

Internet Discourse and Health Debates

Kay Richardson



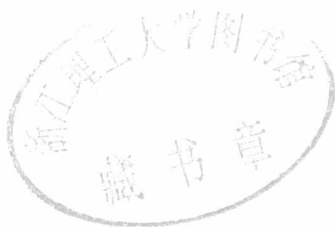
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1

Introduction

The research presented in this book looks at the internet and asks how people and organizations use it to communicate with one another about health risks. It is particularly concerned with forms of online communication that are public (that is, not formally restricted in any way to particular groups of people). Public communication does not begin and end with the internet. Where the internet goes now, the mass media have gone before, and continue to go. But public communication in the age of the internet is not what it used to be and it is important to set up some lines of enquiry to find out how it has changed and is still changing. The present book offers one such line of enquiry.

Public communication about health risks offers a useful point of entry into this territory because health risks are such a universally relevant topic, and the internet, in its public communication mode, is such a universal medium, in principle if not in practice.¹ Although health risks in general are universally relevant, particular health risks of course are not. Not everyone is at equal risk from HIV/AIDS, or lung cancer, or of contracting v-CJD from contaminated beef products. The risks examined in the present volume (cellphones and cancer, SARS, MMR vaccine and autism) were not chosen according to any particular principle, although all of them had at different times attracted mass media attention and all involved uncertainty as to whether there *was* a risk of the proposed kind, and/or what kind of behaviour would entail running that risk.²

Once Americans have internet access, it turns out that finding health information is one of the most common ways in which they use it (Pew 2003a). This is not so surprising in a medicalized world (Lupton 1994; Gwyn 2002).³ Maintaining good health is a universal human priority. The medicalization of health turns over a lot of the responsibility for

this to professional structures, dependent upon types and sources of information which are beyond the reach of the non-professional social networks of individuals. Using the net for health information and communication is potentially of value to the individual in four ways:

- Overcoming the problem of access to professional structures – no medical insurance; can't get an appointment until a week on Tuesday.
- Allowing access to non-mainstream information of which the medical establishment disapproves – such as how to avoid the controversial MMR vaccine whilst still immunizing children against measles as well as mumps and rubella.
- Expanding face-to-face social networks into cyberspace social networks, perhaps 'de-medicalizing' health knowledge, or mediating it via trusted personal contacts rather than 'authorities'.
- Buying drugs and other health related items – legitimately or otherwise.

The public sharing of information about health *risks* via the net introduces other considerations. From a 'top down', social policy perspective, public communication in relation to health risk is all about locating some health responsibilities with the individual, on the basis of knowledge about certain kinds of risky behaviour – unprotected sex, bad dietary habits, smoking; and public information campaigns are the usual approach.⁴ These are unlikely to migrate in full from the traditional mass media to the net because they are less sure of finding their audience in this medium. From the perspective of the individual, traditional information sources may have been issuing confusing and contradictory 'risk' messages, so that the net is embraced as a way of trying to eliminate or reduce the confusion. Or the traditional sources may have compromised their public trust, making the net an option for seeking out different kinds of voices.

The above represents an account of the area which this research is designed to explore. What follows will place the research in the context of 'new media' studies and describe how the theoretical and substantive chapters which follow contribute to the general project.

New media research

Research on the new media is no longer novel. The internet itself no longer seems extraordinary: it is becoming integrated into the eco-

nomic, social, political and cultural affairs of individuals, organizations and societies (Wellman and Haythornthwaite 2002; Liewvrouw 2004).⁵ It is however not easy to establish an overall picture of just what the 'new media' are at this point in time, nor of where and how they are being used, and by whom. There is much discussion of the 'digital divide' (Ngini, Furnell et al. 2002; Rainie and Bell 2004) and the fear that in information-rich societies those on the wrong side of the divide will find themselves seriously disempowered. The digital divide operates both locally and globally; it divides different groups within a society from one another and also establishes a hierarchy of societies, with some being much better off for wired resources than others – an issue meriting the attention of the United Nations at a meeting in December 2003. In the present research a particular segment of the international 'general public' comes into focus. These people represent an English-speaking elite which not only has internet access, and has become accustomed to using it for international communication with known and unknown others, but which is also sharing with these others such concerns as the safety of international travel (in relation to SARS) and of the latest hi-tech consumer goods (cellphones).

The new media are also associated with various kinds of risks for the future. The most publicly prominent risk themes concern the online 'grooming' of children to ready them for offline sexual abuse and the circulation of child pornography in cyberspace. Governments worry about the ease with which crime can be organized with the help of new media technologies; individuals and companies worry about the security of financial transactions conducted online. There has been much practical rethinking of traditional concerns with privacy and intellectual property rights, to ensure an appropriate fit between these concerns and the new information and communication technologies.

Accordingly, research on new media has become multifaceted and multidisciplinary, with many points of entry. This fragmentation of research is reflected in a collection of papers for a special issue of the journal *New Media and Society*, entering its sixth year of publication, February 2004. These articles variously examine the new media in relation to politics and political activism; art, culture and design; communication and language; social theory; economic policy and others – all under the unifying theme 'what's changed about new media'? The collection shows a sustained focus upon the integration of new media with existing social, political and economic realities, and thus upon the reciprocal effects of 'society' and 'media'. Only one contribution to this issue is specifically concerned with changes in the nature (and study) of

computer-mediated communication, often shortened to CMC (Herring 2004). This field, and this term, used to have a more prominent place in new media studies, and it certainly has a long history compared with some other areas – it can be traced back to Hiltz and Turoff (1978), when it came under the designation ‘computer conferencing’, pre-dating the internet.

The displacement of the ‘communication’ aspects of new media from a prominent place in the field of study is neither surprising nor regrettable. The displacement is not surprising because, firstly, as Herring observes, the basic forms of CMC are now well-established and have been well-examined in the literature. Newer forms of CMC, belonging to the first decade of the twenty-first century (for example, ‘blogs’; see Chapter 5 below)⁶ are variations upon more established ones. Secondly, it seems to be in relation to the *uses* of new media that the growth of research has taken place in recent years (Dahlberg 2004) and upon their impact in specific areas of social life, as well as the spread of net access from restricted groups of users to the mainstream. To study these kinds of developments it is not really necessary to understand in depth the particular communicative characteristics of the medium. Such understanding as is required is readily available from classic works and from secondary sources.

Another reason that the displacement is not surprising is that it took a while to learn the lesson that focusing upon ‘new media’ as some kind of free-standing enterprise, in relative isolation from the wider social context, offered too narrow a perspective on why these media took the forms that they did. Criticism of this tendency has now begun to take hold. Slevin, for example, believes that the study of the internet should be subordinated to the study of the kinds of social change which made the internet possible in the first place:

I shall start out from three important developments that have transformed modern societies. These are described by Giddens as the intensification of globalization, the detraditionalizing of society and the expansion and intensification of social reflexivity. Taken together, these developments have resulted in the acceleration of manufactured uncertainty in our late modern world. It was not by accident that the internet originated under such conditions. Its emergence can only be understood if all these developments are seen to interlock. (Slevin 2000: 5)

Slevin’s approach starts from a big picture of late modern society, indebted to the work of Ulrich Beck and Anthony Giddens – see, for

example, Beck (1992) and Giddens (1990, 1999). There is, of course, room for disagreement about the characteristics of the 'big picture' and a danger that time spent debating the merits of the reflexive modernity/risk society thesis risks a long deferral of more specific questions about the internet and other new media forms, whilst the alternative, taking that analysis on trust in order to pursue particular enquiries, seems unduly deferential to the theorists.⁷ Most research, in practice, will have either a theoretical or an empirical bias. In the present research the bias is empirical.

Internet research, health risk and the wider social context

It is of course possible to examine computer-mediated communication in its wider social context without a priori commitment to any particular theory of the contemporary social order. The present research does this in two ways. Firstly, this study makes use of what is *already* known about online communication in its various forms, including such characteristics as multimodality, interactivity and absence of social presence;⁸ secondly, it approaches the internet as a context for public communication.

Rather than trying to develop fresh insights into the nature of computer-mediated communication in its particular forms, the research presented below takes existing ideas about communication over the internet, develops and extends these where appropriate, and uses them in an exploration of specific health risk concerns which have arisen over the last decade or so. The 'social context' enters the picture via the health risks, which are tied to their particular historical moment. Each of them can, for instance, be characterized as examples of 'manufactured' risk – side effects of social and technological progress. Progress in communications technology has given us the cellular phone – but maybe we need to be careful about how we use these machines? Long-distance travel is easier than it has ever been, but when we move between countries we now worry about SARS, as well as deep-vein thrombosis and international terrorism. Progress in disease control has produced vaccines which could in principle eliminate death and illness from measles, mumps and rubella (three of nature's risks) yet mass vaccination may also have its 'downside'. The manufactured risks discussed in this book – that excessive cellphone use will cause brain cancer, that international travellers will contract SARS, that the MMR vaccination will induce autism in susceptible children – are also characteristically modern risks because, thanks in part to internet websites and news-groups, they are risks which are now discussed worldwide.

The other characteristic of the present research which locates it in a wider social context comes from the fact that it makes every effort to understand communication in terms of an epistemologically more important differentiation between *public* communication and *restricted* communication. Instead of setting 'the internet' *against* 'the mass media', the 'new' *against* the 'old', this differentiation recognizes the similarities between some kinds of internet communication and the traditional mass media. Public CMC comprises those forms which, in principle if not in practice (since governments such as that of the People's Republic of China can impose restrictions) are on open access, requiring no passwords or account numbers and involving no vetting procedures. The net of course is not just a forum for public communication in this sense. It can also carry more restricted forms of communication such as email. The most significant forms of public CMC are World Wide Websites and Usenet newsgroups. If you can get online, you can use these forms of CMC, as a reader and, with a bit more trouble, as a writer.

The chapters

The chapters below are arranged as follows. Chapters 2 and 3 together serve to frame the research. Chapter 2 reviews the CMC literature to identify the most important characteristics of public CMC, in relation both to the web and to newsgroups. Chapter 3 frames the research in relation to work on the social construction/representation of health and health risk, with particular reference to discourses of health and risk in the mass media.

The following three chapters each take one case study – mobile phones and cancer, SARS, MMR and autism – and conduct an in-depth study of particular online materials relevant to the topic. Each case study comprises one section which discusses resources on the World Wide Web and one section which examines discussions in Usenet newsgroups. Chapter 7 looks at all three of the case studies together, drawing out some similarities as well as differences. The book finishes with a final short chapter which offers some conclusions based on the preceding research.

The two forms of net-based communication which the research examines are World Wide Websites and Usenet newsgroups. Different considerations apply in respect of each of these, since websites are predominantly monologic in character where Usenet newsgroup threads (collections of messages linked to one another like the utter-

ances in a conversation) are dialogic or 'polylogic' (Marcoccia 2004). Websites go much further than newsgroup threads in the direction of multimodality, that is, using more than one semiotic mode of communication simultaneously, principally combining the visual mode of communication with the verbal. The difference between websites and newsgroups can also be expressed in this way: that whereas websites are 'for the public', in the same way as a TV news broadcast or documentary would be, newsgroups are 'by the public'.

A note on terminology

The present research is heavily influenced by the linguistic study of discourse, but with a light touch. From a linguistic point of view the important thing is to employ the term '*discourse*' in such a way as to keep it distinct from other terms used in the literature, including *medium*, *register*, *style*, *dialect*, *channel*, *genre*, *speech event*, *text* and *literacy practice*. 'Texts' for the purposes of the present research are spoken or written material objects, though their meanings are non-material, since meaning calls for interpretation and is thus located in the subjective domain. Textual meaning can be discussed by analysts on the basis of assumptions about intersubjective convergence between groups of people sharing the same linguistic repertoires and communicative competence. Crystal (2001), in the most linguistic of all the recent treatments of CMC, uses 'medium' to distinguish writing from speech, and introduces 'Netspeak' as a new, third, medium alongside these two. This is the broadest possible use of the term, but the present research requires a narrower one. In this book, 'medium' is used with the sense that it has in the expression 'mass media', in which print is one medium, audiovisual broadcasting (television) is another and sound broadcasting (radio) is a third. For the internet, this means that newsgroups are one medium (any particular group is a forum) and the web is another. I have also referred to use of the web and use of newsgroups as distinct literacy practices, in recognition of the type of work which is required in the construction of texts for these media. The notion of *genre* captures the difference between a web page in the form of a blog (see Chapter 5) and one in the form of an FAQ or Frequently Asked Questions document – a question-and-answer format (see Chapter 4). I have used the term 'discourse' where Crystal prefers the term 'style'. *Style*, for Crystal, includes 'discourse features' alongside *graphic* features, *orthographic* features, *grammatical* features and *lexical* features. 'Discourse features' are defined thus:

The structural organization of a text, defined in terms of such factors as coherence, relevance, paragraph structure and the logical progression of ideas; for example, a journal paper within scientific English typically consists of a fixed sequence of sections including the abstract, introduction, methodology, results, discussion and conclusion. (Crystal 2001: 9)

In multimodal texts such as web pages, where the structural organization is as much visual as it is verbal, it does not seem helpful to assign structure to discourse without elevating the status of 'discourse' to a higher level. The theoretical ramifications of these terminological distinctions are beyond the scope of the present work. There is also a degree of tension between the linguistic concept – after Sinclair and Coulthard (1975) – and a broader sociocultural concept of discourse – after Foucault (1972, 1977) – but the waters have been muddied because of the amount of research which strives to keep a foot in both camps (Fairclough 1992). Although both senses of the word are employed in the present research, the context will determine which meaning is most relevant. In speaking about discourse in relation to the 'social construction of risk', for example (see Chapter 3 and Chapter 8), it is the sociocultural perspective which prevails, since this perspective is as much concerned with *content* as it is with form: with what can (legitimately, authoritatively, sensibly) be said about a given topic. It is also concerned with the institutional arrangements underpinning speech and writing – discourses and institutions are mutually defining (Kress, 1989).

2

Computer-Mediated Communication and Language

This chapter provides a context for the subsequent case study chapters by discussing the study of computer-mediated communication. Pioneers in this field include Howard Rheingold (1993), Susan Herring (1994) and Sherry Turkle (1995). The more linguistic/semiotic aspects of this research have covered such topics as:

- 'Turntaking' and coherence in online interaction (Herring 1999; Beacco, Claudel et al. 2002; Marcoccia 2004).
- Topic development in newsgroup threads (Osborne 1998).
- Generic characteristics of online interaction, especially its relations with writing and with speech (Ferrara 1991; Hawisher 1993; Collot and Belmore 1996; Lee 1996; Yates 1996; Herring 1996a; Davis and Brewer 1997; Baron 1998, 2003; Osborne 1998; Gruber 2000; Harrison 2000; Crystal 2001).
- Gender relations in online textual environments (Dibbell 1993; Herring 1994, 1996/1999, 1996b, 2000, 2001; Turkle 1995; Bruckman 1996; Cherny and Weise 1996).
- Normative constraints on online interaction (McLaughlin, Osborne et al. 1995; MacKinnon 1997; Burnett and Bonnici 2003).
- Web page genres (Crowston and Williams 1996; Kress 1997; Chandler 1998; Benoit and Benoit 2000; Cheung 2000; Lewis 2003).
- Cyberplay (Bechar-Israeli 1995; Danet 2001).
- Multilingualism online (Paolillo 2001; Danet and Herring 2003; Warschauer 2000; Warschauer and El Said 2002).
- Hypertextual discourse structure (Kaplan 1995; Mitra and Cohen 1999; Engebretsen 2000; Tosca 2000; Foot, Schneider et al. 2003; Schneider and Foot 2004).
- The semiotics of screen icons (Honeywill 1999).

However, the study of computer-mediated communication is not a field where disciplinary divisions run deep: experimental psychologists, information scientists, linguists and sociolinguists, as well as discourse analysts in sociology, linguistics and psychology, overlap with one another in the topics they examine and in the references they draw upon. The following discussion reflects that inter- and trans-disciplinarity and tries to do it justice, as well as emphasizing the themes which are most relevant for the present research.

The state of the art

February 2004 saw the publication of the first issue in volume 6 of *New Media and Society* (NMS), an international journal devoted specifically to the study of the new forms of media from the internet to the WAP mobile telephone. (WAP, Wireless Application Protocol, is a format to provide limited internet content to mobile devices.) This issue attempted to take stock of the field after the journal's first five years of publication. A common theme across many of the contributions was that of the 'mainstreaming' of new media, as the World Wide Web, email, wireless communication and so on ceased to be restricted to particular kinds of users and uses, and started to become ubiquitous in many developed countries in work, education, leisure, culture and politics (see Wellman and Haythornthwaite (2002) for more discussion along these lines; and Dahlberg (2004) for an overview of social science approaches to internet studies).

Among the writers in NMS volume 6 who developed this 'mainstreaming' theme, Herring (2004) talks about the development of newer forms of CMC (ICQ – 'I Seek You', IM – Instant Messaging, SMS – Short Message Service, blogs, streaming audio/video) alongside those which are now more established (the web, email, bulletin boards/newsgroups, chatrooms) while pointing out that 'the web' has a dominance now that it lacked previously, since so many CMC protocols, which used to be independent (including Usenet which is in essence a Unix-based protocol) can now be accessed by the user via a web browser interface. Herring also observes that the 'newness' of the recent innovations is a matter of modification: 'all involve text messages that are composed and read via a digital interface' (Herring 2004: 31). Electronic voice-based and image-based two-way communication have seen development too but they have yet to displace or even achieve parity with (written) text-based forms. Her prediction for the future is:

Increasing technological integration, combined with the assimilation of day-to-day uses and the corresponding need to ensure the trustworthiness of one's interlocutors, will contrive to make the internet a simpler, safer and – for better or for worse – less fascinating communication environment. (Herring 2004: 34)

It is not remarkable to find that health risks are a subject of communication on the internet. Where online communication resources have become ordinary, even banal, the fact that they are used to communicate about any particular topic is not, in itself, interesting. Nor is it at all noteworthy that many different voices will want to have their online say – commercial voices, state voices, charity voices, individual voices, scientific voices, and so on – or that some will want to go public with their text/talk/image and others to target their discourse at more specific recipients. It may not be interesting *that* this happens, but it remains interesting to explore *how* it happens, and to reflect upon why it happens in the particular forms that it does. In relation to health risks and society, the big questions are why we (the public) worry about particular harms. Are we right to worry about such things? Are we indifferent to things that we should worry about more? Only some of these will ever be questions about the internet itself – for example, the issue of harm from internet pornography. In most cases the internet only comes into the picture as a provider of resources which contribute, for good or ill, to the social construction/representation of health risks. In this context the particular uses of CMC which are most worthy of attention are those which are publicly accessible on the widest scale. Subject to the reservations regarding economic, social, linguistic and political restrictions on internet access, the most public resources are those of the World Wide Web for one-way communication, newsgroups (Usenet) for asynchronous two-way communication, and chatrooms (IRC, Internet Relay Chat, the original and formerly best-known protocol for online 'chat', or synchronous computer-mediated communication) for synchronous two-way communication. Other online protocols and forums exist but they are deliberately restricted in particular ways. For example, websites involving commercial transactions have to be restricted to ensure security. Email is restricted (though less than many people would like to imagine) because the communication is intended to be 'private', between individuals. Listserv communication is restricted because it is conducted within self-defining communities of interest and some kind of subscription is required. Access to online textual resources

in commodity form (for example, journals and their archives) is also restricted by subscription.

Communication about health risks occurs in these restricted contexts too, but they are beyond the scope and concern of the present research. By circumscribing the enquiry in this particular way, the point is to play *down* the connection between the web/Usenet and email, listservs and subscription products, and instead to play *up* the connection between the web and 'traditional' or 'old media' forms – specifically, broadcast and print mass media. There is a degree of convergence here between the old and the new. The traditional news media have used their news-gathering infrastructure as the basis of new web-based formats alongside their established outlets, some of them (the *New York Times*, the BBC) with considerable success. Before the coming of the internet it was these mass media which ruled the roost in respect of public discourse. They were the interface between other public forums (for example, parliament) and the wider audience. They still serve this function, but now it is easier for the 'wider audience' to access directly *some* of the source materials that the journalists themselves use as resources for their stories. In relation to health risk topics for example, it is the documents produced by such organizations as the WHO and the CDC which are offered via the web on 'direct access' not just to journalists (Trumbo 2001) but also to the browsing public, without national restrictions. This online presence is worthy of examination in its own right. It is also worthy of examination at second-hand, via an exploration of whether or not such resources are actually used by people with internet access.

It is an easy matter for organizations to monitor on an hourly, daily, weekly, monthly, annual basis, how many visitors their websites receive, what pages they access during their visits, what items they download, what domains they themselves are visiting from. The technical, 'behind the scenes' management of who goes where on the web, along with the politics and ethics of such management, is itself the subject of research activity (Rogers 2000). For organizations to know whether their visitors then go on to recommend the site to others and what they think of it, is not so easy. But other kinds of online materials can make a contribution here. Usenet is also a location for public discourse on all sorts of topics. Those parts of the wired population who participate in Usenet can and do employ it to tell one another which websites to visit and which ones to avoid.

Herring's observations about the changing contexts and forms of CMC are relevant to the present research in another way also. They have implications in respect of the question 'When was your research con-

ducted?' This question is a more complicated one than may at first appear.

My dual focus upon websites on the one hand and Usenet discussion on the other is made more interesting by the fact that in the case of websites, I was only able to look at the most recent versions of those sites at the time of writing, whilst in the case of Usenet, I was able to take the study back in time to the earliest mentions of particular topics, using normal keyword search procedures. Notwithstanding extensive archiving on particular sites, the web is a notoriously unstable realm, textually speaking. Since editing is so easy, a webmaster might make an addition one day and remove it the next, leaving no traces.¹ Before the web era, such editing stopped at the point of publication. Thus, my discussions in the case study chapters below of particular websites are intended as 'synchronic' accounts, snapshots, circa February 2004, of what was available at that time. In contrast, my accounts of Usenet discussion are both synchronic and diachronic. The materials have been assessed as a synchronic body of texts principally because of the extensive *thematic* continuity in what people had to say about cellphones, and about MMR, across the 8–10 years that these topics have been available in public discourse. There is thematic continuity in the discussion of SARS also, though this is less surprising in a corpus which spans only three-and-a-half months. Diachronically speaking, the issue is how Usenet discussions responded to the developments in the narratives of cellphones, SARS and MMR, and this is discussed in Chapter 7 below.

The forms of public online discourse: websites and Usenet

The principal differences between the two forms of communicative practice examined in this book, from a CMC perspective, are firstly that websites are predominantly monologic in character where Usenet threads are interactive (Rafaeli and Sudweeks 1997), and secondly that websites are further along the continuum between monomodal and multimodal textual form. To put that another way, websites seem to be 'designed', Usenet messages, like emails, are simply 'written'.

Neither of these distinctions are absolute ones. Websites do not have to be monologic. They can refer to, summarize, quote from other texts in the usual 'intertextual' ways. But webmasters generally want to control the terms on which voices other than their own appear on the site. It is a rare website to which someone other than the webmaster can make changes directly. SARS Watch, discussed in Chapter 5 below,