

# Childhood vaccinations and autism, 1998-2010: Expert domains in formal information exchanges

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## ABSTRACT

Questions about a link between the administration of the pediatric measles mumps rubella (MMR) vaccine and subsequent diagnoses of autism have diffused widely through both the professional medical literature as well as through mass-market media publications in recent years.

A 1998 study in *Lancet* (Wakefield et al.) proposed the initial MMR-autism link, and as of this writing, has received over 600 citations per ISI's Web of Science database. The publication of this study, and the controversy and criticism that followed it, coincides with the rapid growth in the scope of Internet information resources and the number of Internet users (Madden, 2006), and represents a unique opportunity to explore the intersection of expert and non-expert conversations about an issue of health, science, and public policy, mediated, in part, by a digital information environment.

While there is no shortage of bibliometric study examining some of the media dimensions of this issue (Hilton, Hunt, Langan, Hamilton, & Petticrew, 2009; Lewis & Speers, 2003; Smith, Ellenberg, Bell, & Rubin, 2008), this study proposes a novel view by choosing an information-based unit of analysis that qualitatively identifies the invocation of published scientific research and governmental policy as "boundary objects" in published discourse, and as possible evidence of assertions of authority in a controversial arena. This present study represents the first part of this effort – a content analysis of the expert literature domain of a controversial topic in an effort to identify themes and patterns that may be applied to a larger (and more diverse) corpus of non-expert literature, and to ultimately help create a more informed theoretical framework for boundary-spanning digital collections.

## Keywords

Public health, medical information, expert information

## INTRODUCTION

The well-publicized controversy over a possible relationship between the administration of a pediatric vaccine for measles mumps rubella (MMR) and increasing rates of autism has reached nearly every corner of print and digital media. From the publication of the original study in 1998 in *Lancet* (Wakefield et al.) to analysis and commentary in *Rolling Stone* (Kennedy Jr, 2005), scientific research has been cited, summarized, argued over, and incorporated into policy and sub-policy public health conversations for over a decade.

The public conversation over the possible relationship between the MMR vaccine and autism is not only a personal health question that can be situated in the domain of personal information seeking, but also a public policy and consensus-building conversation demonstrating the variability of understanding scientific knowledge in the legal/political domains. Information behaviors that relate to choices of public policy and law come to intersect a broader array of constructs for authority and evaluation criteria than personal health decisions.

As a theoretical foundation, this study relies on constructivist models, such as actor-network theory (ANT), from science and technology studies (STS). Latour and Woolgar's (1986) often-cited model of the "making" of science – a complex activity involving overlapping social worlds, each one with its own norms and measures of authority – informed the development of a coding schema that specifically looks at how information from other domains is presented and interpreted by others. The notion of "black boxing," the process by which certain domain-based understandings are accepted outside of their original domain with little question (Van House, 2003b), helps to define this study's qualitative measures of the role of cited scientific research in medical articles. Also, the "intermediary" concept informs the constructs used to identify types of publications (media as intermediary).

Scientific publications have long been considered "boundary objects" (Star & Griesemer, 1989) that present an opportunity to "bracket" differences of politics and status (not unlike how "black boxing" accommodates differences of expertise) and place empirical research into a broader sphere for analysis and critique. The limitations of scientific publishing, however, have traditionally restricted this audience to domain experts in the same, or closely-

aligned, fields. Within the published research of a particular domain, notions of authority, reliable metrics, and methodological homogeneity are widely shared and may be taken for granted.

However, these criteria of authority and knowledge construction become open for discussion again in the digital environment, where questions of authority re-emerge as an audience develops from vastly different domains. (Van House, 2003a). Databases of scientific journals like PubMed, datasets collected with federal funds, and vast stores of other “expert” data have been made accessible to non-experts by digital initiatives, often without a clear understanding of what the puncturing of these expert “information silos” will do to the social worlds of knowledge construction that surround them. Events such as the hacking into (and publication of) email messages of several climate scientists in the UK in the past year have illustrated a collision of social worlds and domain understandings about a controversial science-policy topic that was almost impossible in a pre-digital era.

A previous qualitative analysis of interviews of users of a California digital library suggests that experts may be concerned with “inappropriate use” of data (Van House, 2003a, p. 276). This type of concern about a broader public’s misunderstanding of scientific research is evident throughout the professional literature on the topic of MMR-autism used in this study (Goodyear-Smith, Petousis-Harris, Vanlaar, Turner, & Ram, 2007; Wolfe, Sharp, & Lipsky, 2002).

Digital initiatives and the creation of digital libraries for the publishing and diffusion of scientific work are provoking an intersection between expert and non-expert audiences in new ways. We do not fully understand the role of authority and its presentation in certain “boundary objects” in these types of intersections.

This study aims to explore the question of 1) how experts writing in expert publications respond to a public controversy that intersects their domain (in this case, doctors and health professionals and the MMR-autism controversy); and specifically 2) how authority is invoked (by scientific study, by governmental action, or by other means) and reflexively expressed by overt statements of the need to insert oneself as an expert into a public policy conversation.

#### **PRIOR WORK**

Two categories of previous research were examined in the formation of this study.

First, as mentioned above, there are several bibliometric studies, primarily emerging from public health and medical journals, that have looked at published reports of MMR-autism research. A 2003 analysis of medical coverage and public opinion surveys about the MMR vaccine in the UK (Lewis & Speers, 2003) analyzed the content of 561 media reports from a period of time in 2002 and found that over

60% of the stories focused on the possibility of a link between the vaccines and autism; mentions of the numerous studies that confirmed the vaccine’s safety were only present in 40% of the articles. The authors suggest that a media focus on the controversy itself (allowing that it is understandably more “newsworthy”) does a disservice to the public’s understanding of the nature of the scientific research. Goodyear-Smith, et. al. (2007) analyze media produced between 2001 and 2003 from 400 different national publications in New Zealand to find an overall “positive trend toward reduction in alarmist anti-immunization messages” (p. 759) and advocate a proactive educational role for health professionals when dealing with the media. Hilton, et. al (2009), in a analysis of six commonly read health professional publications in the UK, found that coverage of the possible MMR-autism link evidenced a period of neutrality immediately following the initial controversial 1998 study. While this approach may represent an understandable hesitancy in waiting for a consensus to develop, authors suggest health professionals may be missing an opportunity to “promote evidence based practice” early in a controversy (Goodyear-Smith et al., 2007).

A media analysis between 1995 and 2004 found little evidence supporting a correlation between news stories and personal vaccine decisions, and suggested that the role of mediating experts (family pediatricians, for example) is likely to play a stronger role in patient decision-making than media messages (Smith et al., 2008). Lai, Lane, and Jones (2009) examine front-page news coverage of a variety of high-profile medical stories, and find that not all media sources are equivalent in terms of the accuracy of the medical information – media coverage of selected medical stories was more thorough among “dominant” (high circulation) publications than smaller-circulation titles.

Second, STS research and theory provides a framework for this analysis, based on the work of Latour and Woolgar (1986), and re-interpreted in Star and Griesemer’s (1989) study of the University of California’s Museum of Vertebrate Zoology. In Star and Griesemer’s analysis of the success of the California museum, the authors identified two elements that contributed to the investment of authority in the natural science work of the museum: methods standardization and boundary objects (Star & Griesemer, 1989, p. 392). The standardization of methods (between researchers in the museum and students in a biology course, for example) enables research to move between heterogeneous domains. Boundary objects (such as the museum) are flexible and adaptable enough to the different needs of the overlapping heterogeneous communities of use, yet are robust enough to maintain their integrity and authority.

#### **THE AUTISM-MMR VACCINE CONTROVERSY**

In recent years, several new vaccines have been introduced into the pediatric market in the U.S. – just since 2008, four have been placed on the routine vaccination schedule

(Smith et al., 2008) and practitioners have perceived increasing skepticism about vaccines and concerns about safety from parents, and in some cases, policymakers. Immunization coverage rates in many western nations (the U.S., the UK, New Zealand, and others) have declined measurably (Goodyear-Smith et al., 2007; Lewis & Speers, 2003) causing considerable concern among health care providers and policy makers that “scaremongering” (Goodyear-Smith et al., 2007, p. 763) was triumphing over reason, science, and good medicine.

The suggestion of a link between the MMR vaccine and autism following the 1998 *Lancet* study, has been one of the most persistent and pervasive controversies in the climate of heightened concerns about vaccine safety.

1998	Publication of Wakefield paper in <i>Lancet</i>
2000	U.S House Reform Committee Hearings
2000	Vaccine makers remove thimerosal
2001	U.S. Institute of Medicine initial report finds no linkage between MMR and autism
2004	U.S. Institute of Medicine concludes no evidence of link between MMR vaccine and autism
2009	U.S. Special Masters panel for Vaccine Injury Compensation Program finds against autism injury claims
2010	UK General Medical Council rules against Dr. Wakefield
	<i>Lancet</i> retracts original 1998 study

**Figure 1. Timeline of MMR-vaccination controversy**

## METHODS

### Corpus

As widely-used consolidated sources for indexed publications for academic and professional worlds, commercial databases are suitably considered as “digital libraries” (Lynch, 2003) and worthwhile to subject to a content analysis methodology that might yield insights into the social contexts of their design and use. The PubMed database from the National Library of Medicine contains approximately 20 million citations from biomedical literature reports and is the largest public resource for biomedical literature (National Library of Medicine). For this study, the database was searched for articles appearing between 1998 and March of 2010 that included both the Medical Subject Heading (MeSH) terms “autistic disorders” and “vaccinations.” 75 articles were retrieved; 53 of these met the additional criteria of being from peer-reviewed professional literature, in English, and accessible in full-text in a timely manner.

### Coding

Following an initial review of the coding schema’s applicability and reliability with a second coder, the corpus of 53 documents was coded by the author according to a framework that included five document types and six

categories of qualitative expression. An intra-rater (code-recode) reliability check was scored at 94%.

The six types of expression were: 1) addresses controversy and role of medical professionals within it; 2) addresses media dimensions (numbers of news stories, media “misinformation, etc.); 3) references declining immunization rates; 4) references 1998 Wakefield study; 5) mentions governmental or regulatory body’s actions; 6) suggests a consensus or lack of consensus among the medical community.

## FINDINGS

Initial findings suggest that while this expert domain is aware of, and responds to non-expert influences and information with respect to a controversial issue, it most frequently cites other professional literature and actions of professional and/or governmental bodies in its published discourse.

Yet health professionals are concerned about public understanding of science. In one example from this study, a 2009 editorial refers to a number of controversial medical treatments and states, “As physicians, we are trained to assess evidence in a linear and logical manner. For some patients, this model of scientific explanation may be convincing, but there are other patients for whom a scientific argument holds little sway,” (Kushner, 2009). Other writers were even more overtly critical of other actors in the autism/vaccines conversation: “Politicians, lawyers, and journalists have weighed in on the discussion and have confounded the science with emotion, belief systems, and the legal system,” (Goldson, 2009).

Unsurprisingly, editorial pieces, as an article type, were significantly more likely to refer to the condition of the public understanding of science. Research reports seem more likely to situate their authority and rationale inside of their discipline rather than explicitly referring to the public (even though “the public” is very much under study) .

Some statistically significant ( $p < .05$ ) correlations were also observed between the presence of informational elements. For example, the mention of decreasing immunization rates was linked to the mention of the initial 1998 Wakefield study. This kind of correlation suggests patterns of reference and authority that could be further explored.

There were no immediately discernable correlations to the timeline of major “newsworthy” events related to this MMR-vaccination controversy. This may be primarily due to the long life cycle for the research and production of scholarly articles, as well as the deliberate hesitation of researchers to gauge the emergence of a possible consensus (Hilton et al., 2009). A comparison of exclusively editorial content may be useful in a future study.

	Research report (N=13)	Review article (N=15)	Editorial (N=12)	Letter (N=8)	News (N=5)	Total
<b>Mentions controversy</b>	9 69%	11 73%	12 100%	7 88%	5 100%	44 80%
<b>Suggests doctors educate</b>	3 23%	6 40%	6 50%	0	2 40%	17 31%
<b>Mentions media</b>	5 38%	3 20%	7 58%	3 38%	1 20%	19 35%
<b>Criticizes media mis- information</b>	2 15%	3 20%	8 67%	1 13%	1 20%	15 27%
<b>Notes declining vax rates</b>	6 46%	4 27%	8 67%	2 25%	3 60%	23 42%
<b>Cites Wakefield study</b>	10 77%	10 67%	8 67%	5 63%	4 80%	37 67%
<b>Cites gov/reg actions</b>	5 38%	10 67%	9 75%	2 25%	5 100%	31 56%

**Figure 2. Content elements by article type**

#### FUTURE WORK

This study is intended be a preliminary effort to understand the nature of authority as invoked in (potentially controversial) public policy conversations where expert knowledge becomes a matter of non-expert discussion. A second study is underway to build on these findings and analyze content of non-expert publications. While the particular kinds of discourse that have developed around the MMR-autism controversy are unique, it is one of a number of recent controversies that suggest an avenue for new forms of analysis of authority in the context of digital information environments.

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