

Facebook and The Anti-Vaccine Movement: A Story of Distrust In Medicine and Government

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**ABSTRACT**

The Anti-Vaccination Movement (AVM) is an anecdotal based social movement. The goal of my research was to explore the current state of the AVM through a content analysis of anti-vaccine Facebook groups, where the structure is an open forum that is widely utilized. In exploring existing literature, I found themes of relying on Web 2.0, an emphasis on freedom of choice, and a lack of communication between parents and the medical community. I then conducted an interview with my key informant, and coded all posts and comments posted on three public anti-vaccine Facebook groups from December of 2017 and February of 2018. I found that while anecdotes are still prevalent across these Facebook pages, a third of all posts and comments coded framed a narrative of conspiracy, meaning that members of the AVM do not trust the government mandate of vaccines and believe that the policies passed are purposefully designed to harm the population. I recommend that there is targeted campaigns for the AVM to convince them of the legitimacy of the government in this policy, and that pro-vaccine groups utilize the power of anecdotes.

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## INTRODUCTION

On June 30th, 2015 California Governor Jerry Brown signed SB 277, making it illegal for parents to leave their children unvaccinated for personal or religious beliefs. Vaccinations help eradicate diseases — for example, in 1980 the World Health Organisation declared that smallpox is no longer a concern for our society, because vaccines have made the disease obsolete (“Smallpox” Accessed 3 March 2018). Vaccinating children ensures that future generations will likely never be exposed to diseases that have seriously harmed or killed people in the past. However, despite all the good that comes from vaccinations, SB 277 was a controversial bill in California. Parents were furious about having the option of exemption taken away from them, and heavily lobbied against the bill. Many of these parents believed that vaccines were dangerous to their children, despite scientific evidence proving otherwise.

This study attempts to understand how the anti-vaccination movement has been so effective, so as to learn from their tactics to benefit future local social movements, and to understand how marginal views can persist despite lack of evidence. Interestingly, anti-vaccine groups have been around for as long as vaccine requirements have been state-mandated - ever since the 1850's. In the last century and a half, these anti-vaccine groups have been repeating a similar argument: vaccines are dangerous, and parents want to opt out of them. As time has passed, there has been more and more evidence that vaccines are beneficial, but there also has been a recent uptick in anti-vaccination groups. The objective of my research is to understand the anti-vaccination movement specifically through the information shared on Facebook. Facebook is a highly frequented social media platform, where many Americans share and discuss news and

opinions. The open forum of Facebook give insight into a largely internet-based social movement.

### **ANTI-VACCINE MOVEMENT THROUGHOUT HISTORY**

Edward Jenner, an 18th century doctor, published a paper describing vaccinations in 1798, after his successful experimentation showed evidence that those who have previously gotten cowpox, a similar but much milder disease to smallpox, were immune to smallpox (Jenner, 1960). Jenner realized that if he could inoculate people with cowpox, smallpox could be prevented successfully (1960). Jenner's paper popularized the practice of vaccination, after his experiments proved successful in preventing smallpox (Wolfe & Sharpe, 2002). Once vaccination became more widespread, governments began to recognize the usefulness of vaccinating their populations.

In the decades following Jenner's publication, the United Kingdom began passing laws in relation to vaccines. First was the Vaccination Act of 1840, that ensured the poor populus was provided with free vaccinations (Wolfe & Sharpe, 2002). The Vaccination Act of 1853 made mandatory that all infants were to be vaccinated before the age of three months, and all parents who did not comply were "liable to a fine or imprisonment" (Wolfe & Sharpe, 2002). After this Act, resistance began to form, leading to riots in towns such as Ipswich, Henley, and Mitford (Wolfe & Sharpe, 2002). During this year, the Anti-Vaccination League in London was founded. In 1867, the next Vaccination Act allowed for parents to wait to vaccinate up until their child's 14th year, "with cumulative penalties for non-compliance" (Wolfe & Sharpe, 2002). After this act, the Anti-Compulsory Vaccination League was founded on the principle that parents should have the right to choose how to ensure the health of their children without punishment (Wolfe

and Sharpe, 2002). In 1885 in Leicester, after an anti-vaccination demonstration that 100,000 people attending, a royal commission was formed to hear testimony about the effectiveness of vaccines (Tafuri et al., 2014). After seven years of testimony, the commission concluded that though vaccines were effective, parents should not be punished for choosing to leave their children unvaccinated (Tafuri et al., 2014). The Vaccination Act in 1898 retracted the penalties for those who do not vaccinate, and added a “conscience clause” for parents to receive a certificate of exemption (Wolfe & Sharpe, 2002).

In 1907, 100 people who were against vaccines were voted on to the English parliament and pulled back the roadblocks to object to vaccines, and by 1946 they removed the compulsory law altogether (Tafuri et al., 2014). In 1974 there was a protest against the pertussis vaccine, leading to the elimination of that vaccine. However, instead of the vaccine being pulled from the requirements it was decided to only be given to children age 2 or older (Tafuri et al., 2014). In the 90’s a French court decided that vaccination caused multiple sclerosis and hepatitis B, but studies later showed that this was not true (Tafuri et al., 2014). All of this happened during a time that anti-vaccination information was spread through newspapers and posters. Now with the internet people have much easier access to this misinformation (Tafuri et al., 2014).

The United states did not experience anti-vaccine activity until the late 19th century, when the United States experienced an outbreak of smallpox. As governments attempted to enforce laws on vaccinations, people with anti-vaccine sentiment began to rise in numbers (Wolfe & Sharpe, 2002). These new laws on vaccinations inspired anti-vaccine advocates from Europe who had recently immigrated to the US to create and found the Anti-Vaccination Society of America, The New England Anti-Compulsory Vaccination League, and the Anti-Vaccination

League of New York City (Wolfe & Sharpe, 2002). These organization successfully blocked vaccination laws in states such as Illinois and California (Wolfe & Sharpe, 2002).

All of this history lead to the question: “to what extent is it ethically appropriate to restrict individual autonomy by compulsory immunization requirements in order to achieve a sufficient collective protection of the community?” (Tafuri et al., 2014, p. 3).

As Wolfe & Sharpe state, in the last two centuries the core arguments opposing vaccines have stayed relatively the same: parents’ choice and the belief that vaccines do not work (2002). As science has changed and as the methods of inoculation and immunization to diseases have changed, vaccines have become more effective and are proven to be safe. However, opposition to vaccines continues to thrive. This study looks to understand the most current climate of the anti-vaccine movement, to understand the process of politicization within the context of modern society.

## **LITERATURE REVIEW**

The anti-vaccine movement (AVM) is heavily based in anecdotes, as Betsch et al. point out in their study, “Opportunities and challenges of Web 2.0 for vaccination decisions” (2012). Narratives are emotionally compelling and experientially effective in swaying opinions. In this literature review I will explore the avenues, including their use of narratives, that have allowed the AVM to continue to thrive amongst some parent groups while health care professionals are in consensus: vaccines are safe and effective.



### Social Movement Theory

The AVM is a social movement — it is a grassroots movement organized around the belief that vaccines are a threat to their children’s safety. Social movement theory provides a framework to better understand the structure the AVM uses to accomplish their goals. Robert Benford & David Snow outline social movement theory through collective action framing in their article, *Framing Processes and Social Movements: An Overview and Assessment* (2000). The frame defines the condition that needs to be fixed, who is to blame for the problem, what is to be done to fix it, and encourages others to work to create this change (2000). One of the five frames they discuss is *consensus mobilization*, where the goal is to change people’s opinions (2000, pp. 615). Consensus mobilization involves information campaigns, attempting to spread enough information that corroborates the issue at hand in order to convince others to recognize the problem. The AVM exemplifies consensus mobilization in that the movement is trying to dissuade people from vaccinating their children using negative narratives about vaccines. The AVM’s goal is to protect children from the perceived danger of vaccines, and in order to do so, they try to change the opinions of parents using these narratives.

The narrative structure of the AVM contributes to its legitimacy among its members. Hahrie Han, a politics professor at University of California, Santa Barbara, recently wrote an op-ed article for the New York Times about the effectiveness of the NRA. She states that “gun control groups focus on persuasion, while gun rights group focus on identity” (“Want Gun Control? Learn from the NRA”, 2017). The ability to connect with another person on an issue makes the issue feel more tangible. Focusing on identity (i.e. being a part of the AVM) creates a sense of being a part of something bigger. Han found that people were more likely to respond

positively to political appeals when they were offered personal information about the person giving appealing to them (2008). The personal information shared by its members on the subject of vaccines makes the ideology more appealing. The AVM is a personal movement that is run by scared parents who distrust the usefulness of vaccinations, and the personal information aspect within their movement is integral to being a part of the AVM.

Social media is a vehicle for the personal and private lives of people to become common knowledge. An example of personal become political through social media, Guidre et al. did a study of the vaccination information being spread on Pinterest (2015). In agreement with their hypothesis, they found that pro-vaccination pins (pins are the posts on pinterest) did use more statistics, and anti-vaccination pins used more narrative structures (Guidre et al., 2015). They suggest that “public health and medical organizations should increase their engagement with the public via social media to communicate the benefits and safety of vaccines” (Guidre et al., 2015, p. 4). Also, they stated that if pro-vaccination people would use more vaccination-positive narratives about how useful vaccines are, the science may become more accessible (Guidre et al., 2015). Social media allows the AVM to tie identity and personal appeals into the movement.

### The Scientific Refusal and the Reliance on Web 2.0

The AVM does not recognize the validity of scientific journals stating that vaccines are safe. Instead, the AVM continually attempts to show that there is still a scientific debate on the effectiveness and safety of vaccines. Naomi Oreskes and Erik M. Conway, in their book *Merchants of Doubt*, discuss this phenomena:

In creating the appearance of science, the merchants of doubt sold a plausible story about scientific debate...A reasonable journalist, not to mention an ordinary citizen, could be forgiven for having been fooled by it (2012, p. 245).

In selling the idea that there continues to be a scientific debate, the AVM portrays itself to be coming from a place of legitimate concern over an unfinished debate.

The AVM is able to create the illusion of a debate through its usage of the Web 2.0

Betsch et al define Web 2.0 as:

Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, e.g. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube...Web 2.0 enables two-way and multi-way communication (2012).

Web 2.0 is an interactive experience, where people who use the internet also get to become part of the internet. The difference between Web 2.0 and Web 1.0 is that in 2.0 anyone can generate content, instead of just the provider (Tafari et al., 2014). If anyone can generate content, then when the AVM claims that doctors and nurses agree with their opinions, it can be difficult to combat.

The sharing of personal opinions on Web 2.0 can create a fear of vaccinations (Betsch, 2012). “Users of these so-called Web 2.0 applications (e.g. social media, online discussion boards, etc. comprise not only consumers looking for information (e.g. about a certain vaccine) but also public health communicators and active, vocal anti-vaccination groups” (Betsch, 2012, p. 1). The Internet is now a resource for parents to read about vaccinations, and while there is a wealth of information, it can become overwhelming when parents want to learn what is best for their kid. However, anti-vaccination information does not always have to be sought out, but instead can easily be stumbled upon through social media, such as Guidre et al.’s study on Pinterest (2015).

In a study by Cornelia Betsch, it was found that newspapers have a more negative tone towards vaccines, while government run informational websites tend to be more neutral (2012). However informational websites are not social media, where people share their opinions without needing a lot of evidence to backup their claims. Betsch found that people use YouTube for vaccination information, and as YouTube tends to be vaccination critical, this can be harmful to people trying to seek out more information (Betsch, 2012). Again, this is further evidence of the use of Web 2.0 in the spread of disinformation of vaccines - people do not go looking at informational websites when they have access to their everyday social media platforms. Web 2.0 is more accessible, therefore Web 2.0 is where parents are going to look for information.

When people do go looking for informational websites, however, the anti-vaccination websites come up along with the ones run by medical professionals. These anti-vaccination websites are incredibly convincing, even though doctors continue to try to convince parents to vaccinate. Sandra Bean did an analysis of what comes up when you search keywords on vaccines, to discover what websites come up and what is the information they are distributing. “An overwhelming 76% of all websites in this study included content that asserted that vaccines cause illness, damage, or death” (Bean, 2011, p. 4). Most of the information being shared does not portray vaccination in a positive light, and though these websites do not appear to have proper sourcing, they look official and informative. According to Bean, “Only 36% of websites in the current study contained disclaimers and only 16% disclosed sponsors or authors” (Bean, 2011, p. 5). The information being shared is not official in any capacity, but Bean discovered a new theme in a manufactured threat of “expert” testimony, where there are quotes from doctors and specialists who only seem to exist on these anti-vaccination websites, and nowhere else

(Bean, 2011). Quotes from people who have official-sounding titles holds sway in that they appear to come from someone with experience on the topic (Bean, 2011). These “experts” create the illusion that there is still a scientific debate on whether vaccines are safe. Compounding this further, Bean found that as the rise in “expert” testimony has gone up, parent testimonials have declined (2011).

While pro-vaccination and anti-vaccination debates have always existed, there has been an increase in the last decade. Lee & Male discuss a report in Australia where the rate of parents conscientiously objecting to vaccines more than doubled between 2000 and 2010 (2011, p.2). The incredible growth of unvaccinated children is related to the internet (Lee & Male, 2011). While Web 2.0 can be useful in reviews and patient empowerment, it also can be used to spread disinformation (Tafuri et al., 2014). Proponents of AVM on the internet can create global consequences with their disinformation, with websites claiming “idiopathic illnesses [are caused by vaccines], [there is an] underestimation of adverse reactions, immune system damages caused by vaccination and include the blame that economic profit is the only reason for vaccination promotion” (Tafuri et al., 2014, p. 4). The AVM claims there is research that backs up the disinformation they spread, but does not provide sources. People go online to find answers, but many do not know how to differentiate between authentic and inauthentic content. Instead of healthcare workers, the internet has become the source of medical information, with a surprisingly large amount of people believing what they read (Tafuri et al., 2014)

### Ideological Tribalism

Paul't Hart states in his paper *Irving L. Janis' Victims of Groupthink* that "groupthink stands for concurrence-seeking, that is, the tendency for group members toward a convergence of opinion about the adoption of certain course of action in a given decision situation" (1991, p. 257). The AVM has shown evidence of such thinking - the idea that only people who believe what you believe are right. In a study where the researcher interacted with parenting groups on social media in Romania, Iona-Alexandra Rusu found that people create these online communities in order to connect with other parents with the same unconventional views, because it is difficult to find these people in real life (Rusu, 2016). Groups like these create a form of tribalism. In isolating oneself from others with differing opinions, it becomes easier to assume that your group's ideas are the only right answer, especially when there is constant validation of these ideas (Rusu, 2016, p. 12). Within these groups, there appeared to be rules on whether information is credible based on who was speaking. People believed those who had similar viewpoints as themselves, those who had a shared history, and those who were either group administrators or "experts" in the field (Rusu, 2016).

The tribalism becomes evident when two groups of differing opinions — such as an anti-vaccine group and a pro-vaccine group — begin an argument. First, they start by accusing each other of being "brainwashed" then they accuse the other of being fanatical, of being imposters, insisting that the other side's information should be "dismissed as anecdotal or plain false" (Rusu, 2016, p.11). In tribalism, what is important is not the facts of the matter, but group loyalty. Tribalism means believing in everything the group is supposed to believe, leading to a disinterest in other perspectives, which creates difficulties in encouraging constructive

communication across differing ideologies. As the AVM involves a narrative structure often based around identity, groupthink likely contributes to the movement's success in maintaining its existence.

### Do Vaccines Cause Autism? The Controversy

In 1998, Andrew Wakefield published a paper in *The Lancet* where he outlined a link between vaccines and autism. *The Lancet* has since retracted this publication, however at the time it caused an uproar - parents were terrified to vaccinate their children for the fear of giving them autism. His findings were proven to have been manufactured, as Wakefield had personal financial gains in creating fear of vaccines in order to fund his own business and research (Deer, 2011). However, even after Wakefield was outed as a fraud, the idea that vaccines are harmful for children and their health continues to persist, pointing to the AVM's existence outside scientific evidence. Jennifer Bracken Scott discusses this controversy in her article, "Boundary Work and the Construction of Scientific Authority in the Vaccines-Autism Controversy" (2015). Boundary work, according to Scott, is the process of deciphering "what does and does not count as science" (2015, p. 61). Despite the retraction of Wakefield's study, and the defining of boundaries by the scientific community (i.e. recognizing that Wakefield's study does not fit within these boundaries) some parents with autistic children blame the MMR vaccine for their child's autism (Scott, 2015). Parents continue to believe in the link between autism and vaccines because of pattern recognition. Because their children were not diagnosed with autism until after they were vaccinated, vaccination must therefore be the problem (Scott, 2015).

Cost-Risk Analysis & Freedom of Choice

The online anti-vaccination movement comes from a place of ethical concern. Parents who intentionally do not vaccinate are usually educated and wealthy and everyone (parents and health care workers) is acting out of concern for children. However, even when coming from moral or ethical reasons, anti- consumption efforts can have detrimental effects on society. (Lee & Male, 2011).

Vaccines are medicine, and all medicine comes with some risks. However, vaccines are low risk medicine and the risk of getting a dangerous disease is much higher. As it stands, because vaccination has been so successful, parents cannot conceive how awful these diseases were (Lee & Male, 2011). It then becomes a question of Freedom of choice vs. freedom from harm. Pro-vaccine groups feel that mandated vaccines free people from harm by creating herd immunity — protecting the vulnerable (infants, the sick and elderly) from diseases because everyone else is immune — but the AVM feels that this is in opposition to freedom of choice, which is paramount (Lee & Male, 2011). Lee & Male accurately sum up the issue of cost/risk analysis parents now go through when choosing to vaccinate their children:

In the past, remaining unvaccinated was considered a high risk since the chances of catching a diseases, such as measles, was much greater than experiencing a vaccine side effect. Post 2009, proponents of the AVM [Anti-vaccination movement] perceive vaccinations as being riskier than the diseases themselves. Ironically, if vaccines are effective, they may have become a victim of their own success. For some parents, the low risk of their child experiencing a vaccine side effect is now being weighed up...against the low risk of catching certain diseases (Lee & Male, 2011, p. 3).

Parents no longer perceive how debilitating these diseases are, and the risk of catching measles or mumps appears to be of a lower risk to them because vaccination has been so successful.

Believing that choosing to vaccinate might create harm for their child, they choose not to do so,



considering it the lesser of two evils (Betsch et al., 2012). However, it is much easier to be unvaccinated when everyone else is vaccinated because it creates herd immunity. If the rates of vaccination falls below a certain threshold, these diseases can come back (Lee & Male, 2011, p. 4). People in the AVM can benefit from vaccinations even if they do not receive any, but when vaccination rates fall below the threshold, “free riders...may then become detrimental to the health of the community” (Lee & Male, 2011, p. 4). When parents have choices to create their own schedule - as in, they decide at what age their child gets a particular vaccine - they can give their children some vaccines, if not all. When companies make combination vaccines, choices become limited, and some parents may choose not to vaccinate at all (Lee & Male, 2011).

#### Narrative Vs. Informational

People find themselves being more involved in their healthcare these days, often first going online to try to find information before going to see a health professional. As parents decide to do their own research, it can be difficult to parse out the misinformation engineered by the anti-vaccine movement, feeling as if the online sources provide a “different perspective” instead of recognizing that the information is wrong (Betsch, 2012). Many websites that present accurate information on vaccines are not good at summarizing the “gist” of why vaccines are good, but the AVM is great at getting the gist across, making the information easier to digest. There should be structures in place to make sure that accurate medical information is readily available (Betsch, 2012). Science is impersonal when compared to celebrities that support the AVM such as Jenny McCarthy and Robert Kennedy, making parents feel connected to celebrity ideals (Lee & Male, 2011).

While there are actual risks that come with vaccines, Leask et al. found that the real risks were not being reported on the anti-vaccine websites: “Our analysis suggests that attributions of harm are not so much linked to the science of the causal association but reflect societal attributes” (Leask et al., 2010, p. 4). The science itself is not the issue, but the social ideas held by parents. Parents are not looking to the science when it comes to possible harms from vaccines, but instead are looking for social knowledge on the subject - what other parents are saying.

Fear is integral to the vaccination debate, and because of this, narratives hold incredible sway among decision makers: “Thus, if individuals observe two positive and two negative narratives, many will assume that positive and negative events are equally likely in the real world. Currently, however, negative narratives about vaccinations are much more widespread on the Internet than positive narratives” (Betsch et al., 2012, p. 4). Narratives create emotional sway, and affect the readers in a personal level the way numbers do not. Numbers need to go from abstract to visceral in order to motivate people into vaccinating their children (Betsch et al., 2012). Narratives are important and should be used more, especially in pro-vaccine context, as they can be useful in ensuring people get the medical care they need. Betsch et al. also suggest that scientists study which narratives are useful and/or persuasive (2012).

### Lack of Communication

With the rise of Web 2.0, there needs to be better communication with parents and health care workers in order to ensure that people are getting the information they need. “In the public arena there is a need to accept and involve the public as a legitimate partner, being clear and working with the media” (Tafuri et al., 2014, p. 4). The public needs to be included in the

conversation, not told what to do, because what is most important is effective communication between healthcare workers and parents (Tafuri et al., 2014; Lee & Male, 2011).

For parents, the science is less important - science can be inaccessible in its technical language. It is not so much the strength of evidence on how harmful vaccines are, but the fear and uncertainty that is spread (Leask et al., 2010). If parents are afraid to vaccinate their children based on what they have read on the internet, then they are going to avoid it, believing that they are protecting their children by doing so. Parents need to feel that their concerns are recognized when making these decisions (Bean, 2011).

There is a decision process, according to Betsch et al., that is incredibly important to whether or not parents choose to vaccinate (2012). There is first the pre-decisional phase, when people are looking at their options, and then the decisional phase, where they “evaluate potential outcomes of alternative actions...based on the obtained information” (2012, p. 2). The information discovered in the pre-decisional phase directly impacts the decisional phase (Betsch et al., 2012).

When parents’ concerns are not recognized, and their worries are dismissed, they go to other sources in order to find the answers and validation they are looking for. Leask et al states, “When parents apply *post hoc ergo propter hoc* (after therefore because of) reasoning, vaccination can become a compelling causal candidate” (Leask et al, 2010, p. 4). Some diseases become apparent in early childhood, around the same time vaccination happens, and because of the timing some parents blame vaccines for why their child has a health issue (Leask et al., 2010).

Parents feel that they have more control when they can create their own vaccination schedule, however in response to vaccination selection, now pharmaceutical companies are creating a combination vaccine for measles, mumps, and rubella (MMR) so that parents will have to either take all or nothing. While this makes sense health-wise, it takes away the choice for parents to create their own schedules, which makes them feel like the companies do not care about their needs or their children's needs (Lee & Male, 2011). The solution to making parents feel included and heard in the discussion is to create trust between healthcare workers and parents. As it stands, there appears to be a divide between what healthcare workers are trying to tell parents and what parents are hearing. Healthcare workers should be informed of the arguments the AVM is using in order to have counterpoints ready, and they should also be vaccinated in order to be promoted as a good example (Tafuri et al., 2014).

Bean discusses how the utilization of narratives could help include parents into the conversation by “enlist[ing] the help of parents with children who had fallen ill from a VPD [vaccine preventable disease] to tell their unique stories to other parents” (Bean, 2011, p. 6). If parents hear from other parents during their pre-decision phase about the benefits of vaccination, and the risks of not vaccinating to children, it will help them make a decision on whether to vaccinate or not. Additionally, another way to combat the anti-vaccination movement is by “providing alternative information sources, including lists of pro-vaccine websites, their own public health-focused anecdotes, and scientifically sound and easily understood risk-benefit scenarios to allay parents’ fears” (Bean, 2011, p. 6). Parents need to feel that healthcare workers hear them and also want what is best for their child in order to make the decision to vaccinate.

### Literature Review - Conclusions

Personal anecdotes influence the AVM's structure. The literature thus far emphasizes the personal as political, recognizing the strength in narratives. Social media is a news source for at least 67% of the US population, according to the Pew Research Center (Shearer & Gottfried, 2017). People get their news on Facebook, a place where they are often shown what their peers believe politically. The open forum nature of Facebook allows for more opinions than evidence, and also carries the weight of personal narratives that is integral to the AVM. There is a lack of studies about the AVM on Facebook, the only study tying the two together in this review is Romanian specific (Rusu, 2016). This study intends to look at the interactive commentary on Facebook groups that are US centered, in order to recognize the process in which the AVM organizes their movement on a commentary based social media platform.

## **METHODOLOGY**

The anti-vaccination movement in California has been incredibly effective in that the debate continues despite all of the scientific evidence to the contrary. The objective of my research is to understand the anti-vaccination movement in California, by looking at what strategies the anti-vaccination movement employs and asking why has it been effective despite scientific consensus about the benefits of vaccination. This study is attempting to understand what ways the anti-vaccination movement has been effective in order to learn from their tactics for future social movements.

My research was conducted using a multi-methods analysis. I administered one interview with a key informant during February of 2018. This interview was conducted over the phone for

approximately one hour. The participant was an anti-vaccine advocate who had experience in organizing for the ability to choose not to vaccinate.

In addition to gathering information from a key informant, I completed a content analysis of three Facebook groups from mid-December 2017 to mid-February 2018 in order to get a present-time snapshot of the anti-vaccine movement. The bill that mandated vaccines in California, SB277, passed in 2015 and yet the anti-vaccine movement continues to hold weight and influence in this state. In order to obtain this snapshot I used a deductive approach, utilizing a key informant in order to inform my analysis of the three Facebook groups.

I recruited my key informant via emails listed on websites for active advocates for the anti-vaccination movement. The founder of one advocacy group, A Voice for Choice, agreed to speak with me. I interviewed the founder, Christina Hildebrand for over an hour to gain information about: 1) the tactics she found effective and ineffective 2) what her organization does to further their cause 3) how organized she judged the movement her advocacy group is a part of to be. The list of semi-structured interview is in Appendix A. My goal was to gain an understanding of why these anti-vaccine advocates believe so ardently in what they do, and to discover the ways in which they accomplish their goals. After speaking to Hildebrand, I utilized the information she gave me to inform my analysis. The interview was not recorded. I used my notes to identify trends amongst the movement from her perspective.

I gathered data from Facebook pages and websites that those in the anti-vaccination movement frequent. Similar to how Lerman et al. did in their content analysis of teen depression groups (2017), I did not record any usernames or identifying information of those participating in these groups. I did not list the Facebook group names to ensure anonymity. I only used groups

that are listed as “open” or “public”, and have at least 2,000 members that have posted at least five times in the last six months, to ensure that these pages are active. On these pages I used deductive and inductive codes to understand their campaign tactics - the events they advertise, the information they spread, and how they frame their movement. With this information I was able to infer how information is disseminated to the public through this social media platform.

To find these groups, I compiled a list of search terms for within Facebook. These terms are: Vaccine, Ex-vaxxers, and Anti-vaccine. Then I narrowed it down by my criteria - did it have at least 2,000 members, and did they post frequently? There was a plethora of groups that fit my criteria, it was a matter of narrowing it down. I picked the three groups that had the most frequent activity, and then I copied and pasted all of the posts and comments in the last two months (from mid-December to mid-February) and came up with about 800 pages of content. From there, I went through the content and started to pick out common trends within the information shared. I utilized the coding software Dedoose in order to do so.

In a broad overview, I came up with a list of 41 codes based on the information they are organizing (Appendix B). Out of these 41, I narrowed the list down to 6 codes that include basic overviews of the information being shared. These codes are: Narrative of Conspiracy, Encouraging Political Action, Advice, Holistic Healing, Outside Link, and Anecdote. In Appendix B there is a table of all the parent codes with the correlated initial codes.

**Advice & Validation:** There is a trend of parents validating each other’s experiences with vaccines, and giving advice to those who want to continue not vaccinating their children.

**Encouraging Political Action:** Repeated posts encouraging people to call senators and write petitions to ensure that they will still be able to not vaccinate their children.

**Holistic Healing:** Posts and comments encouraging alternative medicines.

**Narrative of Conspiracy:** The overarching idea that the government and/or Big Pharma are in conspiracy to endanger people's lives for profit and greed.

**Outside Link:** Linking to a website that is not affiliated with Facebook.

**Anecdote:** A personal story that is presented as proof of vaccine injuries.

I then organized all of the comments and posts by their codes to identify trends in how members share and frame information on these pages.

## **FINDINGS: THE GOVERNMENT IS IN CONSPIRACY WITH BIG PHARMA**

### Interview with Vaccine Choice Advocate

In order to inform my analysis of the Facebook groups, I interviewed Christina Hildebrand, who runs A Voice For Choice, a nonprofit agency that advocates for parents' choice on vaccinations. She had built this advocacy group on her own, and therefore has firsthand experience in the construction of the AVM. In our interview, I discovered a set of themes that affected the way people approach vaccinations.

First, she told me that what is most important to her is that "everyone has all the information. If you knew everything there is to know about vaccines, and you decide that you do want to vaccinate your children, then that is your choice and I respect it. It's just important to me to know that people are making informed decisions" (personal communication, February 9, 2018). According to this informant, the issue is that nobody should have mandated medical treatment, not that vaccines are bad. In essence, they feel the risk of vaccines on their children



outweighs the risk of getting sick, and they should be able to decide for their child based on this information (personal communication, February 9, 2018).

Christina described the likeliness of her children getting the measles to be based in genetics. She herself had the measles as a child, and she survived it fine, and believes that she has passed her immunity on to her children through her breast milk. “It all has to do with genetics,” she said, “and who is more genetically predisposed to getting sick from these diseases. My genetics prove that my children will be fine, so there is very little reason for them to have the vaccination.” She views vaccines as unnecessary treatment for her family, but she might feel differently if she was “living in sub-Saharan Africa” (personal communication, February 9, 2018).

Her organization focuses on advocacy and education, focusing on the ingredients of vaccines so that people know what is being put in their body. She stated that aluminum, which is included in some vaccines to trigger the immune system to attack the deactivated virus, is a heavy metal that can affect the brain’s ability to function (personal communication, February 9, 2018). She stated that she is careful to include credible sources, in order to ensure that the information her organization distributes is taken seriously (personal communication, February 9, 2018).

One argument she made was what I call the “Proof Argument.” She cites the vaccine inserts, the informational paper that is included in the box with the vaccine. The inserts state that it has not been proven whether vaccines are carcinogenic or induce infertility (personal communication, February 9, 2018). . Christina feels that it is irresponsible to give to children a vaccine that has not proven to not cause cancer, or to not cause infertility (personal

communication, February 9, 2018). Her logic makes sense — a parent would like to know for certain that their child will not be harmed (personal communication, February 9, 2018).

However, this assertion ignores what is known by scientists and the FDA about the benefits and risks of vaccines.

Another major theme in the interview was her narrative of pharmaceutical conspiracy in collaboration with the government. She named the National Childhood Vaccine Injury Act of 1986, which removes financial liability for possible vaccine injuries from the pharmaceutical manufacturers so that they do not have to pay for every child that gets sick around the time they were vaccinated (personal communication, February 9, 2018). Christina felt that this law is corrupt because it benefits the makers of vaccines and not the people who take them (personal communication, February 9, 2018).

Language plays heavily into the construction of this movement. The words “anti-vaccine” and “anti-vaxxer” are what Christina called, “negative names that the media has given us” (personal communication, February 9, 2018). Those within the movement call it Vaccine Choice, or Parent’s Choice, and many consider themselves to be called “ex-vaxxers” instead of “anti-vaxxers,” noting that the reason they no longer believe in the validity of vaccines is because someone they cared about developed health issues shortly after their vaccination (personal communication, February 9, 2018). It is a title meant to indicate that they once believed in vaccines and now reject the beliefs they previously held. Those who have not participated in vaccination and who do not plan to call themselves “non-vaxxers” (personal communication, February 9, 2018). The language used implies a peaceful and logical movement, in order to distance themselves from the idea of irrational vaccine-haters.

Social Media Narrative: What People On Vaccine Choice Facebook Groups Discuss

I coded over 400 posts and their comments on these pages. Of the 1,241 codes applied to the three groups’ posts and comments, 30.5% implied a narrative of conspiracy about the US Government with Big Pharma and the medical establishment (Figure 1). The conspiracy narrative occurred most frequently, at nearly one-third of the content coded. After Narrative of Conspiracy, the second most prevalent code was Anecdote (21.4%), followed by Encouraging Political Action (13.8%), Holistic Healing (12.1%), Outside Link (11.5%), and finishing with Advice and Validation (10.7%) (Figure 1). These six codes showed the overarching themes across all three Facebook groups, and the word cloud on the next page visualizes the prevalence of each code by size (Figure 2).

	Anecdote	Encouraging Political Action	Holistic Healing	Narrative of Conspiracy	Outside Link	Advice & Validation	Totals
Facebook group 1	65	54	65	139	70	48	441
Facebook group 2	104	8	20	62	23	41	258
Facebook group 3	97	109	65	178	50	44	543
Totals	265 (21.4%)	171 (13.8%)	150 (12.1%)	379 (30.5%)	143 (11.5%)	133 (10.7%)	1241

Figure 1. Code Counts

Posts that discussed the government and the larger pharmaceutical corporations (otherwise known as Big Pharma) were coded as having a narrative of conspiracy. Many of these posts also had tones of distrust for the medical establishment, with claims that doctors and nurses are trained to guilt and force parents into consenting to dangerous medical procedures in the form of vaccination. Distrust was a common theme among these posts, meaning the deep feeling that those in power did not have the average person's best interests at heart.

Anecdotal posts and comments were comprised of people telling stories detailing vaccine injuries, describing when someone received a vaccine and when they or their parents noticed symptoms. Some stories were first hand, people describing paralysis and autoimmune deficiency disorders that popped up around the time they received a vaccination. Many of these stories were in comments, utilized to validate the poster's experiences. Most of the stories, however, were shared by parents who felt righteous indignation over their child's illness, disability, or death, and who wanted retribution in the form of disallowing mandatory vaccinations. Parents would post pictures of their children with eczema and other rashes in conjunction with posts that named vaccines as the culprit.

Many of the posts that encouraged political action were reposts of images of posters naming a senator that the group members needed to call in order to ensure their right to not vaccinate their child. While many of the posters were the same, those who were sharing them were often different people. Other posts had an overarching narrative that people should fight for their right to choose what happens to their children's bodies. They would encourage people to make different choices about vaccines as a form of protest, and encourage parents to make different political decisions based on the idea that vaccines are harmful.

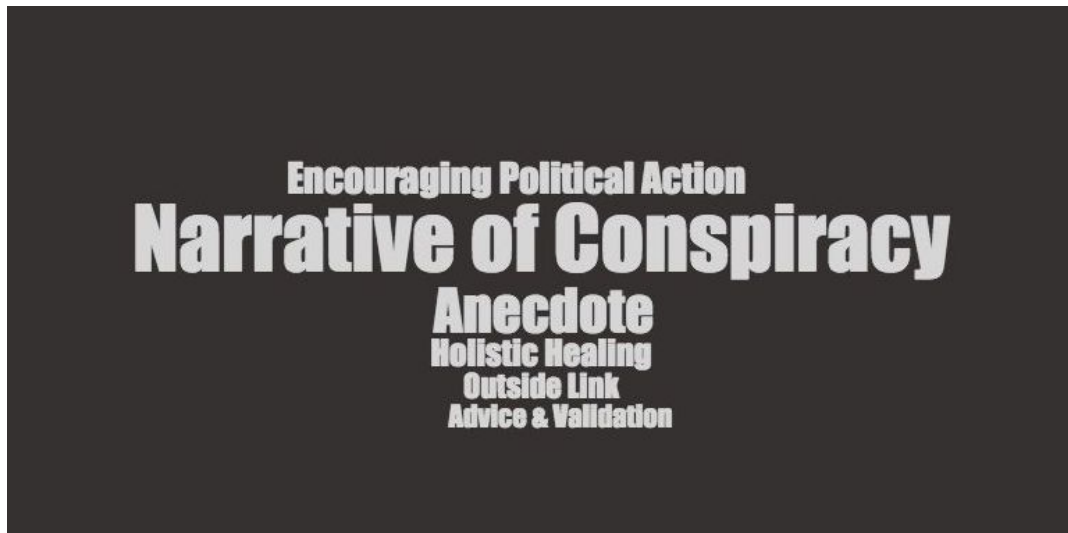


Figure 2. Code cloud

The posts coded for holistic healing were comprised of advice on alternative medicine. Many people cited diet as a form of protection from diseases, claiming that the food they serve their children will ensure their health and safety. Others encouraged doing “heavy metal detoxes” which would then rid their children from the dangers of autism and other mental disorders, and a portion of them encouraged medical cannabis as a cure-all for everyone.

The outside links are primarily comprised of unreliable news sources and blogs (45.8%). These news sources were coded as unreliable based on their lack of fact checking and the frequency of their conspiracy theory articles. The articles linked on these Facebook pages legitimize conspiracies about the government endangering citizens by mandating vaccines. The largest cohort of websites that were referenced were unreliable news sources that wrote about unsubstantiated conspiracies. Of all the websites referenced, only 8 (13.6%) were legitimate news sources (Figure 3). Other sources included government websites, YouTube, advocacy groups, an AVM sympathetic legal team, and four sites that no longer exist under the linked URL. One Facebook page was primarily comprised of links to articles and documentaries, to

reinforce the AVM ideology, while the other two pages used links as proof of their anecdotal claims when arguing or giving advice in the comments.

Type of Website	% of the Total
Reliable News Source <ul style="list-style-type: none"> <li>● Left Leaning</li> <li>● Right Leaning</li> <li>● Unspecified</li> </ul>	8 (13.6%) <ul style="list-style-type: none"> <li>● 4 (6.8%)</li> <li>● 0 (0.0%)</li> <li>● 4 (6.8%)</li> </ul>
Unreliable News Source <ul style="list-style-type: none"> <li>● Left Leaning</li> <li>● Right Leaning</li> <li>● Unspecified</li> </ul>	27 (45.8%) <ul style="list-style-type: none"> <li>● 1 (1.7%)</li> <li>● 2 (3.4%)</li> <li>● 24 (40.7%)</li> </ul>
Government Website	3 (5.1%)
Advocacy Groups	6 (10.2%)
Websites that no longer exist	4 (6.8%)
Other	11 (18.6%)
<b>Total Websites</b>	<b>59</b>

Figure 3. The different types of websites linked in the Facebook groups

While advice and validation only consisted of 10.7% of all of my coded posts and comments, this code is significant in that these pages allowed for those who experienced illness or disability, or those whose loved ones have experienced illness, disability, or death, to have a space where their personal narratives are validated. My coding for Advice and Validation was originally under the Anecdote umbrella, however posts under this code happened frequently enough and disjointed enough from anecdotal stories that I gave them their own code. Parents posted on these pages asking for advice on how to ensure that their child does not get vaccinated in their state, or on other ways to combat vaccines in their everyday life, and other parents

provided resources. The people on these pages validated each other on their beliefs, ensuring that others in the AVM do not feel like they are being ridiculous. The posts and comments in this code affected the overall atmosphere on these pages — people were allowed to share their opinions and ask for help without fearing hateful reactions.

Another trend I noticed was a racial disparity in the groups. Of all the posts I coded, nearly every profile picture of the people who posted portrayed a white face. Only one post was produced by someone with a person of color as their profile picture. Assuming that the profile pictures depict the person posting, this clearly portrays a majority white movement. While I cannot account for everyone who did not have a picture of a person for their profile picture, there does appear to be a trend. Of all of the pictures of children who had passed, or who were injured, every single picture was of a white child. Not once was there a picture of a child who had been “vaccine injured” between December of 2017 and February of 2018 who was not white.

### **THE CONSPIRACY IS EVERYWHERE: AN ANALYSIS**

In this section, I will analyze my findings by exploring each one individually in detail. For each one, I will discuss the content of relevant the posts and comments, followed by the implications of these posts within my codes.

#### The Government Is Out To Get Us

My most significant finding was the overarching narrative that the US government is in a conspiracy with Big Pharma, ensuring that every person gets vaccinated so that they can profit off of the medicine with little thought about how the vaccines hurt children. The conspiracy

narrative dismantles the system of power in place that ensures public safety from harmful diseases. Instead it replaces the structure for public safety with a structure for leeching money and resources from the population.

### **i. Shot Induced Death Syndrome**

Sudden Infant Death Syndrome (SIDS) is traumatizing for any parent to experience.

There is not a lot of science that specifically explains the cause of SIDS, only describing ways to possibly decrease the chances of SIDS happening. Many parents want to have something to blame, a true cause that can be pinpointed to explain the sudden loss of their infant, and for many parents on these pages this explanation is vaccines. One woman stated:

Many autopsies are lied about though. Anything labeled as sids [*sic*] death outside of the first week of life is a vaccine injury. A healthy baby can not suddenly die and dying of unknown causes in this medically advanced of a society is not possible because we can find out how people from hundreds of years ago have died just by looking at the remains of their decaying bones.

There is an overarching idea that Sudden Infant Death Syndrome (SIDS) is a government cover up for vaccine-related deaths. This conspiracy ties into the fallacy *post hoc ergo propter hoc* (after and therefore because), that Tafuri et al. (2014) and Leask et al. (2010) mention in their respective articles. When infants suddenly die, parents want to have something to blame for their loss. As there are many check ups and vaccinations that are scheduled within the first year of life, parents will blame vaccines for the death of their child. One woman commented on a post where a parent laments over the loss of their child soon after their vaccination, calling SIDS “Shot Induced Death Syndrome.”



**ii. Doctors Do Not Know What They Are Doing**

There is a deep suspicion among the AVM against the government and the medical community as a whole in these groups. Members prioritize self-sufficiency in response to this distrust. One member echoes these intentions:

Preventing Diseases? Think for yourself ! Educate yourself! (Self sufficient) Or Rely on these government agencies, Oncologists , Pediatricians and Doctors that make money from you being sick.

This sentiment is repeated across all three pages — vaccine providers and government agencies that enforce vaccine laws do not have your best interest at heart, and in fact prefer to profit off of the suffering masses.

Many members believe that doctors have been brainwashed into believing in the safety of vaccines, that they do not know any better. One mother, when giving advice to another who did not want to vaccinate her children, stated that “the medical personnel are trained to PUSH vaccines. They threaten CPS. Your child will die and so on.” There is very little trust for the experts when it comes to vaccinations. Members believe that they know best about what is healthy for their child based on the articles and information they obtain online. They portray their fight to refuse vaccines as a struggle against tyrannical ideals: “Start becoming informed and act on that knowledge instead of caving in. Be a parent and lead by example. The children are counting on all of us.” Recognizing the validity of vaccines is portrayed as “caving in”, the choice to vaccinate is portrayed in these groups as letting their children down. Criticism of vaccines and of those who encourage people to be vaccinated is highly valued among all three Facebook groups. In their minds, to want to vaccinate is to blindly follow unreliable sources.

One member concluded a long argument about whether vaccines are safe with, “Do you hate thinking? You decide.”

### **iii. The Implications Of The Vaccine Conspiracy**

When people in these groups are fed the idea that the government is hurting more than it is helping, the other information shared by those in the AVM becomes all the more convincing. There is evidence that people who previously believed in the validity of vaccines no longer do so based on the information presented to them on these groups: “Problem is we are supposed to trust the doctors and the government and its too bad you can’t. I am really glad I found this group it has opened my eyes even more to vaccines.” These groups are very compelling - there is prominent indignation and frustration with those in power, moving anecdotes that swear children have been hurt by vaccines, and frequent use of scientific jargon that would sway people with little background in science.

#### The Power of Stories

Anecdotes played a powerful role on these Facebook pages. When people felt the need to prove that vaccines are harmful, they would cite either their own experiences or the experiences of others. When someone shares a moving story of injury and death, it is difficult to not feel sympathy towards those who have been hurt or altered in the narrative. These anecdotes are designed to be compelling, those sharing them want others to believe in their personal truth. There were three types of anecdotes shared on these pages, including childhood injuries, autism as a result of vaccination, and skeptical older generations.

### **i. Childhood Injuries**

The anecdotes are designed to inspire sympathy and then outrage over parents being unable to take action against those that they blame for their child's health. The belief that vaccines caused these issues is almost always intuition based, one mother describing it as a "light turned on in [her] head" that allowed her to "[realize] how lethal these vaccines really are." Parents regularly come to the conclusion that vaccines are the cause of any issue their child was facing. Only twice did I find stories from parents who felt they had corroboration from the doctors, and of those two only one mentioned that the case was reported to the Vaccine Adverse Event Reporting System (VAERS). All other 263 anecdotes (refer to Figure 2) did not have medical corroboration, indicating that there is little expert testimony backing up their claims, only conjectures and assumptions.

### **ii. Autism As A Result Of Vaccination**

These anecdotes continued the narrative that vaccines cause autism. Despite the retraction of the Wakefield article, and repeated deconstruction of this belief through scientific studies (Scott, 2015), there are still people who believe in the hypothetical causation. The proof presented on these groups are anecdotal, claiming that these stories are "absolute evidence of vaccines causing autism" as they write about children who within a day "were never the same again. They all became severely autistic." When there is science discussed, the sources used are not reliable, many involved in pseudoscience instead of peer-reviewed sources. The proof is in the story, not within the science. The stories are much easier to digest than the science, convincing those on the groups more easily than the published scientific articles would.

### **iii. Skeptical Older Generations**

Melancholy anecdotes about children are not the only anecdotes on these pages. People of older generations also tell stories about how they lived fine lives without having “received any other vaccinations other than a sugar cube.” These anecdotes provide a narrative that claims vaccines are unnecessary, one person asserting that “[t]he diseases that are vaccinated for are nothing compared to the consequences of vaccinating.” These anecdotes set a different tone — their purpose is not to create sympathy and outrage against medicine and government, but to discredit the need for vaccinations in the first place.

### **iv. The Implications Of These Anecdotes**

All of these anecdotes create a narrative that despite what those in power are telling the population, the lived experiences are different. This feeds into the Narrative of Conspiracy — members of these Facebook groups believe that the overarching safety of vaccines cannot coincide with the stories of vaccine injuries being shared. There is a disconnect about vaccine safety and the anecdotes shared. This creates a dichotomy: either vaccines are safe and the lived experiences of the people on these groups is a lie, or the government and the medical community are lying about vaccine safety. Again, because the science is inaccessible and harder to utilize to create an emotional impact, members of these groups are more inclined to believe the stories than the science.

### Make Different Political Choices And Support Vaccine Choice

Encouraging Political Action and the Narrative of Conspiracy codes interact within a cycle. Once the systems of power are dismantled, there needs to be action taken to create new systems of

power. Believing that the government's handling of vaccinations is corrupt, members of the AVM encourage those who are undecided to take action against said corruption. Encouraging political action in these groups presents on these pages as both making personal choices to resist, along with taking political action.

**i. "FDA Approved To Kill You" And Why You Should Call Your Senator**

The encouragement of political action involved telling people to vote with their actions. The logic is that if many people decided that vaccines were unsafe and would not do them, maybe the corrupt government would recognize that there are too many people who disagree and would finally investigate vaccines in the ways they wanted them to. One member describes vaccines as "FDA Approved to kill you," encouraging others to find ways to resist vaccination. Political action was to pave the way for vaccines to not be mandatory, finding ways to be exempt as often as possible.

One major political action people on these pages were encouraged to take was to call their senator. A simple action that, in numbers, would have a big impact on their offices. In Florida, there was a bill on the table that would mandate vaccines for the state. Members of these groups felt deeply that mandated vaccines were detrimental to health, so there was repeated posts about calling the state senators to sway the vote. Two of the pages made note that it was important to take action in order to ensure that their rights were met. The encouragement of political action was to ensure that parents were able to make their own health decisions for their children, resisting the government's influence in those decisions.

## ii. Implications of Encouraging Political Action

Encouraging political action helped legitimize the conspiracy narrative. In the eyes of the AVM, if the government and Big Pharma are not going to ensure the safety of vaccines, then the AVM is either going to make them do so, or opt out altogether. Usually, they find themselves opting out, which then puts the rest of the population in danger.

### Alternative Medicine Is Safer Than Vaccines?

When asserting that vaccines are harmful, there needs to be another option available for parents to take care of their kids — alternative medicine. Members of the AVM assert that vaccines are not safe, listing all of their issues with what the medicine has been tested for and the possible side effects of the ingredients.

#### i. Vaccine Inserts — Do Vaccines Cause Cancer?

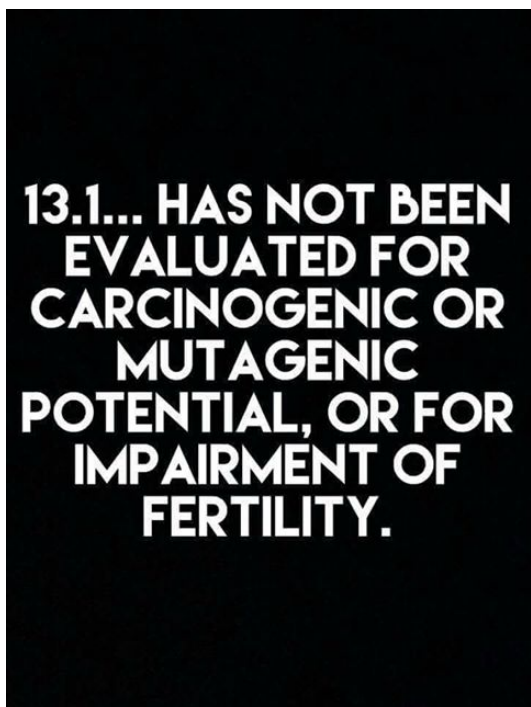


Figure 4. Graphic quoting an unspecified vaccine insert.

Many group members would mention vaccine inserts — the pieces of paper that come with all medicine, listing all possible side effects and what has and has not been tested for when using this medicine. A specific quote from the inserts concerned people on Facebook, which is encapsulated by a black and white graphic one man posted: “13.1...Has not been evaluated for carcinogenic or mutagenic potential, or for impairment of fertility” (Figure 4). Underneath the graphic he wrote:

This is stated in every vaccine insert. Do vaccines cause cancer? Do vaccines cause mutagenesis? Do vaccines impair fertility? You're damn right they do and those are the things vaccines are effective in doing.

This man in particular associated the lack of clinical trial testing for carcinogenic and fertility issues as proof that vaccines do in fact cause these problems. Knowing that the vaccine was not tested for carcinogenic effects, or on pregnant women, set off red flags for people who are unaware how difficult it is to prove that one injection causes cancer, or how difficult it is to test drugs on pregnant women.

## **ii. The Ingredients In Vaccines Do More Harm Than Good**

There also was concern over the ingredients used in the vaccines — there was the scandal about mercury which Lee and Male discuss, where people became concerned with the addition of mercury in vaccines (2011). While the mercury was not harmful, vaccine manufacturers removed it as a good faith gesture (Lee & Male, 2011). Instead of reassuring the skeptics, this action backfired as people felt that removing the mercury was proof that it was dangerous (Lee & Male, 2011). This trend of disbelief in vaccine ingredients has only become heightened, as the people in these groups now distrust all of the ingredients in vaccines. One man commented,

Let me get some mercury, formeldahyde [*sic*], canine kidney protein, bovine serum AND the very disease I hope to avoid injected into my body. “That should keep me healthy”....said no logical person ever[.]

This man, like many others on these pages, listed information without giving legitimate sources and then qualified his argument with a statement that does not leave other opinions open for discussion.

### **iii. The Implications Of Alternative Medicine As A Replacement For Vaccines**

The distrust of modern medicine can be dangerous for the population. People aren't getting treated properly, which negatively impacts their health and the health of those around them. While alternative medicines can be useful, there is not alternative to vaccines. Attempting to alter food diets will not protect children from measles.

#### Facebook Sourcing: The Articles Linked as Proof

Those who recognize the validity of vaccines have a conception that the AVM conspiracy theorists read and believe unreliable sources. This conception, for the purposes of this study, holds mostly true — of the 59 websites linked and sourced, 27 were unreliable news sources and opinion blogs. However, a remarkable amount were valid sources of information. For example, NVIC.gov was regularly cited, which is a government-run website for the National Vaccination Information Center.

#### **i. Concerns About Laws Passed**

Member of these groups also cite the National Childhood Vaccine Injury Act that was passed in 1986, which removes and/or reduces financial liability for vaccine manufacturers to claims of vaccine injuries (US Legal). The NCVIA was passed to limit litigation expenses while also creating a system to report any vaccine adverse events (US Legal). However, members of



these groups consider the act as proof of government conspiracy with vaccine manufacturers, prioritizing the financial well-being of these companies over the health of the population.

### **ii. Bipartisan Movement**

As a US citizen, it feels as if the current political climate in the US is becoming more dichotomous by the day — you are either with someone or against them, based on your political views. Interestingly, the anti-vaccine movement is not partisan based — the concern is not Left-wing or Right-wing based, it is mostly centered around the idea that parents should be able to choose what medicine is given to their children. Rabinowitz et al. discovered that there are a similar proportion of people who endorse anti-vaccine statements across Liberals, Moderates, and Conservatives (2016). Information I collected corroborates this - when I checked the blogs and sources that are linked in these Facebook groups on MediaBiasFactCheck.com I found that 24 of the 27 unreliable sources listed were neither left-leaning or right-leaning, but instead were issue-based. I utilized MediaBiasFactCheck.com to search for the overarching media bias among the different websites, to check if my initial inclination about the website's leaning could be corroborated. Based on the articles linked on my three Facebook groups, while there was more left-leaning sources that were reliable, the majority of the unreliable sources did not specify a political leaning. This movement is interesting in that the consensus among the AVM do not have an overarching partisan ideology that ties to the movement.

### **iii. Implications Of Posting Outside Links As Evidence**

While some of these sources were legitimate, many of them were not, which leads to the spread of misinformation in social media. The sources that were legitimate, such as the NCVIA, were framed within the conspiracy narrative, being cited as proof that the government wanted to

lessen any repercussions a pharmaceutical company would face if they were actually producing harmful vaccinations. Once again, this finding is tied to the narrative of conspiracy, the overarching story telling members of the AVM that the government has designed their structure to not be on their side.

### A Culture Of Validation

A common theme among the groups is a cycle of advice and validation. Parents give each other the validation they did not receive from doctors when their child either became ill or passed. It is a cycle of reassuring grieving parents that their feelings are real and valid, ensuring that these parents feel heard and listened to.

#### **i. Validation of Beliefs Through Anti-Vaccine Advice**

These pages are where parents come for advice. They feel the need to find an AVM friendly doctor, or where to find an exemption form, or possibly about how to help their kid in any way. A frequent question was whether or not a pregnant mother should give her newborn baby the Vitamin K shot after birth. Some parents suggest the shot, or at least using Vitamin K drops that you can buy online, saying at least it is not a vaccination. Others insist that any sort of injection is a terrible idea, one parent stating, “Oh, yes it can cause harm to the baby. It is the first initial assault to your child's body and brain.” These groups foster a culture that distrusts current medicine, encouraging other members to decide against mainstream medical recommendations.

## **ii. The Implication of the Advice/Validation Cycle**

While the culture is distrustful of power systems, there is deep trust within these groups. Members seek advice on these Facebook groups out of trust in the community they find there. This movement is not centered on economic structures, but is a movement run by scared and grieving parents, who do not understand what has happened to their child, and who need something to blame. These groups provide a solace that these parents struggle to find elsewhere.

### Does Race Affect the AVM?

Nearly every person who posted in these groups was white, judging by their profile pictures. All of the pictures of injured and dead children were also white. To have such a racial disparity is significant, and might possibly tie into the effectiveness of the movement and the sympathy created by the anecdotes. If racial bias is significant enough in the movement, it could alter perceptions of the movement itself.

### The Politicization Process

After talking to my key informant and going through the public Facebook groups, I have identified a process that politicizes people into joining the anti-vaccine movement. First, there are series of anecdotes about children that are “vaccine injured”, meaning that in the frame of this story, children have some sort of health issue in relation to their vaccinations. These stories are compelling, creating sympathy for children and teens dealing with disabilities, illness, and death, blaming vaccinations. Parents write out dates, showing that their child got their vaccinations at X date, and X days later they were sick, disabled, or dead.

Next, they encourage you to choose differently for your family. Parents go on these groups asking for advice on what to choose for their babies, and group members encourage them to take alternative routes.

After and during the time they encourage members to take different actions, they start to dismantle the power systems that ensure US citizens get vaccinated. They begin by distrusting Big Pharma, the powerful pharmaceutical companies that have monopolies on medicine, and then distrusting the government for enacting laws that make vaccines mandatory.

Finally, they encourage you to take political action. They post numbers of senators and scripts of what to say, encourage people to write letters and raise their voices. They have laid the groundwork for people to feel outraged and unheard by politicians and the medical community, so they encourage people to take matters into their own hands.

### Limitations

With only three Facebook groups over two months, I had compiled about 700 pages worth of data. As one person, I was unable collect as much data as I would have preferred. This study could have benefitted from a longer period of data collection over a larger variety of Facebook groups, in order to get a fuller depiction of the AVM as it currently stands.

It also would have been beneficial to have more than one key informant. I had made multiple attempts to contact other activists within the AVM for interviews, however I had very few responses to my repeated emails and messages. It is a possibility that my unknowingly using biased language (e.g. “Anti-vaccine” instead of “Non-vaccine”) deterred people from wishing to speak with me.

### WHAT TO DO ABOUT THE AVM?

All of my findings tied back to the distrust of government and medicine. In order alter the tide of the anti-vaccination movement, it would be beneficial to re-establish trust with medical professionals and parents who are confused and upset with their child's health. The AVM feels as if there is no one in power who is in their corner, so they try to make power for themselves. This in part appears to be because of the capitalistic function medicine has in our society — many parents stated that because they have to pay so much to be treated, they do not trust the medicine that they are required to take. One solution to ensure that everyone trusts and feels safe to take medicine is to de-capitalize it, to make sure that people do not get to become rich from others illness and injuries. There also needs to be better communication channels, possibly in the form of training to deal with parents convinced that their child has been harmed by vaccines. These parents seek validation for their concerns, and opening channels of trust and communication would go a long way in decreasing the fervor.

In order to effectively communicate, however, there needs to be a common language. In my research, I found it difficult to find an unbiased way to speak about the anti-vaccination movement. “Anti-vaccination” is seen as biased language for those in the movement, and “ex-vaxxer” and “non-vaxxer” are words that imply anti-vaccine beliefs. The language is built to be biased from either perspective, creating difficulties in communication from either side of the ideological spectrum.

The anti-vaccination movement is incredibly effective in part because of the compelling anecdotes shared. Layperson experiences are incredibly powerful, and they clearly make an impact on people's perceptions of issues. Pro-vaccine groups can utilize this format by telling

stories of children who were harmed because others were not vaccinated. An emphasis on layperson narratives could deeply bolster future and current social movements, as it is important to recognize human experiences.

Recognition of suffering would make a difference amongst members of the AVM. The validation they receive from their peers feeds their need to have their concerns and experiences recognized. Our culture is filled with people who use statistics as a way to convince people to believe in something. While statistics are compelling and useful, if we were to approach the AVM with the recognition that it is largely filled with scared parents, it might be easier to convince people that the issue is not vaccines.

There should also be information campaigns about how there is no alternative solution to vaccinations. The holistic medicine route can only go so far in the disease prevention process, it is not a long-term protection against polio and the measles. If we are to show that there are limited options in protecting children from disease, then more people could be convinced to vaccinate their children.

While compiling my research, I discovered a distinct racial disparity in these Facebook groups. In order to further my analysis, I attempted to find studies about the racial makeup of the anti-vaccine movement, and was surprised to find very little on the subject. I suggest that further study is needed — the racial makeup of the anti-vaccination movement is incredibly interesting, and it might factor into the strength and breadth of the movement. Does race have to do with the willingness to discount expert medical opinions? Why are all the stories posted on these pages about white children? Does race affect the way sympathy has played into the movement?

Without further study it is difficult to make any conclusions or recommendations on this part of the matter.

### CONCLUSION

The Anti-Vaccine Movement spreads misunderstanding and misinformation about vaccines and how they affect health. This study's most significant finding is the overarching Narrative of Conspiracy in relation to the government and medical providers. Creating distrust in the providers of vaccines discredits the validity of the medicine. In order for vaccines to be seen as beneficial, it is integral to reestablish trust with medical providers.

My findings were consistent with the literature in that I found anecdotes and personal narratives to play a major role in the AVM. The stories are integral to the conversion to the movement, playing into the ethos of readers and listeners. Utilizing the narrative format, and attempting to create a group identity are beneficial lessons from the AVM. Bringing people together into a cohesive unit allows for effective policy creation. The AVM involves passion, emotional care, and validation from peers. Moving forward, these characteristics would be beneficial in both combatting AVM ideologies and in other social movements that struggle to find a cohesive identity.

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Appendix A

1. Tell me a little about yourself.
2. How do you self-affiliate?
3. What is your role in the organization?
4. What are your thoughts on vaccination?
5. Do you remember the first time you heard vaccines were dangerous?
  - a. Where did you hear this/find this information?
6. How long have you been working in the Anti-vaccination movement (AVM)?
7. Why did you begin to work in the AVM?
8. Why do you believe that vaccines are harmful?
9. How have you/your organization been fighting against vaccinations?
10. What resources have you used in order to further your campaign?
11. What has been your most successful campaign? What has been your least successful campaign? How were these campaigns successful or unsuccessful?
12. The consensus among scientists is that vaccines are a public health benefit and that vulnerable populations - elderly, infants, immunocompromised individuals - are most harmed by lack of herd immunity. What is your perspective/response to this?

Appendix B

<p><b>Advice &amp; Validation</b></p>	<ul style="list-style-type: none"> <li>● Ambivalence to vaccines</li> <li>● Anti-vaccine</li> <li>● Ex-vaxxer</li> <li>● Vaccine choice</li> <li>● Validating parents</li> </ul>
<p><b>Anecdote</b></p>	<ul style="list-style-type: none"> <li>● Creating a fallacy</li> <li>● Sympathetic stories</li> <li>● One size does not fit all</li> <li>● Outrage</li> <li>● Points out fallacy</li> <li>● Polite refusal of fallacy</li> <li>● Pro-vaccines</li> <li>● Religion</li> <li>● Vaccine Injury</li> </ul>
<p><b>Holistic Healing</b></p>	<ul style="list-style-type: none"> <li>● Ingredients</li> <li>● Inserts</li> <li>● SIDS</li> </ul>

<b>Encouraging Political Action</b>	<ul style="list-style-type: none"><li>● Extrapolation</li><li>● Fearmongering</li><li>● Parents' choice</li><li>● Parents' right</li></ul>
<b>Narrative of Conspiracy</b>	<ul style="list-style-type: none"><li>● Autism</li><li>● Big Pharma</li><li>● Clean Vaccines</li><li>● Informed Consent</li><li>● Medical Professional</li><li>● No source</li><li>● Proof Argument</li><li>● Sub Saharan Africa</li><li>● Unnecessary treatment</li><li>● Using science</li><li>● Vaccines and aborted fetuses</li></ul>
<b>Outside Link</b>	<ul style="list-style-type: none"><li>● Live Video</li><li>● Using sources</li><li>● VAERS</li></ul>