Public Misunderstanding of Science? Reframing the Problem of Vaccine Hesitancy

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*this manuscript has been accepted for publication in *Perspectives on Science*.

Abstract

Public resistance towards scientific claims regarding vaccine safety is widely thought to stem from public misunderstanding (or ignorance) of science. Repeated failures to alleviate this ignorance make the problem of vaccine hesitancy seem intractable. I challenge this presumption of knowledge deficit and reinterpret vaccine hesitancy to be a problem of public mistrust of scientific experts and institutions. This finding invites new corrective measures: self-scrutiny by our scientific and governmental bodies regarding their own credibility as well as investment in dialogical rather than didactic communicative outreach to vaccine hesitant members of the public. Without the oppositional framing of the problem as a conflict of science versusd ignorance, there is more room for conciliation of public health agendas with the concerns of the lay publics.

Introduction: An intractable problem

The public rejection of scientific claims is widely recognized by scientific and governmental institutions to be threatening to modern democratic societies. Intense conflict between science and the publics over diverse health and environmental issues have invited speculation by concerned officials regarding both the source of and the solution to the problem of public resistance towards scientific and policy positions on such hot-button issues as global warming, genetically modified crops, environmental toxins, and nuclear waste disposal. The London Royal Society's (1985) influential report 'Public Understanding of Science' (also known as the ‘Bodmer Report’), which spearheaded the now-thriving area of science studies by the same name, is commonly cited for first expressing the theory that public ignorance of science dangerously prevented citizens from making mature rational decisions in support of scientifically-backed policies (although a similar sentiment was expressed earlier by the U.S. National Commission on Excellence in Education (1983)). The Bodmer report led to the formation of COPUS, the Committee on the Public Understanding of Science, which used grants and other incentives to initiate change in the attitudes of scientists toward outreach activities (Committee on Public Understanding of Science 1987). Internationally, governments have assembled portfolios on ‘science and society’ (National Science Foundation 1995; House of Lords 2000; Canadian Biotechnology Secretariat 2006; European Commission 2008) intended to address this crisis of public misunderstanding and mistrust. Most have committed to cultivating two-way public engagement with science to foster better expert-lay relations in the often-contentious science-policy nexus.

It is against this backdrop of public misunderstanding of science that the problem of vaccine hesitancy and non-compliance in the industrialized North has been framed. A narrative routinely repeated in the biomedical, public health, and popular science literature focuses on the problem of the public, whose ignorance and fear make us susceptible to misinformation by anti-science interests. The problem of the ignorant public is alleged to explain why, despite concerted health promotion and outreach efforts, vaccine hesitancy still persists 16 years after the publication of the notorious *Lancet* study that galvanized current anti-vaccine sentiment.[1] The story goes like this: Despite the scientific community’s unequivocal rejection of the alleged link

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[1] This paper focuses on what historian Mark Largent (2012) referred to as the “current” anti-vaccine movement that started with the Wakefield scandal and continues today. While there were previous anti-vaccine movements, Largent claims that there are very few historical links between previous movements and the current situation. For some history on anti-vaccine movements in the US and UK respectively, see Kaufman (1967) and Durbach (2000, 2002).

between the measles-mumps-rubella (MMR) triple-vaccine and autism, and the finding that the science that first alleged the link was fraudulent, public fear of childhood vaccines persist and cases of measles, mumps and pertussis (whooping cough) are on the rise in previously safe geographical locations. Fanning the flames of public mistrust of the scientific consensus is a well-organized anti-vaccine movement, comprised of self-serving researchers and celebrity spokespeople, mobilized parent groups desperate to lay blame for their children's autism, and a sensationalist media. What results is our current, persistent, and growing problem of vaccine hesitancy. Years of intense public health and health promotion efforts to assuage public fears by correcting public misperceptions have been ineffective in quelling those fears and elevating rates of vaccine compliance in order to reinforce herd-immunity. The problem seems intractable.

Yet this story also has the markings of its narrators, the biomedical and policy elite that have unilaterally framed the vaccine hesitancy problem and thereby dictated its solution. The problem has been framed as a conflict of *science versus ignorance*, the former unproblematic and the latter entirely flawed. I propose that while we can accept that the public is prone to misunderstanding science and failing to appreciate relative risk, these characteristics do not *explain* vaccine hesitancy. Instead, I will draw from social scientific research into parental attitudes regarding vaccination as well as information sourced from vaccine-critical parent advocacy websites to reveal an alternate framing of the question of vaccine safety. What gets described as "public rejection of science" is better understood as a rejection of the values underlying the scientific consensus. But the science and policy agencies tasked with remedying this problem of vaccine hesitancy do not recognize this alternative set of priorities, and instead presume public ignorance of science. Characterizing one's opponents as ignorant is self-serving, as it permits scientific agencies to dismiss those concerns, and thereby unilaterally frame the question of vaccine safety and dictate its solution. It also insulates scientific institutions from much needed reflexive scrutiny of their practices (Wynne 2006), which is ultimately self-defeating, as public trust is damaged, and health outreach programs miss their target. It is only under the auspices of public ignorance that the vaccine hesitancy problem seems intractable.

Outline

After offering a brief background of the notorious *Lancet* study that innervated contemporary vaccine hesitancy over the MMR vaccine specifically and other vaccines more generally, I will turn to the task of reframing vaccine hesitancy from its current characterization as emblematic of public misunderstanding of science. To do this, I will first outline the standard characterization of and response to vaccine hesitancy consistently presented in the health and science literature, which, I will show, presumes an ignorant public. I will then challenge this account of the vaccine hesitancy problem and deny that the public is ignorant. I will demonstrate how the official response has thereby been misguided and numerous opportunities to correct the problem through effective public outreach have been missed. I will then reframe the problem of vaccine hesitancy as a problem of trust and strained expert-lay relations due to poor communication practices. I close by briefly situating my analysis of vaccine hesitancy within a vigorous line of criticism of the "knowledge deficit model" for explaining conflicts between science and the publics.

The catalyst: the Wakefield scandal

Most chronologies of the MMR-autism debacle, and the resulting drop in immunization rates, commence with the publication of British gastroenterologist Andrew Wakefield and colleagues' notorious 1998 study, "Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children", in the *Lancet* (Wakefield et al. 1998).[2] The research team presented an early report of a small case-series where they claimed to have identified, using colonoscopy studies in 12 children with autism or related disorders, a new form of inflammatory bowel disease that they called "autistic enterocolitis". They noted that in 8 of the 12 cases, the parents attributed the onset of symptoms of autism to the MMR vaccine, which the children had received, on average, 6 days before parents first observed behavioral changes. The team postulated a causal sequence in which MMR causes persistent measles infection in the gut (virology had not yet confirmed the finding of measles in the bowels of these children), which produced an enterocolitis that led to the translocation of typically non-permeable peptides into the bloodstream and, subsequently, into the brain, where they affected neurological development and could result in autism symptomology. Being only an early report, the causal theory was speculative. The authors suggested that further epidemiological and virological studies might test their hypothesis that there was a causal link between MMR and autism. Epidemiological analysis should show a rising incidence of autism after the introduction of MMR to the United Kingdom's national vaccine schedule in 1988. Virological studies, they said, were "under way" to establish measles infection in the bowel specimens of those children affected by autistic enterocolitis.

The paper's scientific limitations should be clear. This was a small case series which found a temporal association between autism associated with bowel disease and MMR vaccine. A case series only builds hypotheses (the causal claims) for further testing. These limits are not

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[2] Some commentators still acknowledge that there were precipitating factors leading up to the explosive reaction to Wakefield *et al*'s 1998 study. Fitzpatrick, for instance, notes that a few years prior Wakefield and colleagues' first suggestion of an MMR-autism link, "there were already signs that MMR was in trouble" (2004a, 11). The UK had experienced its first decline in MMR vaccine uptake (from a 92 percent average to roughly 91 percent) in 1997 following bad press over the 1994 "Operation Safeguard" school immunization program that offered a combined measles-rubella vaccine. There had also been publicity in 1995 for Wakefield and colleague's earlier work suggesting a link between measles or the measles vaccine and inflammatory bowel disease (Fitzpatrick 2004a, 11-12).

problematic—they merely invite further study. However, establishing a temporal association via parental recall and testimony *is* problematic, as the source is highly unreliable. The study also suffered from selection bias, as the sample was overrepresented by the children of parents who believed MMR caused their children's autism.

In a commentary that appeared alongside the study, Chen and DeStefano (1998) further indicted the study's methodology for pursuing pathological findings that were non-specific, for offering no clear case definition, and, lacking confirmatory virological evidence, for failing to provide evidentiary warrant for their hypothesis even being worth pursuing. As for the alleged temporal association, the commentators asked: is the finding "*causal or coincidence*"? The developmental regression of one-third of children with autism is typically first reported by parents shortly after the child's first birthday. The MMR vaccine is typically administered around that time,[3] so the temporal association could be mere coincidence.

This study was controversial not only for its methodology and highly speculative findings, but also for the worry of public fall-out once the media picked up the story. The *Lancet* editors deliberated on the appropriateness of publishing the report (Horton 2004).[4] News outlets had a history of publishing provocative medical research findings and failing to follow up when early theories were discredited or revised (Clarke 2008; Offit and Coffin 2006). The harms to public health that result from media-spun vaccine scares had already been witnessed in the pertussis vaccine controversy in the 1970s and 1980s (Blume 2006).

To his colleagues' surprise, Wakefield held a press conference, timed closely to the study's publication release, where he suggested that single vaccines—one each for measles,

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[3] The recommendation is for the first dose of the MMR vaccine to be administered at 12-15 months of age in the USA (Center for Disease Control and Prevention ND), at 12 months in all Canadian provinces (Public Health Agency of Canada 2011), and 12-13 months in the UK (patient.co.uk ND)

[4] *Lancet* editor Richard Horton was strongly criticized for his decision to publish the paper. See, for example, Greenhalgh (2004).

mumps, and rubella—should be offered over a 12-month period in place of the MMR triple-shot until a potential link between that vaccine, enterocolitis, and autism could be further studied (Offit 2008). The *Lancet* study offered neither evidential support for the safety or efficacy of the single vaccine nor any warrant for his 12-month temporal duration (Fitzpatrick 2004c).

In the months that followed, the study was systematically discredited by the medical establishment. A British Medical Research Council hearing concluded that MMR and autism had no association (Department of Health 1998); following a shocking investigation into Wakefield's financial conflicts-of-interest (Deer 2004), all but one of Wakefield's co-authors retracted the analysis of the study data for being overly suggestive of a MMR-autism link (Murch et al. 2004); Wakefield was found to have violated ethics protocol in the study and was thereby stripped of his medical license (General Medical Council 2010); the *Lancet* followed by retracting the study (Editors of the Lancet 2010); *London Times* investigative reporter Brian Deer revealed that Wakefield had fabricated his data and exposed this fraud in a 3-part report commissioned by and published in the *British Medical Journal* (Deer 2011a; 2011b; 2011c). At each point of damning revelation of impropriety and serious scientific misconduct, public officials anticipated a sea change in public attitudes towards vaccination; this attitudinal shift never materialized. To illustrate, a May 2013 *USA Today* headline read, "Measles Surge in U.K. Years after Flawed Research" (Cheng 2013).

The "official" response to a looming public health crisis

In the United States, American vaccine specialist, Dr. Paul Offit, is the most public face of the scientific consensus position that there is no association between vaccines and autism. He has been celebrated for his outreach efforts to correct misperceptions of vaccine safety (George 2011). In his abundant writing on the subject, which include numerous editorials in biomedical journals (2007b;2008c) and news sources (Offit 2007a; 2008b; 2011b), parenting books (Offit and Bell 1999; Offit and Moser 2011), practical guides for physicians (Offit et al 2002; Offit and Hackett 2003; Offit and Jew 2003; Gerber and Offit 2009), and popular science books (Offit 2008a; 2011a) with such inflammatory titles as *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All* (Offit 2011a), he has framed the defensive strategy now emulated by others, including Michael Fitzpatrick (2004a; 2004c), his British counterpart.

The strategy involves both negative and positive components. The negative arm is a vigorous attack of the anti-vaccine message, while the positive strategy is the corrective, the strong body of scientific evidence showing no causal association between autism and vaccines. To start with the negative, vaccine advocates highlight the weaknesses of the anti-vaccine message. First, there is the faulty and fraudulent science performed by Wakefield and colleagues (Offit 2008a; Fitzpatrick 2004a). Second, the untrustworthiness of the anti-vaccine pundits: notably Wakefield, who had received payment for the *Lancet* study by a barrister representing parents suing vaccine companies for causing their children's autism (Fitzpatrick 2004b, 2004c; Offit 2008a); the anti-vaccine celebrity spokespeople, especially Jenny McCarthy (Mnookin 2011, 249-261; Offit 2011, 149-154),[5] who hypocritically, according to Offit (2011), "indulge their own vanity by using injectable cosmetic botulinum toxin while reviling the same pharmaceutical industry for profiting from vaccines" (Brumback 2011, 1329); those profiting financially from the growing industry of "alternative" autism research and treatment that is founded on public mistrust of mainstream science (Fitzpatrick 2009, 57-65; Offit 2008a; Hannaford 2013). Third, Offit and others further blame the media (Offit 2008a, 176-195; Mnookin 2011, 160-169; Fitzpatrick 2004a, 139-144) and the US vaccine courts for distorting

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[5] For an analysis of the influence of Jenny McCarthy on vaccine hesitancy, see Largent (2012), pp. 138-148.

public perception of vaccine safety (Offit 2008a, 156-175; 2008b; 2008c), and finally, criticism is directed at parent groups who mobilized support and research advocacy for families of vaccine-damaged children, offered information resources to the worried public, and garnered media attention and political support for their emotional and unscientific claims. The National Vaccine Information Center in the United States and the British group JABS (Justice Awareness and Basic Support) are strongly-reproached for playing an instrumental role in misinforming the public, misdirecting health resources, engendering spurious controversy, and facilitating declining vaccination rates to levels below those needed for “herd immunity” in some regions by way of their emotional pleas (Offit 2011; Fitzpatrick 2004c, 2004d).

With the integrity of the anti-vaccine message undermined, the public can now presumably be swayed with a generous offering of reliable science. The pundits exalt the global health gains produced by mass immunization campaigns and offer a strong body of evidence in support of MMR’s safety record. In one such publication, written to assist physicians address the concerns of their vaccine-hesitant clients, Offit and co-author James Gerber explain that *even though* Wakefield’s MMR-autism thesis was not supported by biological or clinical findings, “several epidemiologic studies were *performed to address parental fears* created by the publication by Wakefield et al” (Gerber and Offit 2009, 456; my emphasis). These studies, the authors seem to suggest, offer no scientifically relevant information, but instead serve an important public outreach and educational function. Gerber and Offit enlist those studies to deftly dismantle three popular hypotheses regarding the dangers of vaccines:

(1) MMR-autism thesis

(2) Thimerosol-autism thesis—the theory that a mercury-based preservative used in vaccines with inactivated viruses causes autism;

(3) Vaccines “overwhelm the system” thesis—the theory that too many vaccines are introduced too soon into infants’ delicate systems.[6]

Taking on both the MMR-autism thesis and the alternative thesis that autism is caused by the mercury-based preservative, thimerosol, found in vaccines with inactivated viruses (such as polio and pertussis), the authors review twenty epidemiological studies that uniformly fail to make an autism-vaccine association. They highlight the reliability of the findings and the significance of these studies’ convergent conclusion. They note that

> [t]hese studies have been performed in several countries by many different investigators who have employed a multitude of epidemiologic and statistical methods [ecological, case-controlled, retrospective cohort, prospective studies] (Gerber and Offit 2009, 460).

Furthermore, these studies relied on national vaccine records, which provide reliable historical data for excellent descriptive and observational studies. These records permit examination of national rates of autism before and after the introduction of the MMR combination vaccine into national schedules, as well as before and after thimerosol was reduced to trace amounts in vaccines (in response to public pressure, pro-vaccine advocates insist, and not because of sound safety concerns). These large-scale programs allow for a high level of statistical power, and the data are often comparable for meta-analysis due to similar vaccine constituents and schedules across national borders. Electronic medical records also facilitate accurate analysis of outcome data.

The evidence against the last theory—that vaccines can overwhelm the system—is more difficult to convey in accessible terms, as the evidence comes from mathematical modelling of

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[6] This thesis permits the increasingly popular option among parents of a modified or “alternative” vaccine schedule rather than indiscriminate rejection of all vaccines. Some vaccines could be eliminated, combined vaccines could be unbundled, and vaccines could be introduced more slowly. See for instance, “Dr. Bob’s Alternative Vaccine Schedule” promoted by best-selling author and physician, Dr. Robert Sears (Sears 2007).

an infant body's theoretical capacity to respond to immunological challenges. Offit relies on basic immunology and reassurances instead. In an interview with a parenting magazine, Offit said:

> Children have an enormous capacity to respond safely to challenges to the immune system from vaccines…A baby's body is bombarded with immunologic challenges--from bacteria in food to the dust they breathe. Compared to what they typically encounter and manage during the day, vaccines are literally a drop in the ocean (Howard 2005).

Writing to healthcare audiences, he elaborates that

> the average child is infected with 4–6 viruses per year…The immune response elicited from the vast antigen exposure of unattenuated viral replication supersedes that of even multiple, simultaneous vaccines (Gerber and Offit 2009, 459).

Offit's claims can be sourced to the work of immunologists Cohn and Langman (1990), who calculated an average young child's immunological capacity and found it to far exceed the roughly two dozen vaccine antigens that he or she receives as part of routine childhood vaccination. Knowing that antibodies, the component of the immune system most capable of protecting against infection, are made by B cells, and that B cells make antibodies against only one epitope (an immunological unit), the calculation can be made by estimating the "number of B cells in the bloodstream [against] the average number of epitopes contained in a vaccine, and the rapidity with which a sufficient quantity of antibodies could be made [against any offending epitopes]".[7] From this, Offit famously concluded that "babies could theoretically respond to about a hundred thousand vaccines at one time" (Offit 2011, 174).[8] Furthermore, those vaccines induce an excellent immune response to future pathogens.

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[7] Those estimates and the detailed calculations are reviewed in Offit et al. (2002).

[8] Offit made the now-infamous '100,000 vaccines argument' in response to Dr. Sears's claim that the combination-MMR booster should be withheld until age five when the immune system is more mature. Offit hoped to prove, to the contrary, that vaccines given in the first year of life induce an excellent immune response. Instead the 100,000

With the arguments mounted against all three "shifting hypotheses",[9] Gerber and Offit then confidently conclude:

> These [epidemiological] studies, in concert with the biological implausibility that vaccines overwhelm a child's immune system, have effectively dismissed the notion that vaccines cause autism. Further studies on the cause or causes of autism should focus on more-promising leads (2009, 460).

We can draw from this pedagogical exercise that the positive strategy operates with the working assumption that the public's vaccine hesitancy occurs because we misunderstand the science.[10] With Offit and others reporting the consensus view as confidently as they do, perception of the public's ignorance is only reinforced. The epidemiological studies have been done—again and again!—and clinical and virological studies have failed to reproduce the Wakefield research team's findings. The scientific evidence is solid, and the scientific consensus is clear and unambiguous. The only reasonable account of why vaccine hesitancy persists, it would seem, is a fearful public who is unable to integrate this evidence into their worldview.

A 2002 editorial on vaccine hesitancy co-authored by members of the Department of Vaccines and Biologics at the World Health Organization explicitly endorses this disparaging view of the public (Clements and Ratzan 2002). The authors describe the British public as "misled and confused" by anti-vaccine misinformation. They write:

> Because of the huge amount of media coverage of the safety of MMR, the public, not unreasonably, have come to the conclusion that there is no smoke without fire; there must be some truth in all this alarmism (22).[11]

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comment raised the ire of many vaccine hesitators and deniers, who perceived Offit as being insensitive and uncaring towards vulnerable children. See Huff (2012).

[9] Gerber and Offit (2009) described the three popular vaccine danger theses as "shifting" because, by their account, the anti-vaccine movement has shifted public fear and attention from one theory to another as evidence mounted against any one of them and threatened to undermine it.

[10] This theory of public misunderstanding of the science has been stated explicitly in some instances. For example, the 2008 *New York Times* headline, "Measles Cases Grow in Number, and Officials Blame Parents' Fear of Autism" (Harris 2008).

[11] An ESRC commissioned report on science, the public, and the media, which comprehensively reviewed media coverage of the MMR-autism debate in 2,214 newspaper, radio, and television reports from January to September 2002, and surveyed over 1,000 British residents, came to this same conclusion. See Hargreaves et al (2003).

The authors continue:

> Once the peoples' mind is made up, it may be very difficult to change it. Members of the general public are less likely to be able to detect flaws or inconsistencies of argument, analyse the risk benefit ratios, or identify omissions in evidence presented to them. The public may focus more on the presence or absence of risk rather than the relative risk of a situation (ibid.).

Commentators frequently endorse this view of an ignorant public in the popular characterization of declining vaccine rates as a problem of vaccines being "*a victim of their own success*" (Lewis 2004; Offit in Howard 2005,[12] Taverne 2005; Best 2011; Janko 2012). This refrain is sourced from a graph created by Robert Chen, head of Vaccine Safety at the Center for Disease Control and Prevention (CDC), entitled "The Natural History of an Immunization Program", which naturalizes public reaction to vaccines with a three-part historical progression (See Figure 1). In the first phase, people are afraid of the serious infectious diseases that they have witnessed in their lifetimes, and parents readily accept immunization. This is what happened in the United States in the 1940's with diphtheria, pertussis, and tetanus (DPT), the 1950's with polio, and the 1960's when the MMR vaccine was introduced. In the next phase, as vaccines reduce disease prevalence dramatically, vaccines become "a victim of their own success". A new focus on side effects occurs, whether real or imagined, and immunization rates plateau. In the final stage, vaccine fear continues to rise and immunization rates fall. Rates of preventable disease then increase, as we see now in measles, mumps and pertussis outbreaks in the United Kingdom and mainland Europe, USA, and Canada. Eventually, we return to something the like first phase (Chen and Hibbs 1998).

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[12] Offit explained to a reporter for *Baby Talk* magazine that vaccines are "under fire" due to their success. He is quoted saying "It's the natural evolution of a vaccine program" (Howard 2005).

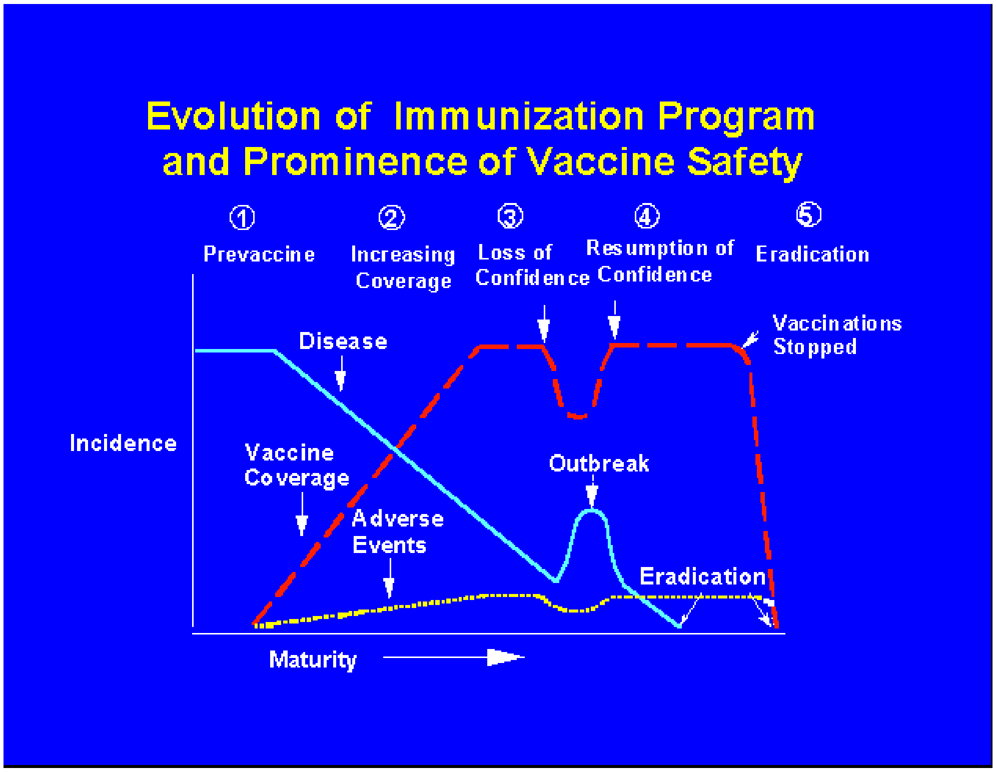

Figure 1. Relationship between people's use of vaccination and the disease rate. (Chen and Hibbs 1998).[13]

The graphic conveys a passive public, motivated by fear rather than sound judgment, lacking in the critical thinking abilities needed to, first, appreciate the long-term benefits of vaccines, second, question the motives and opinions of dissenters, and third, resist the emotional sway of fear mongering and empathic connection with devastated parents.

Of course, those same epistemic vices structure vaccine compliance as well. This has implications for how public health outreach efforts are organized. Health officials widely recognize the importance of public support in achieving public health goals, and so the importance of garnering the public trust and engaging the public are more than academic aspiration or political promise. Even Clements and Ratzan finish their disparaging assessment of the “misled and confused” public with a quick nod to the current vogue of science and the publics:

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[13] Image downloaded from http://www.utoronto.ca/virology/mby480/VaccineSafe/maturity.gif

> Because of these and other potential problems in communicating with the public, professionals somehow need to draw them into a participatory process in any risk communication efforts (Clements and Ratzan 2002, 22).

But it is unlikely that these health researchers are looking for genuine participation from an ignorant and irrational public. Instead, the pro-vaccine message works to create the conditions for mass public compliance—by shutting down dissenting views and amplifying the pro-vaccine message. Both tactics have failed. First, Wakefield's credibility in the eyes of vaccine resisters seems to be bolstered by efforts to discredit him. Wakefield is seen as a maverick, speaking truth to power, while the scientific establishment looks suspect in a seeming organized effort to suppress "inconvenient truths" (Habakus and Holland 2012, 5; see also Holland 2012). This view is reinforced by a general disdain for the cozy relationships between academic medicine and Big Pharma; Paul Offit's ties to the vaccine industry are particularly disliked (Atkinson 2008; Koch 2009), earning him the nickname Paul "for-profit" Offit (Mercola 2009). Second, the amplified pro-vaccine message does not reach its intended audience because it does not address the concerns of the vaccine-hesitant public. This last point will be explored further in the next two sections.

Public misunderstanding of science? A challenge

Health officials were initially surprised by public backlash against vaccine recommendations and reassurances of their safety. A strong scientific consensus is supposed to be the antidote to such occurrences; it functions to "certify facts for the lay public" (Ranalli 2012) and thereby placate public fears or misgivings by offering expert-driven definitive answers that the public can trust. The public's questioning or challenging of the consensus view suggests that the consensus is not serving this purpose. There are several reasons why the public might not accept the scientific majority opinion. One is that the public cannot understand the scientific content of the consensus. A second possibility is that the public fails to appreciate the epistemic stature of widely-held expert opinion.[14] The third and least-considered explanation is that some of the previously secure relations of trust between science and the publics that gave consensus statements their epistemic weight in the eyes of the lay public no longer hold. Our discussion so far has highlighted how government bodies were quick to accept the first explanation.

The scientific and policy establishment's casting of the public as ignorant absolves these institutions of listening to the concerns of anxious parents. I will now challenge the characterization of the public as ignorant or resistant to science. I will not apologize for the general public's predictable lack of knowledge of the complex science of virology, immunology, epidemiology, and other sciences relevant to vaccine safety. But I want to propose that public dissent does *not* reside in anti-science ideology or a misunderstanding of the science. Instead many parents approach the question of vaccine safety from a different perspective—concern for their children—and this individualized approach makes the presence of rare but serious adverse events a safety priority rather than, as health officials see it, a reasonable risk. By failing to see this alternative framing of the vaccine safety question, and instead charging "ignorance", scientific and governmental agencies have misdirected health outreach efforts and missed opportunities to seriously address and remedy vaccine hesitancy.

This individualized approach to the question of vaccine safety has been observed in social scientific research into parental attitudes towards vaccination (Evans et al. 2001; Poltorak et al. 2005; Leach and Fairhead 2007; Yaqub et al. 2014). Leach and Fairhead, for instance,

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[14] Historian of science Naomi Oreskes entertained this option in recent news editorials on public resistance towards the overwhelmingly-strong climate change consensus offered by the Intergovernmental Panel on Climate Change, National Academy of Sciences, American Meteorological Society, the American Geophysical Union, and the American Association for the Advancement of Science. In these writings, she attempted to clarify what the consensus represents (a justified majority opinion rather than unanimous agreement), the rigorous analysis with which the climate change conclusion was reached, and why the public should not be concerned by a few outlier scientists that challenge the consensus (Oreskes 2004a; 2004b).

observed this phenomenon in surveys and interviews with British mothers and a few fathers participating in community-based post-natal groups in the early 2000's (Leach and Fairhead 2007). This was a time of heavy media coverage in Britain of the MMR-autism debate, precipitated by the circulating rumor that then-Prime Minister Tony Blair had chosen not to vaccinate his infant son. The personalized approach adopted by the majority of study participants contrasted the characterization of vaccine safety by health research, policy, and promotion agencies as a public health question, answerable at the population level. These parents expressed vaccine fear that would not be relieved by reassurances that MMR was safe for the general public. They wanted to know: "Is MMR safe for *my* child?"[15]

The interviewees and survey respondents, who came from both working- and middle-class backgrounds and subscribed to a range of political views, were asked about their perceptions of vaccine safety, where they turned for advice and support, and finally, how they intended to act on the options of either vaccinating, not vaccinating, or paying out-of-pocket for an alternative (spread-out, reduced, or unbundled) vaccine schedule at a private clinic.

Parents, with their copious reflections based on experience and observation of their own children, were widely found to hold a distinctively personalized view of their children's health, immunity, and whether their child should have the MMR vaccination. Against the vision of a passive public wholly susceptible to overblown media reports of vaccines' questionable safety record, these parents typically did not endorse either the mainstream reassurances or the dissenting view, not because they were still undecided, but because they were not interested in

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[15] Hobson-West (2007) found this language of individualized needs of the child being heavily used by British 'Vaccine-Critical Groups' (including JABS) in her interviews with the leaders of 10 such groups. This suggests that the anti-vaccine rhetoric is more in-tuned with parental thinking and attitudes (whether influencing or influenced by those parents) than the population-level language of risk employed by pro-vaccine sources. The next section of this paper addresses how this failure to understand the concerns of the public has compromised the effectiveness of public health outreach campaigns aimed at promoting vaccine uptake.

generalities. Many parents readily allowed that “MMR might be safe but not for my child” (Leach and Fairhead 2007, 57).

Leach and Fairhead found that what often followed from this commonly held view was detailed reflection by parents on their child’s particular strength or vulnerability, immune system characteristics, and family health history, all of which underlay concern about MMR or vaccinations in general (Leach and Fairhead 2007, 57; see also Poltorak et al. 2005). The danger or lack of danger presented by the MMR vaccine was not evaluated in general terms but in relation to parents’ assessments of their child’s particular health pathway since birth and his or her genetic heritage (Leach and Fairhead 2007, 58). Some survey responses included:

> My first daughter had milk intolerance and was very ill for the first two years of her life. We didn’t vaccinate her with MMR because she was quite weak (58).
>
> I was more frightened of the potential side effects of measles should I decide not to get Luke vaccinated. Had he been a poorly sickly baby with allergies I might have considered single jabs (ibid.)

Some parents included a family history in their decision-making, such as relatives with autism, arthritis, allergies, and autoimmune problems (ibid.). Others incorporated consideration of broad characteristics such as the child’s birth timing, maturity, sleep patterns, and behavior (Yaqub et al 2014). Some even worried about the possibility of unknown and undetected “weaknesses” in a child, which can be understood to signify fear of even a slim chance of serious adverse events (Leach and Fairhead 2007, 58-9).

These personalized accounts do not align with current scientific understanding of immune response. But this effort by parents to figure out their own children’s risk of adverse events should not be read as ignorance of science or as an anti-science view. Instead parents appear to be incorporating established knowledge that immune responses do vary and are trying to fill the knowledge gap regarding preceding or causal events. This personalized approach is also not clearly demonstrative of fear or selfish disregard for public health either (albeit public health is threatened by this behaviour). Instead it shows attention to a parent's priority—the well-being of her child.

Additionally, the individualized approach accords with other health-promoting influences on parents' thinking. In what sociologist Deborah Lupton (1995) characterized as the "new public health" that emerged in the 1970s, public health discourse adopted the language of choice, empowerment, personal responsibility, and participation. The positive connotations attached to those terms came to shape the "new" public health citizen, patient, and parent into experts on and advocates for their own and their children's health and well-being (Petersen and Lupton 1996). It should therefore be no surprise that qualitative research into parental attitudes towards vaccination found that many respondents prioritized choice regarding their child's vaccine schedule, for example in having the option to select single versus combined shots (Brown et al 2010, 4244). Parents also regarded themselves as personally responsible for making those choices. Brown et al. (2010) reported that "[p]arents felt that personal research was *expected of them*" (4244; my emphasis).

It is within this person-centered framework that current expert parenting advice in both European and American contexts promotes "active, child-centred, and personalized approaches for improved child health and developmental outcomes" (Leach and Fairhead 2007, 51). The individual particularities of each child is frequently highlighted in the many parenting books available on sleep-training infants, negotiating toddler tantrums, helping your child succeed in school, and so on. Similarly for healthcare, with the exception of the "vaccine question", parents are strongly encouraged by their pediatricians and other front-line health workers to actively engage in their children's healthcare and to be experts on their own child. This allied approach is seen to be better for children’s health and better for overburdened healthcare systems that frequently download health work onto the individual or caregiver in the name of “personal responsibility”. In asking for active parents and compliant vaccinators, Public Health seems to want to have it both ways.

Missing the mark in health promotion and outreach

The presumption of ignorance can pre-empt genuine effort to understand the public’s concerns. With this alternative account of the nature of vaccine anxiety among the general public in place, we can now appreciate the missed opportunities by public health agencies to properly reach their audience.

Leach and Fairhead’s subjects wanted to make informed decisions regarding vaccinating their children, and they sought support for doing so. They typically consulted social networks of parents, including parent-lobby groups, for nonjudgmental discussion and access to the information they needed. The children’s pediatricians were generally not consulted in this process of inquiry, not because parents feared reproach, but because they felt that the physicians had to support the “official” line (Leach and Fairhead 2007, 64; see also Evans et al 2001 and Yaqub et al 2014).

Government agencies confronting vaccine hesitancy (including the UK Department of Health, Health Canada, and the CDC in the USA) have followed a didactic model, establishing information campaigns meant to educate parents regarding sound science, the social good, and a true appreciation of the balance of risk (Leach and Fairhead 2007, 79). For instance, in a Health Canada promotional leaflet titled “Misconceptions about Vaccine Safety”, parents read:

> Misconception: Vaccines are not safe.
>
> The Facts: Vaccines are among the safest medical products available. Prior to approval they are extensively tested and they continue to undergo rigorous

> ongoing evaluations of their safety when on the market. Serious side effects such as severe allergic reactions are very rare. On the other hand, the diseases that vaccines fight present serious threats. Diseases like polio, diphtheria, measles and pertussis (whooping cough) can lead to paralysis, pneumonia, choking, brain damage, heart problems, and even death. The dangers of vaccine-preventable diseases are many times greater than the risk of a serious adverse reaction to the vaccine (Health Canada 2011).

Here the sound science and the assessment of risk were expressed relative to population-level analysis, and therefore do not address the concerns of parents who are assessing the risk in relation to *their* child. While the claim that severe adverse events are very rare is meant to be reassuring, it sidelines the very issue that the parents interviewed by Leach and Fairhead are worried about.

Parent advocacy groups like JABS, on the other hand, engage parents on their own terms. These groups were founded on the belief that parents know their children best, and thereby have insight into their children's health not afforded to physicians and medical scientists (Hobson-West 2007). Members of these groups share tales of having their concerns regarding vaccination dismissed by health professionals, and those claiming that their children were harmed by vaccines were routinely ignored (Evans et al 2001; Leach 2005, 8; Kirby 2006, 9-31; Navin 2013, 10-13). While some accept that a serious adverse event after vaccination is extremely rare, they think that research into the factors precipitating those rare events must be a priority. Indeed, JABS and other British parent lobby groups have outlined parent-driven alternative research priorities, and their public communications have called upon the British government to direct resources into pursuing these lines of investigation (see, for example, Fletcher ND). This is not anti-science; it is a demand for participation in setting the research agenda.

Specifically, vaccine hesitators want investigation into the admittedly rare but serious adverse events that they associate with vaccines. The mainstream insistence that, to quote the

Health Canada (2011) brochure, “it is often very difficult to determine if a ‘reaction’ was directly linked to a vaccine or was an unrelated ‘event’ which would normally occur in a population”, is grounds for further research rather than secondary to the overall social benefit that vaccination programs provide.

Starting in the early 1990s, when British parent networks perceived lack of uptake of their concerns by the scientific establishment, they organized popular epidemiological research into this question. JABS was an early user of web-based surveys, where parents’ responses were collected and volunteer researchers analyzed any suggested patterns (Leach and Fairhead 2007, 85).

Several theories have grown from this exercise in “citizen science” (Irwin 1995). The identification of common symptoms have led to the conclusion that these children do not have just “autism” but a novel syndrome linking bowel disorder and autistic symptoms (Trowther 2002). Wakefield and his research team later named this syndrome “autistic enterocolitis”, and although this disease category remains controversial, even vaccine advocates like Fitzpatrick think it warrants further investigation (Fitzpatrick 2004b). Still, it should not be surprising that citizen scientists find disconnect with the mainstream insistence that MMR does not cause autism. This is not the hypothesis that parent advocates are exploring.

Parent researchers are also exploring the possibility of “co-factors” which make an admittedly small number of children vulnerable to vaccine harm. This line of inquiry focuses on the family histories of afflicted children. The JABS survey claims to have highlighted a number of common allergies in the families of these children—asthma, eczema, hay fever—or a history of febrile convulsions, fits, or epilepsy. They wonder if a small subset of children with certain allergies can have allergic responses when presented with several viruses at once (Leach 2005, 13; Leach and Fairhead 2007, 85). This theory speaks to the individualized framing of the vaccine safety question observed in the qualitative research on vaccine attitudes among parents. While the safety of vaccines is sufficiently established for public health purposes, parents want to know if vaccines are safe for *their* kids. Parent researchers argue that population-level studies are "too broad brush" to pick up patterns associated with rare adverse events from MMR that may affect a very small proportion of children (Leach 2005, 17). Instead the science supporting parents' concerns are grounded in clinical case histories and medical and biological processes in individual children.

Parent researchers also insist that the high number of parents reporting autistic symptoms appearing *after* receiving the MMR vaccine regardless of the child's age sufficiently undermines the official claim that autism's onset can be coincidental rather than causal (Trowther 2002). This theory is difficult to defend, however, as the problems of sampling bias and reporting bias present themselves in this claim.

However, the point here is not to argue for the epistemic adequacy or inadequacy of these hypotheses. Regardless of their scientific merit, these proposals—which were organized systematically in a 2002 report by parent-researcher David Trowther—provide important insight for health agencies into both what the public wants and how they measure institutional response to their demands. For instance, those theories regarding how combination vaccines may interact with the genetic illness histories of particular bodies, the details of which are highly speculative but allowable within the expected limits of popular epidemiology, are instructive insofar as they highlight concerned parents' desire to know *which* children will respond badly to vaccines. So is the charge that epidemiological studies are "too broad brush" to pick up patterns associated with rare adverse events. Trowther's report was widely circulated among parent lobby groups and is still available on-line. Yet I am not aware of any official acknowledgement or response to this report.

To be sure, I am not suggesting that the public should redirect the public health research agenda, but I will maintain (uncontroversially, I think) that the public has a stake in establishing its priorities. I have aimed to show that many members of the public frame the vaccine safety question differently, focusing on the particularities of individuals rather than overall response rates at the population level. While there are difficulties with some of the parent-driven theories, what we have here is, at minimum, the points where health promotion agencies ought to be engaging its publics, rather than the current practice of defining the problem and the solution for the supposedly ignorant public. It should be little surprise that public outreach efforts are not changing public perception. To interpret vaccine hesitancy as a misperception of the probabilities of harm is to ignore the normative dimensions of risk assessment. Trivializing public concern as confused "risk *perception*" also damages public trust, the very ingredient needed for effective health promotion efforts (Wynne 1993).

And so, this is not an apologetic for lay perspectives, but a reminder that these voices are part of the expert-lay communicative relationship that fosters the trust seen to be so important for a well-functioning democratic society that increasingly relies on scientific experts and advisors for negotiating complex social and policy issues. Rather than characterizing the lay public as deficient, whereby "outreach" is appropriately limited to scientific education, scientific institutions and governmental bodies must elicit public participation in framing and responding to the issues that the publics care about. This is the best way that public health agencies can meet their mandate of enabling and promoting pro-health behavior among its constituents.

Trust and expert-lay communications

While communication is not a panacea, early two-way communication with the anxious public could have better directed public health outreach efforts. Public health agencies could have learned that the public did not need education into the astounding global health gains that vaccines have afforded us. Resources could have been directed away from repetitive epidemiological studies into the autism-vaccine link. In a dialogical expert-lay exchange, questions can be refined, redundancies and crackpot theories can be collaboratively rejected, and a coherent research agenda that is acceptable to both expert and lay perspectives can be formed. Dialogical communicative practices also encourage trust by the lay public (Grasswick 2010, 394), who find the confident declarations of vaccine safety in absolute terms to be disingenuous.

When we speak of *trust*, we mean "deferring with comfort and confidence to others, about something beyond our knowledge or power, in ways that can potentially hurt us" (Whyte and Crease 2010, 412). We sometimes have some control over who we choose to trust, while other situations render us helpless in the hands of, say, the emergency room physician tasked with treating us (ibid.) In all trust situations, our position of epistemic dependence puts us in a vulnerable position. Members of the lay public as well as policy makers find ourselves in such a position when we must rely on expert scientific advice.

The case for trust and epistemic dependency being crucial for the proper functioning of science has already been well argued with respect to the *internal* relations of science (see Hardwig 1985; 1991). Complex scientific knowledge cannot be produced in isolation by careful self-reliant inquirers, as there is too much for one person to know. Specialization becomes necessary, thus creating a need for trust in the truthfulness, honesty, and integrity of the researchers with whom one collaborates.[16] The vulnerability that this trust places us in (insofar as we can be potentially misled by the expert) can be minimized but never eliminated.

An argument for the necessity of trust relationships *external* to science for its proper functioning has been offered by Scheman (2001). She explains that the many practical aims of the sciences require scientific claims to be accepted by stakeholders outside of those specialized epistemic communities. In keeping with our case study, public health science can only improve population health if the lay publics largely accept and follow its recommendations. The trust requirement once again places the outsider in a vulnerable position, as "those who stand outside of science are urged to trust what goes on within its domains not despite but precisely because of our not participating in its innermost practices" (Scheman 2001, 34). The consensus statement functions to encourage that trust. It is supposed to provide us, the epistemically dependent outsiders, with the reliable scientific information that we need to know. Yet the mechanisms used to ensure the credibility of that information are internal to the scientific community—the negotiation of conflicting views in academic conference settings and in expert journals, replication of findings, peer review, and so on—and are therefore largely shielded from public view. Thus the final step in the expert-lay exchange, where (if all goes well) the publics accept the scientific consensus view, requires some degree of a trusting "leap of faith" that the scientific experts have done their due diligence and reported responsibly. The degree or extent to which that trust is adopted uncritically should be minimized—if only for the reason that parents report being uncomfortable accepting expert advice on vaccination without proper information and discussion (Evans et al. 2001, 907)[17]—through effective communication practices.

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[16] Hardwig's arguments on epistemic dependency in science (1985, 1991) were, on the one hand, radical, given the credence that epistemology lauds on the Cartesian model of epistemic self-reliance, and also trivial, given the unquestionable presence of specialization and collaborative research in the sciences.

[17] Other reasons might include the ethical requirement to foster informed consent.

The link between communication and trust-building has some intuitive appeal and is already presumed in the policy elites' *dernier cri* of championing two-way communications in order to gain the public's trust. But some attention should be given to *why* communicative practices by scientific bodies encourage the publics' trust. Heidi Grasswick (2010) lays some of the groundwork for this conceptual link in her analysis of the important public function of scientific whistleblowers. The reason that (credible) whistleblowers gain public attention is because there exists a lay expectation that scientific communities share significant knowledge with the general public or at least with those who stand to be greatly impacted (whether helped or harmed) by this information. The whistleblower exposes the failure of scientific institutions in fulfilling this expectation to participate in knowledge-sharing practices. The often severe public response to these omissions reflects the importance placed on this expectation. Furthermore, by looking at past egregious cases like the Tuskegee Syphilis Study, we can see how knowledge suppression can erode the publics' epistemic trust in scientific communities. The fraught relationship between African Americans and institutional medicine continues today as a result of Tuskegee and other failures to meet the ethical expectations that the publics place on our medical institutions (Grasswick 2010, 404). On the flipside, by repeated practices of communicating responsibly, scientific bodies build their reputations for being responsive to public interests. They thereby gain and maintain public trust (Grasswick 2010, 394).

Yet there will be those critics who find these "fashionable" appeals to public engagement, democratic science, and engendering trust to be a distraction from science's ultimate aim: to create reliable knowledge (see Taverne 2005, 214-218; Levitt 1999). This view misunderstands public health science's additional outreach mandate and fails to appreciate the damage that has already occurred by *not* taking this communicative route. When parental concerns over the safety of the newly introduced MMR triple-vaccine in the UK started to foment, those apprehensions called for a hypothesis-building science of clinical case histories of individual children. Yet parents faced a medical establishment and government organizations that were reticent to entertain parent-driven concerns for fear that doing so would lend credence to the dissenting view (Leach and Fairhead 2007, 90). The British parent groups reached out to the scientific community against all odds and found an ally within the medical establishment willing to entertain their concerns and take their insights and experiences seriously. This ally was Andrew Wakefield.

Without this willingness for engagement from the scientific and governmental institutions mandated to pursue public health and the public good, parent groups mobilized their own research agenda and permitted Wakefield's insidiousness and opportunism. Wakefield is deserving of blame for inciting vaccine hesitancy and lowering vaccination rates. But the scientific and policy establishment also contributed heavily to the problem they are trying to fix by trivializing public hesitancy and framing the debate as a conflict of science versus ignorance.

Against the knowledge deficit model: A "contextualist" public understanding of science

My analysis of the dominant framing of the problem of vaccine hesitancy, as well as the failures to remedy the problem thus far, join a familiar line of criticism found in the science communications and public understanding of science literature. This literature has largely rejected the "knowledge deficit model" underlying the framing of public resistance to science-backed policies (Wynne 1991; 1992; 1995; 2006; Lewenstein 1992; Layton et al. 1993; Evans and Durant 1995; Irwin and Wynne 1996; Miller 2001; Jasanoff 2005). Vaccine concerns and resistance have been previously tied to this critical approach to public understanding of science by Hobson-West (2003; 2007) and Leach and Fairhead (2007).

The “knowledge deficit model”, first identified by Brian Wynne (1991), presumes that expert forms of knowledge provide a sufficient basis for deciding the most important public policy questions. It follows that lay beliefs that run counter to this expert knowledge are unacceptable and must be corrected through education and public relation strategies. Those who disagree do so because they simply do not understand the science. Furthermore, the science is sound and comprehensive in incorporating all of the values relevant to this policy decision (Brunk 2006).[18]

While scientists, bolstered by numerous science indicators surveys (see, for example, National Science Board 1981; 1983; 1986), have taken the public’s knowledge deficit as fact, sociologists, historians, and philosophers have plied their research methods to explore the interaction of science and the publics and have found a much more complex knowledge exchange. Some have highlighted the “contextual” nature of scientific knowledge—scientific facts are not as unproblematic as the deficit modellers assumed. Instead social context and lay knowledge play a significant role in how science is assimilated into public understanding (Wynne 1995; Irwin 1995; Brunk 2006). Sociology of Scientific Knowledge-practitioners like Bruno Latour (1987) have highlighted the various social processes that precede the designation of any scientific knowledge as reliable. The “contextual approach”, as Steve Miller (2001) called this response to the problematic deficit model, opened the door to more dialogical and communicative approaches to public understanding of science.[19]

While this contextualist critique has been influential in prompting both the British Minister of Science to declare the “demise of the deficit model” in a 1999 address to the British

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[18] Those values are buried, however, as the value-free ideal strongly persists in policy circles (Douglas 2009).

[19] Brossard and Lewenstein (2009) further divide Miller’s second model of public understanding of science, the contextualist foil to the deficit model, into three: contextualist, lay expert, and finally, public engagement models. The latter is the most desirable model by their account.

Association for the Advancement of Science and the House of Lords to suggest that public unrest may not be due to misunderstanding of science but lack of uptake regarding their concerns (Miller 2001; House of Lords 2000),[20] contemporary research by Brunk (2006) and Wynne (2006), among others, indicate that the deficit model still prevails and persists in interpreting public resistance to science-backed policy. My research into vaccine hesitancy further supports that claim.

Conclusion

In this investigation into vaccine hesitancy, I challenged the orthodox reading of the problem as stemming from public misunderstanding of science and anti-science sentiments. I proposed that while the lay publics will suffer from some knowledge deficits with respect to the complexity of vaccine science, it is incorrect to assume that this *explains* vaccine hesitancy, or that this hesitancy amounts to the public's *rejection* of scientific claims. Instead, concerned parents approach the question of vaccine safety differently than does the scientific establishment. This realization sheds new light on why concerted efforts to reform public attitudes towards vaccines have failed so far. By presuming the public is ignorant of the science, and thereby directing outreach efforts at *educating* the public, health outreach efforts are misdirected. The pervasive and reinforcing assumption that publics only hesitate because they are ignorant shields science and government institutions from examining their own practices with respect to earning and maintaining the public trust. I share Brunk's (2006) position that those agencies demonstrate a knowledge deficit of their own when they evade this self-scrutiny. In rereading the supposedly

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[20] The House of Lords claims to have shifted its focus from public misunderstanding, articulated in the Bodmer report, to a communicative approach. A 2004 publication reads,

> While the themes the Bodmer report deals with are still of crucial importance today – not least to encourage young people to study and develop an interest in science – things have moved on since this time. The public understanding of science approach has been questioned as a deficit model of understanding. The implied relationship that support for science can be achieved through better communication overlooks the fact that different groups may frame scientific issues differently (House of Lords 2004, 11).

ignorant public, I highlight the importance of trust and dialogue for remediating supposedly intractable conflicts between science and society.

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