VACCINE HESITANCY AND INSTITUTIONAL CREDIBILITY PRE-COVID-19

PUBLIC TRUST IN SCIENTIFIC INSTITUTIONS: VACCINE HESITANCY AND INSTITUTIONAL CREDIBILITY PRE-COVID-19

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Abstract

This dissertation is an examination of trust in vaccine science, with a focus on ideas about vaccination outside the scientific consensus. It is grounded in empirical research, including 35 interviews and a review of publicly available documents, books, and academic articles. Theoretically, it is informed by theories in the sociology of science, social movements, and the sociology of expertise. In substantive chapters, it investigates the origins of the modern ‘anti-vaccine’ movement, the spread of the movement's ideas in different sociocultural and political contexts, and the perspectives and personal experiences of those who are part of the movement. Overall, it contributes to a growing body of literature that aims to change the conversation around vaccine hesitancy from an information-deficit problem to an issue about trust in institutions.

The dissertation is organized into three main papers. The first is an analysis of a specific historic episode, namely the 1998 MMR (measles, mumps, rubella) vaccine-autism controversy. I find that institutional incentive structures unintentionally circulated misinformation about the MMR vaccine by former medical doctor Andrew Wakefield and posit the role that academic reward structures have in fostering public trust. The second paper examines vaccine hesitancy with a social movement lens, specifically focusing on the strategies used by the anti-vaccine movement to organize and frame their message. I introduce the concept of an ‘anti-scientific intellectual movement’ to understand the increasing trend of social groups opposing science as a set of institutions. The third paper is a study of the lived experiences of participants who were interviewed in 2019 about their views on vaccination and how their individual experiences and meaning-making activities impacted their trust in vaccine science. I find strong distrust in scientific institutions, a desire for open dialogue and debate, and dissatisfaction with the ‘anti-vaccine’ label which participants felt erased the nuance in their perspectives. Altogether, this dissertation makes significant contributions to ongoing discussions about the public face of science and how to effectively engage with public audiences to build trust.

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Contents

Chapter 1

Introduction

In 2019 the World Health Organization (WHO) listed vaccine hesitancy —the delay or refusal of vaccines—as one of the top ten threats to global health. Measles—the most contagious vaccine-preventable disease— had seen a 30 percent increase worldwide, including in countries that had declared measles elimination status at the turn of the 21st century (World Health Organization 2019). Fast forward to a year later, the world faced the unprecedented COVID-19 pandemic. Global attention and resources were streamlined in efforts to create a safe and effective vaccine for this virus. Almost counterintuitively, vaccine hesitancy did not decline with the risk of disease but increased as growing concerns about the credibility of our scientific, health, and media institutions boiled to the surface among some groups (Cowan and Reich 2021; DiResta and Garcia-Camargo 2020).

The WHO has coined the term ‘infodemic’ to describe the growing influence of misinformation on the spread of infectious disease globally and recognized countering the COVID-19 infodemic specifically as essential to the public health responses enacted by member states (WHO 2020). Public health efforts have been made to combat vaccine hesitancy through such groups as the Vaccine Confidence Project founded in 2010, and the SAGE Working Group on Vaccine Hesitancy established in 2012. The SAGE Working Group on Vaccine Hesitancy defined vaccine hesitancy in a 2015 report (MacDonald et al. 2015) and the Vaccine Confidence Project has developed an index survey tool, the Vaccine Confidence Index (VCI) to monitor vaccine hesitancy globally (Larson et al. 2015).

Vaccine controversies have existed since the invention of the smallpox vaccination in England in the late 1700s and the subsequent formation of the anti-vaccination league (Crowcroft 2021). Vaccine hesitancy or opposition to vaccination during this period was mostly characterized by religious opposition, and after mandatory vaccination legislation was enacted in 1853 involved a libertarian opposition as well. In England Reverend Edmund Massey's 1772 sermon, 'The Dangerous and Sinful Practice of Inoculation' argued that the diseases that might be prevented by vaccines were in fact God's tools for punishing sinners (Largent 2012).

Religious objections feature much less prominently in contemporary concerns about vaccination policy. Although some leaders of religious groups have publicly opposed vaccination, few religious doctrines have an official stance against vaccination (Crowcroft 2021; Largent 2012). In the 1950s post-WWII prosperity when the relationship between science and society was at an all-time high, the development of the polio vaccine substantially bolstered public confidence in vaccination (Goldenberg 2021). Most of the vaccine hesitancy since this historical era has evolved into a multifactorial phenomenon existing in a myriad of social contexts (Larson 2020).

Vaccine controversies in the twentieth century often surrounded specific vaccines or vaccine ingredients (Largent 2012). For example, the diphtheria, tetanus, and pertussis (DTP) vaccine and the measles, mumps, rubella (MMR) vaccine prompted safety concerns from parents in the 1990s, followed by concerns about the ingredient thimerosal used as a preservative in certain vaccines (Mnookin 2011). The HPV vaccine, as prevention for an STD that causes cervical cancer, has been enmeshed in debates about adolescent sexuality (Albert 2019), and the COVID-19 vaccine has evoked even broader politically partisan debates about trust in experts and the role of expertise in society (Cowan and Reich 2021).

I was drawn to the debate over vaccination because of the possibilities of the case to explore broader theoretical questions related to the sociology of expertise. In a relational approach to the analysis of expertise, each paper in this sandwich thesis examines the breakdown of scientific expertise surrounding vaccination as social relationships among people or social groups. Taken as a whole, this dissertation aims to address the underlying knowledge dynamics constructed in a ‘post-truth’ era in science studies (Sismondo 2017).

In Science Technology Studies (STS); ‘moral panics about the status of knowledge in the public sphere are as old as knowledge itself’ (Jasanoff and Simmet 2017: 755) and ‘public facts are necessarily debates about social meanings’ (Jasanoff and Simmet 2017: 751). Social science and humanities scholars have been critical of different subdimensions of public health approaches to vaccine hesitancy including framing the issue as primarily an information-deficit problem (Goldenberg 2021), understanding vaccine rumours as an entirely negative social phenomenon (Larson 2020) and failing to place more faith in public audiences in the slow policy move to advocate mask-wearing for the general public (Tufekci 2021).

Following Goldenberg's (2021) critique of Collins and Evans' (2007) 'non-relational analysis of expertise' this dissertation attempts to understand not only the construction of expertise relationally but the *'breakdown* of expertise' relationally as well. The core theme of the dissertation is that vaccine hesitancy is a relationship problem rather than simply a misinformation problem. The dissertation explores the matrix of values surrounding contemporary vaccine hesitancy, how these ideas spread, and the individual thoughts and emotions of the people who hold them.

This research aims to contribute to public health efforts with a detailed analysis of the social dynamics surrounding vaccine hesitancy emerging from three different contours of the debate. In three separate articles unified by the theme of expertise and public trust in society, this thesis will deal with the broad phenomenon of vaccine hesitancy using several qualitative approaches. The first substantive chapter (Chapter Two) addresses the historical specificity of contemporary vaccine hesitancy in a contextual analysis of the construction and breakdown of expertise in the 1998 MMR-autism controversy. Social aspects of knowledge production at the university are examined in terms of the organization of science, its incentive structures, and how this impacts public trust and understanding of science.

Chapter Three examines vaccine hesitancy as an evolving and organized social movement that benefits from social structures at its disposal to spread information, employing the theoretical tools provided by Frickel and Gross' (2005) theory of scientific intellectual movements (SIMs), and developing the conception of an anti-scientific movement (ASIM). The breakdown of expertise is explained as grievances between social groups that gain traction structurally as certain forms of social organization allow ideas to spread in the information environment and culturally resonate with individuals.

Chapter Four closely examines 35 interviews conducted in 2019 to understand vaccine hesitancy as a heterogenous set of experiences and perspectives that are constructed and made meaningful by individuals. Unpacking the variation in accounts, lived experiences, and individual interpretations offer a close examination of meaning-making activities that contains the least construction/imposition of meaning from the principal researcher. The aim of this chapter was to honour the voices and lived experiences of participants to gain an understanding of the micro-social processes that impact their decision-making.

This Study

The methodological approach of this dissertation lies within the interpretive tradition in sociology. This choice of methodology was reached after careful consideration of the main research goals. In accordance with Lamont and Swidler's (2014) call for methodological pluralism in sociology, this dissertation aims to move the public conversation about vaccines forward with a methodology suitable for the research questions being pursued. My research aims to answer 'how' and 'why' questions to complement the breadth of previous studies with a more in-depth examination of the meanings and motivations participants attach to their attitudes and decision-making about vaccination.

A quantitative approach to vaccine hesitancy would have necessitated the assumption of shared meanings across terms in the operationalization of concepts and phenomena into variables. Surveys as a research tool operationalize vaccine attitudes into concrete ordinal variables on a Likert scale, limiting the construction of specific contexts and the development of conceptual depth and meaning. This approach was incompatible with my research questions which aimed to deeply understand the complexity of viewpoints and gather rich data. Participants with minority perspectives may attach different meanings to the same words or phrases employed by the principal researcher or the general public. A qualitative approach allows for an examination of the social context, verbal accounts, and individual meaning-making activities that infuse decision-making.

The theoretical assumptions of this research align with sociologist Max Weber's (1947) notion of *Verstehen* and Herbert Blumer's (1986) notions within the theoretical approach of symbolic interactionism. In an attempt for genuine participation from my research participants and to understand their concerns, I have taken on a sociological approach known as *Verstehen*—an active effort by the researcher to empathize with the meaning-making activities of participants (Hochschild 2016). This was intentionally employed throughout the research design. As an outsider to the social worlds inhabited by my participants, I wanted to do my best to tell their stories and avoid the dismissal and ridicule they so often faced by researchers and the general public. This required crossing empathy walls, the obstacles that impede the deep understanding of another person (Hochschild 2016). Therefore, my primary goal in the analysis was not to determine which understandings were right or wrong but to uncover the social processes involved.

The theoretical tenets of symbolic interactionism offer an interpretive paradigm that is useful for understanding social processes, and more dynamic social phenomena that can be challenging or impossible to capture in a single variable. Herbert Blumer's 1956 presidential address at the American Sociological Association titled "Sociological Analysis and the "Variable," discussed the shortcomings of variable analysis. According to Blumer (1956), these shortcomings stem from neglecting the contextual nature of meaning-making. Mead's concept of the significant symbol is the most important building block of theories in symbolic interactionism and rests on the concept of meanings as socially contingent (Mead 1934).

The meanings of vaccines and the social contexts of vaccine hesitancy have changed over time. Modern vaccine anxieties are different from those expressed in the past because both the vaccines and the contexts are vastly different (Largent 2012). In the eighteenth century, the concerns of the anti-vaccination league in England about the smallpox vaccine centred around religious opposition (Crowcroft 2021). In the 1990s, vaccine hesitancy surrounding childhood vaccines, the measles, mumps, rubella (MMR) vaccine and diphtheria, tetanus, and pertussis (DTP) vaccine were led by parents concerned about safety. Vaccine hesitancy during the 2020 COVID-19 pandemic had an added dimension—refusal on partisan grounds with some individuals reportedly even seeking vaccination in disguise (Harrington 2021).

The interpretive tradition in sociology can help understand and disentangle the meaning-making associated with vaccines and the values and social groups that matter to individuals who are vaccine-hesitant. Moving away from the pragmatics of the situation and focusing on meaning, culture, and reference groups, qualitative approaches in sociology allow us to identify the logic in behaviour and decisions that may seem illogical to some, and how to connect with individuals with these perspectives.

Beyond individual interpretations, the research strategy I adopted evaluates findings in relation to wider social structures, taking a contextual constructionist approach (Best 1993). Chapter Two of this dissertation is oriented within the historical logic of inquiry as it examines specific historical processes that explain a sequence of contingent events. Chapter Three although qualitative, has a multivariate logic of inquiry, identifying variables and structures that lead to certain outcomes. Chapter Four takes on an interpretive logic of inquiry, focusing on how meaning is constructed in social interactions (Alford 1998).

Interview data and secondary documentary sources of data were best to answer my research questions because they allowed me to observe the verbal accounts individuals give for their behaviours and beliefs and to draw comparisons across types of people. The background factors that impact decision-making such as one's emotions, self-concept, and ideals can often only be accessed with direct interview questions. Furthermore, interviews allowed me to challenge the reasoning of my participants by asking for their reactions to arguments that disagreed with their conclusions in order to understand how they distinguish themselves from their opponents. Interviewing allowed me to purposively select participants so that I could make comparisons across individuals with opposing perspectives.

Although surveys and ethnographies are necessary for a multidimensional understanding of vaccine hesitancy, they were not the best fit for the research questions I was asking. Surveys are limited in accounting for multiple interpretations of a given phenomenon and explicating the processes that lead to outcomes. Ethnography would be practically difficult to conduct due to the nature of the individuals I examined who are rarely in immediate interactional situations with one another where they can be observed. Vaccination proponents and opponents are not communities in particular geographic locations that easily lend themselves to ethnographic research. Ethnography and survey research methods would not have allowed me to probe participants about the justification for their views and easily compare different types of participants the way interviewing did.

The thematic analysis of documents in Chapter Two and Chapter Three allowed me to construct the social contexts and cultural repertoires within which individuals make decisions. As an examination of a historic case, Chapter Two necessitated documents to access data and the existing verbal accounts of the phenomena being studied. This data included legal transcripts as well as the primary data gathered by investigative journalist Brian Deer. These documents allowed me to access the viewpoints of those most directly involved in the MMR-autism controversy.

Chapter Three synthesizes documents in a theory-building exercise to explain the organization of vaccine hesitancy as a movement. Utilizing documents and synthesizing current research made the broad range of global discourses that surround vaccine hesitancy accessible. Document analysis also allowed me to readily connect the funding and communication strategies utilized by various facets of the movement and test for compatibility with the theoretical framework at hand. Without document analysis, much of this information would be inaccessible and I would not have been able to take the broad approach necessary to understand the mechanisms that allow vaccine hesitancy to function and proliferate as a movement.

Broadly, this dissertation aims to address (1) the ‘deep story’ (Hochschild 2016) and emotional nuance in the distrust of the scientific consensus on vaccines and (2) to understand the role of scientific institutions in the breakdown of trust in expertise—as institutions have been an important and often overlooked part of science communication.

I believe that if public health officials wish to develop effective strategies for responding to the public dissent surrounding public health interventions —vaccine hesitancy must be carefully understood. This is the core objective of this study.

References

Alford, R. (1998) *The Craft of Inquiry: Theories, Methods, Evidence*. Oxford: Oxford University Press.

Best, J. (1993) “But Seriously Folks: The Limitations of the Strict Constructionist Interpretation of Social Problems” In Hostein, J. and Miller, G. (eds) *Constructionist Controversies: Issues in Social Problems Theory* Routledge.

Blumer, H. (1956) “Sociological Analysis and the “Variable”” *American Sociological Review* 21(6): 683-690.

Crowcroft, N (2021) PHO Talks: The Invisible Heroes of Immunization. Available at: https://www.youtube.com/watch?v=rwDYCq0830w (accessed December 2021).

Frickel, S, and Gross, N. (2005) A General Theory of Scientific/Intellectual Movements *American Sociological Review* 70(2): 204-232.

Goldenberg, M. (2021) *Vaccine Hesitancy: Public Trust, Expertise, and the War on Science.* Pittsburgh: University of Pittsburgh Press.

Harrington, B. (2021) How sociologists can battle covid denialism. *The Chronicles of Higher Education.* Available at: https://www.chronicle.com/article/how-sociologists-can-battle-covid-denialism (accessed 3 Sept 2021).

Hochschild, A. (2016) *Strangers in their Own Land: Anger and Mourning on the American Right.* New York: The New Press.

Jasanoff, S, and Simmet, H.R. (2017). No funeral bells: Public reason in a ‘post-truth’ age. *Social Studies of Science*, 47(5), 751-770.

Lamont, M, and Swidler, A. (2014) Methodological Pluralism and the Possibilities and Limits of Interviewing. *Qualitative Sociology* 37 (2):153-171.

Largent, MA. (2012) *Vaccine: The Debate in Modern America*. Baltimore: John Hopkins University Press.

MacDonald, NE and SAGE Working Group on Vaccine Hesitancy (2015)Vaccine hesitancy: Definition, scope and determinants. *Vaccine*. 33(34):4161-4. 10.1016/j.vaccine.2015.04.036. Epub 2015 Apr 17. PMID: 25896383

Sismondo, S. (2017) Post-truth? *Social Studies of Science*, 47(1): 3–6.

Tufekci, Z. (2021) Why Did It Take So Long to Accept the Facts About Covid? New York Times. Available: https://www.nytimes.com/2021/05/07/opinion/coronavirus-airborne-transmission.html (accessed 7 May 2021).

https://www.nytimes.com/2021/05/07/opinion/coronavirus-airborne-transmission.html

Tyson, A, Johnson, C, and Funk, C. (2020) U.S. Public Now Divided Over Whether To Get COVID-19 Vaccine. *Pew Research Center*. Available at: https://www.pewresearch.org/science/2020/09/17/u-s-public-now-divided-over-whether-to-get-covid-19-vaccine/ (accessed 17 September 2020).

WHO (2020) Cross-Regional Statement on "Infodemic" in the Context of COVID-19. Available at: https://onu.delegfrance.org/IMG/pdf/cross-regional_statement_on_infodemic_final_with_all_endorsements.pdf (accessed 15 Jun 2020).

Chapter 2

The normalization of academic deviance: How universities undermine their own scientific credibility

Abstract

Just as ‘creative work is rarely done by individual genius alone’ (Farrell 2003), misinformation does not come from the efforts of one lone actor. Ex-doctor Andrew Wakefield became a global player over two decades ago as the father of the anti-vaccine movement. The influence of his individual behaviour; however, has been exaggerated in a scholarly literature that highlights his charisma and unethical behaviour at the expense of a more systematic focus on what Diane Vaughan calls ‘the normalization of deviance.’ I offer a sociological account of the 1998 MMR-autism controversy that focuses on the role that university incentive structures and status hierarchies played in allowing signals of

Wakefield's deviance to go unchecked on the research team, during academic publishing, and in the medical school's decision to host a press conference. While Wakefield's dishonesty, political skills, and charisma played an important role—the problems run deeper. Building on but moving beyond models that stress a revolt against experts and a generalized crisis in trust, this analysis examines the internal dynamics within peer-review scholarship, university researchers, and hospital administrators that undermine the credibility of science among mass publics.

Keywords: MMR-autism; vaccine hesitancy; stratification in higher education; research assessment exercise; research excellence framework; sociology of science

2.1 Introduction

Through the 1990s, increasing numbers of parents began to resist having their children vaccinated with the measles, mumps, and rubella (MMR) vaccine – a standard vaccine given routinely to children in two doses in their first six years of life, starting in infancy (DeStefano and Shimabukuro 2019; UK Health Security Agency 2021; WHO 2019). Their reluctance was rooted in rumours that began circulating that there was a causal association between the vaccine and autism spectrum disorders (DeStefano and Shimabukuro 2019; Larson 2020). The rumours were fuelled in large measure by the publication of a paper in *The Lancet,* a top British medical journal. The lead author of the paper was Andrew Wakefield, a gastroenterologist who claimed that he and his research team had found the measles virus in the guts of eight autistic children (Wakefield et al. 1998).

When it was eventually discovered that there were serious problems with Wakefield's data, *The Lancet* retracted the paper. A disgraced Wakefield was shunned by his colleagues and stripped of his right to practice (General Medical Council 2010). But not before the damage was done. After 1999, there was a steady increase in the incidence of measles, even in countries that previously had achieved elimination status (WHO 2019). More significantly, many see the MMR controversy as the temporal starting point of the modern anti-vaccine movement and Wakefield as the 'father' of what has become a rapidly growing global movement (Largent 2012).

The impact of Wakefield's actions, including the role that the MMR controversy may be playing in the current COVID-related anti-vaccine movement, raises several critical questions. How could Wakefield's questionable claims have gotten the serious hearing that they did? How could the many renowned scientists who worked with Wakefield or reviewed his work prior to its publication have legitimized his claims about the MMR vaccine and facilitated their diffusion? How were potential signals of misinformation and scientific misconduct missed by colleagues? In short, how could the Wakefield affair have happened?

Most accounts of the MMR-autism controversy focus on the idiosyncrasies of the historic case, namely, the professional deviance of Andrew Wakefield. For example, in January 2011 Fiona Godlee, editor of *The British Medical Journal* (BMJ) called the controversy an 'elaborate fraud' stating that: 'it is hard to find a parallel in the history of medical science' and the New York Times described Wakefield as 'one of the most reviled doctors of this generation' (Dominus 2011). Brian Deer, an investigative journalist on the case, pointed to unique personal characteristics, a 'natural charisma' (2020:17) that Wakefield possessed, allowing him to navigate social situations with ease and preventing colleagues from suspecting fraud.

Beyond Wakefield's individual actions, *The Lancet*, too, was criticized for the role it played. In the weeks following the publication, experts from the World Health Organization (WHO) and the Institute of Child Health at University College London (UCL) aired their discontent in the journal's correspondence pages. WHO experts called the publication 'tragic' and questioned the merit of publishing findings that fail to make a causal association (Lee et al. 1998; Horton 2003) and experts from the Institute of Child Health similarly stated that they were 'surprised and concerned that *The Lancet* published [a] paper…yet provided no sound scientific evidence' (Bedford et al. 1998).

Social science research on the MMR-autism affair addresses the circulation of Wakefield's ideas in the news media (Boyce 2006; Clarke 2008; Dixon et al. 2012; Holton et al. 2012), the evaluation of his ideas at the United States Court of Federal Claims (NVICP) (Decoteau et al. 2015; Kirkland 2012), and downstream effects on MMR vaccine attitudes and decision-making (Brown et al. 2012; Dixon et al. 2013; Evans et al. 2001; Smith et al. 2007; Tan 2021; Torracinta et al. 2021). While these analyses after the fact have brought important insights about misinformation dynamics in the media and legal settings, they leave out the specific organizational context in which Wakefield's ideas first emerged.

My purpose in this paper is to advance the argument that the MMR-autism affair cannot be fully understood without looking beyond the individuals involved and their ‘deviance’ or ‘mistakes.’ The organizational culture of academic and medical science itself not only allowed the incident to occur but created the conditions that led to its occurrence - and could do so again. Instead of asking what social rules in the scientific process were broken, this paper asks: to what extent can this case be explained by science functioning as usual?

2.2 Methods

The research design takes a case study approach–a method in the social sciences whereby researchers explore a single event in detail to produce in-depth knowledge about a particular subject. This approach is often used for exceptional or deviant cases in order to uncover the specific contextual factors at play in situations that deviate from social norms (George and Bennett 2005). My analysis is based on transcripts from the United Kingdom’s General Medical Council’s (GMC) fitness to practice hearing which convicted Wakefield of professional misconduct in 2010, and the chronologies provided by the award-winning investigative journalist on the case Brian Deer in *The Doctor Who Fooled the World*: *Science, Deception, and the War on Vaccines* (2020).

Supplementary data and context were gained from *The Lancet's* published correspondence and its editor-in-chief Richard Horton's 2003 book *Second Opinion: Doctors, Diseases and Decisions in Modern Medicine,* and his 2004 book *MMR Science* *and Fiction: exploring the vaccine crisis*. The documents selected for examination are methodologically advantageous in that they provide descriptions of the social context under investigation from key social actors themselves. As the longest General Medical Council (GMC) hearing in its history, Wakefield's trial and the investigative work conducted by journalist Brian Deer included detailed information about the scientific process and social interactions between Wakefield, the other scientific authors on the paper, and the university dean and administrators.

After collecting documents describing the institutional backdrop and social setting for this case, I analyzed my data using Braun and Clarke's (2022) six phases of qualitative thematic analysis. First, I immersed myself in the dataset, familiarizing myself with the documents and coding for single meanings or concepts. Then, I identified clusters of code to generate candidate themes with broad meanings while constantly reviewing these themes to assess compatibility with the data. Finally, I fine-tuned my analysis clearly demarcating the themes in the write-up and weaving together data and analytic narrative within the larger story. Throughout this process I kept the possibility of my research question open without assumptions about how people might frame the issue (Braun and Clarke 2022). The explanatory richness of the case study approach and flexibility of thematic analysis allowed me to identify variables that are often left out or difficult to measure and to address complex social mechanisms (George and Bennett 2005).

I have organized my paper as follows: I begin with an account of the MMR-autism controversy and Wakefield's role in generating that controversy. The analysis portion of the paper is divided into the five features of organizational cultures in scientific research and publishing that I identify as key to understanding the Wakefield affair – the hierarchical structure of research teams, the inordinate focus on novel research results in academic publishing, porous boundaries between science and the press, self-referential responses from the scientific establishment, and highly competitive scientific reward systems. My conclusion draws on the classic work of Diane Vaughan (1996) on the NASA Challenger launch disaster, and more specifically Vaughan's notion of 'normalized deviance' to reflect on how deviance can be normalized in academic cultures and organizational contexts.

2.3 The MMR-Autism Crisis

Andrew Wakefield joined the faculty at the Royal Free Hospital in 1988 after graduating from the nearby St. Mary's Hospital (now the Imperial College School of Medicine) and completing a fellowship at the Toronto General Hospital in Canada (Deer 2020). During his appointment at the Royal Free Hospital in London Wakefield took on a leadership role in launching the Inflammatory Bowel Disease Study Group where researchers collaborated to produce several papers exploring Wakefield's hypothesis that measles virus caused the inflammatory bowel disease Crohn's. The first paper was published in 1993 in the *Medical Journal of Virology* and the two subsequent papers were published in *Gastroenterology* in 1995 and *The Lancet* in 1996 (Wakefield et al. 1993; Wakefield et al. 1995; Ekbom et al. 1996). These publications suggested that the measles virus might play a role in Crohn’s disease but were inconclusive and met with critical commentary. It was then that Wakefield began to turn his focus to the MMR vaccine, bowel disorders, and autism in a new research project where he would lead the team as the senior scientific investigator (Deer 2020).

Several conflicts of interest permeated the new research project from the start. Wakefield received funding from the British government’s Legal Aid Board (now the Legal Services Commission), which had awarded Richard Barr, a personal injury lawyer, a contract to represent litigants in a potential class action lawsuit against MMR vaccine manufacturers (Deer 2020). Barr referred children to the Royal Free Hospital to participate in the new study in 1996 and commissioned Wakefield as an expert witness for the lawsuit (General Medical Council 2010). Then, in June 1997 Wakefield registered a patent for his own singular measles vaccine—as opposed to the standard three-in-one MMR (measles, mumps, rubella) vaccine examined in his research—as well as two additional patents for treatments for autism and inflammatory bowel disease. None of these conflicts of interest were publicly disclosed to the Royal Free’s ethics committee, *The Lancet*, or to Wakefield’s academic colleagues (Deer 2020).

In 1998, Wakefield and his colleagues published the results of their research in *The Lancet*. The findings indicated that the measles virus had been found in the guts of eight autistic children (Wakefield et al. 1998). Prior to accepting the paper for publication editors at *The Lancet* had concerns that circulation of the research may carry public health risks and its editorial board deliberated on the decision to publish the paper during three separate occasions (Horton 2004). Editors considered requesting that Wakefield et al.

remove the parental testimony attesting to a temporal association between the MMR vaccine and autism from the paper but eventually decided against this (Deer 2020). In the end, the article was published and although editor-in-chief Richard Horton in retrospect did not feel that it was an incorrect decision to publish the findings based on the information he had at the time— he did recognize that he did not properly appreciate or foresee the importance of the reception of these findings in the media. Horton reflects on his handling of the controversy saying: ‘I failed to do enough to manage the media reaction to this work. Until the Wakefield paper, I had not seen this media management role as one for a scientific medical journal editor. I now see it as one of my main responsibilities’ (Horton 2003: 213).

A few days before the release of *The Lancet* issue in which Wakefield’s paper was to appear, the Royal Free Medical School and Hospital arranged a promotional press conference to which all of Britain’s top media sources - *The Times*, *The Guardian*, the *Daily Telegraph*, *The Independent*, Channel 4, Channel 5, and the BBC - sent journalists (Deer 2020; General Medical Council 2010). At the press conference, Wakefield went further than he did in his paper, stating unexpectedly that there was enough evidence in the paper to rethink vaccination policy in the UK and that for the time being he recommended people opt for the single measles vaccine rather than the combined measles, mumps, rubella (MMR) vaccine (General Medical Council 2010).

There were suspicions about Wakefield’s research from the start, troubles that only mounted as time went on. The United Kingdom’s General Medical Council (GMC) - an organization that regulates medical doctors - organized a daylong meeting on March

23, 1998, attended by fifty-seven scientists to consider his work. Professor of gastroenterology at the University of Edinburgh Anne Ferguson questioned the recruitment of patients for the study suspecting selection bias, and immunologist David Goldblatt pointed out that Wakefield failed to follow protocol for avoiding false-positive reactions in his detection of the measles virus (Deer 2020). A few weeks later, Doctor Andrew Rouse wrote to *The Lancet* about a fact sheet written by a lawyer named Richard Barr he had found posted online by a group called the Society for the Autistically Handicapped, inviting clients to contact Wakefield to participate in the study. Rouse suspected litigation bias, a conflict of interest not mentioned in the paper (General Medical Council 2010; Deer 2020).

The United Kingdom's General Medical Council (GMC) held a hearing in 2007 to determine Wakefield's fitness to practice. The 217-day hearing - the longest in GMC's history - convicted Wakefield of 36 charges, including undisclosed financial conflicts of interests and unnecessary invasive medical procedures that were contrary to the clinical interests of the children, and unapproved by his institution's ethics committee. It was determined that the UK Legal Aid Board had funded Wakefield's research through lawyer Richard Barr on behalf of a class action lawsuit against MMR manufacturers. Wakefield was stripped of his license to practice medicine in 2010 (General Medical Council 2010).

In the aftermath of the GMC's ruling, *The Lancet* withdrew Wakefield's paper (Dyer 2010), and its editor-in-chief, Richard Horton, expressed regrets about having published it in the first place (Horton 2003). Similarly, the Dean of the Royal Free

Medical School - Arie Zuckerman - called his decision to hold a press conference to promote Wakefield's findings 'a disaster' (Deer 2020: 34). The university reached a resignation agreement with Wakefield in 2001, at which point he officially resigned.

But all these steps did little to contain the damage wrought by Wakefield's ideas. His claims, with the force of a prestigious medical journal and a recognized medical establishment behind them, substantially raised parental concerns about the risks that vaccination carried. MMR vaccination rates in the UK declined from 92% in 1995 to 80% in 2003 with even lower rates in some inner-city areas (UK Health Security Agency 2021). The World Health Organization (WHO) recommends a vaccination rate of 95% to prevent measles outbreaks. The prevalence of measles in the UK rose steadily in the following years from 56 cases at the time of Wakefield's publication in 1998, 440 cases in 2003, 1315 cases in 2008, and 2032 cases in 2012 (UK Health Security Agency 2021). In 2019 the WHO listed vaccine hesitancy as one of the top ten threats to global health with a 30% increase in measles worldwide (WHO 2019).

Beyond the impact on MMR vaccination rates, however, is the damage that the controversy caused in terms of public confidence in vaccines and in science more generally. Public health officials tried to alleviate the concerns—but only with limited success (Goldenberg 2021; Largent 2012). The British government launched a $4.4 million information campaign to reassure parents about the safety of the MMR vaccine, but previous false assurances made by then-prime minister Tony Blair regarding bovine spongiform encephalopathy (mad cow disease) and his initial refusal to disclose his son Leo's vaccination status fuelled rumours and distrust (Largent 2012). Wakefield's ideas spread globally, and many consider these events to be the precursor of the modern anti-vaccine movement (Larson 2020; Largent 2012).

2.4 The Hierarchical Structure of Research Teams

In this section, I will discuss how the division of labour on Wakefield's research team contributed to his ability to propagate misinformation. As the leader of the Inflammatory Bowel Disease Study Group and senior scientific investigator, Wakefield held the highest level of authority among the other twelve coauthors and auxiliary personnel for this research project (Deer 2020). The infamous *Lancet* paper had thirteen authors and several clinical technicians (Wakefield et al. 1998). As interdisciplinary research, clinical research tasks were delegated based on specialty, Wakefield's collaborators conducted colonoscopies, histopathological analysis, B12 studies, clinical assessments, psychiatric assessments, neurological assessments, and radiological assessments. Wakefield as the first author was primarily responsible for writing the paper and overseeing the analysis (Deer 2020).

Although other authors sought amendments to the manuscript, it was at Wakefield's discretion whether they would be implemented or not and many authors contended that they were not shown the final manuscript. *Uniform Requirements for Manuscripts,* a guide for writing ethical research contends that each author listed for a study should have made 'substantial contributions' to multiple aspects of the manuscript. This was hardly true for anyone but Wakefield (Deer 2020). Experts in the three main subfields of the paper gastroenterology, psychiatry, and histology took issue with the presentation of empirical phenomena in their specialty after reading the final publication (General Medical Council 2010). Furthermore, a junior assistant and Wakefield's Ph.D. student who was not given authorship on the paper, disclosed to Brian Deer that he had findings of no measles virus in bowel tissue that were omitted from the paper (Deer 2020).

Pediatric gastroenterologist Dr. Simon Murch, who conducted the colonoscopies, disagreed with the diagnosis of enterocolitis in the children, calling the use of the term in the publication 'dreadful' (Deer 2020: 264). The mild inflammation observed was considered normal pathology. However, he did not see the final manuscript before publication and was unable to voice this concern. At the General Medical Council (GMC) hearing one of three pathologists on the team Dr. Deborah Davies stated that she was concerned about the use of the word 'colitis' in the paper and did not believe that the terminology was warranted (General Medical Council 2010). The other pathologist Dr. Amar Dhillon denied reporting colitis at all, writing in the *British Medical Journal* (BMJ) that none of his grading sheet observations included this diagnosis (BMJ 2011). Dhillon also said in a reply to journalist Brian Deer that he did not write the histology sections of the publication—the portion of the paper based on his expertise (Deer 2020).

On day 113 of the GMC hearing, Dr. Simon Murch recalled a meeting in the histopathology seminar room three months before *The Lancet* publication, where Wakefield distributed the latest version of the paper and the team's pathologists Dr. Deborah Davies, and Dr. Amar Dhillon led a debate questioning whether the description of the biopsies' histology oversold it (General Medical Council 2010). Brain Deer (2020) argues that pathologists Davies and Dhillon would have known their field's consensus—that mild elevation in inflammatory cells were often found in normal healthy guts and should not be diagnosed as colitis. This was established in the *American Journal of Surgical Pathology* in 1989—nine years before the publication—in a landmark guide. It stated that diagnosing mild chronic nonspecific colitis in normal colons is a common error that is made due to the presence of mononuclear cells and that as a rule of thumb colitis should not be made as a diagnosis unless there is evidence of injury to the colonic epithelium (Levine and Haggitt 1989).

At this point, Wakefield and his academic mentor Roy Pounder had met with university management, and the Royal Free was already gearing up for the Atrium event—the press briefing (Deer 2020). Roy Pounder—had the status to gain from his protege's publication and potential funding to the gastroenterology department. Authors in the seminar room had reputations at stake and their own resumes to consider, backtracking now would require sacrificing status and potential career advancement. Junior researchers were especially vulnerable and unlikely to object to or contradict senior colleagues. Dr. Walker-Smith's reputation was also on the line if study participants did not have gut inflammation, he had subjected children to powerful Crohn's anti-inflammatory drugs (Deer 2020). In the end, they chose not to discourage *The Lancet* and took authorship credits at an elite general medical journal with the second-highest impact factor internationally just behind the *New England Journal of Medicine*.

Regarding the findings of measles in the bowel tissue samples of children in the study, Wakefield used his monopoly over the write-up and senior status over his Ph.D. student and lab technician Nick Chadwick who conducted the PCR tests to normalize deviance. Chadwick was not given authorship on the paper but conducted analyses for the project at Chester Beatty Laboratories at the Institute of Cancer Research in London (Chadwick 1998; General Medical Council 2010). Arriving at the Royal Free as a Wakefield disciple, he enrolled in the Ph.D. program after a year of working as a lower-ranked lab technician. When he reported his findings of no measles virus found in the examined bowel tissue his supervisor Andrew Wakefield was unhappy with the results. Wakefield argued that Chadwick's PCR test was not sensitive enough and had delivered false negatives. His other joint supervisor molecular biologist Dr. Ian Bruce stood by Chadwick's methods saying that he had produced the best test that could have been developed at the time (Deer 2020).

Even so, Wakefield decided to deliver the samples to Coombe Women's Hospital in Dublin where they were tested in Professor John O'Leary's lab by the ABI Prism 7700 (Deer 2020). O'Leary was a visiting professor at Cornell but returned to Ireland to supervise the Coombe Women's Hospital, and eventually, he would support Wakefield testifying at a hearing on Capitol Hill. Contrary to the machine's instructional manual, PCR tests were run past the thirty-five-cycle limit to about forty-five cycles for most samples. Beyond thirty-five cycles was an unreliable method that would likely yield spurious false positives. Brian Deer in his investigation into Wakefield's biotech business Immunospecifics found that O'Leary was a shareholder and listed as the fifth owner of

Wakefield’s second proposed company Carmel, which was later declined approval by the Royal Free’s head of medicine Dr. Mark Pepys. O’Leary also had his own private Dublin-registered company Unigenetics which was set to receive UK legal aid payments from the very class action lawsuit funding Wakefield’s work. His PCR machine, the ABI Prism 7700 would test samples from children whose parents were involved in the lawsuit and the taxpayer would foot the bill, which amounted to 800,000 British pounds (Deer 2020).

The organizational culture of science often dictates that early career researchers must adhere to projects as defined by senior colleagues (Coser 1965; Whitley 1984). In this case, as a lab technician without authorship, Nick Chadwick had his data completely omitted from the project without valid justification. Chadwick's data was not published in *The Lancet* (Wakefield et al. 1998) or supplied to the Legal Aid Board in Wakefield’s report of the study. Here, deviance was normalized due to the status hierarchy on the research team, which allowed Wakefield to omit relevant data without any accountability.

The last main subfield of the paper was psychiatry, in the diagnosis of autism. Here too, data were fabricated (General Medical Council 2010; Deer 2020). After an investigation of medical records, it became clear that they were irreconcilable with the data tables published in the paper. Children who had never been diagnosed as autistic were labelled as having regressive autism, the onset of certain children’s symptoms after the MMR vaccine was shortened from occurring a few months after receiving the shot to only days after, and some children were listed as having symptoms before ever receiving the vaccine (Deer 2020).

Child psychiatrist Dr. Berelowitz stated that he made several suggestions for the paper to diminish any misunderstandings for public audiences, all which Wakefield omitted in the final version of the paper he submitted to *The Lancet* (General Medical Council 2010). First, Berelowitz pointed out that the temporal association between the timing of the MMR vaccine and the onset of autistic symptoms makes any causal association found potentially spurious. At his GMC hearing, Wakefield stated that he removed it because he thought that it was factually inaccurate. Second, Dr. Berelowitz suggested that the paper should include a clear statement of support for vaccination. Wakefield said that this was omitted due to a consensus issue between the authors. Professor Walker-Smith, however, stated that he agreed with Dr. Berelowitz's suggestion, and he was not party to a discussion about the temporal association. Third, Dr. Berelowitz suggested that the title of the paper should be changed. As far as Dr. Berelowitz's third suggestion, a title change was implemented, albeit in a different form. Berelowitz found the terminology 'regressive behavioural disorder' to be misleading as the word 'regressive' assumes that children were not born with this disorder and that it was caused by some intervening factor later in their lives. Instead, he suggested that the term 'development disorder' be used, as technically it was more accurate, and would prevent one potential area of criticism. The final publication used the term 'pervasive developmental disorder' (General Medical Council 2010).

Overall, deviance on the research team was normalized by an organizational structure that gave the senior investigator and first author Andrew Wakefield monopoly over knowledge production with the data of junior scientists without authorship omitted and the amendments of coauthors left unimplemented. Such a high level of authority for the first author without accountability mechanisms from the wider team allowed Wakefield's deviance to be normalized while the paper benefited from the expert authority of other coauthors. As one of the authors of the paper, junior pathologist Andrew Anthony noted: 'In 1996-1998, you needed very little involvement to be named as an author' (Deer 2020: 264). The authors of the paper had their academic status to consider and wanted an academic credit in a high-status journal to be submitted to the Research Assessment Exercise, a British competition for university funding. Signals of Wakefield's deviance were missed or went unnoticed due to the organizational culture of the research team.

2.5 Inordinate Focus on Novel Results in Academic Publishing

The evaluative culture at *The Lancet* prioritized novelty, allowing Wakefield's article to bypass scientific gatekeeping filters and circulate widely. Siler et al.'s (2015) research on the effectiveness of scientific gatekeeping found that manuscripts rejected by three leading medical journals (*The Lancet*, *The British Medical Journal*, and *The Annals of Internal Medicine*) which later received high citation counts elsewhere were most often rejected by these journals for lacking novelty. High-status generalist journals such as *The Lancet* strive for the novelty to accrue prestige from highly cited articles that are paradigm-shifting or cutting-edge. Replication science or normal science is perceived as the domain of other more specialist journals (Siler et al. 2015). Novelty in the natural sciences most often takes the form of substantive innovation, which confers a very high degree of status to both the associated researchers and the peer-reviewed journal that first publishes the results (Cole 1992). Researchers potentially become pioneers of a new subfield in their discipline and peer-reviewed journals obtain a place in a field's core, which would likely garner a high citation count, bolstering the journal's overall impact factor.

The Lancet is an elite world-class journal with a low acceptance rate of about 5% (Journal Guide 2014) and a tradition of taking a chance on novel research. Founded by 'rabble-rousing surgeon politician' Thomas Wakley in 1823, *The Lancet* has maintained its legacy of entertaining controversial propositions and prioritizing novelty in adjudications (Deer 2020: 24). The journal gained substantial prestige a decade prior to Wakefield's work for its publication of the breakthrough discovery that a bacterium—Helicobacter pylori (H. pylori) causes peptic ulcers. Here, *The Lancet* took a risk on two Australian scientists—Barry Marshall and Robin Warren (1984)—whose ideas were initially unpopular among the medical community but eventually earned a Nobel Prize in 2005 (Nobel Prize Outreach AB 2022).

At the time that Wakefield's infamous publication was under review, *The Lancet*'s editorial board consisted of a relatively new editor-in-chief Dr. Richard Horton who had worked at the Royal Free Hampstead in the 1980s, and a desk editor named John Bignall who journalist Brian Deer refers to as a 'waggish family doctor' (Deer 2020: 63) Bignall employed a strategy for manuscript selection known as ‘Bignall’s rule’ whereby it was determined that journal submissions discussed for over ten minutes had garnered sufficient interest for publication. Previously in his career, this approach conferred status to his scientific reputation for fast-tracking an influential case series that set the groundwork for the discovery of a new variant of the fatal Creutzfeldt-Jakob disease. Richard Horton (1998) concurred in *Lancet* correspondence that the publication of early work on Creutzfeldt-Jacob disease demonstrated the importance of disclosing new data rather than censoring it with good intention. First-time *Lancet* reviewer and pediatric gastroenterologist David Candy received the paper subsequent Bignall’s approval and, as the mentee of Wakefield’s coauthor Dr. John Walker-Smith, Candy remarked to investigative journalist Brian Deer that: ‘I knew, that anything by John would be well written and reliable’ (Deer 2020: 63).

Scientific work organizations are unique in 20th-century post-industrial society in that they have an explicit commitment to novelty (Whitley 1984). The ability to explore and play with novel ideas is essential to scientific creativity and progress. It is in the free expression of ideas and disinterested pursuit of truth that the intellect can flourish. Coser (1965) writes that even medieval court jesters are a historical predecessor to modern-day intellectuals because of their freedom to play none of the expected social roles as members outside of society’s social hierarchy. Contemporary peer-reviewed journals not only apply rigorous standards of scholarship but also serve as a truth spot (Gieryn 2018) where intellectual ideas can be freely explored and tested. Passing peer review entails an endorsement from a journal, as well as bestowing of the journal’s institutional prestige

(Siler 2015). Although pre-prints have become omnipresent, peer-reviewed papers nevertheless retain their status as more credible and are still strongly linked to the tenure, hiring, and promotion of professional reward structures in academia (Lamont 2009). Individual peer-reviewed publications; however, often do not function as a factual scientific consensus, but as a continuous process of criticism and inquiry (Horton 2003).

Free discussion and the pursuit of novel ideas are important to the social purpose of intellectual enterprise and the good of society (Whitley 1984). However, in the current media landscape where journal articles and their abstracts can easily be found by public audiences and circulated online, scientists carry a greater responsibility to promote truthful claims in their publications. Journals are rewarded for their successes but not as often reputationally penalized for their failures. After the publication, Richard Horton was criticized by many physicians who proposed that medical journals should avoid public controversies by confining difficult discussions to professional audiences. Openly rejecting these approaches, Horton has been a strong advocate of open democratic debate and embracing the challenges that come with a wider readership. Confining difficult discussions in the academic field, he argues, can lead to ‘secrecy, complacency, and error’ (Horton 2003). The pursuit of novelty is an integral feature of the scientific enterprise (Bourdieu 1975; Whitley 1984), but considering wider audiences for scientific work, academic journals have an added responsibility to consider the potential unintended consequences of publication for the public sphere.

2.6 Porous Boundaries between Science and the Press

Public health officials widely held journalism and the mass media responsible for generating unnecessary MMR fears in public audiences and the associated decline in vaccination (Anderson 1999; Horton 2004). Indeed, many journalists uncritically disseminated Wakefield's ideas or inaccurately portrayed a crossfire of experts (Deer 2020), but it was Wakefield's academic colleagues who facilitated early contact with the media by hosting a press conference a few days before the infamous *Lancet* publication (General Medical Council 2010). The institutions where Wakefield held his academic appointments—the Royal Free medical school and hospital—invited the press to report on the new findings, providing Wakefield with social capital and media attention largely inaccessible to the average academic (Deer 2020).

Dean of the medical school Arie Zuckerman approved and facilitated the press conference, and the Media Centre Committee—a media group shared between the hospital and the medical school—agreed that the findings on the changes in the bowels of children with autism were important to communicate (General Medical Council 2010). Although Zuckerman later regretted his decision, at the time, he hired a PR company and insisted that the findings should not be described as controversial to the media to not diminish the enthusiasm of reporters (Deer 2020). The Royal Free allowed for a press conference—an event traditionally reserved for breakthrough treatments or infectious disease outbreaks to take place, likely to attract status and publicity (Gieryn 1999). The medical school's company Freemedic stood to benefit from the proceeds of Wakefield's potential patent money and the press conference would boost public hype (Deer 2020). Universities have patented faculty inventions as a source of economic development over the last several decades (Berman 2008), and at the time of the press conference, the Royal Free was in a precarious financial position (Deer 2020).

Months of planning ensued, and the PR company was employed to exercise caution. In order to gauge public reaction and facilitate communication with reporters, extra landlines were installed, and mechanical answering machines were ordered. A twenty-one-minute video was ordered to maximize TV impact and finally, there was a rehearsal scheduled to ensure a smooth performance (Deer 2020). Arie Zuckerman assumed that he could command the media, focusing on the gastrointestinal changes reported in the publication. After all, the paper itself deemphasized any correlation stating: ‘We did not prove an association between measles, mumps, and rubella vaccine and the syndrome described’ (Wakefield et al. 1998).

At the press briefing, Wakefield made it seem like his ideas about vaccines and autism were a discovery made ‘here and now’ and a part of normal science (Gieryn 1999). Moore (2006) calls this ‘science by press conference’—a situation where scientists use the media to spread views that run contrary to the consensus of the scientific community. By blurring the traditional boundary between science and the mass media, Wakefield was able to avoid the cultural rules of normal science that require taking new discoveries back upstream for confidential assessment by scientific peers (Gieryn 1999). Access to the public at the press conference bypassed this step in the scientific process and gave Wakefield a platform to speak directly with public audiences. Coauthor of the paper Professor Salisbury stated that he had only officially become aware that Wakefield’s concerns regarding MMR vaccination extended into the area of safety at the press conference and in subsequent media coverage (General Medical Council 2010). Andrew Wakefield’s statements at the press conference shocked his colleagues as they were very different from what was written in the publication.

Wakefield also broke social norms between science and the press by releasing a video news release before the press briefing and having this video prepared not by the Medical School’s medical illustration unit as it usually would be, but by the hospital through a commercial company (Deer 2020). Professor Zuckerman attempted to stop the video from being released after watching it and realizing that it did not reflect the content of *The Lancet* paper, but because the video had gone out before the press briefing, it was too late. The captions and subheadings for the video were sent to Professor Zuckerman before the release, but a full script was never sent and the language that he reviewed was changed in the final video (General Medical Council 2010).

Weekly UK medical magazine *The Pulse* reported Wakefield as saying that his publication in *The Lancet* provided enough evidence for the health minister Tessa Jowell to conduct an independent review, which could substantially change vaccination policy (The Independent 1997; The General Medical Council 2010). The headline read: ‘Pressure on the government to order a full review of alleged links between MMR immunisation and a range of serious illnesses grew this week with the emergence of fresh research evidence.’ A second institution—the BBC had talent to showcase, a new science correspondent spoke for thirteen minutes on *Newsnight* about Wakefield's claims and the new research (Deer 2020: 35).

Press briefings prior to scientific publications are not common, but their frequency has increased as authors and institutions aim to attract publicity and funding. The decision to hold a press conference was not an amoral action but a mistake based on conformity to the university's organizational culture and reward system (Vaughan 1996). Media attention highlighting research achievements offers universities the opportunity to bolster their public reputations with prestige and funding. Interactions with the public have accelerated as social media platforms give scientists the ability for constant self-promotion. 'Science by Twitter' has become normalized and the risks of this direct communication without vetting from institutional gatekeepers may not be recognized by younger generations of scholars.

The Royal Free medical school was nearly bankrupt at the time of the press conference and its associated hospital was known for very little beyond its liver unit on account of an internationally recognized expert on liver disease, Dame Sheila Sherlock (Deer 2020). Richard Horton, who worked at the Royal Free hospital at the time of Wakefield's first publication in *The Lancet* in 1989 says the Royal Free's Academic Department of Medicine was 'largely moribund' at the time (Horton 2004: 22). At the opposite end of the tenth floor, he remarks that 'Wakefield brought a sudden sense of excitement to the department. He was young, charismatic, and ambitious. The department felt alive again' (Horton 2004: 22). At the time of the press conference, the Royal Free's already demoralized academic department had another hurdle to face: the Research Assessment Exercise (RAE).

The RAE, which has since been renamed the Research Excellence Framework (REF) is a national research competition in the UK that awards funds to institutions of higher education based on publications in high-impact journals (UK Research and Innovation 2022). Put in place during Margaret Thatcher's era in government—a time of severe cuts to public expenditure—the exercise aimed to act as a public accountability mechanism for research funding (Reboraet and Turri 2013). A shift from the previous funding model in which university funds were inherently provided by the state and only varying based on the number of students enrolled, the RAE embodied a new political economy of higher education and an institutional re-orientation towards neoliberal competition (Schulze-Cleven et al. 2017). Scholars criticize structures such as these in national higher education systems as varieties of academic capitalism (Schulze-Cleven et al. 2017; Reitz 2017; Jessop 2017). Institutions of higher education whose faculty fare less successfully in the RAE receive less funding and face a reduced capacity to fulfill their mission statements, leading to steep institutional inequality (Schulze-Cleven et al. 2017).

Requirements for the competition are four pieces of research published within the last six years to be submitted to the RAE. Publications in high-impact journals are the key measure of success and research excellence, the cornerstone of evaluation (Deer 2020). Peer-review panels ranked publications on originality, significance, and rigour, and in later years, the criteria expanded to include robustness, quality, excellence, and international status (Olssen 2016). Ratings of 1 and 2 were allocated no funding at all, and a rating of 5 was allocated four times as much funding as a rating of 3b (OECD 2002). The Royal Free Hampstead only received a 2 and 3 out of 5 in vital areas of assessment during the last RAE in 1996. As a low-status institution in the middle of an RAE, social actors faced incentives to ensure that Wakefield's publication in a top high-impact journal was visible and successful to outside audiences. Furthermore, the school was in the process of merging with a top school in the prestigious Russell Group—University College London (UCL)—and had to prove itself worthy despite all its status anxiety (Deer 2020). During the last assessment exercise, UCL was assessed with straight 5s in the vital areas where the Royal Free had scored poorly. Sociological research on status indicates that those in the middle of hierarchies are the most likely to conform to group norms because they simultaneously retain and are insecure about group membership and strive to demonstrate themselves as worthy of this membership through conformity (Phillips and Zuckerman 2001). The press conference presented an opportunity for the Royal Free to gain status in the RAE and improve its national ranking. Even if the findings were preliminary, in the incentive structure that Zuckerman found himself in, being published in a top journal was prized, and promotion would offer a potential leg-up in the funding competition for a struggling medical school.

With this lens, I argue that the MMR-autism controversy represents a case of the normalization of deviance. Sociologist Diane Vaughan (1996) coined this phrase to describe a phenomenon occurring within organizations whereby risks are socially accepted in pursuit of organizational goals. Although explicit rules were not violated by

Wakefield’s colleagues, signals of misinformation were missed that otherwise could have prevented the public health crisis that ensued. Integrity in science is generally governed by social norms which are more readily bent as opposed to laws (Goldenberg 2021).

The competitive institutional environment set in place by the RAE was key to the normalization of deviance on Wakefield’s research team and the Royal Free medical school. The UK’s Research Assessment Exercise not only rewarded high-impact journal publications but directly linked schools’ publication records to funding. With research funding for a struggling institution on the line (Deer 2020), it is easy to understand the institutional incentive for Wakefield’s colleagues to trust and promote his work. Wakefield’s publication in a high-impact elite general medical journal *The Lancet*—meant funding for both the medical school and the gastroenterology department (Deer 2020). Wakefield was dishonest and broke rules with a certain kind of charisma, but he would not have succeeded if collaborators, journals, and universities had not normalized deviant practices and cultures rooted in the competitive pressures and insular nature of academic science. Potential whistleblowers stayed silent likely due to the career pressures imposed by hypercompetitive cultures.

2.7 The Self-Referential Response from the Scientific Establishment

The scientific establishment was even less prepared for the aftermath of this damaging incident than they were equipped to prevent it from happening. This is because until recently most scientific publications barely garner public attention on their own and in order to combat potential sensationalism and virality of misinformation scientists must effectively engage with public audiences to communicate the scientific consensus. In the case of the MMR-autism controversy institutional mechanisms for reliable knowledge and a trustworthy scientific consensus were mostly shielded from the public view and confined to private conferences and the pages of academic journals. Prior to publication, reviewers of Wakefield's article in *The Lancet* had concerns about the findings' potential to impact public health, so several mechanisms were put in place to thwart any adverse outcomes. Ultimately, these efforts proved unsuccessful. There were three instances where institutional efforts in pursuit of scientific truth took place outside of the public's view and thus did not accomplish their goals in combating misinformation (Horton 2003).

The Lancet itself took efforts to indicate that these findings were preliminary, perhaps part of frontier knowledge—but certainly not part of a knowledge core or scientific consensus (Cole 1992). It signalled this by placing the article in the journal's 'Early Reports' section which aimed to promote innovation by allowing researchers to publish findings at an early stage before the factual accuracy of claims was solidified. *The*

Lancet has since removed its Early Reports section (Horton 2003). The article itself also included a statement reiterating that it was an early report and affirmed that there was no proof of causation for an association between MMR and autism (Wakefield et al. 1998).

A thoughtful and convincing critical commentary was published in the same journal issue alongside the preliminary study, seeking to contextualize the results with an independent assessment about the quality of the paper from external experts on measles eradication (General Medical Council 2010). The commentary was commissioned by Robert Chen and Frank DeStefano from the Vaccine Safety and Development Activity National Immunisation Program in Atlanta Georgia, two researchers who are independent of *The Lancet* and from an internationally recognized centre for public health—the Centers for Disease Control and Prevention (CDC). It asked readers to view the study critically and with an open mind, highlighting possible biases that were discussed during peer review (Chen and DeStefano 1998). These efforts were largely invisible to the broad public and garnered little media attention in comparison to Wakefield's promotion of his 'here and now' discovery.

In their critical commentary Robert Chen and Frank DeStefano (1998) pointed out that for an adverse event to a vaccine to be identified as such, causation must be established. Causation can be established in two ways: the vaccine must be associated either with a specific laboratory observation or clinical syndrome or, an epidemiological study must conclude that the rate of a given syndrome in vaccinated individuals exceeds the rate in an unvaccinated control group. Biological plausibility, reproducibility, and strength and specificity of association should also be evaluated when determining causation (Chen and DeStefano 1998).

Based on Hill's (1965) criteria of causation they argued that the strength of Wakefield's association was diminished when considering the wider context of the findings. Since the 1960s hundreds of millions of people have received the MMR vaccine without developing chronic bowel or behavioural issues, and autism spectrum disorders were recognized before the MMR vaccine was available. Additionally, the diagnosis of ileal lymphoid hyperplasia is non-specific. In terms of reproducibility, they pointed out that Wakefield's detection of the measles virus in patients with inflammatory bowel disease (IBD) had not been replicated by other researchers (Chen and DeStefano 1998).

The commentary also outlined several biases in the paper. First, the report refers to a group interested in studying the relationship between MMR and Inflammatory Bowel Disease (IBD) rather than a population-based study, which may have exaggerated the purported association due to biased case ascertainment. Second, there is a temporal association: children receive the first dose of MMR when they are two years of age, around the same time that symptoms of autism begin to manifest. Inevitably and temporally then, some cases of autism will begin after MMR vaccination. Furthermore, there is also a significant risk of parental recall bias, as it is difficult to pinpoint the onset of autism (Chen and DeStefano 1998).

Following the publication, it took two weeks for the Department of Health to send out a message reassuring general practitioners about the MMR vaccine's safety (Horton 1998). Replication studies that failed to confirm Wakefield's work (Taylor et al. 1999;

Kaye et al. 2001; Madsen et al. 2002). were largely invisible to public audiences and did not receive the viral media attention garnered by his initial ‘findings.’ The UK Medical Research Council panel held a seminar to evaluate published and unpublished evidence on the association between the MMR vaccine and autism. At the seminar 37 experts in epidemiology, immunology, pediatrics, gastroenterology, virology, child psychiatry, and autism concluded that there was not an evidential basis to substantiate the association proposed, officially locating Wakefield’s theory outside the realm of credible science. The UK Committee for the Safety of Medicines also conducted a review of the medical records of 92 autistic children with parents legally claiming MMR damage and did not find a relationship (Deer 2020). These academic responses discredited Wakefield’s ideas in the scientific community but did not gain the wide publicity and cultural resonance of Wakefield’s initial shocking statement. These efforts occurred behind closed doors and academic scientists were ultimately preaching to the choir, while Wakefield was directly engaging with parents of autistic children and listening to their concerns (Larson 2020).

After the Royal Free had merged with the University College London (UCL) in 1999 the new head of medicine at Hampstead Mark Pepys, gave Wakefield two choices: he could either take a paid leave of absence for a year to work on his new biotech business (Carmel Healthcare) or he could use University College London (UCL) funding to replicate his findings and could then get the patents for the tests, vaccines, and products he intended to sell through Carmel Healthcare. Chris Llewellyn Smith, UCL’s provost and president, reiterated this offer and wrote Wakefield pleading with him to stop making public statements until he published the results of the proposed gold-standard study: ‘We urge you not to prematurely publish observations that you may have or be making in this field. Good scientific practice now demands that you and others seek to confirm or refute, reliably and above all reproducibly, the possible causal relationships between MMR vaccination and autism/ 'autistic enterocolitis'/ inflammatory bowel disease that you have postulated' (Deer 2020:144).

Wakefield responded by refusing to conduct the gold-standard study, an essential process for scientific truth, arguing that this would infringe on his academic freedom. He wrote to the provost and president Llewllyn-Smith saying: 'It is the unanimous decision of my collaborators and coworkers that it is only appropriate that *we* define our research objectives, we enact the studies as appropriately reviewed and approved, and we decide when we deem the work suitable for submission for peer review' (Deer 2020:144). This is a further example of how the institution of the modern research university created contradictions that made it difficult to control actors like Wakefield in the interests of public health. Most social scientists, humanities scholars, and many scientists would indeed resist centralized control of their choice of research methods and design in the name of academic freedom. Despite this, things like randomized control trials and declaration of conflicts of interest have become normative over time, at least in certain academic communities. In Wakefield's case, the refusal to conduct a gold-standard study was a manipulative tactic to avoid replicating his work, but the broader culture of the university provided him with a discursive tactic to resist accountability according to existing medical standards.

Furthermore, the settlement agreement reached for Wakefield’s resignation from the Royal Free in 2001 prohibited the medical school from speaking out on the reason for his departure—his refusal to conduct a gold-standard replication test of his MMR-autism hypothesis (Deer 2020). This was key in the failure to quell misinformation. The tensions between lawyers and legal liability prevented the university from fully speaking up and defending the justification for their decision, adding to public distrust.

Two months later Wakefield denied the request that he stop making public statements and appeared on the CBS network’s *60 minutes* program: his biggest chance yet for publicity (Nelson and Bradley 2000). Here, Wakefield again was able to gain some control of the narrative, framing the administration’s request for his resignation as an issue with the content of his ideas, rather than a lack of scientific rigour: ‘I have been asked to go because my research results are unpopular’ he remarked on public television (Deer 2020:166). Five weeks after this event Wakefield’s mutual Termination of Employment began and a settlement agreement was reached in 2001 that gave him a payoff of £109 625, ownership of his patents for tests, treatments, and vaccines, and a reference from the school (Deer 2020). In essence, the university handcuffed itself in the communication battle against Wakefield, by agreeing to legal constraints and legal liability that prevented them from discussing his refusal to conduct a gold-standard replication test.

2.8 The Unintended Consequences of Competitive Scientific Reward Systems

A key analytic piece of this story comes from the sociology of science and higher education literature which examines the competitive and stratified system of the modern research university (Merton 1973; Whitley 1984; Zuckerman 1970). Bureaucratization and the quantification of evaluation inherent to contemporary scientific competitions orient research for publication in peer review and generate incentives for novel findings (Espeland and Stevens 2008; Power 1997; Whitley 1984). This encourages universities and departments to take more strategic approaches to research but constrains excessive concern with public dialogue as scientific researchers are incentivized to prefer the internal channels of peer review (Burawoy 2005). Institutions of higher education striving for international prestige in this competitive environment focus their public engagement efforts on formal public relations units concerned with protecting the university's reputation, rather than the scientific issues being debated.

Sociological theories on stratification and status hierarchies in academic settings focus on intellectual reward structures (Merton 1973; Siler and McLaughlin 2008; Whitley 1984) and processes of decision-making in peer review (Cole 1992; Lamont 2009, 2012). Functionalist accounts (Collins 1971; Merton 1973) assume that scientific status competitions foster academic excellence by recruiting the best talent for scientific work and bolstering research productivity. This is the manifest function of competition and stratification within and between academic institutions that produce research and rank students for the labour market. American Ivy League universities such as Harvard, Princeton, and Yale, as world-class institutions, set the benchmark for academic excellence globally (Bourdieu 1988; Merton 1973).

As competition intensifies with the expansion of higher education and scarce economic resources, the global ranking of universities and academic peer-reviewed journals has become central to the market for symbolic goods. Quantitative measures of performance have rapidly diffused across academia (Espeland and Stevens 2008; Power 1997) with publications in high-impact journals dominating evaluation systems, ultimately serving as cultural capital that is converted into economic capital for individual scholars and their associated institutions (Bourdieu 1988). Publication in high-impact journals is a marker of legitimacy and prestige and a gatekeeper to economic rewards (Lamont 2009, 2012).

Institutional contradictions exist, however, due to the unintended consequences of this scientific reward structure. Competition for institutional prestige contradicts Merton's (1973) norm of disinterestedness when career pressures compromise the pursuit of truth. The 1998 MMR-autism controversy was a rare opportunity to closely examine under what circumstances bad scientific ideas can slip through the cracks of scientific evaluation systems and be promoted. The Research Assessment Exercise (RAE), although increasing research productivity at UK institutions and centralizing audiences so contributions can become more prestigious internationally, has the unintended consequence of cumulative advantage for high-ranking departments and cumulative disadvantage for provincial medical schools whose scholarly activities are left vulnerable due to limited staff recruitment and funding (Ball 1997; Merton 1988).

Robert Merton (1988) refers to this phenomenon as the 'Matthew Effect.' Since its inception, the RAE has awarded a small proportion of schools—the older established research-intensive universities such as the Russell group most of the funding (Ball 1997). Lower-ranking institutions such as the Royal Free are left in vulnerable positions, and economic strains and production pressures generate incentives to publish at the expense of research quality. When a department's survival relies on this funding, it is easy to consider how this would impact decision-making. Scientists may even choose to engage in superficial or fraudulent research practices in order to increase citation counts and gain funding (Schulze-Cleven et al. 2017).

Beyond this specific case, there is evidence of these trends with the phenomenon known as the 'replication crisis' in science (a phrase coined in the early 2010s) whereby some scholars report that an increasing portion of scientific experimental results fails to achieve confirmation in replication studies (Baker 2016; Gelman and Loken 2013; Ioannidis 2005a, 2005b; Open Science Collaboration 2015; Schooler 2014). Publication bias and selection bias have been identified as the major causes of irreproducibility (Antonakis 2017). Publication bias describes the overwhelming tendency of scientific journals to publish statistically significant findings. Statistically significant results are more likely to be published than null results (Antonakis 2017; Dickersin et al. 1987; Dickersin 2005; Fanelli 2012) and with the desperation to 'publish or perish' academic researchers may be motivated to unethically manipulate their models with p-hacking, data dredging, and researcher degrees of freedom to produce erroneously significant results (Gelman and Loken 2013).

Nissen et al. (2016) warn that these issues could lead to the ‘canonization of false facts.’ Predatory journals (Siler 2020) exploit this culture and contribute to the circulation of misinformation under the guise of science. Some peer-reviewed journals attempt to mitigate publication bias by requiring that submissions for publication be pre-registered prior to data collection with organizations such as the Center for Open Science. In 2004 many prestigious medical journals including *The Lancet*, *The New England Journal of Medicine*, *JAMA*, and *The Annals of Internal Medicine* made it a prerequisite for research funded by pharmaceutical companies to be pre-registered in a public clinical trials registry database. These efforts enhance the transparency and validity of the research. Diagnosis of a replication crisis and proposed remedies that reorient cultures and reward structures; however, is still contentious in many scientific disciplines.

Furthermore, the institutional logic of the university (Friedland and Alford 1991) whereby evaluation processes are internal and opaque, and communications with outside audiences often go unrewarded, makes accurate knowledge diffusion extremely challenging and correcting any knowledge errors almost nonviable. The lack of institutional wherewithal for facilitating interactions with the public sphere prevents the scientific consensus from fully achieving its democratic function (Goldenberg 2021; Wynne 2006). Burawoy (2005) notes that professional knowledge has its pathological form when it regresses toward self-referentiality, essentially becoming an echo chamber. We see this to some extent within academic knowledge production especially in cases when it ineffectively interacts with public audiences. Academics may be able to evaluate and discern the credibility of the stratification of knowledge in peer-reviewed journals, but impact factors, methodological flaws and other factors of credibility are largely invisible and meaningless to public audiences. The MMR-autism controversy exemplifies the sort of faddishness that characterizes public knowledge and how media institutions can amplify these failures. Burawoy (2005) is right that all forms of knowledge including professional and public forms of science must be held mutually accountable to prevent the development of pathologies.

2.9 Conclusion

While the notoriety of the Wakefield incident has ensured that it has received an abundant amount of both scholarly and media attention, an insufficient amount of attention has been paid to the specific organizational culture that informed the behavior and decision-making of those around Wakefield who enabled him and legitimized his ideas. As I have attempted to show in this paper, Wakefield's colleagues and the broader medical establishment that supported his work were not corrupt, incompetent, misguided, or evil. They were simply scientists operating and doing their jobs within an organizational context that goes further in explaining their actions than any personal motives they may or may not have had.

In her now classic study of organizational decision-making at NASA, Diane Vaughan (1996) offers a sociological interpretation of the mistakes that lead to the 1986 *Challenger* disaster, a fatal accident whereby a NASA space shuttle exploded 73 seconds after liftoff. Contradicting conventional interpretations of the incident that attribute NASA's decision-making to production pressures and managerial wrongdoing, Vaughan (1996) finds that the organizational culture at NASA had normalized technical deviation for many years before the Challenger launch. Despite concerns voiced by some engineers, signals of deviance were systematically missed at the organizational level in pursuit of organizational goals, and a series of seemingly benign decisions incrementally led to catastrophe.

This paper shows how signals of deviance were systematically missed by scientific colleagues not only at the level of academic publishing but during the research process and post-publication as well. The MMR-autism controversy was not only about Wakefield or other bad or careless actors in the system of science but about contradictions in the scientific enterprise itself that undermine public trust. Diane Vaughan (1996)'s concept of the 'normalization of deviance' precisely captures this phenomenon as risks were socially accepted in pursuit of organizational goals. Like the Challenger launch decision, scientists who worked together on the infamous *Lancet* paper developed patterns that led them to overlook the consequences of their actions.

Although the university system held Wakefield accountable, reaching a resignation settlement agreement with him in 2001 and officially retracting his article from *The Lancet* in 2010, it also initially circulated his ideas. Academic institutions published his ideas and held press conferences to promote them. Elite medical journal *The Lancet* accepted Wakefield's work for publication, and the Royal Free medical school and hospital chose to attract publicity to his findings with a press briefing. These were not mistakes that violated organizational rules but rather mistake based on conformity to the culture of production in these respective organizations.

I offer four considerations: (1) Competent and honest collaborators took on a secondary position in the knowledge hierarchy relative to the first author and were motivated by career pressures and missed signals of deviance to achieve a high-status publication. (2) An academic journal took on novel findings with the risk that they are flawed, in the hopes that they would cultivate creativity, garner citation counts, and lead to advancements in medicine. (3) A medical school promoted research their faculty published in a high-status journal to attract prestige and funding to their institution. (4) Expert core knowledge and the scientific consensus were communicated via channels largely invisible to the public and internal to the university—behind closed doors, and with only brief statements to the media. None of these actions were mistakes, were rooted in dishonesty, or involved the breaking of formal rules; normal science contributed to the Wakefield incident.

This framework highlights how deviance was normalized in the organizational cultures of three important facets of knowledge production: the research team, academic publishing, and university-press relations. My analysis goes beyond traditional interpretations of individual misconduct and responsibility focusing on how internal university decisions at the Royal Free generated contradictions within the scientific enterprise and contributed to the diffusion of the 1998 MMR-autism hypothesis. Actors outside the scientific enterprise bear the brunt of responsibility for the spread of vaccine misinformation; however, it is important for scholars committed to combating vaccine hesitancy to also turn a critical eye inwards to address the unintended consequences of systems within scientific institutions. Beyond potentially fuelling misinformation, unintended consequences risk diminishing public trust and undermining the credibility of science as a knowledge-producing enterprise.

Furthermore, the examination of this case as a negative outcome of professional competition for status contributes to the scholarly literature's emphasis on positive outcomes. By examining a case of unintended consequences, this research contributes to an emerging literature that applies reflexive scrutiny to scientific institutions (Goldenberg 2021; Wynne 2006). Academic competition structures, although generally positive for knowledge production—fostering innovation and ambitious intellectual standards—are relatively new modes of organization that should continuously be examined in terms of their influence on the greater good. The MMR-autism controversy presents a unique empirical glimpse into intense academic competition and how the system can unintentionally generate incentives for bad ideas, ultimately undermining public trust.

These findings have broader implications for science communication. The current media landscape makes accurate knowledge production more important than ever, especially as the information environment on social media facilitates dissensus and bespoke pseudo-realities (DiResta 2019). Science by press conference has become ubiquitous in the absence of the traditional gatekeepers for scientific work, and research enters the public sphere through a multitude of direct media intermediaries. Academic journal articles available with a quick Google search can be cherry-picked to fit pre-existing narratives, without attention to the quality or robustness of the data. Once misinformation circulates it is nearly impossible to put the genie back in the bottle and explanations of methodological flaws are not easily communicated to public audiences. These challenges in science-media relations have been highlighted during the COVID-19 pandemic with the circulation of scientific studies on candidate therapeutics hydroxychloroquine and ivermectin. To reduce the impact of misinformation and more importantly to foster public trust, future research should examine the organization of academic cultures and the social relations between internal scientific processes and the publics they exist to serve.

2.10 References

Anderson, P (1999) Another media scare about MMR vaccine hits Britain. *British Medical Journal*. 318 (7198): 1578.

Antonakis, J (2017) On doing better science: from thrill of discovery to policy implications. *The Leadership Quarterly*. 28(1): 5-21.

Baker, M (2016) 1,500 scientists lift the lid on reproducibility. *Nature* 533: 452–454.

Ball, DF (1997) Quality Measurement as a Basis for Resource Allocation: Research assessment exercises in United Kingdom universities. *R&D Management* 27(3), 281–289.

Bedford, H, Booy, R, Dunn, D, Guiseppi, C, Gibb, D, Gilbert, R, Logan, S, Peckham, C, Roberts, I, Tookey, P. (1998) Autism, inflammatory bowel disease, and MMR vaccine. *The Lancet*. 351(9106): 907.

Berman, PE (2008) Why did universities start patenting?: Institution-building and the road to the Bayh-Dole Act. *Social Studies of Science*. 38(6):835-871.

Bourdieu, P (1975) The specificity of the scientific field and the social conditions of the progress of reason. *Social Science Information.* 14(6): 19-47.

Bourdieu, P (1988) *Homo Academicus*. Stanford: Stanford University Press.

Braun, V and Clarke, V (2022) *Thematic Analysis: A practical guide.* London: SAGE Publications.

Brown KF, Long SJ, Ramsay M, Hudson MJ, Green J, Vincent CA, Kroll JS, Fraser G, Sevdalis N. (2012) U.K. parents' decision-making about measles-mumps-rubella (MMR) vaccine 10 years after the MMR-autism controversy: a qualitative analysis. *Vaccine*. 30(10):1855-64.

Burawoy, M (2005) For public sociology. *American Sociological Review* 70(1): 4-28.

Chen, RT and DeStefano, F (1998) Vaccine adverse events: Causal or coincidental? *The Lancet* 351(9103): 611-12.

Clarke, CE (2008) A question of balance: The autism-vaccine controversy in the British and American elite press. *Science Communication* 30(1): 77-107.

Cole, S (1992) *Making Science: Between Nature and Society.* Cambridge & London: Harvard University Press.

Collins, R (2000) *The Sociology of Philosophies: A Global Theory of Intellectual Change*. Cambridge & London: Belknap Press of Harvard University Press.

Collins, H. (2014) *Are We All Experts Now?* Amherst, NY: Prometheus Books.

Collins, H. and Evans, R (2002) The third wave of science studies: Studies of expertise and experience. *Social Studies of Science* 32(2): 235-96.

Collins, H and Evans, R (2007) *Rethinking Expertise*. Chicago: University of Chicago Press.

Collins, H and Weinel, M (2017) STS as science or politics? *Social Studies of Science* 47(4): 580-86.

Coser, L (1997) *Men of Ideas: A Sociologist's View.* NY: The Free Press. (Original work published 1965).

Decoteau, CL and Underman, K (2015) Adjudicating non-knowledge in the Omnibus Autism Proceedings *Social Studies of Science* 45(4): 471–500.

Deer, B (2004) Revealed: MMR research scandal." *Sunday Times*, February 22, 2004. Available at: http://www.thetimes.co.uk/tto/health/article1879347.ece (accessed 6 April 2021).

Deer, B (2011a) Secrets of the MMR scare: How the case against the MMR vaccine was fixed. *British Medical Journal* 342:c5347.

Deer, B (2011b) Secrets of the MMR scare: How the vaccine crisis was meant to make money. *British Medical Journal* 342:c5258

Deer, B (2011c) Secrets of the MMR scare: The *Lancet's* two days to bury bad news. *British Medical Journal* 342: c7001.

Deer, B (2020) *The Doctor Who Fooled the World: Science, Deception, and the War on Vaccines*. Baltimore: John Hopkins University Press.

DeStefano, F. and Shimabukuro, TT (2019) The MMR Vaccine and Autism. *Annual Review of Virology* 6(1):585-600.

DeStefano F, Shimabukuro TT. The MMR Vaccine and Autism. Annu Rev Virol. 2019 Sep 29;6(1):585-600. doi: 10.1146/annurev-virology-092818-015515. Epub 2019 Apr 15. PMID: 30986133; PMCID: PMC6768751.

Dickersin, K, Chan, S, Chalmers, TC, Sacks, HS, Smith, H Jr (1987) Publication bias and clinical trials *Controlled Clinical Trials*. 8(4): 343–353.

Dickersin, K (2005) Publication bias: Recognizing the problem, understanding its origins and scope, and preventing harm. In: Rothstein, H, Sutton A, Borenstein, M (eds)

Publication Bias in Meta-Analysis: Prevention, Assessment and Adjustments Chichester: Wiley, pp. 9-33.

DiResta, R (2019) Mediating Consent. Available at: https://www.ribbonfarm.com/2019/12/17/mediating-consent/ (accessed 10 October 2021)

Dixon, GN, and Clarke, CE (2013) Heightening uncertainty around certain science: Media coverage, false balance, and the autism-vaccine controversy. *Science Communication*. 35(3): 358-382.

Dominus, S (2011) The Crash and Burn of an Autism Guru. *The New York Times*, 21 April, 2011, Available at: https://www.nytimes.com/2011/04/24/magazine/mag-24Autism-t.html (accessed 5 December 2021).

Dyer, C (2010) Lancet retracts Wakefield's MMR paper. *British Medical Journal* 340: c696.

Espeland, WN and Sauder, M (2007) Rankings and reactivity: How public measures recreate social worlds. *American Journal of Sociology*, 113(1): 1–40.

Espeland, W and Stevens, M (2008) A sociology of quantification. *European Journal of Sociology* 49:401-36.

Evans, M, Stoddart, H, Condon, L, Freeman, E, Grizzell, M, and Mullen, R (2001) Parents' perspectives on the MMR immunisation: A focus group study. *British Journal of General Practice*. 51(472): 904-10.

Fanelli, D (2012) Negative results are disappearing from most disciplines and countries. *Scientometrics* 90: 891-904.

Farrell, MP (2003) *Collaborative Circles: Friendship Dynamics and Creative Work.* Chicago: University of Chicago Press.

Friedland, R and Alford, R (1991) Bringing Society Back In: Symbols, Practices, and Institutional Contradictions. In: Paul DiMaggio and Walter Powell (eds) *The New Institutionalism in Organizational Analysis*. Chicago: University of Chicago Press.

Gelman, A. and Loken, E (2013) The garden of forking paths: Why multiple comparisons can be a problem, even when there is no "fishing expedition" or "p-hacking" and the research hypothesis was posited ahead of time. *Department of Statistics, Columbia University*. Available at: http://www.stat.columbia.edu/~gelman/research/unpublished/p_hacking.pdf (accessed 9 October 2022).

General Medical Council (2010) Fitness to Practise Hearing, 28 January 2010, Andrew Wakefield, John Walker-Smith, and Simon Murch. Available at: http://wakefieldgmctranscripts.blogspot.com/ (accessed 7 January 2021).

George, A and Bennett, A (2005) *Case Studies and Theory Development in the Social Sciences*. Cambridge: MIT Press.

Gieryn, T (1999) *Cultural Boundaries of Science: Credibility on the Line*. Chicago: University of Chicago Press.

Gieryn, T (2018). *Truth-Spots: How Places Make People Believe*. Chicago: University of Chicago Press.

Goldenberg, M (2021) *Vaccine Hesitancy: Public Trust, Expertise, and the War on Science.* Pittsburgh: University of Pittsburgh Press.

Hill, AB (1965) The environment and disease: Association or causation? *Proceedings of the Royal Society of Medicine.* 58(5): 295–300.

Horton, R (1998) Autism, inflammatory bowel disease, and MMR vaccine. *The Lancet* 351(9106): 908-909.

Horton, R (2003) *Second Opinion: Doctors, Diseases and Decisions in Modern Medicine*. London: Granta Books.

Horton, R (2004) *MMR: Science and Fiction: Exploring the Vaccine Crisis*. London: Granta.

Ioannidis, JPA (2005a) Why most published research findings are false. *PLOS Medicine.* 2(8): e124.

Ioannidis JPA. (2005b) Contradicted and initially stronger effects in highly cited clinical research. *JAMA.* 294(2):218-228.

Jessop, B (2017) Varieties of academic capitalism and entrepreneurial universities. *Higher Education* 73: 853-870.

Kirkland, A (2012) Credibility battles in the autism litigation. *Social Studies of Science* 42(2): 237-261.

Lamont, M (2012) Toward a comparative sociology of valuation and evaluation. *Annual Review of Sociology* 38: 201–221.

Largent, MA (2012) *Vaccine: The Debate in Modern America*. Baltimore: John Hopkins University Press.

Lee, JW, Melgaard, B, Clements CJ, Kane, M, Mulholland, EK, Olivé, J-M (1998) Autism, inflammatory bowel disease, and MMR vaccine. *The Lancet* 351(9106): 905.

Madsen KM, Hviid A, Vestergaard M, Schendel D, Wohlfahrt J, Thorsen P, Olsen J, Melbye M (2002) A population-based study of measles, mumps, and rubella vaccination and autism. *New England Journal of Medicine* 347(19):1477-82.

Marshall, BJ, and Warren JR (1984) Unidentified curved bacilli in the stomach of patients with gastritis and peptic ulceration. *The Lancet*. 1(8390):1311-5.

McLaughlin, N (2005) Canada's impossible science: Historical and institutional origins of the coming crisis in Anglo-Canadian sociology. *Canadian Journal of Sociology* 30 (1):1-40.

Merton, R (1942) 1973. The normative structure of science. In: Robert K. Merton (ed) *The Sociology of Science: The Theoretical and Empirical Investigations*. Chicago: University of Chicago Press, pp. 267-78.

Merton, R (1968) The Matthew effect in science: The reward and communication systems of science are considered. *Science* 159(3810): 56-63.

Moore, A (2006) Bad science in the headlines. Who takes responsibility when science is distorted in the mass media? *EMBO reports 7*(12): 1193–1196.

Nelson, T. (Producer), and Bradley, E. (Director) (2000) The MMR vaccine. New York: Columbia Broadcasting System. Available at: https://search.alexanderstreet.com/preview/work/bibliographic_entity%7Cvideo_work%7C2775028 (Accessed 3 September 2022).

Nissen, Silas, Tali Magidson, Kevin Gross, and Carl Bergstrom (2016) Research: Publication bias and the canonization of false facts. *eLife.* e21451.

OECD (2002) Changing government policies for public research: From financing basic research to governing the science system In: *OECD Science, Technology and Innovation Outlook 2002*. Paris: OECD Publishing, pp.157-177.

Olssen, M (2016) Neoliberal competition in higher education today: research, accountability and impact. *British Journal of Sociology of Education* 37(1): 129–148.

Open Science Collaboration (2015) Estimating the reproducibility of psychological science. *Science*. 349(6251):aac4716.

Oreskes, N and Conway, E (2010) *Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Climate Change*. New York: Bloomsbury Publishing Inc.

Phillips, D and Zuckerman, E (2001) Middle-Status Conformity: Theoretical Restatement and Empirical Demonstration in Two Markets *American Journal of Sociology* 107(2): 379–429.

Power, M (1997) *The Audit Society: Rituals of Verification.* Oxford: Oxford University Press.

Reitz, T (2017) Academic hierarchies in neo-feudal capitalism: How status competition processes trust and facilitates the appropriation of knowledge. *Higher Education* 73: 871-886.

Saguy, A and Almeling, R (2008) Fat in the Fire? Science, the News Media, and the Obesity Epidemic. *Sociological Forum* 23(1): 53-83.

Schooler, JW (2014) Metascience could rescue the replication crisis. *Nature*. 515 (7525): 9.

Schulze-Cleven, T, Reitz, T, Maesse, J, and Angermuller, J (2017) The new political economy of higher education: between distributional conflicts and discursive stratification. *Higher Education* 73(6):795–812.

Shwed, U and Bearman, PS (2010) The Temporal Structure of Scientific Consensus Formation. *American Sociological Review* 75(6): 817-840.

Siler, K and McLaughlin, N (2008) The Canada Research Chairs Program and social science reward structures. *Canadian Review of Sociology* 45(1):93 – 119.

Siler, K, Lee, K and Bero, L (2015) Measuring the effectiveness of scientific gatekeeping. *Proceedings of the National Academy of Sciences* 112(2): 360-365.

Siler, K (2020) Demarcating spectrums of predatory publishing: Economic and institutional sources of academic legitimacy. *Journal of the Association for Information Science and Technology* 71(11): 1386-1401.

Smith, N (2017) Why Statistical Significance Is Often Insignificant. *Bloomberg*. Available at: https://www.bloomberg.com/opinion/articles/2017-11-02/why-statistical-significance-is-often-insignificant (accessed 4 August 2021).

Smith, A, Yarwood, J, and Salisbury, D (2007) Tracking Mother's Attitudes to MMR immunisation 1996-2006. *Vaccine* 25(20): 3996-4002.

Tan, CD (2021) Defending ‘snake oil’: The preservation of contentious knowledge and practices. *Social Studies of Science*. 51(4):538-563.

Torracinta L, Tanner R, Vanderslott S (2021) MMR Vaccine Attitude and Uptake Research in the United Kingdom: A Critical Review. *Vaccines (Basel)* 9(4): 402.

UK Health Security Agency (2021) Confirmed cases of measles, mumps and rubella in England and Wales: 1996 to 2020. Available at: https://www.gov.uk/government/publications/measles-confirmed-cases/confirmed-cases-of-measles-mumps-and-rubella-in-england-and-wales-2012-to-2013 (accessed 15 December 2021).

Vaughan, D (1996) *The Challenger Launch Decision*. Chicago: University of Chicago Press.

Wakefield, A (2010) *Callous Disregard: Autism and Vaccines—The Truth Behind a Tragedy*. New York: Skyhorse.

Wakefield, AJ, Ekbom, A, Dhillon, AP, Pittilo, RM, Pounder, RE (1995) Crohn's disease: Pathogenesis and persistent measles virus infection *Gastroenterology* 108 (3): 911-916.

Wakefield, AJ, Murch, SH, Anthony, A, Linnell, J, Casson, DM, Malik, M, Berelowitz, M, Dhillon, AP, Thompson, MA, Harvey, P, Valentine, A, Davies, SE and Walker-Smith, JA (1998) Ileal-Lymphoid -Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children.” *The Lancet* 351(9103): 637-41.

Wakefield AJ, Pittilo RM, Sim R, Cosby SL, Stephenson JR, Dhillon AP, Pounder RE (1993) Evidence of persistent measles virus infection in Crohn's disease. *Journal of Medical Virology* 39(4): 345-353.

Whitley, R (1984) *The Social and Intellectual Organization of the Sciences.* Oxford: Oxford University Press.

World Health Organization (2019) Ten threats to global health in 2019. Available at: https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019 (accessed 11 February 2021).

Will, RG, Ironside, JW, Zeidler, M, Estibeiro, K, Cousens, SN, Smith, PG, Alperovitch, A, Poser, S, Pocchiari, M, Hofman, A (1996) A new variant of Creutzfeldt-Jakob disease in the UK, *The Lancet*, 347(9006): 921-925.

Wynne, B (2006) Public engagement as a means of restoring public trust in science--hitting the notes, but missing the music? *Community Genetics* 9(3): 211-20.

Zuckerman, H. (1970) Stratification in American Science. *Sociological Inquiry* 40(2): 235-257.

Chapter 3

Anti-Scientific Intellectual Movements Outside the University: The Case of the Anti-Vaccine Movement

Abstract

Research on intellectual scientific/intellectual movements to-date finds that in order to maintain prominence ideas must fit with existing cultural and institutional systems (Lamont 1987; McLaughlin 1998, 1998; Frickel and Gross 2005). This approach works well for understanding traditional scholarly movements but very little attention in the sociological literature has been paid to intellectual movements located outside the university (Coser 1965) and intellectual movements that are ‘anti-scientific.’ This article will consider the anti-vaccine movement as an anti-scientific intellectual movement that attacks the very academic, political, and economic authorities that provided the institutional basis for more traditional scientific intellectual movements. In contrast to accounts that depict anti-vaccine ideas as simply irrational and unscientific, this article understands their emergence as an intellectual movement situated in parental grievances against the medical establishment, opportunity structures, micromobilization contexts, and frame alignment strategies that successfully propagated its ideas into cultural products, the natural health movement, and health freedom and populist movements. This case will help us move beyond research agendas on ideas that are socially embedded in the resources and networks of established organizations (Merton 1949; Crane 1972; Cole & Cole 1973; Whitley 1984; Frickel and Gross 2005) and move towards a more holistic understanding of how science interacts with its various publics in a “post-truth” age.

3.1 Introduction

The origin of the modern anti-vaccine movement according to historian Mark Largent (2012) is the 1998 MMR-autism controversy ignited by discredited medical doctor Andrew Wakefield who publicized fraudulent claims that the MMR vaccine causes autism. Although there had previously been public fears over vaccine safety risks such as the pertussis scare in the UK in the 1970s, the 1998 MMR-autism controversy was markedly different because it occurred in a social context that provided fertile ground for this piece of misinformation to gain traction globally, sparking a social movement (Larson 2020). Editor-in-chief of *The Lancet* Richard Horton (2006) wrote in the *Guardian* that Wakefield's 1998 publication 'fueled a smouldering underground movement against the [MMR] vaccine' and physician and infectious disease expert Dr. Peter Hotez (2021) has written that it 'ushered in a new era of distrust for vaccines.' Unlike the anti-vaccine movement against compulsory smallpox vaccination in the eighteenth and nineteenth centuries, the modern anti-vaccine movement has proliferated into several distinctive socio-cultural contexts (Larson 2020).

Popular, scholarly, and public health accounts have often framed the anti-vaccine movement as a debate over the facts, rather than as an organized social movement embedded in social values (Editors 2015; Jacobson et al 2007; Poland and Jacobson 2001; Kata 2012). Wholly irrational and unscientific, 'anti-vaccine' ideas are factually debunked one by one and relegated to the margins instead of contended with in a serious way. The 'war on science' approach has portrayed vaccine hesitancy as public ignorance, cognitive bias, and wilful rejection of scientific expertise (Goldenberg 2021). For example, scholarly work has identified 'a taxonomy of reasoning flaws in the anti-vaccine movement' (Jacobson et al 2007) and a 2002 World Health Organization (WHO) editorial authored by scientists from the Department of Vaccines and Biologics refers to the British publics as 'misled and confused' (Clements and Ratzan 2002). Media reports have similarly presented vaccine-hesitant publics as irrational and possessing cognitive biases (Goldenberg and McCron 2017). For example, the *Conversation* reported that 'The

Science Is Clear: Anti-Vaxxers Are Immune to Truth' (Editors 2015) and a headline in *Time Magazine* stated, 'Nothing Not Even Hard Facts, Can Make Anti-Vaxxers Change Their Minds!" (Alter 2014).

These approaches and perspectives that focus on debunking facts miss important aspects of political organizing and the wider cultural reception context that contributed to the spread of 'anti-vaccine' ideas. Instead of dismissing ideas that are outside the realm of science, this research emphasizes how misinformation about vaccines signals important group dynamics and public sentiments (Larson 2020). I will examine the phenomenon of vaccine hesitancy as a social movement using concepts from Frickel and Gross' (2005) general theory of scientific intellectual movements. Scientific intellectual movements (SIMs) mobilize to challenge dominant intellectual understandings and successful SIMs are defined by collective grievances, opportunity structures, micromobilization contexts, and frame resonance strategies.

The emergence of the anti-vaccine movement represents a SIM in that at the beginning of the movement mothers of autistic children developed grievances with the medical system leading them to mobilize a social movement, recruit followers, and form their own understanding of vaccine science. The following paper takes a contextual approach investigating the emergence and proliferation of the anti-vaccine movement as a unique blend of (1) parents challenging the medical establishment on autism, (2) cultural workers repackaging and mobilizing ideas in self-help books, articles, and documentaries, (3) frame resonance with the natural health movement as an intellectual movement challenging the medical establishment, and (4) frame alignment with health freedom and populist political movements.

3.2 Personal Grievances: Parents of Autistic Children

Grievances

The modern anti-vaccine movement was spurred in the 1990s in part by grievances from a group of parents who felt unheard by the medical establishment. Parents, particularly mothers of autistic children began organizing in autism grassroots and advocacy organizations. Despite being mostly non-experts outside of the university they were dissatisfied with the agenda and priorities in autism research and had a common set of experiences that motivated their opposition to the scientific consensus on vaccination.

The experiences shared within the autism community were a lack of dignity, that their voices were being left unheard by medical professionals and scientific elites insensitive to public needs and concerns. This was a major driver of vaccine dissent early in the movement. Historically, autistic children and their parents have been an underserved patient community. Even today, mothers report not feeling respected and having their questions about vaccination dismissed by medical professionals (Dube et al 2015; Kirby 2006; Navin 2015). When the term ‘autism’ was coined in 1943 by the founder of U.S. child psychiatry Dr. Leo Kanner, it was believed that parents, particularly mothers, were to blame for their children’s abnormal behavior. The Refrigerator Mother

Theory held that autism was caused by a lack of maternal warmth, from children being reared in “emotional refrigerators” (Vicedo 2021).

As the deinstitutionalization and normalization movements in child psychiatry took place in the 1970s and mother-blaming theories were discredited, parents of children with autism became crucial actors in establishing a network of expertise to study modern autism science (Eyal 2013). Parents used their unique position as gatekeepers to knowledge about their children’s behaviour to dismantle Dr. Leo Kanner’s established network of clinical expertise which had devalued their knowledge and stigmatized them as parents. Instead of aligning themselves with child psychiatry, parents chose to collaborate with psychologists, a group of experts who had less power and authority than psychiatrists but cooperated with parents to produce therapies that merged expert and lay knowledge. Since the most valuable data for autism diagnoses came from parents, Kanner lost his monopoly over autism research and therapy and credibility with regards to expertise was reapportioned (Eyal 2013). Dr. Bernard Rimland—a pioneer in our modern understanding of autism, and one of the first doctors to discredit the Refrigerator Mother Theory—championed dignity and respect for parents turning his focus to environmental causes of autism. As a parent of an autistic child himself, Rimland demonstrated compassion and understanding, while revolutionizing the field of autism science. His first book *Infantile Autism* published in 1964 changed long-standing attitudes about autism and provided parents with guidance on understanding and treating autistic children.

Rimland founded the Autism Research Institute (ARI) in 1967 to support research, and educational resources for parents. In 1995 ARI launched Defeat Autism Now!

(DAN!), a controversial program that formed collaborations with medical professionals who were willing to abandon mainstream medicine’s approach to autism and with the 1998 MMR-autism controversy, advocated for vaccines as a cause of autism. The organization had always aimed to be more than a traditional advocacy organization: they had intellectual goals and wanted to shape the direction and scope of biomedical research on autism spectrum disorders by conceiving of planning, and funding projects on their own. Medical outsiders had become more trusted than medical insiders due to past grievances with the medical establishment parent-blaming and failing to listen to parents. Silverman (2012:180) argues that “from its inception Defeat Autism Now! (DAN!) had its own fully developed ontology of autism.” Political advocacy was also important but played a secondary role to the advocacy of intellectual projects and ideas.

In the years prior to the MMR-autism controversy the intellectual groundwork had been laid for alternative approaches to autism outside of the institutional mainstream in parent-led advocacy organizations. Although the Refrigerator Mother Theory had been completely discredited by present-day psychiatry in the 1990s, financial and political commitments to autism research and services for autistic children remained severely lacking. Too few provisions existed in schools and other institutions to support children with autism and deliver services (Mnookin 2011). Richard Horton, editor-in-chief of leading general medical journal the *Lancet* has argued that in the UK—where the MMR-autism controversy originated—the approach to autism research was ‘destined to fail’ (Horton 2004). The UK’s Institute of Child Health 2004 report which represents the National Autistic Society and Parents Autism Campaign for Education found that research on families and services was given extremely low priority in terms of funding, research, and even apparent interest. Furthermore, there was a lack of wider oversight synthesizing the field of autism research in order to raise awareness of findings in the research community.

Resistance and a lack of commitment to long-term funding of autism research in the UK and US in the 1990s led parents to develop their own grassroots initiatives to participate in shaping biomedical research. In 1994 Eric and Karen London, a psychiatrist and corporate attorney living in Princeton, New Jersey with their autistic son, became so frustrated with the lack of resources available to them that they along with a few other parents launched the National Alliance for Autism Research (NAAR), the first U.S. non-profit supporting research into causes and treatments for autism (Mnookin 2011: 137). Notably, this does not indicate ignorance of science but rather a desire to participate and have research goals and priorities listened to. NAAR recognized the limited funding for autism research and raised over $20 million—more than any other non-governmental organization—to support biomedical research grants, programs, and fellowships. The next year in 1995 Hollywood producer Jonathan Shestack and his wife television art director Portia Iverson started their own non-profit called Cure Autism Now (CAN).

Before his controversial 1998 publication in the *Lancet* that sparked the MMR-autism controversy, Andrew Wakefield secured supporters for his ideas by connecting with members of Justice Awareness and Basic Support (JABS), a British parent-led lobby and advocacy group for children with autism. Formed in 1994 as a response to marginalization by the medical establishment, JABS was established to set its own research priorities and has a history of advocacy work suing pharmaceutical companies that make the MMR vaccine. It has also facilitated several online surveys collecting data on parent experiences. Wakefield spoke directly to parent researchers at JABS who claimed to have identified symptoms in children that they believed pointed to a novel syndrome linking bowel disorders with autism as a result of vaccine-injury (Trowther 2002). This challenged the traditional notion of autism as per the International Statistical Classification of Diseases and Related Problems (ICD) criteria used by mainstream experts. Wakefield adopted this new intellectual theory and diagnosis in his subsequent work, calling it 'autistic enterocolitis'.

Parent-researchers had emerged, and the MMR-autism controversy was diffused by parents who felt their concerns weren't addressed by the mainstream medical community and engaged in their own collective efforts to pursue a research program. Frickel and Gross's (2005) theory posits that the innovations that trigger SIMs start from the top. However, in the case of the anti-vaccine movement intellectual innovations began from the bottom-up with a group of parents searching for leadership in someone who would take their concerns seriously and validate their experiences. Scientific pioneer in the field of autism research psychiatrist Dr. Bernard Rimland even supported Andrew Wakefield's ideas about MMR and autism as part of biomedical approaches to autism that ended the persecution of parents. Rimland's DAN! Protocol was similarly based on a biomedical model focusing on environmental factors and toxins but was discontinued in 2011 as Andrew Wakefield was officially discredited with the loss of his medical license in 2010 and the tide had changed towards autism research focusing on genetic factors.

Structural Resources

Social movements are more likely to succeed when structural conditions provide access to key resources such as employment for participants, organizational resources, and intellectual prestige. Social movement scholars refer to organizational resources that are vehicles for collective action as ‘mobilizing structures.’ These are highly correlated with SIM success as they allow for communication and coordination. Frickel and Gross (2005) specify the mobilizing structures that SIMs rely on: departments, communications networks, and scholarly organizations. In scientific and intellectual arenas co-presence at university departments is important for localized information sharing and access to administrative personnel. Institutionalized channels of information flow through publications, informal and institutional networks.

The anti-vaccine movement did not have access to mainstream institutional resources, nor did it offer intellectual prestige—quite the opposite movement members were often stigmatized and branded anti-science quacks. Andrew Wakefield was able to use his newfound fame and identity as a martyr; however, and credibility as anti-establishment doctor, to mobilize resources from benefactors in the United States. Wealthy parents of autistic children privately funded Wakefield’s activities, viewing his exile from the medical community as evidence of his integrity. Furthermore, the proliferation of online academic journals provided structural resources for communication that offered the impression of prestige to unknowing publics even if the journals were known to be illegitimate, low-quality, or predatory by the mainstream scientific community.

Wakefield met his first benefactor lawyer Elizabeth Birth at a conference in Chicago called Cure Autism Now where he offered to help her son autistic son Matthew. It was arranged for Matthew to be scoped at the Royal Free Hampstead Malcom Ward, and just three weeks later Birt incorporated a foundation: 'Medical Interventions for Autism.' Elizabeth Birt also connected Wakefield with a job as research director of The International Child Development Resource Centre in central Florida—a multimillion dollar program in America. The centre advocated for alternative research and treatments for autism and was founded by physician and father of an autistic boy, James Jeffrey Bradstreet. Wakefield garnered support from parents to help Elizabeth Birt fund a clinic and even proposed a hub for a "virtual university' (Mnookin 2011).

A second major benefactor for was real estate agent Troylyn Ball who helped Wakefield get installed as executive director of the Thoughtful House Center for Children in 2004, an organization named after a tiny stone cottage on her property. The original Thoughtful House was a retreat for her son Marshall on their seven-acre ranch. Both of Ball's sons Marshall and Colton had developmental orders. 'It just seemed like; you know what? Here's a smart doctor who *knows*, who's got a *vision*.' Ball said years later, 'I couldn't solve the problem, but I could pull together a bunch of people who could try to solve the problem' (Deer 2020: 227). The older son, Marshall, was somewhat of a celebrity and had appeared on *Oprah* as an author and spiritual guide. 'Although he never spoke, and was severely challenged, it was said he relayed messages from God. With his right elbow cupped by a relative or family friend, it was reported that he channelled divinely inspired poetry by erratically stabbing letters on a board.'

Eventually, the Thoughtful House had a dozen staff consisting of two or three medical doctors leading a schedule of sessions, a therapist, a nutritionist, researchers and administrators. ‘Although Wakefield wasn’t licensed to practice medicine, his employment package—mostly funded through the first benefactor Elizabeth Birt—would top out at nearly twice that of a typical family doctor’s. The Thoughtful House’s Board of directors from its first calendar year in 2004 according to Mnookin (2011) included a prominent executive from Dell Financial Services LLC, a former Major League Baseball player, a movie producer, a retired major general, and a singer with the Dixie Chicks band (Mnookin 2011).

A third benefactor was Jane Johnson, a 38-year-old supermodel and Manhattan socialite whose family had once controlled Johnson & Johnson, the pharmaceuticals and healthcare empire. According to accounts kept by Birt, Jane Johnson’s personal foundation gave Wakefield over $1 million dollars in one year alone. Jane Johnson had a son with developmental issues whose privacy she fiercely guarded. She had met Wakefield three years earlier at a conference run by the Autism Research Institute based in San Diego, California.

Philanthropist Claire Dwoskin has been a fourth substantial donor supporting the anti-vaccine movement with funding for research through her organization the Children’s Medical Safety Research Institute (CMSRI). This organization that was created by the Dwoskin Family Foundation, aims to fill gaps in scientific knowledge by contributing to a body of research critical of vaccine safety (CMSRI 2017). In contrast to the epidemiological emphasis of government-funded research, CMSRI focuses on ‘bench science' to examine the physiological and microbiological processes that could be impacted by vaccination. This research paradigm allows these researchers to test naturalist hypotheses and propose naturalist theories, which have mostly focused on aluminum adjuvants in vaccines as a neurotoxin.

Micromobilization Contexts

Micromobilization contexts are spaces where members of a social movement recruit new individuals. Frickel and Gross' third tenet asserts that 'the greater a SIM's access to various micromobilization contexts, the more likely it is to be successful' (Frickel and Gross 2005: 219). At local sites, recruitment representatives of social movements and potential recruits can come into sustained contact with one another. In the modern university, as depicted by Frickel and Gross (2005) the prime micromobilization contexts for SIMs are academic departments or laboratories where mentorship and training take place. The information ecosystem today, however, has been inundated with misinformation and disinformation movements on the internet that challenge this traditional recruitment process of new members in intellectual settings. Social media has dramatically transformed how people are recruited to intellectual social movements, allowing space for members with marginal but vocal views to successfully propagate their perspectives and recruit new members.

Like the micromobilization and recruitment processes described in Frickel and Gross's (2005) SIM theory, the anti-vaccine movement created strong ties among a loyal cadre of followers with sustained in-person contact and recruited new members at conferences. At first, the MMR-autism hypothesis was discussed among parents in the

Justice Awareness Basic Support (JABS) organization who had sustained contact with one another. However, as the movement continued it was increasingly present online. Emerging initially from non-expert audiences in the margins, the 1998 MMR-autism theory first mobilized to the mainstream via an unlikely press conference where now discredited scientist Andrew Wakefield used access to the legacy media to bypass traditional scientific norms for achieving official consensus. Centrally located as a professor and researcher with ideas published in a high-status mainstream general medical journal—*The Lancet*—Andrew Wakefield equipped the burgeoning anti-vaccine movement with access to mainstream media attention to mobilize their views.

Strong ties and dedicated support from members of the JABS organization bolstered Wakefield's public reputation by emphasizing his devotion to the underserved patient community of autistic children (Deer 2020; Goldenberg 2021). This loyal following along with attention from mainstream media outlets during the MMR-autism controversy formed a geographically distant but organized community. Many new members connected online and then organized annual conferences where they could exchange ideas, network, and recruit new members. These conferences provided space for like-minded but geographically separated thinkers to discuss goals while fostering group identity and bonding. In essence, it formed an invisible college (Crane 1972) consisting of non-expert and marginal expert participants that shared ideas and mobilized for funding.

Micromobilization at autism conferences allowed members of the anti-vaccine movement to connect with powerful actors, eventually gaining a celebrity spokesperson and an ally in congress. It was at conferences where Andrew Wakefield connected with parents who would become benefactors and private donors for his ideas. Wakefield met his first benefactor lawyer Elizabeth Birth at a conference in Chicago called Cure Autism Now, and another doner Jane Johnson at a conference run by the Autism Research Institute based in San Diego (Deer 2020; Mnookin 2011). The AutismOne conference is another central conference for micromobilization that began in 2003 and continues to have its annual meetings today, attracting speakers such as Robert F. Kennedy Jr. (Autism One 2013). After Andrew Wakefield was exiled from his academic institution, the Royal Free medical school and hospital he was able to recruit supporters at autism conferences and act in a leadership role as a keynote speaker at these events. Networking in the tight-knit autism community allowed him to make some very influential contacts in the United States such as the private donors mentioned in the previous section and celebrities.

Wakefield's first mainstream political ally from conferences and online networking was Republican congressman Dan Burton. After vaccine safety concerns had shifted from the MMR-autism controversy to the use of the preservative thimerosal in vaccines—a form of mercury, new micromobilization contexts occurred in the United States. Thimerosal used in some vaccines (ethylmercury) and mercury in the environment (methylmercury) are different compounds and processed by the body differently, with ethylmercury being processed and excreted much more quickly, explaining why research does not find evidence of harm from the use of thimerosal as a preservative. The Centers for Disease Control and Prevention (CDC) and American Academy of Pediatrics (AAP) issued a joint statement in July 1999 committing to reducing or eliminating thimerosal from vaccines as a precautionary measure, despite a lack of evidence for doing so (CDC

1999). Although experts hoped that this decision would increase public trust in vaccination, on the contrary, it led some parents to believe that thimerosal was indeed a cause of autism.

In response to this statement a new parent-led group—Mercury Moms—was founded in 1999 by three geographically distant mothers: Redwood, Sallie Bernard and Liz Birt who started an online mailing list for mercury and autism where parents compared notes about their children’s development and mercury (Mnookin 2011). These online connections formed a community and a movement. The group eventually recruited Danielle Sarkine, mother of an autistic son named Christian, and the daughter of Republican Indiana congressman Dan Burton. Danielle Sarkine encouraged her father to hold congressional hearings focusing on thimerosal in vaccines. Although the hearings did not result in any specific legislation, they served as another powerful micromobilization context for the movement.

As Chairman of the House Committee on Government Reform, Burton became an important ally for Andrew Wakefield when he moved to the United States. At the first hearing held in 2000 parents of children with autism shared stories of their children’s behavioural regression following their MMR vaccination, and Burton discussed his grandson’s experience with autism. Wakefield was the first of a series of testimonies asserting the biological plausibility that the MMR vaccine causes autism (House Committee on Government Reform 107th Congress, 2000). Wakefield’s testimony was reported by American and International media, leading many American parents to decide against giving their children the MMR vaccine. Burton promoted autism awareness and was critical of the use of thimerosal in vaccines at the hearings ultimately aiming for an FDA investigation into the MMR vaccine and a recall of vaccines containing the preservative thimerosal. His daughter Danielle Burton-Sarkine believes vaccines caused her son’s autism and filed a lawsuit against drug companies (Mnookin 2011).

3.3 Cultural Workers: Books, Documentaries, and Celebrities

The diffusion of ideas in the anti-vaccine movement was also developed as a literary movement, with cultural products in the market for symbolic goods and intellectual ideas being published in books, documentaries, and in some cases lower-ranked academic journals. After parents of autistic children had mobilized their collective illness experiences to advocate against the consensus on vaccine science and to access resources from private donors, these views were diffused in a variety of micromobilization contexts.

In 2000 parents of autistic children Bernard, Birt, Enayati, and Redwood founded the Coalition for Sensible Action for Ending Mercury-Induced Neurological Disorders or SafeMinds, with one of its first explicit goals being to publicize research that Enayati and the others had been conducting (Mnookin 2011). Bernard, a Harvard-educated marketing consultant, was adamant that the best way for the group to disseminate its message was to get its work published in a medical journal. In order to be taken seriously, she proposed that they package their claims in academic language and use scientific jargon (Mnookin 2011).

That summer, the leaders of SafeMinds completed “Autism: A Novel Form of Mercury Poisoning” —a review of the medical literature and US government data that successfully mirrored the esoteric style unique to academia (Bernard et al. 2001). Although the team of parents was unable to convince a mainstream scientific academic journal to publish their work, that did not mean that the paper would not be published. In December 2000 it was accepted by *Medical Hypotheses*—a journal that rejects the academic system of peer review, a process it says, ‘can oblige authors to distort their true views to satisfy referees.’ In the Aims and Scope section, the journal emphasizes that it has no desire to ‘predict whether ideas and facts are ‘true’’—in fact, it would print “even probably untrue papers’ if they generated discussion (Mnookin 2011). ‘Autism: a Novel Form of Mercury Poisoning’ was published in April 2001 (Bernard et al. 2001). In this instance, members of the anti-vaccine movement were able to use alternative intellectual channels for their ideas to give the impression of legitimacy, communicate ideas, and recruit new members. They were able to access communication networks and channels from what would be considered by mainstream science to be illegitimate journals.

The Children’s Medical Safety Research Institute (CMSRI) was officially established in 2013 and has funded research and has been published (and sometimes retracted) in a few mainstream peer-reviewed journals, as well as in predatory journals with much less legitimacy (Inbar et al. 2016; Tomljenovic and Shaw 2012; . The second generation of autism advocates invoked after Wakefield’s MMR-autism theory used the

Internet to access cutting-edge research. Before this, the only worthy repository of scientific research papers available to the public was a collection of medical literature maintained by the National Institutes of Health's (NIH) National Library of Medicine. Services providers America Online and search engines like Alta Vista allowed information and databases that were previously restricted to be available for wide circulation online for free (Mnookin 2011).

These naturalist accounts of the autism epidemic, treating the rise in autism spectrum disorders towards the end of the 20th century as a real increase in the number of cases rather than reflecting a change in diagnostic criteria as proposed by the scientific consensus, made their way to the U.S. federal courts in 2002 with the Omnibus Autism Proceedings (*Various Petitioners v. Secretary of Health and Human Services*, 2002). The Vaccine Injury Compensation Fund established these proceedings to evaluate the five thousand cases that had been submitted claiming that vaccines caused autism (Decoteau and Underman 2015). Three main theories were examined: The SafeMinds theory that thimerosal could cause autism, the Wakefield hypothesis that the MMR vaccine could cause autism, and a composite theory that thimerosal and the MMR vaccine collectively caused autism were analyzed for plausibility. Ultimately these intellectual theories were evaluated as lacking the evidentiary basis necessary for injury compensation.

Despite failing to garner institutional legitimation, the anti-vaccine movement's ideas diffused into mainstream and popular audiences with the mass market for self-help parenting books and celebrity culture. The movement's highest profile celebrity supporter was actress, model, and media personality Jenny McCarthy. McCarthy announced that her son Evan had been diagnosed with autism in 2005 and published two books reflecting on her experience in 2007 *Louder than Words: A Mother's Journey in Healing Autism* and in 2008 *Mother Warriors: A Nation of Parents Healing Autism Against All Odds*. McCarthy's activism and support for Wakefield's MMR-autism theory pushed vaccine skepticism into the mainstream and with highly visible appearances on *The Oprah Winfrey Show* and CNN's *Larry King Live* that reached millions of viewers, further legitimizing a movement with a reputation as being on the scientific fringe.

On *The Oprah Winfrey Show* in a 2007 episode titled 'Mothers Battle Autism' McCarthy legitimized Andrew Wakefield's ideas and the MMR-autism theory as she told the story of her son Evan's autism diagnosis and recounted her personal journey challenging the scientific consensus on both vaccines and autism. Prior to Evan's official diagnosis McCarthy recalls that doctors repeatedly dismissed her pleas for help, at times even doing so with anger and condescension. When Evan finally received his diagnosis of autism McCarthy says she wasn't offered any help or specific support for the next steps. In this episode, McCarthy states that in the process of this medical journey she came to trust other parents more than anyone, granting epistemic authority to parents and empowering mothers who know their children best, and encouraging them to trust their 'mommy instinct.' Oprah praised McCarthy for standing up to authority and honouring her faith in herself. In 2008 she appeared on CNN's *Larry King Live* ('Jenny McCarthy's Autism Fight') and *Good Morning America* reaching millions of viewers. She wrote the foreword to Wakefield's 2010 book *Callous Disregard: Autism and Vaccines—The Truth*

Behind a Tragedy which defended Wakefield's reputation and criticized the medical establishment.

McCarthy's online and TV activism eventually led to on the ground activism and micromobilization contexts. In 2008 McCarthy led the 'Green Our Vaccines' rally in Washington D.C. with then partner Jim Carrey and a keynote address by Robert F. Kennedy Jr. which aimed to remove 'toxins' from vaccines. She now is the president of the non-profit organization Generation Rescue. With celebrity status and financial support these micromobilization contexts overshadowed scientific communication. Conferences and rallies were micromobilization contexts that allowed for co-presence and social cohesion in conjunction with the movement's online recruitment. Jenny McCarthy's celebrity status allowed her to use the media to bypass traditional scientific gatekeepers and participate in public conversations about the vaccine debate using the media to make a run-around normal political process.

Two other self-help parenting books appeared in popular bookstores in 2007 and 2016 written by medical doctors critical of the recommended immunization schedule. *The Vaccine Book: Making the Right Decision for Your Child* by Dr. Bob Sears and *The Vaccine-Friendly Plan: Dr. Paul's Safe and Effective Approach to Immunity* by Dr. Paul Thomas and science journalist Jennifer Margulis. Dr. Bob Sears practices pediatric medicine in Capistrano Beach, Dana Point, California and considers vaccine decision-making to be the childcare question of the decade. In his book he describes himself as a pro-information doctor, framing vaccine knowledge disputes as requiring open and honest conversations between doctors and their publics. Temporal constraints at routine medical visits often do not allow pediatricians to thoroughly discuss the risks, benefits, and ingredients of individual vaccines—and so Dr. Sears provides a comprehensive guide that parents can use to make an informed decision regarding vaccination. At the end of the book, he caters to families who are uncomfortable with the recommended immunization schedule by offering two alternative immunization schedules that delay certain vaccines and eliminate others. In this way, he distinguishes himself from pediatricians who discharge families from their medical practices for refusing vaccines (Sears 2007).

Dr. Sears argues that patients who refuse vaccines desire information and are especially in need of support from their pediatricians. In his view, parents today no longer consider vaccination to be an automatic part of childhood as they have more access to information about vaccines and have become more active in their children's healthcare. Sears points to evidence on both sides of the vaccine debate and offers his approach as a balanced perspective that refrains from telling parents what to do (Sears 2007). Critics argue this is a false balance that fails to distinguish between research that is accepted by the scientific community from research that is not, and further does not evaluate the quality of this research based on the scientific virtues of internal consistency and reproducibility (Offit 2009).

Dr. Paul Thomas author of *The Vaccine-Friendly Plan: Dr. Paul's Safe and Effective Approach to Immunity* practices medicine at his clinic Integrative Pediatrics in Portland, Oregon. In his book he depicts vaccines as an overused medical intervention. Employing terminology coined by Dr. Bob Sears, he describes himself as a "vaccine-friendly doctor"—meaning that he does not discharge patients who refuse vaccines and recognizes the importance of delaying some vaccines. Although breaking with the standard of care in the medical profession is difficult, Dr. Sears notes that he has vaccine-friendly colleagues across the country who quietly and successfully deliver individualized care to patients. Patient-centred care is the cornerstone of his practice, which emphasizes that parents are the best people to make health decisions for their children—not doctors or public health officials, or the government (Thomas and Margulis 2016).

The book recounts the shift in Dr. Paul Thomas' views regarding vaccination. Initially administering vaccines as directed by the Centers for Disease Control and Prevention (CDC), in the late 1990s to the early 21st century during his time at the Emanuel Children's Hospital in Portland Oregon he observed a marked increase in chronic diseases and conditions. The children Thomas encountered were not as healthy as he expected, which he attributes to compromised immune systems. The marked increase of conditions he saw were chronic food allergies, attention deficit disorders, childhood anxiety, childhood asthma, childhood depression, eczema, and gastroesophageal reflux (Thomas and Margulis 2016).

Beyond the book market, the anti-vaccine movement mobilized around a 2016 documentary film directed by Andrew Wakefield *Vaxxed: from Cover-up to Catastrophe*. The *Vaxxed* Campaign travelled around the United States in a tour bus promoting the film and recruiting new members to the movement in real-time (Mnookin 2011). The conspiratorial film alleges a CDC cover-up of data which shows a link between vaccines and autism. The idea for the film began in the U.K. when Wakefield connected with Polly Tommey, the parent of a child with developmental issues who combined for-profit businesses with charity ventures. She had launched the Autism Media Channel, a media enterprise, and made a career from campaigning. Together, they collaborated with a television producer Del BigTree who had previously produced the American medical advice show *The Doctors*.

A *Washington Post* investigation in 2019 revealed that resources for the documentary were acquired from New York millionaires Bernard (a wealthy hedge fund millionaire) and Lisa Selz. Wakefield, Tommey, and Bigtree had been given three million dollars including two hundred thousand for Wakefield to sue the *British Medical Journal* and investigative journalist Brian Deer. Eventually, Wakefield got himself introduced to actor Grace Hightower—wife of A-list celebrity Robert De Niro. De Niro brought celebrity support and publicity. In the next six months, *Vaxxed:from Cover-Up to Catastrophe* reportedly grossed more than $1.1 million. The film was screened at nearly one hundred locations some weeks, and employing a theatre-on-demand service, the app Gathr, booked multiplex screens when enough tickets were reserved with some audiences amounting to six hundred attendees (Mnookin 2011).

3.4 The Natural Health Movement

The anti-vaccine movement has come to encompass a coalition of movements outside the university that challenge establishment science including the natural health movement, the health freedom movement, and the MAGA movement. The movement has been particularly successful at frame alignment strategies that connect diverse audiences, catering their messages to the concerns of specific and diverse group identities. According to Frickel and Gross (2005: 221), ‘The success of a SIM is contingent upon the work done by movement participants to frame movement ideas in ways that resonate with the concerns of those who inhabit an intellectual field or fields.’ Snow et al.’s (2000) frame alignment strategies—frame amplification, frame extension, and frame translation—will be used to understand how the anti-vaccine movement employed rhetoric to gain followers.

Successful frame alignment strategies allowed the general sentiment behind Wakefield’s 1998 MMR-autism theory to continue to resonate with the natural health community, even after the factual details of the theory had largely faded from public memory (Attwell et al. 2018; Bleser et al. 2016; Bryden et al. 2018). Although tenets of the original theory were not factually in any direct or obvious alignment with central tenets of the natural health movement such as holism or mind-body dualism (Largent 2012), adherents of the anti-vaccine movement nevertheless were able to successfully extend the boundaries of this interpretive frame to encompass the interests and points of view of potential adherents. Parents of children with autism shared negative experiences with medicalization and paternalism in mainstream biomedicine that resonated with the natural health movement.

Research shows that anti-vaccine views are highly correlated with the use of alternative and complementary medicine (CAM) (Attwell et al. 2018; Bleser et al. 2016; Browne et al. 2015; Bryden et al. 2018; PEW 2017). The California Homeopathic Medical Society and the California Chiropractic Association were both politically active in opposing Senate Bill SB277, which eliminated nonmedical exemptions from school immunization law. This may be unsurprising considering that by definition, alternative medical sects run contrary to the dominant scientific wisdom of the day, but the significance of this frame resonance runs deeper. Attwell et al (2018) conducted in-depth interviews with vaccine-hesitant parents in Australia and found that values of personal agency and a ‘do-it yourself’ ethic resonated with CAM use and that participants rejected vaccines as toxic and ‘unnatural.’

The natural health movement along with the feminist movement denounces the paternalistic therapeutic relationship in biomedical healthcare (Kaptchuk and Eisenberg 2001) and the two groups’ values once again coalesced around MMR-autism concerns. Conis’ (2015) examination of vaccine hesitancy in the United States locates its historical roots in the women’s health movement, and Facebook analyses find that most participants on anti-vaccine pages are female (Smith et al. 2019). Women have historically been ignored and patronized in biomedical healthcare. Today despite significant improvements and patriarchal and paternalistic norms largely subsiding, women continue to report having their concerns downplayed or dismissed by healthcare professionals (Pagan 2018; Fetters 2018). Wakefield first mobilized supporters by listening to the grievances of mothers, who despite being the primary healthcare decision-makers for their children were treated paternalistically in therapeutic relationships with doctors. Experiences of medical gaslighting and ‘testimonial injustice’ whereby the credibility of certain social identities is discounted in the diagnosis of symptoms (Carel and Kidd 2014; Carel 2016, chapter 8; Narruhn and Clark 2020) has led to gender disparities (Fenton 2016a; 2016b; Pelletier et al. 2014; Stamp 2018) and ultimately distrust in science.

From the natural health movement anti-vaccine ideas were able to pivot from concerns about the ingredients in vaccines to environmentalist frames and find consecration from prominent environmental lawyer and nephew of former U.S. president John F. Kennedy—Robert F. Kennedy Jr. The preservative thimerosal in vaccines, a variation of the compound mercury concerned Kennedy who had founded the non-profit environmental group Waterkeeper Alliance in 1999 and was committed to advocacy work protecting the Hudson River and other waterways from contamination. Kennedy founded the World Mercury Project in 2016, now called the Children's Health Defense, to help children suffering from conditions due to exposure to chemicals and radiation. In an unexpected political alliance, he even met with former president Donald Trump in 2017 to discuss the possibility of a Vaccine Safety Taskforce, which ultimately did not come to fruition. The toxicology frame was a successful frame translation for environmentalists. Robert F. Kennedy Jr. continues to be one of the most avid supporters of the anti-vaccine movement. The World Mercury Project was identified as one of two major purchasers of 54 percent of anti-vaccine Facebook ads in late 2018 and early 2019, and since the COVID-19 pandemic, his Instagram followers grew from 121 000 to 454 000 (Jamison et al. 2019).

3.5 Political Movements: Health Freedom and Populism

New frame alignment and frame translation strategies in the anti-vaccine movement occurred in 2015 with California Senate Bill 277 which removed nonmedical exemptions from school immunization law (SB, 277, Pan. Public health: vaccinations). Initially, the content shared on Twitter during Senate Bill 277 under #sb277 focused on themes already prominent in the anti-vaccine network cluster such as autism, mercury, and toxins. However, a shift took place when Twitter users in the anti-vaccine cluster who had previously been active in using hashtag activism to promote a conspiracy theory under the hashtag #cdcwhistleblower in 2014, began to include #sb277 in their tweets (DiResta et al. 2015). The conspiracy alleged a deliberate cover-up of CDC data demonstrating that vaccines cause autism and was documented in the film *Vaxxed: from Cover-up to Catastrophe.* Although these activists had primarily focused on conspiracy and hidden data, the frame of health freedom was particularly effective amidst Bill 277.

After the legislative committee vote to eliminate philosophical exemptions, network graphs show the emergence of a new subset within the anti-vaccine online community researchers referenced as ‘vaccine choice Twitter’ (DiResta et al. 2015). Prior to this rhetorical shift, the social conservative network cluster had minimal overlap with the anti-vaccine cluster. The formation of this digital space located between ‘Anti-Vaccine Twitter’ and ‘Conservative Twitter’ signalled a new political strategy from the anti-vaccine movement. Using this hashtag and employing the rhetoric of medical freedom and health choice, anti-vaccine networks were able to expand and overlap with other clusters and larger central networks (DiResta 2021).

The anti-vaccine cluster leveraged a subnetwork of intensely interested Twitter users from the previous #cdcwhistleblower campaign to gain higher centrality in online networks. The Twitter hashtag had a relatively small reach when it began promoting the conspiracy theory but gained a loyal and active following. Retweets from highly visible figures such as soon-to-be presidential candidate at the time Donald Trump and actor Robert Schneider amplified the message reaching the public at large. Twitter analyses reveal that from August 18th, 2014, to December 2014 there were a total 250 000 tweets containing the #cdcwhistleblower hashtag (DiResta and Garcia Camargo 2020). Although this may seem insubstantial considering the millions of tweets that occur within hours during national conversations and massive events, this group of consistent and loyal followers successfully recruited new members to the movement and propagated their ideas to mainstream Twitter networks in 2015 with the introduction of California Senate Bill 277.

Micromobilization strategies to recruit new members to the movement and address current events with SB-277 was part of a concerted effort by organizers who aimed to improve the Search Engine Optimization (SEO) of the movement's websites. Over 150 instructional Trends and Tips (TaTips) videos were published on YouTube to advance their message with Twitter hashtags. Recruitment not only involved the Twitter hashtag #sb277 but also phone, email, and fax campaigns coordinated by the Canary Party and the National Vaccine Information Center (NVIC). This activist organizing along with the rhetoric of health freedom appealing to libertarian sentiments in conservative circles propagated ideas from the more marginal anti-vaccine cluster to core Twitter networks (DiResta 2015).

The COVID-19 pandemic significantly expanded micromobilization contexts for ideas in the anti-vaccine cluster to the QAnon and MAGA online communities. Social media network analyses of the 2020 COVID-19 conspiratorial film *Plandemic: The Hidden Agenda Behind COVID-19* found that recommendation engines facilitated information overlap between the anti-vaccine and QAnon communities and that the QAnon network served as a conduit connecting the peripheral anti-vaccine network to the larger and more mainstream MAGA network (DiResta and Garcia-Camargo 2020). The film focuses on virologist and anti-vaccine activist Judy Mikovits who asserts that vaccines are ‘a money-making enterprise that causes medical harm’ and promotes a conspiracy theory that the COVID-19 pandemic was orchestrated by Dr. Anthony Fauci, the director of the National Institute of Allergy and Infectious Diseases (NIAID) and head of the coronavirus taskforce.

Eventually, anti-vaccine pandemic posts in the MAGA and QAnon communities surpassed the volume of posts in the anti-vaccine and natural health communities. Health choice and medical freedom rhetoric was a winning strategy for anti-vaccine ideas amongst populist conservative clusters. *Plandemic*, which went viral on May 5-6th 2020, captured the attention of broad audiences until it was removed from all tech platforms for violating misinformation policies. As one of the most widely circulated pieces of

COVID-19 misinformation, it served as a micromobilization context for anti-vaccine ideas to QAnon and MAGA networks (DiResta 2021).

These findings that opposition to vaccination is more prominent on the political right are further substantiated by research employing survey data (Baumgaertner et al 2018; Lewandowsky et al. 2013; 2020 PEW; Rabinowitz et al. 2016). PEW (2020) research has found that science is a politically polarizing issue with Americans who identify as left-wing being three times more likely to trust science than their conservative counterparts. Canada reported this trend as well albeit with less of a difference at 39% between right- and left-wing respondents. Some research attributes differentiation along partisan lines to conservative free market values. In a representative survey of 1000 Americans, Lewandowsky et al. (2020) found that rejection of vaccination was predicted by endorsement of the free market and that this association remained even after removing other measures of socio-political conservatism from models. Theoretically this correlation likely results from libertarian worldviews opposing mandatory vaccination as a government intervention in healthcare decision-making.

Beyond opposition to vaccination on principle as a government intervention, Baumgaertner et al.'s (2018) examination of a nationally representative online survey with 1006 respondents found that a significant correlation between conservative political ideology and intention to vaccinate against measles, pertussis, and influenza was explained by trust in government medical experts, particularly a low level of trust in government institutions such as the CDC. More recent research conducted during the COVID-19 pandemic has found that although survey data in November 2020 supported the institutional trust hypothesis, by early February 2021 this variable no longer explained the partisan gap regarding COVID-19 vaccine acceptance. Political identity eventually trumped demographics and institutional trust as explanatory variables, making science a partisan issue in and of itself regardless of the underlying mediating factors (Cowan and Reich 2021).

The rise of populism internationally has further embraced and promoted anti-vaccine ideas (Kennedy 2019; Lasco and Curato 2019; Lasco and Larson 2019; Zuk et al. 2019, Zuk & Zuk 2020). Stemming from the populist distrust of establishment elites, some populist ideologies pit the average person against scientific experts. Kennedy's (2019) research on Western European countries at the national level found a significant positive correlation between the percentage of the electorate who voted for populist parties in the 2014 European Parliament elections and the degree of vaccine hesitancy. Lasco and Curato (2019) developed the concept of medical populism as an analytic framework to explain the nuances in the politicization of health issues in populist discourse. Medical populism in their definition is a political style that simplifies and/or performs a public health crisis by pitting common people against the establishment.

Lasco and Larson (2019) build on this conceptualization with their examination of medical populism in four national contexts: Nigeria, the Philippines, Ukraine, and Italy. In each of these cases, populist discourse was influential at generating public mistrust in vaccines amid differing vaccine controversies. Regardless of the vaccine involved and the specific medical claims made, across all cases anti-vaccine ideas gained resonance within populist ideologies due to their association with an establishment class in the wider socio-political environment. In Nigeria polio immunization programs were depicted as Western institutions and part of the political establishment class in the predominantly Christian south, leading to five states in the predominantly Muslim north to boycott the polio vaccine in 2003. Italy's far-right The League and Five Star Movement (5SM) promoted false information about the dangers of vaccines during the 2015 and 2018 election campaigns, combining libertarian values and a conspiracy theory linking vaccines to the nefarious interests of the political establishment class. In the Philippines the suspension of a vaccination program for dengue fever due to safety concerns that the vaccine could increase the severity of dengue in previously uninfected people was politicized by politicians who magnified and exacerbated the scare promoting misinformation and significantly reducing vaccine confidence in general. The public's distrust of government and pharmaceutical elites was leveraged for political gain to discredit the Aquino administration in power at the time. Similarly in Ukraine the death of 17-year-old Anton Tyschenko in 2008 a day after he received his MMR vaccination was politicized by individual political actors. Although the death was found to not be associated with the vaccine, conspiracy theories erupted based on long-standing distrust in public health and government as a political class.

The mobilization of ideas in the anti-vaccine movement has gained resonance in both libertarian and populist political movements. Beyond opposition to government intervention, pre-existing mistrust in government and other elites has been conflated with mistrust in scientific experts leading to far-reaching impacts on public health. The resonance of medical populism in various socio-political environments and the associated spectrum of vaccine hesitancy suggests the need for more nuanced analyses of political worldviews. Manufactured by multinational corporations and promoted by governments, vaccines and vaccination programs are often proxies for larger political concerns.

3.6 Conclusion

The emergence of the modern anti-vaccine movement was strongly rooted in the shared personal experiences of parents with autistic children who, when the medical system was unable to meet their health expectations, pursued collective action. In line with Frickel and Gross' (2005) tenet of collective grievances, individual dissatisfactions led to collective action, forming an intellectual movement. Parents bonded together feeling neglected by the medical system, opposing the dominant science and engaging in their own boundary-work demarcating science from non-science and blurring the boundary between experts and lay people (Eyal 2013; Reich 2016). Many activists used the Internet to learn about the medical literature and through networking with parents of autistic children were able to circumvent government gatekeepers and secure funding for research from private donors (Deer 2020; Mnookin 2011). In this way, the anti-vaccine movement had less collaboration with institutional experts than might be expected of most SIMs, working instead to produce alternate science with or without professional allies.

Concerns in anti-vaccine advocacy work and its critique of the medical system were broadened and mobilized into mainstream culture through mass communications in articles, documentaries and self-help parenting books which were amplified by the celebrities involved (McCarthy 2007, 2008; Sears 2007; Thomas and Margulis 2016). Books are often important mobilization sites for ideas in social movements (Meyer and Rohlinger 2012), and although these contributions to the anti-vaccine movement may be considered lowbrow in comparison to the seminal books of larger more mainstream social movements, they nevertheless serve as symbols and focal points for movement members and new recruits. Jenny McCarthy’s books were promoted on international television and served as a platform for organizing on the ground protests. Dr. Bob Sears’ and Dr. Paul Thomas’ parenting books sold at popular bookstores appealed to parents seeking self-help with medical decision-making for their children. Andrew Wakefield’s documentary *Vaxxed: from Cover-Up to Catastrophe* organized around hashtag activism on Twitter and attempted to mobilize collective action to pressure congress to subpoena Dr. William Thompson who they allege is a CDC whistleblower (DiResta 2015).

The anti-vaccine movement involves a health intervention which is a civic duty, and so frame alignment and translation strategies were able to achieve resonance with a broad range of social movements. Beyond the natural health and environmental movement, anti-vaccine ideas successfully translated to the libertarian health freedom movement and in QAnon and MAGA communities, and other populist movements internationally. Algorithms on social media facilitated the diffusion of these ideas linking different movements and ideologies (DiResta 2021). These social dynamics transformed the anti-vaccine movement from an intellectual movement based on direct personal experiences to a more generalized movement challenging the scientific consensus.

Although other health movements such as the AIDS movement have used the internet to challenge institutional expertise (Gillett 2003) and develop alternative expertise as activist-experts (Epstein 1996), the anti-vaccine movement is unique in its frame translations which allowed it to adapt its ideas to a variety of cultural contexts.

Scientific knowledge production today is often challenged by bottom-up anti-scientific movements and counter-knowledge propagated online. Ideas outside of the scientific consensus need to be taken seriously not only because research has found misinformation to be associated with the spread of infectious disease (see ‘infodemic’), but also because these rumours reflect important emotions and public sentiments (Larson 2020).

The prominence of the anti-vaccine movement did not emerge spontaneously as an irrational set of ideas. It involved the key elements of a social movement including personal grievances, opportunity structures and organized political advocacy work. Ideas should not be dismissed from analyses with the lens of a social movement simply because they are outside the realm of currently accepted science. Especially during times of uncertainty, these ideas serve as a medium for social actors to share sentiments, make sense of the unknowns, and negotiate reason and emotion. Conspiracy theories further, become accepted history within specific online communities and impact the intellectual information they will be receptive to in the future. Although most of these ideas will not achieve institutional stability, their adherents nevertheless impact the wider information environment in which the insider/outsider status of expertise has been recalibrated and its traditional boundaries are being challenged and redrawn.

By treating anti-vaccine ideas seriously in this analysis, as an organized social movement, we can better understand how health authorities can mobilize counter-content in the contemporary information environment. In the online information ecosystem, algorithms distort consensus and drive dissensus, furthering the need for constructive dialogical models of interaction between science and society (DiResta 2021). Didactic communication styles can no longer effectively manage and sustain trust in nuanced and diverse public audiences (Goldenberg 2021). Two-way communication and serious consideration of anti-scientific intellectual ideas are needed to understand the concerns and rumours that generate the fertile ground for public distrust in science.

3.7 References

Attwell, K, Ward PR, Meyer SB, Rokkas PJ, Leask, J. (2018) Do-it-yourself": Vaccine rejection and complementary and alternative medicine (CAM). *Social Science and Medicine* 196: 106-114.

AustismOne (2013) Robert F. Kennedy Jr. to Advance Autism Awareness to Action as Keynote of AutismOne Conference. *PR Newswire*. Available at: https://www.prnewswire.com/news-releases/robert-f-kennedy-jr-to-advance-autism-awareness-to-action-as-keynote-of-autismone-conference-202283911.html (accessed 25 April 2020).

Baumgaertner B, Carlisle JE, Justwan F. (2018) The influence of political ideology and trust on willingness to vaccinate. *PLoS ONE* 13(1): e0191728.

Benford, R. and Snow, D. (2000) Framing Processes and Social Movements: An Overview and Assessment. *Annual Review of Sociology* 26: 611-639

Benkler, Y, Faris, R, and Hal Roberts. (2018) *Network Propaganda: Manipulation, Disinformation, and Radicalization in American Politics.* Oxford University Press.

Bernard S, Enyati A, Redwood L, Roger H and Binstock T (2001) Autism: A novel form of mercury poisoning. Medical Hypotheses 56(4): 462–471.

Bramadat, P., Guay, M., Bettinger, J., and Roy, R. (2017) *Public Health in the Age of Anxiety: Religious and Cultural Roots of Vaccine Hesitancy in Canada*. Buffalo: University of Toronto Press.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., and Rebecca Gasior Altman. (2004) Embodied health movements: new approaches to social movements in health. *Sociology of Health & Illness* 26(1): 50-80.

Carel, H, and Kidd, IJ. (2014) "Epistemic Injustice in Healthcare: A Philosophical Analysis." *Medicine, Healthcare, and Philosophy* 17(4): 529-40.

Deer, B. (2020) *The Doctor Who Fooled the World: Science, Deception, and the War on Vaccines*. Baltimore: John Hopkins University Press.

Cowan, S, Mark, N, and Reich, J. (2021) COVID-19 vaccine hesitancy is the new terrain for political division among Americans. *Socius: Sociological Research for a Dynamic World* 7(4): 237802312110236.

DiResta, R. (2015) "Anti-Vaxxers Are Using Twitter to Manipulate a Vaccine Bill" *Wired* Available at: https://www.wired.com/2015/06/antivaxxers-influencing-legislation/amp (accessed 28 June 2020).

DiResta, R. (2018) Computational Propaganda: If you make it trend, you make it true. *The Yale Review.* 106(4): 12-29.

DiResta, R. (2021) "Misinformation. It's Amplified Propaganda: you don't need fake accounts to spread ampliganda online. Real people will happily do it." *The*

Atlantic. Available at: https://www.theatlantic.com/ideas/archive/2021/10/disinformation-propaganda-amplification-ampliganda/620334/ (accessed 30 October 2021).

DiResta, R. and Garcia-Camargo, I (2020). Virality Project (US): Marketing meets Misinformation. *The Stanford Internet Observatory Cyber Policy Center*. Available at: https://cyber.fsi.stanford.edu/io/news/manufacturing-influence-0 (accessed 26 May 2020).

Dubé E, Laberge C, Guay M, Bramadat P, Roy R, Bettinger J. (2013) Vaccine hesitancy: an overview. *Human Vaccines & Immunotherapeutics.* 9(8):1763-73.

Eyal, G. (2013) For a Sociology of Expertise: The Social Origins of the Autism Epidemic. *American Journal of Sociology* 118(4): 863-907.

Frickel, S., and Gross, N. (2005) A General Theory of Scientific/Intellectual Movements *American Sociological Review* 70(2): 204-232.

Frickel, S. (2004) Building an Interdiscipline: Collective Action Framing and the Rise of Genetic Toxicology *Social Problems* 51(2): 269-287.

Frickel, S., and Moore, K. (2006) *The New Political Sociology of Science: Institutions, networks, and power.* University of Wisconsin Press.

Gieryn, T. (1999) *Cultural Boundaries of Science: Credibility on the Line*. Chicago & London: University of Chicago Press.

Goldenberg, M. (2021) *Vaccine Hesitancy: Public Trust, Expertise, and the War on Science.* Pittsburgh: University of Pittsburgh Press.

Horton, R (2006) Heart vs head: The issue of MMR rather than single vaccines is not going to go away anytime soon. *The Guardian.* Available at: https://www.theguardian.com/commentisfree/2006/apr/24/thesadnessofmmr (Accessed 8 November 2020).

Inbar R, Weiss R, Tomljenovic L, Arango MT, Deri Y, Shaw CA, Chapman J, Blank M, Shoenfeld Y (2016) WITHDRAWN: Behavioral abnormalities in young female mice following administration of aluminum adjuvants and the human papillomavirus (HPV) vaccine Gardasil. *Vaccine*. S0264-410X(16)00016-5.

Jamison AM, Broniatowski DA, Dredze M, Wood-Doughty Z, Khan D, Quinn SC. (2020) Vaccine-related advertising in the Facebook Ad Archive. *Vaccine*. 38(3): 512-520.

Johnson, N.F., Velásquez, N., Restrepo, N.J. et al. (2020) The online competition between pro- and anti-vaccination views. *Nature* 582, 230–233.

Kennedy, J. (2019) Populist politics and vaccine hesitancy in Western Europe: an analysis of national-level data, *European Journal of Public Health* 29(3): 512–516.

Lamont, M. (1987) How to become a dominant French Philosopher: The case of Jacques Derrida. *American Journal of Sociology* 93(3): 584-622.

Larson, H. (2020) *Stuck: How Vaccine Rumors Start--and Why They Don't Go Away.* NY: Oxford University Press.

Largent, MA. (2012) *Vaccine: The Debate in Modern America*. Baltimore: John Hopkins University Press.

Lasco G, and Curato, N. (2019) Medical populism. *Social Science & Medicine* 221(1): 1-8.

Lasco G, and Larson HJ. (2020) Medical populism and immunisation programmes: Illustrative examples and consequences for public health. *Global Public Health*.15(3):334-344.

Lewandowsky S, Gignac GE, and Oberauer K. (2013) The Role of Conspiracist Ideation and Worldviews in Predicting Rejection of Science. *PLoS ONE* 8(10): e75637.

Lewandowsky, S., Woike, J. K., and Oberauer, K. (2020) Genesis or Evolution of Gender Differences? Worldview-Based Dilemmas in The Processing of Scientific Information. *Journal of Cognition*, 3(1): 9.

McCarthy, J. (2007) *Louder than Words: A Mother's Journey in Healing Autism*. New York: Dutton; First Edition.

McCarthy, J. (2008) *Mother Warriors: A Nation of Parents Healing Autism Against All Odds*. New York: Dutton Adult; First Edition.

McLaughlin, N. (1998) How to Become a Forgotten Intellectual: Intellectual Movements and the Rise and Fall of Erich Fromm. *Sociological Forum* 13(2): 215-246.

McLaughlin, N. (1998) Why do schools of thought fail? Neo-Freudianism as a case study in the sociology of knowledge. *Journal of the History of the Behavioral Sciences* 34(2): 113-134.

Moore, K, Kleinman DL, Hess D, and Frickel, S. (2011) Science and neoliberal globalization: a political sociological approach. *Theory and Society* 40(5): 505-532.

Mnookin, S. (2012) *The Panic Virus: The True Story Behind the Vaccine-Autism Controversy*. Simon & Schuster.

Parthasarathy, S. (2010) Breaking the expertise barrier: understanding activist strategies in science and technology policy domains. *Science and Public Policy* 37(5): 355-367.

Parthasarathy, S. (2020) Innovation Policy, Structural Inequality, and COVID-19. *Democratic Theory* 7(2): 104-109.

Rabinowitz M, Latella L, Stern C, and Jost JT. (2016) Beliefs about Childhood Vaccination in the United States: Political Ideology, False Consensus, and the Illusion of Uniqueness. *PLoS One.*11(7):e0158382.

Reich, J. (2016) *Calling the Shots: Why Parents Reject Vaccine*. New York: New York University Press.

Reich J. (2020) Vaccine Refusal and Pharmaceutical Acquiescence: Parental Control and Ambivalence in Managing Children’s Health. *American Sociological Review*. 85(1): 106–127.

Sears, R (2007) The Vaccine Book: Making the Right Decision for Your Child. Boston: Little, Brown Spark.

Smith, N. and Graham, T. (2019) Mapping the anti-vaccination movement on Facebook, Information *Communication & Society* 22(9):1310-1327.

Thomas, P. and Margulis, J (2016) *The Vaccine-Friendly Plan: Dr. Paul's Safe and Effective Approach to Immunity and Health-from Pregnancy Through Your Child's Teen Years.* New York: Ballantine Books.

Tomljenovic L, Shaw C. Mechanisms of aluminum adjuvant toxicity and autoimmunity in pediatric populations. (2012) *Lupus*. 21(2):223-230.

Vicedo, M. (2021) *Intelligent Love: The Story of Clara Park, Her Autistic Daughter, and the Myth of the Refrigerator Mother*. Boston: Beacon Press.

Yla-Anttila, T. (2018) Populist knowledge: ‘Post-truth’ repertoires of contesting. *European Journal of Cultural and Political Sociology*. 5(4): 356-388.

Zuk, P, Zuk P, Lisiewicz-Jakubaszko, J. (2019) The anti-vaccine movement in Poland: The socio-cultural conditions of the opposition to vaccination and threats to public health. *Vaccine* 37(11): 1491-1494.

Zuk, P and Zuk P. (2020) Right-wing populism in Poland and anti-vaccine myths on YouTube: Political and cultural threats to public health. *Global Public Health*. 15(6): 790-804

Chapter 4

Fertile Ground for Distrust: Vaccination and its Discontents Before COVID-19

Abstract

Over the COVID-19 pandemic, public health officials have continuously warned of the effects of vaccine misinformation. The World Health Organization (WHO) published a cross-regional statement on the matter in 2020 calling on member states to implement programs and resources to address possible solutions. Despite the efforts of government information campaigns, portions of the public remain distrustful of the scientific consensus on vaccines. To go beyond didactic public health approaches that often treat the vaccine-hesitant or vaccine-resistant as a monolithic group, and their ideas as unscientific and irrational, this paper analyzes the interviews of 35 participants with

varying positions on the recommended childhood immunization schedule. To reveal the nuance in vaccine hesitancy and illuminate broader insights into the sociology of expertise, I address the complexities of distrust in mainstream expertise and the credibility of scientific institutions.

4. 1 Introduction

Before the COVID-19 pandemic, a narrative prevalent in public health discourses was that vaccines seemed to be the ‘victim of their own success’—that the necessity and effectiveness of vaccines are questioned in the public sphere when disease rates are low (Crowcroft 2021; WHO 2017). A 2017 WHO report states that ‘in absence of disease, fear of disease has been replaced by fear of vaccines for some people’ (WHO 2017: 11). In 2019 chief executive of GAVI, the Vaccine Alliance, Dr. Seth Berkley commented that low vaccine uptake was ‘ironically, caused by the fact that vaccines have eradicated the most lethal diseases’ (Fortuna 2019). Public health communications then focused on vaccine hesitancy as an ‘information deficit’ problem whereby publics required accurate information and proper risk-benefit analysis.

COVID-19 has magnified what is now known as the ‘Infodemic.’ Public mistrust of vaccination is clearly about much more than lay misperceptions of risk. Misinformation poses a global and immediate public health risk. WHO published a commitment for member States to combat misinformation in April 2020, but by November 2020 head of the Coronavirus Task Force Dr. Anthony Fauci, described an ‘anti-science feeling’ in the U.S. In July 2021, pediatrician and director of the Texas Children’s Hospital Dr. Peter Hotez (2021) pointed to the growth of ‘anti-science aggression.’

Public health authorities have taken a ‘myth-busting’ approach, systematically correcting misinformation fact by fact. While these efforts are helpful, it is questionable whether this strategy is ultimately effective at changing the hearts and minds of those who distrust the scientific consensus. Facts exist in a matrix of values, social relationships, and identities. COVID-19 facts have become enmeshed in the culture wars that permeate our social and political lives. The WHO (2020) has emphasized that tackling misinformation requires an integrated approach that addresses both the medical and socio-behavioural dimensions of this infodemic and examines the mechanisms and motivations that make misinformation productive, attractive and easier to spread.

This paper takes a sociological approach to understand the emotional and cognitive domains that provide fertile ground for COVID misinformation to propagate. Data was drawn from 35 interviews conducted in 2018-2019, before the COVID-19 pandemic hit. The focus on sources of vaccine hesitancy in these interviews is nevertheless useful in shedding light on responses to COVID-19. The empirical findings are organized around four main themes identified in the data: (1) the anti-vaccine label, (2) the desire for independent thought and open debate, (3) patient-provider interactions, and (4) perspectives on scientific institutions. The analysis critiques how vaccine-hesitant individuals are portrayed as a monolithic group, and how these implications can inform public health responses.

4. 2 Literature Review

Vaccine hesitancy is a technical term employed by public health professionals who aim to inclusively describe the growing group of parents who doubt the legitimacy of the recommended immunization schedule. Health authorities often characterize views on vaccination as a continuum ranging between acceptance and rejection and varying by how likely individuals are to change their minds when presented with evidence (Benin et al. 2006; Gowda and Dempsey 2013; Larson et al. 2014; WHO 2016). Responses to evidence plays a key role in how health authorities understand those with concerns about vaccines.

Vaccine deniers are depicted at one end of the extreme, impervious to evidence that contradicts their views, critical of the entire scientific approach, and the least likely to change their minds. Vaccine refusers do not vaccinate and are unlikely to change their minds but are open to arguments and perspectives that differ from their own. Vaccine skeptics are evaluating claims about vaccination scientifically and are prepared to reach a conclusion based on evidence/facts. Vaccine-hesitant individuals are in the middle of this continuum and either refuse or delay some vaccines—or accept vaccines but are not certain that they were justified in their decision.

The categories of this continuum are difficult to measure at the population-level because data on vaccine uptake does not necessarily reflect attitudes to vaccination. Individuals who are not up to date on their vaccinations may be making a conscious choice, but they also may not be unvaccinated due to a lack of accessibility. Individuals who are vaccinated may actively demand vaccination or passively accept vaccination (Nichter 1995). Data on vaccine uptake is unable to make these distinctions and data on attitudes to vaccination is new and emerging.

Vaccine-hesitant individuals are the target audience for public health messaging (WHO 2016) but are particularly difficult to identify because it is a mindset rather than a behaviour. Recent studies have developed criteria for defining vaccine hesitancy (Gaudino et a. 2006; Opel et al. 2012; Limb 2011; Rees 2011; Luthy et al. 2009) and some of these measures have been able to effectively predict parental decision-making (Opel et al. 2012; Smith et al. 2011). This quantitative operationalization of vaccine hesitancy is important to address the phenomenon amid increasing disease outbreaks and to assess population-level variables such as racial differences.

Qualitative studies have made important contributions to the understanding of the social dynamics and the matrix of values that surround vaccine decision-making. Recent qualitative research has examined the role of patient-provider interactions (Dube et al. 2015; Opel et al. 2012), parenting attitudes and communication styles (Albert 2019; Freed et al. 2010; Gellin et al. 2000; Prislin et al. 1998; Reich 2014, 2020; Shiu et al. 2006), and public health communication styles (Kaufman et al. 2019).

Sociologists Reich (2014, 2016, 2020) and Albert (2019) interviewed mothers examining the impact of child-rearing and parenting perspectives on intentions to vaccinate. Both scholars emphasize that public health messaging that treats parental rejection of vaccines as categorical and/or utilizes binaries that depict vaccine consenting parents as responsible and vaccine nonconsenting parents as irresponsible, miss the spectrum of views of a group that does not have a clearly delineated membership.

In Reich's (2014) and (2020) studies parents primarily mothers were interviewed in the United States between 2007 and 2014 who either refused childhood vaccines altogether or allowed certain vaccines on an alternative schedule. Reich's (2014) examination found that the views of the mothers interviewed were characterized by an ideology of individualist or 'neoliberal parenting' consisting of a combination of privileged frames of choice and intensive mothering practices. Reich's (2020) analysis focused on the variation in healthcare choices and how parents who reject vaccines but accept other pharmaceutical interventions in particular contexts manage their ambivalence to advocate for their children.

Albert (2019) interviewed 28 Canadian mothers about HPV vaccine decision-making divided between vaccine consenting and non-consenting mothers. Vaccine consenting mothers had limited conversations with their daughters about adolescent sexual health and the decision to vaccinate and these conversations were not central to their narratives of consenting to vaccination. Non-consenting mothers on the other hand, emphasized giving their daughters a robust sex education, instilling a sense of autonomy in their daughters even if it was at odds with community HPV protection at large. In this way, narratives between the two groups were more messy/complicated than public health depictions of vaccine consenting mothers as responsible and vaccine non-consenting mothers as irresponsible.

Patient-provider interactions played a prominent role in vaccine decision-making and the differential experiences of vaccine consenting and non-consenting parents. Dube et al (2015) found that vaccine-unfavorable mothers who had discussed vaccination with their healthcare providers perceived these interactions negatively. Some feared that they were being judged and others felt rushed to accept vaccination before they had adequate time to consider all their questions and concerns. Overall, one-third of vaccine-hesitant mothers reported feeling poorly treated by nurses at the vaccination clinic. Other studies have found that parents find it difficult to have open vaccine conversations with their primary care doctors and report feeling alienated when vaccines are discussed (Opel et al. 2012).

Racialized identities and experiences influenced vaccine confidence and decision-making (Shui et al. 2005; Dong 2022). Shui et al. (2005) found that African American mothers had concerns about vaccination and a desire to know more about vaccine ingredients stemming from mistrust in healthcare providers due to their knowledge of the Tuskegee Syphilis Study. Most mothers interviewed felt underinformed about vaccination and emphasized that vaccine information was not provided to them until the actual immunization visit. Dong et al.’s (2022) more recent study of intentions to vaccinate among Black Americans in the early stages of the COVID-19 vaccine roll-out found that systemic racism and medical mistrust were drivers of for lower vaccination intentions. Similar to the Shui et al. (2005) study, participants mentioned the Tuskegee Syphilis

Study and concerns about medical experimentation, as well as negative personal experiences with the medical system. This resulted in a “wait and see” approach to COVID-19 vaccination

The following study aims to contribute to the growing body of qualitative research that examines narratives and experiences surrounding vaccination in greater depth. This research fills a gap in the literature by interviewing scientists who hold a minority position on vaccination that contradicts the recommended immunization schedule. The larger stories of their healthcare choices and perspectives offers rich data on the social norms and values that underpin vaccine hesitancy.

4. 3 Method

4.3.1 Recruitment of Participants

Participants were recruited through non-probability purposive sampling and snowball sampling. This sampling strategy was necessary to access participants with varying positions on the recommended immunization schedule. Although non-probability sampling is not representative of larger populations it permits rich data on a minority perspective that is not well-understood. The goal of this research was to gain a deep understanding of a specialized audience, and so the limited generalizability of findings was a methodological trade-off made in pursuit of a rich and complex data collection. My research design began with purposive sampling of doctors and experts who had taken an ‘anti-vaccine’ stance in the media. Through online exploratory research I had discovered these individuals who had the rare characteristic of being organizationally central as doctors and scientists but marginal in their field with their ideas about vaccination. Using my discretion as a researcher, I selected individuals suitable to the study, and then after conducting interviews I planned to gain a snowball sample from existing participants by asking if there was anyone else, I should speak to during the interviews.

Recruitment began following the approval of my research protocol which was submitted to the McMaster Research Ethics Board for ethical clearance. The ethics process required that I submit all research materials and documents including my recruitment email script, letter of information and interview guide, with special consideration to the social and psychological risks for participants in the study and how I would mitigate these risks. Many had public profiles are ‘on the record’ in terms of having their views on the vaccine issue known (indeed, most are in the position of actively looking for ways to press their claims and be heard), they may nevertheless have concerns about how their views are represented and what impact this will have on their status and/or reputation. The social and psychological risks to participants was mitigated by letting the participants know in the letter of information and before the commencement of the interview that they do not need to answer any question that they would prefer to skip and that they can end the interview at any point if they so wish and keeping participants’ names confidential in the write-up.

After sending out recruitment emails with the interview guide and a letter of information describing the expectations, risks, benefits, and purpose of the study, I received informed consent from participants by email. I then scheduled interviews to be conducted by phone, video chat, or in-person depending on the preferences of individual participants. Most participants chose to be interviewed by phone, but one interview was a video chat conducted on Skype, and two interviews were conducted in-person. One participant opted to respond to the interview questions in a written format and emailed her responses to me in a Microsoft Word document. Interviews ran between 30 minutes to over an hour long, depending on the time constraints or length of responses offered by interviewees.

In total, 35 participants were interviewed including eight doctors (seven critical of vaccines), eighteen scientists (four critical of vaccines, 14 supportive of vaccines), two individuals working in infection control, four alternative healthcare practitioners (one homeopath, one naturopath, one chiropractor, one naturopath turned homeopath), and three parents. Most participants (20) were Canadian. Among them were one 'anti-vaccine' researcher, 13 'pro-vaccine' researchers, one parent, two individuals working in infection control, one naturopath, one naturopath turned homeopath, and one activist. 11 participants were American including all the seven doctors critical of vaccination, one anti-vaccine researcher, one chiropractor, one parent and one doctor/researcher. One Australian pro-vaccine doctor, one researcher from the UK, and one researcher from Israel were also interviewed. The sample had a roughly even split of male and female participants with 10 women (four doctors, one researcher, four alternative healthcare practitioners, one parent), and eight men (three doctors, three researchers, one activist, one parent) who were critical of the recommended immunization schedule and eight women and eight men who were supportive of the schedule.

Professional Status

Medical Doctors	Immunologists	Infection Prevention and Control Professionals	Academic Scientists	Alternative Healthcare Practitioners	Parents
8	14	2	4	4	3

I recruited my first group of participants by doing an online explorative search of doctors who had taken a public anti-vaccine stance in the media. I reached out to 15 individuals and received a response from seven. Eventually, a participant directed me to a non-profit organization Physicians for Informed Consent (PIC) that opposes the recommended immunization schedules. I located the Physicians for Informed Consent (PIC) website and under the ‘Leadership’ section was able to identify a list of directors, advisors, and founding members. The members listed consisted of doctors, researchers, nurses, and lawyers. Using this list, I searched for contact information publicly available for each member and sent out a recruitment email with a letter of information and the interview guide. I received a response from two members of this organization who agreed to conduct interviews and put me in touch with two more participants who practice alternative medicine.

During one of these interviews, the participant disclosed to me that a letter had gone out to the organization urging members not to participate in my research. A leader of the organization and a lawyer warned members that my work had the potential to inaccurately represent their views and linked a psychology research article that had been published, which described vaccine-hesitant participants as having cognitive biases. To not be portrayed in this light, they strongly recommended that members not respond to my email. Although this limited recruitment from this group, I was able to gain a snowball sample of participants from the interviews I had already conducted thus far consisting of researchers, a parent activist, and two alternative healthcare professionals.

Finally, through word-of-mouth a personal contact recommended that I talk to two friends of theirs who were parents with vaccine-hesitant stances. Both parents agreed to be interviewed. An additional personal contact put me in touch with two alternative healthcare providers, a homeopath and a naturopath who agreed to be interviewed.

Convenience sampling. Furthermore, I gained a convenience sample of participants who I word-of-mouth recommendations of parents and alternative healthcare providers who were ‘vaccine-hesitant.’

To capture the views supportive of vaccines, I initially used word-of-mouth in my own personal networks to contact two members of Infection Prevention and Control (IPAC) in Ontario. IPAC is a Canadian organization within Public Health Ontario (PHO) consisting of professionals in nursing, medicine, microbiology, medical technology and epidemiology that implement and evaluate evidence-based policies and practices in healthcare settings to advance infection prevention and control.

I contacted the first member of IPAC whose information I received from my personal network by phone to schedule an interview and followed up with the letter of information and consent form via email. This participant put me in touch with one of her colleagues at IPAC and recommended I reach out to the Canadian organization consisting of vaccine researchers—the Canadian Immunization Research Network (CIRN). I was put in touch with the second IPAC professional by phone and after receiving the information letter and consent form by email she agreed to participate in a phone interview.

Following these interviews, I located the CIRN website and found a list of 19 current members. CIRN members are experts in vaccination across 40 Canadian academic institutions who contribute to research to inform immunization programs and public health decision-making. After sending out a recruitment email to all members on the list 10 agreed to be interviewed. I also contacted experts who publicly took a pro-vaccination stance in the media by accessing their public profiles and sending out recruitment emails. Through this purposive sampling, I was able to interview two medical doctors and two university professors specializing in vaccination and vaccine-preventable diseases.

For my analysis in this paper, I chose to focus on the findings on the perspectives and experiences of participants who were critical or disagreed with the scientific consensus on vaccines. As a minority perspective that is less understood, I wanted to learn more about the social dynamics at play in order to develop solutions for building trust and communicating science effectively. By listening to the ‘deep story’ (Hochschild 2016) of participants, I hope to build bridges for productive dialogue.

4.3.2 Data Collection

Interviews were conducted with a semi-structured guide. I began by introducing myself to participants, telling them a bit about myself, and asking the open-ended questions I had prepared. First, participants were asked general questions about themselves, their work, and what they generally thought about vaccination. Then, once we had built a bit of a rapport, I asked more specific questions about their personal experiences and the rationale behind their views. The interview guide was adjusted throughout data collection to respond to spontaneous topics and probe interesting remarks. For example, issues raised in earlier interviews would often be added as additional questions in later interviews. It was important to keep the research an iterative process in order to accurately portray participant thoughts and beliefs and delve deeply into issues.

Interviews were guided by four main question areas: (1) general position on vaccines and how freely participants feel they can share these views (2) the challenges of taking this position and reactions they have gotten from others (3) views on alternative medicine and mainstream medicine (3) responses to common criticisms of their viewpoints (4) the role of the traditional media and social media in communicating vaccine information. Most of the questions were the same for all interviewees apart from question area 4 which asked each participant to respond to 2 criticisms commonly made against their viewpoints. The questions in this section were tailored to participants based on their public views on vaccination. Participants who were critical of the current vaccine schedule were asked to respond to assertions that this perspective is unscientific and can lead to disease outbreaks. Participants who were supportive of the current vaccine schedule were asked to respond to arguments that their perspective is not sufficiently skeptical of current vaccine research and that the scientific consensus on vaccines is wrought with conflicts of interest due to funding by pharmaceutical companies—therefore lacking objectivity.

I continued to recruit new participants and conduct interviews until it appeared that data saturation had been reached. At a certain point I was no longer discovering new themes or information in the data and the examples provided by new participants echoed earlier themes I had already identified. Furthermore, after the last stage of purposive sampling, I had exhausted the snowball sample I gained from existing participants and no longer had leads on new recruits for data collection. Since I conducted a thematic analysis, the number of participants was less important than the depth of the interviews and the themes I was able to extract. After 35 interviews, when I was repeatedly observing similar codes and themes during analysis—reaching data saturation (Creswell 2007), I began to conduct my analysis.

4.3.3 Data Analysis

All interviews were audio-recorded and transcribed except for one participant who provided written responses. Transcripts were imported into NVivo 12 software and initial codes were identified by reading through the text and selecting key excerpts of data that tied into larger subcategories. I kept track of these subcategories as well as individual participants with the nodes function in NVivo and continuously re-evaluated the language and meanings assigned to these categories. I also compared participant responses to the same questions and took note of similar responses and shared meanings.

Early on I had about 13 subcategories reflecting the experiences and viewpoints of participants including ‘terminology,’ ‘the anti-vaccine identity,’ ‘big pharma,’ ‘the CDC’, ‘informed consent,’ ‘alternative/ complementary medicine,’ ‘biomedicine’ ‘conversations at the doctor’s office,’ ‘censorship,’ ‘tech platforms,’ ‘scientific orthodoxy and heretics’ ‘empowering patient individuality,’ and ‘sources of credible information.’

Inspired by the premises of grounded theory (Charmaz, 2006; Glaser, 1992), but more loosely applying these principles with the procedures of thematic analysis (Clarke and Braun 2022), I began to build levels of abstraction directly from the data and theorize about the empirical findings. Eventually I refined the subcategories into the deeper empirical themes that make up this paper. In the write-up I began to weave themes together with the data utilizing specific quotes to illustrate broader trends. To maintain confidentiality, I assigned a pseudonym to each participant and omitted any other identifying information. I chose to focus primarily on vaccine-hesitant participants or participants labeled as ‘anti-vaccine’ in the media for this paper as their story is less understood than mainstream pro-vaccination stances.

4.4 Results

4.4.1 The Anti-Vaccine Label

The terminology ‘anti-vaccine’ and ‘anti-vaxxer’ was highlighted by many participants as unrepresentative of their views and a source of distrust. Interviewees emphasized that this was a label assigned to them by the mainstream media. Not only did they not identify with this label, but they argued that it carried an associated stigma meant to demonize them and dismiss their views.

In the following quotation, Tim, a scientist and university professor describes the term ‘anti-vaxxer’ as stigmatizing rhetoric that is associated with a set of undesirable characteristics:

> Calling someone an anti-vaxxer is kind of an umbrella term…and what it tends to mean is that you’re dealing with people who are selfish…who are not willing to help their fellow citizens…who are ignorant of science…who are socially irresponsible…you know etc etc etc…there’s all that connotation that goes with it.

Tim continued to discuss how these terms avoid nuance and contribute to polarization by framing issues as ‘us’ versus ‘them’:

> It puts you in a box…and the box is meant to portray the world as the virtuous pro-vaccine world…and the evil anti-vaccine world…and I don’t think that exists…I think certainly there are people who are very pro-vaccine…and then there’s of course people who are skeptical from a range of issues…that usually has to do with more individual vaccines or individual schedules...not against the whole process of vaccination per se…and within that group there’s a small group of people…who truly don’t believe vaccines ever work and they’re all harmful…and they do exist too…but you know to say that someone is an anti-vaxxer sort of implies that there’s only these two polarities…there’s nothing else…and that’s not true…I would suggest to you that most people would fit somewhere comfortably fairly in the middle.

Another scientist and university professor Kevin, echoes these sentiments and laments that the ‘anti-vaccine’ label has been assigned to him in popular media due to the research he conducts:

> Clearly by moving into certain subject areas regardless of the fact that you’re doing your best possible science and publishing it every time…so we have a rule of making sure that everything we comment on is peer-reviewed published science…we are now being labelled by those who would like to undermine what we do as things like anti-vaxxer and others…which you know we are not.

He continues:

> If you put my name into Google now…you'll also get on alternative searches…you'll get the pseudonym *quack*…which you know usually means nutcase…so things have happened to me simply for working in a certain area…and that's really highly disappointing.

The media was criticized for having a central role in promoting divisive terminology that was seen as stigmatizing and stifling debate. For participants the term anti-vaccine had multiple interpretations and dealt with a spectrum of views but was often treated as homogenous in the media. The usage of this terminology as well as a lack of nuance led many participants to distrust media institutions and avoid interactions with the mainstream media altogether. When asked if it was difficult to take the position and stance they had on vaccination one participant, Robert, a parent and vaccine choice activist illustrates this point by focusing on the challenges and stigma they've faced in their interactions with the media:

> Well…it's difficult in some ways in that you know the media so easily dismisses you and makes you out to be uninformed…ignorant…they use inappropriate labels like anti-vax when that's not the position at all…when I've been interviewed…I've been very firm with them saying I don't want you to use that label anti-vax…you can describe me as a parent of a vaccine-injured

> child…describe me as somebody who's pro-informed consent…somebody who's vaccine risk aware…but they refuse to use those more in my view accurate labels and they insist on using a label that is dismissive…and so whenever I see media that uses that language I know they're not really interested in a thoughtful meaningful conversation…that they're interested in advancing an agenda and marginalizing and dismissing people that hold a position that suggests that we need to be more discerning about vaccine safety and effectiveness…so…you know…I find that the media are hopeless to work with.

Even using vocabulary employed in official public health sources such as 'vaccine hesitant'—to some, I was not seen as an honest broker. In my recruitment email I used the term 'vaccine-hesitant and one interviewee disclosed that this led to a low response rate from some of their fellow colleagues at the non-profit organization Physicians for Informed Consent (PIC). To them, this terminology served as an indication that my research would not be a fair portrayal of them or their views, likely dissuading most members from choosing to participate.

Although I had avoided the assumptions of the anti-vaccine label, I fell into the suspicions and mistrust that this group had for mainstream institutions with the term 'vaccine-hesitancy.' Vaccine-hesitant, they pointed out—while avoiding the pejorative connotations and black-and-white thinking of the anti-vaccine label—indicated a lack of knowledge or education on the subject matter, when they considered themselves well-informed. Language was important to participants and the vocabulary used signaled the level of trust that should be conferred in communications.

In the following quotation, Robert, explains why the term vaccine-hesitant does not accurately represent his perspective:

> It’s not capturing what the issue is…to me I’m not vaccine-hesitant…I’m vaccine risk-aware…I’ve done the research…I’ve evaluated the benefits and the risks…and in my evaluation…the benefits of vaccination don’t outweigh the risks…I think I’m very thoughtful…so it’s not about hesitant at all.

Participants who had publicly disagreed with the scientific consensus on vaccines perceived the stigma they faced as a challenge to their moral standing. Sean, a gynecology and obstetrics physician in the United States echoed Tim’s sentiments about the anti-vaccine label, comparing its associated stigma to other serious moral offences, and further contending that it is used by some proponents of vaccination to avoid conversations and end debate:

> If you label someone as being anti-science…or racist or bigoted…or homophobic…or xenophobic…or whatever else…then that’s a great tactic because then you don’t have to have a conversation…why would you have a conversation with someone who’s anti-scientific?

Stigma often led to symbolic and social group boundaries for many participants. For instance, Lisa, a mother from Toronto, Ontario who had recently moved to Guelph, Ontario observed a polarizing social dynamic among parent communities in both cities. In the following quotation, she describes a strong sense of group identity in parents who were favourable and unfavourable to the recommended childhood immunization schedule respectively:

> I think there is, in the parent community, a little bit of being on side with like friends and the people that you're around too….and if you're in a group where everybody is anti-vaccine…and you vaccinate then it's seen as appalling…and the opposite if you're seen being anti-vaccine around people that are pro then you get completely berated and shot down like it's extremely *extremely* heated and political here on like the Facebook groups and all of that.

Lisa had been on the fence about certain vaccines and struggled engaging in discussions and shared decision-making with her husband who felt strongly that their child should receive all vaccinations listed on the recommended immunization schedule. Conversations regarding vaccination were described as difficult and polarizing for many participants.

When I asked participants what terminology best represented their perspectives on vaccination, they replaced what they viewed as polarizing terminology in the mainstream media with more positive 'pro' terminology preferring to characterize themselves as 'pro-safe vaccines' and 'pro-informed consent.' Participants argued that it was not that they were categorically against all vaccines but that they did not believe vaccines in their current form are safe for a myriad of reasons and that patients are not given proper informed consent about vaccination from their doctors. Failing to account for these nuances in their perspectives made it difficult for participants to build trust with the scientific consensus.

4.4.2 Desire for Open Dialogue and Debate

Many interviewees who had doubts about vaccine safety and effectiveness or disagreed with the recommended immunization schedule described intellectual environments in person or on social media as hostile to their ideas. Anti-vaccine labelling and stigma was seen as a tactic to limit competing ideas in public discourse. Many participants mobilized Enlightenment language and values seeking a transparent marketplace of ideas with robust debate.

When I first began my interview with Maxine, she began the conversation laughing and asking me: "so, what led you to poke around at this sacred cow?" Many participants felt that the scientific consensus on vaccines had become a sort of a sacred cow that could not be scrutinized—that effectiveness or safety were accepted on a priori grounds.

Maxine characterized mainstream medicine as dogmatic—and as a member of the medical profession herself being a gynecology and obstetrics physician —she considers herself a pioneer. In the following quotation, she compares her critical stance on vaccines to the unorthodox ideas of famous scientific heretics in history whose theories ultimately led to scientific revolutions.

> I mean again it's like Galileo was nearly burned at the stake during Medieval times…Copernicus…the church didn't want to hear it…so all tribes wound their members in 3 archival ways…when you get out of control…when you jump the fence…when you're not doing what everyone says you should be believing…you're wounded in 3 ways… betrayal…abandonment…shaming…those are the 3 biggies…betrayal…abandonment…shaming…when you're in the tribe of medicine you're supposed to be following the CDC and giving these vaccines.

She recounts self-censoring her views on vaccination at social gatherings and events. When asked, "Do you feel you can share your views freely and openly?" she responded:

> Yes…*but*…in a social situation…I would *never* bring it up at a dinner party…it's just like it's not worth it…it's not worth going there most of the time…it's fine in my business…it's fine *that* way…but otherwise it's not worth it…cause I would sort of have to know where someone is…it must be like being gay in the 1950s

> [laughs]…you would have to hide it until you knew that the other person was also gay and then you could come out…[laughs] it's like that.

Social pressure to conform to symbolic group boundaries (Lamont 2002) was felt by most participants. Interviewees who disagreed with the scientific consensus on vaccines particularly expressed a strong sense of belonging with others who had similar views on vaccination. For instance, when Jen, a general practitioner who did not support the recommended immunization schedule was asked if she'd seen any movement among her colleagues in how they think about the vaccine issue, she responded by saying:

> I do not interact that much with conventional doctors. I do not view them as my actual colleagues. People I view as my colleagues are those doctors who hold views similar to mine. There are not that many of us, or not least not that many who are out in the open. I have seen some doctors give interview to the *Vaxxed* team and expressing views similar to mine. Even though I have not met some of them, I view them as likeminded colleagues.

Roni, a medical doctor and homeopath, recalls being labeled unscientific for engaging in conversation about the risks of vaccination. She remarked on how she found this ironic considering from her perspective—she was being scientific by being skeptical, conducting a risk-benefit-analysis, and discussing evidence:

> You know…those of us that are vocal about the risks and the lack of efficacy are then labelled you know…then you're labelled as an anti-scientific person [laughs] which is actually quite the opposite. But…um…you know…we're looking at the statistics and weighing the risks with the benefits and trying to do a risk-benefit analysis and if you aren't allowed to talk about the risks and can't *know* the risks how can you have a risk-benefit analysis? You *can't.* And that's where it comes that's the problem that's where we're having the problem because we're not allowed to engage in the conversation.

Academic researcher and university professor Kevin lamented the polarization and lack of open conversation he experienced:

> It's also quite ridiculous that the subject area is so polarized…because…as I've said many many times…if many of the individuals including prominent scientists who continuously advocate that all vaccines are safe…if they simply read the vaccine patient information leaflet that comes with every vaccine…they would know it is not true…you don't even have to go into the scientific literature to know that it's not true…that no vaccine is 100 percent safe…some are worse than others…but for some reason…they're so polarized in their views that not allowing people like myself to question the safety of a vaccine…when we know that it's not…when it's clear and obvious…and in fact have been shown not to be safe by

> the people who manufacture it…it does not help the subject area at all…it creates this pro and anti-vaccine movements…now I'm not in either of those movements

When I asked another researcher and university professor Danielle, "What are some of the biggest challenges you've faced trying to share your views with colleagues," she responded point blankly:

> That there's no forum open to a different point of view.

I later followed up asking her, "What are the different reactions that you've gotten?" Danielle replied:

> Pretty negative…not allowing you to speak at their conferences…not allowing your research to be accepted.

Danielle clarified that it was not all vaccines that she took issue with and that her main concern was a lack of open discussion she experienced regarding the HPV vaccine:

> So it's not all vaccines…you know I'm a full supporter of childhood vaccines I think those are important…my issue is with Merck and the way that Merck has rolled out the HPV vaccine…the way in which Merck has completely shut down and became the sole funder of all vaccine research so that you can't truly have

> honest intellectual pursuits within the field because Merck is the funder and they won't fund you unless it's something that will promote their products.

Danielle felt that the manufacturer of the HPV vaccine Merck & Co. was misleading people about the longevity of the HPV vaccine immunity, and further held Merck & Co. responsible for stifling discussion. When I probed asking her "What do you think are the ways that Merck is misleading people about the HPV vaccine?" She responded:

> Well…it's just the general principle and the way in which they've gone about the whole thing is that they've cultivated and created a clique of PhDs and physicians that will support them to the death…and support anything that Merck wants to put forward without any kind of objective thinking or questioning…and they pay back those people by giving them grants to keep their research going which keeps their labs open…and they're very good at driving wedges between groups so that they can get what they want out of it…it's a very classic business move…so they…and they've done that…and they've done that to academics…and as academics…we said at the beginning of this we need to watch out because we don't want these companies to disperse us and to divide us and lo and behold…you know…money comes out and human beings are human beings you know…they fall for the money…so…that's the way it goes.

A few participants distinguished between discussions with the public versus discussions with their scientific or medical colleagues. When I asked Megan, an internal medicine doctor about some of the reactions she received in response to her views on vaccination, she responded saying:

> Well…from patients…and patients' families…I've gotten a lot of gratitude…but from my colleagues…I get a lot of skepticism…and…actually…I welcome the chance to discuss it with them…I ask them questions…I ask them please send me the data…please explain to me where I'm wrong…and what I get is just they don't answer…they are not willing to engage in a discussion.

In response to the same question researcher and university professor Kevin similarly remarked that he received positive responses for his work from the public but was shut down by scientific colleagues. When I asked him what the main reaction has been to his work he responded saying:

> The main reaction…the reaction has two sides to it…the public reaction is incredible…I rarely come across more positive reaction than we get from the public at large…and because these days there's a great deal of open access publishing…we try to publish as much as we can open access so as many people as possible can read it…um you do get the opportunity to get a huge amount of feedback…and I get emails every single day simply from the public asking

> questions about our research…thanking us for all sorts of things like that…but contrast that to science…and the scientific population and it would be almost the opposite in that they'll get anybody criticizing it.

Although many of the researchers interviewed mentioned that they did not face trouble publishing their work in academic journals, they also mentioned that researchers with similarly controversial work on vaccination had experienced reputational attacks and, in some cases, had their articles retracted, meaning they were withdrawn by academic journals after publication. Tim remarks on this in the following quotation:

> All these guys have been…these are part of the group that I've worked with on and off for years…and they've all been attacked in the last year…so they will all have a lot of experience dealing with kind of ad hominin and semi-official attacks…and attempts to retract papers.

Regarding retraction, Tim added: "This is now the method du jour of people who want to cleanse the literature"

A lack of forum for discussion and debate was also felt by participants outside the medical and scientific community. Lisa, a vaccine-hesitant mother who eventually decided to vaccinate her child for most vaccines in the schedule except for two, expressed wanting more dialogue and access to independent sources of scientific information.

> I just want to have a dialogue about it…I feel like I'm a bit in the grey area like I completely see both sides and…in the end…yeah…I went for essentially vaccinating my child but I didn't come to that decision lightly…and for me…I was just about getting balanced access to information rather than like…having essentially like…pharmaceutical research just stuffed my throat by companies that have a vested interest you know.

4.4.3 Patient-Provider Interactions

Interactions and conversations with medical professionals were found to be very important to building trust in vaccination. Medical doctors were described by some participants as intolerant of ideas beyond the medical orthodoxy. In the following quotation, Robert, who describes himself as vaccine choice activist and father of a vaccine injured son, remarks on his overall impression of mainstream medicine after several annual consultations following his son’s vaccine injury. Although the doctors began to see improvement in his son’s medical condition, when Robert attributed the improvement to alternative medical remedies, he found doctors to be “incredibly dismissive” and uninterested:

> I learned how really unopen the medical system is to new information…and in that way they’re very unscientific…they’re only looking for confirmation within

> their own paradigm…and when a different paradigm is introduced that shows promise they’re not interested…to me that’s one of the greatest disappointments of our medical system is how closed-minded they are…and unscientific.

Physician participants who were critical of the recommended immunization schedule were often also critical of the typical structure of conversations about vaccination at doctors’ offices. Many of these participants argued that at medical visits for vaccination doctors often do not live up to the standards of informed consent. For example, in the following quotation, Sean an obstetrics and gynecology physician discusses how he feels the recommended immunization schedule and interactions with medical professionals skew the process of consent in professional medicine:

> You know they’re taught in medical school what the vaccine schedule is…and now they’re being taught about how to convince vaccine-hesitant parents to get vaccinated…to me that’s incredibly poor medical training…and what it suggests to me is that they have no interest in informed consent, what they’re interested in is *compliance*.

He continues to criticize the contemporary patient-doctor relationship regarding vaccination:

> I think one side assumes people are too stupid to come up with a cogent argument and decision and therefore they want to mandate direct and dictate how you should live your life, and the other side believes that we have a right to the information and it's what's called informed consent and refusal, and we have the right to get information, and even if the information is sort of overwhelmingly toward one way, we still have the right to say no.

Megan, an internal medicine doctor similarly remarks on what she sees as a lack of respect for the intellectual qualities of parents making healthcare decisions for their children:

> What is even more interesting is that the strongest vaccine advocates also admit that the parents who are more likely to decline vaccines are the more educated more intelligent parents…and they find that distressing…it doesn't make them think well do you know maybe the parents are onto something…they just think they've been misdirected somehow…they don't really respect the intellectual qualities of the parents.

Roni, a general practitioner, criticizes the time constraints pervasive in the typical patient-doctor relationship. In the following quotation she explains the appeal of her private practice to patients:

> My patients know what I’m about and they come from all over to see me…so…you know…I don’t have that pressure of worrying about being fired…I also don’t…you know I spend 2 hours with my patients so I’m not billing insurance…I’m not you know getting threatened by insurance companies...like there’s just…you know I don’t have that pressure on me. It really is nice to have the autonomy because I can do what’s right for my patients and not what’s right for the medical centre billing department.

Insurance companies and managed care organizations in the United States were often seen as impediments to productive and trusting patient-doctor relationships. In contrast to more negative perceptions of interactions with medical professionals, Lisa, a Canadian vaccine-hesitant mother of two recounts a very positive experience interacting with her family physician when she was struggling with disagreeing with her husband regarding the decision of whether to vaccinate their child:

> My doctor like she was like the best sounding board instead because otherwise it's just it's too difficult when you're coming at it from two different opinions…I needed to kind of understand what he was coming from the question before I make a decision.
>
> Interviewer: I'm glad your doctor was a good sounding board for that because you know those people complain that their doctors weren’t really that open

Lisa: Yeah I think that's extremely rare…she never belittled or made me feel bad about entertaining not doing it…she was just like just kind of matter of fact and you know…I understand your fear I can't imagine having to make decisions like this all the time for someone I'm responsible for…I don't have my own child but I can tell you that if I did this is what I would choose and this is why…you know and so she was very like fair about it and she would just like to speak on kind of a more social and emotional level rather than always just like on that medical level but she would also give me the medical information…so yeah that was definitely invaluable.

Interviewer: Do you feel like some of your parent friends have had negative experiences trying to talk to their doctors?

Lisa: Yeah I think that there's kind of…it's bad to say but I think that there's a lot of *brainwashing* about it like…and I feel a bit hypocritical saying it sometimes because I ended up doing it…but the reason I feel confident in my choice is because I got there with my *own* thought process and with my *own* decision….and not because that's just what you do…whereas I feel like for a lot of people it just gets pushed down their throat…they believe it…they get told to do it…everybody else around them does it…they don't have any opportunity to even have a safe dialogue about it without being made to feel evil for not wanting to…like it yeah definitely I think very very very hard subject to get a broad equal amount of information on both sides.

4.4.4 Perspectives on Scientific Institutions

Most interviewees who disagreed with the scientific consensus on vaccines discredited the official childhood immunization schedules by undermining the legitimacy of specific institutions that regulate vaccines and construct national recommendations. Enforcement of safety standards conducted by The Food and Drug Administration (FDA) and rules for controlling vaccine-preventable diseases established by the Advisory Committee on Immunization Practices (ACIP) within the Centers for Disease Control and Prevention (CDC) were viewed as having insufficient independence from the pharmaceutical industry, a factor that was pivotal in undermining their perceived trustworthiness. In the social contract between science and society, regulatory agencies serve a key function of science in government institutions--enforcing safety regulations on products for the public based on science and establishing rules for conduct during infectious disease outbreaks. Essential to the government's credibility in this role is their independence and neutral position.

However, regulatory agencies have an institutional arrangement that has increasingly relied on pharmaceutical funding since the 1980s. In 1977 the American Academy of Pediatrics (AAP) issued a policy statement asserting that society had a responsibility to compensate those few who were injured by vaccines, suggesting that a vaccine compensation program be established. The American Medical Association (AMA) deliberated with pharmaceutical companies in 1983 to reach agreed upon terms for an injury compensation program. No-fault vaccine injury compensation legislation for vaccine manufacturers was enacted by US Congress in 1986 with the National Injury Compensation Program (NVICP) to offer protection to vaccine manufacturers against liability lawsuits. Many parents vocally opposed the complete protection from liability, arguing that without punitive risk, companies lacked incentive to ensure product safety.

Many participants who disagreed with the recommended immunization schedule echoed these concerns of parents in the 1980s that the formation of the National Injury Compensation Program (NVICP) removed institutional incentive for pharmaceutical companies to ensure safety standards. Many also remarked that the very existence of the program indicated a lack of vaccine safety. Sean, an obstetrics and gynecologist physician points to what he believes is an apparent contradiction between implementing an injury compensation program and delivering public health messages that communicate certainty about the safety of vaccines:

> I always found it funny that somehow the vaccine makers got immunity from being sued for medical injury yet they claim…like there are people out there like Sanjay Gupta who say that vaccines are perfectly safe and yet the government has something called the vaccine injury compensation fund and if you have a vaccine injury compensation fund there's got to be a reason you have a vaccine injury compensation fund…and it has to be because there are people who must have been injured from vaccines…so the propaganda of saying that vaccines are perfectly safe…is…*propaganda*…and…it has to be…I mean common sense would dictate that anybody who thought about it clearly would say that…that

> when someone says something is perfectly safe…they're lying…okay…because nothing is perfectly safe…nothing is perfectly bad…and nothing is perfectly safe…nothing is always or never…not in medicine…never…always [laughs].

When asked how she felt about the Centers for Disease Control and Prevention (CDC), Megan, an internal medicine doctor reacted by explaining that she considered the CDC untrustworthy due to the conflicts of interests on advisory committees as well as the opportunity for profit presented by no-fault liability for vaccine manufacturers:

> I just think that absolute trust in them is not warranted. I think that they and the committees that give advice on mandatory vaccine recommendations are permeated with conflicts of interest…I think that *especially* since the vaccine manufacturers are made virtually immune from any liability for side effects that this is a big profit maker for them because you don't have to wait for somebody to get sick…you can give it to everybody.

As a governmental body, regulatory agencies were discredited by pointing to no-fault liability legislation for vaccine manufacturers in the vaccine injury compensation fund, which was seen as taxpayers subsidizing pharmaceutical companies at the expense of public health. On the surface, this institutional arrangement seems like the government is forgoing patient safety to protect corporate interests, but historically the reason for this legislation is rooted in securing vaccine supply to protect population health. Vaccine injury compensation had emerged with the overarching goal of fulfilling a societal responsibility to those who are injured participating in a medical intervention that protects the community as a whole and practically to secure vaccine supply from vaccine manufacturers who the past had disincentivized to produce vaccines due to the number of lawsuits being filed.

Commercial funding of the FDA began in the 80s due to the HIV/AIDS crisis and the need for rapid assessment and approval of drugs. Previously the FDA was entirely taxpayer funded, but in response to intense public pressure for a prompter approval process which at the time took about 3-8 years, in the early 90s congress changed how the FDA was funded to speed up the process. Instead of being fully taxpayer funded the new setup would include funding from pharmaceutical companies so that the FDA could expand and hire more people to speed up the regulatory process and in exchange the FDA would have to set goal dates for drug reviews that were satisfactory to the drug companies. The FDA and Health Canada charge user fees to pharmaceutical companies seeking licensing and approval, and so ultimately these regulatory bodies are funded by the very industries they regulate. 45% of the FDA’s overall budget comes from user fees paid by companies it's reviewing and 65% of human drug regulation funding comes from Big Pharma itself.

The reputations of pharmaceutical companies were seen as largely irredeemable, not only due to the for-profit production of vaccines but because of major class action settlements amounting to billions of dollars:

> There’s just this like unwillingness to want to hear people’s stories because it rocks your world about we’re being protected by the government…the government’s out for our safety…you know the medical industry is out for our safety…the pharmaceutical companies would never lie [laughs] you know…which is like the *biggest* joke. They’ve been found guilty of criminal charges like I don’t know numerous times for fraud.

Pfizer Inc. received a record-breaking $1.3 billion criminal fine in 2009 and GlaxoSmithKline broke records for the largest civil False Claims Act settlement in 2012 at $3 billion. Recalls of blockbuster drugs such as Vioxx were highly publicized and remain in the public’s collective memory. Furthermore, the opioid crisis fuelled by the manufacturers of OxyContin--Purdue Pharmaceuticals is yet another example of wider societal injustices caused by industry influence and a lack of regulatory oversight. Purdue Pharma pleaded guilty twice to criminal wrongdoing and reached a $601 million settlement for its off-label promotion of OxyContin in violation of the False Claims Act in 2007. Many settlements also included illegal pharmaceutical kickbacks where companies bribed doctors to increase prescribing of their products.

Lisa, a vaccine-hesitant mother recalls part of her experience working at a pharmaceutical company as the primary source undermining her distrust in vaccines. When asked if funding by the pharmaceutical industry caused her concern, she stated:

> Huge….because I actually I guess for me maybe even more so than most because I was in a job in pharmaceuticals for a few years back in my twenties…and just kind of witnessed first-hand how much like Big Pharma kind of runs things and can change things in their favour and feed information to doctors and that kind of thing…like I had no idea until I worked for that company…so that really opened my eyes but in a way that maybe a lot of Canadians don't know and that's maybe why they're less skeptical…. but when I found that out…that it even happens in Canada and it's not just a U.S. issue…that kind of terrified me… because if you think about it their investment is not in health…their investment is in money…. right…and that's usually actually directly opposed to health…ironically…so yeah that was a really big factor for me figuring out like sifting through the information about vaccines.

Lisa had an administrative and logistics position at a pharmaceutical company booking flights, hotels, and cars for doctors attending pharmaceutical conventions and forwarding information to them. She also attended conferences and was present when they presented to doctors. Overall, this experience made her feel that there were inadequate checks and balances in place for conflicts of interest:

> Yeah and especially the fact that they were allotted so many loopholes…even though there's supposed…like I thought before I started

this job that there's supposed checks and balances in place to like to stop this kind of like essentially buying of doctors…but really it just proved to me that like they're useless and that they’re not doing nearly enough…and so it's really gonna be up to the doctor themselves as to whether they want to be ethical or not.

Interviewer: do you have an example of a loophole that you remember or something that maybe could be changed or should be changed?

Lisa: Sure…so like for instance it should be like I think illegal to give honorariums to doctors for attending conferences that have to do with pharmaceuticals…like they get around it because not being supposedly paid….like an honorarium isn’t considered a payment but it absolutely is…like what else is it going towards… money in their pocket…so that alone was the thing that was the most unsettling to me…but I mean on the other hand it’s tough because how do doctors get access to information about new drugs…like that’s relevant…but I think also one other thing that might be helpful is to have a third party involved like I don't think that it should be going directly from the from the pharma company to the doctor…I think that there needs to be a middleman that would be like a intermediary that would essentially allow it to be more like double-blind…so that it's not like directly pharma selling on their behalf directly

> to a doctor…and like it supposedly is that in Canada…but it is not like it's not that way at all…it's basically like we were involved in a botulinum toxin…like a massive conference that happens every year…and I was just like appalled at the fact that it can be like a 4 day like national level conference for whoever wants to attend….and be paid to attend…to be sold on Botox.

Vaccine proponents and immunization experts point out that independent groups recapitulate data on vaccines. Pharmaceutical companies may fund the manufacture of vaccines and clinical trials, but they do not fund the evaluation of vaccine safety that happens after this stage. Phase IV post-marketing studies are conducted by state-funded academic groups collaborating to determine if what was seen pre-licensure also holds up post-licensure. The Vaccine Safety Datalink consists of a collection of academic groups that evaluate studies, and The Vaccine Adverse Event Reporting System (VAERS), a national vaccine safety surveillance program co-sponsored by the Food and Drug Administration (FDA) and the CDC monitors adverse events. VAERS, however, has a passive design whereby the public reports on their own adverse reactions without scientific oversight meaning that some injuries are underreported and other injuries particularly ones that receive lots of media attention are likely overrepresented.

Doctors and scientists who disagreed with the scientific consensus on vaccines were distrustful of these federal bodies due to perceived insufficient processes for holding the institutional apparatus tasked with producing vaccine knowledge publicly accountable. Conflict-of-interest regulation was seen as largely ineffectual due to a revolving door between industry and regulatory agencies. Expert committees were seen as permeated with conflicts of interest. Prominent ‘vaccine-flexible’ pediatrician Dr. Bob Sears for example has stated that vaccination rates will not rise until research and policy are independent of financial conflicts of interest. In the following quotation, an American cardiologist comments on unchecked conflicts of interest as a ‘revolving door’:

> I think the CDC is a fraudulent organization, they’ve got plenty of people there I mean you know it’s a revolving door with big pharma, it’s a revolving door with big agriculture.

Scientists working in regulated industries can move freely to roles as regulators or legislators of these very industries and vice versa. Pharmaceutical companies can hire former government officials in hopes of gaining insider information and favourable legislation/ regulation with no lapse of time required between appointments. Moving immediately from public service to private contracts presents a conflict of interest as pharmaceutical companies can promise high-paying jobs to government officials in exchange for policy-making that serves their business needs. Regarding the revolving door between the agency and pharmaceutical industry jobs, researchers found 27 percent of regulators left the FDA to work in high-paying pharma jobs (Bien and Prasad 2016), thus regulators looking out for their own careers may go easy on pharma in order to stay in their good graces for later job opportunities. The mingling of regulators and company representatives at conferences and lunches held at high-end fancy hotels where regulators can make contacts to get pharma jobs also raises questions about potential conflicts of interest.

Accessing quality expertise while avoiding conflicts of interest is a significant challenge that the CDC and FDA face in assembling expert advisory panels for vaccines. Conflicts of interest often cannot be eliminated as most of the world's leading vaccine experts have ties to research on vaccine development at pharmaceutical companies. Scientists on the ACIP have conducted basic research that has created vaccines, been paid to run clinical trials to license vaccines, and consulted for pharmaceutical companies. Considering the major public health implications of immunization schedules and recommendations, it is important that the expertise employed on advisory committees is competent, credible, independent, and trusted by the public. The CDC and FDA are also obliged to ensure that the public benefits from the best expertise. Most members of federal advisory committees are special government employees (SGEs), a distinct legal category created by Congress to allow those who provide important and limited services to the Government to have loosened conflict of interest requirements (U.S. General Services Administration 2019).

Working relationships with vaccine manufacturers present issues for independent policymaking as conflicts of interest may lead scientists to favour business interests over the public good. Advisory committees manage these conflicts of interest with mandatory annual financial disclosure reports. After being submitted, the agency determines whether there are conflicts of interest that need to be addressed. The central conflict of interest statute in federal ethics, Section 208 of Title 18 of the U.S. Code, states that employees should not participate in matters where their knowledge has a direct and predictable effect on their financial interests or the financial interests of other people, organizations, or employers they are connected to. The law includes the provision of an exception for SGEs who serve on Federal advisory committees, allowing for individual waivers to be granted where the need for individual services outweighs potential conflicts of interest.

4.5 Conclusion

Vaccine hesitancy is a multidimensional phenomenon and by addressing the deeper concerns and experiences of vaccine-hesitant individuals, this research attempts to offer a more nuanced approach that focuses on socio-emotional factors and social trust. Public health officials have recognized that the vaccine debate is more complicated than for/ against positions and have emphasized the importance of thinking about vaccine hesitancy as a continuum and tailoring overtures accordingly (WHO 2020). The qualitative interview-based approach in this paper has allowed for a precise and fine-grained analysis that captures some of the points on this continuum from the perspective of those who hold these views.

Rather than a monolithic group, participants were heterogenous and not necessarily part of a movement with a coherent ideology. Instead, they cited specific values and institutional activities that diminished their trust in vaccination. The label of ‘anti-vaccine’ that had been assigned to some participants was seen as a strategy that blames and shames, stigmatizing individuals and leading to affective polarization.

Beyond labeling, in everyday conversations and at times in professional settings a range of participants felt that their ideas were shut down without a forum for productive dialogue.

Interactions with medical professionals at routine visits for vaccination were problematized by some participants who centred their critiques about vaccines around the professional norm of informed consent in bioethics and emphasized the need for patient autonomy and individuality. One vaccine-hesitant participant, however, described how her physician's respectful, empathetic and dialogical approach was key in conferring her trust in vaccination.

Understanding these social dynamics and underlying social processes is important for developing impactful public health interventions. The primary source of vaccine hesitancy and distrust of the scientific consensus in this group, however, was an institutional arrangement which may be more difficult to mitigate, namely the influence of the pharmaceutical industry on scientific institutions. Most participants felt that this relationship and the conflicts of interest generated compromised the integrity of vaccine science.

These findings are limited in that as a non-probability purposive and snowball sample they have low generalizability, however, by looking closely and in a grounded way at a range of views on vaccination and the individuals who express them, insights might be gleaned into responses to the COVID vaccine and how to best address them. For example, the trends of labeling, stigma and polarization were extended and magnified during the COVID-19 pandemic (Labbé et al. 2022) and tackling ‘infodemics’ continues to be a global problem for public health.

In the current climate of growing political polarization (Pew Research Center 2014; 2019), increasing distrust in institutions (Rainie et al. 2019), and an online information environment that fosters echo chambers and dissensus (DiResta 2019), citizens engaging in meaningful conversations have become more important than ever. Understanding how language, stigma, and trust influence the social dynamics surrounding vaccines is integral for consensus building and social cohesion. As a signal of meaning-making activities, when language misses nuance or involves stigmatizing rhetoric, it can lead to polarization.

4. 6 References

Albert, K. (2019) Beyond the responsibility binary: analysing maternal responsibility in the human papillomavirus vaccination decision. *Sociology of Health & Illness* 41(6):1088-1103.

Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES (2006) Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. *Pediatrics*. 117(5):1532-41.

Bien, J, and Prasad, V (2016) Future jobs of FDA’s haematology-oncology reviewers. *British Medical Journal* 354: i5055.

Bramadat, P (2017) Crises of Trust and Truth: Religion, Culture, and Vaccine Hesitancy in Canada In: Bramadat, P, Guay, M, Bettinger J and Roy, R (eds). *Public Health in the Age of Anxiety: Religious and Cultural Roots of Vaccine Hesitancy in Canada*. Toronto: University of Toronto Press.

Carpiano, R and Polonijo, A (2013) Social inequalities in adolescent human papillomavirus (HPV) vaccination: a test of fundamental cause theory. *Social Science and Medicine* 82: 115-125.

Caufield, T (2017) *The Vaccination Picture*. Viking, an Imprint of Penguin Canada, a Division of Penguin Random House Canada Limited.

Creswell, J. (2007) Five Qualitative Approaches to Inquiry. In J.W. Creswell (eds.) *Qualitative Inquiry and Research Design: Choosing among five approaches* (pp.. 53-84). Thousand Oaks: Sage Publications.Crowcroft, N (2021) PHO Talks: The Invisible Heroes of Immunization. Available at: https://www.youtube.com/watch?v=rwDYCq0830w (accessed December 2021).

Daley, M and Glanz, J (2011) Straight Talk about Vaccination. *Scientific American* 305(3): 32-35.

DiResta, R (2019) Mediating Consent. Available at: https://www.ribbonfarm.com/2019/12/17/mediating-consent/ (accessed 10 October 2021).

DiResta, R. and Garcia-Camargo, I (2020). Virality Project (US): Marketing meets Misinformation. *The Stanford Internet Observatory Cyber Policy Center*. Available at: https://cyber.fsi.stanford.edu/io/news/manufacturing-influence-0 (accessed 26 May 2020).

Dubé, E (2020) Restoring confidence in vaccines in the COVID-19 era, *Expert Review of Vaccines*, 19:11, 991-993.

Dong, L., Bogart, L., Gandhi, P., Aboagye, J., Ryan, S., Serwanga, R., Ojikutu, B. (2022). A qualitative study of COVID-19 vaccine intentions and mistrust in Black Americans: Recommendations for vaccine dissemination and uptake. *PLos One.* 17(5):e0268020.

Dubé, E., Gagnon, D., Nickels, E., Jeram, S., & Schuster, M. (2014). Mapping vaccine hesitancy—Country-specific characteristics of a global phenomenon. *Vaccine*, *32*(49), 6649-6654.

Dubé E, Vivion M, Sauvageau C, Gagneur A, Gagnon R, Guay M (2016) Nature Does Things Well, Why Should We Interfere?": Vaccine Hesitancy Among Mothers. *Qualitative Health Research.* 26(3):411-425.

Dubé, È., Ward, J. K., Verger, P., & MacDonald, N. E. (2021). Vaccine hesitancy, acceptance, and anti-vaccination: trends and prospects for public health. *Annual Review of Public Health*, *42*(1), 175-91.

Labbé, F, Pelletier, C, Bettinger, JA, Janet Curran, Janice E. Graham, Devon Greyson, Noni E. MacDonald, Samantha B. Meyer, Audrey Steenbeek, Weiai Xu, Ève Dubé (2022) Stigma and blame related to COVID-19 pandemic: A case-study of editorial cartoons in Canada" *Social Science & Medicine* 296. 114803.

Fortuna, G. (2019) Vaccines are victim of their own success, global health expert says. *Euractiv*. available at: https://www.euractiv.com/section/health-consumers/interview/vaccines-are-victim-of-their-own-success-global-health-expert-says/ (accessed 15 March 2022).

Fauci, A. (2020). Dr Anthony Fauci warns against violent anti-science feeling in polarised US-video. *The Guardian*. Available at: https://www.theguardian.com/science/video/2020/nov/12/dr-anthony-fauci-violent-anti-science-feeling-polarised-us-video (accessed 15 Nov 2020).

Gaudino, JA. and Robisona, S (2012) Risk factors associated with parents claiming personal-belief exemptions to school immunization requirements: Community and other influences on more skeptical parents in Oregon, 2006" *Vaccine* 30:1132–1142.

Goffman, Erving (1963) *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon & Schuster.

Gowda C, Dempsey AF. (2013) The rise (and fall?) of parental vaccine hesitancy *Human Vaccines & Immunotherapeutics* 9(8):1755-1762.

Guston, D (2000) *Between Politics and Science: Assuring the Integrity and Productivity of Research.* Cambridge University Press.

Hotez, PJ. (2021) Mounting antiscience aggression in the United States PLOS Biology 19(7): e3001369.

Lamont, M, Silva, GM, Welburn, J, Guetzkow, J, Mizrachi, N, Herzog, H, and Reis, E. (2016) *Getting Respect: Responding to Stigma and Discrimination in the United States, Brazil, and Israel*. Princeton, NJ: Princeton University Press.

Larson, H. J, Jarrett, C, Eckersberger, E., Smith, D. M, & Paterson, P. (2014). Understanding vaccine hesitancy around vaccines and vaccination from a global perspective: a systematic review of published literature, 2007–2012. *Vaccine, 32*(19), 2150-2159.

Larson HJ, Jarrett C, Schulz WS, Chaudhuri M, Zhou Y, Dube E, Schuster M, MacDonald NE, Wilson R; SAGE Working Group on Vaccine Hesitancy (2015) Measuring vaccine hesitancy: The development of a survey tool. *Vaccine* 33(34):4165-75.

Link, Bruce G., and Jo C. Phelan (2001) Conceptualizing Stigma. *Annual Review of Sociolog*y, 27: 363-385.

Luthy KE, Beckstrand RL, Peterson NE (2009) Parental hesitation as a factor in delayed childhood immunization. *Journal of* Pediatric *Health Care*, 23(6):388-93.

Opel DJ., Robinson, JD., Heritage, J., Korfiatis, C., Taylor, JA., Mangione-Smith, R. (2012) Characterizing providers' immunization communication practices during health supervision visits with vaccine-hesitant parents: A pilot study. *Vaccine*, 30(7): 1269-1275.

Opel, DJ, Heritage, J, Taylor, JA, Mangione-Smith, R, Salas, H. S, Devere, V, Zhou, C, & Robinson, JD. (2013). The architecture of provider-parent vaccine discussions at health supervision visits. *Pediatrics*, *132*(6): 1037–1046.

Opel DJ, Taylor JA, Zhou C, Catz S, Myaing M, Mangione-Smith R. (2013) The Relationship Between Parent Attitudes About Childhood Vaccines Survey Scores and Future Child Immunization Status: A Validation Study. *JAMA Pediatrics.* 2013;167(11):1065–1071.

Pew Research Center (2014) Political Polarization in the American Public: How increasing ideological uniformity and partisan antipathy affect politics, compromise and everyday life. Available at: https://www.pewresearch.org/politics/2014/06/12/political-polarization-in-the-american-public/ (accessed 17 Mar 2020).

Pew Research Center (2019a) In a Politically Polarized Era, Sharp Divides in Both Partisan Coalitions: Partisanship remains biggest factor in public's political values. Available at: https://www.pewresearch.org/politics/2019/12/17/in-a-politically-polarized-era-sharp-divides-in-both-partisan-coalitions/ (accessed 17 Mar 2021).

Rainie, L, Keeter, S and Perrin, A. (2019) Trust and Distrust in America: Many Americans think declining trust in the government and in each other makes it harder to solve key problems. *Pew Research Center*, 19 Jul 22. Available at: https://www.pewresearch.org/politics/2019/07/22/trust-and-distrust-in-america/ (accessed 4 Apr 2021).

Reich JA. (2014) Neoliberal Mothering and Vaccine Refusal: Imagined Gated Communities and the Privilege of Choice. *Gender & Society*. 28(5):679-704.

Reich, J. (2016) *Calling the Shots: Why Parents Reject Vaccine*. New York: New York University Press.

Reich, J. (2020) Vaccine Refusal and Pharmaceutical Acquiescence: Parental Control and Ambivalence in Managing Children's Health. *American Sociological Review* 85(1):106-127.

Shui, I., Kennedy, A., Wooten K., Schwartz, B, Gust, D. Factors influencing African American mothers' concerns about immunization safety: a summary of focus group findings. *Journal of the National Medical Association* (2005): 97(5): 657-66.

U.S. General Services Administration (2019) Special Government Employees (SGEs). Available at: https://www.gsa.gov/policy-regulations/policy/federal-advisory-committee-management/advice-and-guidance/special-government-employees-sge (accessed 15 July 2022).

Verger, P and Dubé, E. (2020) Restoring confidence in vaccines in the COVID-19 era, *Expert Review of Vaccines*, 19(11): 991-993.

WHO (2017) Vaccination and trust: How concerns arise and the role of communication in mitigating crises. Available at: https://www.euro.who.int/__data/assets/pdf_file/0004/329647/Vaccines-and-trust.PDF (accessed 10 Jan 2022).

WHO (2020) Cross-Regional Statement on "Infodemic" in the Context of COVID-19. Available at: https://onu.delegfrance.org/IMG/pdf/cross-regional_statement_on_infodemic_final_with_all_endorsements.pdf (accessed 15 Jun 2020).

Chapter 5

Conclusion

Taken together, the three articles presented in this dissertation address various dimensions of vaccine hesitancy and mistrust in science as a social phenomenon. Applying a sociological imagination to what is often viewed as individual health behaviours, I have also attempted to theorize broader questions about the current place of expertise in civil society. My journey with this topic began thinking about vaccine hesitancy as an issue about scientific facts, but in the end, I came to see that many of the issues fit squarely on trust in scientific institutions.

While the meso-sociological organization of science remained relevant, I learned the analytic necessity of taking a social constructionist angle to understand the interpretations of participants, and the importance of examining both the construction of expertise and the 'breakdown of expertise' relationally as a social construction. Ontologically, beliefs about science exist only as there exist social groups, processes and interactions. Epistemologically, the social context and structures that interact with these ideas can be arrived at through reason and evidence. This acknowledges the underdetermination of scientific theories, as well as the empirical world as a constraint on the development of scientific knowledge.

In Chapter Two, I examined the specific organizational context and academic cultures in which the 1998 MMR-autism controversy emerged. Using a case study approach, I show that the controversy resulted not only from Andrew Wakefield's individual scientific misconduct but from missed signals of deviance in the surrounding academic culture. This is significant because it goes beyond the immediate actors and points to the social dynamics that may unintentionally contribute to misinformation and distrust in the public sphere. Implications of this specific case study are broadened to understand how seemingly mundane patterns and reward systems in organizations can have far-reaching impacts on trust in science. Although a historic case that occurred over two decades ago, the themes of this analysis of science gone wrong still have relevance for the interface of research incentive structures and scientific credibility today.

The article's application of Diane Vaughan's (1996) concept of the 'normalization of deviance' has not been used in this way before, and future research could examine the applicability of this concept to academic research cultures and potentially examine it in conjunction with the different facets of university relations that undermine scientific credibility. For example, the concept could be specified and elaborated in academic scholarship that considers the reproducibility crisis as a series of varied problems where STS can have insights (Nelson 2021). It could also be expanded to understand broader attacks on the university from political parties or individual whistleblowers (McLaughlin 2021).

In Chapter Three, I introduced the concept of an anti-scientific intellectual movement (ASIM). This contribution to the literature addresses social movements that challenge science as a system of knowledge and a set of institutions. Unlike Frickel and Gross's (2005) theoretical framework of a scientific intellectual movement (SIM), ASIMs mobilize intellectual resources outside of the university to confront mainstream science. This social phenomenon has expanded in contemporary society as social media has increased the speed and diffusion of these ideas (DiResta 2021; DiResta and Garcia-Camargo 2020) and distrust in institutions is on the rise (Cowan and Reich 2021; Rainie et al. 2019).

This chapter aligns with Frickel and Moore's (2006) 'new political sociology of science' research program that focuses on political organization and social networks as units of analysis. Instead of examining science, this chapter examines ideas outside of the scientific consensus and situates them within social structures and an STS lens. In addition to these structures, it engages with the cultural elements of social change and collective action framing to understand how anti-vaccine ideas resonate in a variety of socio-cultural contexts.

The substantive and conceptual implications of this contribution are an emphasis on extra-institutional factors that impact the interface between expertise and civil society. For the case examined, the modern anti-vaccine movement, these factors were parental grievances about the medical establishment's treatment of autistic children, structural resources available from private donors, cultural products in the form of books, documentaries, and amplified by celebrities, frame resonance with the natural health movement, and frame translation to health freedom and populist movements.

Beyond this case, the concept of an ASIM has the potential to deepen our analytic understanding of how the public understands scientific research fields. The scientific consensus has been challenged by diverse audiences not only regarding vaccines, but with climate change, and beyond the scientific consensus, the very legitimacy of the university has been challenged by members of the intellectual dark web (IDW) and opponents of critical race theory (CRT).

Demarcating scientific movements from anti-scientific movements, however, can be complex and at times controversial. For example, Indigenous ways of knowing have been critical of scientific notions of DNA and race but worked alongside mainstream science in tackling solutions to climate change. The transgender rights movement has agreed with the scientific consensus regarding the distinction between biological sex and gender but at times the implications of these biological differences have been the subject of political debate. The complexities of these movements and their relationship to mainstream science makes theory building ever more important. ASIMs build on the SIM theoretical framework in hopes of taking it in new directions.

For Chapter Four of this dissertation, I focused on the individual experiences and meaning-making activities of individuals with unique positions in the debate on vaccination. Everyday interactions have wider impacts on how people perceive the matrix of values surrounding the scientific consensus on vaccines and the proponents of this perspective. Experiences of being labeled or stigmatized, feeling shut down in general discussions and in patient-physician interactions, left participants feeling alienated and at times further entrenched in their views. The deep story in this chapter is about people who feel shut out of conversation and stigmatized, their distrust of mainstream scientific institutions and their apprehension about the profit motive and influence of the pharmaceutical industry. Rhetoric and public health communications that treat vaccine hesitancy or vaccine refusal as a single ideology, therefore, will likely backfire, and the use of nuanced language that addresses specific values and concerns is necessary for the public to feel that these interactions are genuine.

There are, however, several limitations to this research. First, as in-depth qualitative research, this dissertation lacks generalizability. The findings, although nuanced and detailed, are not representative of the population at large. Statistical research from probability samples is needed to complement the observations made throughout this analysis to determine the extent and reliability of data. Additionally, all the coding done for thematic analyses was conducted by a single researcher and so the validity of the findings requires more systematic testing.

The findings in Chapter Two are limited in that it’s difficult to ascertain the extent that academic cultures and incentive structures in the university contributed to the initial spread of misinformation about the MMR vaccine. In line with the limitations of case studies in general, the relative causal weights and magnitude of the contextual factors identified cannot be measured. Further, as a single case study, rather than a comparative case analysis, it is not clear how these findings would translate to other types of cases.

Chapter Three is methodologically limited in that the research included was at the discretion of the researcher. As an attempt to theorize controversial ideas about vaccination as a social movement, the keywords ‘anti-vaccine’ and ‘movement’ were input in the Google Scholar search engine. While these were reasonable choices for the theoretical goals at hand, other researchers may have used a different method of accessing data or focused on different results, garnering different conclusions. As such, certain relevant literature on the topic may not have been identified. This paper aimed to summarize and consider the data’s fit with the theory and did not conduct a detailed comparison of the varying metrics and methods used across studies.

Chapter Four is based on interview data from a purposive sample of individuals targeted based on their professional standings as scientists and doctors with views on vaccination that are outside the scientific consensus. As such, the findings, while able to extrapolate information, are not able to generalize about vaccine-hesitant or vaccine-resistant populations at large. Many participants were homogenous in the sense that they were part of a niche group that had specific experiences and interactions with the media and their critiques of vaccination centered on the institution of science, which they were simultaneously a part of and felt alienated from. Ultimately this was an educated and privileged group that likely voiced different concerns than would a random sample consisting of individuals with varying income and education levels, and racial/ethnic backgrounds.

For example, ethnic and racial groups have been found to have community-specific concerns. Black American mothers have been found to have high levels of apprehension about vaccination. They are more likely to distrust their child's healthcare provider, disagree that their child's healthcare provider was easy to talk to, and more likely to want more information about vaccine ingredients to ensure they are safe (Shiu et al. 2005). Further, during the COVID-19 pandemic black Canadians were more likely to be hesitant about the COVID-19 vaccine and worry about discrimination in healthcare (CBC 2021).

Populist groups have also opposed vaccine mandates and the scientific consensus on vaccines during COVID-19 (DiResta and Garcia-Camargo 2020; Lasco and Curato 2019; Sabahelzain et al. 2021). The populist distrust of establishment elites and tensions between experts, authorities, and the public were played out during the COVID-19 pandemic and political identity eventually trumped demographics and institutional trust as an explanatory factor for vaccine hesitancy (Cowan and Reich 2021).

Beyond sampling biases this research may have been subject to researcher biases. The thematic analysis stage of the research process would have benefited from multiple coders to achieve higher consistency, validity, and inter-coder reliability. This is a limitation that future research could address by employing additional researchers for coding data.

The unprecedented COVID-19 pandemic magnified many of the themes in this dissertation and given the continued centrality of misinformation in public debates and distrust of expertise it is hoped that these findings can illuminate areas where trust can be built between science and public audiences. Misinformation circulating online has often been characterized as an 'infodemic' and the influential accounts involved as ‘superspreaders’ emphasizing their consequences for public health. The World Health Organization prioritized managing the ‘infodemic’ over COVID-19 publishing a cross-regional statement on the matter signed by member states in 2020 and implementing programs and resources to address possible solutions.

The “Disinformation Dozen” is a term that was given by the non-profit Center for Countering Digital Hate (CCDH) to the top twelve influential figures that have disseminated the majority (65%) of online disinformation during the COVID-19 pandemic. Three members of the disinformation dozen list are anti-establishment or contrarian scientists, Dr. Joseph Mercola, Dr. Christiane Northrup and Dr. Rashid Buttar. Others on the list include lawyer and politician Robert F. Kennedy Jr.

Some political commentators and scientists have made calls to de-platform the disinformation dozen (Salzberg 2021). Since the publication of the list Joseph Mercola, Robert F. Kennedy Jr. and Rashid Buttar have all had their accounts removed from YouTube. Facebook took punitive measures against the Disinformation Dozen in August 2021 one month after pressure from the White House and critical comments from Press Secretary Jen Psaki. Dr. Christiane Northup has criticized its formation as a “smear campaign” that is contrary to democratic ideals and open scientific debate. “Science purged of free and open debate is no longer science” she wrote on her Facebook page: “Dissenting opinion freely and openly expressed is one of humanity’s highest standards. In August 2021, Dr. Joseph Mercola announced that he would post articles every day that would be available on the site for only 48 hours. He explained his decision by saying he's facing “blatant censorship” as part of a “McCarthyism-like attack" from "the sitting

President of the United States." He encouraged people to read his 2021 book, *The Truth about COVID-19: Exposing the Great Reset, Lockdowns, Vaccine Passports, and the New Normal*.

Tech platforms implemented stricter misinformation policies to reflect the widespread public health threat of COVID-19. Twitter, Facebook, Instagram and YouTube introduced new labels and warning messages for misleading or false content, directing users to authoritative information from the WHO and CDC, and demoting the false content in people's feeds. Content that was deemed likely to cause imminent harm was removed entirely from these platforms. YouTube terminates channels after three strikes within 90 days. In May 2020 the conspiratorial film *Plandemic* was removed from YouTube and Facebook and prominent conspiracy theorist David Icke had his YouTube channel terminated. YouTube's demonetization and restricted recommendation algorithm policies for misinformation was found to reduce the visibility of anti-vaccine content (Abul-Fottouh et al. 2020).

Approaches that avoid full-on censorship by downranking content on social media feeds and limiting re-uploads while at the same annotating content with credible information have been recommended by scholars at the Virality Project (DiResta et al. 2020) to avoid an unintended consequence known as the 'Streisand Effect' whereby censored information gains popularity based on its status as censored information. However, the widespread imminent threat of COVID-19 meant that a lot of content and some accounts have been entirely removed. Facebook policy states that it removes false content about the existence or severity of COVID-19, COVID-19 transmission and immunity, guaranteed cures or prevention methods for COVID-19, as well as content that discourages good health practices, or inaccurately represents access to or availability of essential health services.

As debates about vaccination continue and concerns about the proliferation of ‘infodemics’ more broadly are brought to the fore, this research sheds light on and attempts to disentangle the factors, social dynamics, and social processes at play that can lead to trust and distrust in public audiences. Contributions from organizational sociology, social movements theory, and insights from fine-grained qualitative data and lived experience allow us to understand and tackle this social issue from a variety of angles.

Further sociological research should delve deeper into these issues and three areas of inquiry:

(1) The organization of ‘normal science’ at the university and in peer-review and how incentive structures may affect public credibility
(2) A more systematic and broader examination of anti-scientific intellectual movements (ASIM)
(3) More extensive interview research examining a wider variety of actors and perspectives, including racialized minority communities and populist conservative activists

My research findings allow readers to understand the factors involved in the value-laden relations between internal scientific processes and the public, while developing insights into the important role of STS scholarship to vaccine hesitancy and the COVID-19 pandemic (Sismondo 2020) and ‘post-truth politics’ in general (Sismondo 2017). These analyses address broad historical changes and their sociopolitical implications as well as micro-sociological interactions in the hopes that immunization programs can be tailored accordingly. At a time when institutional experts are struggling to adapt to the new online information ecosystem, contrarian experts along with other non-expert commentators and influencers have been filling the gap (DiResta 2021). Although dissent is usually encouraged in science and considered indicative of a healthy knowledge enterprise, scientific controversies in the public have not been well-managed.

References

Abul-Fottouh D, Song MY, Gruzd A. (2020) Examining algorithmic biases in YouTube's recommendations of vaccine videos. International Journal of Medical Informatics. 140:104175.

CBC (2021) “Black Canadians more likely to be hesitant about COVID-19 vaccines, survey suggests” Available at: https://www.cbc.ca/news/health/black-canadians-vaccine-hesitancy-covid19-1.6102770 (accessed 5 September 2021).

Cowan, S, Mark, N, and Reich, J. (2021) COVID-19 vaccine hesitancy is the new terrain for political division among Americans. *Socius: Sociological Research for a Dynamic World* 7(4): 237802312110236.

DiResta, R. (2021) “The Anti-Vaccine Influencers Who Are Merely Asking Questions” The Atlantic. Available at: https://www.theatlantic.com/ideas/archive/2021/04/influencers-who-keep-stoking-fears-about-vaccines/618687/ (accessed 24 April 2021).

Frickel, S, and Gross, N. (2005) A General Theory of Scientific/Intellectual Movements *American Sociological Review* 70(2): 204-232.

Frickel, S., and Moore, K. (2006) *The New Political Sociology of Science: Institutions, networks, and power.* University of Wisconsin Press.

Lasco G, and Curato, N. (2019) Medical populism. *Social Science & Medicine* 221(1): 1-8.

McLaughlin, N. (2021) The Jordan Peterson Phenomena: Why Fromm's ideas and public intellectual vision is essential for responding to reactionary populism. *Fromm Forum*. 25: 74-89.

Nelson, NC. (2021) Understand the real reasons reproducibility reform fails. *Nature* 600(7888):191.

Salzberg, S. (2021) De-platform The Disinformation Dozen. Forbes. Available at: https://www.forbes.com/sites/stevensalzberg/2021/07/19/de-platform-the-disinformation-dozen/?sh=29680a773786 (accessed 19 Jul 2021).

Sabahelzain MM, Hartigan-Go K, and Larson HJ. The politics of Covid-19 vaccine confidence. *Current Opinion in Immunology*. (2021) 71:92-96.

Shui I, Kennedy A, Wooten K, Schwartz B, and Gust D. (2005) Factors influencing African-American mothers' concerns about immunization safety: a summary of focus group findings. *Journal of the National Medical Association*. 97(5):657-66.

Sismondo, S. (2017) Post-truth? *Social Studies of Science* 47(1): 3–6.

Sismondo, S. (2020). COVID-19. *Social Studies of Science* 50(2), 173-174.

Vaughan, D (1996) *The Challenger Launch Decision*. Chicago: University of Chicago Press.

Appendix A

Recruitment Email

APPENDIX 1

Email Recruitment Script
Michelle Goldenberg, M.A.
Ph.D. Candidate in Sociology
“The Perspective and Experiences of Vaccine-Hesitant Physicians”

Email Subject Line: McMaster University Study on the Perspective and Experiences of Vaccine-Hesitant Physicians

Hi [insert participant name]

My name is Michelle Goldenberg, I am a PhD student at McMaster University, and I am doing my dissertation on contested knowledge in the medical profession. I am contacting you today to ask if you will be willing to participate in my research study on the anti-vaccination movement. I am using the case of the anti-vaccine movement to explore controversies in medicine and how the medical profession works these out. I am particularly interested in the views of physicians who take a vaccine-hesitant stand and their experiences advancing these views among their colleagues. The interview would cover questions about your background in medicine and your general views about alternative and complementary medicine. But mostly, I will be focusing on what you think about vaccines and your position with respect to the anti-vaccine movement.

If you are willing to be interviewed, I would love to talk to you.

I expect the interview to last about (1) hour. I would be happy to schedule the interview whenever it is most convenient for you. I would be doing the interview either by phone or online. I will ensure on my end that I will be in a soundproof room at McMaster University, and if you choose to connect online, I will use Cisco Web Ex web conferencing application, which encrypts all its media streams.

I am attaching a letter of information that includes more details about the study.

I would like to thank you in advance for your time and consideration. I hope to hear from you. If I do not hear from you, I will send you a one-time reminder.

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Appendix B

Interview Schedule

B.0.1

1. Could you tell me a bit about your medical training and background?
    - How and why did you get into medicine?
    - Where did you do your training?
    - [If relevant] At what point did you decide to specialize?
    - Why this specialty?
2. Can you explain your views on the vaccine issues and how you came to hold these views?
    - Have you always felt this strongly about the issue?
    - Was there a particular experience that led you to these views?
3. How do your views translate into your own practice and how you advise your patients?
4. Are your views about vaccines linked to your views on complementary or alternative approaches to medicine more generally?
    - What do you think about complementary or alternative medicine?
    - Do you think there has been sufficient openness to these approaches in mainstream medicine?
    - Have you seen progress?
5. Going back to the vaccine issue, has it been difficult for you to take the position you have?
    - What are some of the biggest challenges you’ve faced in taking the position you have?
    - Do you feel you can share your views freely and openly?
    - Can you tell me about some of the reactions you have gotten?
6. Do you promote your views on vaccines and try to persuade your colleagues or get them to understand why you feel as you do?
    - How?
    - In what places or under what circumstances?
7. What about some of the arguments that are commonly used to criticize the vaccine movement? Can I get your reaction to some of those arguments?

        - Like the argument that those who take a vaccine-hesitant position are being unscientific.
        - Like the argument that the anti-vaccine movement has led to disease outbreaks.
8. Have you seen any movement among your colleagues at all in how they think about the vaccine issue?
    - If so, what factors do you think are contributing to that movement?
    - If not, what factors do you think are stopping any movement?
9. How does the media fit into all of this? What role do you think the media has played as far as how the public generally thinks about vaccines?
    - What about celebrities?
10. As a movement, is there anything you think the anti-vaccine movement can be doing to either promote its views more effectively or counter some of the negative press it gets?