to vaccinate among the health professionals, with only some countries achieving high coverage among the whole population or targeted risk groups. The lack of widespread acceptance of this vaccine is partly due to the difficulty in transmitting the complex risk communication message that essentially told people that unless they were in a risk group (young children, people with chronic ill health and pregnant women), the chance of severe disease following infection was very low, but not irrelevant, given the peculiar characteristics of the disease.

## 2.4. Middle East respiratory Syndrome (MERS)

### 2.4.1. Clinical information

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

One of the most renown diseases caused by coronaviruses is the Severe acute respiratory syndrome (SARS), which spread initially in Asia and then in other parts of the world in 2003, infecting 8.096 persons and causing 774 deaths, with a case fatality ratio of 9.6%. However, since 2004, there have not been any known cases of SARS reported anywhere in the world.

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

Even if MERS-CoV may spread from person to person in the same ways other coronaviruses do, the risk of sustained human-to-human transmission appears to be very low; this is due to the fact that MERS-CoV infects a lower number (about one fifth) of lung cells compared to other infectious diseases, which means that the number of virus particles needed to be inhaled to cause infection is larger than other cases. General hygiene measures for prevention of infections are still valid for MERS: washing hands with soap and water, cover nose and mouth with a tissue when coughing or sneezing, avoid touching eyes, nose and mouth with unwashed hands, avoid close contacts with sick people.

### 2.4.2. Categories at risk

To date, there is very limited information on transmission and other features of MERS-CoV due to the small number of cases reported so far globally. Overall, the median age of MERS-CoV patients is 50 years and the majority of them (64.5%) are males, while fatal cases were more likely to have an underlying medical condition. Only few cases have been reported in children less than 5 years of age.

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

### 2.4.3. Treatment

Persons who develop fever and symptoms of lower respiratory illness, such as cough or shortness of breath, within 14 days after traveling from countries in the Arabian Peninsula or neighboring countries, should be seen by their doctor and mention their recent travel.

At the moment, treatments for MERS-CoV are supportive. No specific treatments recommended for illnesses caused by MERS-CoV, neither a vaccine, are available. Medical care is supportive and to

help relieve symptoms. Recent studies identified a MERS-CoV receptor – DPP4 – that could be involved in the virus-human interaction; the development of DPP4 inhibitors could thus represent an effective treatment against this pathogen. Treatments with systemic high-dose corticosteroids, which were intended to reverse the progression of respiratory distress and to prevent lung fibrosis, appeared to have been unsuccessful.

### 2.4.4. Epidemiology

As far as 28 April 2014, nine countries have reported cases of human infection with MERS-CoV. All the patients were diagnosed or had travelled in Middle East. Apart from Middle East countries, cases have been reported in France, Germany, Italy, Tunisia and the United Kingdom. In all these countries, Germany being the only exception, there has been the occurrence of limited local transmission due to close contact with laboratory-confirmed or probable cases.

The source of the virus, the types of exposure that may lead to infection, the mode of transmission and the clinical pattern of the disease are still unknown. MERS-CoV has been detected in bats and in camels linked to a human case in Saudi Arabia. However, these findings are not enough to understand the chain of transmission of the virus, neither to identify its animal origin. For these reasons, it is not possible to give specific advice on prevention of infection regarding contacts with animal or animal products.

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# Stigmatisation and discrimination: a guide for healthcare workers

WP3 Prototype Online Course for Primary Care Staff

Responsible Partner: ZADIG
Contributing partners:

Dissemination level:

TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

**Document Management**

| | |
|---|---|
| PROJECT FULL TITLE | Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. |
| PROJECT ACRONYM | TELL ME |
| | Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks” |
| GRANT AGREEMENT | 278723 |
| STARTING DATE | 01/02/2012 |
| DURATION | 36 months |

Stigmatisation and discrimination: a guide for healthcare workers

Task: 3.3

Leader: ZADIG – Other contributors: none

History of changes:

| Vn | Status | Date | Organisation / Person responsible | Reason for Change |
|---|---|---|---|---|
| V1 | Draft | 30/1/2014 | ZADIG | First draft |
| V2 | Draft | 14/5/2014 | ZADIG | Second draft |
| Vf | Final | 22/5/2014 | ZADIG | Final draft |
| | | | | |

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# INTRODUCTION

Being at the interface between institutions and citizens, healthcare workers play a fundamental role within public health. They represent the first line of intervention during an infectious disease outbreak and must be involved in preparedness and emergency plans from health authorities. This also implies that they should be aware of the importance of an effective risk communication in case of an epidemic and the best approaches to be followed, in order to properly manage it. Amongst the many relevant issues of risk communication during infectious disease outbreaks, there are those concerning stigmatisation and, in general, all violation of human rights, which constitute a serious problem for healthcare.

At first, it is important, for healthcare workers, to know why stigmatisation represents a serious issue for public health. Thus, the first section of this dossier will go further into the concept of stigmatisation and describe its negative consequences in terms of health, both in general and in the specific context of an epidemic or pandemic. The second chapter will provide useful information and advices to deal with stigmatisation-related issues within the doctor–patient relationship, while the third part of this dossier will examine the categories most at risk of suffering for stigmatisation. The fourth chapter will explain what differentiates human rights from medical ethics, and show their application in case of an epidemic.

## 1. The concept of stigmatisation

Since Greek times, a stigma was a mark or sign that indicated the individual who had it was of inferior moral quality, such as a slave, a criminal, a prisoner of war (Jones, 1987). Despite the different meaning given to the term by Christianity, related to the virtuous wounds of Christ (Ganzevoort, 2008), modern day use of the word seems to have returned to the original purpose: identifying individuals as not belonging to the normal social class of persons, thus indicating that they merit a higher level of concern than individuals considered normal (Hsin Yang et al, 2007). Stigmatised individuals can perceive themselves of being thought of in such way with psychological harms that can influence behaviour.

Individuals suspected to be carrying infectious disease are at risk of stigmatisation. Differential treatment of individuals in the healthcare process can cause or worsen an already pre-existing situation of stigmatisation than results because of the individual being part of a minority group. Such groups can range from the classic examples that are prone to stigmatising and discriminatory behaviour (e.g. racial, religious, sexual orientation, age) to more specific groups that only arise in specific healthcare contexts.

### 1.1. Negative Effects of Stigmatisation

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. Such behaviour often results from the negative self-judgment that these individuals have made as a result of their stigmatisation and could lead them not to seek help (Courtwright, 2009). For instance, an individual with a particular diagnosis – like HIV or hepatitis – could be scared by the expected social reaction that is likely to result from his condition and could thus feel a need to hide such condition from not only the public but also health care professionals.

In addition, during the context of an epidemic, marginalised groups that are already the source of stigmatisation (HIV again being a prominent example), may often be more at risk of contracting the condition itself, thus reinforcing the stigmatisation that such groups feel by both the epidemic and the healthcare response to it. It is thus clear that stigmatisation has many possible ways to bring about negative outcomes, which can be classified into both direct and indirect effects.

### 1.1.1 Direct Effects on Health

There is evidence that individuals who perceive themselves to be lower in the social order often undergo a chronic physiological stress response. Furthermore, stress has been shown to be more prevalent in more unequal societies. This response is associated with an increase in the production of stress hormones that, in the long term, can lead to a condition of chronic stress, which has been linked to negative health effects like poorer level of cardiovascular health (Marmot, 2004). The relationship between social positioning and health problems has also been recently used to explain why more equal societies do better (Wilkinson & Pickett 2010).

Another possible negative of such chronic stigmatisation is depression (Deacon, 2006), which is harmful in itself but which can also increase the likelihood of substance abuse and other harmful behaviours, including the refusal to follow health prevention measures that can lead to an increased risk to contract a disease, which would in turns strengthen the stigmatisation.

### 1.1.2. Indirect Effects on Health

In addition to the direct stress response, stigmatisation may also trigger a range of indirect negative effects that can be attributed to the notion of self-loathing or lack of individual self-worth (Courtwright, 2009). This alters individual behaviour so as make in several ways that can bring about negative consequences.

One of the main issues is the reduced desire to seek healthcare when needed, typical of group whose members, in attempting to obtain healthcare, are the subject of stigmatisation as a result of their membership of the group itself (Gornik, 2000). For instance, black or other groups with a perceived lower socio economic status are slower to seek treatment than their white counterparts, mainly because they feel they are to be judged more responsible for the condition through irresponsible behaviour than the white peers (Chesney, 1999). It is thus important not to exacerbate pre-existing stigmatisation and to always keep in mind that individuals who are stigmatised may have an increased aversion to using medical services.

Individuals that are the subject of stigmatisation often suffer a lesser motivation to secure important resources in social life. Among these resources, together with education or employment opportunities, there is also healthcare (Courtwright, 2009). It has been demonstrated that lower levels of education and lower incomes have a clear association with lower levels of personal health, which in turns result in disparities in personal health levels between stigmatised and non-stigmatised groups (Courtwright, 2009). Medical authorities should, during the context of an epidemic, aim in so far as is possible not to further worsen such problems.

## 1.2. Stigmatisation during epidemic/pandemic situations

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

The existence of such individuals and their susceptibility to stigmatisation must be taken into account when planning public health responses to epidemic situations. Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. In addition, these consequences could endure even after the epidemic has disappeared.

During a pandemic, as it may be obvious, the group of individuals that will experience the most stigmatisation issues are those who become infected. The stigmatisation of other groups (other than those who are infected) in an epidemic situation is based on assumptions that, because of their various characteristics, they are at increased risk of infection and therefore pose a threat. Individuals who are actually infected obviously pose a greater 'threat' than those who may be infected and so will be subject to a higher level of stigmatisation. Individuals who become infected therefore suffer from two conditions, the disease itself and the stigmatisation that comes with infection.

The SARS outbreak provided a recent example of the potential stigmatisation issues that individuals can face, even after their deaths (Kleinman & Lee, 2005). In China, instances of stigmatisation and discrimination included refusal by some funeral homes to handle the bodies of SARS victims, reluctance of certain medical and paramedical staff to care for SARS patients, discrimination of health professionals, e.g. refusing a service in the barber shop, forcing of employees to take annual leave as they had recently been to the hospital or to parts of mainland China hit by SARS.

# 2. Dealing with stigmatisation

There are two important ways for public institutions and health professionals to act in order to protect individual ability for self-respect and therefore to guard against stigmatisation (Rawls, 1971). First, individuals should be treated equally, irrelevant of any social group they belong to. This is of great importance for healthcare professionals, since they represent the first line of interaction with patients and should therefore act in order to ensure that all minorities and groups in society receive equal protection and treatment in response to epidemic threats. However, stigmatisation can also manifest as private behaviour that prevent individuals in stigmatised groups from using public services to the same extent as individuals in non-stigmatised groups.

An effective method that has been proposed to minimize such sources of stigmatisation was the establishment of independent associations that represent groups prone to stigmatisation, which are able to provide a secure space for stigmatised individuals to associate with other such individuals (Rawls, 1999). Healthcare workers should be aware of the existence of such groups and should foster communication with them, in order to encourage individuals to maintain "self-respect", thus being more likely to continue to seek access to the required public goods such as public healthcare. Such an approach has shown itself to be very efficacious in the reduction of stigmatisation for those individuals who are HIV positive. The engagement of such groups could be optimised not only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue in the planning of a response to a potential epidemic.

Communication strategies aimed to tackle risks of stigmatisation should not be targeted only at those persons belonging to minority groups; it is of great importance to remind all the people that the risks of contracting the infectious agent in question from individuals from the minority group is not usually higher than from someone in the general population.

## 2.1. Being ready and being trustworthy

It is very important to note that all the strategies and approaches that can be adopted to deal with stigmatisation require a good level of trust, which is not something that can be built at the moment but needs to be pursued way before the beginning of an epidemic. This is true at all levels of the healthcare hierarchy and particularly for healthcare workers, since they are those who daily and directly interact with patients.

It is thus important for a healthcare worker to be perceived as trustworthy; during an emergence, such perception will make people, even those at risk of stigmatisation, more likely to ask him for medical help and advice. In fact, the response of medical professionals can be important in the decision of stigmatised individuals to seek medical attention. Individuals are less likely to seek treatments from individuals that hold stigmatising views. This is an important factor that may help in explaining why, even in societies that create systems of equal access to healthcare, one does not always see the same levels of utilisation for the various groups that make up that society.

Stigmatisation in the context of epidemics may result from being part of a minority group, having some kind of "special" connection with the disease due to geographic, ethnic or working reasons, or having particular lifestyles. Healthcare professionals should be aware of these elements when dealing with their patients, in order to be able to identify potential stigmatisation issues in advance and to face them properly. Knowing people's experiences, values and beliefs, and sharing their preoccupations, are two fundamental points on which to build a trust-based relationship, which in turns plays a key role in an effective risk communication, particularly when dealing with stigmatisation.

Healthcare professionals should also report in advance every possible case of stigmatisation they are aware of, in order to help health measures planning and to increase the surveillance level of potential cases.

## 2.2. Social Contact

Social contact plays a key role in every aspect of the doctor–patient relationship. Communication is characterized by two aspects: the content and the way by which it is delivered. A message is not only made of spoken or written words but also of non-verbal elements, such as expressions, gestures, tone of the voice, et cetera. An effective communication with patients should not be considered as a one-way transmission of information by the healthcare professional. The impact of such information on the patient and its awareness should always be taken into account and this may be done through listening, empathy, interaction and feedback. Such an approach helps the doctor to know the patient's history, which is one of the best ways to notice in advance those elements that could lead to stigmatisation.

Social contact is associated not only with individual happiness and contentment but also with human health. Research has shown a clear link between level of social support available to individuals and morbidity and mortality (Uchino et al, 1996). Social contact can also provide an important coping mechanism for those who feel stigmatised. In recent decades, this is a topic that has received a considerable amount of attention from researchers (Reblin & Uchino, 2008). Social isolation has been indicated as an increased risk factor for most types of mortality. Additionally, in recent years research has highlighted that individual health is not only improved by receiving support but by the ability of individuals to bestow care on others.

### 2.3. Personal privacy

Another aspect that every healthcare professional should always keep in mind is the importance of personal privacy as a tool against stigmatisation. Individuals should be allowed to seek care in a manner that will not unnecessarily compromise their personal privacy. In some cases this may mean not adding too much information regarding their condition to the record in order to assuage individual fears – whether rational or not – that the presence of their condition on their record will be used in a negative fashion by future employers or insurers.

The availability of anonymous testing and even treatment would likely mean that an increased number of individuals would feel less restricted by potential stigmatisation and seek treatment for their condition. In order to take advantage of the benefits that an anonymous environment would offer it would not be enough to have anonymous testing procedures in place, but such procedures would have to be actively publicised and disseminated so that individuals were aware of them (Herek et al, 2003).

### 2.4. Facing misinformation

In the early stages of an outbreak of an infectious disease it seems that individuals make use of the little information they have in order to protect themselves as much as possible. This will likely include, for instance, finding information on the possible geographical origins of the infectious agent in question. In an age where non-official sources of information are numerous and, to a certain extent, uncontrollable, individuals will always have access to a wealth of information even if no officially sanctioned information is yet available.

The Internet and social media has the potential to provide both reliable and unreliable information during an epidemic. During a vacuum in terms of official information, such facilities can spread rumour and conjecture widely and almost instantly. In the absence of official information, human instinct tends to take over with a likely result that assumptions will be made as to what constitutes a danger in terms of infection.

Healthcare professionals must be aware of the main rumours and conjectures that are circulating, in order to be able to better debunk them, thus decreasing the risk of stigmatisation they may provoke. They should also report any case of misinformation to medical authorities, allowing them to act by targeting the release of more accurate information designed to dispel any harmful unfounded rumours that may be circulating.

## 3. Categories at risk

Some categories of individuals are more likely than others to suffer stigmatization during the context of an epidemic. These include:

- pre-stigmatised groups e.g. the poor, homeless, immigrants, the old, individuals with conditions that result in a reduced immunity, ethnic minorities;
- individuals that become infected;
- individuals associated with the perceived origin of the outbreak in question;
- individuals that are to be vaccinated;
- medical Professionals.

### 3.1. The "origin issue"

Epidemics of infectious diseases have often been linked in popular perception to groups of individuals that have a particular origin. A good example for that is what happened in 2009, during the H1N1 pandemic: Mexico was perceived as being the origin of the new virus and this caused the outbreak to be called the Mexican flu in many states because it was thought to have first originated there (Gallagher, 2009). Information on the possible origin of an infectious agent is often the source of fear and anxiety and this came out clearly in 2009: for instance, there have been ships refusing to dock in Mexican ports, even in areas where there had been no incidence of infection, but which were willing to dock in US areas where infections had actually occurred. H1N1 fears led Haitian officials to turn back a Mexican ship carrying humanitarian food aid (CNN, 2009). Also, the identification of Mexico as ground zero of the emerging pandemic led to Mexican individuals experiencing numerous problems around the world and even in their own country, like unnecessary quarantine procedures or, in the US, the case of conservative media personalities who blamed Mexican immigrants for spreading the disease across the border, continuing their scapegoating of immigrants (Allison T, 2009).

There are plenty of similar examples in epidemiology: the great influenza pandemic at the end of the First World War, which was mistakenly given Spanish origins by many (Barry, 2004); an outbreak of hantavirus in the southern US, which was attributed to native Americans and dubbed the Navajo disease (Pearson et al, 2004); the Chinese community around the world being the source of negative attention in 2003 due to the SARS outbreak (Xinyu Jiang et al, 2006).

The problem of the disease origin is not merely a geographic one. The H1N1 influenza virus was, in addition to being popularly known as the "Mexican flu", also named the "swine flu". This resulted not only in negative outcomes for humans but also for pigs and the related livestock sector. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also triggered fear of those individuals such as pig farmers who worked in close proximity these animals. These reactions caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This led to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a one-time event. As a consequence, pigs presented no running health risks to humans despite the name "swine flu" being commonly used.

This is why it is therefore necessary for health authorities to be very careful when attributing origins to outbreaks of an infectious disease; references such as "Mexican flu" or "swine flu" should be avoided in favour of a more technical language. Unfortunately, it seems like such a cautious approach still need to be recognized by health authorities, as demonstrated by the recent case of the new SARS, quickly renamed Middle East Respiratory Syndrome (MERS) due to the location of its first cases. Healthcare workers should always keep in mind the importance of the "origin issue" and be ready to face it when dealing with patients, especially when the first ones to mistake are health authorities, as in the case of MERS.

### 3.2. Vaccination

Vaccination is one the most effective methods of combatting outbreaks of infectious disease (Ehreth, 2003) but it may also constitute a possible cause of stigmatisation. One of the irrational fears that many individuals often have about vaccines is that there is a risk that they will become infected with the virus contained in the vaccine. This may give rise to the fear of becoming infected and thus stigmatised as a consequence of vaccination.

Also, there are cases where certain lifestyle behaviours may be associated with an increased risk of infection. Thus, accepting a vaccination could represent a signal to others indicating that an individual is devoted to stigmatised activities. For instance, HIV vaccine trials have encountered difficulties recruiting individuals since many feared to be stigmatised as being sexually promiscuous or as intravenous drug users (Nyblade et al, 2003). This could also result from vaccination campaign targeted to some minorities that are considered at risk for lifestyle or health reasons (e.g. those who are elderly or obese) and that may suffer for stigmatisation as a consequence.

These are some significant examples of how the use of an effective medical instrument may lead to some negative effects. Healthcare workers should be ready to inform people belonging to these groups in order to prevent them from avoidance behaviours that could result in increased health risks, both for themselves and for the others.

### 3.3. Medical professionals

Medical professionals are not immune to stigmatisation. The large amounts of time they spend with individuals that are suspected of being infected or are indeed actually infected, can make them prone to stigmatisation issues and this is a problem, both for them and for their relationship with patients. For instance, general practitioners who worked with SARS patients in China reported higher levels of anxiety and social dysfunction (Verma et al, 2004). Stigma of this type flows from the fact that such workers are perceived as being at a higher risk of infection. Healthcare workers may also face the threat of quarantine under certain circumstances. In the SARS crisis in Canada, healthcare workers accounted for almost a quarter of total infected cases (Flood & Williams 2003). Such a stigmatisation may also come from colleagues who have not had the same contact with infected individual and can be long-term, even after the disease in question has disappeared. In addition, healthcare workers involved in the treatment of individuals during the early stages of an outbreak can feel blamed by other colleagues for allowing the infection to proliferate (Mitchel et al, 2002). Negative media reports and new stories over the performance and behaviour of healthcare workers can add to this sense of stigmatisation and stress.

## 4. Medical Ethics and Human Rights

It is somewhat universally accepted that public health information campaigns should be examined from an ethical or moral perspective, but there are disagreement over which approach to use. Contemporary medical ethics represents a collaboration between different theoretical schools of ethical philosophy (Peel, 2005). There are four principles that have been claimed to represent a combination of the various moral theories accepted throughout the world (Beauchamp & Childress, 1994):

- respect for autonomy;
- non-malfeasance;
- beneficence;
- justice.

Medical ethics have been used by physicians and those providing health interventions for centuries, if not millennia, to decide upon the moral acceptability of possible treatments.

There are advantages to the use of principals in medical practice. They provide a concise and coherent set of principles that doctors can use when making decisions. The system is easily taught to trainee medical professionals and does not require an advanced prior training in ethical or legal issues. The simplicity of the principals allow them to act as ethical trigger points in situations where individual medical professionals are required to make quick decision in urgent circumstances (Faunce, 2005).

This is in contrast to human rights, which, to a certain extent, represents a more complex discipline that is usually the domain of experts in the field. Human rights are designed to provide fundamental protections for individuals that allow them to have as equal as possible a level of participation in society and are therefore also applicable with regards to the provision of healthcare, which in most societies the state is seen as having an important responsibility in regulating. The principles found within Human Rights have been used increasingly by legal systems in the past decades to regulate healthcare provision. For instance, the Australian National University Medical School now teaches its students that human rights will, in the course of their careers, become more important in professional regulation than medical ethics (Faunce, 2005).

One key practical difference between the two systems is that one (human rights) focuses on the relationship between the state and its citizens and the other (medical ethics) is more concerned with a person to person relationship (i.e. between the physician and his or her patient). This results in an emphasis shift from trusting that the doctor always knew what was best for his patient to a situation where individuals were to be regarded as the best arbiter or what exactly was in their own best interests.

The increasingly high level of education and the ability to access types of information, including medical ones, has led to a change in the patient-physician relationship. The result of these developments was that many patients felt able to conduct their own research into their conditions and, where necessary, question or even refuse their physician's desired course of treatment.

Another factor that should be recognised is that the practice of medicine has changed considerably throughout the ages: in times gone by, physicians would act largely alone whilst modern medicine is organised on a greater scale and often by the state (Rastegar, 2004). On such a scale, systems of human rights are often better placed to adjudicate disputes than systems of medical ethics which are better adapted to dealing with dilemmas involving one or a few individuals. Also, human rights principals are also recognised as carrying more legal force. Healthcare workers represent the junction point between health institutions and patients, a position that requires them to know human rights and how to deal, in order to better manage every kind of situations they could deal with.

## 4.1. Human rights relevance to outbreaks of infectious diseases

The primary international sources of human rights are the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Each of these contains principles that may be pertinent during the course of an epidemic. It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies from being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality.

Strategies designed to tackle outbreaks of infectious disease often curtail individual freedoms. Prominent examples of such rights or freedoms can include the right of privacy of the individual, the right to bodily integrity and also the right to physical liberty. Poverty and communicable diseases also often have a close correlation (Dute, 2004). State organisations that engage in public health campaigns usually have good intentions – most notably the limitation of the spread of dangerous infectious diseases. Unfortunately, however, this aim is often pursued without adequate attention to the problems such public health campaigns can cause. The HIV/AIDS epidemic has shown that the potential exercise of public health powers and in particular powers of a compulsory nature have the potential to impact upon human rights, most notably individual liberty, physical integrity and privacy (Dute, 2004).

The human rights that are applicable during epidemic situations vary, from very precise duties to other more general principles that will inevitably apply in such contexts. The most important principles to consider are:

- the Right to life, which concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war);
- the Right to health, which is a social and economic right that foresees a duty upon states to provide healthcare for individuals in need of such services. This right has been used by groups of individuals, most notably in the developing world, to secure access to vital healthcare services such as vaccinations or antiretroviral therapy;
- the Right to freedom from inhuman or degrading treatment, which provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice the right has been closely linked to the concept of informed consent;

- the Right to liberty and security of person, which can be significantly engaged during a serious epidemic. In fact, such a right envisages freedom for individuals from arbitrary detention and there is obvious scope for conflict with such a right with techniques such as quarantine, which have been employed for many years during epidemics.
- the Right to a private and family life, which, in the context of healthcare it has been linked to both positive – a state can be required to act where such action is likely to protect an individual's private or family life – and negative - obligation upon states to desist from acts that may prevent individuals from realising this aim – duties;
- the Right to freedom against discrimination, which may can only be engaged in conjunction with another right and applied to a range of groups such as race, ethnicity and religion and, as been more recently accepted to those who have a different health status. It states that individuals cannot be denied their rights under the convention because they belong to one of the groups in question.

However, whilst human rights principals are useful protecting the fundamental rights of individuals in the context of an epidemic they are not able to completely prevent stigmatization during an epidemic. This is because the self-loathing needed for stigmatisation to exist can arise even where the state has itself done nothing to foster such a feeling. This is due to the fact that stigmatization can occur without discrimination and sometimes even when discrimination is prevented. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

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# Case history 6 – Fear of whispering people

**Topic:** stigmatization

**Instructions for case history:**
- select an answer for each question and click on "Submit answers" button;
- to pass the case history it's needed to answer correctly to 80% of the questions;
- case history's insights and forum are available after first attempt;
- when case history is passed, click on "exit activity" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page;
- if the case history is not passed, it is possible to reattempt it.

**Target:** infected adults

**Step 1**

Said, 51 years old, has changed several jobs and has even been unoccupied for some periods, but now is working as a waiter in a pub, in a small town. He still cannot believe he found a quite stable job. For the first time in the last 12 years, he even managed to save some money for vacancies. He booked a last minute flight and left.
Said spent ten days in his parents' homeland, Saudi Arabia, which he barely remembered, having left it when he was only a child. Since then, he never got a chance to celebrate Ramadan with people sharing his own faith, thus he really enjoyed this first time there. Before leaving, he promised to his distant relatives that he would come back soon: he still has to do the Hajj pilgrimage, which is something he absolutely feels committed to.
"I will come back soon in my homeland to see Mecca. I will remember this 2013 summer for a long time" he thinks while getting on the plane to Europe. And he was right, but he won't forget this summer for a different reason from the one he thought: a couple of days later he begins coughing and suffering for dyspnea, together with a strong fever, immediately followed by a violent diarrhea.

**Considering the whole individual story of Said, which kind of influential like syndrome has to be suspected?**

- avian influenza (H5N1 virus)
- swine flu (H1N1 virus)
- Middle East Respiratory Syndrome (coronavirus)
- Middle East Respiratory Syndrome (H7N9 virus)

**Step 2**

Said immediately understood that something serious was happening, not only because he was feeling really bad, but also because, while he was in his country, he heard local news about persons being suffering for a new disease, which was lethal in almost half of cases. He also knew that such news had already begun circulating even in Western Countries.
“So, they were right about the disease. And the advice about avoiding the Hajj pilgrimage was true too. Such a bad luck! Getting sick the only time I go back to my homeland”.
Said got by himself he could have caught that virus. Nevertheless, he did not go immediately to the hospital, afraid of being discriminated and received with hostility and fear of contagion for the disease contracted in his country.

**Which of the followings is the strongest/hardest stigmatization issue Said has to face in a context where the fear of epidemics is spreading?**

- [x] the fact to have become infected and the geographic origin of the disease
- [ ] only the connection with the geographic origin of the disease
- [ ] only the fact to have become infected
- [ ] only the low socio-economic status

**Step 3**

Thus, at first Said was reluctant to seek healthcare. Nevertheless, after a second, terrible night,when the fear of deaths overcomes the other reasons, he thinks: “I can’t take it anymore”. "All right, I’m going to go to the hospital. But how?”.
Not by bus, since he does not want to run the risk of meeting somebody who knows him. “With such a look, everybody will certainly guess that I’m sick”. He thus decides to walk to the hospital, where he arrives in a very bad condition, shaken by shivers and almost collapsed. After such an adverse fate, and after the serological analysis confirms the presence of the MERS coronavirus in his body, he luckily meets a competent and responsive doctor.

**How should healthcare professionals approach patients at risk of stigmatisation?**

- [ ] being protective and compassionate, able to solace
- [ ] providing a rational explanation of the disease in order to avoid emotional interference
- [x] being able to treat equally and to be perceived as trustworthy
- [ ] communicating with spoken and written word his/her empathy

**Step 4**

Hospitalization lasts for quite a long time and the first days are very critics. Then, slowly, Said begins to recover. Due to the high risk of transmission of the disease also to healthcare personal, he is put under isolation to receive supportive care. During this period, the doctor that follows his case makes everything to show him his full openess to assist him, both medically and psychologically. He follows the procedures, but does not insist on his own risk of a contagion. He goes close to his bed in order to talk to him, with adequate protections, and spends a reasonable time in his room, without leaving in a hurry as other healthcare workers do.

**In this situation, the health professionals should:**

- ● be sympathetic but protect themselves as well to avoid the spread of the disease
- ○ avoid face masks since they make feel the patient stigmatised
- ○ not admit the patient to the hospital where many immunocompromised patients would be at risk
- ○ not enter his room to avoid spread of the disease

**Step 5**

A few days later, the situation clearly improves.
“I’m happy to see that you’re winning this bad match” says the doctor.
At the beginning, Said used to reply in monosyllables. The only full sentence he pronounced was to express one of his biggest concerns: “Doctor, will my employer know about my disease? I’m pretty sure that, if this will be the case, he won’t let me work in his place anymore”.
“Absolutely no”.
“But I will need to bring a medical certificate to justify my quite long absence from work”.
“For sure, but nobody out there, except health authorities, will know the name of the disease you have had. Since we will let you go only when we are sure you are not contagious at all, there is no reason to say that”.

**What do you think of the doctor’s answer to the patients’ fears of discrimination on his workplace?**

- ○ he was wrong, since the employer has the right to know about the disease, in order to protect himself, colleagues and customers
- ● he was right, since the patient’s right to privacy does not hinder others’ right to life
- ○ he was wrong, since European laws make compulsory a public communication about this cases
- ○ he was right, since in his work of waiter he cannot transmit the disease

**Step 6**

“However, we must be sure to check anyone else who has been in touch with you, in order to assist them”.
“I see, but, since I arrived, I’ve neither been at work nor met anyone else. Back from the airport, I immediately went to bed at my place. I didn’t even take the bus to get here”.

“Well, in this case, it’s not necessary to do these checks”.
Said expresses all his esteem to the physician: “Doctor, you and I are on the same page”.
“Nowadays we are more alike than you can imagine” the doctor thinks, without saying a word.

**How can be interpreted the doctor’s thought?**

- during epidemics, medical professionals are exposed to stigmatization due to their supposed exposition to infectious agents
- medical professionals are always exposed to stigmatization due to their supposed exposition to infectious agents
- medical professionals have in general a good experience of stigmatization issues
- this is an expression of empathy, according to the approach followed by the doctor

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**Conclusion**

“Anyway, I understand your fears” the doctor says. “With infectious diseases, we are on the same page”.

If you passed this last case history you have to answer to the customer satisfaction survey and after it is possible to access the course certificate.
Click on "Return to course" button (in the upper right) or "Tell Me course" link, in the navigation box on the left, to return to course page.

# Explanation

# Case 6

## Summary

## Step 1

*Dossier 1 - Epidemics and pandemics - General guidelines*

In September 2012, a SARS-like virus was reported in Saudi Arabia. Further investigations identified it as the responsible of a new severe acute respiratory illness that has been called Middle East respiratory Syndrome (MERS). Retrospectively some infections have also been detected in humans with severe acute respiratory illness in Jordan in the spring of the same year. This new coronavirus (MERS-CoV) is different from the one that provokes SARS, even if they have been both found in bats (Memish et al., 2013) and camels (Haagmans et al., 2013).

Typical symptoms for MERS include fever, cough, shortness of breath and diarrhoea, but also more severe complications like renal failure and severe acute pneumonia, which may often lead to death. As reported by WHO, severely immunocompromised patients could also present with atypical signs and symptoms. Although the primary site of infection has been the respiratory tract, approximately one-third of patients have experienced gastrointestinal symptoms.

## Step 2

*Dossier 3 - Stigmatisation and Discrimination*

Individuals suspected to be carrying infectious disease are at risk of stigmatisation. Differential treatment of individuals in the healthcare process can cause or worsen an already pre-existing situation of stigmatisation than results because of the individual being part of a minority group. Such groups can range from the classic examples that are prone to stigmatising and discriminatory behaviour (e.g. racial, religious, sexual orientation, age) to more specific groups that only arise in specific healthcare contexts.

[…]

**1.1. Negative Effects of Stigmatisation**

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. Such behaviour often results from the negative self-judgment that these individuals have made as a result of their stigmatisation and could lead them not to seek help (Courtwright, 2009).

[…]

One of the main issues is the reduced desire to seek healthcare when needed, typical of group whose members, in attempting to obtain healthcare, are the subject of stigmatisation as a result of their membership of the group itself (Gornik, 2000).

[…]

**1.2. Stigmatisation during epidemic/pandemic situations**

In the context of epidemics, groups that are prone to stigmatisation include people that have a perceived connection with the geographic and/or animal origin of the outbreak, members of the medical profession, those who are part of pre-stigmatised groups and those individuals who actually become infected themselves. It is important to note that stigmatisation can occur even where there is no actual discrimination occurring.

## Step 3

*Dossier 3 - Stigmatisation and Discrimination*

**2. Dealing with stigmatisation**

There are two important ways for public institutions and health professionals to act in order to protect individual ability for self-respect and therefore to guard against stigmatisation (Rawls, 1971). First, individuals should be treated equally, irrelevant of any social group they belong to. This is of great importance for healthcare professionals, since they represent the first line of interaction with patients and should therefore act in order to ensure that all minorities and groups in society receive equal protection and treatment in response to epidemic threats. However, stigmatisation can also manifest as private behaviour that prevent individuals in stigmatised groups from using public services to the same extent as individuals in non-stigmatised groups.

[…]

It is thus important for a healthcare worker to be perceived as trustworthy; during an emergence, such perception will make people, even those at risk of stigmatisation, more likely to ask him for medical help and advice. In fact, the response of medical professionals can be important in the decision of stigmatised individuals to seek medical attention. Individuals are less likely to seek treatments from individuals that hold stigmatising views. This is an important factor that may help in explaining why, even in societies that create systems of equal access to healthcare, one does not always see the same levels of utilisation for the various groups that make up that society.

[…]

**2.2. Social Contact**

Social contact plays a key role in every aspect of the doctor–patient relationship. Communication is characterized by two aspects: the content and the way by which it is delivered. A message is not only made of spoken or written words but also of non-verbal elements, such as expressions, gestures, tone of the voice, et cetera. An effective communication with patients should not be considered as a one-way transmission of information by the healthcare professional. The impact of such information on the patient and its awareness should always be taken into account and this may be done through listening, empathy, interaction and feedback. Such an approach helps the doctor to know the patient’s history, which is one of the best ways to notice in advance those elements that could lead to stigmatisation.

## Step 4

*Dossier 1 - Epidemics and pandemics - General guidelines*

**2.4. Middle East respiratory Syndrome (MERS)**

**2.4.1. Clinical information**

Coronaviruses are a large family of viruses that may cause a wide range of disease in humans, primarily infections at the upper respiratory and gastrointestinal tract. They are also held responsible for a significant percentage of all common colds in adults. Infections with coronaviruses are quite common among humans and they can spread from an infected person to others through the air, by coughing and sneezing, and close contact, such as shaking hands or touching contaminated objects then touching your mouth, nose, or eyes.

[…]

So far, transmission has occurred in family or co-worker clusters, as well as in healthcare facilities. Even if the mechanism by which transmission occurred is still unknown, there is no evidence of a sustained community transmission. Since transmission has occurred in healthcare facilities, healthcare workers are considered a category at risk of being infected and should consistently apply appropriate infection prevention and control measures.

## Step 5

*Dossier 3 - Stigmatisation and Discrimination*

**2.3. Personal privacy**

Another aspect that every healthcare professional should always keep in mind is the importance of personal privacy as a tool against stigmatisation. Individuals should be allowed to seek care in a manner that will not unnecessarily compromise their personal privacy. In some cases this may mean not adding too much information regarding their condition to the record in order to assuage individual fears – whether rational or not – that the presence of their condition on their record will be used in a negative fashion by future employers or insurers.

[…]

**4.1. Human rights relevance to outbreaks of infectious diseases**

The primary international sources of human rights are the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Each of these contains principles that may be pertinent during the course of an epidemic. It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies from being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality.

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- the Right to liberty and security of person, which can be significantly engaged during a serious epidemic. In fact, such a right envisages freedom for individuals from arbitrary detention and there is obvious scope for conflict with such a right with techniques such as quarantine, which have been employed for many years during epidemics;
- the Right to a private and family life, which, in the context of healthcare it has been linked to both positive – a state can be required to act where such action is likely to protect an individual's private or family life – and negative - obligation upon states to desist from acts that may prevent individuals from realising this aim – duties;
- the Right to freedom against discrimination, which may can only be engaged in conjunction with another right and applied to a range of groups such as race, ethnicity and religion and, as been more recently accepted to those who have a different health status. It states that individuals cannot be denied their rights under the convention because they belong to one of the groups in question.

However, whilst human rights principals are useful protecting the fundamental rights of individuals in the context of an epidemic they are not able to completely prevent stigmatization during an epidemic. This is because the self-loathing needed for stigmatisation to exist can arise even where the state has itself done nothing to foster such a feeling. This is due to the fact that stigmatization can occur without discrimination and sometimes even when discrimination is prevented. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

## Step 6

*Dossier 3 - Stigmatisation and Discrimination*

**3.3. Medical professionals**

Medical professionals are not immune to stigmatisation. The large amounts of time they spend with individuals that are suspected of being infected or are indeed actually infected, can make them prone to stigmatisation issues and this is a problem, both for them and for their relationship with patients. For instance, general practitioners who worked with SARS patients in China reported higher levels of anxiety and social dysfunction (Verma et al, 2004). Stigma of this type flows from the fact that such workers are perceived as being at a higher risk of infection. Healthcare workers may also face the threat of quarantine under certain circumstances. In the SARS crisis in Canada, healthcare workers accounted for almost a quarter of total infected cases (Flood & Williams 2003). Such a stigmatisation may also come from colleagues who have not had the same contact with infected individual and can be long-term, even after the disease in question has disappeared. In addition, healthcare workers involved in the treatment of individuals during the early stagesof an outbreak can feel blamed by other colleagues for allowing the infection to proliferate (Mitchel et al, 2002). Negative media reports and new stories over the performance and behaviour of healthcare workers can add to this sense of stigmatisation and stress.