

# How misinformation affected the perception of vaccines in the 20<sup>th</sup> century based on the examples of the polio, pertussis and MMR vaccines

*Prepared by Isabela Cabrera-Lalinde*

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## Introduction

Vaccination, as a modern scientific concept has morphed into more than just a medical treatment, but a matter of choice. Anti-vaccination views are believed to be new, originating as a consequence of the concerns surrounding vaccination initiatives and misinformation on digital channels. However, anti-vaccination movements began during the late the 19th century with the introduction of the smallpox vaccine; Although the methods and language of dissemination may have changed, the debate continues to be controversial to this day.

The perception of vaccination has evolved from a major scientific discovery, drastically curbing the devastating effects of infectious disease during the beginning to the mid-decades, to a more laissez-faire attitude when diseases started to disappear as a result of effective vaccination campaigns mobilised via printed media and radio. The invisibility of disease resulted in the loosening of parents' efforts to vaccinate, which overshadowed the benefits of vaccines and by extension, placing scientific progress at a disadvantage. Historic reports looking into vaccination movements in the 20th century concluded that the rapidly advancing scientific developments coupled with the state's favourable acceptance of its role in public health, the anti-vaccine perspective was considered to be removed from the spotlight. However, it was not long before mandatory vaccination campaigns changed the narrative into accusations of infringement on individual rights at the turn of the century when stricter policies on vaccination were introduced.

It could be argued that considering the widespread access to reliable information on scientific developments and vaccines, it should be relatively easy to educate the public on new scientific developments and address safety concerns. Yet many parents still choose not to vaccinate. Although there are several reasons related to an individual's sociocultural background (religion, education, cultural values and identities among others) influencing the thought processes that lead to this choice, misinformation has played a determining role in how science is perceived.

A lack of trust in the science, the government, and the money-hungry pharmaceuticals has only exacerbated the vulnerability of the public towards conspiracy theories in the natural process of seeking out explanations in the face of uncertainty. Misinformation has been one of the main barriers to rebuilding trust and understanding and in the public, which were once lost amid the many controversies that have arisen since the introduction of the early vaccines. These are now key components to achieve the full eradication of polio and avoid the sporadic measles outbreaks linked to the remnants of the post-Wakefield era.

The measles vaccine was introduced in the late 1960s, and was considered to have a good uptake throughout the following decades until Andrew Wakefield's paper was published in the scientific journal *The Lancet*, immortalising his ideas. On the other hand, Nigeria for example, were highly influenced by the local cultures and religious views.

## Structure

This work aims to present a historical review of the evolution of the anti-vaccination sentiment; It will examine how the role of misinformation in the media has shaped the argument during the course of the 20th century, setting the stage for the modern immunisation policies and discourse surrounding the influence of the digitalisation of the media. Firstly, it will look at the early vaccination initiatives of the polio, pertussis and MMR vaccine, which took place in the UK, USA, and Nigeria, and the long-lasting effects of the influence of fraudulent publications. Secondly, the case studies will be compared from a socioeconomic perspective, to critically analyse how different backgrounds (evaluation of how social dynamics play a role) process misinformation through the available channels, and what challenges this has presented for policy development. Lastly, the potential root causes for the spread of misinformation will be discussed, and how trust is a subject to be addressed to better shape policy, provide effective communication of the science and ultimately improve vaccination uptake.

## Defining moments: case studies and evidence of the effects of misinformation

Historically, the anti-vaccination movement began long before the case studies reviewed in this work had been considered. More specifically, the resistance to vaccination was observed already during the 19<sup>th</sup> century (1), when compulsory vaccinations led to the creation of organisations and associations to that opposed such laws, claiming that it infringed on the freedom of choice (2). However, it is relevant to mention that many of these so-called associations boasted members of the clergy among its ranks, urging that religious beliefs be accepted as grounds for exemption (2).

In the United States, governmental concerns lied with these groups' ambitions to repeal public health legislation that could threaten to regulate the practices of many physicians, which were not traditionally common (such as homeopaths), more stringently; as well as medicine manufacturers that worried legislation could influence their market (3).

In England and Wales, laws on compulsory vaccination against smallpox passed during the second half of the 19<sup>th</sup> century, highlighting social inequalities in the distribution of healthcare access. Individuals who had the means to afford vaccination by an official medical practitioner would do so, whereas those who could not, had the option to see a state-paid vaccinator, which functioned under the Poor Law structure and were considered shameful and stigmatizing of their class. Moreover, non-compliant, working class parents were pursued and prosecuted, further fuelling the need to lobby for the rights of the working class and against mandatory vaccination<sup>1</sup>.

Although in the views of Kaufman (1967), the progression and subsequent passing of the anti-vaccination movement could be explained by the development of scientific and medical practices (meaning less incidents that could be associated to vaccination concerns), coupled with improved regulation of the public health sector, the anti-vaccination sentiment re-surfaced, and strongly, in the

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<sup>1</sup> The resistance was against the compulsory nature of vaccination, rather than vaccination itself. Opposers claimed the right to opt out for reasons of conscience. In 1889, A Royal Commission on Vaccination was appointed in response to the pressure, however it took until 1907 before the law was changed (2).

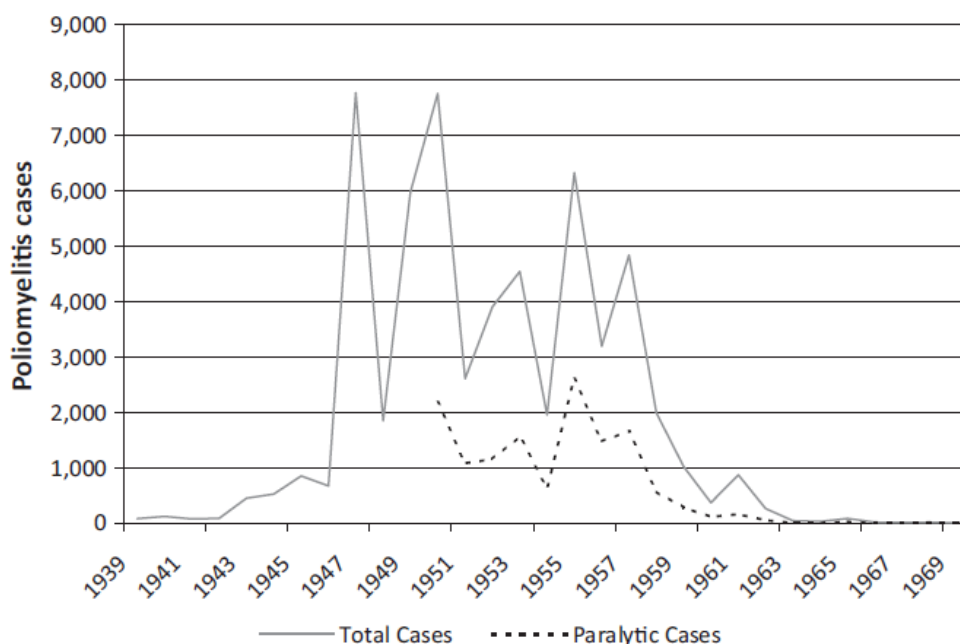
last decades before the turn of the 20<sup>th</sup> century. The re-emergence of the anti-vaccination sentiment begets the question of which factors help prompt the investigation of the causal link and what are the downsides of this process.

It could be considered a natural and instinctive reaction, to seek out explanations to justify negative situations that bring about uncertainty in people's lives, running the risk of falling into a cycle of conspiracy theories.

## Obstacles faced during the implementation of the Poliomyelitis vaccine in Britain – 1950s

The polio virus is a highly infectious disease, it attacks the nervous system and can have severe repercussions such as meningitis, deformities or paralysis, and in some cases even lead to death (4,5). In Britain, the disease reached epidemic proportions in 1947, and outbreaks would become recurring from that year onwards, later known as the “polio season” (6). The polio vaccine was introduced in the 1950s, when public demand was at its highest as a result from these. Leaving behind up to 750 dead during the summer time, and a stream of paralytic cases amounting to over 7,500 each year (7–9).

Since the creation of the Global Polio Eradication Initiative (GPEI) in 1988, the incidence of polio has been reduced by more than 99%, after having been endemic to 125 countries, paralyzing 350,000 children every year (10).



**The development of the vaccination programme:** “Poliomyelitis notifications, 1939–69. Paralytic cases separated from overall notifications from 1950 only” (8).

Prompted by global concern and media attention, public demand drove significant interest in polio research. A number of organisations, such as the National Foundation for Infantile Paralysis in the United States, and its British counterpart, the National Fund for Poliomyelitis Research, established in 1930 and 1952 respectively, were created to fund research to produce a commercially viable vaccine, ultimately advancing scientific development of the polio vaccine and other modern therapies during the mid-50s (8,11).

In the United States alone, there were nearly 60,000 cases reported in 1952, of which 21,000 were paralytic cases and 3,000 resulted in death (12,13). A year later, the formalin-inactivated vaccine was successfully developed, followed by the live-attenuated vaccine in 1956 (14). Shortly after its release, the formalin-inactivated vaccine was formally adopted throughout the United States as it was declared safe and effective [20]. The incidence of the virus decreased from 13.9 in 100,000 to 0.8 in 100,000 by 1961 (15).

After its introduction in the UK in 1956, routine vaccination campaigns effectively reduced the numbers, reporting the last outbreak in the late 1970s, and the last natural polio infection in 1984 (5,8,9). Vaccination programs although effective were met with significant financial and logistical challenges (8).

### The Cutter Incident

In addition to the logistics challenges faced by the British government, three notable incidents shaped the public perception prior to, and during the initial introduction of the Polio vaccine. The first incident, occurred in 1955, just as the vaccine had launched amid the increasingly positive publicity. It ultimately overshadowed the scientific efforts invested into the development of the vaccine, making its implementation that much more difficult.

In April of that year, a batch of the American, formalin-inactivated Salk polio vaccine (IPV) produced at the Cutter Laboratories had failed to properly inactivate the virus, resulting in over 200,000 children receiving a live virus, a regrettable event that caused infection in 40,000, killed 10 and left 260 with varying degrees of paralysis (16–18).

This incident, later known as the Cutter incident, forced a historical risk-averse Britain, and many other countries that were eagerly awaiting the vaccine (16), to reassess their vaccination strategies (8). As a result, the Medical Research Council (MRC) recommended that a vaccine with a less virulent strain should replace the American IPV (Mahoney (type I)), to avoid repeating the same mistakes and effectively increasing immunity (8,14). In addition to this, the Ministry of Health and the Scottish Office established the Joint Committee on Poliomyelitis Vaccine (JCPV), to act as an advisory body and support health institutions to navigate challenges, both medical and administrative, pertaining to vaccination (8).

The Cutter incident can be accredited however, with a positive legacy; Although Cutter laboratories was found liable, and the incident resulted in a surge of lawsuits, it led to “unmatched” enforcement of safety

measures by federal regulators (17). Offit argues that it created an environment of ambivalence, because vaccines were almost eliminated due to lawsuits, threatening vaccine production and innovation “in a field which boasts some of the most impressive achievements of modern medicine” (17).

### Epidemic in Coventry in 1957

Two years after the Cutter incident, Coventry was the epicentre of an outbreak that further highlighted the supply challenges and prompted criticism of the government, who refused to redirect, or import, vaccines to help cover the increasing demand. The criticism towards the shortage was exacerbated by the role the media played in accusing the government of incompetence and trying to navigate the challenges surrounding the demand, a sentiment that was welcome in a post-war Britain (8,19).

In Coventry, both the local and national media, made a joint attempt at not reporting on the demand, to avoid aggravating the situation during the current epidemic. There was however, a general understanding of the need for a vaccine and the science behind it. The registration rate in Coventry was still high, with around 40% in comparison to the national average of 29% (8).

The recurring shortages in supply were concerning for the government, fearing that the public might lose confidence in the program. The MRC guidance was still favouring the British IPV up to this point, and thus protecting the relationship between the pharmaceutical companies and the public sector (8). Drawing upon the views of Blume (20,21), these relationships were considered to be mutually beneficial, since they were crucial to stimulate innovation in the field.

The MRC eventually reconsidered its guidance, and allowed for American imports; however, it was established that this was to be done exclusively to increase supply, thus ensuring the protection of the interests of British manufacturers (8). Moreover, this particular incident set precedence of which difficulties were to be overcome within the registration scheme. It was established that the main issue was that the public was failing to efficiently register, making it difficult to provide an accurate estimation of the demand. The people were opting instead to turn up unannounced, most probably as a result of fear of infection, which appeared to be the main driver.

The Guardian, known as the Manchester Guardian at the time, turned to the public and reported that it needed to take responsibility for its role in influencing the demand and supply, hinting at the importance of following registration instructions. Simultaneously, the British Medical Journal attributed the inconsistencies to the lack of explanation from health authorities on the benefits of the vaccine, prompting extreme reactions which were, ultimately, unrelated to the science of epidemiology (8).

### The death of the professional footballer Jeff Hall in 1959

Following the approval for the importation of the American vaccine, registration rates increased surpassing the estimations with an additional 10% uptake on the 50% that was expected, leading to the realisation that it was not going to be possible to meet the demand (19).

In one of the Times editorials, it was pointed out that there was cause to assume that the Minister of Health was once again misleading the public in regards to what the British manufacturers could actually deliver, presenting only the “best-case scenarios” (8).

In 1959, when Pfizer’s UK branch had begun operating, the idea of finally meeting demand on time was about to materialise. However, not under the Ministry of Health’s terms. Pfizer was planning to market the drug on prescription directly to individuals, affecting the operations of the current scheme, and leaving the NHS to cover the cost of the prescriptions (8). This prompted the Ministry to reconsider the incorporation of all the people under the age of forty in the scheme. Unfortunately, following this consideration, demand among young adults was catalysed substantially, when the death of the 28-year-old footballer, Jeffrey Hall, was vastly publicised. His quick death shocked the public, and was taken advantage of to advertise the vaccine and increase vaccination uptake, solidifying the plan to extend vaccination to individuals under forty (8,22). Although this surge in demand would leave the government in an awkward position to promptly supply the vaccine again, this time around, the affected demographics were different to those in Coventry, since it pertained to young adults, instead of parents of young children.

### Impact on vaccination uptake and general perception

The Cutter incident unleashed a series of challenges in the manufacturing and distribution of the vaccine, that led to the public (and the media) to lose faith in the scheme as a result of what was perceived as an inadequate approach from the government. In 1956, after securing contracts with Glaxo and Burroughs Wellcome, it was announced that children under the age of ten would be eligible to receive two doses of the vaccine, later extended to three, pending registration by the parents. Local health authorities would then vaccinate according to availability (19). The decentralised scheme to vaccinate Britain, caused great discrepancies in the registration procedures and vaccination uptake rates, creating long lasting consequences that would run into the following decade, due to diverging capacities and priorities of the local health authorities. In one example, local mistrust stemming from this decision, led the authorities in Burton-on-Trent to stop the scheme altogether under the belief that the program was part of a large experiment, and resisted any sort of governmental control until further proof of safety was delivered (8). This resistance did not mean however, that localities were, or were turning, anti-vaccine, rather the scepticism was attributed to the administrative arrangements, and consistently negative press coverage and specialist literature (8,16).

Furthermore, the decision to change the vaccine’s formula, left the pharmaceutical companies unable to scale up production in a time for the launch of the scheme. This, coupled with the government’s mandate to test every batch to satisfy safety concerns and maintain public confidence after the Cutter incident, added additional stages to the process resulting in significant delays. These events further emphasised the flaws of the registration scheme, and led to re-examination of the scheme, but failure to meet demand continued (8).

The supply shortages became a matter of embarrassment, given that the significant delays could be attributed to simple negligence and the official announcements were not enough to ameliorate the public's frustration (8). Both the mass media and scientific journals, like the British Medical Journal, chastised the Minister of Health for seeming to prioritize a political agenda, rather than public health policy (19,23). The Minister's announcements to justify the delays had been a topic of controversy, since the national mood was considered to be extremely sensitive at the time, and the media was aiming to make the most out of it with its sensationalist headlines. The Times echoed the same sentiment as the Minister's advisors, who urged against feeding the media with emotional announcements, and stated that he had deliberately announced dates, which could not be upheld by neither the MRC<sup>2</sup> or Glaxo. However, the program appeared to be working, in 1967 it was reported that vaccination uptake against pertussis, diphtheria and polio in children born during that same year, had increased by at least 80% in England and Wales leading to epidemics becoming much rarer (8).

## Political and economic motivations

The British government's choice to use the locally produced vaccine put the immunisation program at risk. Procurement of material and production were complicated, and negotiations between Glaxo and the Ministry of Health had the manufacturers reluctant to invest since the profits would become losses once the majority of the population had been vaccinated. If British companies were allowed to export their product to continue to profit off the technology, it would raise the pharmaceutical industry's profile and help solidify the economy. This incentive led the government to refuse the import of the American Salk vaccine, committing to a supply it could not realistically uphold, at a time when shortages fuelled public outrage (19). The polio vaccine was considered to be one of the most important medical technologies, which signified a remarkable achievement for a country to single-handedly manage the risk of polio.

## International comparison

### Nigeria

The Kick Polio Out of Africa Campaign, was launched in 1988 as a WHO initiative to eradicate polio in the African region by the year 2000 (24). In 2003, the Global Polio Eradication Initiative, launched a final offensive strategy to eradicate polio in Nigeria, which accounted for 45% of polio cases worldwide at the time (6)(21). The plan succumbed to the pressure of religious leaders and resulted in a 16-month boycott and a suspension of the campaign (7)(15). Members of the Supreme Council for Sharia in Nigeria (SCSN) argued that the vaccine was corrupted by the West, and insisted that parents not

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<sup>2</sup> The MRC was conducting independent testing after the Cutter incident: "*Through the course of its research and new trials, the MRC recommended that a British vaccine should replace the Mahoney type-1 strain of poliovirus in the American vaccine with a less virulent strain; this not only would reduce the risk of another Cutter incident, but would also be more effective in conferring immunity*" (21).



vaccinate their children (7). The subsequent importation and re-emergence of the poliovirus remained uncontained, risking 15 years of investment (15)(16)(22).

Opposition at community level presents a challenge to the eradication of polio in selected Muslim communities in Nigeria, leading to a complete halt of vaccination efforts in 2003, resulting in significant repercussions. Religious leaders claimed that the vaccine was contaminated with HIV, carcinogens, and sterilizing agents (14)(17), promoting the misconception that polio vaccination campaigns aimed to control not the spread of disease, but the spread of the Islamic beliefs (16). These claims, initially deemed as religious opposition, concealed regional struggles related to socio-political power, poor health structures and public distrust in the government's health agenda. Contemporary interpretations have concluded that vaccination is permissible within the Muslim faith, and yet extremists choose to alter the connotation of such interventions in order to manipulate communities (13)(14).

Causes for the erosion of trust in the Muslim communities have mainly emerged from an amalgamation of political tensions and social neglect (14)(15). Since the events of September 11, and the war that ensued in the Middle-East following this event, a rift emerged between the Muslim world and the West. This rift altered the public perception towards the intentions behind the polio vaccine campaign (18).

Social inequality exacerbated vaccine resistance as is arose suspicions surrounding the country's efforts to implement cost-free, mass immunization campaigns. These efforts seemed farfetched to many, when taking into account that Nigeria could hardly provide access to basic healthcare. Moreover, traditional medicine utilization rates have always been low in northern Nigeria, accounting for less than 10% of utilization at the times of the boycott (7). This, coupled with fertility regulations adopted during the 1980s which set the limit to four children per woman, led the public to conclude a possible connection between the vaccine and sterilization (18).

### The role of religious leaders

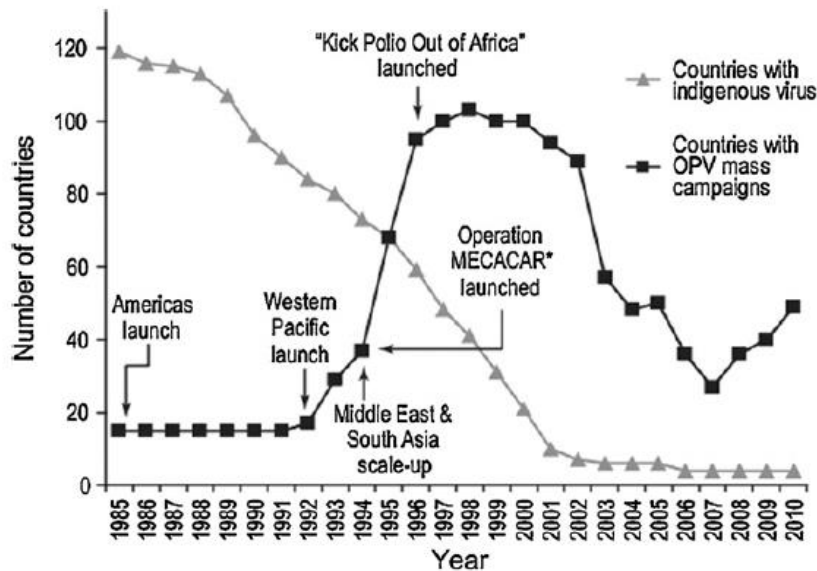
Traditional and religious structures play a strategic role in the control of infectious diseases, and for rural communities, traditional healers compose their first, and sometimes only access to healthcare (17). In many Muslim communities, polio or Shan-inna is considered an ailment of the spiritual world (17). Due to their knowledge and understanding of the local culture, a traditional healer's influence extends beyond the role of healers and often assumes the position of a community leader. In northern Nigeria, traditional rulers have powers derived from their native culture and religion (7), which allows them to assume the roles of both politicians and religious leaders.

What proves to be both an advantage and a disadvantage is that community leaders are the main source of information and authority enforcers. They are considered to be custodians of cultural values and traditional customs and, as such, have the power to manipulate their follower's decision-making process (11). What may appear as a strategic advantage for local and regional public health initiatives can result in a hindrance to the implementation process should leaders not be fully satisfied with the agenda. The familiarity that they inspire allowed them to shape the conceptions surrounding the polio

vaccine. For some, the theory of vaccination to prevent disease is unimaginable, because polio, being a manifestation of a female spirit, that in her anger consumes the limbs of humans, cannot be appeased and contained through a simple liquid. This can only be done through the expert hands of traditional healers, who are believed to have the capability to connect with the supernatural world (17).

These beliefs may, in a first instance, appear as ignorant or highlight the lack of education, but their value to public health interventions is substantial. Nevertheless, it is challenging to determine if vaccine hesitancy or Western medicine, in general, can be solely attributed to cultural beliefs, given that they are usually the result of a combination of several components (20). The federal government's interventions to counteract this, went on unsuccessful, with conclusions always circling back to the Trovan incident in 1996, when Pfizer tested the efficacy of an antibiotic during a meningococcal meningitis epidemic that resulted in the death of 11 children. This event, which implied the cooperation between the Ministry of Health and foreign agencies to deliberately cause harm, left a mark on the region, forever affecting the perception of Western healthcare and establishing the foundation for future vaccine resistance (Jegede, 2007).

The boycott, and public health disaster, came to an end when Kano's religious leaders were encouraged by both the government and the World Health Organization and UNICEF, to take part in the actual proof gathering that the polio vaccine was indeed harmful (7). The events following the boycott in Nigeria were an example of the ramifications that refusing vaccination can have. According to reports from WHO, the number of confirmed cases doubled after the incident, with Nigeria accounting for 80% of the global polio burden in 2006 (25). What is most problematic is that fresh polio outbreaks produce new strains of the virus, which in turn show resistance to the vaccine. Under normal circumstances, three to four doses of the vaccine are usually enough to provide full immunization, yet in Nigeria, the strains mutated so often that children had to be immunized up to eight or more times (7).



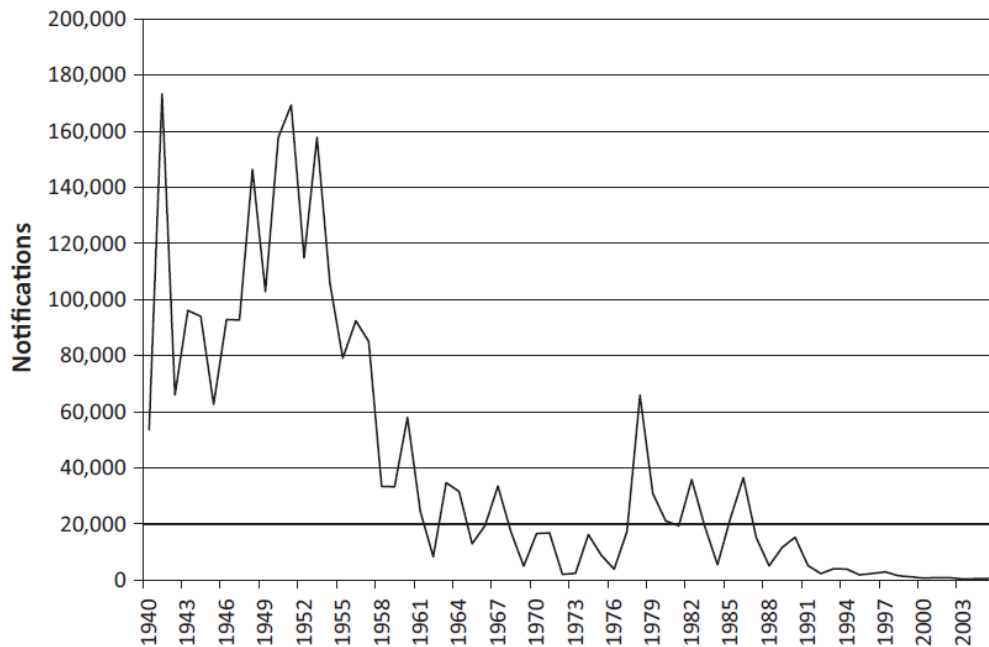
Countries with indigenous poliovirus circulation versus the initiation of eradication efforts, (countries of the Middle East, Caucasus, Central Asian Republics and the Russian Federation), 1985-2006 (25).

## The Pertussis crisis – 1970s

In the 1970s, after having established what role, the British government played in guaranteeing the safety of the public during previous years, the general mood was akin to a sense of security. The public accepted vaccination, and in fact, even demanded it. But this crisis focused mostly on the risk; the risk related to the state's role in the vaccination program and what role did misinformation play in exacerbating the risk-averse sentiment of the public, and the efforts of the government to work around it through education and advertising.

Pertussis is considered to be one the most important vaccines in young children, due to the severity of the symptoms, which often result in complications such as pneumonia and encephalitis, and how difficult it is to treat (8,26). Control efforts rely heavily on effective prevention to minimize risks and vaccines proved successful in decreasing the incidence. As the disease became uncommon the attention that used to be initially focused on the severity of the disease shifted towards possible vaccine side effects resulting in the organisation of anti-vaccination groups (26).

The UK introduced routine vaccination in the 1950s, drastically decreasing incidence in comparison to the 1940s, when it had affected between 60% to 70% of children, and caused over 9,000 deaths, turning it into the deadliest childhood disease at that point in time (27,28). Throughout the 1960s and 70s, morbidity continued to decline significantly from an average of 122,000 cases per year, including 374 deaths (average registered in 1956), to just 20,400 cases and 24 deaths per year. The figure below illustrates the decline (29).



**Pertussis notifications**, England and Wales, 1940–2005 (8,29).

The number of cases represented only around 1% of deadly cases in Britain(30), however, it affected communities in epidemic cycles, with national notifications spiking every two to three years(31).

Local authorities had administered a pertussis vaccine under the diphtheria immunisation coverage, before its official introduction in 1957<sup>3</sup> (8). Eventually, by the 1970s, the trivalent diphtheria-tetanus-whole-cell-pertussis vaccine (DTwP) had become the norm during routine immunization campaigns (27).

In the USA, although pertussis had been under control through vaccination for decades, and paediatric and primary-care organisations have strongly advocated vaccination, concerns regarding the pertussis vaccine peaked in the early 1980s, after the publication of the book *A Shot in the Dark* and the TV programme *Vaccine Roulette*. A reporter named Lea Thompson blamed the vaccine for giving children severe disabilities (32) giving way to the rise of anti-vaccine sentiment. This was not only followed by an upward trend in disease incidence, but also by a significant impact to the market, as vaccine prices rose availability was limited, lawsuits against vaccine manufacturers escalated, and some companies even made the executive decision to halt production due to the difficulty obtaining liability insurance. As a response to this crisis, Congress passed the National Childhood Vaccine Injury Act (NCVIA) in 1986, which established a no-fault compensation system. This act aimed to compensate to compensate people who suffered vaccine-related injuries after being recommended to get vaccinated (26,33–35).

## Media attention and public attitudes

<sup>3</sup> A large-scale MRC trial had confirmed both the effectiveness and the safety of the vaccine in 36,000 children (8).

The use of the vaccine was put into question after case reports between the late 1940s and 1960 suggested that the vaccine could be leading to complications such as encephalopathy, neurological damage, and in some cases death (27). However, it was difficult to assert if these complications could in fact be traced back to the vaccine (36), and the success of the vaccine against the incidence of pertussis made it undeniably clear that the benefits outweighed the risks.

After these case reports emerged, parents of affected children campaigned too for righteous compensation. Two mothers in particular came to be notable in the movement that grew from this: Rosemary Fox and Rene Lennon. They were featured in the Birmingham Post, after their children became disabled and received an outpour of support from likeminded parents. A number of stories in the media and medical press, helped them bring both affected and concerned parents together, resulting in a movement that came to be known as the Association of Parents of Vaccine Damaged Children (APVDC). Their main argument for seeking compensation was based on the fact that parents were often not fully informed of the potential risks and since the government had recommended the vaccine was therefore liable (8). The case for compensation was accepted on moral basis, a solid reason for the press to make it newsworthy (37).

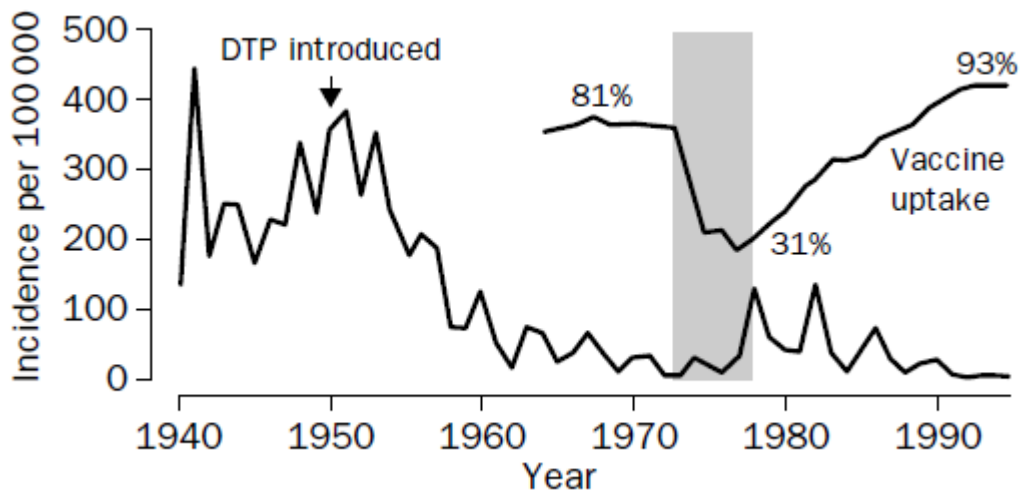
Organisations such as these, took advantage of the attention through the growing mass media, and brought together a set of multidisciplinary sociological research to influence government policy (8,38).

In addition to the creation of organisations that called for policy revisions and pointed the media's attention to the risks of the vaccine, there were two noteworthy medical publications that influenced the perception of the vaccine, and challenged routine immunisation programs.

In January 1974, a publication from the Hospital of Sick Children in Great Ormond Street questioned the safety of the vaccine, suggesting that 36 children had developed severe neurological complications after being immunized (26,27). The paper claimed that the vaccine might have a link to the resulting brain damage that was observed (39). Public scrutiny followed, after the mass media dramatized the devastating stories of the afflicted children, ending in the cessation of a successful vaccination programme due to parents failing to present their children to receive the DTwP shot (27).

The most prominent figure questioning the vaccine within the medical community in the UK was Dr. Gordon Stewart, who repeatedly claimed that the benefits of the vaccine did not outweigh its risks (2,27,33). In 1977, he published a study linking 160 cases of encephalopathy to the pertussis vaccine (40). Stewart, a Professor of Public Health at Glasgow University, was a critical ally to the APVDC and helped shape their case against the government (27,40).

Despite counterarguments from the majority of the medical community(41), his publication was successful in attracting attention to the potential risks of the vaccine and led to a drastic fall in public confidence which was reflected in the sharp drop in vaccination coverage to approximately 40% from 70-80% in 1974 (2,8,26,42). Epidemics followed.



Incidence of pertussis in countries affected by active anti-vaccine movements in England and Wales (26).

### Impact on public perception and impact on vaccination uptake

To boost public confidence and counter the negative publicity in the media, the government (DHSS) set out to commission a report reassessing the vaccine's efficacy, thus establishing its legitimacy by means of concrete medical statistics and expertise, and use its findings to base and promote an advertising campaign targeted towards parents. It was until the mid-1980s that these efforts proved to be successful and infection rates were lowered to a manageable level, after the final court cases against the government brought by parents of children with brain injuries collapsed (27).

The risk of suffering another epidemic and total loss of faith in vaccination programs outweighed any retaliation by concerned parents. The government placed advertisements in all the main daily newspapers, in an attempt to educate the public by outlining facts about the benefits and risks of the vaccine. It was however, always a choice. The adverts pointed to doctors, who were also provided with financial incentives to achieve vaccination targets, as the main point of contacts for information (36).

In 1977, the damage payment scheme had been outlined, before passing in 1979. The argument was a moral one and it quickly gained acceptance, because vaccine damage was politically unacceptable, even if the risk was a low one. It supported the idea that individuals who were vaccinated for the good of society should be compensated for taking that risk if things went wrong. This did not mean however, that there was doubt that vaccinations in general worked. Although the negative publicity surrounding the pertussis vaccine, and the subsequent drop in vaccination presented a challenge for public health authorities, the diphtheria and tetanus vaccination uptakes remained relatively strong (8).

The negative publicity subsided once the Vaccine Damage Payments bill was being worked on. Fox and Ashley were forced to defend their campaign in many occasions against accusations of fearmongering; the narrative surrounding the damage, was shifting towards those who had been left vulnerable without vaccines. The recess in media coverage triggered a substantial increase in demand, causing shortages similar to those experienced during the polio era. Millward point out that "this entire

episode had exposed was that the government's protection role was complex, and public attitudes towards vaccination were not straightforward".

The differences in vaccine rollouts have differed from country to country, leaving loopholes open to interpretation and vulnerable to misinformation. For example, in Britain, children are vaccinated through their primary care physicians as opposed to centralized vaccination centres as in other countries. The introduction of payments to general practitioners to meet immunization targets in Britain in 1990, was seen as questionable by many (26).

According to Gangarosa's findings, there is strong evidence to suggest that there is a causal link between anti-vaccination movements and the pertussis epidemics that resulted from a dramatic drop in vaccination(43). The anti-vaccine sentiment at the core of these movements was inflamed by unregulated news media accounts of the perceived risks related to the pertussis vaccine (44).

It is also important to note, that Gangarosa's findings corroborate previous analyses (45)that suggest that the invisibility of a disease, meaning that once the disease disappears from the public eye as a result of herd immunity, the perception of the vaccine risks shifts, lowering the uptake. From this statement, it can be concluded that the public weighs its options when it comes to risk and benefit of the vaccine vs the disease; once the disease disappears, the risks related to the vaccine gain visibility.

Although anti-vaccine advocates have encouraged that thousands of children go unvaccinated every year, they have had some beneficial effects, calling for safer vaccines. In the cases of pertussis, their efforts to shed light on the risks of the whole-cell pertussis vaccine, was a motivation to monitor the side effects and ultimately pushed for the development of the safer, acellular vaccine (46–48), and the launch of compensation programmes for vaccine-injury (26).

Millward's (2019) view on omission vs commission makes a very important point in relation to the spread of misinformation; in the case of pertussis, he notes that the debate between parents and medical professionals differed because while medical experts weigh the risk and what would be an acceptable odd, parents rationalise acts of omission. In this act of omission, the negative event would be attributed to a deliberate decision on the part of an individual (49). The extensive press coverage on the pertussis crisis incited the debate (27), and led the public to place blame on individuals and organisations rather than technologies, as they were responsible for managing them(50).

Millward concludes that *"neither omission nor commission alone would give the DHSS an easy policy option. The risks of continuing to use a vaccine that might prove to be dangerous were obvious. At the same time, doing nothing about the impending epidemic was also unacceptable"*.

It was crucial that the government restored confidence in the vaccination programme, by establishing that the vaccine was safe and counteracting the press coverage and misinformation dominating the media. To do so, it also needed to reassure the public that if any child was affected, they would receive support; arguments about compensation dominated the popular press coverage and were the subject of much discussion in the medical press, Parliament and government departments.



## The MMR vaccine – 1990s

In 1998, the (former) British physician and academic Andrew Wakefield published a study in *The Lancet* suggesting the existence of a potential link between the MMR vaccine and a predisposition to developmental disorders in children that would lead to a wider debate about the safety of vaccines for years to come (51). Wakefield, who was a clinical research the Royal Free Hospital, was studying the link between bowel abnormalities and autism<sup>4</sup> (8). The study was partially retracted due to the lack of structure of the study small sample size (only 12 children were tested) and the conjectural nature of the analysis, gathered international attention and a noticeable decrease in MMR vaccinations left the medical community struggling to disprove the results and address parental concerns (53,54).

This partial retraction, which involved 10 of the 12 co-authors, stated that no “causal link had been established between MMR vaccine and autism as the data were insufficient” (55), in addition to failure to disclose a conflict of interest, since Wakefield had been funded by lawyers engaged by parents in lawsuits against vaccine manufacturers. Wakefield was however, exonerated from charges of scientific misconduct and ethical violations (56).

The investigative work surrounding Wakefield’s career, describes him as a charismatic man, who was certainly aware of any deficiencies in his research. The 1998 paper followed what was (also) considered a controversial study published by *The Lancet*, which claimed that the measles vaccine was associated with inflammatory bowel disease (57). The question concerning *The Lancet*’s decision to continue to allow him a platform to publish Wakefield’s continuously questionable research, still remains. It is indeed concerning that it was not until an exposé was published, that the real extent of the fraud and the systematic neglect as uncovered, and not through proper academic vigilance (58).

It took *The Lancet* 12 years to officially retract the article, and ultimately hold Wakefield and his colleagues accountable<sup>5</sup> for unethical decisions made in relation to the study’s structure, design and most critical to public trust, financial gain (55,56,59–62). The implications in spite of the substantial efforts of the medical community and scientists across the world to disprove Wakefield’s deliberate intent to deceive are still present in the international anti-vaccination communities, not to mention the costs incurred for additional studies.

Although the article did not make a clear statement that the authors had indeed proven the association of the MMR vaccine to autism, Wakefield was very vocal when it came to expressing his opinions; During a press conference organised by *The Lancet* with the objective of clarifying the contests of the

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<sup>4</sup> “The hypothesis is that MMR leads to a non-specific gut condition permitting the absorption of non-permeable peptides, which in turn cause serious developmental disorders. The data published comprises 11 boys and one girl, each with bowel abnormalities and serious developmental regression. In eight children parents reported regression starting shortly after the children received MMR” (52)

<sup>5</sup> Wakefield’s findings were reviewed in an interdisciplinary committee at the Royal College of Surgeons in 1998, and he was stripped of his license to practise 12 years after that.

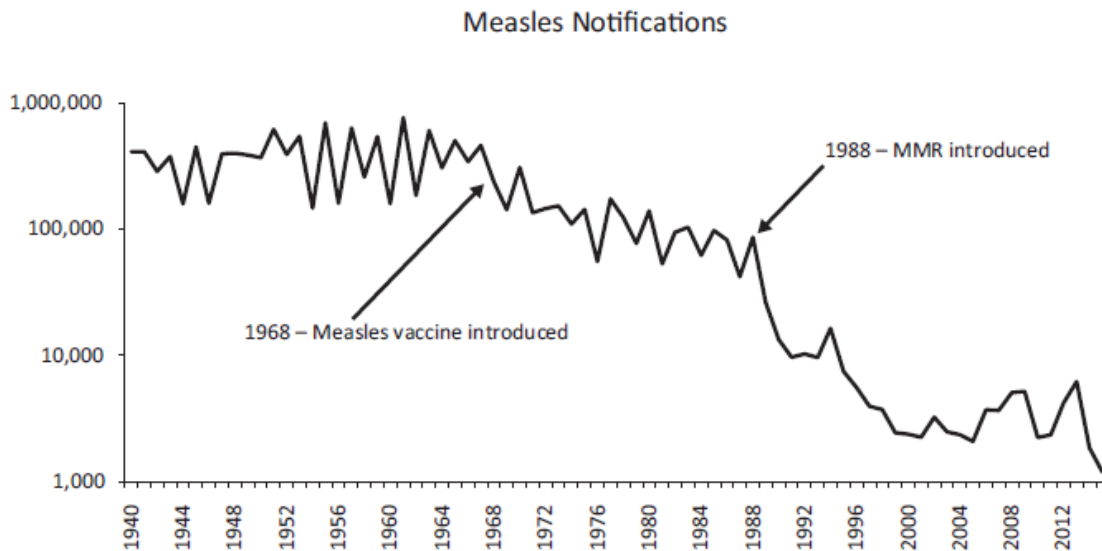


article, Wakefield declared that the MMR vaccine was dangerous, a statement that was received by the media in a most sensationalist manner (63–65). While the authors of the article failed to ultimately prove the association (66), it could be suggested that the retraction of the paper did very little to solve the damage caused by the original spread of misinformation by The Lancet; The attention gathered by this paper has been considered to have had unparalleled damage to public health initiatives, in that it provided the foundation for a debate in both the medical and popular press equally (8,67). In particular, the Sun, Daily Mail and Daily Express gave the matter significant coverage. In the case of the latter two even after most had accepted that the MMR-autism link was unfounded (8). Fear led parents to avoid vaccination in the couple of years following the publication, and the subsequent outbreaks that were observed during the first decade of the 21<sup>st</sup> century in both the UK and the USA, were attributed to a drop in vaccinations during that particular period (62).

Websites run by journalists and non-profit organisations providing parental support, such as Age of Autism (68) and Generation Rescue (69), also played a role in perpetuating Wakefield's unfounded claims (70). The lure of controversial topics resonated with many concerned parents that incorrectly attributed their children's autism to vaccines, and the participation of prominent figures in the spotlight contributed to the solidification of the doubts surrounding the MMR vaccine and undermined confidence (71). Moreover, autism is a disorder that is yet to be fully understood. This makes diagnosis particularly difficult, and can be attributed to many factors that might associate it to the receipt of the vaccine at an early age (53). These attributions attract attention from the media and anti-vaccination groups which serve as ammunition to erode public confidence in vaccines and their uptake, leaving children at risk and delaying the potential eradication of the disease (54).

It is important to note that the incidence of autism related to the vaccine is still not accurately established, since any potential increases might be a result of scientific training and development to better diagnose and record cases. Nonetheless, any increases during 1992 do not suggest a relation to the introduction of the MMR vaccine, which according to Taylor et al., "reached a plateau during a period in which autism incidence was apparently increasing". The WHO published considerable evidence against these claims, since over 600,000 children in their second year receive the vaccine in Britain. Since this is a common age for autism to manifest (52), there was no cause to change an already effective vaccination policy.

While the MMR crisis led to a significant drop in immunisation rates, it was not as drastic as the pertussis crisis. However, the amount of coverage garnered by the popular press and the spread of anti-vaccine sentiment through the growing internet usage, coupled with an equally increasing mistrust in governmental authorities, was proving difficult to contain misinformation. Wakefield's research merely exposed a number of concerns that presented a confirmation bias for many parents. Vaccination rates had begun falling before the publication of his paper, these concerns did not appear unexpectedly (8).



**Notifications of measles in England and Wales, 1940–2015 (8,72).**

Vaccination uptake fell from 92% to 80% in England until 2004, while remaining above 87% in Scotland (72). This fall was not considered to be drastic, on the contrary, it showed that the public had not lost its faith in vaccination completely. It was pushing however, for separate vaccines. Daily newspapers such as the Daily Mail, considered to be sceptic of the trivalent MMR vaccine indicated that many parents still wanted to have their children vaccinated at all costs (8).

The MMR crisis serves as a good example for public health initiatives as the rise in online anti-vaccination movements threatens to reduce vaccination uptake. Especially among certain groups, misleading information can undo years of efforts and public health officials must remain vigilant. This example served as well as evidence for the 2011–12 Leveson Inquiry into the conduct of the press (73–77).

## Social dynamics and their influence on the public's response to misinformation

The public's understanding of science does seem to be affected by the level of education, in terms of sufficient comprehension and understanding of technical knowledge; however, the outcome of the decision-making processes is almost always related to the context in which information is shared and interpreted, and the contentiousness of the discussed topic. Increased familiarity and understanding of scientific knowledge maintain the focus on the science (and its benefits), rather than on a character's negative attributes.

It is common to assume that the public's hesitation to vaccinate is directly related to the level of education that an individual has. This means that the more educated, the more they understand the

science, and hence, low levels of education can be counteracted with factual information. Also known as the knowledge deficit model, this is not the case among vaccine-hesitant parents. Providing factual information alone has not shown to increase the level of confidence enough to encourage vaccination among this group [24].

There is also social pressure on parents who ask questions, to try and understand the practices by themselves. They are seen by professionals as an obstacle, rather than a source of information. There is also ample indication in the literature, that the inability to ask awkward questions has prompted parents to form or seek communities where experiences can be shared in safe spaces. As Rogers and Pilgrim describe it “the social class and professions of many of the parents puts them in a position to affect public opinion. This is not because of messages carried by internet, but because of growing enthusiasm for alternative therapies and healthism”(78).

Most parent's hesitation is fuelled by fear and uncertainty, and seek relationships that make them feel heard and understood and more importantly, reciprocated. Parents expect a particular level of trust from their chosen health professionals, who in turn, share their views, forming a relationship that is built on both knowledge and familiarity (8).

Although throughout all the case studies, there were drops in vaccinations, parent's attitudes towards vaccination were targeted towards specific vaccines. They were not necessarily pro- or anti-vaccination. Even when the pertussis crisis was peaking, vaccination uptake for other vaccines against other diseases remained relatively constant.

There are a series of social dynamics at play that offer an explanation for the sources of anti-vaccination sentiment and how these contribute to the misinformation spread. The main concerns that appear to lead this sort of public opinion can be related to the risk and safety of vaccines and civil liberty and responsibility (2). The former can be perceived a result of the search for a more “natural” approach to healthcare, or healthism, a movement currently growing in popularity. Civil liberty, could be argued, is innately linked to a society's trust in the government; a belief that has been progressively degrading for decades, as evidenced by the events described in the previously presented case studies.

Taking advantage of the amplified impact of information available on the internet, the anti-vaccination sentiment has, through organized groups, exploited the need of mass media to overdramatize, effectively helping them spread misleading information, resulting in the disruption of vaccination campaigns and compromising public health.

Anti-vaccination groups have had different perceived effects on parents varying from country to country, in accordance to the adopted vaccination strategies, largely depending to the quality of the information provided and its source. Better educated parents were more inclined to ask more critical and targeted questions in regards to the risks of vaccinating, concluding that well-informed parents are willing to trust if their need for proper education on the matter is satisfied (2).

However, research has found that although anti-vaccination sentiment in developing countries can be attributed to the lack of access to scientific information about vaccines and the related practices, more

often than not associated with religious beliefs (2). Local vaccination cultures where the communication channels such as relatives, neighbours or religious leaders, can play a significant role in the decision to vaccinate. More so when the experiences shared are negatively portrayed.

The fact that the majority of Muslim countries are at this point polio-free begs the question of why Nigeria would feel targeted by the West, and if the allegations of the religious leaders are merely a distraction to use their influence for political and social advancement. Giubilini suggests that religion often plays a secondary role in justifying vaccine refusal. In this case, it relies on socio-political expectations and the judgement resulting from their value. He adds that in these particularly ambiguous cases, policies with a "higher degree of influence on individual decision-making might be required in order to realize herd immunity" (79). The question here is up to what extent does religion presents a risk to public health.

Culture and religion are inherently related to every action in the prevention of disease, and the role of leaders is fundamental to this. The efforts towards polio immunization and subsequent boycott in Nigeria were defined by a lack of trust in modern medicine and long-standing tensions between the West and Islam, rather than just theological issues. This was aggravated by social determinants such as the poor structure of healthcare delivery and their combined political system. Considering that non-orthodox methods are still an essential part of primary healthcare; the federal government would benefit by aiming to be more inclusive of religious structures.

## Discussion

For many parents, the need to answer questions that arise from the dissatisfaction caused by the poor attitudes of health practitioners, and the lack of availability of information. This has prompted the search for information online, which may contribute to the spread of misinformation, consciously or unconsciously. Properly identifying misinformation can be difficult, since many antivaccination groups strive to base their claims in the language of science.

Public health professionals are convinced that anti-vaccinationists are irrational and misinformed, and are slow to act until it becomes a public health crisis, which has proven to be ineffective.

Political motivations and commercial interests of the pharmaceutical companies have contributed to the public's mistrust in the governmental authorities and their role in public health. Restoring the faith, which would ultimately help vaccination uptake, may prove a challenge. The public's mistrust will return to these "scares" like the Cutter incident and the profit- and politically-driven motivations of the British government during the polio vaccine rollout, to justify their hesitation of not vaccinating.

It can be argued that anxiety about immunisation is associated with the "nature of technological change in general" and the perception of the risk as an old truth (80). This perception will be exacerbated by the role of the media, relying on sensationalism, will circle back to single incidents to link any present sentiment to a past disaster.

In Britain, a considerable amount of the numerous disagreements was published in scientific journals such as the British Medical Journal, whereas in the US, it was limited to the popular press and rarely peer-reviewed journals (2,27). This strategy would allow worthy sources to be less tainted with misinformation.

With the rise in popularity of alternative or holistic therapies, more and more parents are turning to the internet to seek information, causing growing concern regarding the regulation of the recommendations found in these types of websites. Many of them advise individuals not to get vaccinated, a recommendation based on incorrect information. They highlight both unfounded risks such as immunity erosion, as well as the dangerous interests of profit-driven pharmaceutical (81).

The influencing of the public's opinion through the media, has been established as a common strategy used by these groups to advance their agendas. Their ever-growing presence on the internet has given them a seat at the table in the debate of public health interventions, and scientific and medical development. This position has been thought to exacerbate any challenges faced by government initiatives, due to the exaggeration and dramatization of vaccines' adverse reactions in the media without the adequate accompanying scientific knowledge (82), resulting in the halt of routine vaccination programs that led to repeated outbreaks.

In comparison to the UK, in the Netherlands there was no drop in vaccination and Gordon Stewart's statements on the pertussis vaccine did not cause this much public commotion or disagreements among experts in the field. Perhaps due to the different vaccination rollouts and response in the media in the two countries. The Netherlands reported that only 2% of parents seek guidance on the internet, in comparison to 85% who consult published sources provided by health services. The majority of the people surveyed reported general satisfaction with the way they had been informed about the desirability of vaccination, whereas in Britain the Department of Health was reluctant to stop vaccination and tried instead to reassure the public with the commission of a study on the vaccine's safety. After the study was published in 1981, coverage began to gradually increase again, reaching 91% by 1992 from approximately 40% (2). Britain's newspapers saw an increase in articles related to the safety of vaccines from 17% in 1990, to 39% during the first quarter of 2001(83). This meant that changes on a perception level were happening, which did not necessarily mean would end in a change in vaccination uptake. In 1990 Britain observed the creation of several organisations, which pushed for vaccine awareness and publicised alternative therapies. Among these groups were "The Informed Parent" (84) created in 1992, which aimed to provide support and "preserve freedom of choice", 'Justice, Awareness and Basic Support' (JABS) (85) established in 1994 by John and Jackie Fletcher to gain "recognition" and "compensation" for damages, and the Vaccine Awareness Network <sup>6</sup>, founded in 1997. The latter was founded by parents who were allegedly dissatisfied with the lack of available information regarding vaccines and wanted to help other parents decide whether or not to vaccinate. These groups offered

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<sup>6</sup> <http://nuffieldbioethics.org/wp-content/uploads/Vaccination-Awareness-Network-UK.pdf>

biased information, that could be perceived as misleading seeing that the groups aimed to develop communities based on trust, presenting a major challenge for public health authorities.

Despite the increasing number of people who turn to the media to look for advice, studies have shown that parents still rely on face-to-face interactions [5] with trusted doctors.

It is believed that the modern anti-vaccination movement is composed mainly of privileged, highly educated and mostly white communities around the world who support holistic lifestyles and share ideas of “free thinking” and empowerment over their own health [5][34][35]. This belief is linked to the notion that vaccine hesitation is the result of a lack of information and misconceptions associated to low levels of education, but the studies have proven it is quite the opposite; vaccine hesitation is not directly related to socioeconomic status, but rather with the level of health literacy that is displayed [5]. The difference was that parents in affluent positions had more access to options and resources than parents in low-income areas. It also illustrated that the more passionate and committed to learning the participants were, the more engagement and independent thinking they showed [35][36].

Parents noted that their physicians’ attitude towards vaccines influenced them; if they did not insist or promote sufficiently, parents would tend to forego the shot, because what might have been a slight hesitation on their doctor’s part, was perceived as mistrust.

Affluent parents agreed on vaccinations as being “toxic”, because they contain traces of aluminium and mercury, and how diseases were instead, natural. They also chose to prevent and naturally cure disease by boosting their children’s immune system, solutions ranging from herbal teas to hugs. The same idea is conveyed by many other areas around the world, which are particularly prone to low vaccination rates, like California [38][39] and where disease resurgence is currently at an all-time high [40].

Given the rise of outbreaks of preventable diseases caused by gaps in vaccination rates facilitating the spread of disease [41][42], some governments have debated with the decision to make vaccinations mandatory for school-aged children [43]. The introduction of mandatory vaccines has led to public rejection of the law and claims of undermining bodily integrity and autonomy [44]. Several countries have included the possibility of requesting an exemption for parents limited by their religion or if the child has health-related issues that prevent them from getting vaccinated [43].

## Conclusion and take-aways

The general consensus in the narrative after discussing the three case studies, is that vaccinations are safe and effective. Fear of the disease, was the driver for vaccination uptake throughout the second half of the 20<sup>th</sup> century. Negative publicity and the spread of misinformation did have an effect in the public’s confidence in the state and the public health authorities resulting in statistically measurable impacts on the rates. However, these fluctuations did not deter the public to continue to vaccinate in the long term for which it can be argued that misinformation although prevalent, its effectiveness is questionable.

During the pertussis and MMR crises, disputes between medical professionals caused a disarray within the medical community, which the media saw as an opportunity to seize the narrative. It caused a disconnect between the government and the public, which was reflected in the logistical challenges during the program, and left the government invested in a debate to prioritise its citizens.

On the other hand, media attention left some positive changes, as it was considered to be the main driver for the investment and scientific advancement during the polio epidemics, which resulted in the fast development of the vaccine, while also pushing for safer vaccines during all three crises.

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