Evidence, Not Authority

Reconsidering Presentation of Science for Difficult Decisions

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Many online publications offer space for the public to comment on articles. These sections are a window to see readers' reactions to the article and the subject matter. This paper provides an analysis of comment sections from readers on articles about vaccination. The purpose of the paper is to demonstrate reactions to authority, which leads to recommendations on how libraries might remain credible and trustworthy places to seek information about contested subjects. Vaccination is a contested practice that has received widespread public attention. This study demonstrates an atmosphere of distrust toward government, media, scientific funding, and drug companies. Librarians working with the public should be aware of this charged atmosphere. Locally created portals that include multiple points of view on contentious subjects will help people make important decisions and will demonstrate independence that will increase trust.

This research seeks to answer the following questions framed within the context of online conversation about vaccinations:

- *What do people say that they trust and do not trust?*
- *How do they speak of authority?*
- *What sources do they say they use to make decisions about health care?*
- *What can librarians learn about observing talk about authority?*

Section 1 provides an introduction to the problem from historical and philosophical angles. Section 2 describes the method, 3, the findings, and 4, recommendations.

Libraries are one place where people go for health information. There is a wide body of literature about vaccination compliance in the health sciences fields, but it primarily addresses methods to promote compliance. There does not appear to be any library and information science (LIS) research that investigates the information needs of parents who are deciding whether to vaccinate their children or how reference librarians might respond to users who may approach them about this topic.

Authority is one criteria of goodness that librarians use to judge sources, but this is a charged word. There are essentially two aspects of authority that librarians talk about: (1) the credibility of the author of a particular document, and (2) the authority file, meaning the official way of referring to a person, place, or thing. There are additional dimensions of authority that we can discern when the public talks about authority—it is linked more often to police, states, and coercion than to credibility. In the case of medical literature, the two kinds of authority are linked

because the same entities that fund research often pursue compliance, especially regarding public health. Such relationships (real or imagined) build a tangled web of mistrust for wary information seekers. Librarians should be aware of this conflict and be aware of how they present information to patrons.

A brief recap of the history of vaccination shows the historic roots of the current vaccination debates and vaccination's relationship to authority. Humans have sought to induce immunity against communicable diseases for centuries; the first evidence of such a practice is from about 1000 CE in China.[1] The first vaccination mandates in England and the United States in the mid-1850s prompted vehement protests.[2] Early arguments against vaccination focused on freedom of religion, tyranny of the state, criticism of allopathic medicine and the American Medical Association, and a belief that scientific studies of vaccination were faulty or corrupt.[3]

Vaccination was generally accepted in the 1950s and 1960s, and in 1967 Kaufman said that the antivaccination movement was effectively dead.[4] Media's attention to vaccination problems revived the movement in the late 1970s and early 1980s when studies and the popular media publicized links between DPT shots and neurological problems.[5] Andrew Wakefield's paper linking vaccination to autism (retracted) incited widespread fear of, and activism against, vaccinations in the 1990s that persists today.[6]

Fear of vaccination is not irrational; several vaccination disasters in the early and mid-1900s and periodic small (though sometimes questionable) reminders of its inherent dangers give credence to fears about vaccination.[7] For instance, a contaminated batch of polio vaccine caused the paralysis or death of fifty-six children in 1955.[8] Mnookin claims, however, that it was "Eisenhower's emphasis on damage control" that ultimately undermined trust in both the government and vaccines—the link between science, government, control, and death was frightening.[9] There have been no recent *widespread* disasters, but individual cases, such as that of Hannah Poling and Dorothy Werderitsch keep fears afloat.[10] Wolfe, Sharpe, and Lipsky summarized arguments against vaccination:

> Vaccination is unique among de facto mandatory requirements in the modern era, requiring individuals to accept the injection of a medicine or medicinal agent into their bodies, and it has provoked a spirited opposition. This opposition began with the first vaccinations, has not ceased, and probably never will.[11]

Conflicting findings demonstrate that there is no firm profile of people who do not vaccinate. Shurtleff found that trust of vaccinations is decreasing in the United States. She said that "historically, religious objectors, civil liberties groups, and alternative medicine practitioners" opposed vaccination, but now a better description is upper-middle class, white, educated, and married people who use nonallopathic medical practices.[12] Kennedy, Brown, and Gust, though, found that parents with lower incomes were less likely to vaccinate, and that education about vaccines could change their minds.[13]

The current pertussis epidemic is useful in demonstrating confusion about gaps in understanding about vaccinations, even by scientists. In 2010, California reported over 9,000 pertussis cases and 10 deaths; Washington saw high rates in 2012.[14] The public and media have blamed nonvaccinators for the outbreak, but recent studies show that the outbreaks are more likely linked to impotent vaccines rather than noncompliance, thus validating antivaccinationists' claims.[15] Fisher, an antivaccination activist, characterizes the CDC and media's response to the outbreak as an attack:

> Media campaigns designed to create fear about infectious disease are nothing new. This one appears to have three goals: first, to emphasize pertussis risks while ignoring vaccine risks; second, to place blame for whooping cough cases and deaths on the unvaccinated; and, third, to attack religious and conscientious belief exemptions, which serve as informed consent protections in U.S. vaccine laws.[16]

Trust, Authority, and Risk

Risk weighing and trust in authority both influence information needs and the decision-making process. Bennett et al. address trust and authority in decision making, explaining that coercion by law is not the most desirable method for promoting compliance.[17] Education about vaccination is more effective in terms of building trust, but because education does not always work, the government has instituted laws (most notably regarding public school attendance). Gostin explains this as an inherent conflict between public health and civil liberties.[18] Tyler says, "Inferences about the trustworthiness of the motives of authorities had a powerful effect on whether people voluntarily deferred to third-party decisions and to group rules . . . if citizens trust government authorities they are more likely to comply voluntarily with their directives."[19]

Kata explains that "local vaccination cultures" are influential in perception of risk and decision making.[20] They find that vaccine-preventable diseases such as diphtheria and polio are so rare that incidences of harm caused by vaccinations have outnumbered those of harm caused by the diseases, so the risk of vaccination appears to be greater than the risk of disease. States regulate exemptions; some give parents the option to opt out of vaccinations for loosely defined religious or philosophical reasons. For instance, one private school in Portland, Oregon, had a 77.8 percent religious exemption rate, and others trailed closely.[21] Parents who opt out must either homeschool or send their children to private schools that allow their attendance, which validates Shurtleff's findings: they are educated and not poor.[22]

The Internet and Online Communication

Online communication and social media are very influential in helping people connect with other people who hold similar beliefs. Furthermore, as Eli Pariser points out, personalized searching creates a "filter bubble" that reinforces cognitive biases.[23] Furthermore, it is ever more difficult to judge an author's qualifications by website appearance. Clay Shirky writes that the Internet has created a culture of "mass amateurization" as crowdsourcing has replaced investigative journalism.[24] Mnookin describes this mass amateurization superbly within the context of the vaccination debates:

> Hyper-democratization of data [that] unmoor[s] information from the context required to understand it . . . combined with the self-reinforcing nature of online communities and a content-starved, cash-poor journalistic culture that gravitates toward neat narratives . . . has led to a world with increasingly porous boundaries between facts and beliefs.[25]

The Internet gave amateur researchers the power to "connect the dots" and act collectively on their beliefs. The debate is sometimes linked to religion, but such an assessment is incomplete, at best. Wallace explains:

> This isn't a religious dispute . . . it's a challenge to traditional science that crosses party, class, and religious lines. It is partly a reaction to Big Pharma's blunders and PR missteps . . . which have encouraged a distrust of experts . . . [and] ironically, a product of the era of instant communication and easy access to information. The doubters and deniers are empowered by the Internet . . . and helped by the mainstream media.[26]

The 2012 Pew Internet Survey found that 81 percent of adults use the Internet, and that 72 percent of those have looked for health information "in the past year."[27] It is worth considering the characteristics of antivaccination websites. Researchers found that antivaccinationist websites claim that vaccines cause illness, are contaminated with poisons, are ineffective, or only temporarily effective.[28] Zimmerman et al. found that they "encourage alternative medicine, claim conventional medicine is wrong, make emotive appeals, and make ethical allegations about conspiracy, cover-up, civil liberty violations, totalitarianism, and immorality."[29] Davies, Chapman, and Leask found that antivaccinationist sites usually try to make themselves appear authoritative by claiming national or international affiliations, and that they present themselves as the underdog against "doctors, health bodies, governments, and pharmaceutical companies."[30]

Librarians as Health Information Providers

Understanding why people trust and who they trust should be a concern for librarians. Winston explained that librarians are called to be proactive in helping people to make ethical and informed decisions by identifying times when people are likely to need help finding reputable sources.[31] Neutrality is a reason that people trust librarians—it indicates that they have no particular agenda to promote—but this case study demonstrates some problems with neutrality.

Libraries provide the materials to explore all sides of an issue; intellectual freedom and the right to read are fundamental philosophical and ethical guiding principles in librarianship.[32] The Code of Ethics of the American Library Association was created in 1938. This early version included a mandate to "protect readers from harmful material."[33] Later revisions to the code dropped the statement about *harmful material* as paternalism waned in favor of intellectual freedom. The Library Bill of Rights maintains "materials should not be excluded because of the origin, background, or views of those contributing to their creation" and that "libraries should provide materials and information presenting all points of view on current and historical issues."[34] However, librarians are also supposed to direct people toward *good* information, demonstrating the conflict. How does one define "good information" when perceived or real conflicts of interest taint the associations of the information producers?

While the vaccination controversy seems to be a straightforward problem for librarians (refer them to the CDC; it's authoritative!), the problem is actually very complex, as illustrated above. Because vaccinations have indeed caused harm, ignoring or playing down the aspect of harm will only serve to discredit the librarian's role as a trusted place to go for information. Librarians need to understand the different types of materials that users might seek and be knowledgeable about the inaccurate information that is online. This is the concept of authority within collection development and information referral.

Appropriateness is not limited to authority, though; the peer-reviewed scientific studies that skeptical health care consumers seek are written for other scientists within a specific field, and librarians strive to give people materials that they are able to read and interpret. Zuccala distinguishes between the intention of the layperson and the professional: laypeople read for their own knowledge, and professionals or scientists read and write for the sake of advancing scientific knowledge.[35] Zuccala found that many nonscientists felt that being able to access scholarly or scientific information was empowering and would help them make better decisions, but that they were also concerned that the research was not "cognitively accessible."[36]

Borman and McKenzie write that libraries are a preferred source for people searching for information related to health issues. Therefore librarians need to be able to provide users with evidence-based information.[37] Librarians can also offer expert search techniques. Alpi writes, "Expert searching is a key component of making essential information available to population health decision makers. Expansion of the role of expert searching is linked to the growing need for timely, quality information for evidence-based practice."[38] Cobus writes that information literacy is the answer

to public health problems: "Access to increased volume of information does not necessarily guarantee finding the best information on a topic. Moreover, the dissemination of incorrect health data could have a negative impact on the public's health."[39]

Unfortunately, it might be difficult for information professionals to find *good* information. Checklists have been developed that help information seekers; Hjørland provides an example of one comprehensive checklist about mammography, another disputed medical practice. He finds, however, that checklists are inadequate in determining what is authoritative; indeed, librarians must look to scientific evidence, which is a more arduous process. Hjørland explains:

> Do we, as information specialists, really need to consider the scientific arguments to evaluate information sources? My answer is an unconditional *Yes we do*. We need to consider whether the arguments on each side are important, and if so, we have to evaluate information sources in relation to how the arguments are represented in the sources.[40]

Fallis writes that it is difficult to find information—especially online information—that we *know* is accurate, even for librarians and information professionals. Authority is important to the information seeker, but Fallis also notes that the vastness of the Internet makes it difficult to know much about the source.[41] People tend to rely on others to discern the reputation of that source. Repetition of information (in the form of stories) validates even an inaccurate source, and when sources do conflict, "then people simply have to determine which source is more reliable."[42] There are two problems regarding scientific data that he brings up: first, the information must be verifiable to the information seeker, and second, if a person is too skeptical to believe the information, it might not matter anyway. He suggests the librarians "make it easier for people to verify the accuracy of information" by giving easier access to organized bodies of literature through metadata and information portals.[43]

The HON (Health on the Net Foundation) code is one way librarians can determine whether a website holds ethical and reliable health information. Its purpose is to "hold Web site developers to basic ethical standards in the presentation of information, and to help make sure readers always know the source and the purpose of the data they are reading."[44] Health information providers apply for certification from this foundation, and then the website is evaluated by members for credibility, authority, and confidentiality. A search on the HON site for "vaccination" and "immunization" revealed only sources that could be categorized as "pro-vaccination." The relationship between authority and librarians is a crucial idea to explore in thinking about how librarians might treat this issue—can materials that question vaccination be authoritative?

Vaccination is a mainstream medical practice. Some people who question its purpose use complementary and alternative medicine (CAM). In 1988, Caplow and Sapp reported that librarians were hesitant to include alternative medical materials,[45] but in 2002 Curry and Rich found that CAM materials are more accepted.[46] Libraries' collections of the material will continue to grow as CAM and alternative health practices are more widely used.

Crumley interviewed doctors, librarians, acupuncturists, and a variety of other people who might be involved in CAM, finding that librarians sometimes play a significant role in supporting the doctors' use of CAM by teaching classes, searching, and disseminating the literature to practitioners, but found that "while resources exist to help answer CAM questions, they are scattered and varied."[47] Oliphant writes that because CAM is not based on the same types of evidence as allopathic medicine, librarians might be more reticent to refer patrons to such practices.[48] Furthermore,

> many CAM practices are based upon a different value and belief system which often involves a different understanding of what constitutes evidence. Further complicating ideas about healthcare and medicine is that personal experience or lay knowledge is often drawn upon as an information source that supplements or supplants expert medical knowledge.[49]

Oliphant called CAM "counter-knowledge"—it fails the evidence test. Truth is experiential, internal, and contested. Oliphant states this as a dilemma: "librarians and information professionals . . . traditionally privilege vetted, scientific and medically-based sources produced by experts. Should librarians incorporate experiential knowledge into information practice and provision?"[50]

METHOD

Comment sections of news articles can give insight into how people feel about an issue. Manosevitch and Walker explain that newspapers have been using these interactive tools to "promote citizen participation and engagement."[51] Comment sections have sometimes replaced letters to the editor as a way to "incorporate citizen voices within the public discussion."[52] The online forums are essentially preserved, observable evidence—a snapshot in time that demonstrates how people were talking or arguing about an issue. They provide evidence of the social process of deliberation.

Seven files of user comments were selected to represent different types of articles (i.e., news, commentary, and advice) and points of view. They were located by searching Google for "vaccination" and "comment." The articles came from ABC News, Babycenter.com, Sanevax (an antivaccination site), the Huffington Post, NPR, the New York Times, and the Wall Street Journal. The number of comments ranged from 66 to 876 per article; 1,537 comments were analyzed in all.

Two researchers coded the data using Dedoose, a

web-based tool for mixed-method analysis. A preliminary reading allowed the two coders to establish a coding scheme that sought to demonstrate how people (in this limited sample) talk about authority and trust, what people were confused about and how people conversed about the decision-making process. The two researchers discussed any questions that arose about how to code the data, producing a negotiated data set. Each relevant comment was assigned as many applicable codes as needed, which ultimately revealed patterns of code co-occurrences indicating interconnected ideas.

FINDINGS

The comments revealed strong feelings toward a broad range of issues such as trust of journalism, the media, researchers, doctors, and the government. Parents frequently expressed that they had difficulty deciding if and when to vaccinate, and other users offered much advice. It is worth noting that in this study, 404 excerpts indicated that vaccines are bad (i.e., evil, dangerous, etc.), and 373 were coded as "good." This is probably not necessarily indicative of a societal trend, but rather of the bias of social media and limitations of the sample.

The top-tier codes established after the preliminary reading were the following:

- Autism (Subcodes: linked to vaccines; not linked; unsure)
- Authority
- Religion
- Vaccines "bad" (encompassing a wide array of reasons)
- Vaccines "good" (likewise)
- Alternative medical practices (positive and negative)
- Blame and personal attacks
- Distrust (of doctors, vaccines, big pharm, the Internet, government, insurance, media, or scientists)
- Knowledge (related to epistemology)
- Personal choice or freedom
- Trust (of government, doctors, media, personal or second-hand experience, or scientists)

The focus of this paper is limited to authority and trust.

Authority

The 450 excerpts coded for "authority" encompassed statements indicating something that compels a person to act (for instance, the law or religion) or a person or entity who has the credentials to be authoritative or credible. These forms of authority are quite different, but this study demonstrates that there is overlap in how people discuss authority and authoritativeness. This is because in public health, the authorities themselves are funding or doing research, publishing results, and recommending health practices that are enforced by law. This is necessary yet problematic; it induces fear and distrust because people do not feel as if they have control over their own health care decisions (or those of their children).

The following excerpts are cogent examples of themes that arose regarding how people discussed authority in this study.

Blame and Personal Attacks

A total of 105 excerpts connected some aspect of authority with blame and personal attacks. This is no groundbreaking finding; online incivility is very common in comment sections of newspapers, but the passionate feelings about authority in relation to vaccinations provide stark demonstration of different reasons why people choose to either follow or not follow recommended vaccination practices. There was especially wide disagreement about scientific proof and methods of studying the effects of vaccines and their effectiveness as well as about whether or not people should be compelled by law to vaccinate. There is great fear and resentment of laws that people feel violate their civil liberties and compromise their ability to make decisions about their own health.

The following participant expresses anger toward people who refuse to vaccinate, referring to laws that require vaccination:

> If you don't want to vaccinate your children against polio, cholera, rubella, mumps, measles, diphtheria or even the flu, please move to a third world country so you won't endanger the health and safety of everyone else, or face child endangerment charges and child custody laws.

The following participant, on the other hand, criticizes science and people who defend scientific studies, questioning the ethics of scientists:

> Yah. Unfortunately, your characterization is in fact an outright lie (conveniently lacking enough detail for this to be immediately ascertainable), and all of the children to whom you refer were in the control arm. Do you want me to write your response for you? Yes? Sure thing: "What was in the placebos??!!? Teh same POIZONZZ!!!!" You're welcome.

These two participants are illustrative of a common communicative stalemate surrounding differing beliefs and the volatility surrounding this issue.

Personal Experience

Personal experience was often cited as the ultimate authority, and was invoked seventy-four times. Many participants had seen that vaccinations were ineffective, or had seen or experienced a problem due to a vaccination, as shown by the following quote:

> As a child, there were COUNTLESS times where I'd gotten the flu shot and I still ended up getting the flu

> later. So I don't get your analogy of the seat belt in the car wreck. I personally think it's more dangerous to inject yourself (and your family) with a vaccine that contains cancer cells and the threat of an autoimmune disorder when squalene is used as an adjuvant.

Many participants used scientific terms. It is impossible to judge a person's educational level and scientific literacy by forum posts but there are indications that some people were confused about the terms. Some participants referred to hearsay and second-hand experiences that shaped their beliefs about vaccinations. Others believed that wise health practices (vitamin C, cleanliness, and sunshine) provide immunity. These show that experience, for these users, trumps any authoritative source; they will be suspicious of scientific studies that go against what they "know" to be true. Furthermore, there were numerous statements that doctors and scientists' recommendations were tainted by their affiliations with insurance and pharmaceutical companies. A belief that doctors are under the control of the government further undermines their authority.

The following statements demonstrate positive and negative associations between state coercion and vaccinations. Positive viewpoints show that some people believe that the state's role is to protect the populace against diseases, and that scientists who work for governmental agencies are interested in combating disease:

> There is more, much more reliable information on the Internet, aside from the garbage on the notorious anti-vax websites. I suggest that posters visit the WHO (World Health Organization), the AAP (American Academy of Pediatrics) and the Immunize.org websites for unbiased information about the Recommended Childhood Vaccine Schedule, vaccine-preventable diseases and the epidemiology reports of disease outbreaks.

Negative statements outnumbered positive, and corruption between multiple agencies is frequently discussed:

> Actually in the real world we're still waiting for the responsible science that proves adding more and more vaccines to the childhood schedule is safe. The years of pharma-funded research regularly produced by the Centers for Disease Control and Prevention haven't convinced anyone that vaccines are safe.

A strong antiauthoritarian or libertarian thread (102 coded) runs throughout many conversations as well:

> Medical freedom, personal liberty, and autonomy over what goes into our bodies, are God-given rights, despite what pharma would wish.

The following quote represents the belief that the government is responsible for protecting the nation's health:

> To those parents who choose not to immunize their children, the reason so many people are angry with you is because you are making choices that put the health of your children, our children, and the most vulnerable members of our community at risk. You seem to make these choices based on a desperate need to find answers where there are none, a determination to find corruption in research, government, health care, and public health, and in the face of rational, research-based evidence. I simply don't believe that every public health official, researcher, pediatrician, and epidemiologist is involved in a conspiracy to mislead us about the effects of vaccinations.

Trust and Disrust

Trust and Distrust were most often associated with feelings of oppression, fighting, or lack of control. Excerpts were subcoded according to the associated entity (i.e., doctors, personal experience, scientists, vaccine ingredients, media). People make decisions based on information that they trust.

There was a lot of confusion regarding how much money the pharmaceutical industry makes on vaccines. Many users claimed that there is a conspiracy between public health departments enforcing the use of vaccinations (see above, under authority) and "big pharma." The following quote demonstrates a different view—that some people place great trust in medical research:

> The economics of vaccines are different from those of other parts of the medical system. If one looks at the issues in developing new vaccines for HIV, and the old and extremely lethal diseases like Tb and malaria, one finds that one of the major impediments in vaccine development is the lack of a huge potential profit margin. . . . Furthermore . . . these are not new medicines, and have consequently been discounted for a long time, compared with brand new drugs. . . . So, yes, vaccines are different. They work very well, which makes them less profitable.

The following excerpt expresses both personal experience and trust in doctors:

> Since the vaccines has been descovered [*sic*] I think we are more protected from most common viruses and bacterias. Especially for the new borns [*sic*] babies is very important to be protected. Before any vaccine, I read all the leaflets, I read the studies and I spoke with the doctor—and I'm sure I've made the right call for my kids. I immunized my kids with all available vaccines on market and this is no paranoia I've seen cases when just one shot makes all the difference.

A countervailing idea was that people should trust their own intuition rather than science or their doctor's advice

(113). The following excerpt represents this kind of thinking. It was especially prevalent in the Babycenter conversation:

> Follow your own Mommy Intuition. Don't be bullied by doctors, schools, and other parents when it comes to vaccines. If something doesn't feel right or gives you a moment's hesitation . . . follow THAT instead.

The connection between "big pharma," doctors, and the government smacks of conspiracy, but participants offered examples of money driving vaccination legislation—for example, several participants referred to Texas legislation regarding the required (expensive) Gardisil vaccine that they said was driven by closed-session deals with Merck:

> Big Pharma spends a considerable amount of time and money lobbying, coercing, and intimidating for its own interests. . . . Think about Rick Perry's decision to require HS girls to get the Gardasil vaccine (after considerable wine and dining from Merck). . . . When the govt requires vaccines, the gov't subsidies the cost for them in most cases.

And,

> The funny thing is . . . some people actually believe everything the pharmaceutical companies tell them oh i am sorry i meant doctors. This is the only country in the world so controlled by pharmaceutical monsters, they dont [*sic*] care about your health or making things better . . . all they want is your money!

Media

Interestingly, media is both revered/trusted (32) and reviled/mistrusted (62) as an instrument for either exposing the truth or as a vehicle for spreading fear through sensational stories. Participants in the following quotes criticize both the story and media in general:

> This article has more flaws than almost any I have seen. It is obvious that the author is just regurgitating the party line. I expect more from NPR. Obviously there has been a press release sent out about DTaP this week because all the major media outlets are slobbering over it. . . . Don't you think the article should have mentioned that FACT? Or is the goal of NPR strictly to provide scientific sounding rhetoric for a witch hunt?
>
> This article is simply more proof that NPR is corporate, continually pandering to the medical profession and big Pharma where much of their support comes from. For medical journal citations, check out www .vaccine911.com/vacreference.pdf.

Questions

Participants asked a lot of questions in these forums (56 were linked to autism alone). They asked for more data, statistics, and advice, but most often they asked for unbiased information. There was disagreement about what might constitute unbiased information.

Examples of questions were the following:

- What are the autism rates in other countries as compared to their vaccination regimens? Has anyone even tried to gather statistics like this?
- Help me understand! Why would anyone wish to inject or be injected with aluminum? Hep B vaccine, DPT vaccine, and Gardasil contain aluminum.
- How am I putting your child at risk if he is vaccinated and mine is not???? He is vaccinated, right?
- Where are the benefits of delaying or not vaccinating at all?

Many participants clearly did not understand science, confirming Mnookin's claims regarding lay-science and misunderstanding and Zuccala's findings that scientific data are not cognitively accessible for much of the public.[53] The call for unbiased data clearly presents an opportunity for librarians' participation in the online public sphere.

This study suggests that barriers to a resolution of this debate for many people are the result of misunderstandings about the nature of scientific knowledge and a lack of empathy toward the emotional dimension of vaccination. This research finds that when doubt or skepticism is delegitimized or deemphasized as a proper part of knowledge creation or acquisition, participants in the debate will be unable to truly converse with each other. Participants expressed valid concerns regarding the moral actions of pharmaceutical companies, and proponents fail to respond to their claims. This creates a culture of hostility that does not help people who are not sure about how to approach the problem or whom to trust. Furthermore, there is a lack of communication from the scientific community to the public regarding actual risk and scientific facts, which leads to the filtering of science through a third party (either the government/public health or antivaccination groups). Selected facts are presented to the public by media, which has the ability to "spin" the facts for maximum impact (and ratings). The public understands this. The Internet compounds the problem because legitimate sources are difficult to discern. Once a person has misgivings about vaccination, illegitimate sources that claim legitimacy based on "underdog" status gain persuasive power.

CONCLUSION AND RECOMMENDATIONS

Libraries are places where people can freely search for information on all types of subjects, and thus librarians strive to provide access to a wide range of sources. This is extremely important when people need to locate information that will

help them make informed decisions. The decision about whether or not to vaccinate one's child is not only difficult, but also volatile and highly contested. Vaccination is a dangerous subject because public health doctrine says that compliance should be mandatory. The effectiveness of vaccination programs rest on compliance, and decision-making relies on choice. This is why librarians might shy away from building a collection to help people decide.

The goal of this research was to examine what people expressed in unmonitored forums regarding what they think about and how they make decisions regarding vaccination. While much of the conversation recorded in these forums was belittling or overly opinionated, there were good examples of people who were not sure about where to turn to for what might be considered good information—expressed in terms of questions about evidence. Some participants explained evidence well; others dismissed it (i.e., "Rely on your mommy intuition!"). Some presented bad evidence. Some told the inquirer to read a lot, and one said to go to the public library. None, however, presented a variety of sources that would enable the questioner to make a decision.

Librarians can help people make informed decisions. Online forums are essentially ready-made sources of information about what the public (often on the national or international level) finds confusing. They demonstrate where knowledge is contested. By reading online newspapers and reactions to the articles, librarians can anticipate important reference questions and create webpages that will direct people to a variety of sources that present various alternatives and points of view.

Such a grand proposition, though, might simply lead to information overload. That is where Hjørland's advice to present evidence is key.[54] Presenting all sides of an issue might, or might not, be possible (depending on the diversity of thought on the issue). All sides of this issue are certainly not scientifically supportable. If a librarian decides to put together a tool to aid in decisions such as vaccination, good (scientifically supported) sources should be emphasized, and evidence should be highlighted. Oliphant pointed out that CAM practices might fail the evidence test but might be worthy of inclusion in the library's collection or recommended readings lists anyway;[55] a resource collection that aids decision making about something like vaccination might even include "bad" sites that gain credence through frightening the reader. After all, if a person is researching vaccination, it is highly likely that they have already come across those in an Internet search. However, they should be presented in context—alongside scientific literature. When they are all presented together, people will be able to see where the evidence falls. This is the value in "freedom to read" in libraries.

Why should librarians undertake such a project? Public libraries are not affiliated with a particular cause or with a specific governmental entity. This independence is part of the basis for the intellectual freedom that is so strongly upheld within librarianship and is the basis for our patron's trust. That said, the patron comments in this paper provide a lot of evidence that librarians' reliance on governmental sources of information might be very problematic for some users. This illustrates why a middle ground is needed: some governmental sources should of course be included because they are valuable, evidence-based sources, and they are written specifically for the consumer (for instance, MedLinePlus). However, other, nongovernmental sources should be included as well—such as open-access journals and links to scholarly medical journals, lists of books, and links to parenting forums. All of these have potential pitfalls (for instance, Zuccala reminds us that science is not written for laypeople),[56] but the wide swath of materials will help the inquirer and librarians understand controversial issues in a more profound way.

This study also demonstrates the dangers of allowing the repetition of misinformation or retracted data. Information professionals need to be aware of sources of misinformation and of the reasons why misinformation exists, so that they can counter it with both the retraction, reasons for the retraction, and evidence that supports the truth.

An area for further study might be whether such sites should be built and maintained locally, or if a nationwide clearinghouse would satisfy intellectual curiosity. The implication of independence as an indication of credibility is that libraries should develop resources themselves, but such a proposition is hardly feasible. In fact, it is likely that a resource similar to the one described above already exists. I did not come across it, though, despite extensive searching, which indicates that remote patrons would be unlikely to find it as well.

This paper used the vaccination debates as a case study, but its application is much wider. There are issues in the news daily that call for clarification with facts and evidence. Climate change and environmental issues often spark heated conversations that swiftly turn into partisan bickering. Reading the newspaper is an act that anticipates problems in society and decision making. The user reactions to content that are in the comment sections are great sources of evidence regarding the public's perception of, and arguments about, various hot-button issues. These forums are an excellent way to gain awareness about the public's sentiments, confusions, and misperceptions—an opportunity to increase awareness of the issues that librarians need know about so that they can create lists of recommended readings. They are also an opportunity to participate in the public sphere, referring people to lists that will help people make better, more informed decisions, which is much needed in the divisive environment on the Internet.

References

1. "All Timelines Overview," The History of Vaccines: A Project of the College of Physicians of Philadelphia, 2013, www.historyofvaccines.org/content/timelines/all.
2. Robert M. Wolfe and Lisa K. Sharpe, "Anti-Vaccinationists Past and Present," *BMJ: British Medical Journal* 325 no. 7361 (August. 24, 2002): 430–32.
3. Stephen Petrina, "Medical Liberty: Drugless Healers Confront Allopathic Doctors, 1910–1931," *Journal of Medical Humanities* 29 no. 4 (December 2008): 205–30.

4. Martin Kaufman, "The American Anti-vaccinationists and their Arguments," *Bulletin of the History of Medicine* 61 (1967): 463–78.
5. Jeffrey Baker, "The Pertussis Vaccine Controversy in Great Britain, 1974–1986," *Vaccine* 21 no. 25–26 (September 2003): 4004; Seth Mnookin, *The Panic Virus: A True Story of Medicine, Science, and Fear* (New York: Simon & Schuster, 2011), 67.
6. Andrew Wakefield et al., "RETRACTED: Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children," *Lancet* 351, no. 9103 (February 28, 1998): 637–41, accessed February 17, 2014, www.sciencedirect.com/science/article/pii/S0140673697110960.
7. Mnookin, *The Panic Virus*.
8. Ibid., 53.
9. Ibid., 47.
10. Paul A. Offit, "Vaccines and Autism Revisited—The Hannah Poling Case," *New England Journal of Medicine* 385 no. 20 (May 15, 2008): 2089–91.
11. Robert M. Wolfe and Lisa K. Sharpe, "Anti-Vaccinationists Past and Present," *BMJ: British Medical Journal* 325 no. 7361 (August 24, 2002): 32.
12. Anna Shurtleff, "Attitudes, Beliefs and Behaviors of Parents towards Childhood Immunizations" (unpublished doctoral dissertation, University of North Texas Health Science Center Scholarly Repository), accessed March 18, 2013, http://digitalcommons.hsc.unt.edu/theses/73, p. 22.
13. Allison Kennedy, Cedric Brown, and Deborah Gust, "Vaccine Beliefs of Parents Who Oppose Compulsory Vaccination," *Public Health Reports* 120 (May–June 2005), accessed March 18, 2013, www.ncbi.nlm.nih.gov/pmc/articles/PMC1497722/pdf/16134564.pdf.
14. "Pertussis (Whooping Cough): Outbreaks," Centers for Disease Control and Prevention, accessed February 28, 2013, www.cdc.gov/pertussis/outbreaks.html.
15. Nicola Klein et al., "Waning Protection after Fifth Dose of Acellular Pertussis Vaccine in Children," *New England Journal of Medicine* 367 (September 13, 2012), 1012–19; "Pertussis (Whooping Cough): Outbreaks."
16. Barbara Loe Fisher, "Using Fear and Prejudice to Attack Vaccine Exemptions," *Vaccination Liberation*, August 4, 2010, accessed March 18, 2013, http://vaclib.org/news/exemption-news.htm.
17. Peter Bennett et al., eds., *Risk Communication and Public Health*, 2nd ed. (Oxford: Oxford University Press, 2010).
18. Lawrence Gostin, *Public Health Law and Ethics: A Reader*, 2nd ed. (Berkeley: University of California Press, 2010).
19. Tom Tyler, "Trust and Democratic Governance," in *Trust & Governance*, ed. Valerie Braithwaite and Margaret Levi (New York: Russell Sage Foundation, 1998), 276.
20. Anna Kata, "A Postmodern Pandora's Box: Anti-vaccination Misinformation on the Internet," *Vaccine* 28 (2009), 1709–16.
21. Jennifer Anderson, "Religious Exemptions Tilt Immunization's Balance," *Portland Tribune*, February 17, 2010, accessed March 18, 2013, http://thevig.portlandtribune.com/news/print_story.php?story_id=132934613174836100.
22. Shurtleff, "Attitudes, Beliefs and Behaviors."
23. Eli Pariser, *The Filter Bubble: How the New Personalized Web is Changing What We Read and How We Think* (New York: Penguin, 2011).
24. Clay Shirky, *Here Comes Everybody: The Power of Organizing without Organizations* (New York: Penguin, 2008), 70.
25. Mnookin, *The Panic Virus*, 8.
26. Amy Wallace, "An Epidemic of Fear: How Panicked Parents Skipping Shots Endangers Us All," *Wired*, October 19, 2009, accessed March 18, 2013, www.wired.com/magazine/2009/10/ff_waronscience.
27. Susannah Fox, "Pew Internet: Health," Pew Internet & American Life Project, February 20, 2013, accessed March 18, 2013, http://pewinternet.org/Commentary/2011/November/Pew-Internet-Health.aspx.
28. Robert Wolfe, Lisa Sharp, and Mark Lipsky, "Content and Design Attributes of Antivaccination Web Sites," *Journal of the American Medical Association* 287 no. 24 (June 26, 2002), 3245–48, accessed March 18, 2013, http://jama.jamanetwork.com/article.aspx?articleid=195044; Laeth Nasir, "Reconnoitering the Antivaccination Web Sites: News from the Front," *Journal of Family Practice* 49 no. 8 (August 2000): 731–33; Paul Davies, Simon Chapman, and Julie Leask, "Antivaccination Activists on the World Wide Web," *Archives of Disease in Childhood* 87, no. 1 (July 2002): 22–25, accessed March 18, 2013, http://adc.bmj.com/content/87/1/22.short; Richard Zimmerman et al., "Vaccine Criticism on the World Wide Web," *Journal of Medical Internet Research* 7 no. 2 (2005), accessed March 18, 2013, www.jmir.org/2005/2/e17.
29. Zimmerman et al., "Vaccine Criticism on the World Wide Web."
30. Davies, Chapman, and Leask, "Antivaccination Activists on the World Wide Web."
31. Mark Winston, *Opportunity for Leadership: Full and Informed Participation* (Westport, CT: Libraries Unlimited, 2008), 73.
32. Jean Preer, *Library Ethics* (Westport, CT: Libraries Unlimited, 2008), 7.
33. "Code of Ethics," American Library Association, accessed March 18, 2013, www.ala.org/advocacy/proethics/codeofethics/codeethics.
34. "Library Bill of Rights," American Library Association, June 30, 2006, accessed February 17, 2014, www.ala.org/advocacy/intfreedom/librarybill.
35. Alesia Zuccala, "The Layperson and Open Access," in B. Cronin, ed., *Annual Review of Information Science and Technology* (*ARIST*) 43 (2009), 359–96.
36. Alesia Zuccala, "Open Access and Civic Scientific Information Literacy," *Information Research* 15, no. 1 (2010), accessed May 26, 2013, http://informationr.net/ir/15-1/paper426.html.
37. C. Brandi Borman and Pamela J. McKenzie, "Trying to Help without Getting in their Faces: Public Library Staff Descriptions of Providing Consumer and Mental Health Information," *Reference & User Services Quarterly* 45, no. 2 (Spring 2005): 35–45.
38. Kristine Alpi, "Expert Searching in Public Health," *Journal of the American Medical Association* 93, no. 1 (2005): 97.
39. Laura Cobus, "Integrating Information Literacy into the Education of Public Health Professionals: Roles for Librarians and the Library," *Journal of the Medical Library Association* 96, no. 1 (2008): 29.
40. Birger Hjørland, "Evaluation of an Information Source Illustrated by a Case Study: Effect of Screening for Breast Cancer," *Journal of the American Society for Information Science* 62, no. 10 (2011), 1895.
41. Don Fallis, "On Verifying the Accuracy of Information: Philosophical Perspectives," *Library Trends* 52, no. 3 (2004), 469–70.
42. Ibid., 471.
43. Ibid., 478.
44. Health on the Internet homepage, accessed March 18, 2013, www.hon.ch/home1.html.
45. Deborah Caplow and Gregg Sapp, "A Survey of the Reference Sources for Holistic Medicine," *Medical References Services Quarterly* 7 no. 2 (1988), 41–56.
46. Ann Curry and Joanne Rich, "Alternative Medicine Materials in Canadian Academic Medical Libraries: A National Survey" (proceedings of the Canadian Association for Information Science conference, Toronto, Ontario, Canada, May 30–June 2, 2002), accessed March 18, 2013, www.cais-acsi.ca/proceedings/2002/Curry_2002.pdf.
47. Ellen Crumley, "Exploring the Roles of Librarians and Health Care Professionals Involved with Complementary and Alternative Medicine," *Journal of the Medical Library Association* 94, no. 1 (2006), 87.
48. Tammy Oliphant, "'I'm Making My Decision based on My Experi-

ence': Constructing Authoritative Knowledge about Treatments for Depression," *Canadian Journal of Information and Library Science* 33, no. 3/4 (2009): 215–32.
49. Tammy Oliphant, "Alternative Medicine for Alternative Depression: Claimsmaking, Counterknowledge, and Complementary and Alternative Medicine," (proceedings of Canadian Association for Information Science conference, Montreal, Quebec, Canada, June 2–4, 2010) accessed May 26, 2013, www.cais-acsi.ca/proceedings/2010/CAIS018_Oliphant_Final.pdf, p. 1.
50. Ibid., 4.
51. Edith Manosevitch and Dana Walker, "Reader Comments to Online Opinion Journalism: A Space of Public Deliberation," (paper presented at the 10th International Symposium on Online Journalism, Austin, Texas, April 17–18, 2009), accessed May 26, 2013, http://online.journalism.utexas.edu/2009/papers/ManosevitchWalker09.pdf, p. 2.
52. Ibid., 6.
53. Zuccala, "Open Access and Civic Scientific Information Literacy."
54. Hjørland, "Evaluation of An Information Source."
55. Oliphant, "Alternative Medicine for Alternative Depression."
56. Zuccala, "Open Access and Civic Scientific Information Literacy."