

# 7

## Constructions of Risk: Change, Conflict and Trust

The three case studies discussed above have some important similarities. Each involves an element of uncertainty. Each has been responsible for major news events; each has involved accusations that the mass media bear some responsibility for an unjustified level of public concern. Each involves issues about the responsibilities of national governments in protecting citizens from harm.

There are also significant differences between the three cases. In the case of SARS there is a very clear and obvious health effect. The deaths and illnesses caused by the new virus were communicated around the world. The mystery centred upon the biological nature of the disease organism (the pathogen), how it had come into being, how it had spread from victim to victim, what the future course of the disease might be. In the other two cases there are practices – using a particular technology, submitting to a particular medical intervention – and possible consequences – brain cancer, autism – but dispute and confrontation about whether there is any relation between the two. These two studies, although similar, also have differences. There is no obligation to use a mobile phone, but there is an obligation for children to be vaccinated against measles, mumps and rubella, although no absolute compulsion. Vaccination against these diseases is for the positive benefit of the individual, and is also good for the population as whole, helping to contribute to the eradication of the diseases within whole populations. Using a cellphone is a convenience not a therapy, even though there are circumstances where its health benefits may be considerable – calling an ambulance in an emergency is an obvious case of this.

These differences do have consequences for the ways in which the three issues are variously constructed through the World Wide Web and Usenet discussion. Again, the distinctiveness of the topic of SARS stands

out in contrast with the other two. SARS as a news story erupted suddenly, without prior warning, during a period when the headlines had been otherwise preoccupied by another globally significant event – the war in Iraq. Usenet response to the news was very fast, on a very large scale, intense, and took place among online groups of widely disparate kinds. World Wide Web resources, apart from SARS Watch and the WHO resources, lagged a little bit behind the newsgroups. In contrast, the level of Usenet attention to the other subjects was more moderate in quantity, more sustained over time and conducted within narrower boundaries of interests. Usenet discussion of MMR in particular mostly takes place within rather obvious contexts such as the ‘parenting’ newsgroups. A little spills over into other groups, mostly when there are mass media stories to provoke it.

## **World Wide Web and health risks**

### **Types of website**

Each of the topics is quantitatively well served by the World Wide Web. Three important types of website with resources devoted to this subject are web-based news sites, official sites and unofficial sites. Web-based news sites offer news reports and include the websites of established news organizations like CNN and the BBC from the world of broadcasting, or the *New York Times* and the *Guardian* in the world of print journalism. Alternatively, web-based news reports might be posted by organizations like Yahoo News, restricted to the web alone for output, drawing on the same newswire copy as the traditional organizations, as well as on the output of those organizations. Both streams of web news are sustained in whole or in part by advertising revenue unless, like the BBC they are prohibited from doing so.

Official sites are the sites of organizations which have a specific remit in relation to the topic. These topics are all health-related, so the most obvious kinds of official site to show interest in SARS, in mobile phones and cancer or MMR and autism are those of institutions in the public health business. Apart from the World Health Organization, most of these institutions are national bodies with government funding (including their scientific branches), although there is also a respectable ‘web presence’ for non-governmental organizations. Commercial organizations also add to the available resources on the web. Aegisgard tries to make money by advertising its radiation protection shields online; Choice Healthcare Services advertises single-vaccine alternatives to MMR. But for legal reasons they have to be extremely circumspect in

what they say about the potential of harm from the 'risky' product and the scope of the protection offered by their own. The purveyors of single vaccines in particular take their stand on the principle of 'parental choice' rather than engaging in any more explicit forms of promotional discourse.

Unofficial sites can vary enormously. In this material they are represented by the cellphone FAQ, Electric Words, SARS Watch, Wangjian-shuo's blog and Whale. The cellphone FAQ can be regarded as unofficial, since it is the responsibility of a single individual. But this individual is an employee of an academic institution, the site carries the logo of that institution and its reputation, as well as that of the webmaster, is at risk if the information on the site is flawed. SARS Watch moves one more degree in the 'unofficial' direction. It is an individual's site, and designed on blog principles, that is, by date, but much of its information is drawn from the more official sites, especially that of the World Health Organization. The remaining three sites are even less official, but in quite different ways. Electric Words and Whale are, respectively, the respectable and the outrageous face of critique. Both of them set their face against the current majority/official view. But where Electric Words provides a reasoned though impassioned critique of that view, and restricts the critique to specific topics, Whale offers an eclectic collage of textual fragments to support an ethos of opposition to orthodoxy in medicine, to vaccination and to the MMR vaccine. Wangjianshuo's blog is not at all in the business of critique. It is the role of the individual also to offer the voice of experience, the view from the lifeworld. This lifeworld (as also in the newsgroup material) is not just a matter of recording daily experiences, but also of expressing *opinions* – without having the kind of responsibility that other voices do to turn those opinions into ones that readers can or should share.

The web clearly does provide a congenial channel of publicity for extreme voices of all kinds, surpassing anything available prior to the arrival of the internet. However, the evidence from these three studies overall suggests that the voice of orthodoxy and the mainstream view continues to maintain a much firmer web presence than any rival views. In some cases – for example, the Electric Words site – the rival view and the mainstream view share a considerable amount of their beliefs. If the Stewart Report is seen as belonging to the mainstream, its recommendation to keep children away from mobile phones until more is known is quite consistent with the precautionary approach promoted on this site. The MMR case study showed that the non-mainstream voice was struggling to make an impact online.

In coming to this conclusion it is important to remember that even if the defence of MMR has both quantity and quality on its side in respect of the World Wide Web materials, this is no guarantee that the sites defending MMR will be the influential accounts as far as readers are concerned. The problem is one of trust. If readers have reasons for not trusting the voice of government, of industry, of science, of the mass media, then it does not matter what those voices are saying (see Langford, Marris et al. 1999 on public health and trust). To explore the limits of trust it is necessary to examine the voices of those who watch television, listen to the radio, read newspapers and consult the World Wide Web. Some of these people are participants on Usenet and their accounts will be revisited below.<sup>1</sup>

### **Stability and change**

In examining what the web makes available to its users, it is only possible to take a snapshot of provision at a given point in time. The fluidity of the web and the limited amount of public-access archives for superseded web resources means that accessing earlier versions of texts can be difficult or impossible. The question of editing/updating is one that confronts individual webmasters. On the one hand, times change and websites need to change with them; on the other hand, earlier material is not necessarily made redundant by newer information and ideas, and in any event, editing can be labour-intensive and a chore – it is worthwhile, particularly for sites maintained by individuals, to minimize the upkeep effort.

Some sites are designed so that newer versions of the same text need involve only clearly-identified additions, no substantive changes or deletions. Blogs (diary-style sites), discussed in Chapter 5, are of this kind. Thanks to this it is possible to see exactly when SARS Watch began (29 March 2003) and was ‘mothballed’ (8 June 2003):

I’ve spent time researching what little is known about SARS, and I am alarmed about how little attention is being paid by the government and the media to the SARS epidemic. I’ve written about it, perhaps a bit hysterically, to several people who have much wider audiences than I do, hoping that they would focus in on it. They have declined to do so.

Well, I have some time, I’ve been looking for an excuse to play with a new piece of software, it looks like there is a real need for getting more information about this epidemic more widely disseminated, and it seems like an opportunity to turn my formerly useless

knowledge to some good. So I'm launching [www.sarswatch.org](http://www.sarswatch.org). 29 March 2003.

While I am grateful to the many people who contributed financially to SARS Watch Org, I have not received enough contributions to make working on SARS Watch Org full-time a reasonable proposition. Also, in spite of all the protests the last time I suggested closing SARS Watch Org, it is clear that the original impetus for the site, the lack of good sources of information about the disease, is no longer a reasonable concern. Finally, it is clear that the SARS epidemic is winding down, although it isn't clear how much this can be attributed to the public health efforts of the Chinese authorities, and how much to the seasonal life cycle of the virus. So I have decided to mothball SARS Watch Org. I will leave the site in as is, so it can serve as a historical record if anyone is interested in how the epidemic started. The links should still be useful, and the automatic **news** and **weblog** section will still be updated daily, but I am not going to read and write about SARS every day any more. June 8<sup>th</sup> 2003.

There are materials on this site other than the dated entries and if these have been changed during the life of the site, the editing has left no traces.

The World Health Organization deals with the problem of the past by maintaining a distinction between current materials and the searchable archive. It is someone's responsibility in Geneva or wherever the site is maintained to decide when a text has lost currency to the point that it can be assigned to the archive and becomes accessible only through that point of entry. This is not so very different from the blog approach, except that the principle of 'currency' which keeps particular links on the front page of the site is not the same as the arbitrary relentless procession of calendar dates. It is a more relative principle: an item's currency depends on relevant changes in the world. Two documents created on the same day may lose currency at different times thereafter. A report from a particular committee remains current until after the next committee meeting, while announcements about the nature of the pathogen depend upon the speed with which the scientific teams can establish new findings.

Another manifestation of the change/stability dynamic is apparent in the case of the cellphone antenna FAQ. This, like SARS Watch, can be seen as a text which allows additions but not deletions. Given the design principles of the site, around 'Frequently Asked Questions' concerning cell phone antennas and health risks, there is less reason for a non-

deletion, non-change rule. In the case of a blog with entries tied to dates, the dates and their entries pass into history. In the case of an FAQ with entries tied to questions, it is possible to imagine questions changing as well as the answers to those questions. But it is easier and more revealing to add continuously rather than to edit. This also has the advantage of revealing research to be a process, cumulative in its findings, showing how one study follows on from a previous one. This particular FAQ begins with a 'What's New' section devoted specifically to the changes since the previous version. 'What's New' is a set of hyperlinks: the 'new' material itself is found within the main text. Typically a new item is a brief report on the findings of a piece of relevant research. Each such addition is placed within the FAQ in relation to the particular question which it helps to answer. Unlike a blog therefore this approach requires two edits of the text: one within the FAQ proper and one within the 'What's New' section. In the following version of a 'What's New' section from January 2004, only one of the bullet points indicates editing which involved changing text: all of the others involve addition to the previously existing text.

#### What's New?

v6.0, Jan 2004:

- Some out-dated references were removed and Q19C was reorganized.
- A fifth letter to the editor [216C] concerning the 2002 Utteridge et al report [197] that the 1997 mouse lymphoma study of Repacholi could not be replicated.
- A report [166] that mobile phone RF radiation had no effect on immune function in humans.
- A report [243] that mobile phone RF radiation had no 'substantial effects' on immune function in mice.
- A report [244] of subtle changes in the brain function (EEG) of mobile phone users.
- A report [245] that mobile phone RF radiation had no effect on learning in rats.
- A report [246] that mobile phone RF radiation had no effect on melatonin levels in rats.
- A report [248] that exposure of mammalian cells to RF radiation did not produce or enhance genotoxic injury unless the SAR exceeded 50W/kg.

- The international committee working on revision of the IEEE C95.1 RF radiation standard published a set of 13 'white papers' that review the relevant biology and epidemiology [247].

The permanence of older material in the FAQ has a different rationale from the permanence of older material on SARS Watch. In a diary-style composition, entries remain because the past does not change. Each entry belongs to its moment in the past and always will. In the case of the FAQ, time is not the point. Entries persist not because of their place in history, but because they have been added to the permanent knowledge-base for this particular topic. For example, one much-cited study in this research is the Repacholi or Adelaide Hospital study of radiation-induced cancer in lymphoma-prone mice. The significance of this study for the debate is now fixed in the assessment of this webmaster, who has no need to rewrite his own comments on it thereafter. When other researchers try to replicate the results of the Repacholi study and fail, this too is recorded in the FAQ but as an addition: no revision of the earlier entry is required.

### **Usenet and health risk**

SARS was by far the most popular of the three topics on Usenet, followed by MMR and then by cellphones. For the SARS study a month would have been long enough to assemble the 1000 messages required for the sample. For the other two studies, the collection period necessarily spanned years rather than months.

Quantifying the degree of interest is of some value but only when accompanied by an assessment of what people were saying and how they were saying it. They were asking questions, answering them, offering opinions and arguing, coming to the topic from something different, and moving off the topic when struck by other ideas. They joked, teased, pontificated, shared personal information, abused, expressed sympathy, and passed on relevant news from other sources. This is normal enough for any kind of conversation, online or otherwise. Much of this has had to be ignored in the present context, in order to focus upon what is of most interest for the present research: the range of opinion which is possible upon each of the topics, what happens to an expressed opinion in this interactive context, the range of information sources which are acknowledged by participants and the terms on which different sources are accorded the trust or distrust of Usenet participants. Two themes are explored below, one focuses upon divergence and dispute within Usenet and one focuses upon sources and trust.

### **Opinions in conflict**

A survey questionnaire about people's opinions concerning the risk of autism from MMR might start with a proposition: 'children injected with the MMR vaccine are at greater risk from contracting autism than children who are not. Do you agree?' and offer three possible answers, inviting respondents to pick either 'yes', 'no' or 'don't know'. In the context of Usenet, it is possible to examine materials where people spontaneously offer their views on this and equivalent questions for the other topics, and where they do so in their own words. To classify these people, or these messages, as 'yes', 'no' and 'don't know' positions is much harder than with the simple 'check boxes' of the survey questionnaire. There is ambiguity and equivocation alongside more emphatic expression, as well as many contributions where the question is not relevant, and many where it is relevant, but tangential to the participant's central focus in his or her contribution. What looks 'messy' from a survey point of view is also where its value lies as a point of entry into the discourse of SARS, MMR and mobile phones. Rather than viewing messages simply as answers to a question along the lines indicated above, it is possible to examine them as speech acts, in the rhetorical business of 'talking up' or 'talking down' the postulated risk. And since the context is interactive, it is also possible to examine what happens in the encounters between divergent positions.

Accordingly, the preceding three chapters began by assessing the proportions of sampled messages which were engaged in talking up the risk or in talking it down. In each case the figures suggested about equal proportions of fearful voices and complacent ones. Perhaps this is not surprising in an interactive medium (people have more to say when there is something that they disagree about than when they are in accord) not to mention a medium which is thought to be congenial to confrontation.

Whether talking up the risk or talking it down some very similar strategies are adopted for each of the topics. Among those inclined to think that there is little or no risk of the proposed kind, 'blaming the media', generically, for its exaggeration of the danger is one of the most striking. The participants discussing SARS include many who wrote about 'the media' blowing the new illness up out of all proportion to its real significance as a disease – in comparison with major flu epidemics, with AIDS, with deaths from road traffic accidents and so on. Many of the participants discussing mobile phones wrote about the lack of scientific understanding for microwave radiation displayed by 'the media' in general (and sometimes by particular programmes or articles). Many of those discussing MMR wrote that, so far as the science was con-

cerned, Andrew Wakefield's hypothesis *had* been refuted – it was only 'the media' which could not let go of such a controversial, newsworthy possibility. At the same time, in all three cases it is the mass media that people, on either side of the argument, rely on for their information, and in each of the studies, newsgroup participants constantly refer one another to the websites of news organizations for up-to-date input on the relevant topic. Much news citation is uncritical: but citation of specific *non-news* media sources (TV dramas, current affairs programmes, documentaries; in print, features and editorials) introduces a critical note.<sup>2</sup>

Another key similarity between the 'talkers up' and the 'talkers down' is in their preferred points of reference and comparison. The proportion of people who die and suffer injury in car accidents compares 'favourably' with the proportion at risk from injury by mobile phone, SARS infection and MMR injection for those disposed to play down the risk in each case; 'favourably' in the sense that the numbers are much, much higher with road traffic accidents than with these other 'risks'. In contrast, the relevant comparison for those disposed to take the opposite view is not just a matter of contrasting statistics: it involves, specifically, cases where the voice of authority (the government and/or the medical establishment – probably in affiliation with some industry) had proved itself untrustworthy in its reassurances. The 'reference event' function varies as between Britain and the USA. In Britain, the key reference event is the BSE/CJD affair of the 1980s and 1990s. In the USA it is the much longer history of the fight to establish smoking as a dangerous activity.

There is a real risk at stake in Usenet discussion, albeit one of a very different kind from those which are the substantive focus of the study. The real risk is the risk of loss of face. To express an opinion (in a face-to-face context) is to challenge the integrity of an interlocutor who disagrees with you and to risk loss of face yourself when you are confronted with their opposition. The invisibility of the actual face, not to mention most other attributes of personal identity in CMC has been an important research theme in this field of study. This invisibility may be one of the factors inducing more confrontational discourse – more 'flaming' – in CMC than in equivalent face-to-face exchanges. Even in Usenet however, disagreement need not be expressed agonistically. It can be managed with a show of politeness and mutual respect. Parents disputing the effects of the MMR vaccine were often respectful and laid considerable emphasis on the principle that the decision to vaccinate or not to vaccinate was ultimately a personal one.



*Example no. 3 (2001) on a cellphone newsgroup*

God u must be so stupid! Or are you just thick? Or just incredibly gullible? Didn't u ever go 2 school?

Disagreements on these threads tend to begin at the general level of whether there is or is not a health risk of the kind proposed. Some groups have sufficient expertise among the participants to allow them to take the debate on to a scientific and technological level:

*Example no. 4 (1999) on a cellphone news group*

>Actually, buried somewhere in that study released a couple years  
>ago is a portion which noted higher tissue heating and higher  
>possible genetic changes with digitally modulated signals, as  
>opposed to analog modulation. Sorry, can't site the specific part  
>of that study.

XX  
This doesn't make any sense. I am an electrical engineer working in communications, so I have some input that contradicts that statement. Digital transmission is much more resilient to noise than analog transmission. Therefore, a digital transmission requires less signal power than analog. It is the transmitted signal that people fear could cause 'tissue heating' and 'genetic changes'. This is the main reason that the dual band phone show 2-3 times longer battery life in digital mode than analog.

'Informed dissent' of this kind usually puts an end to argument. No further protest is heard from the original contributor in this case. But the 'science' needed to produce this effect is *canonical* science/technology. It gets more difficult if participants attempt to draw upon science-in-the-making to support their arguments, especially if the science in question is epidemiological.<sup>3</sup>

*Example no. 5 (1993) on a science newsgroup*

>There seem to be several questions floating around here and  
>getting mixed up. First is the question of whether non-ionizing  
>radiation can have a carcinogenic effect.

>The evidence here seems to be piling up: the original  
>Wertheimer-Leeper study has been confirmed a number of times  
>(Tomenius, Savitz, London, Feychting, Folderus [occupational  
>but ELF], a new Danish study [Olsen]) and a good sample of  
>occupational studies, mainly of case-control design for brain  
>cancer or leukemia. Then comes the question about particular  
>emf exposures like cellular phones. Since there probably is a  
>window effect for frequency and amplitude, I agree that the ELF  
>studies do not necessarily implicate cellular phones. HOWEVER,  
>most occupational and environmental carcinogens were first dis-  
>covered by astute clinicians who saw something unusual. In this  
>case I believe there was also a neurologist.

XX  
Stuff seems to be piling up, but is it evidence? I assume that all  
of these are epidemiological studies with low incidence and  
various confounding factors?

In this case both participants display some expertise on the subject. Yet the question of ‘evidence’ is not restricted to participants on science newsgroups or who claim expertise in the manner of the second participant in example no. 4. In its many forms it is *the* issue across all of the material in the mobile phone and MMR case studies: a kind of ‘pre-technical’ debate informed by ‘circumstantial’ knowledge of science more than knowledge about particular studies and their methodologies. Here are some of the forms that it takes:

- Asking someone to provide evidence when someone makes a strong ‘risk’ claim, often with the implication that they can’t – because there is none.

*Example no. 6 (2000) on a cellphone newsgroup*

>there is a non-thermal effect that is poorly researched, and  
>that any risk is proportional to exposure. You don’t dispute  
>any of my assertions.

XX  
Well I do. What is this ‘non-thermal effect’ and what evidence  
do you have of its existence?

*Example no. 7 (1999) on a parenting newsgroup and a science newsgroup*

>If you had attended the 'Biological Treatment of Autism  
>Conference' a couple months ago in Orlando, you would have  
>learned first hand from world class researchers and MDs how  
>these vaccines, especially when given in triads, relate to  
>autism and autoimmune diseases.

XX  
Cites, please to the peer-reviewed, published studies of these  
'world class researchers' showing a statistically robust, repro-  
ducible link between vaccine triads and autism.

- Telling someone that the evidence they are citing is unsatisfactory – usually because it is 'anecdotal' or else because it is a citation of an 'opinion' not of 'facts'.

*Example no. 8 (2002) on a cellphone newsgroup*

Anecdotal evidence is very unreliable, someone thinking a  
phone (or whatever) made them ill does not necessarily make  
it so. None of these claims have been substantiated and large  
scale studies have shown no evidence of damage. If the anecd-  
otal evidence was plentiful \_ and \_ it was true the results  
would be measurable, they are not.

*Example no. 9 (1999) on a children/parenting newsgroup*

>>This view was endorsed by editorials in both of Britain's  
>>leading medical 'journals. The hypothesis rests on clinical  
>>anecdote [that is, Dr Wakefield's description of 12 cases]  
>>rather than an epidemiologically sound base (statistics),'  
>>observed Dr Angus Nicoll in the British Medical Journal,  
>>adding, 'Chance alone dictates that some cases [of autism]  
>>will appear shortly after vaccination.'

XX  
>It is amazing how these experts can say with a straight face,  
>when confronted with evidence, that there is no evidence.



Example no. 12 (1999) on a children/parenting newsgroup

Public health officials unblinkingly aver that there's no 'proven' casual [causal] relationship between vaccination and death. \*Literally\* correct, perhaps; the pivotal word being 'proven.' What ISN'T stated, however, is that there's also no proof (i.e., it hasn't been 'proven') that vaccines DON'T cause death.

- Conceding that 'no evidence of risk' is not the same as 'no risk', or that 'you can't prove a negative', while protesting that 'evidence of no risk' is an impossible demand.

Example no. 13 (1995) on one science and one cellphone newsgroup

This is why us microwave types get nuts at the cries of fear and danger. We can't rule out an \*unknown\* effect, but the known effects ARE ruled out, and the level of evidence for some unknown process are pretty lousy small.

Sometimes this line of argument is converted into a *reductio ad absurdum* form. Since you cannot prove a negative, you can also not prove that 'milk' does not cause autism – or even 'breathing' – so the parent who is operating on the logic of avoiding everything where risk has not been completely eliminated as a possibility must, to be consistent, avoid those too.

Example no. 14 (2002) on a children/parenting newsgroup

>My son is 3 years old and as yet has not had his MMR vaccine,  
>I have had several conversations with my doctor, and they  
>still say he must have the vaccine and they wont give it  
>separate. The reason is that two young children in my direct  
>family (cousin's) have had the MMR vaccine and both has  
>been diagnosed with Autism, one is in primary 4 now but has  
>been to several special schools, I do not want to take the  
>chance that my son could end up with Autism.

XX  
Have they both eaten peanut butter sandwiches and drank milk?  
Better avoid those too just to be safe. Oh yeah, and whatever you  
do – don't let them breathe, everyone with autism breathes.

Newsgroup discourse can be used to explore not just overt disagreements, such as the above, but also aspects of conflict which are 'below the line' and which contribute in a different way to construction of meaning, as discussed in the cellphone chapter in relation to the use of the 'brain frying' image and in the SARS chapter over the legitimacy of the term SARS itself and its place in the lexicon of disease (see also Launspach 2000; Hellsten 2003).

### **The limits of trust**

The vast majority of people who have to make decisions one way or another about their own behaviour in relation to a particular 'risk' do not have the technical knowledge to assess the available research evidence on its own terms. So it is not surprising that much discussion and debate turns upon which sources are worthy of public trust and which are not.

The MMR issue and the mobile phone issue are similar in that both have become structured as an opposition between a majority/mainstream view and a minority/fringe view. The mainstream view is broadly confident of the safety of the technology: the fringe view is the sceptical one, although the boundary line between mainstream and fringe is hard to pin down. What this structure produces is a perspective in which the majority view comprises voices from industry, science, government and the medical professions which are seen, collectively, to form a unity, with the same information to convey:

There-is-no-evidence-of- $\left\{ \begin{array}{l} \text{cancer-} \\ \text{autism-} \end{array} \right\}$  from- $\left\{ \begin{array}{l} \text{mobile-phones} \\ \text{MMR vaccine} \end{array} \right\}$

Does this unity, this 'Medical Establishment', also include the mass media? Not necessarily. Mass media accounts may be represented and used as the chink in the armour of orthodoxy. Hence the attacks on 'the media' by proselytizers for the majority/mainstream view: hence also the penchant for citation of sympathetic media accounts by risk promoters. To attack the mass media is to perceive them as having voices in their own right, rather than acting as a channel for other voices. This distinction is not a firm one since one way in which mass media can exercise power is in the way that they include/exclude particular voices and amplify or downplay those which they do include. Whether citation in the mass media detracts from or adds to credibility is an issue in its own right.

The pillars of orthodoxy are susceptible to representation as a 'They ...' whose interests make them culpably blind to the rationality of the

fringe account. What 'They' say cannot therefore be trusted. One (MMR) participant puts up the following resistance to a newspaper report on a scientific study, the report and the study being both generally anti-risk:

*Example no. 15 (2001) on a politics newsgroup*

What a load of bull, I know what to believe, would not trust these people that say there's no connection.  
Our government have a lot to lose by admitting there's a correlation.

Usually the wording in most messages where the risk is 'talked up' is less vague than this. The government, the industry, the medical profession, the scientists, are independently 'named and shamed'. The heavy reliance by doubters and critics upon the BSE and smoking analogies, discussed elsewhere, points the finger of suspicion principally at the government. Governments take their responsibilities to the profitability of industry more seriously than their public health responsibilities; industrialists wield (economic) power over governments and not the other way around. There are also numerous messages claiming that particular research, or all of it, is not independent but has been paid for by the industry, and cannot be trusted for that reason.

*Example no. 16 (1995) on one science and one cellphone newsgroup*

>A recent court case in FLA was settled when studies confirmed  
>that there are no detectable affects on human tissue caused by  
>cellular radio waves. You might check the biology news groups  
>for more info.

XX  
Studies conducted by who and for what organization? These kinds of studies require a much more flexible methodology than the hard sciences (i.e. physics, chem.) and hence can usually be manipulated to confirm a multitude of hypotheses. E.g. in the 70s the tobacco industry was producing 'studies' that showed there was no relationship between smoking and cancer and the Power companies have done the same. So if these so-called 'studies' were paid for by the Cellco and telecom manufacturers, I'd look at some work from an independent agency before making any strong conclusions.

*Example no. 17 (2001) on a local newsgroup*

Sadly most of the 'research' concerning MMR has been carried out by (or sponsored by) drug companies directly involved. This type of 'research' is how the rBST genetically engineered hormone treatment, for cattle got approval in the USA (and here now maybe). He who pays the piper calls the tune perhaps?

There is also, especially in relation to mobile phones, a lot of argument in which scientific facts and findings are discussed on their own terms. This exercise would lack any purpose if either of the arguers believed that scientists were simply producing the results which their paymasters had bought from them. This applies rather less to the SARS case study than it does to the other two because of the different components which were in the public domain in this case.

There is further evidence in this material against the existence of a widespread conspiratorial or radically sceptical frame in the fact that the doubters as well as the defenders on the MMR issue and the mobile phone issue are interested in pulling 'science' on to their side of the argument. In both cases this is an unequal struggle because the weight of opinion and argument favours the defenders of mobile phones and MMR vaccine. But there is extensive belief in the *possibility* of scientific truth so long as scientists are truly independent, and resources are provided for research to continue. The following illustration shows how far the conspiratorial line can be pushed.

The subject line in one MMR message reads: 'I think this is great news' and the message that follows offers a hyperlink to a news report of an epidemiological study in California with more evidence against the idea of an MMR/autism link. This message is posted to an autism support newsgroup in 2001, where participants have spent many years trying to get the link taken seriously. Unsurprisingly therefore the 'great news' spin is resisted by applying a sceptical interpretative frame:

*Example no. 18 (2001) on a support newsgroup*

Why, I think it isn't [great news]. . . .  
What they are missing in their cute little denial studies is the genetic predisposition to problems. If your family has depressed folks, Alcoholics, ADD, ADHD or dyslexia of any kind, DON'T let the next generation get all the shots at once.



health issues. This remains an extreme position among parents from all countries contributing to the Usenet debate.) Nevertheless, Usenet parents seem poised to trust the present British Labour government more if it would only provide them with a choice between MMR and single vaccines.

*Example no. 20 (2003) on a miscellaneous newsgroup*

So it might cost more to offer single jabs, but if the govt's first priority is maximum uptake of the vaccine, instead of being so bloody insistent that MMR is the only option they should offer other options. I'm sure if they hadn't been so suspiciously insistent, a lot more people would've thought 'there is no ulterior motive' and gone for the triple jab anyway.

There is also scope for a position which puts trust in the regulatory agencies such as the IEEE (Institute of Electrical and Electronic Engineers in the USA) and the CDC, viewing these indeed as part of the government apparatus but a part which in good faith seeks to ensure that industries work within guidelines which have public interest at heart. This is an official model of how governments should operate in relation to industry, and many people express faith that the model really does what it says on the tin.

*Example no. 21 (2001) on a cellphone newsgroup*

does anyone REALLY believe, that any manufacturer for that matter would be allowed by the authorities to market a phone which did not comply to these requirements – I don't think so.  
...

What is also very important about relations of trust in this form of discourse is that they are expressed within an interactive context, in contrast with the mainly monologic framing of the web pages discussed previously (SARS Watch stands out in this respect as the website which has gone furthest in the introduction of dialogic characteristics). Just as participants take issue with one another's representations of facts in physics and biology as well as in general knowledge, they also take issue with one another's placement of trust. Consider the following message sequence from the mobile phone material.

Example no. 22 (2003) from a miscellaneous group

>>>>Brain cancer statistics have risen steadily the past decade or  
>>>>so, and a recent study on the subject shows that business  
>>>>men above 40 [in Sweden] (who were the first to use  
>>>>cellphones on a frequent basis) are more likely to develop  
>>>>brain cancer than other groups.

XX

>>>What study is that? The one I quoted earlier\* was published  
>>>by the Swedish Radiation Protection Authority in 2002. It  
>>>examined several years worth of studies and found no link  
>>>between cancer and cell phones [full citation] . . .

XX

>>I don't know if it's published online yet. . . .

XX

>I would be interested in reading the study if it really did find a  
>risk of cancer associated with phone use.

>The FAQ I mentioned in a previous post discusses this a bit in  
>questions 13 and 14:

><http://www.mcw.edu/gcrc/cop/cell-phone-health-FAQ/toc.html#13>

XX

I would be cautious of these studies coming out of Sweden for one very strange reason. I have seen and heard of these studies for years, and they seem to be carefully done. Then there is no independent backup from the rest of the world. Hence I am not sure of their general applicability. I know this is strange, and I am NOT saying that the Swedish scientific community is not capable. This area though is really borderline science and the results so far worldwide look like a null effect.

The attempt to use 'science' to support the anti-phone position is weakened because other participants have not heard of the study and have heard of other research with which it is in conflict. The final contribution hints at problems of a methodological kind with studies coming out of Sweden, implicitly rejecting the alternative interpretation of the anomalous finding which would be to hypothesize some uniquely Swedish vulnerability on the part of the population studied.

'Don't trust the businessmen' is a proposition that both defenders and detractors of mobile phones can sign up to.

*Example no. 23 (1998) on one science newsgroup*

>I don't trust the businessmen when they say mobile phones are  
>safe. I just started a course in EM theory and I don't feel safe  
>about the phones.

XX  
You shouldn't trust businessmen about RF safety, because they  
don't know much of anything about it.

XX

>Can the experts assure me about its safety?

XX

RF safety experts can tell you that there are no known hazards  
unless you use one while driving a vehicle.

There are however, two groups of 'businessmen' (that is, industrial interests) in this particular topic. As well as phone manufacturers there are also the makers of 'protection devices'. Some fearful consumers rely upon information from these sources.

*Example no. 24 (1998) on a health support newsgroup*

There is also Microshield Industries PLC in the U.K. at <http://www.microshield.co.uk> They make a cellular phone cover that they say reduces the amount of energy absorbed by the head. I recall they claimed 90% attenuation. There is some good general information on their Web site.

More characteristically though, uncritical references to information from this branch of the industry are very quickly challenged, by participants with a more robust view of the safety of mobile phones, for preying upon the fears of consumers with products based upon disreputable 'science'.

*Example no. 25 (1999) on four cellular newsgroups*

>Are Cellular phone hazardous to health?  
>And if you think Cellular phones are hazardous to health, would  
>the use of Radiation Shields like the one sold at the URL below  
>alleviate the problem?

>Please see the URL below for details:

>[http://www.goaegis.com/aegisguard\\_phone\\_radiation\\_shields.html](http://www.goaegis.com/aegisguard_phone_radiation_shields.html)

XX

Total con Job, Because the phone has to transmit more power to overcome the power that is absorbed by the shield. If you are truly worried (And you should not be.) get a Hands free Kit. Again see part of the report on.

<http://www.newscientist.com/nsplus/insight/phones/mobilephones.html>

XX

Don't you get it? Acunet is trying to plant the doubt and get you to go to the website and purchase the shield!

However, when a similar critique of 'promotional discourse' was offered in respect of a contribution which suggested that MMR might not be safe, it was robustly challenged. A site called 'Thinktwice: global vaccine institute' at <http://www.thinktwice.com/mmr.htm> which associates itself with the sceptical view is extensively quoted by one participant in a 2002 thread on a health newsgroup. This produces the following response:

*Example no. 26 (2002) on a health newsgroup*

A sales hype site.

If anyone thinks that this site is a source of information to make medical decisions for their children, then read the hype regarding their polio book.

But whereas on mobile phone newsgroups such a reaction was generally sufficient to terminate this line of argument, in this case it is not, and the original contributor defends the site:

*Example no. 27 (2002) on a health newsgroup*

This is a source of information and many shared their concerns. The drug company that makes it has an extensive list of adverse reactions.

Why is that? Are they lying? Why would a company selling the product have such a LONG list?

Saying the MMR is perfectly safe is simple not true.

The industry itself, as represented on the Thinktwice website, is, for this participant, a source of information about the *bad* effects of vaccines, including MMR. Where an industry, with so much at stake, can acknowledge a risk, it must be trusted. This is the principle of: 'They wouldn't say that unless they had to' – and what they have to say, must be true. On the specific issue of *autism* however, no risk admission has yet been made from within the industry, whatever it may say about other possible hazards and contra-indications.

There may be scepticism about what manufacturers *say*, since this can always be framed as mere promotional discourse, like claiming that sugar is good for you because it gives you energy, while ignoring its other health effects. In some cases this can be played off against what they *do*.

*Example no. 28 (2001) from a radio hobbyist newsgroup*

I note that recent cell phone ads promise to include an ear piece free. You need not wonder why.

## **Stability and change**

### **SARS**

SARS as a topic on Usenet began with three messages on 15 March, the day of the WHO travel advisory. All of these started by providing information via references and citations, and two of these added their own comments which linked SARS with other global news stories:

*Example no. 29 (2003) on a health support newsgroup*

Don't know about you but I find this distinctly more scary than Saddam Insane

*Example no. 30 (2003) on a hobby newsgroup (science fiction)*

Well, 9/11 was nasty, but this looks like it could be much worse.

By 26 March there was more reflection on the implications of the outbreak and the wider political/medical context. One thread sought to initiate discussion on the overuse of antibiotics, another on the secretive

tendencies of the Chinese government. By the 29th the 'backlash' had begun, with the first of the threads complaining of 'media hype'—although this was not allowed to pass uncontested in the thread. What also began at this point was the use of newsgroups by participants to improve their information on the subject for personal reasons. Concerned individuals addressed questions to groups likely to have decent local knowledge.

*Example no. 31 (2003) on three local newsgroups*

What's the current situation for SARS in Beijing and Hong Kong? I'm in Taiwan and travel groups to China are all canceled. Hong Kong dimsum stores have no patrons. Companies stop sending people to China for meetings. Any info? This affects my friends from China and affects my schedule.

Circulation of news via reference and citation continued through the subsequent months. At the end of March, for example, someone used the groups to circulate a story about the shortage of face masks in Toronto; in early April there was a story about chlamydia and SARS and later that month, one about SARS in Baltimore. In May *The Lancet* published its first epidemiological study of the spread of the disease and references to this took place on Usenet threads; in June one of the stories was of a second SARS outbreak in Canada.

### *Cellphones*

By contrast with SARS, discussion of mobile phones and health on Usenet is more of a 'slow burn', beginning in the era before the massive expansion of internet access and of Usenet itself (not to mention the massive expansion of mobile phone use), continuing and growing throughout that era, spreading into a range of newsgroups which did not exist in the early period, and persisting into 2003, just as Usenet began its relative decline. The earliest Usenet message on this subject was a question, evidently provoked by mass media attention:

*Example no. 32 (1993) on a science newsgroup*

I've missed the news regarding the claims of cancer being linked to cellular phones. Could anybody fill me in and comment?

This message went on to invite a particular named individual to respond – which he did. This fits with the idea of newsgroups as ‘communities’, acquainted with one another via their use of the medium – although it is also consistent with the idea of pre-existent networks and communities using the medium as an additional communicative resource. Whichever it is, it is a form of ‘intimacy’ which does persist in the later years but alongside much more attenuated and anonymous relationships, with extensive use of nicknames rather than ‘real’ names for online identities. There was one other example in the material where a possible ‘lurker’ on the thread is addressed directly – it occurs in 2002:

*Example no. 33 (2002) on two regional/hobby newsgroups in the cellphone sample*

Are you listening, Lord Ponce-boy? Could be right up your (or any other idiotic conspiracy theorists) alley.

‘Lord Ponce-boy’ is a sarcastic corruption of an online pseudonym. No such person contributes on the thread, though he (the chosen nickname suggests a male not a female participant) does contribute on other threads within the same group. Clearly he is ‘known’ to the group as a promulgator of ‘conspiracy theories’ and despised by this contributor at least for that reason.

Through 1994 and 1995 the only newsgroups to take much interest are either scientific/medical ones, or else about cellphones on the technical side. Even in 1996 this pattern continues, although with one exception (in the sample) in a newsgroup classified as ‘miscellaneous’. This marks the point when the topic seems to take on a ‘general interest’ character:

*Example no. 34 (1996) on a miscellaneous newsgroup*

I do not wish to do any scaremongering, but I read a brief article in the British press yesterday (Mon 15th April) about Mobile phones causing cancer. How the heck can a mobile phone do any damage? I have a phone myself, but I am not familiar with the science of it . . . is it from the radio waves? (in fact what do mobile phones use – radio or microwaves?)

A newsgroup called 'alt.cellular' began in 1994, but did not feature any threads about health risks until 1996. By 1998 there were newsgroups devoted to particular models of mobile phone – Motorola, Fido, Sprint PCS, Ericsson and so on – as the technology became a genuinely mass market commodity. Interest in the health issue spread to these groups, while continuing on the 'older' groups, where it sometimes provoked the reaction 'Not this again!' as time passed and more people joined in the conversations. 'Cancer' groups became interested from 1994; other health-related groups focused upon particular conditions such as tinnitus joined in by 2000. The image of mobile phones 'frying the brain' was not restricted to any particular type of newsgroup or excluded from any: it occurred on threads at the technical end of the spectrum right through to 'misc.consumers'. It was used each year between 1997 and 2001 ('boil your brain' occurs in 1996) and although in the sample there are no 2002 or 2003 examples, the usage certainly continued during this period.

*Example no. 35 (2002) on a cellphone newsgroup and a regional newsgroup*

We have had overhead pylons for decades and only now are people/organizations recognising the health threats; we have had tobacco since the days of Walter Raleigh yet only now are US big and fat corps being forced to pay out; and we have been casually warned for many years that excessive use of a mobile phone can fry your head, oh and by the way, don't use them in petrol stations because they can cause sparks and a very nasty incident.

The 'double voice' of concern on the one hand and reassurance on the other, in response to the 'don't knows' who are just looking for information, was there from the beginning of the story in 1993 as these two messages on that early thread both show.

*Example no. 36 (1993) on a science newsgroup*

I appreciate the comments about non-ionizing exposures and cancer induction. It is quite a public-relations time out there for radiation-related folks. My concern hasn't been about thermal effects. It is the non-thermal effects, which would occur at possibly very low exposures. For microwaves and RF these would include general malaise, anxiety, headache, but, cancer induction is not one of them. Or could it be?

*Example no. 37 (1993) on a science newsgroup*

As for nonthermal effects of RF/MW; there is evidence that such effects exist. I don't find the laboratory evidence for nonthermal effects very convincing, but in any case most of the evidence for nonthermal effects does not point to a human health risk.

By 1994 the pro-risk voice was a little stronger:

*Example no. 38 (1994) on a cellular phone newsgroup*

The danger is real, but don't start to panic. The best way you can protect yourself is with moderation. If you're on the phone continuously, for huge periods of time, your chances will increase. A normal 3 watt carphone antenna has the waves travel through your rear window, rather than drilling through. Now, if it can easily go through your glass window, how easily can it go through your skull? The good thing about that is that handhelds are only .6 watts. Also, switch ears often. With these careful hints, you shouldn't have anything to worry about.

The tone of dispute was still polite at this early stage: other participants on this thread take issue with the wording 'the danger is real' but only to substitute something more like 'the jury is still out, let's not panic before we have to'.

*Example no. 39 (1994) on a cellular phone newsgroup*

IMHO [netspeak: In My Humble Opinion], I would say that until the jury is in, be cautious, but not worried. Your advice about moderation, as I said, makes sense to me. But your statement about 'danger' did not.

There was nothing that could reasonably be regarded as abusive, or even impolite, when this issue was discussed on Usenet until 1996, when it was provoked by a description of mobile phone technology as 'unnatural'. The abuse took the form of ventriloquistic mockery for a 'Luddite' worldview.

*Example no. 40 (1996) on a telecommunications newsgroup*

What a load of bloody rubbish you have written ! Oh dear, those steam cars, they're not natural ! I saw one go 6 miles an hour yesterday – that was faster than the man with the flag !

1996 was also the year when the first really emphatic 'no risk' messages appeared, in contrast to the earlier 'no evidence of risk' ones.

*Example no. 41 (1996) on two science newsgroups*

There is no known physically plausible mechanism whereby non-ionizing electromagnetic radiation such as the radio waves from cell-phones could cause cancer. Such radio waves do =NOT= have sufficient energy to =directly= damage anything in a cell, nor do they resonantly interact with anything that we know of existing within a cell. There is simply =NO= physically reasonable mechanism that could possibly justify the claim that cell-phones can cause cancer.

This was politely contested (no *known* mechanism, but there could be an unknown one): the contestant was a lone voice and was mocked for his efforts. Discussion of 'protection devices' (radiation shields, stickers, hoods and so on) – much of it scornful – also began in 1996. The exception is the hands-free kit, which essentially got the thumbs-up from 1996 and throughout the rest of the period, even from people who wanted to reassure more concerned participants: their line is 'use hands-free if you're worried'. There was a blip in this following the publication of the *Which* report, but it did not do lasting damage to the reputation of the hands-free kit as a safety precaution. In a few threads from 2003 which were also examined, all of the trends and patterns established in the earlier phases of the story were present: voices for and against the idea of risk, in more or less equal balance, recommendations to use hands-free kits, discussion of the value of particular studies, citations of the cellphone antenna FAQ and so on. But there was less animosity in 2003 than in the earlier years which may suggest that although the indeterminacy is still there, it is at a level and of a type that the public has learned to live with.

*MMR*

As it develops over time on Usenet, the MMR story was more like that of mobile phones than it was like that of SARS. But there are important differences. Although the MMR corpus covers almost as long a period as the mobile phone debate (from 1995 as compared with 1993), and although it captures what seem to be the earliest online message on this topic, there was actually very little traffic, comparatively speaking, until the publication of the seminal paper by Andrew Wakefield and his colleagues in 1998. That there was any discussion of the MMR/autism link prior to 1998 at all is of interest. The earliest message wrote of having 'read some discussion' about this – but probably not on Usenet. A curious feature of this thread is that after the first two messages in 1995, the thread 'went to sleep' like Rip Van Winkle until 1997, and then again until 1998, when it became very active. Two other early threads comprised just six messages between them. It seems that there was just not enough 'happening' to fuel extensive discussion in these forums before 1998. All of this changed radically after February 1998. The support groups where the topic began were joined by general health groups and children/parenting newsgroups. For the most part this cluster of groups kept the topic to itself until 2001, when there was some broadening out into regional newsgroups and politics newsgroups. This broadening out continued through 2002, which also brought in a range of more miscellaneous groups. When the topic broadened out across a wider range of groups, the proportion of participants who were already parents of autistic children declined as a proportion of the whole: parents contemplating vaccination for their healthy children then became the most active participants, especially from 2001 onwards, alongside those for whom the issue had become a 'cause', whether or not they had this kind of personal interest in it.

The low profile of the MMR/autism discussion prior to 1998 does not mean that it is also a discussion without conflict at that early stage.

*Example no. 42 (1996) on a science/medicine newsgroup*

>I will reprint an ad from the American Parent's Magazine in 1994,  
 >taken out by Merck, a vaccine manufacturer about the measles  
 >vaccine and then, I'll dig through and forward a few articles that  
 >I have on measles for you to read.

...

>What they don't mention is that measles vaccine can cause, MS,  
>diabetes, autism, ADD [Attention Deficit Disorder], ADHD  
>[Attention Deficit Hyperactive Disorder], Guillian-Barre paraly-  
>sis, ocular neuritis and subacute sclerosing panencephalitis as  
>well as many other disorders (Crohn's Syndrome, ulcerative  
>colitis – the list goes on!)  
XX  
How do we know that it can cause any of these? The rest of your  
post provides zero evidence.

One of the support groups where this issue is discussed did not exist prior to 1998. This phenomenon, of discussion moving on to newsgroups as and when they come into existence (if the topic is relevant), was very marked in relation to the cellphone debate, thanks to the development of all of the brand-specific mobile phone groups. It is less prevalent in this debate which is also a more restricted one in terms of the range of newsgroups involved.

As with the early years of the mobile phone debate there is some indication in the early years of the MMR debate (including the pivotal year of 1998) of a 'community', sharing some degree of online mutual acquaintance, for example via references to conferences which some of them have attended and others will know about.

From 1998 advice was offered and requested not just about whether to vaccinate or not, but also about how to avoid it in the USA where it is normally a requirement for school entry, and where to go to get individual jabs instead of MMR in the UK where only the triple vaccine is available on the National Health Service.

## **Discussion**

This chapter has identified some significant similarities between the three topics. Substantively, the topics are similar in the overall bias towards orthodox/majority views, as well as the consistency with which the mass media are both decried for sensationalism and relied on for basic information amongst newsgroup participants. Formally, all topics produce websites from a variety of sources with greater or lesser institutional backing, and varying styles for appropriating the literacy practices which have developed around this new medium. In Usenet as well, the three topics are similar in the proportions of texts which make use

of practices such as flaming and metalinguistic terms such as 'troll' – the distribution remains fairly constant over time as well.

Where there are differences across these three topics online, it is principally in relation to substantive changes over time: the three topics each have different patterns of 'uptake' which the retrospective analysis of Usenet materials was able to capture. The web-based analysis is much less relevant here, thanks to the tendency on the web to replace 'past' materials with more recent ones.

The considerable common ground shared by these three topics in respect of their 'web presence' may have something to do with the nature of the particular topics chosen. It would be valuable therefore to undertake comparable analysis on other kinds of health risk topics. In particular, it would be important to examine at least one topic with less of a mainstream versus fringe structure, something where opinion was more evenly divided between the arguments for and those against the risk in question.