

Global Awareness of Disease Outbreaks: The Experience of ProMED-mail

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ProMED-mail was established to provide an early global warning of emerging diseases of humans, animals, and plants as well as of disease activities signaling biological warfare and bioterrorist activities. The creation of the ProMED-mail system filled a vacuum highlighted by the 1992 Institute of Medicine's seminal publication of the occurrence of emerging diseases and reasons why we are likely to see increasing numbers of outbreaks in both developing and developed countries. ProMED-mail has electronically knitted together a global cadre of emerging disease specialists and other interested parties. It has been not inaccurately described as "the CNN of outbreaks." Its first posting was on August 22, 1994 on "Sabia and Other Rodent-Borne Viruses." In its five years, it has grown from 40 members to some 18,277 in 160 countries with an unrestricted membership, now more than 20,000 members. During 1999, 2,226 messages were posted, averaging more than six each day, seven days a week. The program has few graphics and loads quickly in locations with slow connection to the Internet; the search engine connects to prior posting, and other links are available.

Veterinary activities play a significant role in monitoring emerging diseases because they are central to understanding new diseases in animal populations. New diseases in animals have an impact in and of themselves, but they can also serve as comparative lessons on disease ecology. Most strikingly, they can involve significant outbreaks in human populations as new zoonoses emerge and are characterized. Time and again, over the past five years, new diseases in humans can only be fully understood when the animal components have been delineated. In 1999, 63% of all postings were of animal diseases and infections; this is not an unusual percentage. In the few years that ProMED-mail has been functioning, one has noticed a significant change in the attitude of the medical fraternity to veterinarians. It was slow at first, but after two years there was a sudden shift as they seemed to become aware of the central position of veterinary medicine to human health, quite apart from food hygiene and the other

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Figure 1.

sanitary aspects. Obviously, this was not just through ProMED-mail, but on a personal note I am always amazed how physicians will tell me about animal disease outbreaks in the furthest corners of the world, knowing only that I am a veterinarian.

RISK COMMUNICATION

A common question in risk communication is why some individuals and organizations are perceived as trustworthy sources of information and others are not. In brief, it is not unusual for government officials to be perceived as being insensitive to the information needs and concerns of the public. If a government department is perceived to be working too closely with an industry that has vested interests, trust in regulations and legislative controls can be reduced. Similarly, sources that are not seen as biased or self-serving are trusted. Sources that are trusted are also perceived as knowledgeable or at least providing research information, possibly a “halo” effect so that highly trusted sources acquire multiple positive attributes. In contrast, distrusted sources are associated with “inaccurate” information. However, high trust does not follow from freedom from accountability, because this can be perceived as sensationalist, but from a moderate degree of accountability. Thus, a member of the medical or veterinary profession may have a vested interest in public health, a concern with public welfare, which makes for trust. This penumbra of “trust” probably explains the success of unofficial sources of information, especially when fellow professionals and expert colleagues are drawn into the web of information providers and commentators. This is essentially what has happened in the case of ProMED-mail.

The information flow is something like:

Information sent to ProMED-mail

Screened, sent to expert moderator

Rejected, more info needed

Returned for posting, often with comments

Sent via e-mail to subscribers and placed on Web site

INFORMATION SOURCES

Because health agencies are not proactive with real news, ministers’ activities and government initiations of new health programs are not real news. Thus, some 90% of our disease reports start with a raw newspaper article, TV segment, or radio report, incomplete and sometimes replete with errors. For those who like their disease reports always complete, rounded, and error free, ProMED-mail is not the right source. Read *Lancet*, *New England Journal of Medicine*, *Nature*, or *Science*. Because ProMED-mail functions on the very cusp of events, it has had to weather charges of unreliability in spite of being considered by experts worldwide an indispensable medium for news of outbreaks. In reality, the incomplete first postings very frequently initiate full reports, sometimes with quite unexpected and invaluable dimensions from the informed membership. The membership is the key to ProMED-mail, and they have contributed mightily, both with informed background reports as well as reports by those dealing with the emergency itself. One should remember that the errors in the initial report can indicate how the people on the ground are viewing the problem and thus are very informative. An analysis of a seven-month period (September 1999–March 2000) revealed that six of 351 (1.7%) outbreak reports were official reports that were subsequently retracted, and nine of 351 (2.6%) were incorrect reports from individual contributors and the media. The latter is an acceptable rate considering the pressures involved. The moderators are all volunteers contributing their time and expertise in the midst of full-time professional careers. We each have our war stories of blunders and oversights.

An impressive aspect of ProMED-mail has been its ability to channel expertise to those needing it. Because virtually everyone in the epidemiological world follows ProMED-mail, a request for advice or expertise can get an immediate response, sometimes from the unique source. Another advantage is, by not having agency or governmental affiliations, ProMED-mail is independent of some governments’ desire to cover up health problems or to be purposefully slow in reporting. This is why a similar government or agency monitoring system can be inadequate.

A knock-on effect of ProMED-mail's success has been the World Health Organization's (WHO) initiation of their confidential early rumor reports to relevant WHO personnel, collaborating centers, and other public health authorities. This is well in advance of laboratory confirmation. Too often in the past there have been times when confirmation has been obtained when the epidemic was over, and the medical cavalry arrives in time to battle the ex-epidemic. Another effect has been the initiation of Global Public Health Information Network (GPHIN) by Health Canada. GPHIN uses a search engine to scan the World Wide Web continuously for all information, including news reports and ProMED-mail originally under six headings—cholera, salmonella, hemorrhagic fevers, antibiotic resistance, encephalitis, and floods—but now 31, including the major zoonoses. Currently, the preparation of intelligence reports from this material has to be done by the GPHIN staff, but eventually it is intended to be done using artificial intelligence. GPHIN has a restricted but interactive readership for those in Canadian public health. US Department of Agriculture started a virtually parallel veterinary project known as CEI (Center for Emerging Issues). It also has an analytical component producing reports on a range of subjects and of various values. Like GPHIN, it is private.

Who's Who in ProMED-mail—

Editors, Moderators

Daniel Shapiro, MD
Boston University School of Medicine,
Managing Editor

Edward Schroeder, PhD, NIAID,
Associate Managing Editor
Bacterial diseases

Marjorie Pollack, MD
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Epidemiology

Craig Pringle, PhD
University of Warwick
Viral diseases

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Texas A&M University
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Louisiana State University
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Parasitic diseases

Luiz Jacintho da Silva
SUCEN, Sao Paulo, Brazil
ProMED-PORT

Alexander Vladyko, PhD
BRIEM, Minsk
Belarus

MODERATION

There are two major aspects of moderating: It is great fun and very time-demanding. The first was obvious from the start when there were only a few members; the latter became apparent over time largely as we became more and more aware of the news resources available and the international response to the postings. Before we acquired an editor for the moderators, the senior moderator for any period (it rotated) could find two-thirds of his or her day consumed, largely with mindless housekeeping chores. Even later with an editor doing the sorting and traffic control, it can take some four hours every day, editing communications (most news reports have a large volume of redundant material), making them more readable, checking with knowledgeable and informed folk as to what was really going on or the scientific background, reading various key newspapers and wire services on the Web for reports, and participating in ongoing discussions with the other moderators. In the meantime, each moderator had his or her job as a medical director, researcher, or university professor to perform, to teach graduate students, research, write, do committee chores, consult, and try to get research funding. We all have other full-time jobs, salaried or otherwise.

MODERATOR'S COMMENTS

First, it is too easy to overcomment, especially when starting out as a moderator, and underimpressed by the hyperactive flaming egos on other sites one may consciously undercomment. If one sometimes gets carried away, one can count on certain friends to quickly rein one in! For myself, I find the unedited communication full of valuable information even when it is wrong or inaccurate and am puzzled why others

do not see what I see. However, being a veterinary epidemiologist, I do realize now that my knowledge and experience may be wider than most.

However, we did note that there was a segment of the membership wanting commentaries on virtually everything, as if they needed someone to point up the important dimensions for them, confirming Pelagius's observation about labels.

As the nonprofessional segment of the membership expanded each year, we found that commentary was needed more and more, starting with the reliability status that should be given to the initial reports and the reason for this, as well as background biological and epidemiological information. In fact, even the professional membership seems to want to be told how to interpret reports. No one is more uninformed than the specialist in another area.

Even internally we find that commentary explaining the veterinary importance is sometimes needed to ensure that certain topics get posted. Too often the medical side considers that veterinary topics are merely the animal aspect of human disease and are biology-blind to the economic and international trade dimensions, quite apart from the wider spectra of diverse related pathogens and their ecologies.

The moderation is an evolving, developing, dynamic process reflecting their individual characters and interaction with the subscribers.

MEMBERS' COMMENTS

People will sit quietly and read the postings, offering nothing in return, but will grouch loudly when they perceive a mistake. The moderator has to actively, even proactively, generate responses from the real specialists and truly informed. Sometimes this involves blatant blackmail. It works, especially with government offices. Alternatively, ProMED-mail has acquired a number of extraordinary people willing to share their deep specialist knowledge. Similarly, when people are contacted out of the blue, the word *ProMED* loosens all tongues.

Another problem has been confidentiality. Although there is a policy that all postings should be from identified sources, there have been occasions when it has to be obscured or when it was necessary to find another quotable source altogether. People could have lost their jobs or even their lives if identified.

At the other end of the scale from uncomfortable truth tellers, we have had messengers of misinformation (MOM) and every now and again, as ProMED-mail became globally recognized, the disseminators advancing disinformation (DAD). MOM is character-

ized by the repetitiveness of the source, such that they acquired nicknames (e.g., Prairie Dog, Bunny, and Hollywood Nutter). In retrospect, DAD was obviously going to be offered us when we became a well-known and much quoted news source. DAD varied from the clumsy to the sophisticated, and we caught virtually all to the amusement of our fellow moderators. One should always remember that lies often can tell you more than the truth.

Take, for example, the Oslo and Glasgow reports of heroin-associated deaths. On May 6, 2000, I received an e-mail message from Per Lausund, chief of the Veterinary and Preventive Medicine Section of the Norwegian Army Medical School, concerning the anthrax death of a heroin addict. At the time there was a newspaper strike, and the report was only carried by the Norwegian Broadcasting Corporation. Over the previous year, Lausund and I had corresponded about various aspects of anthrax recognition and, therefore, knew each other. The import of this death was obvious, but it was important to not make the event a model for imitators. Immediately, messages were sent to the various security agencies and the Surgeon General's Office. Centers for Disease Control and Prevention (CDC) had the "lovebug" in their computers, and so they were informed by telephone. The Food and Agriculture Organization (FAO), WHO, and other foreign institutions were also contacted. Then a posting was crafted so that those who were bioterrorism-aware would appreciate its importance but that others might not get all the potential dimensions. The diagnosis was confirmed on May 9.

On May 11, there was a BBC report of a heroin addict dying in Glasgow, which was posted immediately because it might have been the first of many subsequent "anthrax" deaths. The cause of this death was unknown and remained so until June 15, when it was found to be a *Clostridium novyi* infection. How this anaerobe got into the heroin has never been publicly explained. Once alerted, a string of about 42 reports followed of similar cases and deaths throughout the United Kingdom. The Norwegian series involved some seven cases, but this has yet to be confirmed publicly.

ProMED-mail certainly played an important early role in letting everyone know that a bioterrorism potential event had occurred. This happened because we were contacted by an informed member in the absence of newspaper reports, which we normally depend on. Direct subsequent inquiries by the moderator of those involved in the United Kingdom were answered promptly and completely, and it seems there have been no imitators. I know that various security bodies began checking addict deaths with more care

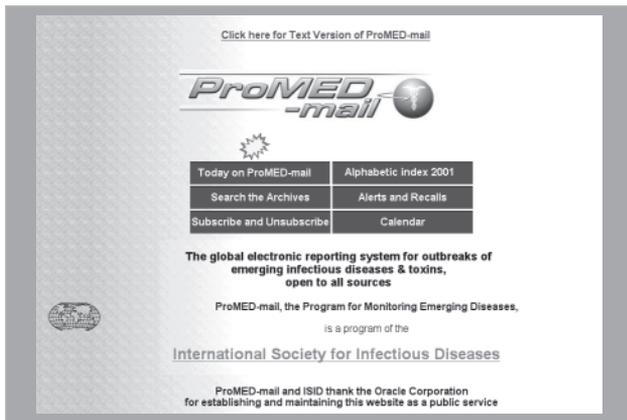


Figure 2.

than before. It worked. However, one must wonder what would have happened if Norway had been totally silent. Would the scattered addict deaths in the United Kingdom have been noticed and a diagnosis reached? One suspects not.

CONCLUSIONS

Last, there is the matter of transparency. To quote John Snow, “the communicability of cholera ought not to be disguised from the people under the idea that the knowledge of it would cause panic or occasion the sick to be deserted” (from “On the Mode of Communication of Cholera,” 1854). Universally, health agencies, whether medical, veterinary, or agricultural,

are afraid of public reaction to reports of disease outbreaks. If they cannot report success, they would rather report nothing and be silent. To quote Charlie Calisher, “bitter experience has taught many countries that reporting some diseases, such as cholera, has a bad effect on trade and tourism. This is all the more reason why there should be frequent official updates of the situation, to curb rumors, put the outbreak in context, and explain what the country is doing to control the disease and prevent further cases.”

Quite apart from the important professional respect and trust that comes from transparency, health authorities also fail to realize that being first, or at least very early, with accurate and complete (as possible) information puts them in a powerful position in setting the tone for all subsequent reports. We can affirm that good, complete, and informative press releases will appear virtually word for word in the various newspapers. Apropos, it is interesting to note how the open and efficient U.K. Parliamentary Inquiry on bovine spongiform encephalitis significantly reduced the volume of external criticism, at least for 12 months. The final Parliamentary Report has laid the standard for clarity and completeness and has been greeted with respect. Within ProMED-mail, the Australians have repeatedly demonstrated the advantages of being proactive with their full reports. Over the past 18 months, we have been increasingly receiving authoritative reports from various responsible agencies written specifically for ProMED-mail. One suspects such reporting encourages others similarly to report key details early.