The price of poor pandemic communication

PERSONAL VIEW Thomas Abraham

Fuelled by public distrust, a season of inquiries has begun into how governments and public health agencies responded to the A/H1N1 influenza pandemic. If these reviews are to be meaningful, they would do well to address the failures in communication both before and during the pandemic that helped create this public distrust.

The principal failure was this: instead of using the tools and principles of risk communication to create public understanding of the risks posed by a pandemic, experts and policy makers used another form of communication, advocacy, which is intended not so much to create understanding but to persuade the public to take certain actions.

These advocacy efforts were spurred by the events of late 2003 and 2004 when, with SARS (severe acute respiratory syndrome) fresh in everyone’s memory, H5N1 outbreaks emerged in poultry and humans in different parts of Asia. These outbreaks seemed to flu specialists and other public health experts a threat for which governments and the public needed to prepare. The public (and governments, except for public health agencies) were initially apathetic. And so there seemed to be a need to ring alarm bells to wake the public from its slumber and urge pandemic preparedness. Two well known risk communications consultants, Peter Sandman and Jody Lanard, captured the spirit of the times when they wrote of the feeling among infectious diseases experts of “a sense of impending disaster, a need to sound the alarm, alienation and frustration that people don’t get it.”

The spread of the virus, the high mortality rates in human cases, and the attendant media coverage created a more receptive public environment for messages about the pandemic preparedness. Two well known risk communication experts focused on the severe human and economic costs of a pandemic, and in order to rouse governments and the public the 1918 pandemic—rather than the 1957 and 1968 pandemics—was used as an example to demonstrate how terrible it could be. These efforts began to pay off and the perception of a pandemic as a catastrophic event began to take root in the public mind.

The pandemic that emerged in 2009 was different from what the public had grown to expect from pre-pandemic communication. It arose not from an avian virus in southeast Asia, but from a swine originated virus in central America. Its severity and global impact were far less than had been expected. This gap between reality and prediction has produced a public backlash, with people questioning the competence and motivation of public health agencies, and a suspicion of the advice that is coming from them, including on vaccines.

Risk communication to create a public dialogue on the risks of a pandemic, rather than advocacy based on appeals to fear, would have been the correct approach to have used in the pre-pandemic phase. There is confusion in the public health community about the aims and goals of risk communication. It is about building a shared understanding with the public, about the nature of a risk and the measures needed to respond to it through dialogue. It is not about trying to persuade people. As a landmark study by the US National Research Council in 1989 put it, the aim of risk communication is not for the audience to accept the views or arguments of the communicator, but to raise the level of understanding so that all those who are involved are adequately informed within the limits of available knowledge.

The experience of pre-pandemic risk communication shows why risk communication should be limited to providing information about risk, rather than attempting advocacy.

The communication of risk is about the communication of uncertainty: risks are events that are likely to occur in the future, but are by no means certain to do so. Any measures taken to mitigate future risks, whether a pandemic or natural disasters, have to be based on a shared understanding between those who have technical and scientific knowledge of the risk, and those who have to bear the risk, and take actions to mitigate it. This can happen only through a two way exchange of information that will contribute to a public understanding of the risk.

In the continuous building up of the scenario of a dangerous pandemic the scientific uncertainty that surrounded these predictions was never adequately conveyed. This was not because the scientists and policy makers were unaware of the uncertainty, but because they tended to downplay uncertainties for fear that advocacy for actions like pandemic preparedness would be compromised. A conflict existed between the needs of advocacy and the needs for transparent risk communications.

If any of the ongoing inquiries into pandemic management lead to greater efforts to understand the complexities of risk communication not merely during a global public health event, but also in the preparatory phases, they would serve a useful purpose.

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See FEATURE, p 1274
Preventing pandemics of panic in a NICE way

PERSONAL VIEW  Luc Bonneux, Wim Van Damme

The decisions to stockpile antivirals and influenza vaccines to control avian flu (2005-6) and swine flu (2009) cost large amounts of money.

Both epidemic threats were mostly iatrogenic pandemics of panic, which caused little human suffering, but the global plans to control them were largely a waste of money.

Was this the consequence of rational risk management in conditions of uncertainty, of fear accompanying any epidemic threat, or of close working relationships between disease experts and the drugs industry?

Severe acute respiratory syndrome (SARS) in 2003 was an epidemic by an unknown and therefore scary new virus, but we know much more about influenza viruses.

The new A/H1N1 swine flu was a far cry from the lethal A/H1N1 pandemic of 1918. There has never been evidence that the recent A/H1N1 virus was anything but mild, and it was not reasonable to consider it the first wave of a much more serious second wave. The theory that the 1918 influenza pandemic was caused by a second wave of a mutated virus that had caused a benign epidemic in a first wave has never been supported by any evidence.

The nature of the organisms that caused mild respiratory disease in the spring of 1918 is unknown, but many better candidates than a “Spanish influenza virus light” exist. Both recent iatrogenic pandemics of panic were caused, or at least exaggerated, by disease expert committees.

The care of health economics and health policy is that resources are scarce. If resources were infinite, all possible measures could be taken to fight disease, including prevention of all hypothetical possibilities. Because resources are limited, wise allocation saves lives. Money spent in stockpiling antivirals with hypothetical effectiveness against a hypothetical pandemic is not available for health care, or for education, or for any other important human need thought to be underfunded.

Organisation of public health can be compared with the organisation of individual health care. Resources are best managed if a patient visits a general practitioner first. The general practitioner may ask expert advice from a specialist, but he or she has a global overview of health and disease, knows the patient and the social context, and is best placed to take a balanced decision and contain costs.

Similarly, the modern disease expert knows a lot about the disease in question, but does not necessarily know much about general public health, health economics, health policy, or public policy, which are much more about priority setting and hence resource allocation between competing priorities. As specialists, disease experts are often biased and are increasingly part of industrial networks.

In recent decades, cooperation between industry and academia has become intense. This combination of skills has led to better and faster development of innovative drugs and technology. However, closer working relationships between industry and university may distort priorities.

The priority of the drugs industry is to make a profit. The aims of academic science are less well defined. Department policies are determined independently by senior academics and are often guided by the potential to obtain funding from public and private sources. Disease experts and the industry share a common strategy: both try to expand demand for research and drugs for their disease of interest. Few checks and balances exist to preserve the needs of society: the need for a wise allocation of scarce resources among competing priorities.

Disease experts are therefore less competent in judging a disease’s relative importance. Overall health policy decisions should be the responsibility of general practitioners, informed by disease specialists, but also by the many other stakeholders in a modern and pluralistic health system.

The United Kingdom has a growing tradition in rational decision making in health: the principles of healthy health policy making have been explored by the National Institute for Health and Clinical Excellence (NICE). As an independent organisation, NICE uses independent, general scientists from epidemiology and public health, health economics, and medical ethics. The teams review the best available evidence and involve all stakeholders, including administrators, healthcare professionals, patients, carers, industry officials, and academic disease experts, in a transparent and collaborative process. Costs are explicitly and transparently evaluated and compared against the expected value of a certain policy. NICE introduces checks and balances necessary to safeguard cost effective health care. NICE is held “accountable for reasonableness” by the public in a continuous debate.

The World Health Organization failed to give appropriate guidance in both pandemics of panic. To prevent this from recurring, WHO should “do it the NICE way.” Disease experts are necessarily and fatally biased. It is not reasonable that they bear the entire responsibility for decisions related to their disease. This has been convincingly shown over the past years with the two iatrogenic pandemics of influenza panic. Advice of disease experts, of course, is valuable and indeed crucial, but this advice should be tested against the available evidence, balanced by other stakeholder views, and checked by the transparent evaluation of costs and values. At last, the final evidence based policy advice should be drafted by independent scientists trained in evaluation and priority setting.

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See FEATURE, p 1274
Arsenic and old ways

Whenever I enter a medical library and look at the ranks (that I dare not call serried) of buckram-bound journals, I think I have entered a graveyard of ambition, with all those heavy, unregarded tomes being the tombstones of the hopes and efforts that produced them.

Still, once they are old enough, they might become of antiquarian interest. It is only the recent past that we do not invest with romance because it is too close to present mundanities.

Recently I bought an isolated volume of the Dublin Journal of Medical Science—namely, that for July to December 1879. It was advertised as being particularly interesting because it contained Lister’s lecture to the University of Dublin on the occasion of receiving an honorary degree there.

Lister’s lecture was indeed interesting, though whether it would have been rejected for publication nowadays as being insufficiently scientific, and containing far too much anecdotal evidence—for example, of his treatment for psoriasis abscesses—is an open question.

But in fact the whole volume of the journal—all 516 pages of it, excluding the index—was irresistibly fascinating. For example, there was Dr (later Sir) Charles A Cameron’s mathematical proof that an outbreak of typhoid in Dublin was traceable to the provision of milk from a single dairy. And there was a review of the Annual Report of the Sanitary Commissioner for Madras in 1877, which was a year of disastrous famine. In that year, 1 556 312 deaths were registered, three times the average number in the previous five years (an excess, therefore, of about a million). I have no space to quote at length, but here is something startling: “During the past year many thousands of persons in Southern India have committed offences with the sole object of finding refuge and food in the State Jails.”

Arsenic in wallpaper was on the journal’s mind, with two articles mentioning the fact that it was not green coloration only that was dangerous in this respect, the presence of arsenic in other wallpapers explaining many children’s otherwise inexplicable illnesses. And a case is described of a mechanical draughtsman who died from arsenic poisoning from licking the tip of his paintbrush to make it fine.

A heavy tax on dogs—especially those kept purely as pets—is proposed as the means to combat rabies: for once such a tax was introduced in France, the numbers of cases of rabies declined there.

Reviewers of books were more forthright in those days than they are in ours. Half of the review of Aids to Therapeutics and Materia Medica, by C E Armand Semple, consists of these words: “Its proper title would be—‘Hindrances to Therapeutics and Materia Medica.’”

I even had a Proustian moment as I went through the journal. There was an article about wry neck, with pictures of children before and after treatment by a surgeon. Firstly he put them in a contraption consisting of a plaster jacket and a mechanical neck-wrench; then he divided the sternomastoid surgically (giving rise to “an audible snap”).

Between the ages of 6 and 11 I suffered from episodic wry neck, though I had quite forgotten it. The condition was agonising, but for some reason my father thought it was funny. A close friend of mine also suffered from wry neck and his father, too (a doctor), thought it was funny. But better, perhaps, a little mockery than that audible snap.

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**MEDICAL CLASSICS**

A new look at medicine and politics

J Enoch Powell
First published 1966

Cyril Chantler, one of Britain’s wisest doctors, likes to give people a photocopy of Enoch Powell’s book on medicine and politics and tell them that it’s the best thing ever written on the NHS. Younger readers may not have heard of Enoch Powell, but he was a Tory minister of health in the early 1960s. He is most famous for his racist “rivers of blood speech,” and I can remember protesting outside his Belgravia home. Could he really have written the best book on the NHS? I think that Cyril is right. One of Powell’s strengths is that he was a distinguished classicist and writes beautifully, with directness, clarity, and wit: it’s like reading Tacitus on the NHS. Another strength is his inability to dilute the source of his catastrophic speech, his weakness as a politician, and his most famous observation that “all political careers end in failure.”

Powell addresses many topics that are as alive today as they were 50 years ago. Rationing has always been a difficult word for politicians to use and was banned outright during Tory rule from 1979 to 1997, but Powell regarded rationing as inevitable and wrote in 1966, “The task [of rationing] is not made easier by the political convention that the existence of any rationing at all must be strenuously denied.”

He continues: “The worst kind of rationing is that which is unacknowledged; for it is the essence of a good rationing system to be intelligible and consciously accepted.” Powell would surely have welcomed the National Institute for Health and Clinical Excellence (still known as NICE), not least because he despaired of limiting the “cascades of medicines pouring down British throats” when as a minister he was confronted by “an array of parties all severally interested in maximizing the value and volume of the drugs supplied.”

Another contemporary issue is whether the NHS can in some way be insulated from politics. Powell is clear that it’s impossible. “The plain rule is that wherever the taxpayers’ money is being spent, a minister must be held responsible for how it is spent.” He imagines how a member of parliament might respond to a constituent dissatisfied with the NHS if it was administered by a body like the BBC: “My dear Sir, I have no standing in this matter: you must complain to the Corporation, and if you do not like their answer I can only advise you to grin and bear it.”

Powell is strong on how doctors and politicians necessarily have different views of the world in that whereas “the politician practises the subordination of individual judgment, the doctor glories in the development and the exercise of it.” He makes his famous observation that “The unnerving discovery every Minister of Health makes at or near the outset of his term in office is that the only subject he is ever destined to discuss with the medical profession is money.” And he despairs that because the Treasury is the sole source of funds for the NHS those working in the service must constantly denigrate it in order to win more funds, which is why the BMA is known to some as the British Misery Association.

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Compulsive doing

The wonder that is the football World Cup has started. Footballers get a lot of stick for being young and overpaid, which is odd because the wealthiest in this country inherit their money doing nothing for their status. But of course they’re known for the sarongs, silly hair cuts, poor vocabulary, high end cars, and their litany of fashion crimes, WAGs (wives and girlfriends), and affairs. A professional sportsperson needs talent but above all discipline and dedication. Some people care about sport more than others. For some national conflict reduced to 90 minutes of collective pain can bring admiration for the other side rather than anger.

Sport is directly linked to health. The observational data are beyond refute and obvious—longer life, less obesity, better bones, better hearts, and better mental health. So why has sport fallen from favour, particularly in our state school system, especially as negative body image is a big problem among teenagers. Have the nerdy overprotected kids who produced letters from their parents to get off cross country running grown up to head the education department, and is their revenge to banish competitive sports? Or perhaps sport is viewed as male—competitive, aggressive, and therefore negative. But the school system obsesses with selection and league tables and yet academic competition is not considered divisive or aggressive. The paradox is that the enlightened elite avoid the state sector by sending their children to private schools, which remain focused on sport and exercise.

But sport in all its many guises, from hockey to handball and even ballet, has an obvious purpose because games are a proxy for teaching teamwork, discipline, communication skills, and unity in adult society. And the current thinking around childhood physical and mental health is fractionated, counterintuitive, contradictory, and, frankly, broken. I would shred every book on the topic.

We can improve the mental and physical health of our children only in part through promotion of competitive team sport in childhood. An equally unfashionable suggestion is that because all adults must take part in society these sports should be compulsory for all children. We are denying children the basic human right of being slim, athletic, and happy. The World Cup is coming: just turn on the television to see its power.

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Marie Lloyd’s bruises

I’ve just watched a one woman play about Marie Lloyd, the music hall entertainer. She was born in 1870 in London’s east end, and her real name was Victoria Wood. Coached by her father, she made a stunning debut aged 14, when she silenced audiences by flirting with the men. Two years later she was earning the huge sum of £100 a week.

For a modern audience her story is uncomfortable as well as inspiring. It is disturbing to realise that the sex appeal of adolescent girls was being exploited long before the era of the pop video. On the other hand, Marie clearly had a unique talent—her sense of pitch was praised by George Bernard Shaw—and she later used her success to fight the theatre owners who paid peanuts to her fellow performers.

The gynaecologist in me wondered why this sexy woman had had only one child. I think I can guess the answer, having recently written a paper that involved typing “criminal abortion” into the online BMJ archive. (The many articles before 1914 are a revelation.) Knowing the euphemisms used for coitus interruptus in the railway age added piquancy to the innocent lyric “Oh Mr Porter, what shall I do? I wanted to go to Birmingham but they’re taking me on to Crewe.”

But the real discomfort came when we learnt that Lloyd’s third husband used to beat her up. Here was one of the most liberated women in the British empire being struck repeatedly by a former jockey. “Please, not on me face! You can’t hide them bruises, can you, girls?” This line, which would have bonded her to a Victorian audience, is met with uneasy silence today.

The more we study marital brutality the more confused we become. It is now called “intimate partner violence” by academics who study women and worry about nomenclature. Its original name, “wife beating,” placed the blame squarely on the perpetrator. If there is ever to be a cure, it will involve men talking to men.

The play, Marie, written by Steve Trafford and starring Elizabeth Mansfield, is full of music. It is a wonderful example of the fact that you can learn more from two hours in the theatre than from a month in the library. In the dark nobody sees your tears.

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