

Vaccine Hesitancy:

Changing Priorities Towards a Lens of Compassion and Opportunity

by

Isabel Clasen

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## **Abstract**

Vaccine hesitancy and refusal is an increasingly important topic, especially as concerns appear to be on the rise after the COVID-19 pandemic and subsequent vaccine rollout. While concerns about vaccines are often brushed off as ignorance or conspiracy, this is not necessarily the case. Rather, vaccine hesitancy and refusal highlight a lack of trust in the larger institutions these vaccines come to represent, such as medical, scientific, and political institutions. This is often rooted in both personal and historical reasons which need to be addressed, as they highlight larger societal issues. My research focuses on recent vaccine concerns in the Global North, with my own research being conducted in Southern Ontario, however, this is an issue that spans across space and time. Similarly to previous research on the topic, I found that underlying distrust due to negative experiences appeared to correlate with increased vaccine hesitancy and refusal. Hesitancy is also noted as an important potential area of intervention, as those who are hesitant appear to be more likely to change their minds with the help of compassionate interactions based in trust. Thus, hesitancy offers a much-needed opportunity for public health to engage with the public in a meaningful way, thereby both building trust in vaccines and the institutions they come to represent, as well as aiding in the maintenance of herd immunity in order to protect those who are vulnerable.

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## List of Abbreviations

WHO	World Health Organization
US	United States of America
SIDS	Sudden Infant Death Syndrome
CDC	Centers for Disease Control and Prevention
OPV	Oral Polio Vaccine
GPEI	Global Polio Eradication Initiative
PHAC	Public Health Agency of Canada
VCC	Vaccine Choice Canada
IPAC	Infection Prevention and Control
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, 3 <sup>rd</sup> Edition
VISP	Vaccine Injury Support Program
HRSA	Health Resources and Services Administration
DTP	Diphtheria, Tetanus, whole cell Pertussis
DTaP	Diphtheria, Tetanus, acellular Pertussis
MMR	Measles, Mumps, Rubella
JABS	Justice, Awareness and Basic Support
UK	United Kingdom

# Chapter 1

## Vaccine Hesitancy: Changing Priorities Towards a Lens of Compassion and Opportunity

### 1.1 Introduction

The COVID-19 pandemic highlighted the importance of understanding social resistance to vaccination. While it is often attributed to ignorance and a rejection of science, the problem is more complex and requires deeper analysis and understanding (Goldenberg 2021). Instead, vaccine choices can be understood as processes, with trust playing a central role (Goldenberg 2021; Sobo 2016). Issues of trust are largely related to both personal experiences with healthcare providers, and on a larger scale, how one views the healthcare system and related governing bodies (Dubé et al. 2015; Goldenberg 2021). Thus, many with concerns about vaccines are questioning or rejecting something much larger than vaccines themselves, such as the people and institutions in power that vaccines come to represent (Goldenberg 2021). This often highlights larger societal issues, which cannot be dismissed, as it risks creating further distrust and refusal.

In this thesis, I will begin with a brief outline of the origins of vaccination, as well as a discussion about the most prominent vaccine controversy, that of the MMR vaccine. It is important to understand this context as it highlights the, at times, problematic and controversial past of vaccination, which impacts hesitancy and refusal. This offers insight into potential reasons for vaccine concerns, which I will discuss in the context of the Global North, prior to the COVID-19 pandemic. Finally, I will discuss my own research, focusing on vaccine beliefs and choices in Southern Ontario, Canada. While not solely about COVID-19 vaccines, my research took place in 2023, a few years after the initial outbreak. Therefore, the focus of many participants was centred around the pandemic and COVID-19 vaccines. I will end with a brief discussion of the limitations and proposed future directions for research regarding vaccine hesitancy and refusal, focusing on the importance of taking a compassionate approach and zeroing in on hesitancy specifically, as a zone of intervention that should not be ignored.

Throughout my thesis I will discuss both vaccine hesitancy and refusal, however, I hope to make clear the specific importance of vaccine *hesitancy*. One study by Dubé et al. (2016) conducted in Quebec, Canada showed similarities between mothers who accepted and refused vaccines, in the way that despite their differing viewpoints, both groups expressed confidence about their vaccine decisions. Oppositely, the hesitant mothers were shown to be more precarious, weighing both the potential risks and rewards for each vaccine for each of their children (Dubé et al. 2016). Additionally, these hesitant mothers were the least likely to have confidence in their decisions about vaccination, and because of this, they kept changing their minds (Dubé et al. 2016). This indicates that hesitancy is potentially more malleable; that those with burgeoning concerns are potentially more likely to change their minds depending on the circumstances. This is why it is crucial to better understand those who are vaccine hesitant, so that concerns can be addressed and dealt with properly while there is still a chance. Furthermore, I think it is also increasingly important to consider long term goals referring to building trust in the public healthcare system and long-term vaccine acceptance, rather than using pressure tactics to gain short term acceptance. While it is understandable to

be focused on short term goals, especially during a pandemic, it is worth considering if short term acceptance, created by pressure, is worth it at the expense of long-term vaccine uptake.

Vaccine hesitancy offers those within the healthcare space desiring vaccine acceptance an often-missed opportunity for engagement with members of the public who have concerns (Goldenberg 2021), wherein they have the chance to not only change minds about vaccination, but also make people feel heard, thereby building trust. Understanding the multiple factors that shape vaccine hesitancy and refusal is important to public health, especially as herd immunity relies on vaccine acceptance from a majority of the population (World Health Organization (WHO) 2020). A dismissal of those who hesitate or refuse vaccines as simply ignorant fails to acknowledge the myriad and complex factors that shape such attitudes. Instead, I propose approaching vaccine concerns with compassion. While I am pro-vaccination, I am also firmly pro- a humane response to vaccine concerns, and I think doing this can be beneficial for all.

## **1.2 The Origins of Vaccination**

### **1.2.1 From Inoculation to Vaccination**

Vaccination's predecessor, known as inoculation or variolation, was being used in various regions prior to the 17<sup>th</sup> century to protect against smallpox, which has a 30% fatality rate (Gross and Sepkowitz 2004; WHO n.d. "Smallpox"). Introduced in Europe in the 18<sup>th</sup> century, inoculation slowly became accepted, but was met with resistance as it spread throughout North America (Riedel 2005). Dr. Boylston and Reverend Mather are credited as popularising the practice in the US, with their campaign after the 1721 smallpox epidemic in Boston, Massachusetts (Gross and Sepkowitz 2004).

#### **1.2.1.1 Jenner and Smallpox Vaccination**

Smallpox inoculation was widespread enough in the Western world by the time that a young Jenner was inoculated in 1757 (Gross and Sepkowitz 2004; Riedel 2005). Englishman Edward Jenner is often credited as being the discoverer of vaccination, using cowpox to protect against smallpox in 1796, however, it appears there were others using the same method prior (Gross and Sepkowitz 2004; Riedel 2005; Thurston and Williams 2015). Jenner did, however, coin the term "vaccination" from the Latin for cowpox "vaccinia" and he was its loudest advocate (Riedel 2005; Thurston and Williams 2015). Denoting a problematic start both practices in Europe, inoculation and vaccination were tested on prisoners and orphans, and Jenner used his gardener's son, James Phipps, as his first test subject and other vulnerable people in his following experiments (Gross and Sepkowitz 2004; Riedel 2005; Ellis 2021; The Science Museum Group n.d.). This problematic history, and that of medical experimentation on minorities and vulnerable people more broadly, is important in relation to vaccine hesitancy and refusal. While it is beyond the scope of my own research, medical racism throughout history is crucial to consider regarding vaccine hesitancy and refusal, as instances such as the Tuskegee Syphilis Study in the US and the coerced sterilisation of Indigenous women in Canada, create valid reasons for distrust in the respective healthcare systems and governments which allowed for these occurrences (Leason 2021; McVean 2019).

### 1.2.1.2 Early Social Resistance to Vaccination

Social resistance to vaccination, by which I mean the combination of vaccine hesitancy and refusal, has always existed (Riedel 2005). Religious groups in the US were against inoculation, seeing disease as either a test or punishment (Gross and Sepkowitz 2004). When inoculation later became widely accepted, many were resistant to the introduction of vaccination, as they only knew and trusted inoculation (Boylston 2013). Furthermore, the immunity conferred by Jenner's vaccine waned and was not always successful in the first place, leading to scepticism, as some who were vaccinated started contracting smallpox years later (Boylston 2013). Certain members of the British public who were already against vaccination began to feel "that the medical establishment had sold out to Jenner and were censoring all criticism" (Boylston 2013). For example, Daniel Sutton informed the Royal College of Physicians of two instances of Jenner's vaccine failing to protect people against smallpox, to which they essentially claimed he was lying (Boylston 2013). This criticism shows an underlying suspicion of the healthcare system and governing bodies, something that follows vaccination to this day (Goldenberg 2021). Finally, some philosophers were against vaccination as they saw disease as a method of population control, which vaccination impeded (Gross and Sepkowitz 2004).

### 1.2.2 The Smallpox Eradication Campaign

Eventually, the stability and safety of the smallpox vaccine was improved, and the World Health Organisation (WHO) launched their smallpox eradication program in 1959 (Gross and Sepkowitz 2004; WHO n.d. "History of the Smallpox Vaccine"). The WHO's page paints a romanticised version of smallpox eradication, calling it "an unprecedented demonstration of global unity in the face of a common threat" (WHO n.d. "History of the Smallpox Vaccine"). However, it leaves out some of the more unsavoury aspects of the program, such as constant negotiations, unexpected issues, and the fact that much of its success was accidental (Bhattacharya 2008). The importance of tailoring campaigns to local contexts was consistently brought up, with this being viewed "as [...] challenging and inconsistent" (Bhattacharya 2008). Aggressive measures were also used in the mid-70s in India and Bangladesh, including containment methods which were said to have started off as "almost military style attack[s] on infected villages" (Greenough 1995, 635). American WHO advisors themselves reported chasing people, breaking into homes, holding people down, and vaccinating them as they resisted (Greenough 1995). While the use of aggressive tactics may lead to short term results, it is likely not effective and usually counterproductive to long term acceptance (Greenough 1995). This is especially important to consider as many diseases are unlikely to be completely eradicated like smallpox, therefore requiring ongoing acceptance to control their spread (Greenough 1995).

Smallpox was officially declared eradicated in 1980 (Riedel 2005). While its eradication was a huge global health achievement, that does not mean it was without challenges. It is important to continue to learn from both the mistakes and successes of the program. While my own research focuses on vaccine hesitancy and refusal in a Canadian context, drawing on literature from North American and Western European contexts, understanding the history of vaccine refusal globally is important to know about and

understand for context. This is because similarities exist across time and space, and past vaccination campaigns can still impact beliefs and behaviours today.

### **1.3 The True Story of the MMR Controversy**

#### **1.3.1 The Infamous Wakefield Study**

The MMR vaccine controversy was not the first (See Appendix A), however, it is possibly the most well-known. This controversy is where the persistent myth, that vaccines cause autism, stems from, and it was driven by the infamous 1998 MMR vaccine study published in the *Lancet* by British gastroenterologist Wakefield and colleagues (Goldenberg 2016). Despite persistent (and scientifically successful) efforts from experts in debunking this study, vaccine hesitancy and refusal still exists because of this publication (Goldenberg 2016). The story begins with a few mothers in the UK who were concerned about what they perceived to be changes in their children's health after they had received the final dose of the MMR vaccine (Leach 2005). This was followed by the 1998 publication of the Wakefield et al. paper, *Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children*, in the *Lancet* (Goldenberg 2016). This publication, which has since been retracted and discredited, claimed that a new type of inflammatory bowel disease had been identified, which they called "autistic enterocolitis" (Goldenberg 2016, 555-557). Without the knowledge of his co-authors, Wakefield then called for single vaccines for measles, mumps, and rubella instead of the standard combined vaccine, until further studies could be done, despite a lack of evidence for the safety or efficacy of this recommendation (Goldenberg 2016).

##### **1.3.1.1 The Study's Flaws**

Wakefield's study had many flaws. It was a small case study, composed of speculation, and their "evidence" of the connection they alleged was the memories of these mothers who already believed that the MMR vaccine had damaged their children (Goldenberg 2016). Further, a financial conflict of interest was later revealed: Wakefield was being paid for the study by a barrister suing vaccine companies (Goldenberg 2016). Wakefield was eventually stripped of his medical licence for violating ethics protocol (Goldenberg 2016). However, despite continuous debunking, the myth diffused out of its originating country, the UK, and it still lingers, likely because the current method of addressing concerns with corrective science does not truly address the problem (Goldenberg 2016).

The MMR controversy and subsequent social resistance movement was started by mothers; this relationship between vaccine hesitancy and refusal and mothers has historical roots in the women's health movement, as well as the shift towards self-governance and individual-based decision making in healthcare in the Global North (Goldenberg 2021; Leach 2005). The women's health movement, beginning in the US a few decades prior to the MMR controversy, was partially focused on positively changing the way women were treated in healthcare (Nichols 2000). There was pushback against the biomedical model, and demand for control of their own health and the choices they made, especially relating to childbirth (Nichols 2000). Furthermore, hysteria was only removed as a mental diagnosis, one that was notably only given to women, from the DSM-III in 1980, and issues of sexism in healthcare

persist to this day (Nichols 2000; Tascia et al. 2012). Thus, the combination of a shift towards women's empowerment within healthcare, alongside a general move towards self-governance and individual-based decision making, as well as the immense societal pressure put on mothers to be responsible for their own children, could lead to vaccine hesitancy and refusal (Goldenberg 2021; Leach 2005; Nichols 2000; Rabinow and Rose 2006). This is because there is a disconnect between the focus on individuality in healthcare, with vaccination being the exception, which demands compliance in the name of public health (Goldenberg 2021). Furthermore, tasked with the responsibility of their children's individual wellbeing, mothers may struggle to make vaccine decisions, especially if they perceive any negative effects as being their own 'fault.' Many make vaccine decisions at least partially based on the individual risk or benefit to themselves, which correlates with how vaccination is often discussed and promoted in health messaging in the Global North; again, causing disconnect (Goldenberg 2021). This obscures the community benefit of vaccination and how individual vaccine choices can impact others (Goldenberg 2021).

### 1.3.1.2 An Unexaggerated Version of Events

The true story of the MMR vaccine controversy is often unknown. These original mothers who spoke out against this vaccine are often thought to be against all vaccines, for all children, when this is not the case. Rather, organisations like JABS, created by one of the original mothers who voiced concerns about the MMR vaccine, reject "anti-vaccine" and "anti-MMR" labels (Leach 2005, 9). Instead, they call for further research into other factors which may make some children more vulnerable to reactions, as well as alternative vaccination options in the meantime (Leach 2005). Thus, despite Wakefield et al.'s study being disproven many times over, it is important to note that, prior to the diffusion of this myth, the concerns were more specific to rare incidences of alleged vaccine damage involving a few, vulnerable children; that the call was for single vaccine options rather than no vaccines at all; and that the claims were not that the MMR vaccine caused autism, but something that included similar symptoms (Goldenberg 2021; Leach 2005; Poltorak et al. 2005). While it is true that the anti-vaccine message in the Global North does often get wrapped up in more moderate terminology so as not to appear too extreme, it is important to acknowledge that people can have concerns about vaccines without being extremists, against science altogether, or conspiracy theorists - in fact, I would argue the majority are not. Thus, understanding an unexaggerated version of the MMR controversy can allow for the consideration of vaccine concerns through a more realistic and compassionate lens.

## 1.4 Social Resistance to Vaccination in the Global North

Vaccination and anti-vaccine groups have always co-existed in the Global North, with smallpox vaccination being met with outrage at the beginning, as groups claimed it was unnatural, invasive, and potentially dangerous (Jacobson et al. 2015, 1563). Now, in high-income regions, with increased internet access and its usage as an information resource, there is growing concern about increased refusal, as the anti-vaccine message becomes easier to spread (Dubé et al. 2015). While past anti-vaccine movements, such as those formed after intensive smallpox vaccination campaigns in both the UK and the US, were vehemently against vaccination, framing their motivations as being in opposition to state control over

their bodies, there has been a shift in the presented reasoning (Dubé et al. 2015). Current anti-vaccination groups in the Global North now market themselves using more neutral terms, seemingly more concerned about protecting children and making sure parents have the ability to make “informed-decision[s]” (Dubé et al. 2015, 106). For example, a Canadian anti-vaccine group, Vaccine Choice Canada (VCC)’s website is littered with unsubstantiated claims about the alleged dangers of vaccines. However, their “About VCC” section outlines their goals as being related to the provision of information, support regarding adverse reactions and individual choice, as well as protecting peoples’ rights to “informed consent and bodily autonomy” (VCC n.d.). This demonstrates similar concerns of past anti-vaccine groups regarding state control over individual health choices while using more palatable terminology.

It is important to note that the majority of pre-COVID-19 research on vaccine hesitancy and refusal in the Global North has largely focused on white, financially stable individuals (Goldenberg 2021). Therefore, trends are largely based on this group. As factors such as medical racism can affect trust and thus vaccine acceptance (Goldenberg 2021), it is important for further research to focus on marginalised groups, and not only in the context of COVID-19 vaccination, as currently seems to be the case. A limitation of both the pre-pandemic literature and my own research is the lack of representation of all members of the public, regarding vaccine beliefs and subsequent decisions. This means that when social resistance to vaccination is being discussed, only certain members of the public’s experiences are being highlighted. For instance, of my known research participants, all were white, and thus unable to speak on the potential effects of medical racism specifically. It is crucial to continue to study vaccine hesitancy and refusal in a variety of contexts to be able to create research that encompasses the experiences of all members of the public; this can also help us to further understand both the differences and similarities that may exist within those who share similar concerns.

#### **1.4.1 Assessing Risk**

How one assesses risk has an impact on vaccine decisions. For instance, while public health assesses risk at a population level, Leach (2005) demonstrated that, when making vaccine decisions, people do so on an individual level, demonstrating a difference in priorities. She found that often parents, when making MMR vaccine decisions, were more concerned about the potential for complications to their individual child’s health, based on their personal medical histories (Leach 2005). Vaccination can also appear riskier, because it requires doing something to a healthy individual rather than leaving them to only potentially encounter a virus/bacterium; it is also often assumed that anything post-vaccination was caused by the vaccine itself (Dubé et al. 2015; Jacobson et al. 2015). The MMR controversy is an example of this, as the relationship between MMR and autism has since been shown to be temporal (Goldenberg 2016). Additionally, vaccine side effects or alleged potential adverse reactions can start to appear riskier compared to disease itself, especially as instances of disease decrease with vaccination’s success (Jacobson et al. 2015). The DTP vaccine is an example of this (See Appendix A) (Blume and Zanders 2006).

### 1.4.2 Belief Systems

There is a rising rate of personal belief exemptions in schools in countries like the US, allowing children who do not have the often-mandatory childhood vaccines to be enrolled (Sobo 2015). Exemptions allow some to bypass mandatory vaccines without a valid medical reason - the cited reason is instead often “philosophical or religious objections to vaccination” (Jacobson et al. 2015, 1563; Sobo 2015; 381). Exemptions often coincide with a preference for “natural” medicine, and often exist in specific areas, one of these being private schools (Dubé et al. 2015; Jacobson et al. 2015; Sobo 2015). Sobo (2015; 2016) demonstrated a relationship between these personal belief exemptions and sociality in her work featuring vaccine decisions at a Waldorf school and the surrounding community, in the US. This is supported by the way that advertising that fewer parents are vaccinating can lead others to follow suit, as they believe they are following the majority (Kahan 2013). Sobo (2016) found that this school’s environment and local culture led to a decrease in vaccination in incoming students, as parents felt the social pressure to conform. Here, parents who did continue to vaccinate their children often did not discuss this, due to fear of ostracization (Sobo 2016). This further buttressed the idea that fewer parents were vaccinating, exacerbating the social pressure to conform to what appeared to be a majority; essentially creating a feedback loop of assumed vaccine refusal on the part of their peers causing others to do the same (Sobo 2016).

In her work, Sobo (2016) explores the concepts of refusal and becoming in relation to vaccine choices, essentially highlighting the generative and processual nature of vaccine decisions. At this school, parents were shown to accept a new set of values associated with the specific community they wished to belong to, prior to the rejection of an old set of values, therefore demonstrating both the importance of values and the impact of social relationships on vaccine choices in this process (Sobo 2016). The important role of values and sociality in a Global North context is further supported by Goldenberg’s and Leach’s work on vaccine hesitancy and refusal, respectively. Goldenberg (2016) argues that social resistance to vaccination is not, as it is often framed, a rejection of science, but rather a rejection of the values that underpin it. For example, public health messaging often promotes “naturalness” positively to mothers, something that is also often a common value amongst those who are hesitant or refusing, therefore, this could be viewed as a selection of the value of “naturalness” over the ever-increasing role of technology in our lives (Goldenberg 2021). Additionally, bodily autonomy and choice are other common values associated with vaccine hesitancy and refusal, thus refusal can be viewed as the rejection of government control over the choices we make for ourselves and our families (Goldenberg 2021). Leach (2005) highlights the social aspect, noting that parents who believe their children have been harmed by vaccines created social networks, forging common identities based on shared experiences. This further demonstrates the important roles values and relationships take on in the process of vaccine choices.

Overall, the sociality of beliefs about vaccines can be viewed as what Streefland et al. (1999) call “local vaccination cultures,” referring to the combination of beliefs about disease, modern medicine, and prevention, combined with what we hear about the experiences of those around us (1707). Most notably vaccine choices can be viewed as processes, meaning they are subject to change (Sobo 2016). Thus, vaccine beliefs and decisions do not exist in



isolation and are not simply about rejection, but rather they can be a process by which some form and find community, as well as an expression of the values which are important to them. In understanding the processual nature of vaccine beliefs and choices, the importance of maintaining acceptance is also highlighted - this involves improving public trust in the people and institutions representing vaccines (Goldenberg 2021; Sobo 2016).

### **1.4.3 The Trust Issue**

While many factors impact beliefs and behaviours surrounding vaccination, much of this can be related back to trust. Trust, as conceptualised by Georg Simmel, is extremely important and operates at various levels of society, from the personal to the institutional level (Möllering 2001, 405). Trust is a process that uniquely requires faith; it allows one to accept interpretations and suspend unknowns momentarily to become ‘certain,’ thus while it may appear irrational at times, it can otherwise be viewed of as a rational attempt to cope with one’s limits (Möllering 2001, 406-414). To better understand the Simmelian model of trust, it can be conceived of as an equation of sorts, wherein one’s subjective interpretations/weak inductive knowledge require a “leap of faith” to suspend the unknowable to reach a state of trust (Möllering 2001, 404-412). Therefore, trust allows for the continuity of belief where the end of personal knowledge would have otherwise stopped it (Möllering 2001, 410). The “faith” aspect of trust is a crucial requirement (Möllering 2001, 412). The value of trust is that it allows for a higher tolerance of uncertainty by reducing complexity, allowing social relations to proceed confidently (Möllering 2001, 409-410).

In terms of science, which requires trust to function, this involves both trust within the scientific community, as well as trust from the external public, made up of a vast array of individuals, all of whom have differing levels of knowledge – meaning, they must, at some point, be able to place their trust in experts (Goldenberg 2021; Sztompka 2007). As it is impossible for everyone to know everything, eventually everyone will meet their limit where trust (and faith) is then required for science to continue to function (Goldenberg 2021, 115). Trust can also then be understood as “mak[ing] a bet that the actions of others will be beneficial to ourselves” (Sztompka 2007, 212), and for people to do this, respect, honesty, and time is required (Goldenberg 2021). Trusting can be difficult because it creates vulnerability (Goldenberg 2021). Therefore, similarly to vaccine choices, as discussed in the above section, trust can be understood as a process that is subject to change. As the ‘objective lens’ of science falters, and the problems of power and privilege in the scientific community become clearer to the public, some may begin to lack trust (Goldenberg 2021). This occurs because certain factors oppose the four important Mertonian norms - universalism, communalism, disinterestedness, and organised scepticism - which are crucial to trust in science (Goldenberg 2021, 148; Sztompka 2007, 214-215). For instance, science has become increasingly wrapped up in financial conflicts of interest, exclusionary knowledge, marketable results, and the boundaries between academic and political spheres are becoming increasingly blurred, affecting trust (Sztompka 2007, 218-219). Goldenberg (2021) echoes similar themes of financial conflicts of interest and brings up health injustices, as well as the problem of Merton’s norms lacking “inclusion, representation, and public service” thus not encompassing all that is expected by nonexperts of scientists, further exacerbating distrust (139; 149). Furthermore, returning to the increasingly close relationship between science and

politics, Goldenberg (2021) argues that scientific experts informing policy can be viewed as “undemocratic” and worsen distrust as science becomes increasingly associated with large institutions that certain members of the public may already lack trust in (160-165). This lack of trust can be related to historical instances of medical racism and sexism, as previously discussed.

More narrowly, in the context of vaccine hesitancy and refusal, Goldenberg (2021) argues that while it is often framed as the rejection of science and expertise, it is really a “crisis of trust” (168). Therefore, current methods based in dismissal, ridicule, and threats aimed at those who are hesitant or refusing are unsuccessful, because they do not address the real problems these individuals are highlighting, which Goldenberg argues are concerns relating to technology, regulations, privatisation, autonomy, health inequalities and injustices, as well as a distrust of those creating and delivering the science on vaccines, and those who are meant to govern them (Goldenberg 2021). These are problems that are unlikely to disappear and must be recognized and addressed. A lack of trust, alongside concerns regarding power imbalances, is exactly why someone like Wakefield maintains his popularity within social movements against vaccination (Goldenberg 2021). This is because he does what conventional experts fail to - he addresses “questions of power and privilege in regard to scientific discourse” and he also specifically listens to the concerns of non-experts, such as mothers; who have historically been ignored (Goldenberg 2021, 140; 156). Despite flawed science, he addresses many of the root concerns about vaccination, causing him to be seen as honest and trustworthy in contrast to conventional experts who uphold the idea that science is completely objective (Goldenberg 2021).

#### 1.4.3.1 Personal Experiences

Trust is critical to vaccine uptake, and this starts at the patient-provider level. Positive relationships between patients and healthcare providers have been shown to play an important role in vaccine acceptance, and dismissal of parents’ concerns by providers can exacerbate refusal (Dubé et al. 2015; Goldenberg 2021). These relationships are especially important as many do trust their individual providers, but not the healthcare system at large (Goldenberg 2021, 115). Certain mothers’ stories, as told by Leach (2005), are examples of this trajectory. One mother described what she perceived to be the almost immediate effects of the MMR vaccine on her son and how healthcare providers dismissal led her to alternative sources of information (Leach 2005, 6). This demonstrates the potential effects of dismissive behaviour, which can lead to a decline in patient trust and steer them towards unconventional sources of information. It is important to handle questions and concerns about vaccination with care, as this can impact how patients decide to move forward. Recommendations to vaccinate and how that information gets delivered to patients is a top predictor of acceptance, and this requires trust and tailored communication (Dubé et al. 2015). Underlying this is the need for a well-funded and supported healthcare system, so that providers have the time and resources to properly do this (Goldenberg 2021).

#### 1.4.3.2 Healthcare and Government Context

Trust in vaccines can be impacted on both an individual- and institutional-level. Much of what drives vaccine hesitancy and refusal, Goldenberg (2019) argues, is caused by issues of

trust relating to medical, scientific, and governmental institutions. Science can exacerbate concerns because of its revisionist nature; science goes through cycles of normal and revolutionary science - normal science is familiar, solvable, cumulative, and solution-oriented, and only when it ceases to be this do we enter a period of revolution, which can be understood as a paradigm shift (Bird 2018; Jacobson et al. 2015). This revisionist nature of science can be confusing and make it look less reliable than it is (Bird 2018). Paired with the conundrum that vaccines, while safe and effective, do not guarantee absolute protection and can have side effects, this can create cause for concern (Jacobson et al. 2015). Similar concerns have also been expressed with respect to the availability of certain medications despite severe side effects, and some have suspicions about the motives of the government and the pharmaceutical and biologics industries (Dubé et al. 2015; Goldenberg 2019). These concerns are not illogical, as vaccination can be understood as a form of “regulation, surveillance and control of bodies by the state” (Streefland et al. 1999, 1714). As previously discussed in Section 1.3, the disconnect between the shift towards individual-focused healthcare, with vaccination as an exception, alongside the additional context of vaccination having the potential to be viewed as a means of control by institutions people may already lack trust in, it is possible that the logical conclusion for some is to trust themselves instead. Therefore, decisions would be made based on what they feel is best for themselves/their child, rather than based on public health recommendations which could be perceived as focused on the health of the population, even at the expense of a few.

Essentially, it is crucial for all members of the public to feel confident placing trust in both their everyday providers, as well as the larger institutions that are supposed to keep them safe. Social resistance to vaccine recommendations is not born out of ignorance, rather it can be viewed as individual and collective pushback against larger institutions’ control over the very decisions we have been told to make for ourselves and our children; some individuals are highlighting that they no longer trust the motives of these institutions tasked with taking care of them (Goldenberg 2021).

Similarly, despite differing contexts, vaccine hesitancy and refusal in the Global South has also been shown to relate back to trust, especially regarding the healthcare system, governing bodies, and external health interventions (Closser et al. 2006; Richardson 2019) (See Appendix B).

#### **1.4.4 Contextualising This Study**

##### **1.4.4.1 The Canadian COVID-19 Climate**

Past, present, and global trends about social resistance to vaccination can offer insight into the phenomenon as there are similarities, however, it is important to contextualise this study. This study was conducted in Southern Ontario using a small sample size that I had access to, and was supported by past research on the topic, focused on the Global North, most specifically the US, the UK, and Canada. The increase in available vaccines in high-income countries, many of which are for milder diseases, paired with an overall decline in disease, can make parents question the need for and safety of vaccination (Dubé et al. 2015). One study found that most concerns about vaccines centred around newer ones, such as the chickenpox (varicella) vaccine (Dubé et al. 2016). This is relevant to the current COVID-19 pandemic and subsequent vaccine rollout. COVID-19 vaccines use mRNA technology and

are thus viewed as new and different from more familiar vaccine technologies; they also protect against a disease which is often described as being mild in most individuals (IPAC Canada n.d.).

While all vaccines work to trigger a safer immune response than natural infection, they do so in various ways. More traditional types of vaccines include inactive, subunit, toxoid, and live attenuated versions (Pfizer n.d.). Inactive vaccines, such as polio and flu vaccines, function by triggering an immune response through the introduction of a killed version of the pathogen, thus doing so without risk of infection (Pfizer n.d.). Subunit vaccines, such as acellular pertussis vaccines, only use a piece of the pathogen to trigger an immune response, also without the risk of causing disease (Pfizer n.d.). Toxoid vaccines, such as tetanus and diphtheria vaccines, target the specific bacteria's toxins, rather than the bacteria itself, using inactivated toxins (Pfizer n.d.; US Department of Health and Human Services 2022). Finally, live attenuated vaccines, such as smallpox and MMR vaccines, use weakened versions of pathogens generally creating a strong immune response (US Department of Health and Human Services 2022).

Newer vaccine technologies include viral vector and, most notably, messenger RNA (mRNA) vaccines, both of which were used in the development of COVID-19 vaccines (Pfizer n.d.; US Department of Health and Human Services 2022). Viral vector vaccines, such as the Johnson & Johnson and AstraZeneca COVID-19 vaccines, use a modified version of a different virus as a vector for the targeted pathogen, triggering an immune response (Pfizer n.d.; US Department of Health and Human Services 2022). However, most popular is the mRNA vaccine technology, used during COVID-19, because this technology is adaptable and allows for quick production (Pfizer n.d.). These types of vaccines use RNA to teach the body to produce a specific protein unique to a virus, thus triggering an immune response without the risk of infection, as they contain no live virus (Pfizer n.d., US Department of Health and Human Services 2022). Overall, while older vaccine technologies might seem more familiar and therefore, safer, this is not necessarily the case. The COVID-19 pandemic was a new experience for everyone, and it has been shown that “everything unfamiliar - staff from another town, a different site, strange jargon, extra media attention, new vaccination technology, a new introduced vaccine - will be experienced as campaign” therefore, different, and external to regular healthcare, leading to suspicion and rejection (Streefland et al. 1999, 1707). A disconnect between poor or declining healthcare services in contrast with aggressive single vaccine campaigns has been shown to affect vaccine acceptance in the case of the polio vaccine in certain regions, specifically, Kumbotso LGA, Kano, Nigeria and SITE Town, Karachi, Pakistan (Closser et al. 2016). In contrast, Closser et al. (2016) found that in Purba Champaran, Bihar, India, polio vaccine acceptance increased alongside improved basic healthcare. Despite differing circumstances, this should be explored in a Canadian context as the COVID-19 pandemic impacted healthcare services, many of which were put on hold to avoid overwhelming the system. The combination of this alongside restrictions and mandates and a prominent COVID-19 vaccine campaign could have led to an increase in distrust, affecting vaccine decisions.

#### 1.4.4.2 Emerging Themes

While there are many reasons cited for vaccine concerns, a few key themes emerge from the literature, many of which are also reflected in my own research. These are themes of trust, power, process, choice, individuality, and sociality. These do not exist in isolation from one another. This will be further discussed in the analysis portion. It also becomes clear how important vaccine hesitancy is especially, as it differs from refusal. Hesitancy, which coincides with less entrenched negative beliefs about vaccination, could function as an area of intervention to address public concerns, foster open communication and compassion, thereby building trust.

### 1.5 Methodology

My goal with this study was to gain a better understanding of peoples' beliefs about vaccines and how this impacts the choices they make. In doing so, I hoped to humanise those who hesitate or refuse vaccines. Qualitative methods were the best choice for me to be able to not only understand the context of hesitancy and refusal, but also to uncover those who were hesitant in their beliefs, regardless of their choices. Hesitancy is about beliefs, so behaviours may vary: some might accept all vaccines, refuse some, or simply delay (Dubé et al. 2013). I conducted a survey and semi-structured interviews to better understand peoples' beliefs and behaviours surrounding vaccination. The survey was included for those who did not have time for an interview or preferred to stay anonymous, even to me. The interviews provided more in-depth insight into peoples' experiences with vaccines and other relating factors.

#### 1.5.1 Survey

I conducted an anonymous survey asking respondents questions about vaccination. Surveys are limiting for many reasons, including that they often lack information and that it is difficult for them to be representative of a population, especially when they are anonymous (Andrade 2020). I attempted to mitigate this by creating open-ended questions and providing extra space for participants to elaborate. I also had a final question box with free writing space for respondents to add anything they felt had not been brought up in the survey that was relevant. I did this to address a lack of contextual information that surveys sometimes suffer from. Additionally, the purpose of my study overall was to add to the pool of qualitative information on vaccine hesitancy, rather than to use the data to make broad generalisations about the number of people accepting or refusing vaccines.

I posted the survey to my online social media accounts, sent it to colleagues, friends, and family members, who also passed it along. I organised the survey data in a spreadsheet, using a colour coding system to analyse the results. I created a scale to measure respondents' responses: green signified positive/accepting responses, red signified negative/refusing responses, and yellow signified responses that were hesitant. I then categorised respondents as overall either generally accepting, refusing, or hesitant about vaccination based on their responses. A mismatch of positive and negative responses was categorised as hesitant.

#### 1.5.2 Interviews

I conducted semi-structured interviews which included questions about vaccines, as well as peoples' experiences with the Canadian healthcare system, and their general views on

healthcare, politics, education, and related topics. These were based on a literature review I had previously conducted. Similar questions and prompts were used for all interviews, with adaptations being made for everyone. After completing the interviews, I created an overview of each person and categorised them as either accepting, refusing, or hesitant. I then highlighted major themes that were brought up by interviewees. Many of these themes were congruent with those brought up in the literature.

## 1.6 Findings and Analysis

All names are pseudonyms.

Table 1. Survey and interview participants demographics and categories.

	Survey Respondents	Survey Demographics	Interviewees	Interview Demographics
<b>Accepting</b>	13	unknown.	7	<ul style="list-style-type: none"> <li>• 2 female, 5 male</li> <li>• Age range: 20s-80s</li> <li>• Caucasian</li> <li>• 6 parents</li> </ul>
<b>Refusing</b>	2	unknown.	1	<ul style="list-style-type: none"> <li>• Female</li> <li>• 50s</li> <li>• Caucasian</li> <li>• Parent</li> </ul>
<b>Hesitant</b>	12	unknown.	6	<ul style="list-style-type: none"> <li>• 5 female, 1 male</li> <li>• Age range: 20s-50s</li> <li>• Caucasian</li> <li>• 5 parents</li> </ul>

As previously mentioned, key themes which emerged in my literature review were also present in my research regarding vaccination beliefs and choices. These are themes of sociality, individuality; most importantly power and trust, and vaccine choices as processes - most notably regarding vaccine hesitancy.

### 1.6.1 The Social Nature of Vaccination

Sociality, referring to making decisions based on what the majority is thought to be doing, plays a role in vaccine choices (Kahan 2013; Sobo 2016). This social aspect to vaccine decisions has less to do with the community benefit of vaccination, but rather the acceptance of the shared values of a desirable community one wishes to be a part of (Sobo 2016; Goldenberg 2021). This is demonstrated by how vaccine refusal is often localised, as newcomers attempt to either form a community based on similar beliefs and experiences or

try to conform to an already existing community that they wish to become a part of (Leach 2005; Sobo 2015; 2016). This can also coincide with a rejection of biomedicine in favour of 'natural' medicine (Jacobson et al. 2015). This preference for naturalness and the environment was noted in about half of the hesitant interviewees, as well as in the refusing interviewee. For example, three mothers had sent their children to environmentally focused schools, noting this as a priority; one of these mothers, Evelyn, also denoted a preference for her naturopath over her medical doctor, saying:

“I love my naturopath because she looks at health in its entirety. She focuses on my uniqueness as a person and my health, instead of treating everyone the same.”

Althea also shared her preference, mentioning that she came “from a very all natural family and was not fully vaccinated as a child.” This contrasted with some of the accepting interviewees, who noted a preference for biomedicine. For example, when asked about their approach to health, Marilyn said she used “some alternative care...but medical over alternative” and Cyril noted a specific focus on “Western medicine.”

The focus of some on naturalness seemed to primarily relate to a desire for a more genuine, personal form of care, something that many did not feel they received from conventional healthcare services. For instance, Joy said that “[the healthcare system] feels old-fashioned,” and, in reference to one negative experience with a medical professional, she also said “I don’t think there’s a lot of awareness of sexual assault survivors’ experiences and interactions with medical care” leading to discomfort and even traumatic experiences. Similarly, Evelyn said she’d had “mixed experiences [with the healthcare system] - some very traumatic...I felt like I wasn’t treated like an actual human being.” She went on to say:

“I do feel lucky to have access to medical treatments...but it’s very prescribed; there’s only one standard of care and not much outside of that...you have to pay if you want something else.”

Biomedicine and 'natural' medicine were thus often described as having different underlying values, with those associated with the former being undesirable. However, aside from a slight link to the 'natural' medicine community, those who were accepting and hesitant did not demonstrate much of the sociality discussed by Sobo (2015; 2016). The only participant who did was the one refusing interviewee, Cecelia, who had changed her mind on vaccination over time, coming to refuse all during the pandemic. During the pandemic she became more active online, becoming a part of an online community that was against vaccination, believing them to be dangerous. She eventually turned towards this community in lieu of her past community of friends, whose beliefs no longer aligned with hers. Potentially notable was that this came after years of working in the alternative medicine sphere, which she expressed a preference for, describing it as “a completely different way of viewing everything” and “refreshing” in comparison.

## 1.6.2 Individual-Based Decision-Making

Individuality, referring to vaccine decisions often being made based on personal risk or benefit, depends on how one views oneself and personal health experiences. For example, mothers making decisions about MMR tended to focus on individual risk based on the personal health of their children (Leach 2005). Those in the accepting group were not exempt from this type of decision making, although it was less prominent. In this group it was mostly related to the flu vaccine. For instance, Cyril said he had never gotten it because “[he] d[idn]’t feel it [was] necessary” (instead he opted to avoid elderly relatives when ill), and a young man, Zackary, said “[he] d[idn]’t even think about it” when asked why he did not get it. This is notable because it is a vaccine for an illness often viewed as being mild, and it is also a vaccine that often must be personally sought out during adulthood, unlike most vaccines which are administered in childhood. Those who were vaccine accepting but refused the flu vaccine did not seem to do so out of fear, rather it was because they seemed to view it as unnecessary for themselves personally. Therefore, despite accepting vaccines and having little concern, this is at least likely partially done for personal protection, and the larger community benefit of vaccination is not always fully considered.

In the hesitant group, while the community benefit of vaccination was still considered, potential risks seemed to be weighed on a more personal level. Some examples of this were three individuals who had stopped getting the flu vaccine after poor reactions: Gordon said he had a reaction to the flu vaccine making him “never [want] to get it again;” one survey respondent stated:

“I’ve skipped some flu shots, I tend to get sick after the shot and because it is always around my winter school exams [it’s] hard to rationalize taking time off if I know I will be getting sick.”

Another said:

“I tended not to get sick, but ended up getting the flu after both times I got the flu vaccine. I stayed away from them after that and have not gotten a flu since.”

There was also one mother who had not gotten her child vaccinated for COVID-19 because her child had already had the illness without complications, and Gordon had also only gotten two COVID-19 doses, the reasons being, he said:

“I wasn’t required to get one, I wasn’t high risk both with my health and my work” and “I didn’t want to get another shot unless it was necessary both for my own health and as a person in society.”

Finally, another hesitant survey respondent said they refused COVID-19 vaccines because they had “observed others with autoimmune issues following [...] vaccination.”

Mira and Evelyn also viewed themselves as “sensitive,” impacting their vaccine decisions on a personal level. Here, a preference for ‘natural immunity’ was expressed, with Evelyn asking, “why not just build immunity by getting the disease if it’s not deadly to the



majority of people?” This ties back in with the notable emphasis on a ‘natural’ lifestyle and alternative medicine from at least half of the hesitant interviewees and the one refusing interviewee, denoting perhaps a relation to this community that is often associated with social resistance to vaccination. This often came alongside a rejection of biomedicine. Concerns regarding a lack of personalised treatment in healthcare is important to note, as I believe it highlights issues within biomedical care, as well as the larger healthcare system that ought to be addressed. The Ontario healthcare system is currently underfunded and understaffed (CUPE 2023), which would affect the ability of healthcare professionals to provide more personalised care, due to resource constraints. This leads to distrust, which plays a crucial role in vaccine decisions.

### **1.6.3 Trust and Power**

Trust plays a central role in vaccine choices, something that is impacted by power, operating at different scales. Patient-provider relationships are important to vaccine uptake, and mothers who have felt judged and rejected when voicing concerns to providers have turned to alternative information sources (Dubé et al. 2015; Leach 2005). Furthermore, it has been shown that distrust in the government and healthcare system also impacts vaccine choices (Closser et al. 2016; Goldenberg 2021). My research also demonstrated the importance of trust both regarding individual healthcare professionals, as well as larger institutions. Above this, I want to also consider this within the context of the COVID-19 pandemic, which stood out for many as “different.” This study took place in 2023, when the pandemic and COVID-19 vaccines were still at the forefront of many peoples’ minds, and often was the first thing people thought of when the topic of vaccination was broached.

#### **1.6.3.1 Small Scale**

A majority of those who were accepting described positive relationships with their doctors, based in trust. Marilyn said she had “recently switched doctors, and [she] was apprehensive, but he’s been extremely kind and compassionate.” An older man, Gene, also described his relationship with his doctor as “really good,” saying that “she really takes her time with me, she doesn’t rush me to get to the next patient.” He also said she explains things to him and “is willing to talk about potential side effects.” Riley, also described a good relationship with his doctor, saying he would feel “comfortable asking her questions or bringing up concerns.” They also described positive experiences with healthcare in general.

Similarly, those who were vaccine hesitant still denoted trust in their primary physicians, but this did not always extend to other healthcare professionals. For example, five of six interviewees noted negative healthcare experiences, four of which were related to childbirth. Much of this centred around issues of sexism within the healthcare system. For example, Evelyn, who had had many negative experiences during the pandemic, described the healthcare system as “sexist,” saying, “it needs to be more holistic and supportive of women because, right now, it feels very male-oriented.” Overall, she felt that the communication tended to be poor and “dismissive.” Joy also said she thought there were “certain struggles [...] specific to women,” while discussing certain negative experiences she’d had with healthcare professionals throughout her life. While this group still generally

expressed trust in experts, their judgements seemed to be more often weighed against their own personal experiences, as well as those of trusted friends and family.

### 1.6.3.2 Large Scale

While a majority of the accepting and hesitant group described trusting relationships with their doctors, this started to break down at the institution level, even for those within the accepting group. Those who were categorised as vaccine accepting expressed trust in experts, biomedicine, and science, but they did have concerns regarding the healthcare system in Ontario, and underlying financial motivations of larger institutions, like the government. For example, Gene said that he thought the “caring” aspect of healthcare was disappearing. He said, “there’s an increase in medications...treatments...but less care.” Zackary said he thought that the healthcare system “seem[ed] like a mess of conflicting interests making it harder for those on ground level...” Riley noted that “the healthcare system we have is good, but now it’s overburdened,” going on to say that he “would be willing to pay more tax to help with [it].” Regarding long wait times, he expressed concern, saying “it’s a problem.” While Riley said he did not “hate ‘Big Pharma’ [...] [he did] think there [was] something wrong with capitalism and healthcare being linked.” He also said he thought that “Doug Ford [was] kind of ruining Ontario.” Similarly, in terms of politics, Marilyn expressed concern regarding the potential for privatisation in Ontario, saying she was “not happy that seems to be where we’re headed,” and Gene said he felt that “the government ha[d] gotten greedy.”

For those who were hesitant this was even more apparent, as many felt that good care felt inaccessible unless one was able to advocate for themselves, which could be difficult. Gordon described experiencing a loved one go through health issues, saying the doctors were “very dismissive.” He went on to say, “you have to push the system in order to make sure you get the right care” and that “you can’t always take everything that’s recommended at face value.” Joy described a time where she felt pressured into doing something, saying that they “just don’t give you all the information, it seems like they just want you to sign the waiver.” She went on to say that “the system is good when you can advocate for yourself, but you have to ask for more,” but she also felt that “it’s hard to advocate for yourself when you don’t know.” She was also very upset by the current healthcare system and how healthcare workers are treated, saying “I feel disappointed in the value put on people in healthcare...why aren’t we funding our healthcare system?” Finally, summing up much of the discourse on the development of the COVID-19 vaccines, a hesitant survey respondent stated:

“I trust the science and the scientists, but I am sometimes wary of the financial motivation behind the development. This concern isn’t exclusive to vaccinations, but financial motivation of companies to develop ahead of others makes me wonder if concerns could have been brushed under the rug in the name of profits.”

Concerns about the government specifically were often related to the COVID-19 pandemic response and a subsequent decline in healthcare services, something that was more heavily noted by the refusing interviewee, who did not seem to trust conventional experts or the government at all.

### 1.6.3.3 COVID-19

As previously mentioned, COVID-19 was an area of focus for all participants. This was not my intention but was rather unavoidable given the timing. Minor concerns regarding COVID-19 vaccination were expressed by those who were accepting, but the fear of disease outweighed that of potential side effects. For instance, when asked about COVID-19 vaccines, Marilyn said they “stand out” and that she had “concerns about long term effects [...] but not as much as about the virus itself.” For Gene, his mindset was that “it’s probably better to get it than not to” at his age. Overall, they expressed little issue getting vaccinated. Rather, some within this group felt very strongly about the importance of COVID-19 vaccination for the sake of public health, expressing anger and frustration at those who refused to get vaccinated. One man, Gerald even stated that:

“My opinion on the importance of vaccinations has become stronger in response to the foolishness that those who for non-medical reasons refuse the vaccination, as their choices negatively impact all those around them. Such individuals seem to not take the responsibility that corresponds to their rights.”

This group seemed more aware of others in general, at times expressing compassion for healthcare workers, vaccine refusers, and trying to understand concerns. Many also, despite their positive feelings on vaccination, disagreed with enforcing it; Marilyn said she felt that “[the vaccines] should have been presented differently so people didn’t feel forced into it.”

Those who were hesitant or refusing were also highly focused on COVID-19 vaccines. There were concerns about what people felt to be a lack of research prior to the vaccines being made available to the public, and some felt coerced into getting vaccinated. A hesitant survey respondent stated:

“My concerns would be if the vaccine has been [thoroughly] researched and tested and I would be concerned about any potential risks or symptoms.”

Another stated that they felt that:

“The science behind the vaccines continues to evolve. Testing and findings will change. What we ‘know’ now is based on learnings to date and there is always room for human error.”

A refusing survey respondent stated they stopped getting the COVID-19 vaccine after “it wasn’t mandatory anymore, [they] wanted more facts, and would rather know what [was] going into [their] body, and have complete [c]onsent.” Their concerns were regarding “the lack of research before it was world widely distributed, and the fact that there are now 7+ Covid shots shows me they don’t know what they were doing.” Another survey respondent who was hesitant said they skipped some COVID-19 doses because of a “lack of data for long term effects” and “concerns about reactions or side effects.” Finally, Althea said that she

did get “vaccinated against Covid-19 and got the vaccine as soon as it became available,” but she also acknowledged that part of this was due to “social pressures of work and community.” In fact, across all categories, COVID-19 vaccines were noted as feeling mandatory, regardless of if people took issue with this. Furthermore, the pandemic was said to feel divisive, and many noted that they felt vaccination became “political” and “controversial” during this time. Marilyn expressed frustration regarding the way she felt vaccination became “political” during the pandemic; Riley said he felt “disappointed that they’re so controversial,” and Zackary, when asked about his thoughts on vaccination, said he “immediately thinks of the public controversy.” Evelyn said that “the Covid vaccines really changed [her] mind” and that she no longer “fe[lt] confident about [vaccination]” because she felt like it was “shoved down our throats” and that “it got too political, [she] felt coerced into getting it, [she didn’t] feel like peoples’ concerns were respected, and the communication wasn’t realistic or honest.” Althea said she “fe[lt] like the dialogue and politics around the Covid-19 vaccine quickly divided and spread fear,” and Joy described the choice of vaccination both as “so politicised” but also “so personal.” There seemed to be a lot of conflict relating to the government’s pandemic response, leading to distrust in politicians. Again, concerns were raised about potential underlying financial motivations of COVID-19 vaccines, as some questioned whether profit was being prioritised over safety, with Cyril even saying he thought there likely were side effects that medical professionals did not want to divulge for fear of creating refusal.

Thus, both personal experiences, alongside witnessing the large-scale pandemic response and a decline in healthcare services, seems to have fostered more distrust in the Ontario healthcare system and government. This demonstrates that these issues exist at both the individual level with healthcare workers who are unable to fully perform their duties, shaped by the lack of necessary resources provided at the institutional level. This is exemplified by the repeated concerns about the Ontario healthcare system, long wait times, and poor care, as well as underlying financial motivations. One might start to question what the goal is when there only seems to be care for preventing and treating something like COVID-19, but a seeming lack of consideration for any other medical concern. This is supported by Closser et al.’s (2016) findings regarding distrust being more prevalent when there is a disconnect between the focus on a single disease, and the ignorance of all other health problems affecting a community.

While all in the hesitant group had concerns about vaccination and some distrust towards healthcare professionals and larger institutions, this appeared to have two potential outcomes: either hesitancy and distrust became all-encompassing or it could be mitigated through nonjudgmental conversations with trusted individuals, for example, primary physicians or even loved ones. Joy discussed countless negative experiences with healthcare providers, however, she also said she was “so grateful for her” and she “trust[s] her” in reference to her current doctor, because of these past experiences. Joy felt she could bring up concerns with her doctor, saying “she suggests things in a way that feels well researched, but also caring.” Another woman shared a similar story about having concerns regarding COVID-19 vaccines, which her doctor took the time to address properly and respectfully, quelling her hesitations. This demonstrates the process by which many make vaccine

decisions in relation to trust, as well as reiterates the importance of doctors having the time to do this.

#### 1.6.3.4 Rejection of Something Bigger?

Vaccination and the methods by which governments and public health encourage the public to get vaccinated can be understood as forms of biopower. Biopower, as conceptualised by Foucault and elaborated by Rabinow and Rose (2006), is a form of power that “is [...] situated and exercised at the level of life” (196). Thus, the focus of power has shifted towards the optimisation of life, with the methods used to enact biopower being understood as biopolitics (Foucault 1976; Rabinow and Rose 2006). Doctors and experts, as well as the state, hold power over life and much of this revolves around not only the ability to “let die” but also to “mak[e] live” (Rabinow and Rose 2006, 203). Public health interventions, like vaccination, can be viewed as forms of biopower because of their focus on enforcing optimal livelihood in the name of the health of the population (Rabinow and Rose 2006). This, however, does not mean that vaccination is decidedly negative. Vaccination has been hugely beneficial, as herd immunity can protect even those who remain unvaccinated (Dubé et al. 2013). As Rabinow and Rose explain, “power over life is [not] unambiguously nefarious” (2006, 200). Power in and of itself is neither good nor bad but can become either given the context.

Regardless of motivations, issues of trust in these biopolitical governing bodies appear to lead to vaccine hesitancy and refusal. Largely, this can be viewed as a rejection of the power that governing bodies may wield over the personal choices one makes for themselves and their life (Goldenberg 2021). Furthermore, in some cases this could also be viewed as a rejection of the type of life people are being made to live. Foucault discusses an interest in suicide as a “private right to die” in the face of fostering life in the *Right of Death and Power Over Life* (1976, 43). While I am not proposing vaccine refusal equals a desire to die, I think it could be beneficial to at least consider it as, on a macro level, potentially a rejection of the type of power that is focused on maximising the usefulness of humans within a capitalist framework; a rejection of humans only retaining value if they are viewed in such a way. Additionally, then it may also be viewed as a rejection of the force enacted on people to live simply for the sake of living itself. Circling back to Simpson’s theorising of “refusal,” this is, again, something that can be viewed as much greater than resistance to a certain power, but more deeply a critique of the power structures that exist first and foremost (McGranahan 2016; Simpson 2007). In the case of vaccination, a critique of the way in which some are allowed to enforce what the public does to their bodies.

Based on my research, many with vaccine concerns appear to have negative experiences with healthcare services. With the focus of biomedicine often being on the physical health of the person, there may be instances wherein people are forced to endure certain conditions in the name of “life.” An accumulation of those experiences, as seemed to be the case with my hesitant participants, could lead to a rejection of things like vaccination, if they are perceived as another method of governing bodies enacting power over their choices and life. Thus, this refusal could be viewed as an attempt to regain control in an area where they had previously felt this loss; firstly, a taking back of their power of choice regarding their health status, and secondly, the rejection of this larger goal of the optimisation

of human life, more broadly. Again, this is not to say this is an expression of a death wish, but rather a desire for autonomy, and the rejection of someone else's right to choose how they live their lives and in what capacity.

This was best exemplified by my interviewee, Evelyn, whose relevant experiences were the most recent and had occurred at the same time as the COVID-19 pandemic. She brought up many concerns about vaccination regarding what she viewed as a focus on living simply for the sake of biological survival. She asked questions like “Are we doing everything to try to remove all risk?”; “Are we trying to live in a bubble?”; “Are we so afraid of death?” and “Prolonging lives for what?” This alludes to a thought process, alongside discussions of recent traumatic healthcare events, wherein she felt that everything that was done to her in an effort to keep her physically alive was done at the expense of other important factors to her health - for example, feeling comfortable, safe, happy...the other, more mental aspects of health, were something she also felt was ignored during the pandemic, as lockdowns may have kept people physically safe, but carried an emotional toll. It is no wonder, then, that some exit these experiences with reduced trust (or even outright suspicion) regarding the motives of the healthcare system, public health, and their governments. The pandemic especially, regardless of circumstance, could have led many to feelings of a loss of control, creating a desire to control *something* – for example, vaccine choices.

Despite her currently more negative-leaning view of vaccination, this had not always been the case and she still did not refuse all vaccines. However, she felt vaccination should be a personal choice, and disagreed strongly with mandates. Evelyn struggled with the idea of forcing anyone to do anything to their body against their will, as this was something she fundamentally opposed in all circumstances; she said the government telling her she had to get a vaccine was “like being told I can't have an abortion.” While public resistance to vaccination is often thought to be associated with right-wing politics, this is not always the case (Goldenberg 2021). In fact, all those I interviewed in the hesitant group were actually left leaning politically. The hesitant mothers that I spoke with had all noted various negative experiences with healthcare, often referring to feelings of a loss of control over the choices they made regarding their own bodies. Thus, resistance to vaccination did not stem from far-right political views or conspiracies, but from a desire to have control over what happened to their bodies, something they had previously been denied, alongside a distrust stemming from these experiences. They had often felt themselves to be at the whim of medical personnel, who had treated them as either representations of statistics or uninhabited sacs of flesh on a table. These experiences should not be ignored, and I think it is important to examine why we are once again taking the concerns of what seems to be primarily women and disguising them as something akin to hysteria.

#### **1.6.4 Oscillating Beliefs and Space for Opportunity**

All the factors leading to social resistance to vaccination are important to consider, and further, I argue that it is crucial to consider them with compassion. While the topic of vaccination is complicated by the fact that, in this instance, individual choices do affect other members of a community, I believe that using a compassionate lens with which to view vaccine hesitancy and refusal is not the same as ignoring this ethical dilemma; compassion and critique can co-exist. Ekman discusses something similar, regarding critical and

compassionate interviewing; she states that “compassion allows us to make sense of every agent in the field while at the same time retaining the ability to point out injustice and suffering” (Ekman 2014, 120). In using compassion to consider how concerns about vaccines come to exist in the first place - much of which appears to be related to valid concerns about the healthcare system and government - there is the possibility for both acknowledging peoples’ underlying reasons for vaccine hesitancy and refusal, while remaining aware of its effect on others. Furthermore, in adopting a compassionate view of concerns and responding in such a way, it could be possible to halt these concerns before they become refusal.

#### 1.6.4.1 The Process of Choice

Vaccine hesitancy, if it is to be understood as the space between acceptance and refusal, occupies a vast scope. In these circumstances, vaccine beliefs and decisions can best be understood as existing on a continuum, with vaccine acceptance and refusal on either end, and hesitancy occupying the vast middle (Dubé et al. 2016). Therefore, hesitancy can appear very different from person-to-person, sitting more closely to acceptance or refusal, moving back and forth on the continuum depending on circumstances. [See Image 1].

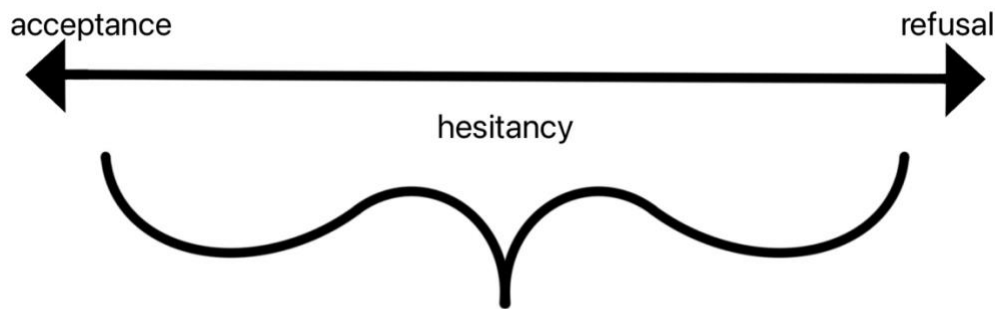


Image 1: Vaccine beliefs and decisions as a continuum: acceptance and refusal on either end, with hesitancy occupying a vast scope in between, as conceptualised by the author and digitised by Shannon Brandreth.

This can also be related back to the concept of trust and how it functions – if trust is equal to peoples’ own subjective interpretations or knowledge in combination with a “leap of faith” allowing for the suspension of the unknown (Möllering 2001), then for vaccine choices, individuals’ own subjective knowledge about vaccines (for example, “vaccines protect from disease” or “vaccines can cause side effects”) in combination with faith may lead them to either accept or refuse vaccines. This outcome is in line with the previously discussed study by Dubé et al. (2016) of mothers in Quebec, demonstrating more similarity between the confidence in the decisions of both vaccine accepting and refusing mothers. Thus, vaccine hesitancy, often tied up in uncertainty, can be viewed as a struggle to take this leap of faith that is required to make a decision either way (Dubé et al 2016; Goldenberg 2021) [see Image 2].

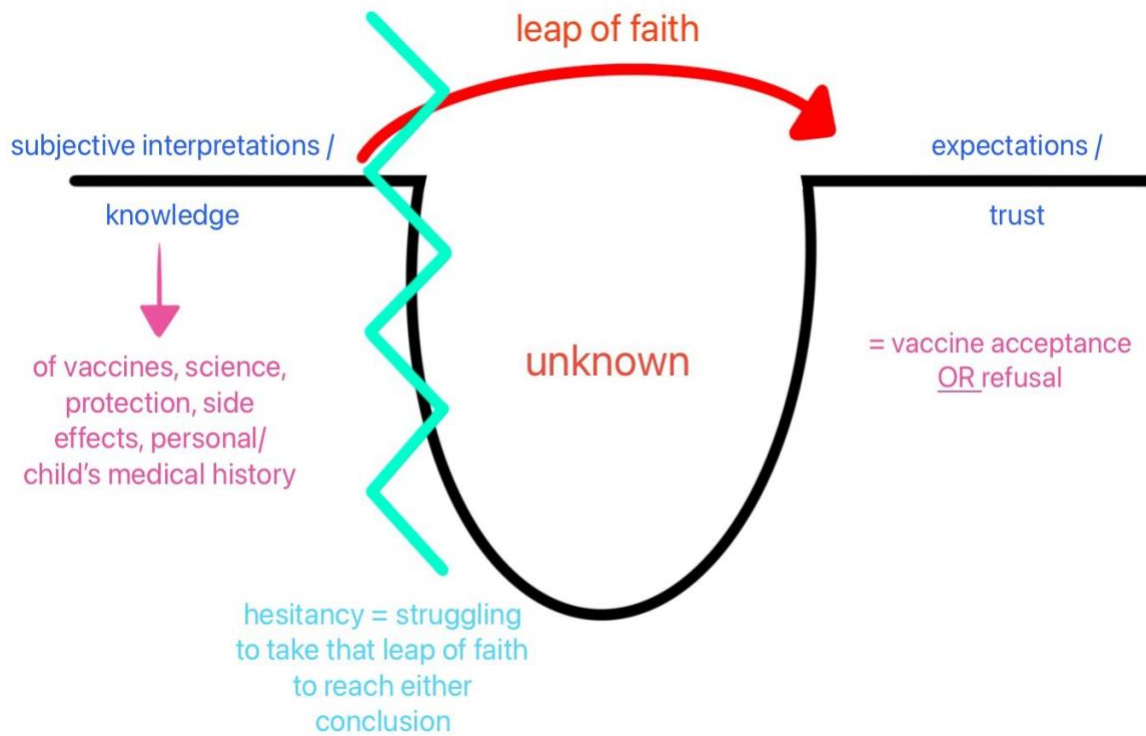


Image 2: Where vaccine decisions, specifically hesitancy, might be placed over the imagery of trust, as conceived of by Simmel & others, based on Möllering’s 2001 article “The Nature of Trust: From Georg Simmel to a Theory of Expectation, Interpretation and Suspension” as conceptualised by the author and digitised by Shannon Brandreth.

The one thing these hesitant individuals seem to have in common is that their choices regarding vaccination are subject to change, based on previously mentioned factors. The pandemic especially was a notable time for all participants, when many had felt vaccination became “controversial” and “political.” While most of my participants who had changed their minds about vaccination were in the hesitant group, some who were accepting, despite their firm stance on the positive benefits of vaccination, had questioned COVID-19 vaccines. One woman also came to refuse vaccines during the pandemic, after years of accepting them despite hesitancy. She viewed this as a time before she knew the “truth” and wished she had been “more curious when [her] kids were little.” Many within the hesitant group noted changing their minds about vaccines: two individuals had changed their minds about the flu vaccine, opting out of it after having reactions; another had decided against getting the COVID-19 vaccine because of witnessing others’ reactions, and Evelyn said the pandemic really caused her to change her mind about vaccines, leading her to no longer feel confident in getting them, as previously discussed.

Despite hesitancy, participants did not always change their minds towards the negative - three women, despite concerns, had accepted vaccines because of productive



conversations with trusted individuals. Another person had changed their mind because of the ease of accessibility, stating that they got “the flu shot” because “after moving to Canada and seeing the shot campaigns, and how easily available they were I was like oh okay, and started getting them yearly.” Therefore, instead of simply accepting or refusing vaccines regardless of context, vaccine decisions within this group appeared to be made more thoughtfully, based on various factors including the vaccine itself and what it protected against, their own individual health status, and recent experiences with healthcare providers, the system, and larger events like the pandemic, which affected their current beliefs. Thus, their decisions regarding vaccination on a whole were never concrete, but multifaceted and ever-changing. These oscillating beliefs about vaccines and deciding whether to go through with vaccination seemed to centre around a feeling of anxiety about the act, as many noted that simply the topic of vaccination brought up feelings of immediate stress, with Joy saying the topic made her feel “immediately stressed out...angry” and Evelyn saying “it stresses me out.” It was frightening and upsetting for some to vaccinate their children, seeds of doubt were difficult to dispel once they had been planted, and sometimes certain vaccines were not seen as “worth it” for diseases viewed as “milder,” something that was even noted in the accepting group with the flu vaccine specifically.

Joy described the first time she encountered negative vaccine messaging, which came from celebrity Jenny McCarthy. She said this was the first time she became “aware people were against vaccination” and then the “seed [was] planted.” This led her to “feel frustrated about it,” saying “like why are we focusing on this stupid misinformation?” She said, “I try to inform myself...I did more research when I had kids, because I had been scared” She then spoke with her doctor, whom she trusts, because she said doing her own research was difficult and hard to know what was “true.” Overall, she did admit to feeling hesitant about vaccinating her children, explaining that “concerns did cross [her] mind,” but she also expressed a lot of frustration regarding that fear, saying “I’m annoyed because that fear was created in the first place” and “I’m angry that people want to make us afraid.” Likewise, Evelyn said, “it’s very scary vaccinating your babies,” but she also spoke more positively about older vaccines, saying that she “would rather wait then jump on the bandwagon” when new vaccines become available. She said, “I think we sometimes take vaccines out of fear,” saying this fear comes from “doctors telling you you have to get this vaccine because your child might get a disease. At face value, all of this can be seen negatively, but upon closer inspection what it should be viewed as is an opportunity, and one that should not be taken for granted.

## **1.7 Discussion and Conclusion**

### **1.7.1 The Importance of Hesitancy**

Overall, regardless of their stance on vaccination, participants had a few things in common. Firstly, vaccine choices seemed to at least partially be based on the individual risk/benefit, with consideration for the opinions of those they trusted. Secondly, there is distrust of larger institutions and governing regarding profit being put before safety, as well as concerns about the ethics of enforced vaccination. Trust is also then extremely important on a patient-provider level, as some can at least place trust in their individual providers, even if they lack trust in the overall system. Finally, vaccine beliefs and choices are a process and can change

in relation to these factors. Most importantly, those who are vaccine hesitant appear more likely to have alternating vaccine decisions, and their concerns can either be addressed and mitigated, or made worse, leading to a firmer, negative stance on vaccination. This makes vaccine hesitancy specifically important because it offers an opportunity for engagement with public concerns (Goldenberg 2021).

Those who are hesitant have been shown to be more unsure about their vaccine decisions and to change their minds frequently (Dubé et al. 2016). In understanding that vaccine choices come to be as part of a process based in trust, the necessity of addressing vaccine concerns early on, in a trust-promoting way, becomes clear (Goldenberg 2021; Sobo 2016). Trusted healthcare providers can change minds, and this was reflected in my research. When concerns about vaccines were met with empathetic and effective communication leading to productive and nonjudgmental conversations, both with healthcare providers and family members, it appeared to promote vaccine acceptance, even when concerns remained. Those who trusted their primary physicians were more likely to not only listen to their recommendations, but to also approach them with their concerns in the first place. We cannot ignore how significant these relationships, built on honesty, respect, and trust are to vaccine uptake. Concerns may never be fully eliminated for those who are already hesitant, but they can be mitigated, and this is something that takes time and continuous effort. Finally, in understanding the need for continuous effort, we cannot ignore an underfunded healthcare system, which cannot support its healthcare workers in their attempts to provide care for their patients.

Discussions regarding vaccine hesitancy and refusal sometimes get caught up in arguments from opposing sides, about what is “fact” and what is “fiction;” who is “right” and who is “wrong,” when, rather, I think the better question is” what is *important*? (Goldenberg 2021, Latour 2004). This thought process is inspired by Latour’s 2004 piece “Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern.” Here, I would like to call for an approach to vaccine hesitancy and refusal which reconfigures the problem as one that is less about opposition, and rather about what is truly important: what is at stake if we ignore the humanity on both sides. In essence, this is a plea for those who are pro-vaccination, and for those who hold power, to not only focus on changing peoples’ minds, but also to really hear what people are saying and to reconsider the environment that vaccines concerns develop in, and to extend empathy to those who sit with this unease, despite how frustrating and difficult it may be to do so. It is a plea for those in power to care for the public healthcare system and its workers, so they have the mental and physical resources to do this.

Personally, as someone who knows and loves both immunocompromised individuals and vaccine hesitators and refusers, I feel for those who are frustrated, angry, and saddened by vaccine resistance. I also feel for those who hesitate and refuse because of trauma they are still dealing with, because they feel they can no longer place trust in the system meant to care for them. There needs to be reconsideration of the long-term goals of vaccine uptake and public trust. Pressure might work to reach short term goals, but the long-term effects might be detrimental to the health of the population, especially those who are most vulnerable (Greenough 1995). I think we need to publicly reconfigure how we view and discuss vaccine hesitancy and refusal, at least trying to understand the root cause of these concerns, especially when they are based in medical trauma. These are real human beings, they are not

statistics or jokes, and treating them as such is not the solution. Perhaps in seeing the humanity in a side we may not agree with, and in extending compassion towards them, they will do the same.

### **1.7.2 Limitations and Future Directions**

The goal of my research has been to provide additional qualitative data on vaccine beliefs and choices, and more specifically, vaccine hesitancy. I have shown that vaccine hesitancy is an important area of focus, as concerns in their early stages could have the potential to be mitigated. Regardless, my research is not without limitations, most notably the lack of demographic information, especially for my survey respondents. Furthermore, of the known demographics, all are white and middle class. Thus, my research echoes much of the pre-pandemic research on vaccine hesitancy and refusal, which often focuses on white individuals, in higher income brackets (Goldenberg 2021). At the time that Goldenberg (2021) was writing her book, there were fewer studies done on vaccine hesitancy and refusal within racial minority groups. More recently, considering the pandemic, there has been increasing research in this area, in relation to COVID-19 vaccines specifically, many of which have demonstrated increases rates of vaccine hesitancy amongst Black and African Americans, as well as other racial minorities (Razai et al. 2021; Troiano & Nardi 2021; Willis et al. 2021). Further research on vaccine hesitancy and refusal in various contexts is crucial in the future, to fully understand how it comes to exist in all contexts, as well as to further understand the impacts of the pandemic.

Additionally, there are a few areas of focus that I believe my research has raised that deserve deeper study. These are, firstly, gender differences. I have found that much of the research on vaccine refusal, especially in the context of childhood vaccines, has focused on mothers - they are often the ones shown to be hesitating or refusing, and the ones most often making decisions regarding vaccines (Goldenberg 2021). This was also notable in my own research, wherein mothers seemed to overall have a more difficult time with vaccine choices, compared to the fathers I interviewed. However, my interview data is, as previously discussed, modest and therefore, I think it important to further explore this potential gendered difference regarding public resistance to vaccination, as well as why it is if this is the case. In this case, I think it might be beneficial to gather more qualitative information from men, specifically fathers, in the context of childhood vaccines to see if there are any trends in their beliefs and choices surrounding vaccination. I believe this could be related both to the way in which our society is structured here, wherein it is mainly mothers taking maternity leave and taking infants to doctors' appointments where they get vaccinated, as well as related to the way in which women tend to be viewed and treated within society - both in relation to treatment within a healthcare system context, as well as how mothers are treated in society and the pressure that is put on them. This relates back to the history of women's treatment within medicine (Goldenberg 2021).

Secondly, there were two individuals whom I interviewed who accepted vaccines, but rather passively. Their acceptance was less enthusiastic than others in the accepting group, and while they still viewed vaccination positively, they were neither overly enthusiastic about it, did not always seek them out, and sometimes skipped some due to forgetfulness or a lack of motivation. The difference in those who are enthusiastically compared to passively

accepting vaccines could be another area of focus, as it could demonstrate the importance of accessibility regarding vaccination, as ease of this could increase vaccine uptake in those who are less motivated to actively seek out vaccines. Furthermore, this could also relate back to the potential gendered differences that I mentioned, as these two interviewees were both men, one of whom was a father, who said he did not really recall thinking about or going to vaccinate his children, as his wife had been the one to do that.

Finally, gathering more qualitative information on vaccine hesitancy is important and beneficial because it can help inform practical methods of dealing with this public health issue. This is something that is already occurring, with some proposed solutions being based in motivational interviewing, as well as changes in public health messaging - for example, focusing more on the community benefit of vaccination, as well as the use of targeted campaigns (Gagneur 2020; Goldenberg 2021). An example of this is the successful vaccine campaign, “I Immunize” in Western Australia, which focused on the identities of those commonly refusing in a specific community, using locals instead of medical experts and focusing on values, rather than on facts (Goldenberg 2021). This also demonstrates the importance of public health messaging that is context specific. Overarchingly, however, I think it is especially important to begin to address the larger issues within the healthcare system context to build trust. Vaccination does not exist in a vacuum - otherwise just reiterating the scientific facts on its safety and efficacy would be effective - and therefore, as has been demonstrated, other experiences with healthcare services can impact how one views and makes decisions regarding vaccination.

### **1.7.3 Conclusion**

It is becoming increasingly important to not only understand vaccine hesitancy and refusal, but also to find a better solution to this important public health issue. The COVID-19 pandemic led many to feel as though vaccination had become political, and alongside a noted decline in healthcare services during this time and after, it appears there are increasing concerns about the ability of those tasked with our care to do so properly. While vaccine concerns are being born out of ignorance, the literature and my own research demonstrates that it is about something much deeper: concerns about vaccines are a manifestation of distrust in healthcare professionals and larger institutions, causing a rejection of what they are seen to be enforcing. In this sense, vaccination could be thought of as a physical representation of the, at times, invasive nature of those in power. This distrust is shaped by various factors and operates on different levels – for example, experiences with individual healthcare providers, as well as at the institutional level, highlighting important societal issues within both a healthcare and government context. This is why it is crucial to reconfigure how vaccine hesitancy and refusal is perceived. The current framing does not allow for any real solution, and concerns will continue to proliferate in this environment of distrust (Goldenberg 2021).

Instead, there must be a willingness to accept and address reasons for public concerns about vaccination, leading with compassion rather than the same ignorance it is argued that the other side holds. Doing so can help build and maintain trust, something that should always be a focus of public health. Furthermore, engaging with public concerns about vaccines can only benefit the health of the population, as it treats everyone as deserving of

adequate care. Vaccine hesitancy specifically is highlighted as an area of utmost importance, as it offers a much-needed opportunity for true engagement with public concerns and the space to address and mitigate them before they become too deeply rooted (Goldenberg 2021). While it may be more difficult to reach those who have already so strongly made up their minds, those who simply want to be heard, understood, and to have their concerns validated might still be reachable if someone is willing to try. Therefore, my goal has been to humanise hesitators and refusers, in the hopes of spurring a more compassionate approach to vaccine concerns. In doing so, it is my hope that an open dialogue can be created regarding these public concerns, building trust in those charged with our care, protecting vulnerable members of society who rely on herd immunity, and fostering an environment where people also desire to take part in this communal act of protection.

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## **Appendices**

### **Appendix A**

#### **Vaccine Controversies: DTP and Polio**

The bacteria *Bordetella pertussis*, which causes pertussis, was first cultured in 1906, with attempts to develop a vaccine following suit (Blume and Zanders 2006; Public Health Agency of Canada (PHAC) 2020). The first effective version of this pursuit began in the 1930s in the US, when Doctors Pearl Kendrick and Grace Eldering started working together (Shapiro-Shapin 2010). Unlike in the past in North America and Europe, when vulnerable populations were used as test subjects, Kendrick and Eldering used community volunteers (Gross and Sepkowitz 2004; Riedel 2005; Shapiro-Shapin 2010). This later became the combined DTP vaccine in the 1940s, also protecting against diphtheria and tetanus (Children's Hospital of Philadelphia 2014; Zarrelli 2019).

While largely accepted at first in the Global North, due to the fear surrounding pertussis, over time, fear increased surrounding the vaccine's potential side effects (Blume and Zanders 2006; Kuchar et al. 2016). These side effects were associated with the pertussis portion of the DTP vaccine, because it required a certain amount of killed organism for efficacy, but too much could lead to worse reactions (Cherry 2019). The controversy escalated in the 1970s in the UK when a hospital report alleged that there was truth to the rumoured connection between the DTP vaccine and neurological disease (Cherry 2019; Dubé et al. 2015). Concerns then spread throughout Europe, Japan, the US, the (then) Soviet Union, and Australia (Dubé et al. 2015). The DTP vaccine was then suspended in Japan and Sweden, and decreased vaccine coverage was observed in other countries due to concerns (Kuchar et al. 2016). Additionally, in the US, WRC-TV, an NBC-owned station based in Washington, created the 1982 documentary *DTP: Vaccination Roulette* which further alleged these connections (Dubé et al. 2015; Hilts 1982). It went on to win an Emmy Award, potentially lending more credibility to the documentary in the eyes of Americans (Dubé et al. 2015). Outrage ensued, with the creation of more anti-vaccine groups, lawsuits, and the passing of the National Childhood Vaccine Injury bill and the Vaccine Adverse Event Report System by the US government (Dubé et al. 2015). Similarly, Canada has the Canadian Adverse Events Following Immunization Surveillance System (PHAC 2023c)

The locus of the controversy was the pertussis component of the vaccine, which originally used whole-cell pertussis (Cherry 2019; Dubé et al. 2015). This came to be incorrectly associated with neurological conditions and Sudden Infant Death Syndrome (SIDS), leading to the development of acellular versions in the 1980s (Cherry 2019). These contained significantly less antigens compared to whole cell versions, leading to both fewer reactions but also diminished protection (Cherry 2019; Dubé et al. 2015). Despite side effects, the DTP vaccine was still considered safe and even more effective than its acellular counterpart, but pressure from anti-vaccine groups forced change in these countries (Cherry 2019).

The whole cell versus acellular debate is complex. Essentially, whole cell versions contain more pertussis components, thus, they tend to be more effective but also more reactogenic (Blume and Zanders 2006; Cherry 2019). Comparatively, acellular versions have less components and, therefore, tend to be less effective but also less reactogenic (Cherry

2019; Kuchar et al. 2016; Ministry of Health n.d.). However, other factors must be considered: there are different versions of the DTaP vaccine, and the amount of pertussis antigens used varies, therefore so does the efficacy (Blume and Zanders 2006; Cherry 2019). Despite switching to an acellular version in the 1990s, Canada saw a reduction in pertussis cases, because they switched from the worst whole cell DTP vaccine to the best acellular DTaP vaccine (Blume and Zanders 2006). Stakeholders, such as members of the public accessing these vaccines, usually for their children, also need to be considered. The Netherlands eventually switched to the DTaP vaccine partially because of public demand (Blume and Zanders 2006). Thus, the importance of public opinion and trust is demonstrated, as a less protective version of a vaccine that a larger percentage of the population is willing to take will likely be more effective at bolstering herd immunity than a more protective version that no one is willing to risk.

While one would hope that making changes to vaccines after concerns arise or science is corrected would prove to non-experts that vaccine safety and public input is taken seriously, this can also backfire. For example, concerns about inactive ingredients in vaccines, such as thimerosal exist, despite a lack of evidence for negative effects (Jacobson et al. 2015). Thimerosal is a mercury-based preservative, typically found in vaccines with inactive viruses (Goldenberg 2016). The low amount of thimerosal in vaccines has been shown to be safe, but it was removed due to parental concerns and pressure from anti-vaccine groups (CDC 2020; Jacobson et al. 2015). Unfortunately, this led those who had voiced their concerns to feel justified, the argument being that it would not have been removed unless their concerns were valid (Jacobson et al. 2015).

Vaccination against polio was largely unsuccessful until American scientist Jonas Salk developed his version of the vaccine in the 1950s, using inactive virus (Pearce 2004). Salk's vaccine was used from 1955 to 1962, until it was replaced by Sabin's attenuated live oral version in most countries, due to its ease of administration and improved immunity (Blume and Zanders 2006; Pearce 2004). Sabin's vaccine was later replaced in most countries because it carried the possibility of causing polio cases, by a modified version of Salk's original polio vaccine (Fitzpatrick 2006).

Polio vaccination was so successful that not even the 1955 "Cutter Incident" in the US led to a significant decline in acceptance (Dubé et al. 2015). Salk's vaccine used killed virus, but an incident at Cutter Laboratories led to over two-hundred thousand accidentally live polio vaccine doses being given to children in the US (Fitzpatrick 2006; Pearce 2004). Those live polio doses became polio cases, leading to hundreds of children being paralyzed and even a few deaths (Dubé et al. 2015; Fitzpatrick 2006). This led to further safety regulations and, in 1986, the National Vaccine Injury Compensation Program was introduced, providing legal protection to vaccine manufacturers in the US (Fitzpatrick 2006). The Canadian equivalent is known as the Vaccine Injury Support Program, which operates under a similar "no-fault" system (VISIP n.d.; HRSA n.d.).

The live oral polio vaccine (OPV) was phased out in countries like the US and Canada in the late 90s and early 2000s, in favour of the inactive version (CDC 2022 "Polio Vaccination"; PHAC 2023a). Despite this, OPV continues to be used in certain countries, including ones that the WHO's Global Polio Eradication Initiative (GPEI) targets, such as

“Nepal, India, Pakistan, Ethiopia, Nigeria, Rwanda and Angola” (CDC 2022 “Polio Vaccination: what everyone should know”; Closser et al. 2016, 322-323). This is because OPV is easier to administer, it stops the spread from person to person, and it is affordable (GPEI n.d. “OPV”; WHO n.d. “Poliomyelitis”). Despite these benefits, OPV does carry the risk of paralysis and, when vaccine coverage is not high enough, the weakened virus can revert and cause illness, which can then spread to others (CDC 2022 “Polio vaccine: vaccine-derived poliovirus”; GPEI n.d.).

The use of OPV in countries that are often poorer and have histories of Western intervention, contrasted with the fact that it is not even offered anymore in countries like the US and Canada, is troubling. Some of the reasons are logical, given that OPV is easier to administer and works better in stopping outbreaks, but it is worth considering the difference in comfort levels between taking certain risks with other countries’ children, but not our own. Aggressive campaigns using coercive measures may yield short term results, but the effect on long term vaccine uptake and disease prevention may be detrimental to the cultivation of sustained acceptance (Greenough 1995). For instance, the GPEI continues to this day despite efforts (GPEI n.d.). Similarly, pressure tactics used during the pandemic to increase initial COVID-19 vaccine coverage may have harmed continued acceptance, as vaccine uptake has declined in Canada, with a stark difference between the 83.7% of Canadians who have received 1 dose of the COVID-19 vaccine and the 15% of Canadians who have received the recommended number of doses by December 2023 (PHAC 2023b). That is not to say these are the only reasons for increased resistance, but they are likely at least partially responsible given the way that aggression, coercion, and pressure can create distrust and further resistance. Thus far, the history of prominent vaccines has been riddled with controversy, which provides important context for contemporary beliefs about vaccination.

## **Appendix B**

### **Vaccine Hesitancy and Refusal in the Global South**

Largely, on a global scale, distrust underlies social resistance to vaccination, although the regional contexts differ. For example, in the Global South there is a history of external health interventions, such as single vaccine campaigns; distrust of governing bodies and the healthcare system is also often expressed (Closser et al. 2006; Richardson 2019). Distrust for internal and external governments often gets expressed as concerns about side effects and infertility/sterility (Ezezika et al. 2022; Dubé et al. 2015; Streefland et al. 1999). For example, the polio campaign was boycotted in Northern Nigeria due to fears that the vaccine was purposefully used to cause infertility and HIV in Muslim populations, due to past efforts of population control, unethical drug testing, and distrust for local and external governments (Dubé et al. 2015; Streefland et al. 1999). Similarly, it was believed in the Philippines that the tetanus vaccine was being used to cause spontaneous abortions and sterilise women, due to beliefs that the WHO and local Ministries of Health were working together to regulate fertility (Streefland et al. 1999). There were also suspicions of ulterior motives of the polio vaccine in Pakistan relating to the US invasion of Afghanistan, affecting Pakistan, post-9/11 (Ataullahjan et al. 2021). This was felt by many to be confirmed when Osama Bin Laden was killed after being found through a fake hepatitis vaccine program by the CIA, leading to beliefs that the polio campaign was a similar ploy (Ataullahjan et al. 2021).

Vaccination also occurs within a broader healthcare system context, shaping perceptions about it based on experiences. In general, vaccination, in relation to the healthcare system, can be categorised as routine, campaign, or specific (Streefland et al. 1999). Whereas routine vaccination is integrated into the overall healthcare system, making it familiar, campaign and specific campaign vaccination is external and unfamiliar, thus causing questioning (Streefland et al. 1999). For example, Closser et al. (2016) found that across various regions there was a relationship between perceptions of the broader healthcare system context and polio vaccine campaigns. A disconnect between lacking basic healthcare and aggressive single vaccine campaigns appeared to lead to increased distrust and refusal, whereas the opposite led to acceptance (Closser et al. 2016). This is best exemplified by one mother from Pakistan stating that:

“I cannot trust the polio workers and those drops that are given in the polio campaign...Polio campaigns should be stopped now. Routine immunisation is a good thing. Medicine should be free, and there should be a doctor sitting in the clinic”  
(Closser et al. 2016, 332-333).

This demonstrates a call for improved healthcare in general and the suspicion that single vaccine campaigns are viewed with when in contrast with a lack of basic healthcare (Closser et al. 2016). Here, this mother does not necessarily reject vaccination - even she notes the benefits of routine vaccination - but shows a rejection of the single polio vaccine campaigns, which she says she cannot trust, when she cannot access even the most basic of healthcare. This demonstrates the sentiment of many that the focus on only one disease/vaccine while disregarding other health concerns of the community is suspicious.



It is known that marginalised communities are more likely to show resistance to vaccination, and distrust of outside intervention from governments and countries often exists within colonial contexts (Closser et al. 2016). It is crucial to understand the colonial context of vaccine refusal in many of these regions as it exists within this historical framework, wherein these beliefs can exist as a method of self-protection against the same forces that have historically inflicted harm upon them (Richardson 2019). In the context of the Ebola outbreaks in the Democratic Republic of Congo, Richardson (2019) discusses how refusal of medical treatment and vaccines is logical within the historical context of the region. Conspiracies here are “a practical logic of engagement with [...] ‘disaster’ or ‘great tragedy’” wherein conspiracy theories and postcolonial critiques merge and “become truth claims that demand reparations and redistributive justice” (Richardson 2019, 105). Essentially, people are expressing valid concerns about problems in their region, stemming from external forces often connected to external aid organisations and workers; they are suspicious that “this is just another thing brought from outside to kill [them]” (Richardson 2019, 108). Their concerns do not stem from nothing.