Social Science in Epidemics: Influenza and SARS Lessons Learned

This report is the third instalment of the ‘Social Science in Epidemics’ series, commissioned by the USAID Office of U.S. Foreign Direct Assistance (OFDA). In this series, past outbreaks are reviewed in order to identify social science ‘entry points’ for emergency interventions and preparedness activities. The aim is to determine tangible ways to address the social, political and economic dynamics of epidemics and to ensure that interventions build on the social and cultural resources of the communities they aim to support. This report explores lessons about the social dimensions of past and recent influenza epidemics and the emergence of SARS-CoV.

How to read this report:
this document provides an in-depth review of evidence on different aspects of Influenza and SARS epidemics. It is organised into the following categories, and readers with a specialist interest can skip to the relevant category:

- Emergence
- Surveillance and identification
- Interpretation of symptoms
- Transmission and vulnerability
- Public health communication
- Prevention measures
- Health system response and treatment-seeking
- Antiviral and vaccine rollout
- Burial practices
- Waves and post-epidemic

Page 2
Page 4
Page 8
Page 10
Page 15
Page 19
Page 22
Page 25
Page 27
Page 28

PHOTO: ENEAS DE TROYA FROM MEXICO CITY, MEXICO / CC BY 2.0

People in Mexico City wear masks on a train due to the H1N1 outbreak throughout the surrounding region.
In each category, social science lessons learned are highlighted and followed by a series of recommendations. Recommendations are divided into those that are operational, i.e. they are immediately applicable in the event of an outbreak, and those that are orientated towards longer term capacity building. This report will provide the basis for a set of programme-oriented case studies and operational tools that will be published in 2019.

For the purpose of this paper, we will focus on the lessons learnt primarily from the 2009 H1N1 influenza pandemic (inappropriately still referred to as ‘swine flu’ by the media), the 2005 H5N1 epizootic (the ‘avian flu’ or HPAI- ‘highly pathogenic avian influenza’), and as an example of a catastrophic influenza pandemic (infected 5 percent of the world population and killing 2 percent), we will gather lessons from the 1918 H1N1 pandemic (‘Spanish flu’). To explore lessons learnt from the emergence of unexpected events and the importance of incorporating uncertainty, we will include lessons learnt from the 2002–2003 outbreak of a previously unknown disease resulting from a novel coronavirus, severe acute respiratory syndrome (SARS), which spread from Southern China and Hong Kong to 37 countries, killing 774 people in under 9 months.

1. Emergence

Influenza A viruses are widespread in a large number of mammals and birds, and some subtypes circulate between humans causing seasonal epidemics and outbreaks. An influenza pandemic occurs when a new strain of Influenza A virus emerges for which humans have no underlying immunity, and spreads from person to person. A new strain can emerge when an animal influenza virus changes to acquire the ability to transmit from person to person or when genes from multiple influenza viruses recombine to form a new influenza virus.

Certain influenza viruses circulate in the human population continuously at varying levels of intensity depending on geography and climate. This is what we call ‘seasonal influenza’. Seasonal influenza has characteristic high morbidity and low mortality although this varies by the individual and the virus. Severe disease and deaths are predominant amongst infants, the elderly, the immunocompromised and people with underlying conditions. In temperate countries seasonal influenza activity peaks in the colder winter months. An influenza pandemic may be characterized by different timing (with high circulation in summer, and even higher in the winter), or increased transmission rates, morbidity or mortality, compared to seasonal epidemics. Interestingly, the pandemic virus strain continues to circulate and joins the cohort of ‘seasonal influenza’ strains, as happened with the 2009 H1N1 pdm strain (WHO 2018).

The influenza virus can reconfigure itself in two ways that can make it more likely to infect humans: through (i) antigen drift, and (ii) antigen shift.

- **Antigen drift**: viruses mutate slightly after repeated successive replications. Influenza virus has a high rate of mutation, and small changes in its genome may mean it is no longer recognised and targeted by the immune system or vaccines. This drift enables influenza to infect the same population at different times.

- **Antigenic shift**: represents significantly larger genetic changes, and this occurs when a species hosts two or more strains of virus (from human or animal origin – bird, pig) and the infected cells recombine these strains into a new strain. For example, a person can be infected by bird flu, and this strain can be recombined with human influenza strains and go on to infect other humans. Also, pigs or other animals can simultaneously be infected by human and bird strains, generating a combined virus. This new strain can be difficult for human immune system to recognise, leaving the population more susceptible to infection. Antigenic shift is what happened in the 2009 H1N1 pandemic – the virus originated from animal influenza viruses, and was unrelated to the human seasonal H1N1 viruses circulating at the time (WHO, 2014). The 2009 H1N1 virus that emerged in Mexico had two genes from flu viruses that normally circulate in pigs in Europe and Asia, avian genes and human genes.
There are some structural elements that make reconfiguration of the virus (and hence emergence of pandemic strains) and its spread more likely. For example, high concentrations of animals can contribute to increased mutations of the virus/antigen shift, among many other factors. Global processes of urbanisation, crowding, international and national travel and migration are key risk factors to take into account. In terms of antigenic shift:

1. Ecological changes (deforestation, climate change, urbanisation etc.) shape the migratory patterns of wildfowl, which are vectors of the disease, and cause them to congregate by particular water sources, enabling opportunities for recirculation and reconfiguration, or migratory routes that contribute to transmission from farm to farm.

2. Current models of industrial animal production, with their dense populations of host animals and continuous cycle of viruses may be more likely to yield a novel virus. Meat and egg productivity is prioritised over immune-competency, and non-therapeutic antibiotic use may exacerbate virus circulation in subclinical animals (as well as contribute to antimicrobial resistance, which is relevant to synergic diseases such as TB and pneumonic bacteria). Extensive models of livestock production, where hardier breeds are kept outdoors, make the virus more exposed to cold temperatures and sunlight (to which it is vulnerable) and animals are more immunologically strong. The greatest risk comes from industrial animal production that does not meet biosecurity requirements: ‘As matters stand, novel flu viruses are increasingly likely to be generated and spread by industrialised agricultural systems, particularly those operating in unindustrialised or industrialising regions’ (Forster, 2012: 14). Further, production models that enable the cohabitation in close quarters of swine and poultry (or other species of birds) also risk the emergence of species jump and antigenic shift.

Recommendations for emergence:

Operational

• Identify and distinguish how different production methods are linked to enhanced risk of influenza emergence, and how different kinds of producers may be impacted by prevention measures.

• Incorporate industrial-scale and small-scale producers into participatory processes to determine lines of action in risk prevention and designing response actions.

Building capacity

• Engage industrial-scale producers and smallholder farmers in the design and implementation of appropriate and effective (biosecurity) regulation, and ensure legislation is implemented and farms are biosecure.

• Promote extensive, small-scale livestock farming with lower animal numbers and locally and scale-adapted biosecurity measures, with therapeutic-only antibiotic use.

• Explore biosecurity measures that are adapted to small-scale and backyard farming.

• Support local authorities to consider disease transmission in their urban planning, and to diagnose risks and make plans for disease control at both city-wide and neighbourhood level.

• Model climate change and urbanisation impacts on ecological shifts in virus and host ecosystems e.g. bird migration patterns.
2. Surveillance and identification

Surveillance in animals

Influenza is one of many infectious diseases that are important for poultry and swine health (many of which are not zoonoses). Farmers have other animal health priorities and concerns which are not necessarily connected with public health. These concerns need to be addressed if producers are to be engaged in developing effective prevention and response mechanisms.

The kind of public health strategy pursued by authorities in response to influenza in animals will shape the trust and participation of animal farmers in the surveillance system. A conventional response to zoonoses in animal health in the Global North has been vigorously ‘stamping out’ the disease, which may entail the killing of healthy animals, which comes at a great cost to farmers. Doing this effectively requires an efficient system of compensation to ensure the willingness of farmers to participate. Even other approaches such as preventative vaccination will require a system of veterinary support. Farmers’ willingness to participate in surveillance and be forthcoming about illness in their farms will depend on their readiness to accept ‘stamping out’ measures such as culling, something that is unlikely in small-scale and backyard production, as well as many industrial poultry producers in the developing world. Alternative approaches that only involve “the destruction of known infected flocks or even parts of flocks, but not contiguous flocks, coupled with other measures such as ring vaccination and short-term movement restrictions and market closures can be equally effective as mass slaughter of poultry in an infected area or zone” (Sims, 2007: 177). These alternative mechanisms, which have been tested and assurances (and proof) of compensation as well as clear and practical communication strategies, have enhanced compliance in the past e.g. in Hong Kong in 2002 and 2003.

There are very practical questions about who bears the costs of different intervention strategies and the kinds of support which need to be in place to make interventions effective: Who foots the bill? (Veterinary surveillance and compensation systems carry costs.) Who covers those costs? This is particularly important in developing countries, whose state veterinary services are systematically underfunded, and farmers themselves cannot be expected to ‘pay up’ fully for public health risk management in their countries and globally.

Note that different kinds of farmers, butchers and poultry traders will be able to take different financial and resource burdens of public health. Large-scale industrial farmers have more funds to be able to implement biosecurity measures, perform culling and await compensation, yet these forms of production also entail mass movement and crowding of animals, hence heightening the risk of pandemic emergence. Small-scale businesses and backyard farmers are more challenged by these measures. Public health measures that wish not to undermine these livelihoods should aim to adapt to their realities. As examples of the above, across Western Europe and emerging economies, the burden of public health standards on meat hygiene has meant a massive corporate concentration of the production and abattoir industry. A similar process has happened in China (as shown below), in which the backyard and small-scale hog and poultry farming industry has been decimated, with an increase in mega-farms. The number of hog farms dropped 70 percent between 1991 and 2009. Over the same period, the average hog farm grew from 945 head to 8,389 head (Brasch, 2014).

Success of surveillance systems depends on the relationship between producers, institutions carrying out the surveillance and those who implement the response. Vested or competing interests can complicate the detection, reporting and response to disease. Producers are likely to feel an ambivalence towards veterinarians, as they are simultaneously in charge of helping their animals survive, as well as killing the herd if an outbreak occurs. In some cases, the same animal health institution (e.g. the national veterinary service) detects cases and then implements the public health response (e.g. culling) (Scoones, 2010). There are experiences in the past of poultry farmers hiding dead or ill animals from veterinary services (Scoones and Forster, 2008). Similarly, the same institution that is in charge of protecting the livestock industry should
not be in charge of animal health surveillance to avoid conflicts of interest (ibid.: 158). This tension occurred even at the international level in the 2009 H1N1 outbreak where the World Organisation for Animal Health (OIE) contradicted messages sent by WHO regarding the pandemic, downplaying the role of the animal sector and the relevance of a trade ban (Butler, 2009). This illustrates another important institutional dynamic to take into account which exists at a national and international level between different animal and human health institutions, exploring the potential for (and barriers to) coordination.

One important lesson learnt from the H5N1 epizootic in Asia is not to expect one single virus to be at the heart of an event. The epizootic was caused by multiple viruses, a range of genotypes and considerable variability within genotypes (albeit linked to the Goose/GD/96 lineage). Furthermore, these different strains of virus had been circulating for almost a decade in poultry and waterfowl before the rise in incidence and widespread reporting of the disease in 2003/2004 (Sims et al., 2005). This can be partly explained by previous underreporting and circulation of subclinical animals (see modes of transmission below). However, it was likely that some change occurred around 2003 in the rate of virus excretion by waterfowl due to a change in the make-up of the virus and an expansion beyond the well-established reservoir populations of poultry and waterfowl. In similar areas confronted with the same exposure, trade in animals and contact with waterfowl, in some cases the outbreaks emerged and didn’t in others (Sims et al., 2005: 163). This illustrates the uncertainty and unpredictability of influenza: the appearance and expansion of new virus strains in animals don’t necessarily lead to zoo-epidemics, or to outbreaks in humans. There is a need to be prepared to incorporate uncertainty into the response.

**Surveillance in humans**

**Detecting emergence in human populations**

In developed countries like the UK, influenza surveillance relies on primary care clinical surveillance, through sentinel schemes such as in general practitioners’ (GP) surgeries which report weekly consultations for influenza-like illness (ILI) and other acute respiratory illnesses. Note that this sentinel surveillance ‘catches’ not only influenza cases, but also respiratory illnesses such as SARS and MERS coronavirus. Historical analysis is made to analyse trends in prevalence, severity of symptoms and mortality. Schools, care homes and hospitals, also report acute respiratory outbreaks. Surveys are conducted online with volunteers reporting on their health status. Reporting consists of clinical diagnosis as well as sentinel virological tests to identify strains in circulation. Swabs are sent to reference clinics and genetic and antigenic data are compiled. These data are in turn sent to WHO to be used as evidence to the annual formulation of the seasonal influenza vaccine (see below) as well as reporting on influenza outbreaks (UK Government, 2018).

Developing countries, with support from the WHO and other institutions such as the U.S. Centers for Disease Control and Prevention (U.S. CDC) have expanded their surveillance systems: increasing the number of sentinel sites (watching out for both Influenza-Like Illness (ILI) and Severe Acute Respiratory Infection (SARI), as well as identifying circulating virus strains and seasonality (Radin et al., 2012). Under the umbrella of WHO Global Influenza Surveillance and Response System (GISRS), individual countries have set up National Influenza Centres (NIC) which gather and share the epidemiological information on influenza. These NICs were pivotal in strengthening communication among countries in the 2009 H1N1 epidemic (Fineberg 2014). The political nature of these systems has been contested, and threatens their effectiveness and neutrality. In 2007, for example, Indonesia refused to share H5N1 virus strains as they perceived that developing countries would not reap the benefits in terms of accessing vaccines, and that it would be the pharmaceutical companies who would benefit (Lowe, 2010).

It is important to note that a pandemic need not occur from an emergence of a new antigenic subtype HN. In the case of the avian flu, a new subtype did emerge (H5N1), however excess mortality and severity related to flu in the middle of the 20th century occurred mostly due to a shift within the H1N1 subtype rather than new subtypes (ibid.: 1339).
The need to create networks of epidemiologists and virologists to share data across countries emerged after the SARS outbreak, for which many institutions were unprepared. In reaction to this, real-time knowledge sharing of virus strain, spread and vaccination (underpinned by the commitments of the International Health Regulations) is reported to have prevented a bigger spread in subsequent outbreaks such as the H1N1 pandemic (Fineberg 2014; Scoones, 2010). That said, while there were limitations from the point of view of communications and incorporating social science perspectives, the SARS response is considered a success from the point of view of epidemiologists and virologists working together.

Data gathering in health services and trials

As will be discussed below, people infected with influenza will not necessarily attend biomedical clinics when seeking treatment, particularly so in countries where biomedicine is not the mainstream health provider. Private clinical doctors, shop-owners of pharmaceutical products, herbalists, healers, etc. may be the first professionals to perceive increases in patients with flu symptoms. In those contexts in which these alternative health providers are of significance, incorporating them into the information systems would allow epidemics to be detected at an early stage. WHO information systems already capture a small number of private biomedical clinicians in their surveillance, yet the other providers are not included. In the detection of influenza outbreaks as well as trends in seasonal influenza, there is a lot of potential in ‘community-based surveillance’ (CBS), in which volunteers from communities work to detect and report unusual trends in community health. CBS is useful as it can temporarily replace a non-functioning surveillance system (either due to lack of financial resources or due to conflict), or it can strengthen an existing national disease surveillance system to ensure early detection and early response (IFRC, 2017). CBS also allows for a context-adapted surveillance, for an integration of influenza amongst a diversity of health concerns, and to enable a dialogue with communities even before the outbreak occurs (ibid.).

Public trust is as essential in preparedness as it is in response. Surveillance will be more effective to the degree that health service relationships are based on trust and a respect for different worldviews. This is particularly important for gathering data for surveillance, encouraging participation in medical trials (of vaccines, antivirals), allowing for autopsies, and so on. Colonial histories of negative engagement with medical science in the Global South may underpin resistance to participate in these activities, although such mistrust of the intentions of clinical medicine can also arise in the Global North (Fairhead and Leach, 2012; Geissler and Molyneux, 2011).

Other forms of expertise and surveillance capacities

Surveillance systems normally rely on public health, veterinary and epidemiological expertise. There is scope for the incorporation of ecological knowledge as well as contributions from social science and non-experts into surveillance. The integration of animal, human and environmental health is what the One Health approach aims to achieve (Pappaioanou and and Gramer, 2010). One Health strategies include among others ‘the need for capacity building as well as closer and more effective and coordinated communication between human and animal health authorities locally, nationally, and internationally for more effective and appropriate outbreak investigations. […] [Other strategies are] communication platforms (e.g., joint committees, task forces, virtual meetings, executive dashboards) and protocols that support multiple disciplines and sectors coming together to share information and participate in joint planning, investigation, analysis, and decision making on response.’ (National Research Council, 2010; Pappaioanou and Gramer, 2010: 276).

Disease modelling is often used for decision-making, and on occasions there is an over-reliance on modelling as it appears to be ‘more scientific’, and it allows for simulations and elaborate presentations whereas the assumptions behind them are often unchallenged (Forster 2012). In the case of H1N1, models rely on ‘estimates derived from past data concerning the microbiological characteristics of the virus, the effectiveness and safety of pharmaceutical interventions, and estimates for parameters such as transmissibility’ (Forster, 2012; Mansnerus, 2009, 2010)) which may not be too reliable in a new outbreak.
Surveillance systems would benefit from the input from ecologists (to detect the shifting ecologies), anthropologists (to understand cultural approaches to epidemics) and political scientists (to look into the 'political and institutional dimensions of disease responses') (Scoones, 2010: 160). Scoones also recommends incorporating non-expert input, who may flag things earlier than doctor or experts, for example, the Mexican communities near the swine industries had already complained to the Ministry of Health before the epidemic was declared. Zoonoses are often detected in human populations first. Scoones calls for an ‘embedded, systemic surveillance’ (ibid.: 159) in which decentralised information coming from different types of expertise (lay and scientific) and different sites are ‘mapped’. This decentralised gathering can take place in developed countries, through search engine use (see section on symptoms) or low-tech solutions e.g. mobile phone use in countries in the Global South (Li, Moore, Akter, Bleisten, and Ray, 2010). These technological solutions can be problematic, as they are limited to different social groups’ access to technology (Erikson, 2018). What emerges is the importance of assessing the communication channels that are important in a particular context, and then referring to them for reporting illness or deaths.

There are always uncertainties in surveillance. In the case of the 2009 H1N1 pandemic is a case in which the disease went undetected in the swine populations of several countries (from the Global North and South) until it reached Canada (Butler, 2009). Further to this, the disease was expected to emerge in Asia, and it took surveillance by surprise by emerging in Mexico. The likelihood of influenza outbreaks spreading and being undetected increases in ‘less extensive surveillance systems’, characteristic of low income countries (Radin et al., 2012). That said, the quick identification of the virus when it was detected in humans in Mexico and California in March 2009, as well as the development of sensitive and specific diagnostics are considered areas of outstanding performance in the H1N1 2009 response (Fineberg 2014: 1336). One has to be cautious in the modelling that is carried out to predict future emergence of pandemics such as the ones carried out by the PREDICT project. These models that take into account ecological changes and virus configurations work with data from previous outbreaks. Thus, using those models, they would have been unable to predict MERS, Middle East Respiratory Syndrome (MERS), (which was first detected in Saudi Arabia in 2012). There is a need to incorporate uncertainty:

Complex disease dynamics means that we do not know what is going to happen when, and when outbreaks do occur, their pattern and impact are highly context-specific. Uncertainty and ignorance prevail. Such complexity is not amenable to simple outbreak models, and requires a deeper understanding of changing ecologies, demographics and socio-economic contexts - and in particular, their interactions and dynamics in particular places. (Scoones, 2010: 151)

There have historically been gaps in capacity and funding resources both in developing countries and UN agencies such as the WHO in terms of pandemic preparedness. WHO acquired the responsibility to lead responses to pandemics, whereas a lack of funding, pressures from individual donor countries (which may counter global objectives) and organisational complexities may hamper WHO’s capacity to fulfil that responsibility (Fineberg 2014: 1339). This situation has been addressed by the Pandemic Influenza Preparedness (PIP) framework, through which the Partnership Contribution High Level Implementation Plan I (HLIPI), has strengthened both global and national preparedness capacities: Laboratory and surveillance, Burden of disease, Regulatory capacity building, Risk communications, and Planning for pandemic product deployment (WHO, 2018).

Recommendations for surveillance and identification:
Operational
• Ensure combined animal, human and environment surveillance.
• Support animal health surveillance processes separate from the response implementation.
• Support surveillance networks in developing countries which expand beyond biomedical services to incorporate alternative health providers, non-health expertise and data, and community-based surveillance.

• Promote learning exchanges and real-time communication between animal and human influenza health workers involved in surveillance and response.

**Building capacity**

• Assume a significant degree of uncertainty and unpredictability in surveillance.

• Map through a political economy analysis (exploring power, interests and knowledge) the cooperation/competition between different institutions and people involved in surveillance, communications and response (CDC, OIE, national governments, etc.) and how that influences knowledge-sharing. Understanding these dynamics will help organisations like WHO act as mediators and facilitators throughout the response.

• Study the economic and social justice impacts of ‘stamping out’ public health models vs. models that ‘live with’ the disease in particular contexts.

3. Appearance and interpretation of symptoms

Symptoms vary depending on the strain of virus and the immune response it generates. Symptoms related to seasonal influenza include high fever, unproductive cough, aching muscles, watery eyes, nausea and vomiting in some cases, along with headache, malaise, fatigue and weakness. The acute phase lasts 3-5 days and includes coughing and apathy. More often it is complications such as pneumonia or bronchitis that are fatal rather than the flu itself. SARS has flu-like symptoms, including fever, fatigue, headaches, muscle pain, loss of appetite and diarrhea.

In the case of the 1918 H1N1 pandemic, the bodies’ inflammatory overreaction to the virus (what is called a cytokine storm) was the cause of death, in which inflammatory cells ‘infiltrate pulmonary tissues and ... create airway congestion, impair gas exchange, and precipitate the acute respiratory distress syndrome’ (Simmons and Farrar, 2008). The Spanish flu symptoms were so unusual that it was ‘initially misdiagnosed initially as cholera, typhoid and dengue. Some people died within 24 hours of the first symptom. The most horrific feature was bleeding, not just from the nose and mouth but also from the ears and eyes’ (Barry, 2009). A similar immunological overreaction was characteristic of H5N1 human patients in the onset of the 2005 H5N1 epizootic (Simmons and Farrar, 2008). In less extreme cases of H5N1, ‘the symptoms were typical of influenza and, in many cases, gastrointestinal symptoms such as diarrhea and abdominal pain.’ The symptoms are equivalent to viral pneumonia, and in those who die, the death comes as respiratory failure and multi-organ failure (Black and Armstrong, 2006).

There are often discrepancies between folk or local understandings of influenza symptoms and those adopted by biomedicine and in turn in epidemiological research. In some Latin American cultures, there isn’t a specific word for the flu, as it is conflated with common colds (Baer et al., 1999). Even in countries and cultures where biomedicine is dominant, there may be discrepancies, such as the description of diarrhoea and vomiting as symptoms of a ‘stomach flu’ (Garcia, 2007).

How people speak of symptoms will help identifying flu cases more effectively and asses the morbidity, as well as avoid unfortunate cases in which influenza patients are dismissed by doctors due to folk conceptualisations of ‘cold’ causality. Misunderstandings of folk descriptions of flu can lead epidemiologists down blind alleys (Baer et al., 1999; McCombie, 1999). Ultimately, as above, only a PCR test will be able to determine if it is influenza.

Influenza is a ‘syndemic’ disease: it works in conjunction with other diseases to enhance mortality. The destruction of ciliated cells in the respiratory tract makes way for pneumonic bacteria (Staphylococcus aureus, Streptococcus pneumoniae). Other diseases such as tuberculosis, asthma, malnutrition and diabetes can also work in synergy with the flu virus (Merrill Singer, 2009). These co-morbidities are more likely to appear...
Lessons Learned

in developing countries (Radin et al., 2012). Local interpretations of these synergic diseases will need to be
recorded in order to aid the identification of the disease and its epidemiological analysis.

Mortality rates differ depending on the epidemic. In the 1918 H1N1 pandemic, in which no antibiotics were
available to treat secondary infection, Case Fatality Rates reached 2.5 percent, whereas in other influenza
epidemics it was around 0.1 percent (Taubenberger and Morens, 2006). It is important to note that there are
significant disparities in mortality rates across countries. In the case of the 2009 H1N1 pandemic: 51 percent
of pandemic deaths were estimated to have occurred in South-East Asia and Africa (although they are home
to 38 percent of the population). African mortality rates were 2-3 times higher than in other regions (Dawood
et al., 2012: 691).

Note that flu symptoms need not be only respiratory as are most prevalent in seasonal influenza, but a whole
range of other ways of framing potential symptoms should be incorporated. For example, in the 2009 H1N1
pandemic, cardio-vascular diseases appeared in parallel to respiratory distress. In the same pandemic, 50
percent of patients presented gastrointestinal symptoms including diarrhoea and vomiting (Girard, Tam,
Assou, and Kierny, 2010). In the 1918 flu pandemic, neurological symptoms were also salient: depression,
delirium, cycloplegia (paralysis of the ciliary eye muscle), encephalitis lethargica that would often derive into
a Parkinsonian disease1 (Henry, Smeyne, Jang, Miller, and Okun, 2010). Hence, when preventatively collecting
local descriptions of symptoms, other clusters of symptoms beyond respiratory symptoms need to be collected.

Inevitably, it is difficult to disentangle local descriptions of disease without understanding local models of
disease. Local models of disease can exist side by side with biomedical germ models of disease, or frequently,
icorporate them. There is a high diversity of models of disease (based on Greenwood 1981): models can be
(i) humoral and/or prophetic, (ii) models can incorporate natural (cold, contamination, etc.) and supernatural
causes of disease, (iii) with causal origins that may be ‘moral’ (and thus shaped by the social relations of the
‘patient’) or with no moral element. (iv) The ailments may be treated allopathically, with herbs, home remedies,
spiritually, or a combination of these. A key task of anthropological analysis will be to situate the emerging
pandemic in this constellation.

These models of disease vary across cultures, even within subpopulations in the same geographical area.
For example, in Latin American models, hot-cold diseases are based on humoral models of disease. They
conform to an ‘equilibrium model’: foods, medicinal remedies, and other substances are believed marked both
by (usually) unchanging hot and cold metaphorical qualities, and by fluctuating thermal temperatures that
reflect environmental exposures of the moment. Health is thought to depend on maintenance in the body of a
temperature balance, an equilibrium constantly threatened by the metaphorical and thermal forces to which
it is exposed. (Baer et al., 1999). Respiratory illnesses such as a cold and flu are attributed to an imbalance
generated by the consumption of cold foods or the exposure to cold temperatures. In Central America, there
would not be a diagnostic difference between cold and flu, and the treatment was the same (ibid.). Treatment
that doesn’t conform to these models might be resisted (Logan, 1973).

Another illustrative example of the complexities of lay models of disease is a model of disease that understands
clusters of symptoms to be caused by different factors, such as the Moroccan model of disease (Greenwood,
1981). If this model had to interpret the 1918 H1N1 pandemic symptoms, acute respiratory problems would be
explained by humoral colds, and the neurological problems could be understood as related to spirits, to which
some moral explanation needed to be sought, and the help of spiritual healer would need to be invoked (ibid.: 313).

What is important to raise here is there need not be a cultural confrontation between biomedical models and
local models of disease. In many cultures, biomedicine is subsumed within broader spiritual and religious
notions of illness. For example, in Somalia, traditionally, disease and wellbeing is explained through the flow

1The patients in Oliver Sacks’ book ‘Awakenings’ had been victims of Encephalitis Lethargica linked (although the aetiology is still contested) to the Spanish
Flu pandemic.
of humoral substances (bile, stool and blood) and spirits, yet addressing these humoral flows and spiritual imbalances can go in parallel to preventing contagion and germs, using allopathic medicine and diagnostic equipment (Carruth, 2014).

Local understandings and descriptions of symptoms can be recorded in clinical visits, biomedical or other health providers, as discussed in the surveillance section. In developed countries, there is potential for detection of outbreaks through clusters of symptoms searches in internet search engines (Leach, Scoones, and Stirling, 2010).

Methodologies that have been tested to gather local understandings of the disease in an emergency scenario include light-touch surveys and qualitative interviews that explore local understandings of modes of transmission, illness, preventative behaviours and attitudes towards response measures (Weiss 1997, Weiss 2001). The Explanatory Model Interview Catalogue (EMIC) methodology, for example, was used in India to gauge people’s understandings of the 2009 H1N1 pandemic (Sundaram et al., 2015; Sundaram, Schaetti, Purohit, Kudale, and Weiss, 2014). This simple methodology involves interviewing people with different demographic characteristics to examine ‘community ideas of illness-related experience, meaning and behaviour’ (Sundaram et al., 2014: 2). Through the discussion of a vignette of a person with symptoms of influenza, ideas about ‘priority symptoms, perceived causes, health seeking and prevention of the illness’ are elicited (ibid., see also Weiss 1997).

**Recommendations for appearance and interpretation of symptoms:**

**Operational**

- Conduct an anthropological survey of different social groups to understand:
  - How do different social groups understand/interpret symptoms? How do they speak of the disease (what concepts/categories)?
  - How do they contrast with epidemiological findings and biomedical descriptions?
  - What are the different understandings of causal mechanisms disease (e.g. humours, germs, hot-cold, witchcraft, spirits) and how do these relate to respiratory or other symptoms (neurological, etc.)?
  - Relate this information to the surveillance mechanisms in place (e.g. clinics, National Influenza Centres, etc.).
  - The above understandings of the disease are likely to develop throughout the epidemic. Monitoring of changes can be done through light-touch repeated surveys.
  - Communicate these findings to those involved in the response, particularly those who are new to the context.

**4. Transmission channels and vulnerability**

**Animal to Human**

**Close proximity**

When making the interspecies ‘jump’, the avian influenza virus H5N1 relied on people’s close proximity to poultry. The majority of the initial reported cases were counted amongst populations involved in livestock farms or in meat value chains. People got infected through poultry raising, butchering, de-feathering, meat cutting, etc.

This ‘close encounter’ between animals can be, to a limited degree, managed. There are ways of avoiding close proximity between animals and humans or mitigating its effect on risk of illness. What is being hypothesised is that in the case of the Mexico’s first outbreak of H1N1 in 2009, the proximity of the farms to human populations may have also played a role in the species jump (Merrill Singer, 2009). Therefore, there is a role in spatial planning in managing the proximity between humans and livestock, in terms of proximity to animal farms,
abattoirs and cutting plants, as well as ways of protecting people who work with live animals and animal products with relevant equipment and work practices, as well as influencing work cultures. As mentioned above, these would need to be adapted to the scale of the different ventures. For example, within small scale markets, different bird species were being sold together allowing for jumps across bird species (e.g. ducks, turkeys, hens), whilst a separation of birds into species within those markets would mitigate that (Sims et al., 2005). Market cleaning and not mixing deliveries of similar species from different points can also mitigate transmission.

Regulating trade flows and quarantine

In the case of the H5N1 epizootic (avian flu), the virus was transmitted from country to country primarily through livestock trade – both legal and illegal – and movement of contaminated equipment, and to a lesser degree by the movement of wild birds (Sims et al., 2005). Human-to-human transmission, however, was significantly limited and not sustained, even in the case of health care workers attending them (Black and Armstrong, 2006). The 2009 H1N1 pandemic, on the other hand, relied on the movement of people and effective human-to-human transmission for it to reach pandemic proportions, rather than the movement of animals.

An important measure against the expansion of outbreaks to other countries is the imposition of trade bans. This played an important role in the contention of the H5N1 epizootic. Problems may arise when countries use ‘health related’ trade bans to engage in unfair competition with other countries. For example, the US accused India in 2012 of using influenza as an excuse to impose trade barriers to chicken products (BBC News, 2012). These trade bans have a massive impact on countries’ export incomes, and on the livelihood of producers. In the 2003 H5N1 epizootic, China, Cambodia, Indonesia, Laos and Thailand, in which ‘one third to one half of the population derives income from poultry’, the effects of the trade ban were ‘devastating to their economies and worsened food security for rural communities’ (Chmielewski and Swayne, 2011: 40). Thailand, for example, lost 50 percent of its export market (ibid.). When assessing the impact of trade bans, note that different kinds of producers in the countries affected will be impacted differently by the trade bans. Particular elements of the industry will be more export-oriented, whilst others, which rely mainly on local and national markets, will be less affected. This is important because the public health measures to ‘unlock’ those trade flows and that export-oriented farmers are willing to undergo, (creation of buffer zones, culling and so on) will have consequences also on those types of farmers who weren’t involved in the export market anyway. There is a need to understand each animal industry as a diverse one, where different kinds of farmers stand to gain in different ways by the imposition of public health measures and free trade, and in which these different kinds of farmers have a different ‘voice’ when influencing national governments (often large-scale export oriented farmers have a stronger voice in policymaking). In fact, Indonesian small scale farmers argued that the global response was demonising them, when they perceived their flocks to be ‘stronger’, that the risk of flu infection in their animals was lower than in commercial farms (Kleinman, Bloom, Saich, Mason, and Aulino, 2008). These perceptions are in fact supported by research by Graham et al. (2008).

Whilst the World Trade Organisation’s (WTO) regulations have provisos to judge if a trade ban on health grounds is legitimate, it works a posteriori and is a slow process which can play little part at the beginning of an epidemic. The configuration of the International Health Regulations (IHR) in 2005 aimed to position the WHO as a ‘neutral’ actor to determine if a trade ban was necessary or not. The IHR required that ‘member states implementing unilateral measures that interfere with international traffic and trade inform the WHO and that they also provide a public health rational and scientific justification for those measures’ (Fineberg 2014: 1336). According to the WHO, the IHR regulations played an important role in preventing unnecessary trade and movement barriers in the 2009 H1N1 pandemic (WHO, 2018). The US pork lobby also played a role in preventing these measures (Forster, 2012).

\[^{2}\text{That said, the original ‘swine genes’ before its recombination in Veracruz in 2009 did not come from local Mexican varieties, but rather from an Asian origin and it entered North America through trade in live hogs (Mena et al., 2016). In turn, many swine flu strains in Asia originate in Europe and North America! (Nelson et al., 2015). In conclusion, trade in live animals plays a key role in the circulation and recombination of flu viruses.}\]
As mentioned above, the different institutions involved in zoonotic preparedness and response have different objectives and ‘constituencies’ in terms of erecting trade barriers (FAO, OIE, WHO, and so on). As mentioned above in the H5N1 epidemic, the OIE resisted WHO recommendations to impose a trade ban on live poultry. In the H5N1 epizootic, affected animals and those in the ‘buffer zones’ delineated around them were put under quarantine, and wet markets (in which dead and live animals are sold) were closed. The intensity of these coercive measures varied depending on the country and within countries. In Hong Kong, where the authorities wanted to be seen taking swift action before the Olympics, the State restricted the small-scale poultry sector and banned wet markets. However, resistance from producers, traders and consumers arose. Informal, unregulated markets made up for those closures, and consumers were unwilling to shift to frozen chicken products, when their preference was to purchase live animals (Scoones and Forster, 2008). This example shows that States have a limited capacity to implement these bans unless they seek collaboration with those whose livelihoods are at risk. It also shows that States in crisis need ‘to be seen as effective’ more than actually being effective in addressing the epidemic. Hence, there needs to be an analysis between what a policy says – as government discourse – and how it actually plays out in reality. Drawing attention to the poultry and swine industries in influenza epizooties have had massive impact on consumer behaviour. Despite no risk arising from the consumption of well-cooked poultry or hog meat, sales of pork and chicken plummeted due to mistrust.

**Human-to-Human**

**Close encounter and susceptibility**

As mentioned above, H5N1 had limited transmission from human-to-human (through inhaled droplets and fomites), and reported cases only occurred amongst those who had been in close contact with a person who in turn had got it from a bird (family members sharing the same room, nurses, carers, etc.). It had limited transmission, but a high fatality rate of over 60 percent (Korteweg and Gu, 2010). This limited transmission is often assigned importance as a ‘what could have been’ scenario rather than a real demographic impact, because we had encountered a virus jump from birds to humans and then transmission between humans. The idea being that perhaps a future strain could be more effective in transmitting across humans. The same self-limitations occurred in the case of the SARS epidemic, in which the coronavirus would also be transmitted through droplets and fomites, but it also needed to infect people at very close quarters. Nosocomial (hospital-acquired) infection was particularly important in the case of SARS and MERS. SARS also arose in spring in the Northern hemisphere (rather than in the winter) which meant less people were crowding indoors.

The 2009 H1N1 virus was however more efficient in human-to-human transmission, and also used inhaled droplets and fomites as a vehicle. It was as easily transmitted as the seasonal flu (WHO, 2014). Nosocomial transmission also contributed to the transmission. At its onset, the outbreak seemed particularly dangerous, as well as being easily transmissible, a high number of hospitalised patients became critically ill (6.5 percent) and out of those, 41 percent died (Fineberg 2014: 1336). This severity of disease did not carry on after its spread to other countries, and in the end, the mortality was similar to that of seasonal influenza.

This high circulation was key to increase the Phases of Pandemics by the WHO in the 2009 H1N1 pandemic. Pandemic Phases 1 to 6 increase depending on the capacity of the virus to ‘sustain community outbreaks’ and then to be circulating in more than one country and finally in more than one WHO region. Thus, when WHO declared the pandemic, 74 countries had laboratory-confirmed cases. However, when the severity of the disease was low, it led to public confusion. According to Fineberg, ‘the WHO lacked a consistent, measurable and understandable depiction of the severity of the epidemic’ (Fineberg 2014: 1339). This was incorporated as part of the lessons learnt review conducted by the WHO after the crisis. As shown below, in order to build trust in the response, there is a strong role for communication to convey these nuances to the population, not only severity and circulation, but also the degree of uncertainty that the response is grappling with.

There has been speculation on the role of particular individuals playing a greater role in circulating the disease, who have been called ‘superspreaders’. Depending on the disease, the importance of these superspreaders
would vary, with SARS being an example in which superspreaders played a strong role. It would be speculated that these individuals might be able to spread the virus through different modes of transmission, or that their life circumstances made them more likely to infect others (Lloyd-Smith, Schreiber, Kopp, and Getz, 2005). The pursuit and identification of superspreaders can potentially stigmatise victims and feed into fear and scapegoating, as happened in the SARS epidemic (Wald, 2008: 4).

Social difference and susceptibility

Populations are not equally affected by these influenza epidemics. Their predisposition to the disease varies, and also different virus strains will affect different demographics. One of the key mechanisms to detect an ‘unusual’ flu outbreak is when the people affected are different. In seasonal influenza, it is often infants and the elderly (who are not fully immunocompetent) who are affected. Part of the epidemiological surveillance is to detect these changes. In the 1918 H1N1 pandemic the picture was the opposite of seasonal influenza, it was mostly young people who were killed by the flu. This has several potential explanations; during the war it was mostly young men who were mobilised by the war effort, and hence crowded in camps and boats and then moved around from front to front. In addition, many of the deaths were produced by the exaggerated immune response to the virus, rather than by the virus itself, and hence those immunocompromised weren’t affected. Lastly, some of the oldest people had some residual antibodies to a previous flu pandemic that occurred at the end of the 19th century.

In the case of the 2009 H1N1 flu, the disease also killed younger people, ‘including those who were otherwise healthy. Pregnant women, younger children and people of any age with certain chronic lung or other medical conditions would also be at a higher risk’ (WHO, 2014). In the case of SARS, transmission seems to equally affect old and young, healthy and ill.

The experience of the 1918 great flu pandemic is the role that sustained overcrowding had in the transmission of the disease. This may have relevant importance in preparedness to shaping the likelihood of overcrowding: there is a role for spatial planning programmes to avoid overcrowding, and a role for long-term development programmes to enquire about the dynamics on internal and global migration.

As mentioned above, influenza is a syndemic disease, which means it often works in conjunction with other diseases, and hence to understand vulnerability, these other disease dynamics need to be understood. For example, influenza can work in collaboration with tuberculosis, smallpox, measles, pneumonic bacteria, HIV and malnutrition (Sattenspiel and Mamelund, 2012; Merrill Singer, 2009; Merrill Singer and Clair, 2003). The prevalence of these diseases is highly dependent on the country’s wealth. Countries in the Global South are thus more likely to have these syndemics, with young people more likely to be affected (Dawood et al., 2012). For similar reasons, the death toll of older people in the 2009 H1N1 pandemic was three times higher in South Africa as it was in the US (ibid.: 692). This syndemic effect in enhancing disparities in mortality is exacerbated by poor access to health care, characteristic of Global South countries.

Social difference was crucial in determining who was affected by the 1918 flu. Prevalence of pregnancies, underlying health and nutrition, smoking and diabetes, are often shaped by social class. This, coupled with the lack of adequate housing for low-income families in the times of the First World War, disproportionately affected the working classes. These health inequalities persist today, and would shape the outcomes of a new pandemic, especially in the Global South.

There is a trade-off between remoteness, mobility and susceptibility to influenza. In 1918, remote and nomadic communities were less likely to get infected by the viruses. However, in the cases where the epidemic did reach them, the lack of adequate health services meant that a high mortality occurred (Sattenspiel and Mamelund, 2012). In the case of indigenous communities, the influenza virus disproportionately affects them. Due to the syndemics, by which they would be more likely to have diseases that work with influenza, poorer nutrition and poor social and health services, indigenous people are more likely to be affected by the flu. This is compounded by a lesser degree of previous exposure to the disease. In 2009, flu deaths were up to six
times higher in indigenous populations compared to non-indigenous populations (La Ruche et al., 2009). The same vulnerability to influenza arises in racial and ethnic minorities (Hutchins, Fiscella, Levine, Ompad, and McDonald, 2009). These cases show that there is a strong element of social justice in vulnerability to influenza that should be addressed before an epidemic emerges.

Relative exposure
Since exposure is highest amongst the caring and nursing populations, there will also be differences in flu infections depending on the make-up of those populations. In countries where women do most of the care work and nursing, they will be more likely to be infected. The same with particular countries of origin, castes etc., if they are more likely to be in direct contact with patients.

Local perceptions of risk
Social difference generates different perceptions around how the virus circulates and is transmitted. There can also be a mismatch between people’s perceptions of risk and their understandings of susceptibility with the results that emerge from the epidemiological results. This mismatch will need to be addressed by public health communication (see below).

People may assume that influenza pandemics follow similar patterns as seasonal influenza, with children and the elderly being most at risk. Due to this, they may also think that a relatively mild version of influenza is occurring. Alternatively, they may also greatly fear the risk of becoming infected, such as the case of the SARS epidemic in China, despite there being limited official information at the onset of the outbreak. These unjustified fears of SARS emerged in other countries where the likelihood of infections was significantly lower. The local perceptions of risk and danger is easily shifted, depending on the information received, through either media or communication networks.

As shown in the section on symptoms, different social groups have different understandings of disease and differing cultural models of disease. As part of this, they will have different understandings of what constitutes a disease, and how it is transmitted. For example, with constellations of symptoms like those of the flu, some cultures might assign causality to exposure to cold drafts (Foster, 1987), water contamination (Sundaram et al., 2014), germs etc. Local perceptions of vehicles of transmission are not set in stone; they can shift as the epidemic progresses. It is a dynamic process and incorporating different narratives of risk in preparedness is a way of acknowledging the limits of our knowledge, crucial for an effective response. A narrow risk framing that does not effectively acknowledge issues of uncertainty and ignorance – and the ambiguity of alternative interpretations of likelihood and outcome - can act to narrow assessment and response in ways that may fundamentally undermine the effectiveness and resilience of responses. Incorporating alternative narratives about risk and response allows the debate to be reframed, and surveillance systems in particular to be rethought (Scoones 2010: 150).

Recommendations for transmission channels and vulnerability:
Operational
- Gauge the differential impacts of health-related trade barriers (and subsequent public measures to reinstate trade flows) between different kinds of farmers and traders.
- Incorporate a political economy analysis of relevant global institutions (understanding their respective interests, constituencies, strategies etc.) involved in shifting phases of pandemic (and advocating for curtailing movement of people or animals) so as to be better placed to advise on processes.
- Ensure epidemiological investigations do not contribute to stigma and scapegoating (e.g. ‘superspreaders’)
- Identify the efficacy of transmission and contrast it with local understandings of transmission and risk, and prior influenza outbreaks which may inform public views. Address misconceptions through communications, including noting if there are differences with prior experience.
Incorporate health workers in participatory discussions around influenza preparedness and throughout an influenza response, incorporating their perceptions of the disease and the response as well as considering their needs and supporting their work (see more below).

For marginalised patients (indigenous groups, ethnic minorities, the poor) ensure their access to care and treatment for influenza and underlying illnesses. This will require identifying specific cultural needs and addressing these in triage and treatment.

Advocate for greater resources for affected countries in the Global South to adequately respond simultaneously to influenza epidemics and to other concomitant illnesses.

Building capacity

- Promote local and scale-adapted regulations to avoid overcrowding of animals and proximity of industrial farms to human populations.
- Promote local and scale-adapted livestock, meat processing and ‘wet market’ practices, procedures and cultures that mitigate risk, ensuring to incorporate affected farmers, traders and consumers in the discussion of policy options.
- Support WHO in incorporating an ‘objective’ understanding of severity of disease as well as spread (in parallel to adequate communication to the population).
- Advocate for support for Global South health systems to address diseases that work with influenza (TB, HIV, malnutrition, and so on), diseases which often have significantly less funding.
- Work to address socio-economic inequalities, and improve health system access for minorities and indigenous peoples.

5. Public health communication

History has shown that appropriate public health communication is key for a successful response to an influenza epidemic. Good communication builds trust between the institutions in charge of the response and the communities they aim to serve, in turn ensuring that the response can roll out and adapt accordingly. This ‘trust’ needs to go both ways, also in terms of institutions understanding that the public are not helpless victims, but active agents that can be critical in the response itself. Rather than panic, citizens are likely to cooperate with each other and the emergency response, if they are well-informed (Glass and Schoch-Spana, 2002).

Barry, a specialist in the 1918 great influenza pandemic, showed that the US experienced very high mortality because both politicians and the medical profession did not inform the public of what was going on. On top of the censorship due to the war, there were no lists of the dead on the newspapers, or public health recommendations. People started believing rumours about how the flu was transmitted, breaking down trust and social bonds between people (Barry, 2009). On the other hand, in places where information was made available, people reconnected and cooperated:

Better communication led to better results. In San Francisco, for example, despite a slow reaction to the initial onslaught of flu, in October 1918 the mayor, health officials and business and union leaders all signed a full-page newspaper advert in huge type reading: ‘Wear A Mask and Save Your Life!’ It was a rare, bold statement. In this city, society, although reeling, functioned. Food was delivered, and the sick were cared for. Where people had accurate information and knew what they faced, they often performed heroically. Red Cross professionals, physicians and nurses routinely risked their lives. (Barry, 2009: 325)

Unfortunately, communication problems have occurred in more contemporary scenarios. In the beginning of the SARS outbreak in Guangzhou, China, the health authorities declared the outbreak a state secret for over two months. This failure to inform the citizens ‘heightened anxieties, fear and widespread speculation’ (Huang, 2004).
SMS mobile phone messages circulated rumours about a deadly flu and solutions (sometimes inadequate solutions) to prevent infection. Even when the Ministry of Health informed the public, it underplayed the risk of the illness. The different risks and incentives that moved the Guangzhou health authorities (worried about the economy taking a hit) and of the Ministry of Health communications with the National leadership shaped whether they prioritised communication with the public or keeping the disease under the radar (ibid.). It was only when national and international pressures (including high coverage in international media) mounted against the leadership, together with a heightened awareness and concern by the public, and a growing epidemic, that the Chinese authorities took swift and effective action (Huang, 2004). The same initial cover up has been reported in Thailand and Indonesia in the first outbreaks of H5N1 bird flu (Barry, 2009). These experiences have highlighted the importance of honesty and transparency in public communications, and States are today more likely to be transparent in the event of an outbreak.

Even when the authorities are candid, public health communication in epidemics often have to work within a high degree of uncertainty on the origin of the disease, of the vehicles of transmission, the epidemiology, and so on. There can also be uncertainty about the effectiveness of the specific interventions to reduce infection. Further, these may change in the process of the epidemic, for example, the 2009 H1N1 and the SARS epidemic were very severe at the onset, but then turned out to be less severe in the subsequent infections. The SARS epidemic is an example of the sense of uncertainty that will emerge around a future emerging ‘disease X’. A rapid geographical spread of an unclassified disease, SARS was a ‘mystery disease with the aura of being able to strike anyone, anywhere, anytime. The relatively high case-fatality rate, methods of transmission and uncertainty over identification and control of the disease all contributed to public alarm …’ (Smith, 2006: 3119).

In the case of SARS, a success was built on globalised communication between research and healthcare agencies. The networks (such as the WHO Global Outbreak Alert and Response Network- GOARN) between international researchers who identified the virus, set procedures for identification at a clinical level, and gauged the epidemiology of the disease, reduced to a degree, the uncertainty (ibid.). However, uncertainty is guaranteed, and it is recommended that health authorities are open about the ‘limits of available information and resources’. When the public feels reporting is inaccurate, they will seek alternative sources of information (Glass and Schoch-Spana, 2002: 221). As mentioned above, this accuracy was questioned when the severity of the H1N1 was not incorporated into the decisions to shift to a maximum pandemic phase, a contradiction that the public could not understand.

Communication inequalities and social diversity

In order to understand trust and how to build it, it is necessary to understand the history of that interaction between the authorities and the different social groups that make ‘the public’. That history (particularly in the colonial experience) can be difficult. Trust is ‘highly influenced by previous experiences, shared cultural or historical knowledge and pre-existing belief and value systems’ (Vaughan and Tinker, 2009: 326). Hence ‘efforts to build a strong foundation of trust among vulnerable populations must being in earnest prior to the pandemic stage through engagement with targeted individuals or groups and those who serve them’ (ibid.: 327). It is relational, both over the longer term (i.e. in terms of colonial and post-colonial histories), and in the short term (i.e. people’s interactions with governments or health systems), during or just before the outbreak.

It is important to acknowledge the importance of informal communication mechanisms. Even in the SARS media blackout in China, 40.9 percent of urban residents had already heard about the disease through unofficial means (Haiyan 2003 in Huang, 2004). People acquire information through their personal everyday exchanges, and today, rely on mobile phones, social media and the internet as much as they do on conventional media (Funk, Gilad, Watkins, and Jansen, 2009).

In order to ensure that the communication strategy for influenza response is successful, it needs to acknowledge that there is a diversity of social groups, which have different worldviews and needs as well as access to different channels of communication. Therefore there is a need to identify different target groups,
and make sure that the communications are situation-specific and thus are ‘directed to venues and channels that vulnerable populations perceive as informative, credible and accessible’ (Vaughan and Tinker, 2009: 327). Before thinking about messaging, there is a need to compile knowledge ‘about pre-existing community beliefs and needs’, as well as gather information about ‘pre-existing community resources and plans for detecting and responding to a pandemic’ (Reissman, Watson, Klomp, Tanielian, and Prior, 2006: 8). Local/cultural responses to epidemics are explored in the following section. This cultural assessment will enable incorporation of ‘local customs into messages and interventions where appropriate’ (ibid.).

Leach and Dry emphasised that we need to move away from social and cultural factors as ‘individual beliefs’ that are immutable, but rather see these working at different scales and in a changing dynamic, from ‘the most intimate aspects of bodily comportment and behaviour, to intra-household, community and societal norms and practices.’ (Dry and Leach, 2010: 11).

Community engagement

Working with trusted and credible information sources are a way of mitigating fear and mistrust. Different groups will have different people whom they respect, hence ‘communication intermediaries’ will need to be identified, and they are crucial in making knowledge actionable. These brokers can be community leaders, faith-leaders, trusted people in education or work establishments, and so on. It is important to not take for granted, that the self-appointed or official community leaders are the ones that command public trust. This might not be the case, and it might also be other leading figures that are trusted by the community (Wilkinson, Parker, Martineau, and Leach, 2017). In those cases where there is a diversity of health providers, these will be important intermediaries to communicate key messages about the epidemic (alternative medicine doctors, healers, herbalists, pharmacists, etc.) (Vaughan and Tinker, 2009).

Communities cannot only be recipients of risk prevention messages, but need to be engaged in every step, from conception to delivery. This communication that puts communities first should bring solutions that ‘are simple, doable, culturally compatible and action based, and they tap into local media sources’ (Vaughan and Tinker, 2009: 327).

Amongst other guidelines, Glass and Schoch-Spana (2002: 217) have the following recommendations for communication in a catastrophic event such as bioterrorism or severe pandemic:

- ‘Treat the public as a capable ally in the response to an epidemic
- Enlist civic organisations in practical public health activities
- Invest in public outreach and communication, and
- Ensure that planning reflects the values and priorities of affected populations.’

Working from the communities’ values, rather than ‘information’ is crucial. Social trust comes from ‘telling stories expressing salient values’, because people trust ‘value-bearing narratives’ that highlight values, goals and processes shared between communities and authorities, rather than direct-evidence (Prati, Pietrantoni, and Zani, 2011). Experience from other influenza pandemics encourage a diverse use of media, appropriate for each target group and particularly to use language (and translation), imagery and messaging that is culturally appropriate 3 (Vaughan and Tinker, 2009).

Stigma and scapegoating

Response communication has to be very careful to not generate or exacerbate stigma or scapegoating. This is particularly important in the early stages, when the event is declared. How a disease is discussed will have consequences. For example, 2009 H1N1, was initially called ‘swine flu’, which shed a negative light on

---

3 For further information, please find detailed recommendations for communication for Influenza pandemics in Reissman et al. (2006) and Vaughan and Tinker (2009).
the hog industry. This was misleading since H1N1 was a recombination of bird, human and swine flu, and the pandemic transmission happened mostly from human-to-human. Similarly, attributing the origin of the flu to a particular region or country can ultimately lead to discrimination or stigma of particular social groups. This was the case of Asians in the H5N1 bird flu epidemic and the case of Mexicans in the case of the 2009 H1N1 flu (Merrill Singer, 2009). Those involved in the epidemiological analysis must also be aware of this risk, and be aware of the politics and prejudice that may surround their socio-demographic categories, how they design their questionnaires and define (and communicate about) target groups, and how this might lead to blaming particular social groups for the flu epidemic e.g. poultry farmers, poor citizens in inadequate housing, nurses and carers etc. Note that scapegoating can shift and intensify in an epidemic, and there is a role for communication strategies to monitor and adapt to this. This scapegoating emerges from a concrete historical context, hence existing social and political divisions may play out in an epidemic, for example, between Muslim and Hindu communities in a plague outbreak in Surat, India (Barrett and Brown, 2008) or between Muslim political authorities and Christian communities in Egypt (Leach and Tadros, 2014).

**Recommendations for Public Health Communication:**

**Operational**

- Survey pre-existing community beliefs and needs (as part of a broader cultural model of disease (see below) for adequate messaging: through KAP surveys, focus groups and embedding anthropologists in the response.

- Understand how different social groups are characterised and differentiated locally (both by themselves and others), including the historical context to these identities. This can be achieved by a rapid social science analysis of the context, including a desk review and engaging with key social science experts in the country, combined with a rapid ethnographic analysis on the ground, engaging with key stakeholders both at the national and local levels.

- Identify and monitor power dynamics between social groups which might lead to stigmatisation and scapegoating in the case of an epidemic, and address negative patterns in programming

- Avoid stigmatising groups or industries by naming the epidemic after them (e.g. swine flu, Mexican flu).

- Epidemiological work, in terms of categorising and tracking particular demographic groups must be aware of the risks to generating stigma for those particular groups.

- Response institutions must be honest about what they know about the epidemic, being candid about the limitations of their knowledge to mitigate misinformation and conspiracy theories.

- Communication specialists for pandemic response must acknowledge that their messages circulate in a broader network of information: peer-to-peer, SMS, social media and so on. Trusted communication channels must be identified and used to deliver messages. Identify channels that allow for a two-way discussion between the response and communities, allowing for the public to raise questions and give suggestions, as well as receiving useful information on the disease.

- Institutions like national government or the WHO must be transparent about their engagement with ‘experts’ and the pharmaceutical industry to explain how they deal with conflicts of interest.

- Identify trusted local intermediaries, looking beyond people with formal authority and leadership.

- Messaging about the disease and prevention methods must be framed within the point of view and language of the communities affected, and through trusted intermediaries/brokers, including alternative health providers.

- Emphasising shared values and ‘togetherness’ is as important as adequate information.
Building capacity

- Trust in public institutions has to be nurtured in advance, both in terms of communication, but also in delivering other services that build public trust.

- The relationships with trusted community leaders (e.g. religious leaders, schools, trade unions, etc.) and local authorities in order to engage with community and establish two-way communication channels must be established beforehand, and incorporated into contingency plans.

6. Prevention measures and reactions to them

Animal to animal

Bird culling according to epidemiological zoning

Measures that are designed for a particular context (e.g. large-scale biosecure farms and meat-processing plants in the Global North) are likely to be inappropriate for other contexts. As mentioned above, the ‘stamping out’ animal health approach to epidemics can easily meet the resistance of poultry farmers and traders, who may refuse to report to the authorities, or sell potentially infected poultry to make up for the losses of culling (Lowe, 2010). However, there are examples in which social and political circumstances enabled cooperation with the authorities. Previous positive experiences of farmers with the health authorities, by maintaining public health infrastructure and the continuity of medical insurance in East China, made farmers more collaborative in the avian influenza interventions, ‘disinfecting farm premises, immunizing chickens and destroying diseased chickens’ (Zhang and Pan, 2008: 28).

It is important to note that an epidemic response is often not entirely based on health objectives, but can easily get caught in political dynamics. In 2008, China was preparing for the Olympics, and responded to H5N1 cases with policies to put poultry producers and wet markets out of business, as a way of being seen to take firm action (Scoones, 2010). More recently, Korea underwent a similar process including the culling of large bird populations for the Winter Olympics during an infection of bird flu H5N6. A similar situation happened with SARS, in which the Chinese authorities had to show they were ‘on the case’ (after a period of cover-up), firing the Health Minister and Beijing Mayor and hundreds of public health officials, as well as starting a massive prevention campaign (see below) and putting together new institutional mechanisms for epidemic response (Huang, 2004). On some occasions, public authorities may ‘weaponise’ public health to pursue political or economic goals. This was the case in the H1N1 epidemic in Egypt, in which global narratives of health were used to ‘suppress and delegitimise’ the Coptic Christian communities of Cairo who kept pigs, with planned culling of 300,000 pigs (despite being unwarranted by the epidemiology of 2009 H1N1), a media demonisation of pork and pork producers, and repression when culling was resisted (Leach and Tadros, 2014). In terms of economic goals, the restructuring and consolidating of the hog and poultry industries that played in favour of national and international actors were mentioned above.

Human-to-Human

Local/cultural responses to epidemics

Most of the literature, particularly dealing with developing countries, does not acknowledge that there are already existing response mechanisms to epidemics in general (not only flu) and that there are local methods for containing and organising around epidemics.

McGrath (1991) sought to find responses across several cultures when they encountered high-mortality epidemics, and found six common responses to epidemics in 229 cultures:

- Flight or migration from the epicentre of the of the epidemic (46 percent)

- Implementation of extraordinary kinds of therapies and preventative measures, such as quarantine and isolation (24 percent)
Lessons Learned

- Blaming or scapegoating individuals, authorities or institutions (11 percent)
- Resignation and despair (9 percent)
- Ostracism of the ill or those at risk of becoming ill (9 percent)

Whatever the initial reactions are, it is important to note that there exist local, culturally mediated responses to endemic diseases and epidemics. These response practices include work to curtail the transmission of the epidemic, such as quarantine, movement control and isolation. These ‘common responses’ can indeed occur in a flu epidemic, yet it is important to identify the underlying socio-cultural understandings and practices vis-à-vis epidemic illnesses of a particular community or cultural group, in order to build on them.

Medical anthropologists have argued that ritual and spiritual responses play a role in making sense of the epidemic, in some ways mitigating it, reducing fear and anxiety. Dialogue and cooperation with communities using local categories and values are important to incorporate public health goals (in the biomedical sense) into the response.

Non-pharmaceutical measures: travel restrictions, quarantining and social distancing

Influenza, when it spreads easily (as in the case of seasonal flu, 2009 H1N1) is particularly challenging when considering measures that decrease contact between the infected and the healthy. Travel restrictions, social distancing and quarantining are the measures at hand.

Travel restrictions and quarantining have a limited impact in stopping the disease spreading due to the specific nature of influenza. It can play a positive role at a local level when the communities are remote. For example, in the case of the US in the 1918 great flu, control of movement of people in the heads of rivers and in between communities mitigated the spread (Sattenspiel and Mamelund, 2012). In the US, cities that implemented school closure; cancellation of public gatherings; isolation and quarantine, doing so in an ‘early, sustained and layered’ fashion, ensured mortality was mitigated (Markel, Lipman, Navarro, and et al., 2007). Social distancing (used in flu as well as many other epidemic diseases) is often implemented by the closure of schools, workplaces, public transport and congregations. In a sense, the illness itself imposes a degree of social distancing, in which the symptomatic ill people stay at home in the worst days of the disease. It is important to highlight here that recent literature advocates against enforced/coercive social distancing, but rather advocates for working with community and faith leaders to promote people staying at home, so it is a voluntary process (Schoch-Spana, Bouri, Rambhia, and Norwood, 2010). Otherwise, there could be significant resistance, particularly when banning congregations with spiritual/religious meaning (e.g. attending mass). The same voluntary element has to come in social sequestration (separating the ill), and is best carried out by communities. Travel restrictions represent strong trade-offs in terms of people's liberties (and hence should be decided taking into account people's human rights) (Lor, Thomas, Barrett, Ortmann, and Herrera Guibert, 2016), and in terms of economic cost to livelihoods. Similarly, travel restrictions work best when they are managed and implemented by the local communities rather than imposed as mentioned above (Vaughan and Tinker, 2009). In sum, containment, isolation and social distancing can be effective, but there is a balance between positive outcomes (mitigating the spread) with negative outcomes (livelihood losses, human freedoms), and this balance has to be negotiated with communities, aiming for voluntary compliance rather than forced. In the contextual analysis it is important to understand who these local communities are, and how they are organised. Also determining who the relevant local authorities are and who manages what, especially in pandemic circumstances is paramount, looking at power relations.

Disruption of movement of people and produce without community involvement can have consequences beyond the epidemic, and if the political circumstances are volatile, they can lead to conflict. For example, the 1918 epidemic (together with smallpox) had a massive impact on Sierra Leone's inhabitants, due to the disruption of the movement of people, agricultural production and trade, sparking anticolonial sentiment and social resistance (Rashid, 2011).
Lessons Learned

In the case of SARS, public health measures successfully prevented the spread. This success can be attributed to the strict measures that were indeed implemented, but also due to the limiting nature of the strain, in which infection only occurred at very close contact, and through fomites rather than through inhalation. In China, once the outbreak was acknowledged and politically driven, a mass mobilisation of people engaged in non-pharmaceutical measures, a degree of social mobilisation that would be unlikely to occur elsewhere:

Driven by political zeal, they [local government officials] sealed off villages, apartment complexes and university campuses, quarantined tens of thousands of people, and set checkpoints to take temperatures .... In Guangdong, 80 million people were mobilised to clean houses and streets (People’s Daily, overseas edition, 1st May 2003).

In the countryside, virtually every village was on SARS alert, with roadside booths installed to examine all those entered or left’ (Huang, 2004). Local cultures of ‘collective consciousness’ will enable cooperation or resist such a strong response (Zhang and Pan, 2008).

Glass and Schoch-Spana (2002) highlight the importance of enlisting community support in the context of bioterrorism, events to which the authors draw parallels with influenza (Schoch-Spana, 2000). In their view it is important to understand ‘the public’ as a myriad of social networks the response can tap into:

Individuals are members of organisations and groups whose social ties, resources, communication links, and leadership structures might be used to facilitate a better and more coordinated response ... Examples of these networks include civic networks (e.g., churches, social clubs, and schools), occupational networks (e.g., businesses, labour unions, and professional organisations), and information networks (e.g., libraries and Internet chat rooms and bulletin boards). Each network can be thought of as a potential conduit for organising or facilitating public responses that are beneficial. For example, church groups might distribute antibiotics, convene vaccination meetings, or arrange visits to the homes of people who are ill. Social groups, such as the Kiwanis or Rotary Clubs, might activate phone trees to gather case reports, trace contacts, or disseminate instructions on appropriate use of medications. (Glass and Schoch-Spana, 2002: 219)

**Non-pharmaceutical measures decreasing contact with virus: hygiene and PPE**

Responders will need to assess the communities’ understanding of protective equipment, and their readiness and reluctance to engage in washing hands, wearing masks, and how they view disinfection and ventilation. As mentioned above, trust in the medical authorities, an awareness of the outbreak, and a sense of urgency and danger may encourage people to follow these measures (Funk et al., 2009), although it cannot be counted on. The relationship between people and the health authorities is key. Appropriate explanation of them needs to be made, as protective suits may create a barrier that ‘distances’ the medical responders from the patients and communities. Hygiene is crucial particularly in the case of hospitals and clinics, given that an important number of cases can be nosocomial. Due to the high transmission of flu, whenever possible giving people care in their own homes and communities (and not concentrating them in hospitals) should be prioritised.

Non-pharmaceutical measures are only part of the response, on their own ‘they will only slow the spread of the disease rather than contain it; and the response will ultimately become critically strained.’ (Capps and Lysaght, 2013: 112). Hence, in parallel there is a need of deployment of health measures and pharmaceutical responses (mainly vaccines and anti-virals). Further, non-pharmaceutical interventions require significant work in preparedness, as it is difficult to deploy them from a ‘standing start’ (Forster, 2012: 42)

**Recommendations for prevention:**

**Operational**

- Understand the existing cultural responses to epidemics present in the current context: some cultures will have traditional norms and practices to address high mortality epidemics, which can involve social isolation, movement controls and treatment. If these exist, understanding them in advance and building on them (in terms of the language used and justifying the initial public health measures) will mean a prompt positive
reaction by the community to the response. Use context analysis and rapid ethnographic analysis to identify these responses (see above)

- Similarly, understanding the communities’ models for epidemic illness, i.e. how people speak of an illness, its causality and transmission, its ‘cure’ and who the appropriate health provider is, will help in preparing for the response: identifying trusted people regarding health in the community, how alternative causal explanations of illness may be counter to public health measures (e.g. witchcraft), and how to design messaging that uses local categories and logics.

**Building capacity**

- The relationship between authorities and people is key. Travel and movement restrictions work best when they are managed and implemented by the local communities and institutions. These arrangements and relationships must be established beforehand in preparedness activities as well as during the response. The balance between positive outcomes (mitigating the spread) with negative outcomes (livelihood losses, human freedoms), must be negotiated with communities, aiming for voluntary rather than forced compliance.

- Enlist support of local institutions, social and community networks in the response, starting from the preparedness phase.

- Gauge the local meaning assigned to protective equipment and hygiene measures, and communicate transparently their purpose, to avoid mistrust.

**7. Health system response and treatment-seeking behaviours**

**The international response**

The successes of the 2009 H1N1 response were ‘the timely identification of the pathogen, the development of sensitive and specific diagnostics, and the creation of highly interactive networks of public health officials’ (Fineberg 2014). In his recommendations, Fineberg also advocates transparency with the public and the different response institutions in terms of the experts being consulted, and the potential links these experts have with the pharmaceutical industry. Fineberg implies that the lack of transparency of the WHO around these potential conflicts of interest, aimed at ‘shielding the experts from political or commercial influences’, instead generated mistrust and conspiracy theories (Fineberg 2014: 1340). Countries from the Global South questioned the ‘neutral’ role of the WHO and, on the ground, members of the public suspected that the conflict of interest meant that the risk to health was overstated by the authorities due to collusion with the pharmaceutical industry. Transparency around WHO’s and countries’ engagement with pharmaceutical companies can help mitigate these rumours.

These relationships between ‘experts’, national states and their relevant institutions, business and international organisations such as the WHO, are particularly important, and are mediated by their institutional cultures. Understanding these dynamics through the prism of political economy (exploring power and interests) and culture is key to understand why particular explanations of the epidemic are prioritised over others. In addition, understanding these dynamics may show leverage points to ensure collaboration rather than competition.

The International Health Regulations (IHR) emerged in 2005 and entered into force in 2007 in part as a response to the sometimes arbitrary imposition of trade and movement barriers erected in previous epidemics. It acknowledged the need for surveillance and early warning systems at a global level, and the need for support for countries in developing these capacities. It promoted national structures like the National Influenza Centres to circulate information about emerging illnesses. In addition to the IHR, the Pandemic
Influenza Preparedness Framework (PIP) ensures that, when developing countries share the virus strains for the creation of antivirals and vaccines, they in turn will have access to these products. These countries were concerned about pharmaceuticals making a profit whilst developing countries were handing them information. There was a concern that developing countries would not necessarily see the benefits (e.g. vaccines) derived from their contributions. For this reason, Indonesia refused to share H5N1 viruses in 2006 (Fidler and Gostin, 2011).

Media and donor interests are volatile and can have implications in sustaining the response. This problem was highlighted by the effect of ‘flu fatigue’ in which both media and donors moved away from the H5N1 epizootic, despite it not having finished. Even when funding was available, it wasn’t necessarily available at the onset of the epidemic (Fineberg 2014). The ‘flu fatigue’ arose in part because the H5N1 never turned into a pandemic, despite warnings in the media, and because the 2009 H1N1 pandemic had a lesser impact than initially predicted. The funding structure of emergency response was flawed in onset of the 2009 H1N1 pandemic, and it continues to be a problem. There are not enough funds to deal with endemic diseases or a surge capacity to react to epidemics when they emerge, and the flows are too linked to ‘donor visibility’. By the end of 2018, media concern and funding were at their lowest for ten years, despite the threat being greater: with more poultry and pigs, larger human populations and movement, and more virus types in circulation (Forster, personal communication). One learning point from the 2009 H1N1 epidemic and the 2014-16 Ebola outbreak in West Africa was the creation of a WHO Contingency fund for public health emergencies (CFE)\(^4\). This is a flexible funding instrument – not earmarked to any particular interventions – that can be mobilised in 24 hours. There is a similar need for a ‘ready reserve of public health experts’ in case an epidemic occurs (ibid: 1341). WHO’s Health Emergency Programme, GOARN and many response offices from State and UN agencies are addressing this need. Incorporating social scientists in these reserves will allow for contextual knowledge and inquiry being deployed from the onset of an outbreak.

Resilience of human health systems

As mentioned in the surveillance section above, access to quality health care is a key determining factor in mortality in flu epidemics. This is particularly lacking in developing countries, where health systems do not have the capacity to deliver symptomatic treatment, antivirals, and vaccination as readily as in OECD countries. This is why it is expected that, like in the case of 2009 H1N1, the next influenza pandemic will ‘overwhelmingly’ effect the developing world (Murray, Lopez, Chin, Feehan, and Hill, 2006). Poverty and fiscal disciplining as a result of structural adjustment policies has meant underfunding of health systems, limiting their capacity to react to a surge in influenza patients: in many developing countries, there are insufficient clinics, beds, ambulances and staff necessary to care for victims of the next pandemic.

This lack of surge capacity applies to the Global North as well, as health budgets are constrained in austerity programmes. Influenza cases come in waves, with peaks and troughs in caseloads for health services. This means at peak times there is a high number of patients and mass casualties in a short period of time. In the US during the 1918 pandemic, ‘most influenza cases and deaths happened over 3-4 weeks in autumn 1918, crippling the health system’ (Schoch-Spana, 2000). One important response is to try and move cases away from the peaks and into the troughs. In the 1918 H1N1 pandemic in the US, the influenza hit one-third of doctors and even more nurses, as well as other nursing, hospital and pharmacy staff, undermining the capacity of the system to deal with the influx of patients (ibid). The inadequate surge capacity for beds and hospital staff was also evident in the 2009 H1N1 pandemic. The geography of the spread was also important in shaping the caseloads, some places were hit before others, or patients were moved from some more bio-contained areas to less affected areas (Paul Forster, personal communication). For example, in the 2009 H1N1 pandemic a patient was moved from the UK to Sweden for treatment for extracorporeal oxygenation.

\(^4\) The CFE is so far underfunded, with donations reaching US$ 23 million whilst the WHO funding target for the fund is US$ 100 million.
**Biomedical response as a social response**

The high morbidity and mortality amongst nurses, doctors and other care workers means that their perceptions of the event, its transmission mechanisms and care available are crucial. In some US cities during the 1918 H1N1 pandemic, doctors and nurses fled the area with their patients (Hewlett and Hewlett, 2008), in others, they refused to go to work, and in others they remained in their posts (Schoch-Spana, 2000). There is a need to seek their own understanding of the disease and transmission, as this may differ from that of epidemiologists. Furthermore, carers might need some extra health assurance, so that they perceive that they are conducting their work as safely as possible. Personal and professional recognition, support from other teams and access to counselling are relevant to encourage nurses caring for H1N1 flu patients (Honey and Wang Wendy, 2013). Note that carers and surviving patients might be stigmatised or scapegoated for having played a role in spreading the disease. This scapegoating can happen at the level of a social group if there have been many cases in its population (Hewlett and Hewlett, 2008: 138).

The health response in a pandemic is a product of diverse institutions working together: Ministry of Health, hospitals, regional and local government, the CDC-equivalent institutions, and so on. As we saw in the surveillance above, these different institutions have different interests, objectives and constituencies, different agendas and worldviews. It is important to unpack the different power relations in order to ensure that the different incentives are aligned.

**Non-medical providers**

As mentioned in the section on surveillance, there are many countries in which biomedicine is not the only health provider. In these pluralistic health systems, biomedicine coexists with home remedies, herbal and faith healers, private doctors, pharmacy shopkeepers, and so on. There is scope for the response to work with alternative providers, sharing health knowledge (for example ways to avoid contagion) and together creating mechanisms for referrals to biomedical clinics when relevant. It is important to note here that the reliance on an alternative health provider does not necessarily mean that they refuse to seek biomedical help, people often are able to use both providers (Hewlett and Hewlett, 2008).

**Triage and hospitalisation**

The use of protective gear, processes of triage, the use of isolation chambers and respirators may create a barrier with the community. The need for sequestration of patients, if there is little trust in the authorities, may lead to resistance and avoidance, with rumours and conspiracy theories around treatment and the ultimate objectives of the epidemic response. As mentioned above, communication and community participation may mitigate these misunderstandings, and there is potential for the non-critical cases to be managed through community health provision.

When people do indeed attend hospital, when resources are scarce, such as in the case of ventilated beds in intensive care units (as in the case of vaccines below), there is a potential of misunderstanding about what the criteria for prioritisation are.

**Absenteeism and public services**

Doomsday scenarios fear that flu can lead to a social breakdown in which absenteeism translates into lack of delivery of essential public services (water, electricity, policing, etc.). Whilst it is true that the illness will leave public sector workers temporarily at home, there is evidence that people in crisis are more likely to cooperate and work together than to panic (Glass and Schoch-Spana, 2002). Absenteeism is directly correlated with the quality of information people receive: absenteeism was very high in the US 1918 pandemic because of the lack of information (Barry, 2009).
Recommendations for health-seeking behaviours:

Operational

- Give healthcare workers a chance to share their understandings of the epidemic and discuss and assess how it may differ from epidemiological assessments. Create a safe and supportive work environment, with recognition of risks and carer’s practical expertise.
- Ensure messaging counters potential scapegoating of medical and care staff.
- Identify trusted institutions and individuals to communicate health messaging.
- Work with alternative health providers, sharing health knowledge (for example ways to avoid contagion) and establishing mechanisms for referrals to bio-medical clinics.
- Assess what connotations personal protective equipment, triage and hospitalisation measures have to the public, and work with communities to explain processes and get their input into design. There should be transparency of criteria to access scarce resources (e.g. ventilation beds).
- Support community-based and home patient care in non-critical patients to mitigate overburdening of health facilities. This involves triage systems to keep low-risk patients at home, the provision of vaccine and antiviral packages, and linkages to social care institutions and community organisations to provide food and help when necessary.

Building capacity

- The relationship between experts, national governments and their respective institutions (e.g. Ministry of Health, CDC-equivalent and so on), as well as their regional counterparts is crucial for rapid response and relationships should be established in advance, and are now actively encouraged by the response. An understanding of the underlying political economy (incentives, strategies and constituencies) can serve to align incentives for best outcomes. In advance, consider political economy of relations between these institutions and civil society. ‘Alignment’ can consist on facilitating exchanges and coordination meetings, and communicating each other’s activities and priorities through briefings and reports in surveillance and during the response.
- Ensure procedures and communications channels of different human, animal and environmental institutions are established beforehand as part of a One Health response and ensure these processes could adapt to severe absenteeism (up to 10 percent-25 percent) due to illness
- Ensure that the procedures for global pandemic response do not discriminate against low-income countries e.g. access to vaccines.
- Assess the surge capacity of local health services (beds, equipment, ambulances, staff, and so on).

8. Antiviral and vaccine rollout

Antivirals

Antivirals today only have a very limited health impact: they need to be taken early in the onset of the disease; they do not prevent the disease, but rather reduce the number of days in which people have symptoms (van Essen, Openshaw, Myles, Monto, and van der Vries, 2015). It is mostly recommended for those patients such as infants or the elderly. In the case of the 2009 H1N1 pandemic, the response was too slow, and when the antivirals arrived, they were too late (Donaldson et al., 2009). The rollout of antivirals was caught up in theories about collusion with pharmaceutical companies and US elites, with doubts about their effectiveness and relevance.

Vaccination

Vaccination will be the main weapon against the next big flu epidemic, together with communication (Barry, 2009). The story of the H1N1 2009 flu vaccine is one of success and failure. Success because ‘32 days after the WHO had declared a public health emergency of international concern, the first candidate re-assortant
vaccine viruses were developed, and vaccine seed strains and control reagents were made available within a few weeks’ (Fineberg 2014), and this was achieved through international collaboration of experts. Yet it was a failure in the rollout: even in the advanced Global North, for example in the UK it arrived 3 months after the first peak and 1 month after the second one (Forster, 2012). The distribution of 78 million vaccines came too late: the time delay occurred due to in-ovo production (which takes months) and logistical problems, ‘including lack of willingness of Northern countries and manufacturers to donate vaccines to the Global South, legal barriers to approve imports and local capacities for transport, storage and administration’ (Fineberg 2014: 1340). Unless a major breakthrough is achieved in shortening the vaccination incubation time, or creating a cross-strain influenza vaccine (an unlikely scenario), the working assumption is that we must plan the response as if there were no vaccine available immediately.

In addition, some countries received the vaccines earlier than others did. The unequal distribution of vaccines in the 2009 epidemic deepened the chasm between developing countries and developed countries in terms of sharing virus strains and participating in the benefits, and led to the creation of the Pandemic Influenza Preparedness framework (Fidler and Gostin, 2011). In return for countries sharing biological materials, the pharmaceutical industry would need to pay half of the GISRSs's annual costs and donate vaccines in case of an epidemic.

What is significant from a social science point of view are the institutional relationships between researchers (national and international) identifying viruses and identifying potential vaccines.

Vaccination is one of the most controversial pharmaceutical responses that can meet resistance by communities. They involve people getting injections or oral droplets, on occasion they have side-effects (e.g. a mild version of the disease), and people perceive them differently to other drugs. This is particularly so in those contexts shaped by previous historical experiences of coercive vaccination campaigns. Colonial vaccination campaigns in many parts of Africa and Asia ‘relied on compulsion and coercion, sometimes orchestrated and enforced by military troops’. Similar strategies happened in early postcolonial times in Africa, with the WHO and national governments enforcing smallpox vaccination (Fairhead and Leach, 2012). A distrust of vaccinations is also emerging in the Global North with the emergence of the anti-vax movement. Mistrust of vaccines is inevitably embedded in a broader sense of trust of medical and State authorities. Furthermore, different social groups within a same context will have different attitudes towards vaccination, and different logics about what vaccination does, and the risks assigned to them (ibid.). Understanding people’s attitudes towards and meanings attributed to vaccination will give insights on how they would react to an emergency pandemic flu vaccination campaign.

For example, in the 2009 H1N1 pandemic, many people did not seek vaccination despite being given the opportunity. In Western Australia, pregnant women were prioritised but only 10 percent of women were vaccinated, and only 15 percent among other adults. In the UK, 80 percent of people chose not to be vaccinated. In these cases, low uptake was often due to people’s perceptions that the disease was mild or that they would not be at risk, or concerns about its vaccine safety (Forster, 2012). The demand for these vaccines is crucial, and relies on a longstanding trust in the health authorities and other State institutions. Even if the pharmaceutical industry is able to roll out the vaccine in a timely fashion, there needs to be a more accurate perception of risk amongst citizens (Forster, 2012). Seasonal vaccine uptake can be an indicator of people’s ambivalence towards influenza vaccines (ibid.).

When vaccines are rolled out in an emergency, and initially there is a relative scarcity of them, it is important to establish who is prioritised, and under what criteria, and communicate this effectively, as it might risk rumours about inequalities and discrimination. There will be vaccine demand of those who are not in priority groups. There will also be vaccine hesitancy when the new vaccine is recommended for children and pregnant women, which generates confusion since some people may think these people would be adversely affected by it. As such, clear communications on who can be vaccinated, what it entails, what the risks are, and so on must be clearly communicated. Further, timely provision of vaccines (as well as antivirals) is crucial to maintain public trust in the response.
Recommendations for antiviral and vaccine rollout:

**Operational**
- Identify local understandings of immunity/strength and how they fit with local models of disease (biomedical, humoral, herbalist, and so on): work within local rationales of strength and healing to promote vaccination.
- Communicate the benefits and risks associated with vaccination adapted to the cultural models of disease.
- Be transparent about the roll-out of vaccines and the criteria for prioritisation.
- Communicate the benefits and risks associated with vaccination adapted to the cultural models of disease.
- Be transparent about the relationship between WHO, national governments and pharmaceutical industry, making the participation of industry experts in the different stages of the response public, and sharing publicly the agreements made with industry in terms of vaccine and anti-viral development and purchase by health systems.

**Building capacity**
- Identify the cultural politics of researchers (international and national) in the identification of viruses, selection of strains and the creation of vaccines to understand what drives research and the impact it may have (e.g. Global North-South divide).
- Understand historical and current resistance (or trust) in vaccination and different social groups’ attitudes to vaccination.

9. Increased death rates and impact on burial practices

A flu pandemic can entail mass mortality in a short period of time. In the 1918 H1N1 pandemic, funeral systems were unprepared for the rise in bodies that had to be laid to rest. In the US, coffins ran scarce and were all used eventually. Mortuaries were over capacity, with hundreds of bodies piled up. Undertakers themselves fell ill, and were unable to bury the bodies. It reached such a critical situation in which bodies stayed for days and weeks in the homes where they had died, or illegal burials by family members were conducted (Barry, 2009). In some cities, mass graves were prepared, people were buried without caskets, which, to many, felt like the ‘sense of propriety’ had been undermined (Schoch-Spana, 2000). Mourners also resented the swift removal of bodies, without guarantees of a ‘proper’ funeral. Building the capacity of local funeral systems to respond to high mortality is important.

Care of the dead is a very meaningful event in all cultures, and hence it needs to incorporate the mourners’ and the communities’ needs in the transition, as well as the public health goals of containing the spread. Unlike other diseases (such as Ebola), influenza is not infectious by contact with a dead body. In the case of a pandemic, there might be added requirements for the disposal of bodies of influenza victims. In this case, a successful public health measure would be to integrate public health inputs into the broad spiritual ritual (e.g. in cultures in which body washing is practiced, getting family members preparing the body to wear protective equipment and use disinfectant), and in the cases where practices have to be shifted, to reach these as a dialogue and agreement with the communities rather than an imposition. It is important that this dialogue with religious institutions and civil society occurs in advance of the pandemic. Materials and protocols would need to be developed and tested in advance.

Mass congregations of people in funerals are a source of contagion of influenza. There is a need for a dialogue in advance between mourners, funeral homes/undertakers and communities to find alternative ways of honouring the dead (e.g. only having a small number of people).

**Recommendations for preparedness:**
- Gauge the surge capacity of funeral systems and build capacity to mobilise staff, and to obtain culturally relevant assets or items: e.g. caskets (or equivalent), burial space, etc.
**Recommendations for response:**

- Work with communities to respectfully and in culturally appropriate ways incorporate public health priorities into existing funerary rituals.

- In those communities in which funerals entail a large congregation of people, work with faith leaders, funeral providers and mourners to find alternative forms of honouring their dead (e.g. smaller number of people).

**10. Reconfiguration of virus, subsequent waves and post-epidemic**

**New waves**

Influenza is a constantly changing virus, and during an epidemic, it may mutate (particularly strains may be more changeable than others). In any flu epidemic, there may be several waves. For example, the 1918 H1N1 pandemic had four waves, yet certain potential explanations exist: the timing of school vacations, mutations of the virus, the split of the outbreak into two (or more) distinct subpopulations, re-infection due to virus changes or loss of immunity after convalescence (Mummert, Weiss, Long, Amigó, and Wan, 2013). What is important here is that populations who succeed through non-pharmaceutical measures (social distancing and so on) to mitigate contagion in one wave may be susceptible to subsequent waves. That said, the introduction of measures early on in an epidemic achieve ‘moderate but significant reductions in overall mortality. Larger reductions in peak mortality were achieved by extending the epidemic for longer.’ (Bootsma and Ferguson, 2007: 7591)

**New communication goals**

People’s attitudes towards and knowledge of epidemics are not static, they shift with the epidemic as communities interact with the responders and experience the disease. Thus, there will be changes in the public perceptions of transmission, symptoms and treatment-seeking behaviours. The local models of disease are also constantly evolving and hence will incorporate the social changes and biocultural insights that emerge through the epidemic.

Hence, shifts will also occur in terms of public and community reactions towards the epidemic response, with further potential avenues for collaboration or resistance, the development or rumours, or fatigue, when despite cases still emerging, people or institutions disengage.

Hewlett and Hewlett have highlighted the stigma that many may suffer even after the height of the epidemic is over in the case of a high mortality epidemic event (Hewlett and Hewlett, 2008). Survivors of the disease, nurses and carers, as well as members of affected populations can be accused of having transmitted the disease. In the case of the H1N1 2009 epidemic, Mexican immigrants were further marginalised as they were accused of being disease vectors (Schoch-Spana et al., 2010), or, as mentioned above, in Egypt Coptic Christian community discrimination was reinforced by the epidemic (Leach and Tadros, 2014).

**Recommendations for subsequent waves and post-epidemic:**

**Operational**

- Monitor changes in public perceptions of transmission, symptoms and treatment-seeking behaviours; as well as shifts in the indigenous cultural models of disease as a reaction to the pandemic.

- Assess how these changes impact people’s attitudes and understandings of the pandemic and the response, new narratives or rumours, as well as potential scapegoating or stigma, to redirect conversations with communities and appropriate messaging.
Lessons Learned

Pdy.


annurev-food-022510-133710


Carruth, L. (2014). Camel Milk, Amoxicillin, and a Prayer: Medical Pluralism and Medical Humanitarian Aid in the Somali Region of Ethiopia. Social Science and Medicine, 120: 405-412. doi:http://dx.doi.org/10.1016/j.socscimed.2014.03.007


References


Lessons Learned

About

The Social Science in Humanitarian Action Platform (SSHAP) aims to establish networks of social scientists with regional and subject expertise to rapidly provide insight, analysis and advice, tailored to demand and in accessible forms, to better design and implement emergency responses. SSHAP is a partnership between the Institute of Development Studies (IDS), the London School of Hygiene and Tropical Medicine (LSHTM), Anthrologica and UNICEF Communication for Development (C4D).

Social Science in Humanitarian Action
E info@socialscienceinaction.org W www.socialscienceinaction.org

This Lessons Learned paper is part of a portfolio on Social Science Lessons Learned in Epidemics and was supported by the Office of U.S. Foreign Disaster Assistance (OFDA) and UNICEF.

Credits

This SSHAP Lessons Learned report was produced by Santiago Ripolli and Annie Wilkinson from the Institute of Development Studies, University of Sussex. The authors thank Paul Forster, Melinda Frost, Aspen Hammond and Katelijn Vandermaele for reviewing this report.


This document has been funded by UNICEF and the U.S. Agency for International Development (USAID) Office of U.S. Foreign Disaster Assistance (OFDA). However, the views expressed herein are those of the author(s) and do not necessarily reflect those of USAID or OFDA, or the partners in the Social Science for Humanitarian Action Platform (SSHAP).

This is an Open Access paper distributed under the terms of the Creative Commons Attribution 4.0 International licence (CC BY), which permits unrestricted use, distribution, and reproduction in any medium, provided the original authors and source are credited and any modifications or adaptations are indicated. http://creativecommons.org/licenses/by/4.0/legalcode.

© SSHAP 2020