

SYMPOSIUM

Talking to the Public about a Pandemic: Some Applications of the WHO Outbreak Communication Guidelines[‡]

Jody Lanard

Senior Advisor for Pandemic Communications, World Health Organization, Geneva, Switzerland; Risk Communication Consultant, The Peter Sandman Risk Communication Website, Princeton, New Jersey

A QUESTION AT THE START OF THE TALK

Introducing the symposium's communications panel, moderator Derek Yach asked us: Who is likely to be the leader in a pandemic in the United States? Dr. Yach's serious question was met by a wave of laughter from the audience; perhaps the absence of an obvious leader led to the laughter. I certainly didn't have an American name to offer. But here is the over-arching tech spec for such a leader: Before a pandemic begins, this leader will help the public grapple with, rather than avoid, the agonizing dilemmas involved in pandemic planning.

The Western public, when it pays attention to pre-pandemic news, often hears from two main categories of experts. Some experts stress the low odds of a severe pandemic (partly because we only really know about one pandemic as bad as the Spanish flu). Other experts stress the potential horrific magnitude of the next pandemic (partly because H5N1 avian influenza that jumps from poultry to people has a case fatality rate that is terrifying).

The public also hears from experts who give the impression (without exactly saying so) that a pandemic is imminent. Other experts more overtly state their reasons why a pandemic is unlikely any time soon.

It takes experts with unusual communication skills or instincts to convey both halves of both of those extremes: "This virus might become much milder if it becomes easily transmissible, or it could retain an unprecedented virulence." "This could start tomorrow, or not for decades."

It is very hard to help people hold this two-by-two table of ideas in mind at the same time — soon/distant, mild/catastrophic. On the one hand: Drop everything, and get ready for a Category 5 storm! On the other hand: Let's continue to beef up All Hazards planning and think about re-building public health capacity.

But to prepare rationally, we have to balance both of those emotionally and cognitively conflicting thoughts. So, future pandemic leaders will have to help us begin to hold the catastrophic possibility in our minds at the same time as the possibil-

To whom all correspondence should be addressed: Jody Lanard, jody@psandman.com.

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ity that it may never happen. If they help us balance and integrate this in advance, they will have a better chance at leading us if the pandemic comes — and a chance at keeping our respect if it never comes. That is what I would advise leaders to do — help people balance the conflicting and unknowable “what ifs,” and help people bear the anxiety that this will cause.

THE WHO OUTBREAK COMMUNICATION GUIDELINES

A year after the Severe Acute Respiratory Syndrome (SARS) outbreaks ended, the two of us [1] on this symposium’s communication panel helped the World Health Organization develop a draft framework for “outbreak communication guidelines.” After input and feedback from ministries of health and WHO officials from all over the world, the final guidelines were published early in 2005 — this lovely brochure [2]. It contains five main recommendations for good outbreak communication. I will mention three of the guidelines to raise questions about ethical aspects of pandemic preparedness: trust, transparency, and involving the public.

Trust, transparency, and candor are aspirational goals — we do not expect complete let-it-all-hang-out transparency from officials, and people rarely put blind trust in officials. Officials do wish that the public would trust them — often without showing much trust in the public in return and without being very transparent. I am going to address the less familiar side of this equation: agencies’ and governments’ lack of trust in their publics, and the clouded communication which this distrust generates.

TRUST, TRANSPARENCY, AND TAMIFLU STOCKPILING

Trust in the public, and transparent communication, have been sorely lacking with regard to Tamiflu stockpiling — an issue generating a wide range of medical

and ethical opinions, nearly all of them against personal stockpiling.

Many official and expert statements about personal Tamiflu stockpiling show various types of distrust of the public:

- Apparent distrust of the public’s ability to accept official decisions.
- Fear of involving the public in debate about government-mandated priority groups.
- And, all too often, overt contempt and disdain for the public’s intelligence and competence.

Here are some excerpts from WHO’s internal pandemic contingency plan [3]. You probably could have guessed that WHO has an internal pandemic plan — but outsiders didn’t know about it until it was leaked to a science reporter named Declan Butler at the journal *Nature* [4]. Someone at WHO thought that an organization citing trust and transparency as two of its five outbreak communication guidelines should share its internal contingency plan. *Nature* published the news in mid-August 2005. Excerpts from the plan:

WHO Health and Medical Services Contingency Plan For an Influenza Pandemic, May 30, 2005

The purpose of this contingency plan is to ensure preparedness [...] in the event of an influenza pandemic which will affect WHO staff and their dependents.

The WHO preparedness plan should be used as a model for other agencies and bodies of the UN system. However, it is not intended as specific guidance for diplomatic missions or other public and private sector organizations.

The WHO pandemic preparedness plan is required for the following reasons:

- The WHO must maintain essential WHO functions, even in the face of a crisis.
- The WHO has a duty of care to its staff and their dependents.

Stockpiling Oseltamivir

If a pandemic is declared it is very likely that all stocks of medicine useful against influen-

za, particularly Oseltamivir, will be rapidly exhausted. Therefore WHO offices must be prepared and stockpile some Oseltamivir.

[...] WHO offices each should have a basic stockpile ideally allowing for a 5-day course of Tamiflu for approximately 30 percent of all their staff and their dependents. [...] Because antivirals will become valuable commodities during a pandemic, they should be stored in a secure place.

This advice is quite similar to the openly available guidance on the U.S. State Department website:

Based upon limited data, the CDC has suggested that the anti-viral medication Oseltamivir (brand name: Tamiflu) may be effective in preventing or treating avian influenza. Using this input, the Department of State has decided to pre-position the drug Tamiflu at its Embassies and Consulates worldwide, for eligible U.S. Government employees and their families serving abroad.[5]

Got it? The United States is openly positioning Tamiflu for its overseas embassy employees and dependents; WHO is privately recommending that WHO and other United Nations offices consider stocking enough Tamiflu for up to 30 percent of staff and dependents. But the U.S. government and WHO strongly recommend against private stockpiling.

International SOS, a company that provides private medical and security services in far-flung places like arctic oil rigs and remote mines, started working on pandemic preparedness long before most other companies (and many countries) were even interested. In a June 2005 update, the company stated:

International SOS has been unable to locate any internationally issued recommendations regarding corporate stockpiling of Oseltamivir [6].

So, it came up with its own guidance for the companies, schools, and individuals that subscribe to its medical and security services. Its guidance, released in early August 2005, turned out to be fairly similar to the WHO internal pandemic plan that was reported a week or so later. During the

time International SOS had been developing its recommendations, the U.S. government kept saying it was only planning to stockpile 2.3 million treatment courses of Tamiflu. But around the same time that International SOS announced its recommendations, the U.S. announced its intention to buy 20 million treatment courses.

Responding to the International SOS announcement, here is what a respectful U.S. official said, invoking the national interest but not showing any disdain or contempt for the company's plan. The *Atlanta Journal Constitution* reported:

A senior science advisor at HHS, who helped write and revise the U.S. pandemic plan, said the government is concerned that corporate purchases of Tamiflu could threaten the nation's response to a flu pandemic.

Our ability to purchase drugs nationally depends on having that drug available. If companies purchase it, that will potentially decrease what is available [7].

The quoted HHS official was Ben Schwartz. Ben and I have discussed the stockpiling issue at HHS meetings on pandemic communication planning. We agree about the importance of a national stockpile. We disagreed at times about raising public alarm and about how to involve the public early in planning efforts. But as with his other arguments, Ben's reasons for arguing against corporate and individual stockpiling were direct and honest, compared with many of the arguments against stockpiling that follow.

The question of whether governments should control the Tamiflu supply or whether private entities should do so is a respectable, debatable question with ethical and practical pros and cons on both sides. As the expression goes, "These are matters about which good people can disagree." Most official pronouncements against private stockpiling, unfortunately, are more like the next few examples.

In our paper, "The Dilemma of Personal Tamiflu Stockpiling"[8], Peter Sandman and

I support the public health arguments on behalf of a national stockpile. But we mainly highlight several categories of specious arguments against personal stockpiles, arguments often based on distrust of the public's ability to reason, follow directions, learn new information, or refrain from freaking out.

Two of our four "You're incompetent" arguments:

- You're likely to take your Tamiflu when you don't have the flu: "They hear 'bird flu' on the radio, and they'll take their Tamiflu that day," a Kaiser Permanente infectious disease expert told the *New York Times*.
- You might forget where you put your Tamiflu. "Personal stockpiles may get lost — people may not track where they store the Oseltamivir, once again making it unavailable when needed." (Various state health department guidelines regarding patient requests for Tamiflu [9].)

Two of our eight "It's futile" arguments

- A pandemic isn't happening yet. "We're trying to explain to parents that avian flu is really not a concern at this point for their children," a Maryland pediatrician told Bloomberg News in December 2005, explaining her refusal to prescribe Tamiflu.
- What if the pandemic comes after your Tamiflu has expired? "Stockpiled drugs might pass their expiration date before a pandemic starts," the New Jersey Tamiflu prescribing guidelines point out.[10]

One of our six "More harm than good" arguments

- Having Tamiflu may give people false confidence. It may therefore deter them from other useful precautions, such as frequent hand washing.

Most people making these bad arguments do not even acknowledge the rational basis for wanting one's own Tamiflu. They make that horn of the dilemma just

disappear. To revisit the question at the start of this paper: Who will lead during a pandemic? Probably not officials and experts who consider most members of the public to be fools.

It would be much better for officials to be candid and acknowledge the truth: "Look, of course it's best for you if you have your own Tamiflu. But it's best for the country if we decide who gets it."

That would be debatable, but not insulting and not dishonest. And it would be respectful if the government would throw open the debate about how to use its stockpile.

On the day of the Yale symposium, a communication officer from an overseas regional WHO office sent me a Reuters article with the headline: "Worried about bird flu? [sic] Wash your hands — Common sense can help people protect themselves against pandemic" [11].

The article started with three "common sense measures" against a pandemic:

- Number one is hand washing
- Number two, do not try to buy your own personal supplies of Tamiflu
- And number three, stay home if you do get sick.

Then the article included a long list of prominent experts giving technically true but disrespectful reasons why people shouldn't stockpile Tamiflu, including:

- While Tamiflu might help cope with an outbreak of H5N1, it is not going to offer outright protection.
- If you were to take it as a preventative, you'd have to take it for probably weeks, a pill a day.
- The average person is not going to know when, precisely, to begin taking the drug. Many infections look like flu.
- If you have Tamiflu at home and you take it for a cold or give it for a respiratory virus that is not influenza, we will be unable to use these drugs when we encounter a lethal strain of flu.

At the end of that list, the WHO official wrote a note: “So maybe we should explain HOW TO USE IT WISELY, instead of recommending that people not get it!”

Compare the examples above with New Zealand’s official, respectful statement about personal Tamiflu stockpiling [12]:

[Question] I’m worried about bird flu and an influenza pandemic. Is Tamiflu available, should I wish to add it to my first aid kit?

[Answer] This is something you will need to discuss with your doctor. Tamiflu is a prescription-only medicine in New Zealand and is not subsidised by the Government.

Whether it is prescribed by a GP to a patient or not, at the patient’s request, is at the discretion of the GP.

With a prescription, Tamiflu can be purchased at community pharmacies, but some pharmacies may have to order in stock.

It is worth noting that any community prescriptions for Tamiflu will not come from the Government’s national stockpile.”

Now, is that so hard? Apparently it is, for many officials.

INVOLVING THE PUBLIC

The lopsided emphasis on vaccines and antivirals leaves the affected — and unaffected — publics out of the planning.

Again, from the WHO internal plan:

If a new pandemic virus strain emerges it will be critical to identify the first cases, using the virus to rapidly develop an effective vaccine. It would be a number of months before a vaccine would be available. It should be noted that any new pandemic vaccine will initially be in short supply. Demand will far outstrip availability.

Availability — for whom?

Virus to develop a vaccine — virus from whom?

Now that is an ethical issue you don’t hear about much. Western officials push so hard for samples from dead or dying H5N1 patients in Vietnam or Indonesia, and now Turkey. What is the main thing they will

need the samples for, if human-to-human transmission begins? What are they going to do with those virus samples? “To rapidly develop an effective vaccine.” For whom? Mostly for the First World, where vaccine production capacity lives. This is rarely if ever mentioned when Western experts and commentators rail at the poor countries that are not sharing virus samples.

All statements about shortages of vaccine suggest that non-medical preparedness and local preparedness — planning for how to maintain essential community services during a pandemic — should be an extremely high priority for most of the world. But it is hard to imagine poor countries diverting their scarce resources toward a seemingly distant threat, which may even attenuate to the point of causing barely a pandemic ripple.

At the time of the Yale symposium, there had not been much official emphasis on non-medical preparedness even in the U.S. That has changed since the release of a revised U.S. pandemic plan as well as the gradually increasing involvement of the business community, civil society, and the growing online communities of citizens working to help each other raise awareness in schools, local governments, hospitals, and elsewhere.

There is still almost no emphasis on non-medical pandemic preparedness in the developing world. In the ever-increasing number of countries trying to cope with bird flu outbreaks in poultry, the main urgent task is trying to stomp them out and teach both affected and unaffected poultry handlers how to protect themselves and their flocks.

I am going to quote from Peter Sandman’s October 2005 article, “The Flu Pandemic Preparedness Snowball” [13], to argue some of the problems with the lopsided emphasis on vaccines and antivirals.

- The focus on the pharmaceutical fix is excessively optimistic. It is keeping people from focusing enough on worst-case scenarios.

- The focus on the pharmaceutical fix is excessively medical. It is keeping people from focusing enough on non-medical preparedness.
- The focus on the pharmaceutical fix is excessively governmental. It is keeping people from focusing enough on what civil society, the private sector, and individuals can do.
- The focus on the pharmaceutical fix is excessively national. It is keeping people from focusing enough on local preparedness.
- The focus on the pharmaceutical fix is excessively First World. It is keeping people from focusing enough on ways to help Africa, Asia, Latin America, and the Middle East prepare for a pandemic.

How does this relate to risk communication and pandemic preparedness? The price we are paying is that the emphasis on vaccines and antivirals leaves the public imagining themselves in a passive position, waiting for the cavalry to ride in with a syringe. This misperception is perpetuated by officials who think there is nothing for the public to do and, even worse, that the public is incompetent.

But citizens all over the developed world are coming up with ideas for public involvement in pandemic preparedness. (Check out the Flu Wiki [14] for the most remarkable and heartening example of this.) And some of their ideas have implications for the developing world as well.

I will leave you with two recommendations for involving the public now, in advance of a pandemic. The first one doesn't raise any ethical issues that I can think of, but it is such an available, cost-effective preparedness measure that I can't resist.

CHANGE PUBLIC WASHROOM FAUCETS AND DOORKNOBS!

One of the main non-pharmaceutical pandemic preparedness efforts is communication about hand washing. Same old, same

old, just like your mother always told you — but there is some real evidence behind it.

So, how can you get people's attention about hand washing, and at the same time reduce disease transmission starting right now? By making a visible (and relatively small financial) commitment on the job: Change the faucets and doorknobs on public washroom doors. Enable people to turn off the water with their elbow, and escape from the washroom the same way — without re-contaminating their hands.

The model comes from the medical world, but it is not “medical” — picture the surgical suite, with its scrub sink and doors. This does not need a billion dollar budget, or changes in liability laws, or intellectual property rights negotiations with companies. Any workplace can decide to do this on its own. Parents can put pressure on the schools. Local officials can lobby for restaurants and other public places to make the change. HHS, CDC, and WHO headquarters should go first: Think pandemic preparedness hand-washing photo-op!

INVOLVE THE PUBLIC REALLY EARLY — BRAINSTORM ABOUT VOLUNTEERS DURING A PANDEMIC

I'm going to end with my favorite trick question, because it incorporates the public, transparency, and candor — and some degree of trust.

Everyone reading this already knows there will be hardly any vaccine early on in a pandemic, right?

Okay. Who will not need vaccine at all, early on in a pandemic?

Picture it: What happens early on in a pandemic? Lots of people get sick. And then what happens? Most of them get better. And then what? Presumably, they are immune — at least for that wave of the pandemic (but no guarantees). And they can do high-risk jobs — like delivering food to home-bound sick people or

answering phones at the hospital or covering for a fellow worker if they have cross-trained for the job. And they can volunteer.

The best time to help people understand that they will likely be immune (for at least awhile) after surviving the Great Pandemic of 2___ is now, before it happens. People may be too anxious or distrustful to absorb that information quickly during the pandemic. Imagine officials trying to tell them, “Hey, you’re all better? Come work in the hospital laundry.” Yeah, right. Better to talk about this in advance.

There are ethical issues involved with telling people they may be immune. What if you are wrong? What if what they had wasn’t the actual flu, but a “flu-like illness?” What if there are no lab tests available to assure them it was really the flu? But what if they are really needed, and really valuable, because they are probably immune? Communicate and share the dilemma. Ask people for their ideas and their concerns. Figure it out now.

This suggestion — planning in advance for a Flu Survivors Corps — always gets people’s heads shaking or nodding, sometimes simultaneously. This wonderful suggestion is actually in the WHO Checklist For Influenza Pandemic Preparedness Planning:

Consider how recovered cases, who are presumably immune to the new virus, can be identified by occupation (for example, health-care workers or workers in designated essential services), in order to facilitate the development of a resource of workers presumed to be immune [15].

Now, before the next pandemic virus emerges, there are endless opportunities to help the public come to grips with the terrifying, perplexing prospect of an event that might be like a global tsunami or like the tiniest of ripples, and which might start tomorrow or not happen for decades. Officials will have a better shot at leading during a pandemic — and inspiring people’s resilience, maturity, imagination, and altru-

ism — by communicating candidly now. Ask the public to become involved, and start to notice (I won’t say “start to trust”) that the public — most people, at least — will adjust to the scary news, and rise to the occasion.

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