

Public Health Response to Influenza A(H1N1) as an Opportunity to Build Public Trust

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IN JUNE 2009, THE WORLD HEALTH ORGANIZATION (WHO) declared the 2009 influenza A(H1N1) pandemic and in October 2009, President Obama declared it a national emergency.¹ The influenza A(H1N1) virus is being monitored around the world for changes in virulence or epidemiology. There has been a push to have vaccines ready, yet vaccine supply may be insufficient in some areas. The public wants to be assured that there is enough vaccine, but at the same time, some are questioning the safety and effectiveness of the vaccine. It is a time of uncertainty both for the public health community and for the public.

Times of uncertainty and risk are times when public trust is most needed. But trust is built long before the time that trust matters most. As the public weighs the perceived risks of the A(H1N1) virus against the perceived risks of vaccination, they are taking into account multiple, often conflicting, sources of current and historic information, as well as their own personal experiences. Questioning the safety of A(H1N1) vaccines is for some influenced by memories of the 1976 US swine flu alert, of the follow-up swine flu vaccination campaign and the ensuing cases of Guillain-Barré syndrome (GBS), and of a swine flu pandemic that never materialized. For others, questioning may come from memories of severe acute respiratory syndrome (SARS), which had severe but rapidly contained health effects; for others, questions may arise from warnings about avian influenza A(H5N1) and its continued pandemic threat. Perception of risk about A(H1N1) vaccination is also influenced by a broader environment of distrust and vocal antivaccine groups.

Questioning and mistrust of the measles-mumps-rubella (MMR) vaccine in the United Kingdom that began during the late 1990s was prompted by the claimed association between the MMR vaccine, bowel disease, and autism.² This claim came shortly after a loss of public trust around the government's lack of transparency and understating of the risks of bovine spongiform encephalopathy.³ Even after clear evidence emerged that these

claims about autism being related to vaccines were unfounded, historic levels of distrust, compounded by massive media coverage that amplified the unproven links between the MMR vaccine and bowel disease, played a role in contributing to lower vaccine coverage and consequent disease outbreaks.

In France, public trust in hepatitis B vaccine plummeted after the government's precautionary decision to stop the school vaccination program because of suspected, but not proven, links with multiple sclerosis, despite recommendations by WHO and French pediatricians to continue the program.⁴ This followed concerns over the French government's management of the human immunodeficiency virus (HIV)—contaminated blood crisis in the mid-1980s, and public opposition and rumors associating hepatitis B vaccines with not only multiple sclerosis but also autism and leukemia led to low levels of hepatitis B vaccination.⁵

In Nigeria, the mistrust and 2003-2004 boycott of the polio vaccination program by predominantly Muslim states in Northern Nigeria emerged at a time when false rumors of the safety of polio vaccine—linked to HIV, hormonal contamination, or both—weakened trust in global initiatives such as polio eradication. This followed a 1996 drug trial of an antibiotic for meningitis in Nigeria in which children died.⁶ Adding to the mistrust, repeated door-to-door polio vaccination campaigns are thought to have increased levels of suspicion in historically marginalized states. In these states, health services are inadequate, immunization coverage is lower than in the rest of the country, and communities questioned why other diseases, perceived by them to be more important, continued to be neglected. The loss of public confidence and vaccination boycott led to a resurgence of polio cases in Nigeria. The Nigerian virus spread to more than 12 neighboring countries that had been certified as polio-free⁷ and polio caused by the Nigerian strain was traced as far as Indonesia. Significant efforts have since been made at the community level in Northern Nigeria to build public

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confidence in the polio vaccination efforts. The vaccination uptake rates have increased, but the crisis could have been averted with a much earlier effort to engage communities and build trust in the areas where overall levels of mistrust were well known.

Lack of trust can cause health programs to fail with harmful consequences. Measles outbreaks in the United Kingdom and the United States and the spread of polio across Africa from Northern Nigeria underscore the importance of building—and maintaining—public trust in health interventions and in the authorities who provide them. Trust relationships must be built over time so that they become the social framework in which health interventions—and positive health outcomes—can thrive.

Transparency is an essential criteria for trust. The 2009 WHO guidance document *Pandemic Influenza Preparedness and Response*⁸ calls on affected countries to “maintain trust across all agencies and organizations and with the public through a commitment to transparency and credible actions.” Transparency includes being clear about what is unknown and what is known and requires clarity about the basis for decision making. Listening and taking into account what the public is thinking and saying—even though the public’s reactions may not be scientifically based—is critical to building trust relations. Trust is not a one-way relationship.⁹ Public perception affects individual choice and must be taken into account.

Building and maintaining trust is challenging in an environment and time when the public is wary and distrusting of institutions—and in the face of contradictory information on the Internet. The Centers for Disease Control and Prevention has put on its Web site a tag line, “Your Online Source for Credible Health Information.” New social media and the emergence of a postdeferral society are challenging traditional trusted sources of information. However, rather than becoming defensive in the face of an increasingly questioning public, the medical and public health communities must recognize the importance of changing the conversation with individual patients and the public and the importance of being open to hearing real concerns that will affect the acceptance or rejection of health services. The public health community must recognize that the realm of rumors and perceptions may include clues about reasons for concern.

The environmental risk communication literature can share many lessons on public trust with public health. One study on the determinants of trust¹⁰ identified 3 key elements: knowledge and expertise; openness and honesty;

and concern and care. It is not only the “what” that matters, but “who” is conveying the information or concerns and “how” it is communicated. Concern and care also implies listening.

Now is the time to consider the long-term implications of the current response to the influenza A(H1N1) virus. The experiences of the A(H1N1) pandemic will not be forgotten, but they will remain a factor in public trust the next time a public health threat or pending pandemic occurs.

Several approaches may contribute to longer-term public trust. For instance, while alerting the public to the real, although uncertain, risks of the A(H1N1) pandemic, the messages should not be sensationalized. Public health officials should listen genuinely to public concerns and questions because they can help to target where information is needed. It is important to educate and engage citizen advocates on the relative benefits and risks of the vaccine. Citizens listen to their peers as much, if not more, than health “experts.” Finally, it is essential to maintain perspective about other important health concerns of the public. These concerns will be present for the long term, well after the current influenza A(H1N1) pandemic has resolved.

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