

# The significance of Trust in Public Health Governance<sup>1</sup>

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Social science and medical research indicate that epidemics represent a major test of a society's governance effectiveness. If the current avian influenza outbreak becomes a human epidemic, we will be preparing for a third major health crisis. Fortunately, the analysis of successes and failures in the governance of HIV/AIDS and SARS offers an outstanding lesson in public health governance for nations around the world that hopefully will help us to be better prepared.

A person's perception of disease severity and of his/her own susceptibility to the disease help to shape the public image of HIV/AIDS and SARS. These two elements in turn help to explain the differing prevention effectiveness of the two diseases as I have discussed elsewhere (Quah 2007). In this brief paper I focus on another major factor in the governance of epidemics: the need to nurture public consensus or "collective informed consent" on the nature of the problem and the range of solutions available. I propose that the presence of collective informed consent is a crucial prerequisite for the successful governance of epidemics, and I explore four major factors that influence the presence of collective informed consent. The first and most immediate factor is the level of community's trust in the health authorities' expertise and integrity to solve health crises fairly and successfully. The three other factors influencing the community's level of trust are the transparency of state's actions and decision-making; the state's implementation of consensus-building by disseminating objective information on the nature of the problem, the available and recommended solutions, and incentives to facilitate preventive action; and the facilitation of community involvement in decision-making and crisis management.

These four factors must be present if the health authorities are to obtain collective informed consent and gain the corresponding cooperation from the community to address the epidemic promptly and effectively. These factors are dynamic and do not necessarily constitute a chain of events but, rather, a set of prerequisites. After considering the notion of collective informed consent, I discuss each of the four background factors separately, and then explain their impact on the successful governance of epidemics.

## Collective Informed Consent

According to internationally approved informed consent guidelines for clinical research, clear, complete, and unambiguous explanation of a given procedure—including its justification, benefits, and all known risks—must be given to the patient or human subject. Questions are encouraged, and answered. Once the patient/subject is satisfied with the information, then he/she is invited to participate and, if he/she accepts, to sign a consent form to proceed with the intervention or clinical trial, as the case may be.

In some instances, the clinical context of individual informed consent intersects with public health practice. For example, medical practitioners offer immunization and/or screening tests for an infectious disease, or bring these options to the attention of their patients. Prenatal HIV testing for pregnant women (Lo, Wolf, and Sengupta 2000) and routine HIV testing for other individuals also provide relevant illustrations of this intersection. Both situations tend to occur as practitioner-patient interactions in a private context, but it is widely acknowledged that patients' private decisions have significant public consequences for the management of the HIV/AIDS epidemic (Baldwin 2005, 287; D'Amelio et al. 2001, 7–11; United Nations 1985). Unfortunately, the concept of informed consent remains anchored in the

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doctor-patient encounter. If informed public choices are mentioned in the realm of public health, their discussion regularly focuses on the needs of decision-makers (Haines et al. 2004). For this reason I propose we consider the scope of informed consent at the wider, community level.

What is collective or community informed consent? The concept of community informed consent is different from individual informed consent in two ways. First, in community informed consent the subject is not one person but the entire community affected by the disease or disease threat. Community means the total population, involving persons affected by the disease (for example, persons living with HIV/AIDS, SARS patients), their immediate families and networks, and the rest of the population residing in the same political jurisdiction (city, municipality, county, state, province, or nation state) and enjoying autonomy in health policy decisions. So defined, the community should be treated as a collectivity of rational and autonomous individuals entitled to make decisions and weigh the benefits and risks of alternative solutions to their health problems or a health threat. The same requirements of informed consent mentioned earlier apply: clear, complete, and unambiguous explanations of the nature of the problem or health threat should be distributed; solutions, including their justification, benefits, and all known risks, should be suggested; and questions should be encouraged and answered. Second, community informed consent differs from individual informed consent in the manner in which the consent is taken. The process community informed consent includes an assessment of the community's level of information on the health threat or problem, of what is needed to solve it, and the level of agreement or consensus on what is needed to implement a proposed solution to the health threat.

To deal successfully with an infectious disease epidemic, health authorities need an informed and committed community as an active partner. Health authorities cannot deal with a crisis without the community's cooperation, regardless of the authorities' level of expertise, number of healthcare personnel, and the level of medical technology available. The seriousness of the crisis is compounded when health authorities fail to mobilize the indispensable cooperation from a community of uninformed, indifferent or, at worst, misinformed and hostile individuals or groups. In other words, the most immediate factor influencing the successful governance of an epidemic is the presence of community informed consent. Because the containment and preventive measures vary in each epidemic and the socioeconomic, cultural, and political contexts are constantly changing, collective informed consent must be obtained for each public health crisis.

### **The Challenge of Building Trust**

The discussion of trust has occupied philosophers and social scientists for a long time. Beyond the philosophical side of this idea are the stark implications of trusting or distrusting someone on whom you depend. The history of epidemics around the world is rich with instances of people in an affected community trusting—or distrusting—the state in general, or government officials, or health authorities, and the reasons to which they attribute this trust (or distrust). I propose that trust is a precondition to informed consent, and that in the context of public health, the level of trust the community places in the health authorities influences the likelihood of granting informed consent. Put differently, it is reasonable to assume that you would consent to undergo a medical procedure, intervention, or action provided that you understood the problem (threat or danger) and the solution intellectually, and trusted the people who informed you and who would work on the solution. Trust has a socio-emotional side represented in social norms that suggest who is or is not trustworthy. Trust also has a rational side that involves the calculation of risk (however subjective) and benefits we face when trusting someone (Wuthnow, 2004:148).

Both the socio-emotional sphere and the rational sphere of trust are relevant in the analysis of what influences the presence of informed consent required to manage epidemics successfully. These two spheres point to the importance of the social context, in which trust may exist or be impeded. Wuthnow (2004, 154) identifies ten reasons—or “warrants”—for why A may trust B: *sincerity* whereby “A is persuaded” of the sincerity of B. Applying Wuthnow’s trust “warrants” to the matter of epidemics we may

ask: Why should members of a community trust their health authorities? Research findings based on direct data (Quah and Lee 2004; Quah 2006) and indirect and historical data (Barry 2004, 448–61; Rollins 2004; Kleinman and Watso 2006; Lee and Yun 2006; Zhang 2006) suggest that of the ten warrants outlined by Wuthnow, nine are directly relevant to the presence of community consensus and cooperation (informed consent) in a public health crises. People in the target community tend to trust (or distrust) the government and/or health authorities based on their perception of the government's sincerity, empathy, affinity, altruism, accessibility, effectiveness, competence, fairness, and reliability.

Citizens' perception of these attributes on the part of the government (or government agencies, or officials) are shaped primarily by citizens' make observations of and experience with government's past behavior and actions (Hardin, 2002:153-156). Sociological research demonstrates that trust is embedded in the community's values and norms (Hardin 2004; Wuthnow 2005; Tilly 2005). But time is crucial. Psychological and sociological studies show that building trust is a slow process: the bricks of the trust edifice are the accumulated positive interactions among the individuals concerned over a period of time (Murnighan, Malhotra and Weber 2004, 294). The level of trust may increase with time, "as each additional positive interaction becomes more valuable in establishing mutual trust" (2004, 294). The history of the interaction or relationship is also important. Consequently, the community's warrants for trust in their government and health authorities need to be nurtured and strengthened over time—well before a health crisis strikes. The HIV/AIDS and SARS epidemics have brought to light this simple but important principle (Merson 2000, S159). In the case of SARS, the initial reaction to the outbreak, both among health authorities and the public, differed markedly from country to country: there are indications that governance effectiveness in controlling the outbreak differed across countries in tandem with a given country's governance style and a given community's level of trust in their health authorities (Zhao 2003; Quah and Lee 2004; Fidler 2004b; Chiu and Galbraith 2004; Kleinman and Lee 2006).

### **Transparency in State Actions and Decision-making**

The discussion of trust raises three factors that contribute to the building of warrants for trust: transparency in state's actions and decision-making, implementation of consensus-building mechanisms, and facilitation of community's involvement in crisis resolution. The building of warrants for trust depends, among other things, on transparency in the state's actions and decision-making. Transparency is important in normal times, but it becomes crucial in times of crisis. In the case of an infectious disease epidemic, distribution of information on the disease and rapid response are vital for the effective prevention and containment of the disease. With the current speed of transmission of infectious diseases such as HIV/AIDS and SARS, and the heavy toll that epidemics inflict on individuals and communities, timely and effective distribution of information on infectious disease outbreaks is needed to improve the global disease monitoring capabilities recommended by the United Nations (UN) (United Nations 2004, 29–31; Fidler 2004a, 801; Gostin 2004).

The need for transparency and, specifically, for global reporting guidelines is well understood and generally accepted by most UN member nations (Sim and Mackie 2006; Olowokure and Roth 2006; Shaw 2006). But the implementation of collaborative guidelines is less than ideal, even among modern industrialized countries. The European Community, for example, is still fine-tuning a system of collaboration in global case reporting and there is hope that the European Centre for Communicable Diseases will provide the answer; a similar situation is found in the United Kingdom (Goddard et al. 2006). The slow pace of implementing transparency measures is problematic but not as serious as the problem of complete secrecy. Regrettably, historical and current events suggest that—until a problem is verified, until a solution or way of controlling the danger is found, or until it becomes politically appropriate to reveal it—secrecy or concealment tend to be the most common impulse of officials who discover a potential danger. Indeed, concealing a threat or danger has been justified in many ways. For example, it has been cited as an effort to protect the community, to avoid panic, to keep the bad news from enemies or competitors, or to maintain for as long as possible the normal pace of work of those affected (Barry 2004, 169–75; Garrett 2005). In some countries, concealing disease outbreaks may be

actually mandated. In addition, state secrecy confounds and interrupts the lives of individual members of the community facing a health crisis. State secrecy in a health crisis not only impedes a rapid and effective response to epidemics but also breeds, at best, misinformation, and at worst, panic among individuals and families. Without accurate information on what is happening and why, people activate their informal networks in whatever way possible, face-to-face, by telephone, through mobile phone text messages, and email. People who can avoid or overcome panic resort to their traditional ways of thinking and of doing things, including traditional healing practices. During the SARS outbreak in Guangzhou, Hong Kong, and Taiwan, for example, rumors of disaster circulated, fast creating panic buying of traditional remedies like herbal medicines to increase body strength, and white vinegar. Residents believed that boiling white vinegar in a room would prevent the disease by killing germs (SARS Expert Committee 2003, 13; Kaufman 2006, 65). Unfortunately, families used charcoal stoves to boil pots of vinegar inside closed rooms and this method led to cases of carbon monoxide poisoning (Abdullah et al. 2003, 1043). On the other hand, some traditional procedures people used in the absence of other guidelines may turn out to be useful. The traditional Chinese belief in the sterilizing properties of white vinegar has been confirmed by scientific research: white vinegar has sterilizing properties not when it is boiled but when added to diluted household bleach (Miner et al. 2006).

### **Consensus-building and Community Involvement**

The second and third factors associated with trust are the implementation of consensus-building mechanisms, and facilitation of the community's involvement in crisis resolution.

The consensus-building mechanisms I discuss here presuppose respect for citizenry and a commitment to share rather than to conceal information. State authorities need to concern themselves with consensus-building to bring all the different sectors of the community together as partners in the collective endeavor of conquering a common problem or threat, whether poverty, crime, addiction, or an infectious disease epidemic. For public health, three consensus-building mechanisms are necessary. First is the distribution of objective—that is, empirically verifiable—information on the problem, its nature, etiology, diagnosis, and prognosis. Second is the distribution of objective—again, empirically verifiable—information on the range of available solutions, and on the known benefits and risks of the recommended solutions. The key feature of these two types of information is that they *must* be empirically verifiable, which makes them the exact opposite of propaganda. Propaganda is the exercise in “mass suggestion or influence through ... the dexterous use of images, slogans and symbols that play on our prejudices and emotions” (Pratkanis and Aronson 2001, 11). History shows that opportunistic politicians and interest groups do not hesitate to use propaganda to take advantage of people's vulnerability during a health crisis (Barry 2004; Baldwin 2005). In contrast, in the battle against an epidemic, the goal is to educate the population on all known relevant aspects of the problem at hand, all possible solutions available, and the current limits of that knowledge.

These two first steps provide the community with complete and useful information on the problem and on what the community can do, collectively and individually, to solve the problem. As discussed earlier, information sharing in a transparent and verifiable manner is conducive to creating and strengthening trust. However, research findings indicate that information alone is insufficient to motivate preventive behavior (Gochman 1997; Quah 1985, 1988; Quah and Lee 2004). Thus, a third step is necessary: to identify and introduce incentives to practice preventive action. This third consensus-building mechanism is indispensable, because in the prevention of infectious disease epidemics it is crucial to ensure that all members of the affected community follow the recommended preventive actions. Like all infectious disease epidemics, SARS showed us clearly that one individual's actions may be enough to spread the disease to unsuspecting communities.

When the problem or crisis is sufficiently serious—to the point of threatening life and limb—the desire for safety becomes the built-in incentive to follow a recommended course of action that is believed to be effective. This desire for safety works as an incentive if two of the warrants for trust (Wuthnow 2004) are present: effectiveness and competence. The belief in the health authorities' effectiveness means the

community regards health authorities as capable of getting the job done or achieving the desired results, and believes that the government has the required resources to deal with the crisis and is able to mobilize them. The belief in the health authorities' competence means the community perceives the health authorities as having appropriate training, information, skills, and talents to control the crisis and protect the population.

To facilitate community's cooperation and involvement, the state must not only share information but also create diverse channels of communication. But effective communication must be a two-way system, rather than a top-down transmission of directives. Community feedback and queries from individuals, groups, associations and other sectors of civil society are crucial elements in the health authorities' search for solutions to the crisis and in its effective implementation of those solutions.

### **In conclusion**

The *sine qua non* of successful crisis governance is the groundwork that is laid before the crisis. My research indicates that the same requirement applies to the successful management of health crises (for example infectious disease epidemics) by the state and its citizens. I propose that community involvement, transparency, consensus-building, and efforts at strengthening trust constitute the groundwork needed to create prompt and effective responses to a crisis.. These features take time to build. Crises are likely to cause more harm and take longer to resolve in countries where the spectrum of factors needed for successful governance (collective informed consent, transparency, procedures for consensus-building mechanisms, and the warrants for trust) is weak or not present when the crisis strikes.

The governance of SARS in some Asian countries illustrates the importance of preliminary groundwork. For example, community involvement and the three consensus-building mechanisms were already present in Singapore before SARS struck (Quah and Lee 2004). Many countries affected by the SARS outbreak could not respond in the same systematic manner. As the SARS outbreak developed and spread to other countries, a process of learning by doing began to take place. Hopefully, today we are wiser from the experience, but future epidemics may find some countries still unprepared. Without the crucial factors of effective channels for community participation in decision-making, transparency, effective democratic mechanisms of consensus-building, warrants for citizens' trust in the health authorities, and collective informed consent, the prospect of successful governance of health crises remains uncertain.

Some of the actions taking place in countries currently battling the avian influenza outbreak among fowl give cause for optimism. One of the actions, for example, is to provide public announcements on what authorities are doing about the disease (Chou 2005), such as setting up emergency surveillance arrangements. Such regular publicity keeps the topic in the media and ensures that people remain alert to the problem. Nevertheless, there are also indications that the groundwork for successful governance of future epidemics has not begun in some countries and that very few have learned from the SARS experience. The manner in which the culling of birds and poultry is being planned and implemented to avoid the Avian flu epidemic indicates that the lessons from SARS on the importance of collective informed consent have not been learned. The task is multiple and challenging: to reach farmers (usually poorly educated) in remote rural areas, to communicate to them the seriousness of the disease and the necessity of bird culling—which typically terminates their main source of income—and to provide real incentives for their cooperation. However, in many affected countries the health authorities apparently have concentrated their energies on the logistics of bird slaughtering (transport of slaughtering equipment, personnel, paraphernalia, and the like) but have neglected or paid less attention to informing the farmers of the etiology, diagnosis, and prognosis of the epidemic affecting their flocks and, particularly, to explaining the nature, justification, and effectiveness of culling as preventive action. Not surprisingly, farmers have protested and failed to cooperate. Some have even tried to salvage their source of livelihood by hiding their ducks and chickens from inspectors (Farmani 2006; Cheviron 2006; Ingham 2006; Rompress 2005; Chiriac 2005; Akhaine et al. 2006). The affected farmers are naturally

anxious and wary of health inspectors, unwilling to trust government officials from far away cities. In the farmers' eyes, most officials know nothing about farming and do not care about what happens to farmers.

Finally, then, in addition to the factors needed to create informed consent, the governance of a health crisis or epidemic must include effective international and national coordination. The international or global governance of infectious diseases is particularly crucial for global cities like Hong Kong and Singapore. Equally important are national governments' arrangements to adapt internal procedures and personnel and shift their civil service and health care systems into a crisis management mode. Such internal arrangements will vary across countries, given differences in political system, political ideology, geographical constraints, and socio-economic context. Still, irrespective of these differences, three arrangements are likely to bear fruit in most countries. The first is the active coordination of ministries and other state agencies to share information, to deal with the problem in a synchronized fashion, and to respond to the crisis promptly and consistently. The second is to design a multi-pronged approach to the solution of the health crisis. No single solution is likely to be sufficient in combating an epidemic. A multi-pronged approach means rallying of significant sectors of society to cooperate—including, among others, scientists, professionals, security experts, university students, schools, the armed forces, religious groups, retired people, businesses, and nongovernmental organizations. This collaborative effort may be formalized by establishing one or more task forces entrusted with specific responsibilities. The third arrangement is begin by using existing legislation. Then, because each crisis or epidemic brings its own demands, health authorities must be prepared to introduce specifically designed regulations to deal with each crisis within the framework of collective informed consent. These three additional arrangements require, of course, constant fine-tuning, both in light of advances in technological and scientific knowledge, and changes in the demographic, socioeconomic, and cultural features of a given population.

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