



Robert M Wolfe, MD
 Department of Family Medicine,
 Northwestern University, Feinberg
 School of Medicine, 710 N. Lake Shore
 Drive, Room 1417, Chicago, IL
 60611, USA
 r-wolfe@northwestern.edu

Vaccine safety activists on the Internet

'By heavily emphasizing the word "vaccination" and a strong use of cross-links between antivaccination sites, antivaccinationists have essentially commandeered the search term "vaccination" on the Internet.'

Expert Rev. Vaccines 1(3), 249–252 (2002)

Almost immediately after Jenner's introduction of smallpox vaccination at the end of the 18th century, his innovation began to face stiff opposition from a minority opposing vaccination. Some opposed it because they felt it was unnatural and an interference in God's will to use disease to punish sin. Others were convinced that the vaccine contained poisons or animal contaminants that would cause different illnesses. After various countries passed legislation making vaccination compulsory (Denmark – 1810; Sweden – 1816; Germany – 1834; England – 1853), antivaccination leagues were formed to oppose these laws as a violation of civil liberty and to serve as a forum for antivaccination sentiment.

In our era, antivaccination opponents have continued to wage war on immunization, with modest successes in fanning public fears about pertussis vaccine in the 1970s and measles–mumps–rubella (MMR) vaccine in the 1990s. The Internet has proved a particularly effective forum for them to voice opposition to vaccines [1]. In the USA, recent studies indicate that 66% of adults (137 million) are online, and that 80% of adults online use the Internet to look for health information [2,3]. By heavily emphasizing the word 'vaccination' (antivaccinationists eschew the word 'immunization' since they do not believe that vaccines produce immunity) and a strong use of cross-links between antivaccination sites (which enhances site ratings on search engines), antivaccinationists have essentially

'Sending your child to the doctor to be vaccinated is a little like sending your child off to fight in a war. In both cases, society asks the parent to accept a small risk for their child to benefit the whole of society'

commandeered the search term 'vaccination' on the Internet. A recent study by Australian researchers found that, averaging the results of seven online search engines, 43% of the first ten results were antivaccination sites when searching with the word 'vaccination' [4]. On one search engine, Google (www.google.com), 100% of the first ten results were antivaccination sites. When

you consider that a USA study showed that 81% who go online to access health information use an Internet search engine to find the information they are seeking [5] and that a German study showed that 97.2% of health information seekers only look at the first ten search engine results, these are sobering statistics indeed [6]. By contrast, the words 'immunization' or 'immunisation' returned antivaccination sites in the top ten results only 6% of the time.

Recently, my colleagues, Lisa Sharp, Martin Lipsky and I published a study of 22 modern antivaccination websites to evaluate content and design attributes [7]. The types of ideas we found closely matched the content found in a 1998 Australian study of antivaccination ideas in the press media and so can be considered fairly representative of modern antivaccination thinking [8]. I have summarized some of the data and included a few quotes from past and present to demonstrate, as we tried to show in our recent article in the *British Medical Journal*, that few of the basic ideas have changed over the past two centuries [9].

'Vaccines cause idiopathic illness'

All of the 22 studied sites suggested that vaccines cause idiopathic illness. Many references were cited to try to prove this, mostly from the alternative medicine press, self-published works, or letters to newspaper editors [4]. Of the sites, 95% accused vaccines of weakening the immune system or causing autoimmune disorders. Invariably, modern studies that have shown no correlation between vaccines and certain illnesses, such as MMR vaccine and autism, were ignored or disparaged. The list of ills attributed to vaccines was long and varied. One site asserted a connection between vaccinations and a rise in adolescent crime and suicide and the decline in SAT scores.

'Adverse vaccine reactions are under-reported'

"...the belief [that the percentage of smallpox deaths is higher in the unvaccinated than in the vaccinated] is due solely to the fact that doctors register all deaths from small-pox as 'unvaccinated' when they can possibly find any excuse for doing so." 1904 – Alfred Russel Wallace, National Anti-Vaccination League (England).

"Vaccine reactions are notoriously under-reported. Many factors contribute to the reluctance of physicians to report a vaccine reaction, not the least of which is outright denial," 2002 – [101].

Although 95% of the sites asserted that adverse vaccine reactions are underreported, the reasons given for this varied. Many sites asserted that the medical profession does not recognize these adverse effects because they do not occur for *"...years or even decades after a shot"* [10]. Other sites insisted that doctors deliberately refused to report vaccine reactions, or that there was collusion between the government and the vaccine manufacturers to cover up the true extent of vaccine injuries.

'Vaccination policy is motivated by profit'

"And then the money we make out of it! There is 1s. or 1s. 6d. for each vaccination, and a bonus for good work..... Seeing how it pays, you certainly must not go to the parties paid for disinterested advice." 1883 – Allinson, *The Vaccination Inquirer* (England).

"The drug companies have co-opted the system – the regulatory and the legal system....there are billions of dollars in this." 2002 – [102].

Of the sites studied, 91% insisted that vaccine policy is strongly influenced by the huge profits made by vaccine manufacturers, which influences the large number of mandated vaccinations and also promotes the cover-up of vaccine adverse events. Some sites argued that many physicians who carry out research concerning vaccine and vaccine adverse events are co-opted by gifts or research grants. This attitude was expressed by US Congressman Dan Burton (Republican) who presides over the US House Committee on Government Reform, and who seems concerned that his grandson may have become autistic from vaccinations. At hearings in April

2001, after a committee from the Institute of Medicine (IOM) concluded that MMR does not cause autism, Burton grilled IOM witnesses about the financial interests of the committee members and threatened to subpoena financial records from all of the reviewers, leading one witness to say that *"Congressman Burton is alleging that the IOM was in conspiracy with the vaccine manufacturers"* [11].

'Vaccination policy is a violation of civil liberties'

Of the antivaccination sites we studied, 77% attacked mandated vaccinations as a violation of civil liberties. This has been a common theme in antivaccination writings since governments began mandating vaccinations in the 19th century – at the time, such mandates were a political innovation that extended government powers into areas of traditional civil liberties in the name of public health [12]. Many sites attacked the idea of electronic vaccine registries as an example of 'Big Brother' intruding into the private lives of citizens.

'Diseases have declined without vaccines'

"...small-pox mortality is in no way influenced (except it be injuriously) by vaccination, but that ... when uninfluenced by vaccination, it follows the same law of decrease with improved conditions of general health as does the total death-rate." 1898 – Alfred Russel Wallace, *Vaccination A Delusion* (London).

"...vaccinations can be credited with only a small percentage of the overall decline of disease deaths this century. Yet even this small portion is questionable, as the rate of decline remained virtually the same after vaccines were introduced." 2002 – [103].

We found that 73% of sites stated that what medical authorities consider to be vaccine-preventable diseases had already begun to decline due to improved nutrition and hygiene and that vaccines were given undue credit for this. Many of these sites promoted alternative methods of enhancing natural immunity, such as breastfeeding or homeopathy (68% of sites specifically promoted homeopathy).

Design attributes

The design attributes we looked at showed an approach that relies heavily on emotional appeal and shock effect – 55% of the sites contained disturbing personal stories of children allegedly injured or killed by vaccine reactions and 23% displayed pictures of these children. We found that 32% of the sites displayed menacing hypodermics, often with elongated scary-looking needles.

Our overall impression is that the driving emotional force behind such sites is both the rage of parents who feel a child or loved one was damaged by a vaccine and the feeling that mandated vaccination is a violation of the human right to choose one's own medical treatments without government interference. Throughout the sites, the theme was expressed that the establishment – doctors, the government and public health agencies, and vaccine manufacturers – cannot be trusted.

What can we make from all of this? The process of studying this phenomenon has led me to some thoughts:

Vaccine opposition is here to stay

Members of the antivaccination movement, or what one Centers for Disease Control (CDC) representative prefers to call ‘vaccine safety activists,’ have been attacking the use of vaccines for over 200 years. We should give up any thought that hard-core vaccine opposition will end, or that education will ‘enlighten their darkness.’ Vaccine opposition is primarily based on emotion – attachment to alternative philosophical views of medicine and healing, or a visceral response to perceived injury in a loved one. What little is scientific is highly slanted to a conspiratorial view that amplifies adverse event reports and discounts studies that support vaccine safety.

Safety activists versus safety-concerned

Hard-core ‘believers,’ at least in the USA, probably only account for 1 or 2% of the population at best, based on a Colorado study showing in 1997, that philosophical exemptions from immunization were claimed for just under 2% of school-children [13]. However, there is probably a significantly larger audience of ‘safety-concerned’ individuals that is influenced by activist ideas. A recent US study by Gellin *et al.* found that 25% of parents believed vaccinations could weaken their child’s immune system and 23% expressed a concern that children get too many immunizations [14]. Although most of this 23–25% probably still get their children immunized according to the recommended schedule, they are vulnerable to persuasion by the activists.

Having said this, you may be surprised by what I am going to say next:

This fuss about vaccine safety is all quite normal

Sending your child to the doctor to be vaccinated is a little like sending your child off to fight in a war. In both cases, society asks the parent to accept a small risk for their child to benefit the whole of society. The normal reaction of every parent is that every other child than his own should go to war or get the vaccine. That is, someone else should take the risk and me and mine should get the benefit [15]. In this sense, it is also probably inevitable that some groups will oppose the idea of war, and some groups will also oppose the idea of vaccines.

Much has been written about how to approach parents resisting vaccinations for their children and several websites such as [104] and [105] have excellent informational resources. However, I am going to make just a few suggestions about how to handle certain aspects of the vaccine safety issue from the vantage point of communicating risk on a public health level, based on sound advice from an expert in risk communication, Peter Sandman [16].

Avoid the impulse to overly reassure the public about vaccine safety

Trying to reassure people too much usually backfires. Rather than convincing them there is nothing to worry about, their reaction often is that either you are not taking the risk seriously enough, or the risk is so terrible you do not dare tell the truth. This is exactly what happened in the UK with the crisis over bovine spongiform encephalopathy (BSE, or ‘mad cow’ disease).

“In the 1990s the epidemic was in the upswing. British government officials at the time said don’t worry, there is nothing to worry about. This of course only led the public to become more skeptical.” [17].

The end result was so great a collapse in public confidence in the health authorities that last winter the Health Minister in the UK blamed loss of confidence in MMR vaccine on the BSE crisis [18]. The message is: if we convince the public that vaccine safety is a real concern and we’re constantly working on it, the public can relax. If we seem to be too relaxed, then they have to be worried about it.

The control issue

People are much more upset about risk when they feel they do not have any control over it. I know of a family physician who has many parents in his practice who resist vaccinations for their children. Yet he has managed to get most of these children fully vaccinated. How? By giving the parents the option of delaying some shots by a month, sometimes a year or more. I am not advocating this as a general policy, but there is something to be learned here about sharing control. The greater the extent that we allow the public to get involved in the decision-making process about who gets what vaccines and when, the less outrage and concern we will have to face later.

A matter of trust

As experts, we feel justified exaggerating or oversimplifying if we feel it is in the public’s ‘best interest.’ Yet, we are outraged when the ‘vaccine activists’ exaggerate or oversimplify to make their point. The problem is that the public is more forgiving when safety activists exaggerate than when government or industry officials do the same. As Peter Sandman puts it:

“Activists are like society’s smoke detectors. If the smoke detector goes off when there is no fire, that is an inconvenience; if it fails to go off and the house burns down, that is a disaster.the public does not mind much when activists exaggerate a risk. We expect them to warn us too often. But when a company or an agency is found to have understated a risk, the loss in credibility is disastrous [16].”

A consistent policy of honesty and openness will go a long way to defusing much of the criticism that has been leveled at agencies promoting immunizations.

Last winter, public confidence in MMR vaccine fell so low in the UK that 75% of parents expressed a desire to get the measles, mumps and rubella vaccines separately rather than as a single MMR shot [19]. Our goal should be not to persuade the 1 or 2% of hard-core activists, whom I do not believe are persuadable. Our goal should be to reduce the concerns of the 25% of

the public who are worried about vaccine safety, and prevent that 25% from blowing up into 75% as occurred in the UK. The public can be surprisingly sensible about vaccine safety risks if they are given the facts. What we need to do is talk straight with them – and let the vaccines sell themselves.

References

- 1 Nasir L. Reconnoitering the antivaccination websites; news from the front. *J. Fam. Pract.* 49, 731–733 (2000).
- 2 Taylor H. Internet Penetration at 66% of Adults (137 Million) Nationwide. Harris Poll No. 18. Rochester, NY, USA: Harris Interactive; April 17, 2002. Available at: www.harrisinteractive.com/harris_poll/index.asp?PID=295. Accessed September 5, 2002.
- 3 Taylor H. Cyberchondriacs Update. Harris Poll No. 21. Rochester, NY, USA: Harris Interactive; May 1, 2002. Available at: www.harrisinteractive.com/harris_poll/index.asp?PID=299. Accessed September 5, 2002.
- 4 Davies P, Chapman S, Leask J. Antivaccination activists on the world wide web. *Arch. Dis. Child.* 87, 22–25 (2002).
- 5 Pew Internet & American Life Project. The Online Health Care Revolution: How the Web Helps Americans Take Better Care of Themselves. Washington, DC, USA: Pew Internet & American Life Project; 2000. Available at: www.pewinternet.org/reports/toc.asp?Report=26. Accessed September 5, 2002.
- 6 Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *Br. Med. J.* 324, 573–577 (2002). Available at: bmj.com/cgi/content/full/324/7337/573. Accessed September 5, 2002.
- 7 Wolfe RM, Sharp LK, Lipsky MS. Content and design attributes of anti-vaccination web sites. *JAMA* 287, 3245–3248 (2002). Available at: jama.ama-assn.org/issues/v287n24/abs/jbr20117.html. Accessed September 5, 2002.
- 8 Leask J, Chapman S. An attempt to swindle nature: press anti-immunisation reportage 1993–1997. *Aust. NZ J. Public Health* 22, 17–26 (1998).
- 9 Wolfe RM, Sharp LK. Anti-vaccinationists past and present. *Br. Med. J.* 325, 430–432 (2002). Available at: bmj.com/cgi/content/full/325/7361/430. Accessed September 5, 2002.
- 10 Jillani LK. Five baffling vaccination facts. PAVE (People Advocating Vaccine Education) website. Available at: www.vaccines.bizland.com/lkj.htm. Accessed September 5 2002.
- 11 Vastag B. Congressional autism hearings continue: no evidence MMR vaccine causes disorder. *JAMA* 285, 2567–2568 (2001). Available at: jama.ama-assn.org/issues/v285n20/ffull/jmn0523-1.html. Accessed September 5, 2002.
- 12 Porter D, Porter R. The politics of prevention: anti-vaccinationism and public health in nineteenth-century England. *Med. History* 32, 231–252 (1988).
- 13 Felkin DR, Lezotte DC, Hamman RE, Salmon DA, Chen RT, Hoffman RE. Individual and community risks of measles and pertussis associated with personal exemptions to immunization. *JAMA* 284, 3145–3150 (2000).
- 14 Gellin GG, Maibach EW, Marcuse EK *et al.* Do parents understand immunizations? A national telephone survey. *Pediatrics* 106, 1097–1102 (2000).
- 15 King S. Vaccination policies: individual rights *versus* community health. *Br. Med. J.* 319, 1448–1449 (1999).
- 16 Sandman PM. Responding to community outrage: strategies for effective risk communication. American Industrial Hygiene Association, Fairfax, VA, USA. 1993.
- 17 Henahan S. Mad Cow Disease: The BSE Epidemic in Great Britain. An Interview with Dr Frederick A. Murphy, Dean of the School of Veterinary Medicine, University of California Davis. Access Excellence. The National Health Museum. Available at: www.accessexcellence.org/WN/NM/madcow96.html. Accessed September 10, 2002.
- 18 Southerton S. BSE legacy to blame for low trust on MMR, says health minister. *Epx. News*, Feb 21, 2002. Available at www.epolix.com/bos/epxnews/000004E0920.htm. Accessed September 10, 2002.
- 19 Travis A. Three out of four parents favour single jabs for MMR. *Guardian Unlimited*, London, UK, Feb 20, 2002. Available at: society.guardian.co.uk/publichealth/story/0,11098,653081,00.html. Accessed September 10, 2002.

Websites

- 101 www.healthy.net/asp/templates/article.asp?PageType=Article&ID=525#advcreff
- 102 whale.to/m/belkin1.html
- 103 www.gval.com/myth2.htm
- 104 www.immunize.org/genr.d/vaxsafe.htm
- 105 www.immunize.cpha.ca/english/resourc2.htm#providers