Lessons Learned Summary

Social Science Lessons Learned from Influenza and SARS

In this 'Social Science in Epidemics' series, different aspects of past disease outbreaks are reviewed in order to identify social science 'entry points' for emergency interventions and preparedness activities. This evidence will come together to determine tangible ways to better 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 SSHAP Lessons Learned Summary explores lessons about the social dimensions of past and recent influenza and SARS epidemics, highlighting recommendations for future responses.

People in Mexico City wear masks on a train due to the H1N1 outbreak throughout the surrounding region.
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1 Influenza and SARS pandemic viruses are more likely to emerge and spread in crowded animal (poultry and pig) and/or human environments.

Urban crowding, changing human and animal migratory patterns, human expansion into animal habitats and large-scale industrial animal production fuel the reconfiguration and spread of influenza viruses. Emergence of zoonotic influenza is driven by industrialised agricultural systems, particularly those operating in unindustrialised or industrialising regions. In order to respond

to the high potential for inter-species circulation (e.g. pigs to human as in the 2009 H1N1 pandemic, also called swine flu) a joint approach between animal and public health organisations is required. Increased capacity for joint holistic approaches addressing human, animal and environmental health (One Health) is necessary across respondent agencies, involving learning across the human, animal and ecological sciences, including social sciences. Urbanisation and densification is occurring rapidly in many parts of the world, but trends across and within cities vary widely. The form and extent of urban planning can influence health risks significantly. Policy approaches that ignore or attempt to stem urbanisation can lead to extensive informal expansion with poor disease control capacity (e.g. crowding, sanitation, service provision and governance). Public health and urban planning can be integrated to improve public health and make feasible plans to mitigate disease risks.

- 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.
- Support local authorities to consider disease transmission in their urban planning, and support contingency planning exercises to diagnose risks and make plans for disease control at both city-wide and neighbourhood level.
- Promote learning exchanges and real-time communication between animal and human influenza health workers involved in surveillance and response, as well as environmental and social scientists.

2 Farm size and intensity of production of pigs and poultry determine the risk of zoonotic influenza; control measures can have disproportionate impacts on lower-risk farms.

Different livelihood groups are impacted differently by control measures. For example, large-scale industrial farms may pose a higher risk of influenza (e.g. mutations, rapid transmission, higher caseloads) than non-intensive small-scale farms, but they are better able to survive trade and market bans or emergency biosecurity procedures. Small farms are more vulnerable to the negative consequences of control measures (e.g. loss of livestock and/or livelihoods). The response to the H5N1 epizootic (also called 'avian flu', which emerged in poultry in China in 1996, and in 2003, in the spread to other countries), transformed the poultry industry in Asia and put many small and backyard poultry producers out of business. As such, backyard, small, medium and large animal farmers (export-oriented and local market-oriented), wet market traders, meat abattoirs and the cutting industry will have different views on response measures and different degrees of political influence, and variable impacts should be considered.

- Identify and distinguish how different production methods are linked to enhanced influenza emergence, and how different livelihood groups will be impacted by prevention measures. Incorporate a diversity of farmers and producers into participatory processes to determine lines of action in mitigating threats and epidemic response.
- Enhance biosecurity of large and mid-sized farms in industrialising countries and explore biosecurity measures that are adapted to small-scale and backyard farming.

3 Surveillance systems can be strengthened by the inclusion of non-biomedical health providers and non-health inputs.

Private doctors, shop-owners of pharmaceutical products, herbalists, healers, etc. are often people's first port of call when sick. As such, these providers may be the first to perceive increases in patients with flu-like symptoms. As part of a 'One Health' surveillance approach, incorporating alternative providers into health information systems could assist to detect epidemics at an earlier stage. Community-based surveillance (CBS), and identification through internet searches, radio and mobile phone has proven useful in previous flu epidemics.

- Support surveillance networks in developing countries that expand beyond biomedical services to incorporate alternative health providers, non-health expertise and data, and community-based surveillance.

4 Surveillance systems must incorporate the fact that influenza and SARS involve a collection of symptoms that may be spoken of in different terms and categories depending on cultural backgrounds.

People may interpret and describe influenza or SARS symptoms in ways that differ from biomedical understanding (e.g. as humoral shifts, imbalances in the body heat). It is possible that each collection of symptoms (respiratory, digestive, nervous) may be attributed to different causes, including non-natural causes, and hence people may seek different health providers and treatments for these causes.

- Conduct an anthropological survey of different social groups to answer the questions below, and consider the implications for surveillance information systems:
  - 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 do how these relate to respiratory or other symptoms (neurological, etc.)?
- The above understandings are likely to develop throughout the epidemic. Monitoring of changes can be done through light-touch repeated surveys in health clinics.

5 The speed of transmission will vary with each strain, and this may contrast with local ideas of transmission

In particular, H5N1 influenza had limited human-to-human transmission, and SARS was harder to transmit than seasonal influenza (through inhaled droplets and fomites). H5N1 occurred amongst those who had been in contact with birds, and then the close contacts of these people (family members sharing the same room, nurses, carers, etc.). The 2009 H1N1 pandemic was, however, more efficient in human-to-human transmission, yet the public did not see it as a danger as many associated it with seasonal flu and believed the outbreak had been exaggerated by the authorities. With seasonal influenza, you have some immunity in the population, but with a new pandemic virus there is little to no immunity in the population.

Identify the efficacy of transmission of the virus and contrast it with local understandings of transmission and risk, and prior influenza outbreaks that may inform public views. Address misconceptions through communications, including noting if there are differences with prior experience.

6 Vulnerability to human influenza infection and mortality is shaped by biological and social-demographic factors.

When there is a species jump from poultry or pigs, those working closely with animals will be particularly vulnerable, such as workers on livestock farms. Differences in human impact arises as a combination of virus, host factors and access to health care. Vulnerability may depend on whether mortality is due to immune overreaction, as in the case of the Spanish flu, or due to the effect of the disease itself and its complications (e.g. pneumonia): in 1918, more young and healthy people died, whereas the victims of seasonal influenza are often infants, elder and immunocompromised. Influenza is a *syndemic*, it works in conjunction with other diseases – such as tuberculosis, smallpox, measles, pneumonic bacteria, HIV/AIDS and malnutrition – diseases that are much more prevalent in developing countries, explaining higher mortality rates. People with underlying chronic conditions – the very young and old, and pregnant women – are at high risk for severe outcomes. Due to economic and social marginalisation, low-income populations, ethnic minorities and indigenous people have been associated with higher death rates. Remote communities may escape or delay infection; yet remoteness may also mean that if infection happens, medical treatment is far away. Health staff and carers are more vulnerable to infections (not severity of outcome), and these tend to be gendered professions and activities.

- Identify vulnerable populations (occupational risks, the elderly, immunodepressed, infants, pregnant women) and enable initial isolation and swift symptomatic treatment in an outbreak.
- 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.
- Ensure there are resources for affected countries in the Global South to adequately respond simultaneously to influenza epidemics and to other concomitant illnesses.

7 Risk prevention messages should be based on shared values and delivered by trusted intermediaries.

Public health messages circulate in a broader network of information: peer to peer, SMS, social media and so on. These sources may offer different narratives about the epidemic. Trust in the health system and the response must be built over time; it is not a static property. Uptake of risk prevention recommendations has been highest when messages were delivered by trusted intermediaries and based on shared values and trust. Depending on the social group, different people will have trust and legitimacy; these people will need to be identified as they are crucial in making knowledge actionable. These brokers can be community leaders, faith-leaders, trusted people in media, education or work establishments, and so on.

- Identify trusted local intermediaries, looking beyond people with formal authority and leadership.
- Build trusted media relations and sources. ensure consistent and up-to-date messaging, and be transparent about past reporting mistakes.
- 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.

8 History and political relations may mean particular groups are at risk of stigmatisation in an influenza pandemic.

Power differences between different social groups may play out as stigma or scapegoating when an epidemic emerges. For example, Christian hog breeders in Egypt were stigmatised in the H1N1 flu epidemic in 2009. They were accused of harbouring disease and their hog farms were culled by the State even when epidemiological data did not support the measure.

- Understand how different social groups are characterised and differentiated locally (both by themselves and others), including the historical context to these identities.
- Identify and monitor power dynamics between social groups that 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).

9 Withholding information from the public is potentially very damaging.

When the public feel reporting is not accurate they will seek other sources of information and will lose trust in the response. In the 1918 H1N1 pandemic, silence by the US authorities translated into a distrust of the health systems, fuelling the epidemic and the search for non-biomedical explanations and alternative remedies. Links between the pharmaceutical industry and scientists involved in controlling the epidemic can fuel conspiracy theories and assumptions of vested interests when the public perceive they are not appropriately disclosed. In the 2009 H1N1 pandemic, the neutrality of the World Health Organization (WHO) was questioned when people thought the risk had been overstated for the benefit of drug manufacturers who stood to gain from medicine stockpiling.

- Be transparent about what is known about the epidemic and be open about limitations of data.
- Institutions like national governments or the WHO must be transparent about their engagement with 'experts' and the pharmaceutical industry to explain how they deal with conflicts of interest.

10 Voluntary approaches are preferable to coercive approaches when seeking compliance to movement restrictions, quarantining and social distancing.

Coercive movement and trade restrictions, as well as forced social distancing may infringe on individual freedoms and undermine livelihoods, and may be met with resistance. The effectiveness of these non-therapeutical prevention measures depends on the ease of transmission, and in general, worked better with SARS and the 2003 H5N1 in humans than with the airborne 1918 and 2009 H1N1 pandemics. Travel restrictions and quarantining 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 H1N1 pandemic, control of movement of people in between communities mitigated the spread. In the US, cities that implemented school closure, cancellation of public gatherings, isolation and quarantine, mitigated mortality. When communities have been engaged and are well informed, they have shown willingness to take a leading role in preventative measures and to comply

voluntarily. Local authorities and civil society organisations can play a role in implementing these measures. Enlisting community support through social networks is important; churches, social clubs, schools, labour unions, professional organisations, and so on can take responsibility for prevention and home care activities.

- Travel restrictions work best when they are managed and implemented by local communities and institutions. The balance between positive outcomes (mitigating the spread) with negative outcomes (livelihood losses, human freedoms) must be negotiated with communities during preparedness and in the response, aiming for voluntary rather than forced compliance.
- Enlist support of local institutions, social and community networks in advance and during the response.

11 People may seek treatment for influenza or SARS from alternative health providers.

Affected populations in previous influenza outbreaks sought treatment from alternative health providers as well as from health clinics. They did so for a number of reasons (e.g. trust, cost, belief in different models of disease, distance to health clinics, personal relations and preference). In pluralistic health systems, biomedicine coexists with home remedies, herbal and faith healers, private doctors, pharmacy shopkeepers, and so on.

- Work with alternative health providers, sharing health knowledge (e.g. ways to avoid contagion) and together establishing mechanisms for referrals to bio-medical clinics.

12 Systems of triage, hospitalisation and resource allocation need to be transparent.

The use of protective gear, triage processes, the use of tents and isolation chambers and respirators may create a barrier with the community. The need for sequestration of patients may lead to resistance and avoidance, with rumours and conspiracy theories around treatment and the ultimate objectives of the epidemic response. When people do indeed attend hospital, influenza-specific resources (e.g. ventilated beds in intensive care units) may be scarce. This may generate misunderstandings about what criteria are used to prioritise some patients over others. The mechanisms for resource allocation, when they are not transparent, can potentially create mistrust, anxiety and rumours of mismanagement.

- 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 if available, and linkages to social care institutions and community organisations to provide food and help when necessary.

13 The experiences of health staff need to be carefully considered.

Nurses and care staff will have understandings and approaches towards the disease that are rooted in their professional experience and that may contrast with epidemiological assessments. Staff may have a different perception of risk of getting infected and different degrees of trust in the systems and procedures to care for influenza patients. As a group who risk their lives and work under pressure, they need support and empathy. It is possible to alienate care staff if their views and experiences are dismissed or not engaged by seniors or authorities. In the US during the 1918 flu, many healthcare workers fled the cities with their patients when such support was not forthcoming. Medical staff are also at risk of stigmatisation.

- Give healthcare workers a chance to share their understandings of the epidemic, 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.

14 Prepare mortuary and funerary providers for mass mortality and ensure burial practices reconcile public health concerns with the social and emotional needs of communities.

Cultural practices of preparing and disposing of bodies may contrast with public health priorities. This is particularly critical in high mortality scenarios with mass mortality in very short timeframes. Funerals can involve congregations of people and hence risk contagion of flu.

- 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.).
- 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).

15 Attitudes to vaccine safety and efficacy will vary and how vaccination is rolled out in a pandemic can heighten mistrust.

People's attitudes to vaccination and its associated risk varies widely between contexts and social groups. Cultural notions of strength and resistance to disease and how to achieve it are different (e.g. building up of blood in West African humoral medicine, or building up of immunity in the UK), and may contrast with biomedical rationales. Even under the biomedical paradigm, influenza vaccines in the 2009 H1N1 pandemic arrived too late and were perceived as less effective and riskier than non-vaccination (due to low mortality and prevalence of the disease). Also in the 2009 H1N1 pandemic, the role of the pharmaceutical industry in the response led to rumours about conflicts of interest and created scepticism about the need for

vaccination. When new vaccines are created, they have to be prioritised and rolled out at high speed, often with some groups prioritised over others. This can create rumours of mismanagement.

- Understand historical and current resistance (or trust) in vaccination and different social groups' attitudes to vaccination.
- 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 rollout of vaccines and the criteria for prioritisation.

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

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This SSHAP Lessons Learned Summary was produced by **Santiago Ripoll** and **Annie Wilkinson** from the Institute of Development Studies, University of Sussex.

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