London School of Economics and Political Science

VACCINE OPPOSITION IN THE INFORMATION AGE:
A STUDY ON ONLINE ACTIVISM AND DIY CITIZENSHIP

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A thesis submitted to the Law School at the London School of Economics and Political Science for the degree of Doctor of Philosophy, London, April 2022.

DECLARATION

I certify that the thesis I have presented for examination for the PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

I warrant that this authorisation does not, to the best of my belief, infringe the rights of any third party.

I declare that my thesis consists of 99,705 words.

ABSTRACT

Vaccination critics have been at the forefront of much recent media commentary, and ever more so after the spread of COVID-19 and the implementation of vaccination programmes to tackle the pandemic. However, vaccination critics had attracted the attention of academics, media commentators and public health institutions in the years preceding the pandemic. My research relies upon data collected pre-pandemic, focusing specifically on online activism targeting routine childhood vaccinations. While seeking to understand internet-mediated vaccine-critical activism, this thesis addresses the following research questions: how do online vaccine critics construct knowledge that feeds into vaccination controversies? What kind of values underlie vaccine critics' policy demands, and how are these demands advocated for? How do critics understand and represent their collective identities? Finally, and most importantly for my study, how do online vaccine critics engage with their surrounding legal landscapes?

Drawing upon an analysis of qualitative data from more than 700 posts linked to six vaccine-critical blogs, collected during nine months of fieldwork informed by an internet-ethnographic approach, I suggest that online vaccine-critical activism needs to be understood as a complex phenomenon embedded in its socio-legal context. While vaccine critics are often depicted as an anti-establishment force, I contend that their relationship with the law in particular is more complex than that. Rather than merely 'resisting' the law, vaccine-critical activists mobilise and co-opt different legal discourses and concepts in intricate and sometimes surprising ways. Vaccine-critical activism is an historically persistent phenomenon which if misunderstood risks further alienating current activists and potentially aggravating the issue of vaccine hesitancy. Investigating vaccine critics' online practices and learning more about their shared worldviews is therefore important (and has become even more so in the light of the SARS-CoV-2 pandemic) in order to frame effective public health communications about vaccine safety.

ACKNOWLEDGMENTS

My deepest thanks go to my supervisors, Emily Jackson and Linda Mulcahy, for all their time, kindness, encouragement and generosity in advising and guiding me throughout my candidature. I am also extremely grateful to Nicola Lacey for reading and offering insightful comments on Chapter 4 of my thesis, as well as for her invaluable support as I took my first steps as a graduate teaching assistant for Introduction to the Legal System.

I would like to thank Alain Pottage and Insa Koch for their very valuable feedback on my upgrade chapter, and to Alain in particular for his guidance and support since the days of the MSc in Law, Anthropology and Society at the LSE.

I am grateful to Rita Astuti of the LSE PhD Academy for her brilliant work supporting the LSE PhD community, as well as to Susan Marks, Gerry Simpson and David Kershaw for offering help and encouragement to the Law School doctoral students. To all the fellow doctoral students, from the Law School and beyond, I have had the pleasure to meet in the last few years – thank you for the moments of light-heartedness and fun which have made the PhD a more enjoyable journey.

This research would not have been possible without the financial support provided by the ESRC - Rena Field Scholarship, which was created to honour Weightmans LLP's late partner Rena Field, a highly respected clinical negligence partner who worked at the firm for many years. I am humbled to have been awarded the Scholarship and grateful to Weightmans for their generosity. I would also like to give a special thank you to Rena's family – it is a huge honour to have received a PhD scholarship that was named after her.

To my family – my parents, brothers, and nonna – thank you for your unconditional support and understanding of my choices, even when they have meant being away from home for a long time.

Finally, to Andy, who has shared every day of this journey with me, and offered his time, love, as well as much patience and understanding – thank you so much. I am looking forward to our next adventure.

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INTRODUCTION

Few technologies have been as persistently controversial as vaccination. In 1796, Edward Jenner tested his first vaccine against what was then known as the 'speckled monster' – smallpox, a dangerous and dreaded disease – on his gardener's eight-year-old son James Phipps. For this procedure, Jenner inoculated material from a milkmaid named Sarah Nelmes who had previously been infected with 'cowpox', a much milder disease than smallpox which affected dairy cattle and could be also passed on from cows to farm workers. James was subsequently exposed to smallpox ('variola matter') through a procedure, variolation, which was a widespread (albeit risky) form of immunization at the time. 'The [variolous] matter was carefully inserted, but no disease followed', Jenner reported in his historic 1798 paper *An inquiry into the causes and effects of the variolae vaccinae*, which detailed the results of his experiments with cowpox (the 'variolae vaccinae', or 'smallpox of the cow'), including James's case (1798, 32). At the dawn of the 19th century, the paper soon attracted the attention of physicians in continental Europe as well as of prominent personalities of the time, including Napoleon and Thomas Jefferson. The latter reportedly personally 'vaccinated' his own children with cowpox matter (Hays 2009, 126).

But negative attention and controversy also swiftly followed the publication of the paper. In 1805, Jenner complained to a corresponding friend about one of his opposers, a family physician named Richard Moseley who supported the previous 'variolation' technique of immunization. 'Have you seen Moseley's infamous pamphlet?', Jenner wrote in a letter to the Plymouth surgeon Richard Dunning, 'You ask for fatal cases of the vaccine. This gentleman, in one single paragraph, furnishes you some of the most terrible deaths that were heard on this cause. One would suppose he was speaking of the small-pox [...] What punishment does a man of this description merit?' (Baron 1838, 349). Just a few years later, in 1812, Jenner was lamenting to another friend that '[t]he *Anti-Vacks* are assailing me [...] with all the force they can muster in the newspapers' (1838, 383 emphasis in original). These early critiques of Jenner and his vaccine intensified and turned into popular dissent in the following decades, particularly – as will be seen in the next chapter – after the passing of the Vaccination Act 1853, which made vaccination compulsory for all new-born children in Britain (Williamson 1984). As historian Nadja Durbach (2005) recounts, '[a]ntivaccinationist movements were organized across Europe and

North America in the late nineteenth and early twentieth centuries, as riots, acts of civil disobedience, and other forms of resistance erupted around the globe' (4).

All this may sound familiar in our age of COVID-19. While the development and introduction of vaccines against the disease towards the end of 2020 have been welcomed with relief and gratitude by the majority of people, they have also been staunchly opposed by some. Protests occurred in London throughout 2021 – media reports of a well-attended rally in December that year detail how '[t]housands of protesters had gathered from 12pm in Parliament Square, from where they marched through the capital, with the hashtag #londonprotest trending on Twitter' (PA Media and Gayle 2021). Other protests counting from a few dozens to thousands of participants have taken place in cities including New York City, Cape Town, Rome, Moscow, Paris, Sydney and Tokyo.

But COVID-19 is not the only instance of contemporary resistance to vaccines. In fact, before the pandemic, the World Health Organisation had proclaimed 'vaccine hesitancy' as one of the ten major threats to global health (WHO 2019).[1] Starting from the second half of the 20th century, routine childhood vaccinations have been a particular subject of critique and opposition by organized activist groups. These groups are similar to their Victorian counterparts in that they have engaged specifically with parents, attempting among other things to influence and re-orient parental vaccine decisions against the recommendations (or mandates) of public health. Their activism therefore relates to the private sphere of the family and its interaction with state power, speaking to issues of parental authority to make health decisions for one's children.

It is this kind of vaccine opposition which is investigated in this work, which was started in 2017 and is based upon data collected in 2018-2019, before the beginning of the COVID-19 pandemic. While the emerging new wave of anti-COVID vaccination activism does not represent the subject of this thesis, the advent of the pandemic makes the question at the root of the research ever more salient: what is it exactly that has made vaccine-critical activism so persistent, and impervious to the overwhelmingly clear evidence of vaccine safety and efficacy?

In certain respects, as I contend in this work, current activism opposing childhood vaccinations mirrors past concerns. However, much has changed since the times of Jenner's vaccine and Victorian 'anti-vaccination leagues'. A crucial difference that is investigated further in the thesis is the role of the internet, and particularly social media, in enabling and shaping modern vaccine-critical activism. The

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[1] See the relevant news report from 2019 on the WHO website, available at: https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019.

underlying idea embraced in this project is that rather than simply providing a new, easily accessible forum through which to study vaccine opposition, the advent of information and communication technologies ('ICTs') has substantially changed the landscape in which activism and social movements emerge and develop. In this regard, the present study has been influenced by scholarship at the intersection of media theory and political science (Cammaerts 2012; 2013; Halupka 2016; Bennett and Segerberg 2012), as well as work in media anthropology on 'networked publics' (Ito 2008; boyd 2010) and 'organised publics' (Fish et al. 2011; Kelty 2012). While retaining distinct conceptual frameworks and research priorities, these bodies of literature all emphasise the emerging interconnections between ICTs, activism, and citizen participation in a democratic society and the need for further study of such interconnections. In the words of media scholar Bart Cammaerts (2012), '[t]here is an urgent need to theorize and encompass the various ways in which media and communication are enabling and constraining for activists and activism in the current ultra-saturated media and communication environment' (118). Drawing on similar concerns, this work aims to investigate how the internet is shaping novel forms of vaccine-critical activism. By doing so, it attempts to provide an answer to the following overarching question: how can we understand mediated vaccine-critical activism in our information age?

Of course, the focus of this work on the online dimension of vaccine-critical activism also responds to the growing attention paid to internet activism by the literature on vaccine opposition published in medical journals,[2] as well as an ever-increasing collection of media reports and commentary on 'vaccine misinformation' spread online by anti-vaccine activists (also referred to as 'anti-vaxxers').[3] In a context in which online misinformation is increasingly being framed as a pressing public health issue, there is a need for empirical research which investigates in depth the nature and contents of online vaccine-critical talk.

More specifically, there are a number of recurring assumptions which seem to underlie public conversations related to vaccine misinformation and the online 'anti-vaccination movement' which deserve further and thorough examination. In recent media commentary, for instance, people opposing vaccination have been variously depicted as ignorant (Foges 2021; Sheridan 2016), anti-science (Hotez 2021; Kale 2021), irrational (Pollitt 2021), and selfish (Reich 2021; Horsey 2021). Other voices have

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[2] Studies belonging to this body of research will be reviewed in the next section of this introductory chapter, and further referenced in the course of the thesis. It should be pointed out that medical and health communication journals have been publishing articles about the internet in connection to vaccine opposition for a relatively long time now, with the first published work on the subject appearing in the early 2000s (see e.g., Nasir 2000; Davies, Chapman and Leask 2002; Wolfe, Sharp and Lipski 2002; Zimmerman et al. 2005; Richardson 2005).

[3] Numerous articles have been published in different news websites on the issues of vaccine misinformation and disinformation just in the past few months. For a few examples, see Schraer 2022; Escalante 2022; Allegretti 2021; Prakash 2021; Scott 2021.

framed anti-vaccination activism as part of broader social shifts towards a 'post-truth' society in which the value of expertise is increasingly put into question, and where it is common to dismiss objective facts in favour of personal opinions and appeals to emotion.[4]

It should be clarified at the outset that this research does not seek to assess the general validity of 'post-truth' as a framework with which to analyse current societal developments. Nor do I intend to argue that individual vaccine-critical activists are never anti-science, irrational or selfish. However, what I would like to suggest is that these kinds of generalisations hide more complex and nuanced realities which should be unpacked in order to understand vaccine-critical activism as a social phenomenon. To offer an accurate, theoretically-grounded, and ultimately more helpful picture of what mediated vaccine-critical activism is, it is therefore necessary to temporarily 'bracket' some of the assumptions and framings embraced in common responses to the anti-vaccination movement. Instead, I would argue that a good place from which to start understanding mediated vaccine opposition is among vaccine-critical activist groups themselves. By researching vaccine-critical beliefs and practices in their own (mediated) contexts and 'from the inside' – that is attempting to see things through vaccine critics' own perspectives – the objective is to make these beliefs and practices more intelligible, following the anthropological mantra of 'making the familiar strange and the strange familiar'.[5] In order to do this, this work adopts a qualitative research approach informed by internet-ethnographic methodologies, and employs an inductive form of thematic analysis as method, which will be described in more detail in the methodological chapter of the thesis (see Chapter 3).

Investigating vaccine critics' online practices, and learning more about their shared worldviews, is important from a public health perspective, as it can help to support evidence-based public health communications about vaccine safety. In addition, understanding this kind of activism from the insider's perspective, taking into account how vaccine critics portray themselves to the world and how they *would like to be perceived* by the broader public, can contribute to better understanding the appeal of vaccine-critical arguments. It is to be hoped that this could lead not just to more informed ways of addressing the general public, but also to better engagement with at least a section of the activists themselves, with the aim of preventing their further alienation and marginalisation, which (as will be suggested) may push them towards even more extreme politics and ideologies. Some activists, as we will see in the course of this thesis, perceive themselves as having been let down by certain institutions and expert actors who are supposed to provide support and assistance. Moreover, some of the activists'

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[4] Two examples of this stimulating body of writing on 'post-truth' which will be further discussed in the thesis are the books (both titled *Post-Truth*) written philosopher Lee McIntyre (2018) and of journalist Matthew D'Ancona (2017).

[5] This expression appears to originally come from T.S. Elliott and to have referred to his views of what constituted 'good poetry'. See Myers (2011).

concerns around the power of 'Big Pharma' and lack of democratic accountability of institutions involved in the determination of public health policies, reflect broader and legitimate concerns which have been raised by social scientists, as well as by legal and public health scholars. This is the case, for example, in connection with whistleblowing and pharmaceutical fraud (see Jackson 2019, 183 et. ss.; Nicholl 2019; Kesselheim et al. 2010), research misconduct (Jacob 2016; 2017), informed consent (see e.g. Wolinetz and Collins 2020; Rubinstein Reiss and Karako-Eyal 2019; Kukla 2009), and the role of non-profit actors in influencing the global health policy agenda (McGoey 2015). Even if many of these concerns are arguably misguided in the particular case of childhood vaccine safety, failing to address them risks conferring added credibility to the more 'conspiratorial' vaccine-critical worldviews as a whole, thus potentially aggravating the issue of vaccine hesitancy.

While scholarship in public health and the social sciences has paid considerable attention to individual parental attitudes towards vaccination and vaccine refusal, the collective dimension of vaccine-critical activism has not received the same levels of scholarly consideration.[6] This is particularly true in the field of socio-legal studies, in which this research is situated. As it will be discussed in the following section, there is a lack of socio-legal research focusing on vaccine opposition generally, and more specifically on vaccine-critical activism.[7] However, I would suggest that this is a very relevant topic for socio-legal scholars, as it can enrich a socio-legal understanding of the 'everyday life' of law in society while simultaneously benefitting from being studied from a new, different angle. A socio-legal perspective can offer novel insights to existing conversations on vaccine opposition in other disciplines, such as public health and science communication.

A 'law in society' approach to vaccine-critical activism is especially valuable because – as I hope to have demonstrated in this study – there is much to be said about the multiple ways in which online vaccine critics 'bump up against' the law, or enter into the law's orbit through their everyday practices and narratives.[8] In trying to bridge this gap in the literature, then, the thesis also seeks to offer an original contribution to a still relatively small but growing body of socio-legal literature on law and activism. Despite the small size, this body of literature includes a diverse and fascinating range of research work. Part of the socio-legal work on activism shares the conceptual lens of 'legal consciousness' (particularly

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[6] Two notable exceptions here are the already mentioned landmark study on the Victorian anti-vaccination movement by historian Nadja Durbach (2005); and sociologist Pru Hobson-West's (2005; 2007) work on UK-based vaccine critical organisations. I draw on the former especially in the next chapter of the thesis, which provides an historical background to contemporary vaccine-critical activism. Hobson-West's work is also further discussed below in this introduction.
[7] Here, an exception is represented by the work of socio-legal scholar Anna Kirkland (2012; 2016), who has considered vaccination controversies from a 'law and society' perspective. However, as we shall see, Kirkland's work is mostly concerned with analysing the US National Vaccine Injury Compensation Program (US NVICP), and it does not have a primary focus on interpreting and understanding vaccine-critical activism.
[8] I would like to thank my supervisor Emily Jackson for coming up with the image of 'bumping up against the law' to convey the idea of vaccine-critical activism intersecting with its surrounding legal landscape.

as articulated by Ewick and Silbey 1998) to analyse activists' experiences of law and legality (see e.g. Kirkland 2008; Fritzvold 2009; Wilson 2011; Halliday and Morgan 2013; Gill and Creutzfeldt 2018).[9] Another branch of the socio-legal scholarship on activism adopts theoretical frameworks from the sociological literature, and specifically the 'new social movements approach' to the study of social movements (see Della Porta and Diani 2020, 9). Much of the research carried out in this strand of the literature employs the concept of 'collective action framing' which, as Gwendolyn Leachman (2013) notes, refers to '...the process wherein social movement actors deploy words, symbols and other interpretive devices to impose political significance on social situations or events' (26).

Specifically, socio-legal scholars have been interested in 'legal framing' and 'rights framing', seeing law as a resource which can both enable and constrain social movements' action and its outcomes (Leachman 2013; see also McCann 1994; Pedriana 2006). While the present study has been influenced by these legal consciousness and legal framing literatures, it adopts a different lens to investigate online vaccine-critical activism and its relationship with the law, relying on the concept of 'counterpublics' (Negt and Kluge [1972] 1993; Fraser 1990; Warner 2002) for analytical purposes. While counterpublic theory has not been as frequently used as a framework in studies of law and activism, it was deemed particularly appropriate for the analysis of the mediated form of resistance represented by online vaccine-critical activism, as I will expand on later in this chapter.[10]

In sum, the present research aims to offer an original contribution to both the existing body of literature on vaccine opposition and socio-legal scholarship focusing on the relationship between activism and the law. It seeks to do so by providing an in-depth qualitative analysis of vaccine-critical activists' talk and practices as they emerge in selected online settings. Throughout this study I will address the following research questions: how do online vaccine critics construct causal beliefs and knowledge that feed into vaccination controversies? What kind of values underlie vaccine critics' policy demands, and how are these demands advocated for? How do critics understand and represent their collective identities in ways that assert their own perceived 'credibility' over expert institutions and actors? Finally, and most importantly for my study, how do online vaccine-critical activists engage with the law?

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[9] Socio-legal scholar Simon Halliday (2013) situates legal consciousness research on activism mainly within the 'critical' tradition of legal consciousness studies which most strictly follows the theoretical path set out by Ewick and Silbey (1998). Some of the work cited by Halliday, however, such as Kirkland's (2008) study on 'fat activism', seem to belong to what he calls the 'interpretive' strand of legal consciousness research, which focuses on exploring perceptions of legality from the perspective of particular individuals or groups.

[10] Despite the seemingly sparse engagement between socio-legal studies and counterpublic theory, some excellent research relating to the wider area of intersection between law and resistance and using counterpublicity as its analytical lens has come out in recent years. This includes Méadhbh McIvor's (2019) legal-anthropological study of Evangelical Christian lobbying groups in England, as well as research by communication scholar Erica von Essen and her colleagues looking at illegal hunting movements in Sweden and Finland (von Essen et al. 2015).

Before moving further, however, it is necessary to clarify what is meant by 'vaccine-critical activism' as well as how this relates to other phenomena such as vaccine hesitancy and refusal which have been previously examined by public health scholars and social scientists.

Vaccine hesitancy, vaccine refusal and vaccine-critical activism

To define with more precision the main subject matter of this thesis, I will outline here some of the research which has been previously carried out on issues related to the social acceptance of vaccinations, with a particular focus on the concepts of vaccine hesitancy, refusal and opposition. While acknowledging that it is impossible to provide here a comprehensive review of all the social scientific literature which has been published on vaccine-related topics, in this section I focus on previous research on childhood vaccinations in order to identify some of the main analytical lenses which have been adopted to understand scepticism towards childhood vaccines specifically.[11] I do this so I can situate my research and the category of 'vaccine-critical activism' in the context of existing analytical frames, and make a better case as to why qualitative research focusing on online activism constitutes a valuable contribution to the current social-scientific scholarship on vaccine opposition. It should also be noted that the body of research looking into the social dimension of vaccinations and vaccine attitudes has been growing rapidly, especially since the advent of the COVID-19 pandemic (see e.g. Ransing et al. 2022; Burki 2020; Smith and Reiss 2020).

In considering alternative scholarly approaches to childhood vaccines in the social sciences, I organise my discussion around three main areas of the literature: the first includes health communication research and expert commentary from a public health perspective (mostly published in medical journals), the second is represented by qualitative sociological and anthropological research, and the

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[11] I should also specify that this thesis does not purport to offer a 'global perspective' on the public questioning of vaccines, and its qualitative approach prioritises depth rather than breadth of analysis (including from a geographical point of view). I have decided to focus on the English-speaking world and specifically on the UK and US for a number of reasons, including achieving a degree of continuity between the narration of 'historical' and contemporary vaccine-critical activism (as historical activism dating as far back as Jenner's smallpox vaccine is well documented in both these countries) and the prominence given to the phenomenon of online misinformation in commentary addressing vaccine-critical movements in these national realities. Further on this point will be discussed while reflecting on methodological choices in Chapter 3. For the moment, it is important to make clear that the choice to focus on the UK and the US in this research does not imply a judgment that studying vaccine confidence in Anglo-Saxon (or more broadly Western) contexts should be prioritised over other geographical and national realities. In fact, further research into how online activism may impact public perceptions of vaccines in other Western and non-Western contexts and the history of vaccine resistance in non-English-speaking countries would arguably be very helpful in enriching the current state of knowledge on the social dimension of vaccination (see also Chapter 8 for my reflections on potential avenues for future research on vaccine opposition).

third by legal and socio-legal work.[12] I will argue that despite the significant progress that has been made in understanding parental vaccine hesitancy and refusal, in these academic discourses the collective phenomenon of vaccine-critical activism has been either under-studied or misunderstood as the product of an 'anti-vaccination movement', spreading misinformation among a passive audience of 'vaccine-hesitant' parents.

Medical and public health perspectives

In commentary and research published in medical journals, the 'anti-vaccine movement' and the 'misinformation' that is linked to it is often discussed as one of the factors implicated in parental vaccination decisions (see Dubé, Vivion and MacDonald 2015). Generally, this scholarship tends to focus on the less extreme vaccine-related attitudes held by the general public, rather than looking specifically into those individuals and collectives that are outright opposed to vaccinations (see e.g. Dubé et al. 2013; Larson et al. 2014; Leask 2011; MacDonald et al. 2012). More than an object of study and theorisation in its own right, then, this literature generally frames anti-vaccination activism as an issue to be addressed in order to restore an acceptable degree of vaccine confidence among the general population (see Marshall 2013).

A key concept elaborated by public health scholarship is that of 'vaccine hesitancy'. While there is some variation in how this concept has been defined in different studies, vaccine hesitancy is seen as an issue related primarily to individual parents' decision-making around vaccinations (see Dubé et al. 2013). For example, the SAGE Working Group on Vaccine Hesitancy (established in 2011 by request of the Strategic Advisory Group of Experts (SAGE) on Immunizations – an advisory body to the WHO on immunisation-related matters) has provided an authoritative definition of 'vaccine hesitancy' as something '[referring] to delay in acceptance or refusal of vaccination despite availability of vaccination services' (MacDonald and the SAGE Working Group on Vaccine Hesitancy 2015). Because of the particular interest in immunization-related *behaviours* (specifically the 'acceptance' and 'refusal' of vaccines) across the general population, a shared thread in the literature on vaccine hesitancy has been that of developing models to account for different parental attitudes towards vaccine choices. As Eve Dubé and her colleagues have noted, a common approach is to see vaccination refusal as one end of a spectrum of attitudes towards vaccinations, with active vaccination demand at the opposite end, and

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[12] This subdivision has been employed for analytical purposes and reflects the positioning of the research into particular academic conversations rather than the disciplinary backgrounds of individual study authors. It should be noted that literature identified as 'public health' in particular often involves multi-disciplinary groups of researchers.

'vaccine-hesitant' parents occupying a middle ground between the two (see Dubé et al. 2013; Dubé, Vivion and MacDonald 2015).

Some authors, however, have critiqued the notion of vaccine hesitancy as defined by the SAGE Working Group, on the grounds that this would constitute 'more a catch-all category than a real concept' (see Peretti-Watel et al. 2015). For example, Peretti-Watel et al. (2015) argue that approaches linking the idea of vaccine hesitancy to particular immunization-related behaviours would overlook how the former 'is associated in the literature with various and non-specific behaviours and outcomes (due to reluctant conformism and vaccine-specific behaviours)' (4). 'Moreover,' they continue, '[vaccine hesitancy] is not the only possible explanation for each of these different outcomes: acceptance might also be due to strong support, refusal to strong opposition, and delay to procrastination, oversight, or ignorance' (2015, 5). Instead of focusing on the behavioural outcomes of vaccine choices, these authors suggest centring the definition of vaccine hesitancy around the decision-making process itself, proposing two main vaccine hesitancy 'axes' represented by individual degree of commitment to vaccination issues (e.g. the length of time and consideration given to vaccine decisions), and the level of trust placed into health authorities (2015, 10; see also Opel et al. 2011).

While 'vaccine hesitancy' is undoubtedly a helpful tool for analysing parental vaccination decisions, especially in this more sophisticated 'process-oriented' formulation, it may also be helpful to clearly differentiate between vaccine hesitancy and vaccine-critical activism (also referred to in this thesis as 'collective vaccine opposition'). First, linking vaccine-critical activism to parental vaccine choices, or even decision-making processes, risks missing out on those critics of childhood vaccines who are not parents and did not have to make vaccine decisions for their own children.[13] Second, as I will show in the course of this thesis, many of the vaccine critics who identify as parents claim to have held positive attitudes towards vaccinations before having their children immunised, recounting how they were not concerned about vaccinating and even gladly accepted the vaccines, becoming opposed to these only following their children's experiences of 'vaccine injury'. These parent-activists sometimes refer to themselves as 'ex-vaxxers' (see Chapter 7). Third, the concept of 'vaccine hesitancy' does not capture the crucial distinction (for the purposes of this study) between those who simply hold negative attitudes towards vaccines and health institutions (but keep their feelings to themselves), and those who take their stances a step further and become active vaccine-critical advocates, opposing vaccines and immunisation policies, and trying to dissuade other parents from vaccinating their children. As Heidi Larson and David Broniatowski (2021) have argued, it is especially important to avoid conflating

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[13] The journalist who co-founded of one of the blogs analysed in this study, for example, was apparently not a parent (see https://www.ageofautism.com/2017/01/daniel-j-olmsted-obituary.html).

vaccine hesitancy with vaccine-critical activism, as '[a] failure to understand the distinction can feed both fires' (1289).

Taken together, these considerations suggest that vaccine opposition should be regarded and treated as a phenomenon which is distinct from vaccine hesitancy.[14] Organised, collective forms of vaccine opposition, however, have arguably not been subject of much in-depth, theoretically-informed investigation by the medical and health communication literatures. In the health communication field, there is a body of research looking into the content of 'anti-vaccination websites' (see Nasir 2000; Wolfe, Sharp and Lipski 2002; Zimmerman et al. 2005; Davies, Chapman and Leask. 2002; Keelan et al. 2010; Kata 2010; Bean 2011). The main aim of this literature is to educate healthcare professionals on the arguments made by 'vaccine sceptics' to better enable them to counter such arguments (see Tafuri et al. 2014). However, while these studies are valuable in that they offer a good sense of what kinds of claims vaccine critics are making on their websites, they do not tend to offer a deeper insight into the nature of the online collectives that produce vaccine-critical content, or consider the broader social, cultural, legal and technological contexts which contribute to enabling and shaping vaccine opposition.

To be sure, some of the literature published in medical journals has explored in more detail the impact of recent social and technological developments on vaccine opposition (see e.g. Witteman and Zikmund Fisher 2012; Kata 2010; 2012), looking for instance at the effects of Web 2.0 and what Andrea Kata calls the 'postmodern model' of healthcare (2012, 3781). However, these kinds of studies remain rather isolated efforts. The dominant account in the medical journals and public health literature remains that of an 'anti-vaccination movement' influencing vulnerable parents with misinformation spread through the media (see e.g. Poland and Jacobson 2012; Marshall 2013; Offit 2010). This view of vaccine opposition has also been largely embraced by journalistic accounts, which often depict vaccine critics as ignorant and misguided.[15]

It is perhaps because of these framings of the 'anti-vaccination movement' that these strands of the academic literature have not tended to involve in-depth, qualitative analyses of vaccine-critical groups. Rather, the focus has been on themes such as the 'emotional' nature of vaccine critics (see Poland and Jacobson 2012; Ropeik 2013; Caplan 2013) and anti-vaccination movements' use of the internet as a sort of corruptive influence on vaccine-hesitant parents (see Marshall 2013). However, as Leach and

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[14] It should be pointed out that the literature on vaccine hesitancy does not generally claim to offer a special insight into the views of individuals who are campaigning against vaccines. Rather, as stated above, they refer to the views of the general public as distinct (but influenceable by) the activities of the 'anti-vaccine movement' (see e.g. Dubé et al. 2013).

[15] For examples of this kind of popular coverage in the U.S. see the commentary by Hiltzik (2014a; 2014b) on the *Los Angeles Times* and the writings of science journalist Seth Mnookin (2012; 2017). Mnookin has also written more extensively on the MMR-autism controversy, which will be further discussed in the next chapter (see Mnookin 2011).

Fairhead (2007) argue, the narrative of an anti-vaccination movement influencing a 'passive' public of vaccine-hesitant parents through the spreading of misinformation online may be overly simplistic, as it assumes a gullible audience which would take anti-vaccine stories at face value (35). The relationship between vaccine-critical activists and parents has been empirically interrogated and more carefully unpacked by sociologists and anthropologists writing about vaccination anxieties and refusal, as discussed in the next sub-section.

Sociological and anthropological perspectives

Sociological and anthropological studies have generally been less condemnatory of vaccine critics than the more widespread accounts of 'anti-vaxxers' and the anti-vaccine movement found in the media. More specifically, sociologists and anthropologists have emphasised the importance of the social contexts surrounding negative attitudes towards vaccination, and provided nuanced explorations of vaccination-related experiences and beliefs in light of such contexts. For instance, in Leach and Fairhead's (2007) seminal study of 'vaccine anxieties', the accounts that dismiss vaccine opposition as the product of ignorance and unreasonableness are critiqued in favour of a more elaborate view that pays attention to the socio-political background underlying parents' views on vaccines. Relatedly, Reich (2016) and Kaufman (2010) have noted a parallel between official public health discourses emphasising patients' responsibility and parents' own ways of navigating vaccine-related doubts by trying to incorporate 'the "fragments" of information, trust, rumor, therapeutic possibility, advice, and consumer know-how at their disposal' (Kaufman 2010, 27). Moreover, Gottlieb (2016) has framed parents' concerns as an expression of care instead of 'unsophisticated or disengaged refusals' (154). Taken together, this research seeks to move beyond the generalisation of the merely ignorant and misinformed parent, pointing towards the relational, social dimensions of vaccination beliefs and choices. As Heidi Larson (2020) has recently noted:

> Vaccine acceptance is about a relationship, about putting trust in scientists who design and develop vaccines, industries that produce them, health professionals who deliver them, and the institutions that govern them. That trust chain is a far more important lever of acceptance than any piece of information. Without these layers of confidence, even the more scientifically proved and well-communicated information may not be trusted.
> (2020, xxxv)

The role of trust relationships and discourses in vaccine-critical talk is something that has been of particular interest to scholars in the social sciences studying issues of vaccine refusal and opposition (see Leach and Fairhead 2007; Hobson-West 2007). Trust (particularly in the form of 'epistemic trust' – see Zagzebski 2003; 2012) is also one of the conceptual areas that will be further explored in this thesis, as I contend that the selection of and discrimination between different more or less trustworthy sources of vaccine-related information is a crucial element of activists' collective identities as 'well-informed citizens' (see Chapter 7).

For our purposes here, the biggest takeaway from the social science literature discussed above is that there is more to vaccine refusal than simple ignorance, or biased or mistaken reasoning. This is a position that has also been embraced by recent voices in the medical-anthropological literature. For instance, a large-scale study by Emily Brunson (2013) has found that, more than any other individual characteristic, such as ignorance or individual beliefs, the main predictor of parental vaccination choice is a parent's social network (and particularly the 'people network' of personal interactions related to vaccine decisions). This finding is supported by Elisa J. Sobo (2015), who has argued that 'social relations themselves are paramount drivers of vaccine refusal and delay' (395). Moreover, Sobo notes, the strong connection between social networks and vaccine refusal suggests that the latter is not just a matter of 'confirmation bias', that is, individual selection of particular information and exclusion of other depending on one's own pre-existing worldview (2015, 383). Rather, it is an instance of 'cultural cognition' (Kahan 2012; 2017; see also Douglas 1992; Douglas and Wildavsky 1982), whereby people tend to match their ideas with those of favoured groups and social circles.

However, even if we admit that the general assumption of cultural cognition is true, so that people tend to 'accept science' only to the extent this does not collide with their social identities, we would still be left with a lack of understanding about the processes through which these social identities come into existence, and how they are expressed, as well as how they may develop through time. Further, Brunson's and Sobo's studies refer to 'average' parents' decision-making processes and the issue of vaccine refusal rather than to the construction of vaccine-related beliefs among vaccine critics more specifically. Collective vaccine opposition may be seen as equally influenced by individuals' sense of belonging to particular 'cultural' and social spheres, but should also be thought as a social phenomenon embedded in wider contexts involving particular social, political, legal, and technological influences.

In general, much like the public health literature on vaccine hesitancy, sociological and anthropological studies have tended to focus more on individual parents and their vaccine-related concerns than vaccine-critical activism. However, as highlighted by sociologist Pru Hobson-West (2007, 200), opposition to immunisation also has a collective dimension which goes beyond parental attitudes and the expression of individual vaccine choices. Hobson-West's own work (2005; 2007) focusing on UK-based 'vaccine-critical groups' indeed provides a rare and fascinating insight into some of the broader social discourses underlying collective vaccine opposition, including the interaction between vaccine opposition and discourses of scientific and medical progress, risk and trust. The present thesis pays renewed attention to the collective dimension of vaccine opposition by investigating vaccine-critical activism, understood here as a trans-national collective phenomenon involving active and vocal critique of vaccination, both as a public health practice and as a set of public policies. This phenomenon has arguably not received the same level of empirical and theoretical attention from qualitative social scientific perspectives as parental refusal or anxieties.[16] Even more specifically, I found a lack of in-depth qualitative research looking into vaccine-critical activism as a form of internet-mediated resistance.[17]

By exploring online vaccine-critical activism the present study reveals the special significance of legal discourses and institutions for vaccine critics, and particularly how digital activists are building upon certain aspects of the law and the regulation of medicines and vaccines when they construct claims and arguments to support their worldviews. The effects and implications of the law for vaccine-critical activists have not been investigated in detail by sociological and anthropological studies on vaccination. My research therefore seeks to offer an original contribution to this literature by exploring the phenomenon of internet-mediated vaccine-critical activism and specifically interrogating online activists' multifaceted relationship with legal norms and legal concepts.

Legal and socio-legal perspectives

In terms of the legal contexts surrounding vaccines, it should be noted that, throughout the 20th century, there has been a general move away from the mandatory vaccination paradigm of the previous century towards optional vaccines.[18] In addition, particularly from the 1970s into the early 1990s, specialised schemes for the compensation of vaccine-related injuries have been introduced in countries

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[16] Aside from Hobson-West's research, collective vaccine resistance in the UK has been analysed in one chapter of Melissa Leach and James Fairhead's (2007, 83 ss.) book *Vaccine Anxieties* on the MMR vaccine controversy in the UK. However, neither Hobson-West, nor Leach and Fairhead have looked specifically into the internet-mediated dimension of vaccine opposition.

[17] It should be noted that while not a primary theme in her analysis, Hobson-West (2005) has touched upon the importance of the internet as a resource for at least some of the UK-based groups she investigated.

[18] This trend has arguably been reversed once again following the advent of the COVID-19 pandemic and the introduction of national legislation in different countries making COVID-19 vaccination mandatory in specific circumstances (see e.g. Jaffe 2022; Hayes and Pollock 2021).

across Europe (including the UK), as well as in the US and Quebec in North America, and Japan, South Korea and Taiwan in Asia (see Looker and Kelly 2011).[19]

Much like public health researchers, scholars writing from a legal perspective have been concerned with the potential negative consequences of refusing vaccination (see Gostin 2015; Laskowski 2016; Reiss 2017). But while public health research is interested primarily in the factors underlying vaccine refusal (see e.g. Dubé et al. 2013; Larson et al. 2016) the legal conversation has centred on the desirability of, and ethical justifications for vaccine mandates (Holland and Zachary 2014; cf. Laskowski 2016 and Gostin 2015; see also Salmon et al. 2006; Hendrix et al. 2016; Pierik 2017), the role of vaccine litigation in our legal system (Sanzo 1991), and the rights of children and parents in case of parental disagreement over the administration of childhood vaccines (English 2017; Reiss 2017). In his discussion of ethical justifications for mandatory immunisation policies, Colgrove (2006) maintains that the critical issue is striking a balance between the benefits of immunisation for individuals and society, and the right to parental autonomy; he also notes that such a balance cannot be objectively determined, but depends on one's ethical framework, which may variously emphasise the role of individual choice or communitarian commitments to society.

However, even within an ethical-legal framework which prioritises immunisation and its benefits, and where certain vaccines are mandated, adequate levels of vaccine confidence may not be achieved. A recent large-scale experimental study on vaccine decisions by Betsch and Böhm (2016) has shown that, when there is compulsion, negative attitudes to vaccination may be reinforced, and vaccine-critical individuals become less likely to accept non-compulsory vaccines. These findings are particularly relevant at the time of a pandemic in which, amidst the introduction of 'Covid passes' and restrictions in areas like travel and work for those who have not been vaccinated, countries such as the UK have seen coverage of some routine childhood vaccinations drop to the lowest levels in years.[20] They also raise the important question of whether or not vaccine-critical activism may be the product of a growing anti-authoritarian sentiment. The answer to this question is more nuanced than might be expected as I will contend throughout the thesis, with childhood vaccine critics alternating between, on the one hand, the questioning of state and expert authorities, and, on the other, the deployment of re-

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[19] It is important to note that vaccine injuries are very uncommon. Cases of severe reactions to vaccines are particularly rare. No causal links have been found between vaccines and certain neurological conditions, such as autism, that have been at the centre of claims made by vaccine-critical groups (see Gasparini et al. 2015). In addition, the risks of serious complications from vaccine-preventable diseases have been found to be 'many times greater' than those of serious adverse events following vaccination (Dittman 2007, 80).

[20] In the UK, specifically, coverage for the two recommended doses of the MMR vaccine have decreased to 85.5%, reportedly the lowest coverage rate in a decade for this vaccine, and well below the 95% coverage target required to prevent the spread of measles at a community level (Roberts 2022).

interpreted official sources and legal discourses in order to construct and support vaccine-critical claims, narratives and identities.

In order to unpack the relationship between legal authorities and vaccine-critical sentiments, further empirical investigation into vaccine critics' beliefs is necessary. Nonetheless, besides Betsch and Böhm's (2016) experimental study, there appears to be a lack of empirical research focusing specifically on how the legal regimes which cover vaccination are framed and understood by vaccine critics. As previously mentioned, socio-legal scholars have for the most part yet to look into opposition to vaccines. The notable exception here is the work of Anna Kirkland on the US 'Vaccine Court' (formally known as The Office of Special Masters within United States Court of Federal Claims), a specialised judicial body dealing with certain vaccine injury claims. In *Vaccine Court: The Law and Politics of Injury*, Kirkland (2016) analyses the ways in which the court has become a democratic forum to settle medico-scientific controversies, allowing for the easier management of vaccine injury claims by handling these in ways which reflect their surrounding legal culture. While Kirkland does pay attention to the beliefs and arguments of certain US-based vaccine-critical groups which have interacted with the court, her book is more focused on the workings of the vaccine court against its social and cultural backdrop, than it is with understanding vaccine opposition.

Understanding how vaccine opposition emerges and how it is nurtured and sustained in a real, contextualised environment is important in order to be able to assess the effects of the regulatory regimes to which vaccines are subject. Accordingly, in this doctoral project I have decided to conduct an empirical socio-legal study, in which doctrinal expositions of vaccination-related laws become relevant only to the extent that they are taken up by vaccine-critical narratives and claims (or when they act as a backdrop to the emergence of such narratives and claims).[21] This is in line with an interpretive tradition in law and society studies that sees law as an ideology rather than merely a tool which operates by constraining behaviour, where ideology is defined 'as a set of categories by which people interpret and make events meaningful' (Merry 1986; see also Trubek and Esser 1989; Ewick and Silbey 1998).[22] To make sense of these different framings of vaccination laws I will therefore attempt to study how these emerge in 'everyday', real-life interactions among vaccine-critical publics. A particular emphasis is placed upon how the law acts both as a context in which vaccine-critical talk by activists emerges and takes shape, and as a cultural resource that is actively remodelled in counter-discourses around immunisations.

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[21] I would like to thank Insa Koch for the suggestion to pay equal attention to the structural aspect of how the law can act as a context or backdrop in which vaccine-critical narratives are formed.

[22] It should be noted that the notion of ideology has different meanings in the interpretive and Marxist theoretical traditions (see Trubeck 1989).

Why we need qualitative socio-legal research into online vaccine opposition

To address the outstanding gaps in our understanding of vaccine opposition highlighted in my discussion above, the present research aims to empirically investigate a particular set of vaccine-critical activist social networks. The focus will be specifically on vaccine opposition which is expressed, articulated, and participated in online. This is firstly motivated by the internet's now fully-established role as a medium with major influence on health-related information-seeking and decision-making (see Fox 2011) and on vaccine perceptions (Betsch et al. 2010). But, I suggest, the role of the internet goes beyond that of a 'Pandora's box of misinformation' (Kata 2012) as it is often conceived of and discussed in the public health literature. In particular, Web 2.0 has been shown to allow not only for the gathering of information but also for the sharing and understanding of one's health experiences (Ziebland 2004). For Witteman and Zikmund Fisher (2012), Web 2.0 may influence vaccination decisions in multiple ways, including increasing the reach of personal narratives and emphasizing the social nature of decision making.

In the past couple of decades, media anthropologists have produced a fascinating body of literature on the ways the internet at the same time enables and complicates social practice. The work of Christopher Kelty, Adam Fish and their colleagues, for example, has looked into how the internet has enabled the emergence of new formations, the 'organised publics' which are involved in the production of 'resources', including knowledge-based resources, through different forms of open participation (see Fish et al. 2011). Along similar lines, technology and society scholars Mizuko Ito (2008) and danah boyd (2008) have developed the notion of 'networked publics', which Ito has referred to as '...a linked set of social, cultural, and technological developments that have accompanied the growing engagement with digitally networked media' (2008, 2). Building on Ito's definition, boyd (2008) suggests that online 'networked publics' support the same social practices as offline publics, while inflecting such practices in novel ways though Web 2.0's unique properties and dynamics. According to her, networked publics are simultaneously constituted by '...the space constructed through networked technologies and [...] the imagined community that emerges as a result of the intersection of people, technology, and practice' (2008, 1-2). As I will discuss in the next section of this chapter, the notion of internet-mediated publics can offer a very helpful theoretical reference point for the study of online vaccine-critical activism.

Despite the important role the internet has been found to play in contemporary vaccine-critical activism, we lack in-depth, theory-driven empirical studies of the social life of online publics questioning vaccination. I suggest an empirical-interpretive study into this area of research is needed particularly as an a-historical, a-contextual approach aimed at measuring vaccination attitudes in the abstract would fail to capture the nuance and complexity of vaccine-critical worldviews. Some voices in the social science scholarship on vaccine refusal have remarked on the scarcity of empirical studies on how 'today's information ecology relates to vaccination decision-making' (Sobo et al. 2016, 53; Brunson 2013). I would suggest a similar argument could be made with respect to the relationship between the new digital media information ecology and the emergence of mediated vaccine-critical collectives. This thesis therefore endeavours to bridge a specific gap in the literature to understand vaccine opposition at the intersection between media, law and society. In doing so, the present research will offer an empirical exploration of some significant narratives and practices which are constitutive of online vaccine-critical activism, to better understand how lay interpretations of the law and science behind vaccines and vaccination policies unfold in a real, mediated and historically situated context. In sum, this exploration aims to investigate the multiple ways in which what I call 'vaccine counterpublics' become separated from and opposed to legal and public health ideals of vaccination-compliant citizens, while simultaneously embracing their own reinterpretations of the law relating to vaccines.

Counterpublics, DIY citizenship and the law

Throughout this research I engage with different analytical frameworks in order to understand different facets of online vaccine-critical activism. This rather eclectic approach to the theoretical literature followed a methodological choice made at the outset of the project to pursue an inductive approach to analysing my data. This meant I did not rely on any pre-determined theoretical lenses to guide and colour my interpretation of the data. Letting the data guide the analysis process, directing it towards particular theories or concepts, however, did not exempt my study from having to commit to specific theoretical perspectives to inform my understanding of online vaccine-critical collectives at a more general level.

Even though I could have simply referred to the online texts produced by vaccine critics as the main object of my analysis, or employed the generic labelling of 'online community' to identify my vaccine-critical groups, I felt this could take away analytical depth from the study, and potentially make my findings more limited in their scope and reach. In addition, failing to offer some theoretical grounding while investigating these online groups would risk missing out on important aspects of their activities and identities as transpiring from what their members are doing and saying, as well as leaving the contours of the thesis blurry and undefined. Last, but not least, the methodological approach informed by internet ethnography embraced in this research required open-mindedness at the outset of the fieldwork process with regards to the nature of the social entities investigated. As will be seen in further detail in the methodology chapter (Chapter 3), seeking to understand and define particular online-based formations has been argued to represent a key aspect of internet-ethnographic research (see Caliandro 2018). It was therefore important to enter the field without any *a priori* conceptions of what I was going to encounter and observe, looking at the data first and then settling on analytical categories to better grasp and organise the research findings.

As seen in the above discussion, some strands of the existing literature dealing with vaccine-critical activism have favoured the concept of 'anti-vaccination movement' to refer to this phenomenon. As Stuart Blume (2006) has argued, however, it is not clear that the notion of 'movement' can aptly describe the 'claims, actions and discourse' of vaccine-critical groups (628). Addressing the question of whether it makes sense to conceive of vaccine-critical organisations as a movement, Blume acknowledges that these organisations may be seen as fitting 'new social movements' perspectives which emphasise the 'questions of redistribution and of recognition (or identity)' over requirements of mass mobilisation in social movements (2006, 638). In this regard, Blume references scholars of health-related movements (e.g. Shakespeare 1993; Carroll and Ratner 2001; Epstein 1995), stressing how '...for these authors mobilization is but one of the essential tasks of such organizations: others include the formation of an alternative 'community', and "addressing existing needs in innovative and empowering ways"' (2006, 638). However, he continues:

> How much theoretical sense it makes to view antivaccination groups as (new) social movement organizations (as distinct, for example, from pressure groups or self-help organizations) seems to depend on the theoretical assumptions and questions with which the study of social movements is approached. In any event there is no simple and unambiguous demarcation criterion that would enable us to say that they do or do not constitute a social movement. The utility of social movement theorizing then remains to be established through further empirical research.
> (Blume 2006, 638)

Although I do not wish to suggest that the notion of 'social movement' (particularly in the form employed by new social movement theorists) cannot be usefully applied to the study of vaccine-critical activism, in this work I have adopted an alternative theoretical lens to analyse online vaccine-critical groups from the perspective of counterpublic theory.

As a conceptual frame, 'counterpublic' (and the related notion of 'counterpublicity') has been originally discussed by critical theorists Oskar Negt and Alexandr Kluge [1972] (1993), who in *Public Sphere and Experience* used it to refer to an alternative arena for political action, incorporating experiences and interests seen as distinct and opposed to those of the mainstream public sphere. While these authors have focused specifically on the dialectic between 'bourgeois' and 'proletarian' publicity and counter-publicity, the idea of counterpublic has subsequently been taken on, expanded, and applied to different contexts by many other scholars across disciplinary boundaries. One notable example is Nancy Fraser (1990), who has applied the term to feminist collectives, defining these 'subaltern counterpublics' as '...parallel discursive arenas where members of subordinated social groups invent and circulate counterdiscourses, which in turn permit them to formulate oppositional interpretations of their identities, interests, and needs' (67). Perhaps more so than Negt and Kluge, Fraser presents her analysis of counterpublics as challenging assumptions underlying theorisations of the 'public sphere' as developed by Jürgen Habermas ([1962] 1989), pointing to how the construction of a liberal public sphere has historically relied on a number of conflicts and exclusions – based, among other things, on one's gender and class position in society (Fraser 1990, 62).

Communication and rhetoric scholars have also embraced the notions of counterpublics and counterpublicity, looking particularly at the discursive dimension of counterpublics while further contributing to theorising the relationship between counterpublics and the broader public sphere. Robert Asen (2000), for example, has, cautioned against reductionist approaches to counterpublic theory that attempt to frame '...a particular person, place, or topic as necessarily defining the limits of a counterpublic' (426). He has also challenged another form of reductionism that would involve a binary view in which one monolithic counterpublic is opposed to a single mainstream public, arguing that such reductionism '...may be averted by emphasizing manifold relations among multiple publics, some of which may articulate an explicitly counter status' (426). Other scholars have linked the idea of counterpublic to the production and dissemination of oppositional discourse (see Palczewski 2001; Warner 2002). Catherine Helen Palczewski (2001) in particular, has very early on envisaged an emergent connection between counterpublics and what she called 'cyber-movements'. More recently, a growing body of studies has been looking into internet counterpublics (also variously called 'online' or 'networked' counterpublics - see e.g. Törnberg & Wahlström 2018; Lee 2021; Chan 2018; Kaiser and Rauchfleisch 2019; Mendes 2015). All these studies emphasise the 'mediated' dimension of counterpublics.

These framings of counterpublics and counterpublicity have been particularly influential to how I started to think about and understand online vaccine critics. The discursive nature of online interactions among vaccine critics, and their 'counter' status with respect to mainstream narratives of public health was what pushed me towards counterpublic theory. I found that counterpublic frameworks resonated more with the data I was collecting and analysing, and consequently with what vaccine critics were doing and saying online, than alternative lenses such as 'online community' or even the concepts of networked and organised publics, which I believed did not sufficiently convey the dimension of 'clashing of discourses' (see Pason, Foust and Rogness 2017) that is instead crucial to the understanding of the nature of counterpublics as well as of collective vaccine opposition.

In drawing on counterpublic theory, I embrace the perspective shared by Amy Pason, Christina Foust and Kate Rogness, who have argued that (particularly compared to early social movement theory) '...counterpublic scholarship recognizes this clashing as existing between multiple publics and directed at a variety of power structures' (2017, 6; see also, in the same volume, Palczewski and Harr-Lagin 2017). Consistently with this, as will be seen throughout this research, vaccine counterpublics engage with and oppose not only the state, but a multiplicity of powerful agents and institutions, including the mainstream media, social media companies, national and international public health organisations, philanthropic foundations and pharmaceutical corporations. While not 'applying' a single theoretical framework to my data, I have also been influenced by Pason, Foust and Rogness's view of social change as '...exist[ing] as an interaction between various material and symbolic elements defined by and coordinated through communication, where change is about shifting power' (2017, 17).[23] More specifically, I share their and their volume contributors' '...preoccupation with social change as a clash/ing of forces, as implicating collective identity and rhetorical form, and as illustrative of material and symbolic effects in the world' (17-18).

Throughout this work, 'counterpublic' is then intended as an analytical category, or an organising device. Alongside the framework of the 'epistemic community' (see Haas 1992; Akrich 2010), which will be discussed further in Chapter 4, counterpublic theory has been instrumental to informing the structure of this research and its findings, enabling an analysis of how the law comes into play in relation to a number of distinctive aspects characterising online vaccine-critical collectives. These distinctive aspects, each of which showcases different ways in which counterpublics engage with the

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[23] The views expressed by Pason and her colleagues on social change have, in turn, been influenced by Castells' (2015) work on social movements in the internet age as well as by the theorisations on power of Hardt and Negri (2000). Castells' (2015) work particularly, with its framing of 'the construction of meaning in people's minds' (5) as a more stable source of power than (state-centric) 'coercive power' has also had a direct influence on how I conceive of vaccine-critical talk as a form of resistance and counter-power in this research.

law, are represented by vaccine counterpublics' construction of causal knowledge around claimed immunisation adverse reactions; their shared normative beliefs on vaccine decision-making and advocacy for policy change in relation to 'vaccine choice'; their symbolic representations of matters of vaccine safety; and, finally, the rhetorical constitution of vaccine-critical collective identities, connected to a struggle around how critics are perceived and represented by the broader public.

As I will argue, in their activities and activism, vaccine counterpublics 'bump up against' the law in different, and sometimes unexpected ways. More precisely, in the process of making their claims about vaccine injuries, vaccine counterpublics firstly invoke and expand the scope of the right to 'free speech', to defend their ability to produce and disseminate vaccine-critical content, while challenging social media companies' framings of such content as 'medical misinformation'. Secondly, in counterpublic talk, the right to informed consent is appropriated, and informed consent discourses are 'hijacked' in an attempt to not only advocate for 'parental choice' in vaccination matters, but also actively to influence non-counterpublic parents' vaccine decisions. Thirdly, vaccine counterpublics recast certain aspects of national regulatory frameworks which are supposed to ensure the safety of immunisations in order to undermine the very notion of vaccine safety. Finally, the liability protections granted to pharmaceutical companies in the US through the National Childhood Vaccine Injury Act 1986 are co-opted to serve vaccine counterpublics' rhetorical constructions of their collective identities as righteous 'whistle-blowers', speaking out against 'Big Pharma', unveiling 'true' science and expertise, and fighting against the systemic collusion between state and private interests.

In accounting for how vaccine counterpublics' are re-modelling official discourses emanating from their surrounding legal and scientific cultures in ways that ostensibly support their views, needs, experiences and interests, I will also draw an important connection between counterpublic theory and the notion of 'DIY citizenship' (Hartley 1999). By doing so, I suggest it is possible to compare the activities of vaccine counterpublic members to those of DIY citizens such as '..."modders", hackers, artists and activists who redeploy and repurpose corporately produced content or create novel properties of their own, often outside the standard systems of production and consumption' (Ratto and Boler 2014, 3). What I suggest more broadly in this study is that it is important to look beyond individual-centric approaches or binaries relating to the production and consumption of misinformation in order to understand online vaccine-critical activism. Instead, vaccine counterpublics and their members should be understood as an emergent form of political agency, expressing their citizenship through the appropriation and reworking of mainstream culture and official discourses.

Structure of the thesis

Following this introductory chapter, Chapter 2 offers an historical perspective on vaccine-critical activism, focusing on vaccine critics' evolving relationship with their surrounding legal landscapes and media ecologies. The chapter looks specifically at three significant historical 'waves' of collective vaccine opposition. The first wave of vaccine opposition is represented by the movement championed by the 'anti-vaccination leagues' active in England and the United States between the second half of the 19th century and the early 20th century. The second wave refers to the vaccine-critical campaigns conducted in the 1970s and 1980s, which mainly targeted the diphtheria, tetanus and whole-cell pertussis (DTP) vaccine. The third wave corresponds to the so-called 'vaccines-autism controversy' which started in the early 1990s and captured media attention throughout the 2000s. In the chapter, I show how vaccine-critical activists' ways of relating with the law have changed through time, moving from an outright rejection of vaccination laws as an oppressive expression of state power to more sophisticated forms of active engagement with the legal system. At the same time, in this chapter I suggest that an ever-evolving media ecology has been crucial in enabling and shaping collective vaccine opposition, giving rise to a collection of alternative 'vaccine counterpublics'. The final section of the chapter raises a number of questions on the nature of mediated participation in online vaccine counterpublics, and the ways in which these counterpublics relate to scientific and legal institutions. These questions are addressed in later substantive chapters of the thesis (Chapter 4 to Chapter 7).

Before getting into the main substantive chapters of the thesis, in Chapter 3 I discuss the research design process, methodology and methods employed in this study, as well as the ethical issues I have encountered in the course of the research. The chapter starts by providing some background on the design of the project, discussing the formulation of the research questions based on a framing of online vaccine-critical activism as a social phenomenon inflected by its surrounding social, technological and legal contexts. The chapter then moves to set out the qualitative research approach informed by internet ethnography adopted in the thesis, explaining the reasons for taking this approach, and the interpretive epistemology underlying my chosen methodology. I then describe how the research has been carried out in practice through the choice of particular research methods, discussing my approach to sampling, data collection and analysis. Finally, the chapter looks into the ethical challenges which have resulted from the choices made throughout the study, elaborating specifically on issues related to the 'blurring' of the line between public domain and private content in online settings and to carrying out non-participatory (or 'lurking') online research.

Chapter 4 is the first of the four main data chapters of this thesis. It draws on an epistemic community framework and the concept of 'causal knowledge' which is central to this framework (see Haas 1992; Akrich 2010) to consider how counterpublic members are constructing and sharing online knowledge resources intended to support claims about the existence of causal links between childhood vaccinations and a range of severe and long-term health conditions. I refer to these knowledge-making and -sharing activities as the 'epistemic practices' of vaccine counterpublics. The chapter shows that scientific knowledge plays an important role in counterpublic epistemic practices. Perhaps surprisingly, considering the widespread image of 'anti-vaxxers' as ignorant or anti-science, counterpublic members across the blogs considered in this research embrace positive framings of science and scientific knowledge. In addition to these positive framings of science, the chapter discusses how vaccine critics' epistemic practices are founded upon a (re)use of scientific evidence according to a 'DIY' praxis, and a learning ethos based on individual self-reliance. The epistemic practices of online vaccine critics are also shown to have given rise to tensions with social media companies which have in recent years introduced 'medical misinformation' policies restricting the sharing of vaccine-critical content on their platforms. In the final part of the chapter, I discuss how counterpublics have responded to these growing restrictions by appropriating and expansively reframing the legal notion of 'free speech' in order to support narratives painting vaccine critics as involved in a righteous fight against perceived online 'censorship'.

Chapter 5 examines the 'normative beliefs' around vaccine decision-making which orient online vaccine-critical advocacy, drawing again on an epistemic community approach to explore how these beliefs relate to the kind of policy changes pursued by counterpublics. In the first part of this chapter, I argue that some of the beliefs of vaccine-critical activists emerge from notions of vaccine decision-making which are not incompatible with official discourses according to which individual parents should thoroughly research the risks involved in any medical interventions in order to make informed decisions for their children. At the same time, contrary to views which depict vaccine critics as selfish or individualistic, an analysis of counterpublic beliefs on vaccine decision-making shows a clear 'communitarian' or public-oriented dimension to vaccine-critical activism. The second part of the chapter analyses how vaccine counterpublics reframe the legal concept of 'informed consent' in order to support of their advocacy for vaccine choice. In doing so, counterpublics refer to both the individual-family and the community-oriented aspects of vaccine-related decisions, managing to use 'informed consent' as a vessel to simultaneously emphasise the sanctity of individual parental rights to make medical decisions for their children, and a more collective right to which they refer as 'fully informed consent'. The latter specifically involves the active input of counterpublics in identifying what kind of information should be given to parents in order to obtain valid consent to vaccinations.

Following on my discussion of vaccine-critical advocacy, in Chapter 6 I examine how certain legal and regulatory sources are recast by counterpublics in support of vaccine-critical narratives about the purported unsafety of vaccinations. Conventional representations of the regulation of medicines usually emphasise the stringency of the safety controls to which vaccines are subject (see CDC 2018; Oxford Vaccine Group 2021). The expectation is that strict systems of regulation will therefore enhance public confidence in national immunization programmes. However, some aspects of these regulatory systems have instead been drawn upon and reframed by vaccine critics in order to 'prove' that vaccines are fundamentally unsafe medical products. Specifically, the chapter looks at how patient information leaflets (PILs, also known as 'package inserts' in the US), pharmacovigilance systems and vaccine damage payment schemes have been incorporated into vaccine-critical narratives framing vaccine risks as being simultaneously underestimated and concealed by authorities, and depicting the state and public health institutions as concerned only with population-level statistics rather than caring about the wellbeing of individual children and their families.

Chapter 7 looks into the collective identities of vaccine counterpublics. In the first part of the chapter, I consider collective identity narratives around the concept of 'truth', discussing how vaccine critics frame themselves as courageous 'whistle-blowers' defending 'facts' about vaccine dangers which will one day be proven to be true and acknowledged by the scientific establishment and mainstream public. Following this, I move to look into a set of identity narratives through which vaccine counterpublic members represent their abilities as learners and knowers. Contrary to views framing vaccine opposition as the result of pervasive sentiments of uncertainty and doubt in late-modern societies (Giddens 1990; 1991; Beck 1992; see Leach and Fairhead 2007, 30-31) or a growing societal scepticism towards expert knowledge, these narratives suggest that vaccine counterpublics create confident members who are self-assured about their epistemic competence and who do not outright reject expertise. Rather, drawing on the work of Alfred Schütz (1946), the chapter argues that vaccine counterpublic members cast themselves as 'well-informed citizens' who, distinctively compared to both laypeople and fully-fledged experts, feel themselves as uniquely qualified to appropriately discern which expert sources they can rely on. Finally, I discuss 'outward-looking' counterpublic narratives portraying pharmaceutical companies and vaccine policy-makers as colluding for the sake of profit to the detriment of children's health. Significantly, these narratives rely on the existence of legal provisions offering liability protections to vaccine manufacturers against vaccine damage claims as 'evidence' that the state is on the side of 'Big Pharma'. In the end, I suggest that the 'whistle-blower' and 'well-informed citizen' identities claimed by vaccine critics and their narratives of systemic collusion among public institutions may be seen as two sides of the same coin, supported by alternative interpretations of existing laws.

In Chapter 8, I offer some observations on the impact of the COVID-19 pandemic on current vaccine opposition and the relevance of the present research to these newly emerging developments, before returning to my original research questions on online vaccine-critical activism and how internet-mediated counterpublics opposing childhood vaccinations are relating to their surrounding legal landscapes. In addressing these questions, I synthesise the findings of this research and draw out some theoretical implications around the relationship between the law and internet-mediated vaccine counterpublics. In this context, I reflect more broadly on the ways in which the new digital media technologies have redefined how citizens can engage with the legal system, opening up new opportunities for campaigners in particular to appropriate and circulate critical interpretations of the law in pursuit of their activist interests and objectives. Considering vaccine-critical activism more specifically, I draw on theories of 'DIY citizenship' (Hartley 1999; Ratto and Boler 2014) to account for how online vaccine counterpublics are appropriating and reworking elements of their surrounding scientific and legal cultures in order to make their vaccine-critical arguments and construct shared collective identities. Following this, the chapter moves to discuss some significant implications of the research findings for policy and science communication. I conclude by reviewing some potential avenues for future research which I suggest can further enrich our understanding of vaccine-critical activism and its relationship with vaccine hesitancy.

2

LAW, MEDIA AND THE EMERGENCE OF VACCINE COUNTERPUBLICS

Introduction

Vaccine opposition, fuelled by the use of media technologies, is not a recent phenomenon. Rather, the creation and circulation of vaccine-critical media has a long history. In order to put this study into its historical context, it is therefore important to analyse how current vaccine opposition is both similar to and different from previous 'waves' of vaccine-critical activism. In this chapter, I look specifically at the emergence of three major historical 'waves' of collective vaccine opposition in England and also the US, focusing on the role played by an ever-evolving media ecology in shaping vaccine-critical talk as well as the changing ways activists in different eras have engaged with their surrounding legal landscapes.[24]

The first wave of activism considered in the chapter is represented by the movement championed by the 'anti-vaccination leagues' active in Victorian England in the United States from the second half of the 19th century, which started by opposing mandatory smallpox vaccination and attracted widespread popular support before running out of steam in the late 1920s. The second wave refers to the vaccine-critical campaigns conducted in the 1970s and 1980s, which mainly targeted the diphtheria, tetanus and whole-cell pertussis (DTP) vaccine. The third wave corresponds to the so-called 'vaccines-autism controversy' which started in the early 1990s and captured media attention throughout the 2000s.[25]

In order to shed light on the public, social and political nature of the kind of citizen participation expressed through collective vaccine opposition, and to capture the role of the media in enabling such participation, throughout the chapter I refer to the notion of 'counterpublics' (Negt and Kluge [1972] 1993; Fraser 1990; Warner 2002) to frame vaccine-critical activism. This concept is used to highlight

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[24] It should be pointed out that this chapter is not meant to offer a comprehensive history of vaccine-critical activism, and I mainly rely on the secondary literature to construct my analysis. Primary sources have also been consulted to inform the chapter, and some of these sources (mainly examples of historical anti-vaccine media) will be referred to when relevant. However, I do not purport to be providing here an exhaustive review of primary sources relating to historical vaccine opposition.

[25] It may be argued that the recently emerging movement against COVID-19 vaccines has given rise to a new, fourth historical wave of vaccine-critical activism following the three I examine in this chapter.

how the emergence of this instance of publicly-voiced and health-related opposition has given rise to novel, critical discursive spaces offering the possibility to at once resist and engage with state-sanctioned narratives and institutions. By tracing the historical footsteps of 'vaccine counterpublics', my main aim is to show how changing media ecologies have gone hand-in-hand with different forms of vaccine-critical activism, and particularly with different modes of interaction between vaccine counterpublics and the law.

My analysis of the three waves of vaccine-critical activism mentioned above reveals the changing nature of vaccine counterpublics from a force of 'pure' resistance, involving an outright rejection of legislative intervention in health-related matters, to one that becomes more and more engaged with the law as a potential resource through which to redistribute vaccination risks across society, and even challenge established medico-scientific expertise. In the conclusion, I raise a number of open questions about the nature of contemporary vaccine counterpublics and their relationship with the law which I address through empirical research in this thesis.

'Anti-Vaccinationism' in England and the United States in the 19th to early 20th century

While the practice of vaccination itself had engendered suspicion among part of the population since it was first introduced in late 18th century England (Leask 2015, 2), it was the introduction of mandatory vaccination laws which prompted opponents to consolidate and organise their resistance. In 1853, mandatory vaccination for all new-born children was introduced in England through the second of a series of 'Vaccination Acts' passed by Parliament (Wolfe and Sharp 2002, 431).[26] Statutory vaccination was not strictly enforced by the authorities in the first years after the passing of the Act (Williamson 1984). However, after subsequent smallpox epidemics hit the population in the following decade, restrictions were tightened with the passing of a stricter Vaccination Act in 1867. This third Act made vaccination mandates enforceable through prosecution and the imposition of fines on non-compliant parents.

In a climate of growing state intervention into the realm of vaccination and public health more generally, organisations devoted to the cause of fighting compulsory vaccination started to spring up in many English towns. The first of the anti-vaccination groups established in this period was the Anti-

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[26] The first of these acts, the Vaccination Act 1840, had previously made the practice of variolation illegal and provided for free vaccination for the poor.

Compulsory Vaccination League (ACVL), which was founded in London in 1867 shortly after the passing of the third Vaccination Act (see Porter and Porter 1988, 235). By the 1870s, the ACVL counted more than 100 branch leagues, 10,000 members and hundreds of thousands of sympathisers (Durbach 2005, 38).

Not all anti-vaccination leagues shared the same ideological and political commitments. For example, the National Anti-Compulsory Vaccination League (NACVL), established in Cheltenham by social reformers Mary Hume-Rothery (the daughter of a Benthamite Liberal Member of Parliament) and her husband William Hume-Rothery, had a more 'elitist' approach which discouraged working-class anti-vaccination campaigning and appealed more to middle and lower-middle class anti-vaccinationists (2005, 39). By contrast, the Anti-Compulsory Vaccination and Mutual Protection Society (ACVMPS, later named National Anti-Vaccination League) had more success mobilising the working classes to the anti-vaccination cause, helping its poorer members by paying the fines that were imposed for non-compliance with mandatory vaccination rules (2005, 39-40).[27]

According to historian Nadja Durbach (2005), author of a seminal work in the social history of Victorian anti-vaccination activism, these early anti-vaccination groups largely followed in the footsteps of the diverse range of single-issue political pressure groups, friendly societies and associations which were active in this era, such as temperance and anti-vivisection societies.[28] In a similar fashion to these other grassroot organisations, anti-vaccination leagues promoted themselves and their cause through a variety of public engagement activities, including distributing membership cards and organising '...debates, concerts, conversaziones [sic], tea parties and mass meetings in Temperance halls and Corn and Cotton Exchanges' (2005, 38). Most importantly for our purposes, the establishment of anti-vaccination leagues was accompanied by the emergence of a vast collection of publications such as journals and pamphlets devoted to the cause of opposing mandatory vaccination.

Porter and Porter (1988) note specifically how '[a]nti-vaccinationist literature proliferated during the 1870s and '80s' (239). They mention the NAVCL's *National Anti-Compulsory Vaccination Reporter*, the ACVMPS's *Vaccination Inquirer*, and the *Anti Vaccinator* (created in 1869 by Henry Pittman, an anti-vaccination and temperance activist from Manchester), as prominent anti-vaccination journals of the era. Other types of publication by anti-vaccination authors, such as books and pamphlets, also proliferated at this time (1988, 239). The emergence and popularity of anti-vaccination media in this

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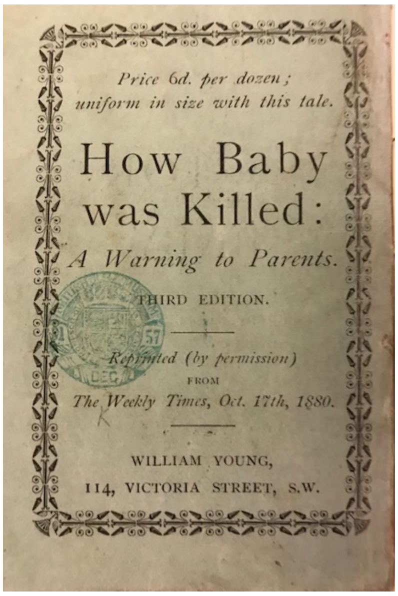
[27] The ACVMPS, founded in 1880 by the 'triad' of wealthy merchant William Tebb, chemist William Young and bookseller William White, subsequently dissolved to form the National Anti-Vaccination League (NAVL) (Durbach 2005, 40).

[28] Among these Durbach (2005) mentions anti-vivisectionists, abolitionists, temperance adherents, spiritualists and vegetarians (for more information on some of these related social movements see also French 1975; MacLeod 1967; Gregory 2007).

period is not surprising if seen in the social context of the dramatic development of the press in Victorian England. As Walter Houghton (1959) has contended, '[t]he nineteenth century, especially from 1825 to 1900, was the golden age of the magazine and the review' (554). This was due to a multiplicity of factors, including increasing population literacy, technological innovations in printing, and the abolition of so-called 'taxes on knowledge'.[29]

Early anti-vaccinationists showed remarkable resourcefulness in their engagement with printed media and literary forms of propaganda. According to Youngdahl (2012), anti-vaccination leagues carefully planned their public presence, and considered creative measures to advance their cause, such as offering prizes for the production of anti-vaccination essays and fiction, and even composing songs and hymns against vaccines. Durbach (2005) notes how the English anti-vaccination movement generated '...hundreds of handbills and pamphlets of various shapes, sizes and genres […]. These relied not only on sensationalist stories and dramatic events but also on reports of routine acts of civil disobedience and on statistical data' (47). Indeed, some features of early vaccine-critical texts seem to anticipate and echo later developments in vaccine-critical campaigning. One of these features is the use of narratives – alleged accounts of vaccination victims, but also fictional stories, often in the form of morality tales addressed to parents – which offered dire warnings about the alleged dangers of vaccination (see Image 1 below).[30]



Price 6d. per dozen;
uniform in size with this tale.

How Baby
was Killed:

A Warning to Parents.

THIRD EDITION.

Reprinted (by permission)
FROM
The Weekly Times, Oct. 17th, 1880.

WILLIAM YOUNG,
114, VICTORIA STREET, S.W.

Image 1: Anti-vaccination pamphlet cover 1880s. Source: British Library. General Reference Collection 1607/2904.(21.)

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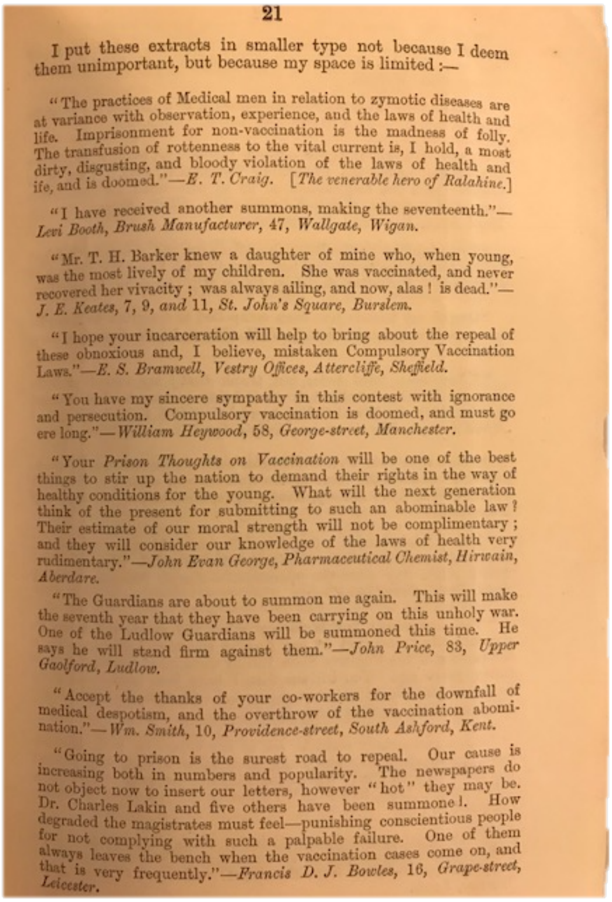
[29] These included the excise duty on paper and stamp duties for newspapers, pamphlets, advertisements and almanacs, which happened in the 1850s-1860s. The reduction and eventual abolition of these taxes in the 19th century marked a dramatic increase in the circulation of newspapers and printed media more generally. For extended accounts of the historical developments occurring in the areas of press and journalism in Victorian England see Dagnall (1998) and Hewitt (2013).

[30] Similarly, contemporary vaccine critics have been found to rely on 'the power of storytelling to infect […] parents with fear of and doubt about vaccines' (Shelby and Ernst 2004).

A second line of continuity between earlier and more recent vaccine criticism lies in the fostering of public participation and engagement with vaccine-critical talk. Anti-vaccination journals made reference to and reported extracts from readers' letters, and sometimes also contained the author's replies to readers' comments, in a way that does not seem too distant from the flow of a conversation in the 'comment' section of a contemporary blog or website.[31] A common target of these print format antecedents of today's 'comment sections', was the penalty of imprisonment for parents who did not comply with vaccination mandates. This has been referred to variously by readers of anti-vaccination literature as 'the madness of folly', 'an abominable law', 'medical despotism', and an 'unholy war' (Image 2 below).



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I put these extracts in smaller type not because I deem them unimportant, but because my space is limited :—

"The practices of Medical men in relation to zymotic diseases are at variance with observation, experience, and the laws of health and life. Imprisonment for non-vaccination is the madness of folly. The transfusion of rottenness to the vital current is, I hold, a most dirty, disgusting, and bloody violation of the laws of health and ife, and is doomed."—*E. T. Craig.* [*The venerable hero of Ralahine.*]

"I have received another summons, making the seventeenth."—*Levi Booth, Brush Manufacturer*, 47, *Wallgate, Wigan.*

"Mr. T. H. Barker knew a daughter of mine who, when young, was the most lively of my children. She was vaccinated, and never recovered her vivacity ; was always ailing, and now, alas ! is dead."—*J. E. Keates*, 7, 9, *and* 11, *St. John's Square, Burslem.*

"I hope your incarceration will help to bring about the repeal of these obnoxious and, I believe, mistaken Compulsory Vaccination Laws."—*E. S. Bramwell, Vestry Offices, Attercliffe, Sheffield.*

"You have my sincere sympathy in this contest with ignorance and persecution. Compulsory vaccination is doomed, and must go ere long."—*William Heywood*, 58, *George-street, Manchester.*

"Your *Prison Thoughts on Vaccination* will be one of the best things to stir up the nation to demand their rights in the way of healthy conditions for the young. What will the next generation think of the present for submitting to such an abominable law ? Their estimate of our moral strength will not be complimentary ; and they will consider our knowledge of the laws of health very rudimentary."—*John Evan George, Pharmaceutical Chemist, Hirwain, Aberdare.*

"The Guardians are about to summon me again. This will make the seventh year that they have been carrying on this unholy war. One of the Ludlow Guardians will be summoned this time. He says he will stand firm against them."—*John Price*, 83, *Upper Gaolford, Ludlow.*

"Accept the thanks of your co-workers for the downfall of medical despotism, and the overthrow of the vaccination abomination."—*Wm. Smith*, 10, *Providence-street, South Ashford, Kent.*

"Going to prison is the surest road to repeal. Our cause is increasing both in numbers and popularity. The newspapers do not object now to insert our letters, however "hot" they may be. Dr. Charles Lakin and five others have been summoned. How degraded the magistrates must feel—punishing conscientious people for not complying with such a palpable failure. One of them always leaves the bench when the vaccination cases come on, and that is very frequently."—*Francis D. J. Bowles*, 16, *Grape-street, Leicester.*

Image 2: Readers' comments to English anti-vaccinator Henry Pitman's 1876 tract 'Prison Thoughts on Vaccination'. Source: British Library. General Reference Collection 1607/2904.(1.)

According to Durbach (2005), anti-vaccinationists '...made the most of an ever-widening public sphere, using visual as well as literary forms of propaganda' (48). As regards visual propaganda, Durbach (2005)

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[31] This continuity in forms of public opposition has not been lost on some commentators. Howard (2003) for example remarks on early and modern vaccination critics' astute use of the press, stating that '[l]ittle has changed save that the power of the Victorian pamphlet has been replaced by the website'.

mentions the use of pictures of children allegedly killed or maimed by vaccination, which found their way into pamphlets as well court proceedings for vaccination non-compliance. The use of satirical cartoons was also widespread, both among English and North American vaccine opponents (Image 3 below).

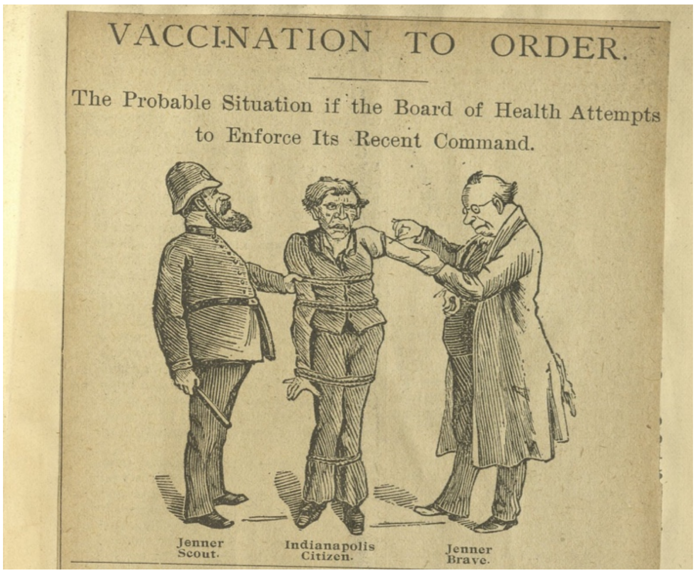

Image 3: Vaccination to Order/anti-vaccination satirical cartoon depicting a citizen being forcibly vaccinated, 1890s. Source: Historical Medical Library, The College of Physicians of Philadelphia, Anti-vaccination clippings 8c242. The image is used by kind permission of The College of Physicians of Philadelphia.

Like their English counterparts, North American anti-vaccinationists vigorously campaigned against vaccine compulsion, established local anti-vaccination leagues, and published pamphlets and journals. English and American vaccine critics also had in common a link with alternative medicine (particularly naturopathy, hydropathy and homeopathy) and its practitioners, for whom anti-vaccinationism formed a part of a broader fight against 'regular', or 'allopathic' medicine (see Porter and Porter 1988; Durbach 2005; Kaufman 1967). Significantly, and as in England, organised opposition to vaccination in the US took off only after the adoption of legal measures which introduced mandatory vaccination, or tightened its enforcement. As Kaufman (1967) writes, although vaccine-critical ideas were being embraced by 'irregular physicians' and advocates of 'unorthodox medical theories' in the US since at least the 1850s, more widespread opposition only arose when, following a series of smallpox epidemics in the 1870s, many states started to pass new compulsory vaccination laws or to increase enforcement of pre-existing vaccination ordinances (464).

During this period until the early 1900s, numerous anti-vaccine organisations were established (1967, 466). These included the *Anti-Vaccination Society of America*, which was established in New York in 1879 following a visit from William Tebb (the wealthy English merchant who was also a co-founder of the

ACVMPS in London), the *New England Anti-Compulsory Vaccination League*, the Indiana-based *Anti-Vaccination Society of America*, among a host of other state-level and local organisations. In his book *Pox: An American History*, historian Michael Willrich (2011) draws a distinction between what he calls 'vaccine refusers' – the parents who resisted governmental authority on vaccination '[b]y rioting, forging vaccination scars, scrubbing vaccine from their children's arms, or driving vaccinators from their neighborhoods...' – and the 'antivaccinationists' (583). As he explains,

> [Vaccine refusers'] actions emboldened antivaccinationists, but that did not make every "vaccine refuser" an antivaccinationist. For most refusers, resistance was an act in and of the moment; it lasted only so long as did the threat of compulsion itself. Antivaccinationists were different. They were activists—people with a cause. They aimed to win converts, move public opinion, change laws.
> (Willrich 2011, 583)

Along the same lines, Durbach (2005) notes how the activities of anti-vaccination leagues and their members did not represent the whole picture of Victorian opposition to vaccination – vaccine resistance in fact involved larger swathes of the (mostly working-class and lower-middle class) population, whose activities were often locally-based and not centrally planned or organised (40-41).

As mentioned previously, the leadership of anti-vaccination leagues tended to come from more privileged class backgrounds and to have different tactics, preoccupations and motives than the wider base of 'vaccine refusing' parents.[32] Durbach (2015) highlights how portions of the Victorian working class regarded vaccine-related legislation – such as the Compulsory Vaccination Act of 1853 – as part of a broader system of regulation and control of working-class bodies, marked by state intervention in the 'previously private and domestic realm of medical practice and bodily care' (see Durbach 2000, 45). It is important to note in this regard that compulsory vaccination in Victorian England was linked to the pre-existing 'poverty relief' legal framework which had been introduced under the 1834 'New Poor Law' (see Porter and Porter 1988; Durbach 2005, 96-99).

This framework had been staunchly opposed because of the harsh conditions it imposed– and particularly the forced hard labour in the dreaded 'workhouses', which became a requirement for relief claimants.[33] Because Victorian vaccination reforms had also originated out of the New Poor Law and

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[32] Anti-vaccination league membership, on the other hand, seems to have differed somewhat in the UK and the US, with the UK leagues attracting more working-class members, and the US organisations mostly comprising members from the educated middle classes (See Willrich 2011).

[33] For a more comprehensive insight into the New Poor Law and its implications, see Hamlin (1995).

were administered under the same regime, vaccination was associated with an oppressive normative framework which marginalised and stigmatised the working classes, hurting their ideals of 'independence and respectability' (Durbach 2005, 96).

For many working-class Victorian parents, therefore, vaccination evoked both the 'stigma of relief' and the 'specter of the workhouse' (95). On the other hand, middle-class anti-vaccinationists appeared to be more preoccupied with either abstract principles such as personal liberty and individualism (Durbach 2000, 45), or questions related to 'natural healing' and 'spiritualism' (Porter and Porter 1988, 235). In the US, the more committed anti-vaccination activists also embraced distinct ideologies, with many subscribing to what Willrich (2011, 585) calls 'a largely forgotten American tradition and subculture of libertarian radicalism', which was generally opposed to state intervention in social life.

These significant differences in the concerns of anti-vaccination leagues leaders and vaccine-refusing parents may be better understood by reference to the social context in which vaccination was practiced at the time. For example, imprisonment as a sanction for non-compliance with vaccination was much more likely to be enforced against working class parents, who could not afford to pay the repeated fines imposed under mandatory vaccination laws. As an English anti-vaccination pamphlet phrased it: '[…] Vaccination Law is most unjust because it always must be a most unequal punishment; it is one that is a mockery as regards the poor, for they cannot avail themselves of the alternative; as regards the rich it is a flea bite' (Longman 1900).

Additionally, according to Stern and Markel (2005) '[w]hile nineteenth-century fears of vaccination might have been based on anecdotal horror stories of other infections, the statistical risks of vaccine-induced infection from that era would not be medically acceptable today' (617). Health concerns grounded in the reality of smallpox vaccination risks therefore appear to have played a role in early opposition to smallpox vaccination. Such concerns may have been accentuated by the social divisions and inequality of the era. As Willrich (2011) suggests, many smallpox vaccine complications were actually due not to the vaccine itself, but to its methods of administration– which at the time did not involve inoculation, but lancing performed by a vaccinator. In practice, this meant that it was again poorer, working class individuals who bore the brunt of the risks involved, as the wealthy had access to private doctors who could administer vaccines in more sanitary conditions than the mass 'arm-to-arm' procedures performed on working-class children by public vaccinators. (see Durbach 2000; Weber 2010).

Against this broader historical backdrop, I suggest that the blooming anti-vaccination press scene, including widely circulating anti-vaccination league journals, books and pamphlets, has been crucial in bringing anti-vaccination leaders and vaccine-refusing parents together. Despite their different backgrounds, concerns, and tactics of resistance, the anti-vaccination press created a powerful link between the two, a shared forum connecting local action to national and even international audiences. Durbach also highlights the role of the media in coordinating vaccine resistance in this period, noting that:

> [w]hile anti-vaccination activities were largely local initiatives, their forms were not necessarily regionally specific. Rather, protest manifested in similar ways in cities and towns across England and Wales. This was due in part to the strength of the anti-vaccination press, which provided models for agitation and a national audience for otherwise local events.
> (2005, 47)

Similarly, writing about vaccine opposition in the US, Willrich has argued that what American anti-vaccination leagues lacked in terms of organisational capabilities and membership numbers they made up with their remarkable literary output (see Willrich 2011, 590-591).

The anti-vaccination propaganda of this era was arguably particularly well-suited to a form of resistance against the law, with mandatory vaccination laws specifically representing the intrusive nature of state power and its affirmation over the private domains of health and the family. According to socio-legal theorists Patricia Ewick and Susan Silbey, resistance always entails a 'positioning of self' as 'being up against something or someone', and a 'consciousness of opportunity'. The latter is a feeling that it is possible to intervene to change one's situation when power has produced unjust conditions. Resisting the law, Silbey and Ewick write, involves 'perceiving legality […] as a net in which [people] are trapped and within which they struggle for freedom' (183). I would argue that this kind of 'against the law' consciousness encapsulates well opposition to vaccination mandates in Victorian England and the United States from the second half of the 19th century to the early 20th century.

As a form of collective action directly opposing mandatory vaccination laws, some Victorian working-class opponents would refuse to pay the fines imposed on them for non-compliance. For Durbach (2005), accumulating fines was a strategy intended to demonstrate the 'folly of the law' – or to expose, as anti-vaccinationists put it, the true nature of the 'vaccination law tyranny' (102). These everyday acts of resistance were then widely reported and celebrated by the anti-vaccination press. Narratives presenting parents willing to go to jail to avoid vaccinating their children as 'martyrs', or exposing the perceived oppression of ordinary citizens at the hands of doctors and state authorities, as well as frequent reports of local acts of civil disobedience all served to construct and cement a collective vaccine-critical identity based around a sense of moral outrage against unjust laws interfering with people's liberty and children's health.

In harnessing the power of the printed media, I suggest therefore that anti-vaccinationists acquired a distinctive form of public agency. A useful lens to better understand these discursive and mediated aspects of vaccine opposition may be found in theories of the public sphere, and particularly in Nancy Fraser's (1990) notion of the 'subaltern counterpublics'. According to Fraser, these counterpublics constitute 'parallel discursive arenas where members of subordinated social groups invent and circulate counterdiscourses to formulate oppositional interpretations of their identities, interests, and needs' (Fraser 1990, 67). As Fraser (1990) makes clear:

> […][S]ubaltern counterpublics are not always necessarily virtuous; some of them, alas, are explicitly anti-democratic and anti-egalitarian; and even those with democratic and egalitarian intentions are not always above practicing their own modes of informal exclusion and marginalization. Still, insofar as these counterpublics emerge in response to exclusions within dominant publics, they help extend discursive space. (67)

Counterpublics are therefore, at their core, alternative publics opposed to dominant publics. But like all publics, counterpublics may also be seen as cultural agents. Particularly relevant here is Mizuko Ito's (2008) definition of publics as 'reactors, (re)makers and (re)distributors, engaging in shared culture and knowledge through discourse and social exchange as well as through acts of media reception' (3). With their range of alternative publications, including journals, pamphlets, letters and handbills, but also networks of distribution, lectures, conventions and local meeting spaces, I suggest anti-vaccinationists started to emerge as counterpublics with a shared political and cultural repertoire around the second half of the 19th century.

These 19th- and early 20th-century counterpublics were counterpublics of radical liberalism, fighting for liberty and freedom from state interference at a time when governments were becoming increasingly important actors in economic and social life. Durbach (2005) has highlighted the importance of individual rights as placing a limit on state intervention for Victorian anti-vaccinationists. As she writes:

> The anti-vaccination movement was a cross-class campaign that often drew on populist discourses to unite agitators against what they interpreted as the coercive policies of an

> increasingly interventionist state. Campaigners from all social classes claimed their rights to govern their homes and families. These rights, they maintained, derived from their English citizenship. Both working- and middle-class agitators used the discourse of citizenship to argue that the state had no right to compel them to vaccinate their children.
> (Durbach 2005, 69)

This kind of resistance against state institutions and their broadening powers in the realms of health and the body was very much shared by American anti-vaccinationists. As Willrich (2011) puts it, '[anti-vaccinationists] challenged the expansion of the American state at the very point where state power penetrated the skin' (630). As discussed above, the primary target of this challenge was represented by mandatory vaccination laws, which led to non-compliers being prosecuted in court and fined if not imprisoned.

At the same time, the law provided vaccine counterpublics with a repertoire of arguments around individual freedom, civil liberties and personal rights flowing from the Anglo-American common law tradition which could be used to oppose mandatory vaccination. For example, John Gibbs (one of the first British league leaders to oppose the Vaccination Act 1853) authored a pamphlet titled *On Medical Liberties* (1854), criticising mandatory vaccination as something suited to the centralised and bureaucratised national realities of continental Europe, but decidedly incompatible with English liberty (Durbach 2005, 32). A few decades later, American anti-vaccinationist John Pitcairn referenced John Stuart Mill's (1859) treatise *On Liberty* and even Blackstone's *Commentaries on the Laws of England (1765–69)* in his book *Vaccination* (1907), arguing that mandatory vaccination laws were infringing the 'right of personal security' – also known as the right to life and limb – which was protected under English and American common law (see Willrich 2011, 625-626). These invocations of a legally-informed vocabulary of civil and personal liberties in the independent publications of early vaccine-critical publics are especially fascinating as they seem to anticipate some of the ways in which contemporary vaccine critics engage with the law through digital media, as will be seen in later chapters of this work.

For the moment, it is important to note that while appeals to personal liberty and individual freedoms were widespread in both the US and English vaccine-critical literatures of this period, some US-based anti-vaccinationists went even further, attempting to rely upon these principles in order to present constitutionally-grounded arguments against compulsory vaccination in court. Perhaps the most well-known instance of such an attempt is the that of Massachusetts minister Henning Jacobson, who found himself at the centre of the landmark case *Jacobson v Massachusetts* (1905) after refusing vaccination in the midst of a smallpox epidemic affecting the city of Boston and the surrounding area.[34]

Jacobson had initially represented himself before a state court of first instance, and his arguments – mostly based on the dangers of vaccination and his own purported special susceptibility to the procedure – were dismissed. With the support of a Massachusetts-based anti-vaccination society, which hired counsel to assist him, he filed two subsequent appeals with higher state courts, both of which were unsuccessful. The case was finally heard by the United States Supreme Court in 1904. Jacobson's defence here mainly relied on constitutional arguments about the scope and limitations of the *police powers* of the state – that is the constitutionally-granted power of US states to legislate in a way that may affect individual rights in order to protect the health, safety, morals and general welfare of the public (see Legarre 2007). The argument, in essence, was that Massachusetts's mandatory vaccine legislation deprived Jacobson of the liberty from state interference he was constitutionally entitled to as an American citizen. As a consequence, it was maintained, the state vaccine legislation was unconstitutional.

The Supreme Court disagreed with Jacobson's defence, embracing instead a narrower, progressivist view of individual liberty as subordinated to the 'common good' in circumstances of 'great danger'. As Justice John Marshall Harlan, who delivered the Court's 7-2 majority decision, stated:

> The defendant insists that his liberty is invaded when the State subjects him to fine or imprisonment for neglecting or refusing to submit to vaccination; that a compulsory vaccination law is unreasonable, arbitrary and oppressive, and, therefore, hostile to the inherent right of every freeman to care for his own body and health in such way as to him seems best, and that the execution of such a law against one who objects to vaccination, no matter for what reason, is nothing short of an assault upon his person. But the liberty secured by the Constitution of the United States to every person within its jurisdiction does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint. There are manifold restraints to which every person is necessarily subject for the common good. [...] Real liberty for all could not exist under the operation of a principle which recognizes the right of each individual to use his own, whether in respect of his person or his property, regardless of the injury that may be done to others.
> *Jacobson v. Massachusetts*, 197 U.S. 11, 26 (1905).

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[34] See *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

The Supreme Court decision in *Jacobson v Massachusetts* signalled that the judiciary was not ready to accept anti-vaccinationists' broader framings of personal liberties as fundamentally incompatible with mandatory vaccination laws. But while the individual freedom arguments embraced by early vaccine counterpublics failed to obtain judicial sanction, they proved more successful in persuading politicians and legislators to attenuate or remove mandatory vaccination requirements. In England, for example, anti-vaccinationists obtained a major victory with the granting of a conditional exemption from vaccination to 'conscientious objectors' through the Vaccination Acts of 1898 and 1907. In the United States, according to Wolfe and Sharp (2002), they succeeded in repealing compulsory vaccination laws in a large number of states (431).

Following these turn-of-the-century victories in their crusade against compulsory vaccination, organised anti-vaccinationism went through a period of gradual but steady decline. Most leagues ceased to operate over the first half of the 20th century, as the science of vaccination affirmed itself among the medical mainstream and the wider public.[35] Along with them went their independent press and anti-vaccine publications, which – as argued here – had given rise to a first generation of 'vaccine counterpublics'. With their radical libertarian identities and primary concern with championing personal freedom and parental choice in health matters, these historic counterpublics had framed the state and its laws as a source of oppression for individuals and families. From a Victorian (or, in the US, a Gilded Age and Progressive Era) anti-vaccinationist perspective, this oppressive legal power had to be fought against and curtailed as much as possible. In the following sections I will analyse how, as changed social conditions and a novel media ecology establish themselves in the late 20th century, different kinds of vaccine counterpublics start to emerge. As we shall see, these new counterpublics start looking at the law not merely as an unjust force constraining individual freedom, but as a *resource* opening up new opportunities for the acknowledgment and promulgation of allegations about vaccine-related risks.

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[35] This does not mean that opposition to vaccination had completely ceased in the mid-1900s. In England, the NAVL (and its successor, the Howey Foundation) was active throughout the 1970s, although it seems that towards the end of its existence it started to veer towards ever more marginal and extreme positions, having connections with far right politics (see Durbach 2005, 201 and accompanying notes). Class-based vaccine refusal also seemed to have carried on at a local level in this period (see Beier 2001), raising the question of inter-generational transmission of anti-vaccination beliefs. In the US, anti-vaccinationism was also still present, albeit in a more subdued shape, during the 1940s and 1950s, when it was largely connected to alternative medicine proponents and far right political views (see Johnston 2004, 248).

The DTP scandal and vaccine-critical activism in the 1970s and 1980s

While the circulation of early vaccine-critical talk had largely taken place through the independent publications of anti-vaccination leagues, the growing influence of the mass media in the second half of the 20th century afforded new opportunities for the making of collective claims which empowered and shaped a new generation of vaccine critics. The significance of this novel landscape of mass communication for collective vaccine opposition, as well as its relation to concurrent political, social and legal developments in the sphere of consumer rights, tort litigation and compensation can be glimpsed with particular clarity from historical accounts looking into the diphtheria, tetanus and (whole cell) pertussis (DTP) vaccination controversy of the 1970s and 1980s.[36]

Starting in the mid-1970s, the DTP controversy – which mainly concerned the whole-cell pertussis component of the vaccine – may have constituted the most significant setback for immunisation efforts since the smallpox vaccination opposition of the previous century (Baker 2003, 4003). The scare originated in the UK, where it has been linked to the publication of a medical case series by three doctors based at the Hospital for Sick Children at Great Ormond Street, alleging that the whole cell pertussis component of the DTP vaccine had caused a neurological reaction in thirty-six children (Kulenkampff, Schwartzman and Wilson 1974; see Gangarosa et al. 1998).[37] According to public health scholar Eugene J. Gangarosa and his colleagues, the case series received 'persistent television and press coverage' (Gangarosa et al. 1998, 358), and for years the medical opinion in Britain was divided on whether or not the pertussis component of the vaccine could be the cause of severe, long-term neurological adverse reactions which could make children 'brain damaged'. These already pervasive doubts were further aggravated as a member of the government's advisory body on vaccine safety, the

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[36] A 'whole cell' vaccine contains a suspension of the killed bacteria cells of the disease it is supposed to prevent.

[37] Fourteen years before the publication of the Kulenkampff paper a Swedish physician, Dr Justus Ström – a specialist in paediatrics and infectious diseases – had also published a paper on the *British Medical Journal* attributing thirty-six cases of neurological conditions to the whole-cell pertussis vaccine and claiming a rate of neurological reactions to the vaccine of 1 to 6000 (Ström 1960). According to Hoyt (2004) both Ström's methods and conclusions were subject to strong criticism by other Swedish Medical Association members. Ström's 1960 paper was cited and defended in the Kulenkamff report. It is also interesting to note that both the Kulenkampff and the Ström articles relied on a previous American paper detailing 15 cases of encephalopathy following pertussis vaccination in the period between 1938 and 1948 (Byers and Moll 1948). One of the co-authors of this article, paediatrician Randolph Byers, was well-known for another report written with psychologist Elizabeth Lord and published few years prior titled 'Late Effects of Lead Poisoning on Mental Development', which linked lead ingestion to learning disabilities in children and was instrumental to campaigns to discontinue the use of lead-based paint in the US (Byers and Lord 1943; see also Markowitz and Rosner 2000; 2013). While, of course, these remain two separate issues, there are some fascinating broader parallels between the fight against lead paint and the narratives of current vaccine critics, including the connection of learning difficulties and cognitive disabilities in children to chemical poisoning, the role of the media in disseminating medical research among the general public and issues related to industry cover-up and corporate responsibility. Although it is not possible to investigate these parallels further here, they may represent an area worthy of study for future medical-historical research.

Joint Committee on Vaccination and Immunisation (JCVI), added his voice to those expressing concerns regarding the use of whole-cell pertussis vaccination (see Dick 1975).[38]

As it might be expected, this lingering medical uncertainty translated into vaccine refusal among the public – with pertussis vaccine rates in the UK suffering a sharp drop and multiple pertussis outbreaks emerging in the country in the following few years (see Gangarosa et al. 1998). Even before the publication and subsequent media coverage of the Kulenkampff paper, however, a number of parents who attributed their children's intellectual and physical disability to immunisation had joined forces and started to set the ground for a new wave of organised vaccine-critical activism. The *Association of Parents of Vaccine-Damaged Children* (APVDC), originally founded by two mothers who blamed the polio vaccine for their children's injuries, proved to be one of the most outspoken critics of pertussis vaccine in this period (Millward 2017). One of these mothers, Rosemary Fox, who played a leading role in the organisation in the decades that followed, had a daughter who was severely cognitively impaired and suffered from epilepsy.[39] An APVDC founder interviewed by Hobson-West (2005) stated to have been initially unaware of the potential risks posed by vaccines, only starting to realise the dangers involved after finding out that 'lots of specialists' acknowledged that vaccine damage existed, and that a scheme had been established in Germany to compensate victims of vaccine injury (120).[40]

Accounts of the circumstances surrounding the creation of the APDVC (including interviews with the organisation's founders) highlight the crucial role played by the media in allowing for connections to be forged between otherwise isolated parents suspecting or believing that their children had been injured following vaccination. Indeed, the mothers who went on to set up the group had originally issued an appeal in a regional newspaper, the *Birmingham Post*, calling for parents with similar experiences of vaccine injury to join a campaign to obtain compensation for their 'damaged' children. Following the *Post* article, the APVDC founders were contacted by hundreds of parents, the vast majority of whom blamed the pertussis vaccine for harming their children (see Millward 2019). If mass media was crucial

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[38] The JCVI member in question, George Dick, was a microbiologist working at Queen's University Belfast who had already previously expressed concerns regarding smallpox vaccination during the 1960s. In a 1962 speech to the BMA he claimed the vaccine was causing more deaths than smallpox itself (see Sheeran 2021). A year later mandatory vaccination was abolished in Northern Ireland.

[39] Fox has also written a book detailing her daughter Helen's vaccine injury story (Fox 2006). According to Fox's account, her own mother was adamantly against the idea of her granddaughters being vaccinated (2006, 18). This fact is interesting as it raises the question of a possible inter-generational transmission of vaccine-sceptical beliefs among some families (see Beier 2001).

[40] For previous medical research on pertussis vaccine reactions which the interviewee may have been referring to here, see note 37 above. The mentioned compensation scheme is likely the one introduced by the German government in 1961, following a 1953 German Supreme Court ruling that individuals who had been injured by compulsory smallpox vaccination were entitled to compensation (Looker and Kelly 2011, 3). It should be reminded that the smallpox vaccine is acknowledged by the scientific literature as the cause of rare but potentially severe neurological adverse events (see e.g. Sejvar et al. 2005).

in enabling the creation of the APVDC, it also played an important role in the group's subsequent campaigning activities. As historian Gareth Millward (2019) notes:

> The APVDC drew on the sort of campaigning that had characterised the small but respected groups of the "poverty lobby" that had successfully convinced the Heath government to institute the first disability benefits. These organisations articulated the lived experience of their members through the growing mass media, allying it with sociological research and professional organisational structures to influence government policy. During the 1970s, at least, governments of both parties were receptive to such overtures, given that they both spoke the language of policy makers and exerted enough pressure on public opinion to make elected representatives take notice. (2019, 159)

The combination of lived experience and mass communication that had helped disability activists to push for the introduction of disability benefits was therefore also an important feature of the vaccine-critical activism of this period, along with the ample media coverage of expert commentary and research emphasising the risks of pertussis vaccine. The shared personal cases of vaccine injury '...helped to turn this into a scandal which the press could parse as a news story' (2019, 157). It should be noted how, alongside a mutated media ecology, the different social and political context of post-war Britain and the central role played by the welfare state within this context meant that the new generation of vaccine critics had different approaches towards the law than their Victorian predecessors. The law was not any more merely a nefarious expression of state power to be curtailed. Rather, it became a key resource, offering activist-parents the opportunity to make concrete demands of 'fairness' and 'justice', involving a redistribution of the risks linked to vaccination through financial compensation.

Legislative intervention to create a new right of compensation for the 'vaccine damaged' was then actively pursued by these newer vaccine counterpublics. During the 1970s, the APVDC heavily campaigned for the creation of a vaccine victims' compensation programme in the UK. After some initial reluctance, the Labour government in power at the time eventually caved in to the group's demands. Historian Gareth Millward (2017) mentions fears regarding the decline in vaccination rates and the likelihood of new pertussis outbreaks, as well as political concerns about negative publicity, as the main factors that led to the passing of the Vaccine Damage Payment Act in 1979. The system of compensation established by the 1979 Act provided for a lump sum award of £10,000,[41] under a no-

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[41] Vaccine Damage Payments Act 1979, s. 1(1A). The sum that may be awarded has now been increased to 120,000£.

fault liability regime,[42] and was based on a balance of probabilities assessment that a 'severe disablement' resulted from vaccination.[43] Furthermore, according to the Act, the determination regarding the vaccine injury claim would have to be made by the Secretary of State.[44]

The Act provided for administrative, rather than legal proceedings, with the final determination of a vaccine-injury compensation claim made by a civil servant. Although this may be seen as a success for vaccine critics, and particularly the APVDC, it did not prevent other parents from bringing negligence claims to court in subsequent years. A test case on vaccine damage, *Loveday v. Renton and the Wellcome Foundation*, was only decided in 1988. In this case, the High Court dealt with a claim for damages against the doctor had who administered the pertussis vaccine to the claimant, with a major health charitable foundation, The Wellcome Foundation, intervening for the defendant. The Court decided that it was not satisfied on balance of probabilities that the pertussis vaccine had caused permanent brain damage to the claimant.[45] This decision exemplifies the difficulties encountered by claimants in establishing causation in vaccine-injury claims. In addition, these court proceedings took time, involved hefty costs and necessitated obtaining proof of both negligence and causation.

This could explain why the APVDC had pushed for the adoption of a separate, non-fault compensation scheme, which did not require claimants to prove that the pharmaceutical companies manufacturing the vaccine, or the doctor administering it, had been negligent. In addition, Millward (2017) has argued that the specific way the legislator responded to the DTP crisis in the UK and also the way vaccine compensation activism articulated its demands at the time must be understood in the context of the national disability and social security policy of the 1970s. For example, the references to 'severe disablement' in the Act, defined in terms of percentage of disability, was 'a traditional tactic in restricting access to new benefits' (2017, 442).

One particular instance of disability campaigning from this era that immediately preceded and influenced vaccine counterpublics is the fight for compensation for thalidomide victims and their families.[46] There are some direct connections between these campaigns: Jack Ashley MP, a politician who was a close ally of the APVDC and had an important role in spearheading the pertussis vaccine damage campaign in Parliament had also fought for the compensation of thalidomide injured children

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[42] Vaccine Damage Payments Act 1979, s. 1(1).

[43] Vaccine Damage Payments Act 1979, s. 3(5).

[44] Vaccine Damage Payments Act 1979, s. 3(2).

[45] Years after the decision was taken, in 1991, a major review from the US Institute of Medicine came out and concluded that there was no evidence that the whole-cell pertussis vaccine could cause permanent brain injury (see Baker 2003, 4006).

[46] The 'thalidomide scandal' followed the discovery that the drug thalidomide, which had been developed by a German company in the 1950s and prescribed to pregnant women to treat morning sickness, caused children to be born with severe intellectual and physical impairments.

(see Fox 2006). In addition, the Royal Commission on Civil Liability and Compensation for Personal Injury (also known as the Pearson Commission after its chairman, Lord Pearson), which had been set up partly as a response to the thalidomide scandal and concerns that the victims' families had not been adequately compensated, also considered the issue of vaccine damage, hearing evidence from John Wilson (co-author of the Kulenkampff article) and APVDC's Rosemary Fox in 1975 (Millward 2019; Fox 2006). The final Commission Report, published in 1978, explicitly referred to the vaccine damage question, stating that 'there is a special case for paying compensation for vaccine damage' when one undergoes vaccination to protect the community (Royal Commission on Civil Liability and Compensation for Personal Injury 1978, 296).

Like pertussis vaccine activism, the thalidomide campaign was parent-led and heavily relied on the mediation of mass communication technologies - particularly national newspapers. Newspapers were key in publicising the stories of the injured children, raising awareness among the public and highlighting the unfairness of the outcome of the lawsuit that parents had started against the UK distributor of thalidomide. The lawsuit had resulted in a controversial settlement which was described as 'immorally low', and prompted a campaign on behalf of thalidomide-injured children by *The Sunday Times* starting from 1972 (Knightley 1997). Like the pertussis vaccine scandal, the case of thalidomide reveals broader contextual interconnections between activism, the mass media and the issues of liability and compensation for medical damage, against a backdrop of increasing state intervention in social issues.

The role of civil litigation has been emphasised by Susan Silbey (2009) as a fundamental part of what she calls the 'solidarity regime' of the 20th century, with state regulation rapidly expanding to cover previously unsupervised areas of life (see also Galanter 2006). In this context, which also involved a historical shift from contractual to tortious litigation, an increase in legal spending and a broader 'celebration of lawyers and legal work in popular media and film', civil litigation emerged as an important force that 'independently generated rights' (Silbey 2009, 347). In the United Kingdom civil litigation played a less prominent role in vaccine-critical activism, with counterpublics' mediated voices focusing on the establishment of an ad-hoc compensation scheme. In the United States, however, the response to the crisis was rather different, and tort litigation soon became central to vaccine critics' activities.

According to Jeffrey Baker, public controversy did not really start to emerge in the US until the screening of a TV documentary called *DTP: Vaccine Roulette* (2003, 4007). In his book *NeuroTribes*, Steve

Silberman (2015) also notes how *Vaccine Roulette* ignited the flames of pertussis vaccine opposition in the US. The documentary featured, as he puts it,

> ...a parade of experts who played down the risks of pertussis (which had killed 7,500 children in 1934 alone, out of 265,000 cases) while highlighting the risks of the vaccine, intercut with wrenching footage of brain-damaged children being cared for by their parents.
> (2015, 695)

Similarly to the initial media coverage of vaccine damage cases in the UK, *Vaccine Roulette* caused widespread outrage among the public in the US. Parents claiming their children had been injured by vaccines started to form advocacy groups around the notion of vaccine damage. As recounted by Mnookin (2011, 73-74), one of these parents was Barbara Loe Fisher, who founded the National Vaccine Information Center (NVIC) – a vocal anti-vaccine group active to this day – soon after the airing of the documentary.[47] DTP vaccine rates in the US did not drop to the extent they did in the UK. However, vaccine litigation increased significantly, and the size of the awards accorded to defendants by 'sympathetic juries' led most companies making the DTP vaccine to stop production, with the remaining major manufacturer threatening to follow suit (Sugarman 2007).[48]

Availability of adequate vaccine supply became a political concern, and is often cited as one of the main reasons for the adoption of a special vaccine compensation scheme in the US (2007; see also Kirkland 2016). Indeed, in 1986, the US Congress passed the National Childhood Vaccine Injury Act (NCVIA), which established the Federal Vaccine Injury Compensation Program (VICP).[49] Providing that vaccine manufacturers should not be held liable for vaccine-related injuries - unless the product in question is defective or not accompanied by proper directions and warning - the VICP effectively excludes manufacturers' liability in vaccine-related injury claims, except in specific cases where negligence is involved. Such claims are thus in the first instance handled by the government-appointed special masters of the Vaccine Court, under a regime of strict liability.

As is the case with the UK's vaccine compensation scheme (VDP), causation has to be established on the balance of probabilities.[50] If causation is established, compensation is paid to the petitioners from a federal vaccine injury fund financed by a patient tax imposed on vaccine doses (Sugarman, 2007).

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[47] The organisation was originally named 'Dissatisfied Parents Together', or 'DPT'.

[48] It should be pointed out that, unlike the UK, the US tort law system normally allows for punitive damages, which poses a greater financial risk for defendants in tort lawsuits. For a more detailed comparison of the two systems, see Atiya (1987).

[49] 42 U.S.C. §§ 300aa-1 to 300aa-34.

[50] 42 U.S.C. §300aa–13(a)(1).

Nevertheless, the US Vaccine Court system involves judicial proceedings, and is enshrined in litigation rules and terminology, rather than being structured as an administrative determination under a social welfare scheme, as in the UK.

More on the UK and US vaccine compensation systems, and current vaccine-critical activists' perceptions and framings of such schemes will be explored later on in this work. For the moment, I would just like to highlight three points emerging from the historical background to vaccine-critical activism set out in this section. First, it may be argued that the different responses of the UK and US legislators to the same vaccine-critical arguments surrounding DTP were informed by the local specificities of their surrounding legal environments. Thus, as Millward (2017) has noted, 'the Vaccine Damage Payments Act 1979 could not have operated without the legal framework of disability that had been established over decades of legislation' (443). And in relation to the VICP, Kirkland (2016) suggests that the United States have elected to deal with vaccine injury claims 'in the classic American way', that is through litigation involving the confrontation of lawyers and experts before a court of law (199).

Second, despite these local differences in the character and features of the compensation schemes, vaccine-critical activists from both countries in this period arguably shared a novel way of approaching and framing the state and its institutions, which distinguished them from the organised critics of the previous century. This new approach involved a higher level of engagement particularly with legal and judicial institutions, demanding the active intervention of the law to address the inequities emerging as an alleged consequence of vaccine damage. As part of the mid-to-late 20th century 'solidarity regime' context described by Silbey (2009), the law – including civil litigation and legislation introducing ad-hoc compensation schemes – then became an important resource for parent-activists campaigning for the creation of new rights of compensation for vaccine injured children.

The third and last point concerns the key role of the mass media in enabling and shaping US and UK-based collective vaccine opposition of the 1970s and 1980s. As discussed above, newspapers (both at the local and national level) and the broadcast media especially have been crucial to the creation of the new wave of vaccine counterpublics campaigning for vaccine injury compensation. Indeed, the mass media ecology allowed for not only a wider diffusion of the stories of 'vaccine-damaged children', but also for a deeper exploration of the social impact of vaccine injury and the realities of the families claiming to be affected by it, as well as the sharing of expert medical literature and opinion, which was presented as if it proved the dangers of the DTP vaccine. The mass media also played an important connecting role between parents who, after watching DPT-critical shows and reading critical press coverage, felt they shared common experiences of vaccine injury – leading to the creation of vaccine critical organisations such as the APVDC in the UK and the NVIC in the US.[51]

It is important to note how the media emerged in this period as a powerful force within a broader context involving increasing state intervention to address different societal problems. For example, as Millward (2019) has emphasised, the disability activism of post-war Britain which influenced the UK pertussis vaccine campaign in the 1970s had also relied on its surrounding media ecology to advocate for the introduction of disability benefits. The mass media could convey activists' lived experiences to national audiences, putting enough pressure on public opinion to push the government to intervene with new legislation (2019, 159). In addition, Deborah R. Hensler and Mark A. Peterson (1993) have argued that the mass media represented one of the factors promoting the general recourse to mass tort litigation in the US in the second half of the 20th century. As they put it:

> ... [i]n comparison with twenty-five years ago, Americans are now more likely to be exposed to information through the mass media that suggests or establishes causal links between injuries and product use or exposure, attributes blame for such hazards to business or industry and provides information about the potential for litigation-all of which are critical to establishing a claim. As a result, individuals injured in "mass injury" circumstances may receive more support for claiming than in the past.
> (Hensler and Peterson 1993)

This wider social landscape made up of a series of interweaved media, cultural, and political developments provides a valuable backdrop against which to understand the activism of pertussis vaccine counterpublics. In particular, I suggest that these developments help to explain the more active engagement with the law and legal institutions embraced by these counterpublics and their thinking of the law as a resource, rather than just an external constraint to push back against. As with the prior 19th- and early 20th century vaccine counterpublics, the relationship between pertussis vaccine counterpublics and the law can therefore be better grasped by contextualising it within its broader socio-historical picture. In the next section of this chapter, which focuses on the MMR and thimerosal scandals of the 1990s and internet-mediated vaccine-critical activism, I will analyse how vaccine counterpublics' active engagement with the legal system has evolved and transformed yet again.

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[51] I have discussed above how, in the UK, an article published on the *Birmingham Post* attracted a response from many parents, leading to the creation of the APVDC. Something similar happened in the US, where a local television station rebroadcasting *Vaccine Roulette* started providing the numbers of other callers to viewers who called in about the documentary. According to Silberman (2015), this is how the co-founders of the vaccine-critical organisation 'Dissatisfied Parents Together' (subsequently named NVIC) initially connected with each other (696-697).

From anti-vaccinationist to 'anti-vaxxer': the thimerosal and MMR scandals and the emergence of the internet as forum of vaccine opposition

As Kirkland (2016) writes in *Vaccine Court*, immediately following its creation in 1986 the US VICP faced issues with regards to both the source of its funding and the establishment of its procedural rules. While the question of deciding where the Court funding would come from was eventually solved by introducing a fixed surcharge tax on individual vaccine doses, setting up the VICP procedures turned out to be a more complicated issue. As we have seen, the Court ended up embracing a model that displays many of the adversarial features of tort litigation, with 'petitioners' and 'respondents' (represented by the US Department of Health and Human Services, or HHS) having to dispute about the existence and causation of vaccine damage before the Court's judges, who are known as 'Special Masters'.

Compensation for many alleged vaccine reactions may only be obtained from the VICP if the petitioners provide adequate expert evidence to support a causal link between vaccination and the claimed injury. Kirkland calls this stage of VICP practice the 'off-Table period', stating that following these more stringent procedural rules, 'children with a wide range of brain injury and seizure conditions could no longer qualify as claimants' (81). The term 'off-Table' refers to the so-called 'Vaccine Injury Table', a document used by the Court to 'fast-track' claims based on a number of conditions that are acknowledged to be vaccine adverse reactions, based on 'the best state of the scientific knowledge' at a specific point in time (78). As Kirkland puts it, '[t]he Table is quite literally a record of officially recognized vaccine injuries' (79). If a condition is listed in the Table, a petitioner is only required to prove temporal association with the receipt of that vaccine. If a condition is not on the Table, a petitioner additionally has to prove that there is a plausible causative mechanism linking the vaccine to the injury.

When the VICP was first established in 1986, there was a political consensus that there was enough evidence to compensate children who suffered chronic neurological impairment following the DTP vaccination. This consensus was based, at least in part, on the scientific literature available at the time. As seen above, there were a number of case reports linking specifically the pertussis component of the vaccine to severe neurological adverse events. A further study conducted by British researchers in the 1970s, the National Childhood Encephalopathy Study (NCES), has been described as providing 'much of the basis for scientific suspicion that DTP caused brain damage' (79; see also Offit 2010, 35). Based on 39 children (out of more than 1000 children with neurological illnesses reported to the study) who developed symptoms shortly after receipt of the vaccine, the NCES found an association between the whole-cell pertussis vaccine and acute encephalopathy (UKHSA 2016; WHO 2015).[52]

However, in the following decades, scientific consensus consolidated around findings that the DTP was not the cause of brain damage and other conditions like epilepsy and Sudden Infant Death Syndrome (SIDS) which had been the focus of the pertussis vaccine campaigns of the 1970s and 1980s. In the US, two new reports by the Institute of Medicine published in 1991 and 1994 found evidence to support the existence of a link between DTP and acute encephalopathy in very rare cases, but not enough evidence to support or disprove claims that the vaccine could cause permanent neurological damage (see WHO 2015).[53] This research led to major changes to the Vaccine Injury Table by the US HHS, including the redefinition of what kinds encephalopathy would be recognized as DTP-induced vaccine injury. The new definition of encephalopathy was so narrow and specific that, according to a lawyer from one of the major US law firms representing petitioners at the VICP interviewed by Kirkland, '[HHS] effectively said there's no more injuries caused by the DTP vaccine' (2016, 81).

Newer generations of vaccine-critical activists faced a more complicated challenge than their predecessors: in the absence of compelling scientific evidence supporting a connection between vaccines and certain severe adverse reactions, they had to show *how* such a connection might be possible, at least in a small subset of 'vulnerable' children. This is something which the novel vaccine counterpublics emerging in the 1990s and early 2000s tried to do when they mobilized around the notion that vaccination, and particularly the combined MMR (measles, mumps and rubella vaccine) and vaccines containing the preservative thimerosal were implicated in causing autism.

Contrary to common assumptions, the origins of the vaccines-autism connection are more complex than a simple scare over the (now infamous) 1998 *Lancet* article by Andrew Wakefield and colleagues.[54] In the early 1990s, parents confronted with an autism diagnosis encountered little support from a medical environment which was often poorly informed on what was then considered a relatively rare and obscure condition. At the dawn of the internet age, these parents started to '[turn] to one another and the Internet', assembling an 'alternative community of autism research' online (Baker 2008, 249).

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[52] According to the UK Health and Security Agency's 'Green Book', the NCES supported the existence of a link between acute encephalopathy and DTP, but there was not enough evidence in the study to conclude that there was also a link between the vaccine and 'chronic neurological dysfunction' (UKHSA 2016, 20; see also Griffith 1989).

[53] Subsequent studies provided evidence against the existence of a connection between DTP and chronic conditions or death: see Edwards and Decker (2008); UKHSA (2016, 20-21); WHO 2015.

[54] For more information on the role of Wakefield in the MMR scare of the 1990s, see Rao and Andrade (2011).

Against mainstream views, this community recast autism as a biomedical condition that could be cured, and as a growing 'epidemic' caused by environmental factors.[55]

As Baker recounts, in a context of growing concerns about environmental mercury poisoning and institutional confusion over the safety of the *ethylmercury* present in the vaccine preservative *thimerosal*, the US alternative autism community started to focus on these substances as the source of the 'autism epidemic' (250). One particular factor of confusion has been represented by the question of the relative safety of *ethylmercury* in comparison to the different chemical *methylmercury*. Methylmercury had been linked to profound intellectual disability and severe neurological symptoms in children whose mothers had been exposed to it following two industrial disasters in Japan and Iraq (246). Claims that autism is the result of brain damage caused by mercury poisoning, however, have been subject of heavy criticism, both in the medical literature (see e.g. Parker et al. 2004) and in the context of disability activism, where the notion that autism is a condition that can and should be cured has been deemed problematic for its ableist connotations (see e.g. Cohen-Rottenberg 2013; Mamone 2017).

But what is important to note about the alternative autism community here is not the accuracy of its claims, but its nature as a new kind of vaccine counterpublic. Unlike the previously mentioned examples of collective vaccine opposition enabled by the press and broadcast media, these parents were not simply engaged in anti-state intervention, or redistributive activism, claiming for compensation or opposing vaccination mandates. In recasting 'autism' as a biomedical condition, sharing evidence to support their claims of an autism epidemic and actively looking for cures, these networked parents were effectively co-creating knowledge, filling a gap left empty by official medical science. Simultaneously, this allowed for the creation of a new social space where previously isolated parents could build a communal identity, marked by a shared language to talk and share beliefs about autism and vaccination, as well as specific attitudes towards science and – crucially – a focus on learning and the 'bottom-up' development of expertise.

Similar developments took place in the UK, where new vaccine-critical organisations started to spring up in the same period. One of these organization, called JABS (Justice, Awareness and Basic Support), was created in 1994 by a mother who believed her son had developed encephalitis leading to epilepsy and brain damage following his MMR vaccination (Fitzpatrick 2004, 87).[56] Soon after its establishment,

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[55] For more background on the US vaccine-critical autism movement and the organisations linked to it see Kirkland (2016, chapter 3). See also Silberman (2015), for a very thorough look into evolving conceptions of autism and the collaboration between parents and doctors in the context of autism research from which the autism-vaccine link has emerged.

[56] The founder of JABS was eventually awarded a damage payment by the VDP for her son in relation to her son's epilepsy (see Millward 2019, 193).

JABS started assembling a 'computer database' with information on vaccine reactions reported by parents, with the group stating in an interview with Hobson-West (2005) that '[i]t's only through building up that database that we started to identify bowel disorders, epilepsy, autism, speech and learning difficulties, and all these things that parents were reporting' (180).[57] According to Millward (2019), '[t]he group was much more overtly anti-vaccine than the APVDC, and made use of the visibility afforded by the internet to spread their message directly (through their website) and indirectly (through responses in the press)' (193).

Although the UK organisations tended to focus more on the MMR vaccine rather than thimerosal (which the MMR vaccine does not contain), they shared with the US groups the 'biomedical' framing of autism as a curable condition. In addition, as in the US, most of the UK-based organisations used the internet to coordinate their activities and as 'their major means of publicity' (Leach 2005, 8). For Melissa Leach, the internet was central to both the internal practices of the 'core' vaccine-critical organisations and in order to expand support for these organisations across broader social fields (2005, 12). Drawing on new social movements theory, she contends that:

> MMR mobilisation is thus linking people in virtual networks which link localities both within and outside the UK, forging aspects of common identity in the process in the ways that Melucci (1996) and Castells (1997) see as typical of contemporary social movements.
> (Leach 2005, 12)

These 'virtual networks' of anti-MMR activists, with their internet-mediated information collection, exchange and propagation activities, were therefore rather different from the previous pertussis counterpublics, who were able to, and did rely on a body of existing scientific evidence to support their claims about DTP vaccine damage. The MMR and thimerosal counterpublics of the 1900s and early 2000s were arguably much more actively involved in the production of 'knowledge' around autism, its nature, the potential causal mechanisms linking it to vaccination, and even possible 'cures'. While engaging in this kind of citizen science (Epstein 1995) or popular epidemiology (Leach 2005), these counterpublics simultaneously also shifted towards a more anti-establishment approach. Writing about the organization DAN! (Defeat Autism Now!), founded in 1995 by renowned autism researcher (and parent of an autistic child) Bertrand Rimland, Fitzpatrick (2004) remarks on how:

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[57] Other vaccine-critical groups established in this period include Allergy Induced Autism (AiA), an organisation promoting the idea that certain diets could treat autism and operating a website with an internet messaging board; and the Vaccine Victims Support Group, founded by 'MMR parents' who had originally joined the APVDC but subsequently created a new group to pursue a different litigation strategy over claims of MMR vaccine damage, using a solicitor who at the time was also assisting JABS parents (see Hobson-West 2005; Fox 2006, 195-196). The UK MMR litigation will be further discussed below.

> The combative name (with obligatory exclamation mark) signalled the militant spirit of the organisers (who include the veteran campaigner Dr Bernard Rimland) and their determination to take on the medical establishment, the government and the corporations in the cause of defeating autism.
> (2004, 71)

The focus of these counterpublics on finding treatments, along with their marked oppositional stance towards medical experts, state authorities and pharmaceutical corporations may be contrasted with the more cautious approach of previous pertussis campaigners. In her introduction to *Helen's Story*, for instance, APVDC's Rosemary Fox (2006) writes that, after realising the severity of her daughter's condition, she became set on '...find[ing] out what action I could take that, while not making her better, might secure an acknowledgment of the *debt which was owed to her and others in her position'* (14-15, emphasis added). Seeking redistribution is here explicitly acknowledged as the objective of vaccine-critical mobilization. The idea was that society, as a whole, was under an obligation to compensate vaccine-damaged children. In order to promote this idea, counterpublics campaigning for compensation schemes had to make the case that, as Burke (2002) puts it, '...vaccine injuries should be handled as a social problem, an unavoidable cost of vaccination for which all should pay, rather than a sin of the pharmaceutical companies' (145).

These differences between older and newer counterpublics were also reflected in their different approaches to the law. While both actively engaged with the legal system, and asked for its intervention in addressing questions of vaccine damage, for MMR-thimerosal counterpublics the issue was not (just) redistribution. More specifically, I suggest that these counterpublics went a step further by using the law as a tool with which to challenge the medical establishment and mainstream scientific views on autism causation and vaccine safety. They did so primarily by starting litigation in which they attempted to prove their alternative theories of 'autism causation', introducing supportive 'experts' to provide evidence against the scientific consensus that autism was not linked to vaccines.

The most well-known among these 'experts' is arguably gastroenterologist Andrew Wakefield, who was contacted by MMR parent-activists because of his previous (and already controversial) research implicating MMR in another chronic condition, Crohn's disease (see Silberman 2015, 705). Despite admitting that he did not know much about autism, Wakefield started forging connections with some of the UK's vaccine-critical groups which linked MMR to autism. In 1996 – following an application by a lawyer associated with one of these groups, who represented parents involved in MMR damage litigation – Wakefield received funding from the UK Legal Aid Board to produce a study investigating the MMR-autism connection (Goldberg 2013, 116).[58] This study, looking at ten of the children named in litigation, involved at least four children who were included in Wakefield and colleagues' later 1998 *Lancet* study.

In the US, vaccine litigation has also been described as a 'big chance for [...] parent advocates to prove the scientific basis for their accounts' (Kirkland 2016, 176).[59] Both in the US and in the UK, then, vaccine critics at the turn of the last century tried to prove their autism-vaccine damage causation theories in court, using law 'against' (mainstream) science in a way never before attempted by previous counterpublics. Eventually, the major vaccines-autism lawsuits started in both countries failed to achieve their goals. In the UK, the MMR group litigation was dissolved after the Legal Aid Board withdrew its support to the claimants following the failure to replicate the results of Wakefield's initial studies, and the publishing of epidemiological studies finding no evidence of a link between MMR and autism (Goldberg 2013, 117). In the US, the VICP also ended up rejecting the petitioners' causation theories, leading to final court rulings against compensation.[60] Although the autism-vaccines counterpublics' litigation approach failed to achieved its intended purposes, it still demonstrates these counterpublics' increasing tendency to co-create medical 'hypotheses' and actively engage with the legal system in order to galvanise support for these hypotheses.

This increased engagement with the law raises fascinating questions about how contemporary vaccine-critical counterpublics are referring to and interacting with legal institutions and concepts, particularly following the failure of the MMR-thimerosal litigation and an evolving media landscape, in which the more 'static' reality of Web 1.0 has given way to the more complex, collaborative spaces characteristic

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[58] This initial funding (of £50,000) was followed by even more substantial funding (amounting to £800,000) paid to a company of which Wakefield was co-director to perform lab tests looking to find vaccine-derived measles virus in bowel tissue and blood samples provided by children (Goldberg 2013, 116). The credibility problem encountered by these tests and their results was an important factor leading to the failure of MMR-related litigation in both the UK and the US (see Kirkland 2016, 191).

[59] More detailed analyses of the so-called 'Omnibus Autism Proceedings' (OAP), in which the VICP considered six test cases and two vaccines-autism causation theories (the first linking autism to a combination of the MMR and thimerosal-containing vaccines, the second looking at thimerosal-containing vaccines only) are offered by Kirkland (2016) and Goldberg (2013). It is interesting to note that litigation in both the UK and the US was started outside of the context of vaccine injury compensation schemes. In the UK, funding from the Legal Aid Board was sought to pursue Group Litigation before the High Court (2013, 116). And in the US, before the OAP litigation started, parents had tried (generally without success) to circumvent the NVICP and shoehorn vaccine tort lawsuits in state courts. According to Kirkland, this was done in part to have access to the civil courts' discovery process (not available with the VICP), revealing that the claimants' objective was not just 'individual recovery', but exposing the government and corporations as involved in a 'cover-up' around the toxicity of vaccines (see 2016, 85).

[60] See *King v Secretary of Health and Human Services*, No. 03-584V (USCFC Spec Mstr 2010); *Dwyer v Secretary of Health and Human Services*, No. 03-1202V (USCFC Spec Mstr 2010); *Mead v Secretary of Health and Human Services*, No. 03-215V (USCFC Spec Mstr 2009); *Cedillo v Secretary of Health and Human Services*, No. 98-916V (USCFC Spec Mstr 2009); *Hazlehurst v Secretary of Health and Human Services*, No. 03-654V (USCFC Sp Mstr 2009); *Snyder v Secretary of Health and Human Services*, No. 01-162V (USCFC Spec Mstr 2009).

of Web 2.0. In the next and final section, I am going to highlight a few of these more recent developments in mediated vaccine opposition, showing some significant continuities between past and present vaccine critics, particularly in their use of (independent) print and digital media. Finally, I will start presenting the outstanding questions on current childhood vaccine counterpublics which I set out to address in my research.

Vaccine-critical activism now: vaccine counterpublics 2.0 and open questions in the post-MMR/thimerosal litigation era

The attention of scholars studying vaccine-critical activism has in recent years largely shifted to online based activism. This has been justified by the now ubiquitous presence of the internet and its burgeoning role in the arena of health information,[61] as well as the prevalence of vaccine opposition on digital media (Kata 2012). The first works on online vaccine opposition started to appear in medical journals in the early 2000s, focusing on the content of 'antivaccination websites' at a time when childhood vaccine opposition had become a controversial public topic, due to the publicity given to the MMR vaccine and thimerosal (see e.g. Nasir 2000; Davies, Chapman and Leask 2002; Wolfe, Sharp and Lipsky 2002; Zimmerman et al. 2005). This early research was specifically intended to raise awareness among physicians and parents of the arguments of online 'groups' against the benefits of universal immunization, while calling for further research to explore ways to counter such arguments (see Nasir 2000).

Academic interest in online vaccine criticism did not fade away with the failure of the autism-vaccines litigation in the UK and the US. Instead, a growing number of new studies on internet-mediated vaccine opposition have been published since the early 2010s, mainly employing content analysis techniques in order to consolidate and update what is known about the content of online vaccine-critical talk. For example, Bean (2011) has grouped anti-vaccination websites content into four categories: 'safety and effectiveness', 'civil liberties', 'alternative treatments' and 'conspiracy theories/search for truth'. Building partly on Bean's findings, Anna Kata (2012) has identified a series of tropes in online anti-vaccination talk. These include allegations that vaccines are toxic or unsafe, that vaccinating is not 'natural', and that vaccine supporters are 'Big Pharma shills', as well as claims of personal expertise and appeals to non-mainstream vaccine-critical authorities.

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[61] A 2011 study, for example, has estimated that around 80% of U.S. Internet users seek health information online (Fox 2011).

For Kata, the ‘anti-vaccination movement’ has adopted ‘cunning techniques’, and rhetorical strategies to conceal its opposition to vaccines under euphemistic labels such as ‘health freedom’ and ‘vaccine safety’ (3784). These strategies, she argues, work because they are enabled by the emergence of a new ‘postmodern medical paradigm’. This paradigm involves the ‘redefinition of expertise’ and allows for ‘information to be interpreted in various ways – rather than an interpretation being wrong, it can be reframed as ‘another way of knowing’ (3784). This is compounded by the ease of access to health knowledge, made possible by the internet. ‘With this paradigm in place,’ Kata concludes, ‘it is not difficult to see how Internet users attending “Google University” may be convinced by what they might find’ (3784).

Kata’s emphasis on the dwindling success of appeals to ‘facts’ and ‘science’ may sound appealing as it seems to resonate with recent developments in our political and social landscapes. This contextual backdrop to current vaccine opposition will be explored in greater detail in future chapters. For the moment, I would just like to point that this kind of analysis might be limited in its applicability to vaccine opposition. Indeed, as seen earlier in this chapter, questioning the findings of science and challenging the establishment is not an exclusive prerogative of our times or culture. A Victorian anti-vaccination league member for instance – with her steadfast refusal of smallpox vaccination, engaging in marches, reading and writing to anti-vaccination journals, and burning copies of the Vaccination Act in public places (Williams 2011) – hardly appears to represent the receptive, non-questioning, non-postmodern patient postulated by Kata.

While some preliminary doubts might therefore be cast on whether or not the internet has given rise to a new, post-factual vaccine-critical movement, it cannot be denied that as both Kata (2012) and others in the literature cited above have emphasised, the internet plays a crucial role in contemporary vaccine opposition. In the same way as the production and use of media by 19th and 20th-century vaccine-critical groups contributed to the shaping of vaccine critics as counterpublics, I would argue that the advent of the internet has contributed to the refashioning of these counterpublics in ways that require further investigation. More specifically, while the making of Web 1.0 saw an unprecedented proliferation of information resources - as a combination of static text, images and hyperlinks - Web 2.0 produced an even deeper shift, structurally altering the way in which we engage with information and decision-making (Witteman and Zikmund Fisher, 2012). For Holly Witteman and Brian Zikmund Fisher (2012), Web 2.0 may influence vaccination decisions particularly by increasing the reach of personal narratives, producing expectations of more accessible and detailed information, and emphasising the social nature of choice.

As Alex Green (2017) has noted, there seems to be a fascinating continuity in the visual forms of vaccine opposition across different times, with anti-vaxxers' use of 'internet memes' as the contemporary counterparts of 19th century anti-vaccination cartoons. Memes are visual artefacts that take different formats – from static images, to videos or animated GIFs – and they are characterised by co-opting pre-existing media content and reworking such content in a subversive way, conferring upon it new and unexpected meanings. For Milner (2012) memes are the product of 'networks of mediated cultural participation', which use them as 'multimodal artifacts, where image and text are integrated to tell a joke, make an observation, or advance an argument' (11). 'Anti-vaccination memes', Green (2017) observes, 'draw from this broad visual language of resistance by co-opting and subverting existing images to carry anti-vaxxer messages'.[62]

Online media thus has a significant role in shaping current vaccine counterpublics. Through the internet, vaccine-critical themes with a long-standing tradition (such as opposition to state interference) as well as more novel topics – such as the linking of vaccines to specific neurological and developmental disorders – can reach broader and potentially more receptive publics. However, the point is not just that internet has scaled up vaccine-critical talk. Rather, what I am suggesting is that in some cases the particular media ecology and counterpublic talk might mutually influence each other, giving rise to new social spaces and opportunities for mobilisation. This may be seen, for example, in the emergence of online counterpublics involved in the construction of 'knowledge' linking vaccinations to autism, and the subsequent pursuit of litigation to assert this 'knowledge', against the scientific consensus refuting it.

The idea that 'networked publics' (see Ito 2008; boyd 2008) may be engaged in collaboration and the creation of knowledge is not novel. Anthropologists Adam Fish, Christopher Kelty and colleagues, for example, have argued that the internet has enabled the emergence of new formations, the 'organised publics', which are mediated social entities related to some 'formal enterprise', which allow for enhanced public participation and involvement in the production of resources, including knowledge (Fish et al. 2011). But what kind of publics are current internet-mediated vaccine counterpublics? How is their participation structured and how do they interact with and represent themselves to the external world? How do they react to scientific information which contradicts their beliefs? How should we frame their relationship with the law, as compared to the approaches adopted by previous counterpublics? These are the some of the questions that will be addressed in the following chapters of

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[62] See Green (2017) for an insightful commentary on vaccine-critical visual media through history, including many examples of 'anti-vaccination memes'.

this thesis, which aim to empirically trace discursive practices and legal engagement among online vaccine counterpublics.

Conclusions

In this chapter, I have analysed three significant historical waves of collective vaccine opposition in the UK and the US. While doing so, I have emphasised the inter-connections between media ecologies, the activities of vaccine counterpublics and their ways of engaging with the law, arguing that vaccine-critical activism can be more meaningfully understood by reference to its surrounding cultural, socio-legal and media-technological contexts. I have also suggested that, considering the diversity which exists among historical vaccine counterpublics, and especially their very different ways of engaging with the state and the law, the narrative of a single 'anti-vaccination movement', with roots in our 'postmodern' era may be an excessively reductionist view of the phenomenon of vaccine opposition. In contrast to this approach, I have argued that vaccine opposition is better understood as a complex multiplicity of ideas and practices that have been embraced through history by a collection of alternative vaccine counterpublics.

But what can be said about vaccine counterpublics today? How are they engaging with the law following the (unsuccessful) conclusion of the vaccines-autism litigation in the late 2000s? In the final section of the chapter I raised these and a number of related questions on the nature of online participation in current vaccine counterpublics, and the ways in which these publics may frame and respond to challenges to their worldviews coming from legal and scientific institutions. It is these, as yet, unanswered questions that lie at the heart this research. In the following part of this work I endeavour to unpick these outstanding gaps in our knowledge of vaccine-critical activists by focusing on vaccine counterpublics in our information age. My study embraces an approach informed by internet ethnography in order to allow me to understand vaccine-critical practices and arguments through the lens of the members of the counterpublics themselves, as I will explain in greater detail in the next chapter.

3

PROJECT DESIGN, METHODOLOGY AND METHODS

Introduction

In this chapter I discuss the research design, methodology and methods employed in this study, as well as the ethical issues and concerns that have emerged in the course of the research process. The chapter starts by providing some background on the design of the project, detailing specifically how the research questions have been formulated based on a framing of vaccine-critical activism as a social phenomenon worthy of study, and as a form of mediated activism inflected by its surrounding social and legal contexts. The chapter then moves to set out the qualitative, interpretive methodological approach adopted in the thesis, explaining the reasons for taking this approach, how it has been implemented in practice through the choice of particular research methods, and – finally – what ethical challenges have been raised as a result of the choices made throughout the study.

For the sake of clarity and to maintain a coherent narrative, the research process will be presented as a series of analytically distinct and chronologically ordered steps. However, if the account offered here may give the impression of a straightforward and linear process, it should be kept in mind that the reality of research practice is always more complex and messier than this. As Hammersley and Atkinson (2007) have put it, 'it is frequently well into the process of inquiry that one discovers what the research is *really* about; and not uncommonly it turns to be about something rather different from the initial foreshadowed problems' (160). In an apt analogy, Maxwell (2013) compares this flexible character of qualitative research design to paleontological fieldwork. This kind of fieldwork entails, in the words of palaeontologist Neil Shubin, a 'paradoxical relationship between planning and chance. […] We make all kind of plans to get to promising field sites. Once we're there the entire field plan may be thrown out the window. Facts on the ground change our best laid plans' (Shubin 2008 cited in Maxwell 2013, 9). Keeping this in mind, the act of setting out the research process assumes a different significance. Rather than laying down a plan, or an abstract logical procedure that can be followed step-by-step, this chapter attempts to capture what is actually a dynamic relationship between methodological approach and research environment.

Project design: vaccine opposition, the internet, and the choice of a qualitative approach to address the research questions

As seen in the last chapter, vaccine opposition has always relied upon the power of media to coordinate action among vaccine opponents, and to try to extend participation in their cause. However, as also previously noted, there is arguably a lack of in-depth social-scientific scholarship approaching vaccine opposition as a form of mediated activism, leaving collective vaccine scepticism and its relationship with our digital media ecology as both understudied and under-theorised areas of research.

In this this study I endeavour to address these gaps in the literature by focusing on vaccine opposition as a form of collective action which is at the same time enabled and inflected by information and communication technologies (ICTs). I have therefore tailored my main research questions to fit in with wider academic debates on the role of information and communication technologies in shaping social activism and citizen participation.[63] Specifically, this research engages with theoretical approaches to new media, social activism, online 'lay-person' participation and knowledge-making, with an emphasis upon how online activists construct legal and scientific knowledge. It should be noted, however, that this focus on the dynamics of mediated vaccine-critical activism was not the result of a decision made at the outset of the research process. Instead, the project's attention turned to the nature of mediated vaccine-critical activism, and its relationship with the law, as well as its intersection with issues of collective identity and social change, only throughout the process of data collection and prompted by my analysis of the data derived from the blogs. In fact, like many of the pre-existing sociological and anthropological accounts of vaccine opposition focused on individual vaccine refusal by parents (see e.g. Leach and Fairhead 2006; Kaufman 2010; Sobo 2015; Reich 2016; Gottlieb 2016), I had originally expected to build on this scholarship and look into the underlying motives of individual activists through the narratives they were sharing online. Only after becoming more acquainted with the blogs did the research goalposts move towards the theme of internet-mediated collective resistance.

Further, by looking at online vaccine opposition as a form of societal activism, I could explore some issues which remained unaddressed (or addressed only tangentially) by most scholarship on individual vaccine refusal. These include the mediated practices through which vaccine-critical knowledge is constructed and justified online, the kind of social change pursued by critics, as well as issues of

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[63] In developing my main research question, I have also been influenced by Hobson-West's (2007) seminal study of UK-based vaccine critical groups, which focuses on how to best understand organised vaccine resistance as a social phenomenon, rather than looking at the issue of parental vaccine refusal through the lens of the vaccine decisions made by individual parents.

collective identity-making by vaccine counterpublics.[64] As will be seen in the course of the following four data chapters, the writings on blogs and social networking platforms have also been an invaluable source shedding light on the social, legal and historical contexts in which vaccine-critical activism takes root.

The broader issue addressed by this study is therefore *how to interpret and understand internet-mediated vaccine-critical activism in our information age*. This issue has been articulated through a set of more specific research questions: how are online vaccine critics constructing causal beliefs and knowledge that feed into vaccination controversies? What kinds of values guide vaccine critics' policy demands, and how are they advocating for these demands? How are critics understanding and representing themselves in ways that assert and reinforce their credibility over 'official' expert institutions and actors? Finally, and at a more general level, what role does the law play in online vaccine-critical activism?

To tackle these questions, a qualitative methodological approach was chosen based on the understanding that an a-historical, a-contextual approach aimed at measuring vaccination attitudes in the abstract would fail to address the complexities involved in online vaccine opposition and its relation to its socio-legal environment. To be sure, qualitative research and data have limitations, including their widely acknowledged non-generalisability (see Denny and Weckesser 2019). However, as Silverman (2006) contends '[q]ualitative research's greatest strength is its ability to analyse what actually happens in naturally occurring settings' (2006, 351). In contrast, quantitative research 'turns this phenomenon into a "black box", defined by the researcher at the outset' (351). Always according to Silverman, instead of being competitive, qualitative and quantitative approaches can complement each other, where the causal (or 'why questions') asked by quantitative researchers can be stimulated by the findings of qualitative research, which tends to concentrate on the 'how' and 'what' questions about social phenomena.[65] Indeed, if successful, 'qualitative research studies can offer people a new perspective on issues that they usually take for granted' (Silverman 2006, 351).

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[64] The choice to pivot the research questions towards issues related to the collective dynamics and nature of online vaccine-critical activism of course carries some implications for the scope of the research and its limitations. I will come back to reflexively address the impact of this decision on methodological issues in the next section of the chapter.

[65] This is not to deny that there are research projects in which qualitative and quantitative techniques are combined together, or 'triangulated', and that in some particular instances the boundary between what is considered quantitative and qualitative research may indeed be not so clear-cut (Deegan 2001, 20). However, I tend to agree with perspectives that warn against the uncritical acceptance of 'mixed-methods' approaches, and emphasise the different overall perspectives on reality and knowledge, or 'paradigms' (Guba 1990) that subtend qualitative and quantitative research. According to these perspectives, qualitative and quantitative methods can be used for 'complementary purposes', but not combined for triangulation and validation (Sale, Lohfield and Brazil 2002; see also Hammersley 2007). This is arguably consistent with what Silverman's (2006) point that qualitative and quantitative approaches are used to address different kinds of research questions.

In addition to this – and not less importantly – a qualitative approach was chosen here having in mind its value in understanding the 'actual production of meanings and concepts used by social actors in real settings' (Gephart 2004, 457). This leads me to the question of defining the methodological orientation of this study and the particular epistemological perspective underlying the choice of methodology. I elaborate on these aspects of the research process in the following section of the chapter.

Not really an ethnography? Internet-mediated ethnography and ethnographic-adjacent approaches to setting out in a (digital) field

This project sets out to explore the ways through which online vaccination critics negotiate their beliefs and knowledge claims in mediated spaces. More specifically, I not only examine *what* these beliefs and claims are in relation to their socio-legal contexts but also look at *how* they are constructed and supported within online vaccine-critical groups. I have suggested that a qualitative approach is best suited to address these 'what' and 'how' questions, which involve understanding vaccine critics' perspectives towards vaccination in a more holistic, contextualised and theoretically-grounded way than would be possible in a quantitatively-oriented research project. The decision to focus on vaccine critics' internal or 'emic' perspectives – as they are referred to in the anthropological scholarship – however, needs to be elaborated on further as it has a profound influence on the methodological approach of this research project.

In this project, vaccine-critical perspectives are not valued in so far as they paint a 'true' representation of the world, or accurately mirror any objectively determined, or 'factual' external reality. Rather, vaccine-critical views are considered valuable in order to understand them on their own terms, as a collection of shared constructed meanings which can tell us something about the social environments from which these meanings emerge. In other words, instead of a positivist preoccupation with 'factual' knowledge, in this study I have chosen to rely on an interpretivist perspective in order to understand my data. Denzin and Lincoln (2005) consider interpretivism as intrinsically linked to a qualitative research approach involving the study of social phenomena in their contexts, or 'natural settings'. As they put it, '...qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena *in terms of the meanings people bring to them*' (2005, 3 emphasis added).

As Thomas A. Shwandt (1998) notes, interpretivist researchers are concerned with understanding people's lived experiences, their 'life-world'. Influenced by the philosophical traditions of hermeneutics and phenomenology, the goal of interpretive social research is identified with the notion of *Verstehen*, a well-known concept derived from the social theory of Max Weber, and referring to the understanding of social action from the point of view of the actors themselves. This way, social actors are considered and treated by the researcher not as the passive ‘objects’ of the natural sciences, but as active ‘subjects’ who constitute the lived reality they inhabit through their meaning-making activities. Shwandt portrays the nature of interpretivist epistemologies as follows:

> The constructivist or interpretivist believes that to understand this world of meaning one must interpret it. The inquirer must elucidate the process of meaning construction and clarify what and how meanings are embodied in the language and actions of social actors. To prepare an interpretation is itself to construct a reading of these meanings; it is to offer the inquirer's construction of the constructions of the actors one studies.
> (1998, 222)

At this point, it should be acknowledged that there are no straightforward, universally accepted sets of procedures, techniques or formulas which social researchers use to ‘prepare their interpretations’, or construct the meanings of the social actors they are studying. What I encountered instead, as a novice just starting to think about research design before entering the field, is an ever-expanding range of approaches available to deal with qualitative research. Many of these approaches are compatible with interpretivist and constructivist epistemologies. However, each approach involves distinct ways of conducting research activities such as sampling, data collection and analysis, and may look at different aspects of the same data, focusing more on some things than others when interpreting social phenomena.

Choosing a particular methodology for this study then proved to be far from a simple ‘step’ – in fact, it has probably been one of the most challenging aspects of my research. I have had to think through and at times reconsider the paths I had taken in this study. My methodological discussion below should therefore be premised with the earlier caveat that whenever a seemingly linear account is encountered, the everyday research reality was likely more complex and messier, and not lacking a fair share of what Schmidt and Halliday (2009) have called the ‘MAS’ (or ‘methodological anxiety syndrome’ – seemingly a broadly shared experience among socio-legal researchers).

At the outset, my choice of methodology has been influenced by the type of data that I needed in order to answer the research questions posed – for the most part these were written textual communications, having chosen to investigate online vaccine-critical talk. While there are different methodologies which can be adopted for the study of texts, an exploration of the methodological literature first directed me to ethnographic approaches. Ethnographic approaches generally treat textual data as *constitutive* of social phenomena rather than representational of external, objective 'facts' (see Silverman 2006). In this regard, writing about social research in the health field, Jan Draper (2015) has recently noted how '[e]thnographic research is firmly rooted in the interpretative paradigm' (37). As she concisely puts it:

> Human beings experience the world through a web of meaning that includes rituals, symbols and languages. Ethnography seeks to investigate and interpret these meanings: it does not claim to be the 'true' picture but, in acknowledging that there is no universal knowledge, it provides the opportunity for a range of interpretations.
> (2015, 37-38)

Ethnography therefore was considered to be a compelling option, compatible with the interpretive paradigm embraced in this research. In my initial reading of the literature, I have also been influenced by Frank's (2012) claim that 'all qualitative research begins as ethnography' (38). More specifically, he argues that it is possible to 'enter into dialogue with people's stories only if the researcher has sufficient proximate experience of the everyday circumstances in which people learn and tell their stories' (38). I therefore started considering an internet-mediated, multi-platform ethnography, believing this would be an appropriate choice for my project, allowing for an in-depth, situated study of vaccine-critical activists across a range of social media platforms. Specifically, my idea was to join a small number of online vaccine-critical communities and, after an initial period of 'lurking', get involved in the communities as a participant observer, not too dissimilarly (from my perspective) from how a 'traditional' ethnographer would engage with her real-life participants.

Doing ethnographic work on the internet is today a relatively established enterprise. As Haverinen (2015) notes, '[s]ince the late 1980s, anthropologists have been increasingly interested in the internet and what it means to create "thick descriptions" in such a space (Geertz 1973), in other words, they are interested in conducting contextually rich analyses of networked lives and relationships' (79, citation in original). There are different ideas and approaches in the literature about how to do internet-mediated ethnography, each with its own conceptualisations of the online and its relationship with the offline, as well as different views on how to define the research field and conduct fieldwork (see e.g. Sade-Beck 2004; Postill and Pink 2012; Hine 2017; Kozinets 2015). For my research purposes, I relied on perspectives looking at internet-mediated ethnography as an *approach* to studying digital communication involving specific epistemological commitments, rather than just a method of enquiry reducible to one or more particular techniques, such as participant observation (see Varis 2016). I also drew inspiration from studies focusing on what Gabriella Coleman (2010) calls the 'prosaics' of digital media, drawing on Bakhtin's work on the 'lived experience' of language as used in context. According to Coleman,

> Looking at digital media in similarly prosaic terms means uncovering the lived experiences of digital media; discussing the conditions in which they are made, altered, and deployed (finance, religion, news); attending to particular genres of communication (blogs, spam, video-sharing sites); and finally placing attention on the material and ideological functions produced and sustained by digital technologies.
> (Coleman 2010, 495)

Internet ethnography in this more holistic sense as a methodological approach has shaped my research in different ways. However, before proceeding further with the methodological details of this study, I have to elaborate on how I came to question the exact nature and definition of my methodological approach.

During the early stages of data collection on the blogs, I decided that my study would be limited to the online world. This decision followed an already mentioned shift in the focus of the project – which has moved from the personal motives and reasons for vaccine refusal, as expressed by individuals on the internet, to how online vaccine opposition 'works' as a form of mediated activism. Additionally, I deemed the vast amount of rich data found on the blogs to be worthy of in-depth, structured analysis. This kind of analysis, however, would require many months to complete, leaving little time to potentially conduct interviews or interact with vaccine-critical users in a second phase of the research. In the end, I made the choice to concentrate on online texts as an important subject of research in their own right, and focussed on their reading, analysis and interpretation.

This decision challenged me to critically engage with how I conceived of and defined my methodology. I wondered particularly whether it was legitimate to refer to my research as an 'ethnography', rather than a type of online-based archival study. To answer my questions, I had to look more deeply into the meaning of ethnography, its relationship with internet-mediated ethnography and the commonalities and differences between the latter and alternative qualitative approaches to the study of online phenomena. I have discussed these theoretical-methodological issues in detail in a separate article (Uberti 2021). For the purposes of this chapter, what I would like to make clear is that although this study is not intended to be or claimed as a 'pure' internet ethnography, it has been influenced and informed by internet-ethnographic approaches in different ways.

The methodological approach chosen here reflects ethnographic research approaches in so far as it seeks not to make generalisable observations, but to offer an in-depth understanding of human interactions *in context.* As Blommaert and Dong (2010) have noted, ethnographic findings should not be used to achieve population representativeness, they are not exactly replicable, nor do they claim objectivity on the part of the researcher (17). These are all acknowledged limitations of this study. However, the interpretive, subjective nature of ethnographic research, along with its focus on interaction in a situated environment, may allow for the investigation and theorisation of complex social realities through the lens of the subjects observed. This is apparent from Hammersley's (2006) definition of ethnography as a 'form of social and educational research that emphasises the importance of studying at first-hand what people do and say in particular contexts' (4). It is also in line with Brewer's (2000) definition of ethnography as 'the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities' (10).

The idea of contextuality was essential to my study – in order to discover what worldviews were emerging from vaccine critics' online talk, I wanted to get a fuller picture of their narratives, interactions, questions and debates taking place in a relatively self-contained setting over a prolonged period of time. In other words, I wanted to become familiar with the digital spaces of the blogs, their comment sections and their social networking pages as a whole, rather than dealing with a series of disconnected 'snippets' of data. In addition, I was interested not only in analysing online narratives but also investigating the knowledge-making practices in which critical bloggers and commenters engage, in order to obtain a better understanding of what online vaccine-critical activism is, and who vaccine-critical activists are.

Another way in which this research has been influenced by ethnography (but which applies more broadly to qualitative research) is the particular attention paid to the meanings expressed by vaccine critics themselves, rather than to external interpretations of such meanings. As Brewer argues, ethnographers participate directly in a particular setting, although not necessarily in the activities of the people they are studying, '...in order to collect data in a systematic manner, *but without meaning being imposed on them externally*' (2000, 10 emphasis added).[66] In addition, as Sherry Ortner (1995) has argued, ethnography 'has always meant the attempt to understand another life world using the self – as much of

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[66] This latter requirement not to impose one's meanings on the data is important, because even as it does not purport to provide an objective picture, ethnographic research cannot avoid critiques levelled at qualitative approaches which see the researchers embroiled in asymmetrical power relationships with the researched. This ideal, however, needs to come to terms with the reality that perfect 'neutrality' may not be achievable, as the self of the researcher, her identity, experiences, and background cannot be completely set aside during the research, as I discuss in this chapter in relation to the present research.

it as possible – as the instrument of knowing' (173). While I did not have direct interactions with the authors of the texts I studied, this perspective on the role of the researcher has also influenced my 'ethnographically-inflected' research approach, and the way I looked at the vaccine-critical narratives, arguments and claims I encountered during my digital 'fieldwork'. These have affected me in different, and at times conflicting ways. At the same time, my previous views, experiences and prejudices – all part of my researcher 'self' – have undoubtedly contributed to colouring my perceptions and shaping my approach to the data.

Following a hermeneutical philosophical perspective, 'prejudice' (to borrow a term from philosopher Hans-Georg Gadamer) is not seen here in a negative light, as something to be avoided, but instead acknowledged as a necessary starting point for any form of textual interpretation (see Barak 2020). Rather than attempting to pursue an (arguably unachievable) ideal of total objectivity, I have tried to be reflexive about the ways in which my subjective standing could shape my inquiry. Firstly, I am not vaccine-critical myself. At the same time, while acknowledging that I am not an expert in vaccinology or immunology, nor do I have a background in medicine, I have set out to gain at least some technical knowledge about how vaccines work, what they do and the potential adverse events which have been linked to routine childhood vaccinations particularly. I deemed it important to do so because, as will become apparent in the next chapter, these are all matters of high importance to online vaccine critics and are regularly brought up in vaccine-critical talk throughout the blogs sampled in this study. To an extent, I had to adopt a similar mindset to vaccine critics and 'do my own research' on vaccine safety, not stopping at the summaries of 'risks and benefits' of vaccination found on public health organisations' webpages and news articles (as well-written and informative as these may be), and look at the 'actual evidence' in the scientific literature myself.

However, the way I conducted my research and the resulting knowledge I have developed about vaccines would in all likelihood not be approved of or considered valid by the critical bloggers and commenters whose online talk and practices I have studied. In my research, I have relied on academic sources such as Plotkin's *Vaccines* (Plotkin et al. 2017) and *Pediatric Infectious Diseases Revisited* (Schroten and Wirth 2007), the US Institute of Medicine's recent report on the adverse events of vaccination (IoM, 2012) and a series of studies (mostly epidemiological) on vaccine safety published in the peer-reviewed scientific literature. While I by no means claim to have developed any form of expertise in vaccines following this reading of the scientific literature, I believe my newly-acquired status of 'informed citizen' in this field (to borrow a concept from Alfred Schütz referred to later on in this research) allowed me to better understand the claims articulated on vaccine critical blogs.

On the other hand, however, this initial research made me more aware of the times when vaccine-critical arguments clashed with mainstream scientific views. Further, relying on these sources for vaccine information put me at epistemological odds with online vaccine critics. This is not because, as will be seen, vaccine opposition consists in a wholesale rejection of scientific knowledge. However, I realised that as someone enmeshed in a particular academic social environment, economy and culture which sanctions certain ways of constructing and sharing knowledge, my determination of what constitutes 'reliable' research does not necessarily correspond with that of members of vaccine-critical groups. Indeed, what I considered to constitute unproblematic resources for information on vaccines, part of a reliable body of scientific literature that I could draw on and refer to, would be (and at times actually were) dismissed by vaccine critics as biased, wrong, methodologically unsound, misinterpreting or misrepresenting data, self-contradicting or even a combination of these things.

To be sure, while collecting my data and reading through the blogs I did not end up 'going native' and was not converted to the broader vaccine-critical worldview which is described in this work. However, in my mind it was clear that the goal of this ethnographically-shaped study was not to correct or 'debunk' critics' views about vaccines, but to better understand what these views are, what dynamics underpin their construction, and how they relate to their surrounding socio-legal contexts. In addition, and also related to reflexivity in approaching the data, I felt that despite these epistemic differences I could empathise to an extent with narratives about the difficulties encountered by families of disabled children shared by some of the vaccine critics in their accounts. Having a close family member who is disabled and has complex needs, I am not a stranger to the challenges facing disabled people (and their carers) in society. On the other hand, my views on this subject have also been shaped by literature in the field of critical disability studies (CDS), and I am aware of the sometimes uneasy relationship between self-advocacy organisations led by disabled people and parent-led groups, and the ways in which parent advocacy may in some instances become problematic from the perspective of disabled activists (see Carey, Block and Scotch 2019).

A reflexive approach was adopted throughout data analysis, scrutinising my reactions – both positive and negative - to what I was reading on the blogs. I took breaks particularly after reading passages I felt I strongly disagreed with in order to interrogate my views and interpretations of the data. I have rewritten parts of this work multiple times until satisfied that my account of the narratives and practices in which vaccine-critical bloggers and commenters engage was a fair and accurate representation of what I was observing online. Nonetheless, it is important to remember that this research study is not claiming to eliminate researcher bias in order to discover objective and universal facts about the world.

This meant that the research process involved subjecting to scrutiny and interrogating my prior assumptions as I interpreted the data, rather than to trying to eliminate them.

In addition to an interpretivist epistemology and an emphasis on reflexivity, a final way in which ethnographic approaches to internet research more specifically have informed my research methodology is represented by a concern with empirically investigating and theorising the nature of the online phenomena which form the object of enquiry. In practice, this meant that rather than taking for granted or assuming the kinds of social agencies I was looking at while analysing online interactions – for example employing vague notions such as 'online community' to refer collectively to blogs or Facebook pages – I made these agencies part of what was being researched. Indeed, as Caliandro (2018) has argued, 'within a fluid and dynamic context such as that of social media, the definition of an online social formation cannot be considered an a priori task but rather an a posteriori one' (560). In my own research experience, while I found that the more fragmented social realities I ended up observing in practice could not be helpfully defined as 'communities', the notion of 'counterpublic', which was introduced in the previous chapter and will be further discussed later on here, instead seemed to capture the mediated character of vaccine critical groups, their discursive nature and the 'stranger sociability' aspect involved in their interactions (see Warner 2002).

While the choice to conduct this study entirely online was consistent with the focus on the nature and dynamics of *mediated* vaccine-critical activism embraced by this work, and I have defended the use of online contexts as valid settings for a qualitative-interpretive study, the limitations of this sort of approach should likewise be acknowledged. While the internet has arguably increased the potential for citizen participation and the formation of issue-specific counterpublics, it has not done so homogenously at the population level. In the UK, for example, roughly 90% of the population say they have used the internet in the past 3 months – the figure rising to almost 100% for 16 to 34-year olds (ONS 2018). However, figures are significantly lower among older users, with 80% of adults aged 65-75 years and only 44% aged 76 years and over stating they have recently been online. Even if these figures may have increased since 2018, there is still a wide gap between younger and older segments of the population in terms of internet usage.

Age is not the only factor in what is referred to as the 'digital divide' (van Dijk 2020): socioeconomic status, race, disability and geographical location are among other criteria which are associated with less engagement with information and communication technologies. In addition to the digital divide having an impact on the composition of my sample, confining my study to the online world means I cannot confirm the identities of the bloggers and commenters whose writings I am analysing. This means I am not able to make claims regarding the make-up of counterpublic member populations with regards to demographic details such as ethnicity, race, gender and age. It will then be important for future studies using different approaches to ascertain not only the demographic characteristics of vaccine-hesitant individuals, but also those of online vaccine-critical activists. In any event, it should be pointed out that the main focus of this study is not vaccine-hesitant parents or individuals, but rather by what I call 'vaccine-critical counterpublics'. These are online collectives actively opposing vaccinations on websites, blogs and other social media platforms – in the case of this research I looked specifically at blogs with comment sections and their public Facebook pages. In the next sections I will discuss in more detail the process of sampling, collecting and analysing the data from the vaccine-critical counterpublics which make up the subject of the study.

Finding and sampling vaccine-critical blogs

To locate online-vaccine critical groups to include in this research, I started by creating a list of 63 vaccine-critical websites, all from the English-speaking world, assembled through a combination of online searches[67] and review of the existing literature (see e.g. Bean 2011; Smith 2017; Hobson-West 2007). It is important to keep in mind that the design of this research project predates the COVID-19 pandemic. My digital fieldwork started in April 2019 and ended in December 2019, while the posts collected and analysed in the research refer to a period ranging from April 2018 to June 2019. Both the original list of vaccine-critical websites and the final sample do not include newer, COVID-focused websites and blogs emerging in response to the introduction of COVID-19 vaccination programmes and lockdown measures. The list of websites included in Appendix A includes all the (English language) vaccine-critical websites that were found during this (pre-COVID-19) search.

The websites identified were reviewed and coded for main geographic/national areas of focus, thematic areas of interest and type of website (individual/multi-author, comment section/no comment section, non-profit/commercial). [68] It was then decided to exclude from this list static websites without an active

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[67] A list of 'anti-vaccination websites' available at https://vaxopedia.org/2018/01/13/anti-vaccine-websites/ was particularly helpful at an early stage of research.

[68] In the process of coding the blogs in terms of the main themes focused on by the groups or individuals who own and/or manage them, I have also engaged with the previous literature on vaccine-critical websites, and particularly the thematic attributes of the websites previously identified by Kata (2010). In this research I focus on blogs on four thematic areas (see Table 1 below): vaccine injury activism, alternative health, medical choice activism, and personal enquiry/other (this latter area was treated as a residual category). A further category comprising a small number of more generalist 'alternative news' or 'conspiratorial' blogs and websites was also identified, however these types of blogs ware considered as distinct, especially

comment section. While I do not wish to diminish the value of these 'read-only' online spaces for vaccine opposition, my interest in mediated activism led me to concentrate on interactive and connective media, in which the vaccine-critical voices of the bloggers interact with those of their readers, rather than more traditional 'top-down' forms of communication. Additionally, the choice of interactive online spaces was made in order to be able to examine how mediated activists are currently using what Silvio Waisbord (2018) calls 'a broader, creative, sophisticated set of communication platforms', giving rise to 'digital networks' which 'facilitate the regular expression of personal and collective politics, opinion, sentiments, arguments and identities' (3).

Blogs were also chosen over more 'open-ended' social media platforms, such as Twitter, as they can offer researchers the opportunity to study 'contextual digital fields' (Airoldi 2018) which provide a higher degree of stability and boundedness, constituting self-contained digital fora with interactions taking place among a smaller group of self-selecting users. Finally, but not less importantly, the decision to choose blogs with active comment sections was made as the dynamic online spaces characteristic of Web 2.0 have been recently linked to significant developments in vaccine-critical activism (see Kata 2010; 2012; Mitra, Counts and Pennebaker 2016; Hoffman et al. 2019; Smith and Graham 2019).

Non-US or -UK focused blogs, blogs not concerned with routine childhood vaccinations, and 'generalist' blogs were likewise excluded from the framing sample. The choice to research UK- and US-based blogs was made as these are both countries with long, well-documented and – most importantly – interconnected histories of vaccine opposition as discussed in the previous chapter. By maintaining the focus on vaccine-critical activism in these two countries, I aimed to achieve a degree of continuity and 'situatedness' in my research, so that the findings on vaccine-critical activism set out in this study may be read in conjunction with, and in relation to, the historical literature on anti-vaccine movements previously explored in this work.[69] At the same time, as one of the goals of this project was to better understand how vaccine critics relate to the law, in order to keep the scope of my research manageable it was important that my analysis remained specific to particular jurisdictions and legal systems. Looking back once again at the previous chapter, investigating past vaccine-critical movements has revealed a rich history of engagement with the law in the UK and the US, as well as different legislative-policy developments in the separate legal contexts of these two countries. It was considered that

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as unlike the other types they do not seem to display an overall predominant concern with health-related issues. These generalist blogs were excluded from my sampling frame, as explained in more detail in this section of the chapter.

[69] It should be pointed out that in online-based research it is often not possible to ascertain the nationalities of those who post the messages or comments which make up the object of analysis. While some of the bloggers and commenters in this research explicitly mention their nationalities, for most of the users whose posts were analysed this is not the case – this is why it was decided to link the blogs to specific geographical 'areas of focus' based on their content rather than on the nationality of their users. I believe that this content-based geographical selection has been effective in allowing my study to emphasise vaccine critics' interactions with the (UK and US) national legal systems this research is focusing on.

exploring how present vaccine critics have responded to these developments would offer some relevant insights into the role played by different legal landscapes within vaccine-critical arguments and views.[70]

The reasons why blogs not discussing routine childhood vaccinations were excluded is similarly grounded in the decision to make the research more focused by restricting its scope to reflect a more homogenous and 'manageable' range of concerns. For example, while the HPV vaccine was discussed in some of the sampled blogs, blogs focusing exclusively on HPV vaccines have not been included in the sampling frame, as HPV vaccination raises some distinct legal, ethical and social-scientific questions (see e.g. Haber, Marlow and Zimet 2007; Colgrove 2006; Charo 2007; Karafillakis et al. 2022). Generalist blogs only tangentially referring to vaccination issues were likewise not considered in the present research.

In this regard, it should be noted that beyond the four main categories of vaccine-critical blogs this research focuses on (that is vaccine injury activism, alternative health, medical choice activism, and personal enquiry/other – see 'Table 1' below), an 'extra' thematic area was identified in my initial list of websites (see Appendix A). This further category encompassed a small number of 'alternative news' or 'general conspiratorial' blogs primarily aimed at the dissemination of extreme political views. The relationship between vaccine opposition and extreme politics (particularly in connection to alt-right or 'general conspiratorial' perspectives in the case of the websites identified here) is, without doubt, a worthy and important subject of research. However, because of complexity and the sheer breadth of the topic, I had concerns that including these kinds of websites in my analysis would have resulted in an excessive expansion of the scope of the study, possibly diluting its findings and diverting its more specific concern with medical and health-related issues. This focus on health is also something which is shared by of all of the blogs which have been included in the study.

After eliminating from the list websites without an active comment section, those not focusing on a US or UK context, or on routine childhood vaccinations, as well as those referring to vaccines only tangentially while promoting broader political perspectives, I was left with twenty-one blogs meeting

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[70] As already mentioned in the introductory chapter, the decision to focus this research on vaccine-critical activism in the UK and the US should not be intended as taking away from the need to address vaccine opposition in different national realities. More research addressing vaccine-critical activism in non-English speaking and/or non-Western settings, including particularly research providing an historical perspective on vaccine opposition beyond an Anglo-North American context would provide an especially valuable contribution to the existing literature (see Simas and Larson 2021).

the set criteria (see Appendix B).[71] From this final sampling frame, six blogs were purposefully selected in order to obtain diverse data from the various typologies of blogs identified (see Table 1 below).[72]

Table 1 Sampled blogs classified by relevant national areas, main thematic areas, individual/collective authorship, commercial/non-profit status

No	Blog Acronym		Relevant National Area(s)	Main Thematic Area(s)	Multi/ Single Author	Commercial/ Not-for-profit
1	AoA	https://www.ageofautism.com	US / UK	Vaccine injury activism	Multi-author	Not-for-profit
2	ANHI	https://anhinternational.org	UK	Alternative health	Multi-author	Not-for-profit
3	FP	http://fearlessparent.org	US	Medical choice activism	Multi-author	Not-for-profit
4	LW	https://www.livingwhole.org	US	Alternative health	Single author	Commercial
5	VCUK	http://vaccination.co.uk	UK	Personal enquiry/other	Multi-author	Not-for-profit (personal blog)
6	VP	https://www.vaccinepapers.org	US	Personal enquiry/other	Not known	Not known

Textual and visual data from more than 700 blog posts, all in the public domain, and spanning in time from April 2018 to June 2019 were collected and analysed with the support of a QDA software (NVivo 12). For four of the blogs (*AoA*, *ANHI*, *FP* and *LW*) a sample of Facebook posts from their respective public pages spanning in time from March 2019 to May 2019 was additionally collected and analysed. The use of NVivo was important for this research as the amount of online data retrieved on blogs and social media platforms would have made completely 'manual' collecting, managing and coding processes (e.g. storing data and coding it in a Word document) highly impractical.

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[71] As of the moment of writing, one of the blogs (*LW*) has gone offline. Historical posts are still accessible through the Internet Archive (https://archive.org/). The blog still has an active Facebook page.

[72] In selecting the blogs for this research, consideration has also been given to the frequency of posting and amount of content shared on the individual blogs, in order to create a rich and varied dataset but not one so large that would be too unwieldy for a qualitative research project involving manual coding of the data. For the blogs with a lesser number of posts (*FP*, *LW*, *VCUK* and *VP*), I have analysed posts from April 2018 to June 2019, while for the two remaining bigger multi-author blogs the dates of the posts range from April 2018 to March 2019. It should be pointed out, however, that even doing this a high degree of variation in terms of posting frequency remained (from around thirty posts a month for *AoA*, to a handful of posts in total for *FP* and *VP*). I considered that this variation was partly offset by the fact that posts on smaller blogs tended to be longer and have more extended comment sections than those on bigger blogs. In addition, for some of the smaller blogs, Facebook page content has been included as well if available (more on this is discussed below in this section).

Even so, the data collection stage of the research process has not been completely unproblematic. Web pages on blogs corresponding to different posts were 'captured' through NCapture, a web-browser extension which allows online content to be downloaded in files that can subsequently be added to NVivo. The problem is that this software is not perfect, and sometimes after the file containing a particular blog post had been added to NVivo, and I opened it to check its content, I would find an illegible, jumbled up (or 'scrambled', as a reviewer on the software developers' website aptly puts it) version of the original page with texts and images overlapping each other. Alternatively, in the case of Facebook pages especially, the downloaded files were often incomplete. Whenever the NCapture extension-derived file did not match with the online content in my browser I would have to delete the file, go back to the original web page and download the page again manually and re-upload it on NVivo.

The 'messiness' I encountered at this stage of the research process was not completely unexpected. Before entering the field, I kept in mind Herbert M. Kritzer's (1996) observation that methodology textbooks tend to offer rather 'sanitised' descriptions of research processes which do not account for 'the messy reality of what happens when researcher meets data' (761). Even when things went more smoothly, however, it should be noted that downloading and uploading online data onto NVivo can be a time-consuming, repetitive and lonely activity, especially when large amounts of data have to be repeatedly added to the system over a prolonged period of time. On average, during this digital fieldwork phase which spanned over a period of nine months, I would spend about 7-8 hours a day in front of a computer screen (on a day without other commitments such as teaching). This is a very different experience from that of a 'traditional' offline ethnographer. Without any moments of socialisation and interaction with research participants, feelings of boredom and lack of focus are more common than might be expected, and should be taken into account when planning an online-based research project.[73] However, during this phase of the research just part of my day was spent collecting data, as I divided my time between data collection and analysis. These two stages of the research process were therefore carried out alongside each other, following Markham's (2013) view that in ethnographic research 'understanding culture has never been a matter of collecting everything and then analyzing it later' (440).

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[73] In this regard, Clark and Sousa (2018) have identified the handling of large volumes of data 'requiring many hours of sometimes repetitive work' as one of the main areas of risk for the mental health of qualitative researchers.

Approaching data analysis through qualitative-inductive thematic analysis methods

In analysing the data collected from the sampled blogs, this research has been informed by thematic analysis. This is a diverse family of research approaches which at the most general level aims at 'identifying patterns ("themes") across qualitative datasets' (Clarke et al. 2019, 844).[74] While different traditions of thematic analysis exist in different fields of research, my approach was particularly influenced by Braun and Clarke's (2006) 'reflexive thematic analysis' model, which is a flexible version of this method emphasising 'an organic approach to coding and theme development and the active role of the researcher in these processes' (Braun and Clarke 2017, 297; see also Braun and Clarke 2013). More specifically, reflexive thematic analysis is a form of qualitative analysis distinct from both partially quantitative 'coding reliability' approaches and more structured qualitative approaches requiring the drafting of a 'codebook' to apply to the data at the outset of a research project (see Braun and Clarke 2019).

The kind of thematic analysis adopted in this study therefore does not make use of quantitative coder reliability metrics to assess the validity of the developed codes in objective terms. Further, following an inductive approach, it was decided not to have any set of pre-determined questions or issues guiding the coding process. A reflexive approach to thematic analysis was chosen over a 'reliability' approach as it better matched the qualitative perspective and interpretivist epistemology adopted by this study. Although initially I had expected to prepare a codebook including detailed questions to rely on for coding the data, I decided to abandon this idea after an initial stage of analysis revealed that this approach was too restrictive for the complex picture of themes and sub-themes that could be identified in the data (a final list of codes has been included as Appendix C).

The choice to have the data 'ground' the analysis, however, should not be taken to suggest that the reflexive thematic analysis method employed here is equivalent to grounded theory (see e.g. Charmaz 2006; Strauss and Corbin 1998). Although these two approaches undoubtedly have similarities, and both can involve inductive data coding, reflexive thematic analysis is a *method* and as such it allows for more flexibility through combination with other research approaches, compared to the comprehensive methodology that is grounded theory. In the case of this research, I used thematic analysis, in combination with a methodological approach informed by internet ethnography. Another important difference is that while in grounded theory, codes are sometimes described as 'emerging' from the data,

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[74] In a reflexive thematic analysis approach, themes are intended as 'patterns of *shared meaning* underpinned or united by a core concept' (see Braun and Clarke 2019, 593, emphasis in original).

in reflexive thematic analysis 'themes' and codes are expressly conceived as something constructed by the researcher.

As previously mentioned, the data in this research has been coded inductively. In a way, this means handing over some 'control' over the research process to the data, letting this 'lead' the analysis down certain paths over others. As Charmaz (1995) has noted, 'by studying your data, you learn nuances of your research participants' language and meanings. Thus, you learn to define the directions in which your data can take you' (36). This means that the researcher may be led in unexpected directions during the course of the research and stray away from the original paths taken at the beginning of the fieldwork. Nevertheless, as Braun and Clarke (2006) note, even when coding inductively 'researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum' (84). In this regard, reflexive thematic analysis is more flexible than a purely inductive grounded theory approach in that it allows for theoretical analysis and coding driven (at least in part) by the researcher's interest in a particular area or topic.

As far as this research is concerned, although the coding was carried out inductively, it was not completely unaffected by my pre-existing interests and orientations. For example, as I was specifically interested in the relationship between vaccine-critics and the law, I actively looked in the data for instances which revealed more about this interaction. At the same time, I have attempted to keep an open mind about how law-related topics might manifest themselves in vaccine-critical talk. Indeed, during the analysis process it was revealed that online vaccine critics do not just relate to the law by critiquing mandatory vaccines legislation or vaccine injury compensation schemes – as I had expected. Instead, critics display their relationship to their surrounding legal landscapes through a much more diverse range of issues and via different modes of engagement. For example, I have created codes to account for how vaccine critics act as 'advocates for free speech', how informed consent rights are 'hijacked' in support of 'vaccine choice', and how certain aspects of vaccine regulation (specifically vaccine patient information leaflets or package inserts, pharmacovigilance systems and vaccine injury compensation schemes) are 'recast to support views that vaccines are unsafe'. In other words, while I entered the field with some pre-existing interests and concerns, ample room was still left for unexpected findings to emerge from the research process.

This openness to unexpected findings, which is a characteristic of inductive approaches to analysis, can also be seen in relation to other topics explored in this study. For instance, some surprising data has been found in relation to how vaccine critics frame and relate to notions of science, rationality and truth. As I entered the field aware of widely held assumptions about the 'anti-vaccination movement' as an expression of anti-science sentiment, irrationality, or 'post-truth' society, I did not expect to find vaccine critics across different types of blogs embracing positive views of science and drawing on scientific knowledge, while recontextualising it in order to support their claims on vaccine-related injuries. I also did not expect that many vaccine critics would claim to be relying on rational cost-benefit analysis when justifying their view that vaccines should be rejected by parents, nor that they would defend ideals of objective truth while defining their collective identities as 'whistleblowers' fighting to reveal the 'reality' of vaccine dangers.

During the analysis stage, consistently with the reflexive thematic analysis model, I have also partly relied on theoretical coding, meaning some of my codes reflect pre-existing theoretical frameworks. This can be seen in relation to individual codes such as 'DIY science', which refers to previous scholarship on DIY culture and alternative media (see Chidgey 2014; Atton 2004; Ito 2008), and which I use in the next chapter to refer to the ways in which vaccine counterpublics engage with, repurpose and reuse scientific knowledge. Another significant example is the code 'disaster threshold', which captures vaccine critics' emphasis on the quality and nature of vaccine risks, rather than the quantitative frequency of such risks (see Chapter 5). This code links back to sociologist Niklas Luhmann's (1993) reflections on risk, and specifically the idea of a socially-constructed threshold – which he calls the 'disaster threshold' – beyond which the possible consequences of a particular risk are considered too severe to be acceptable, regardless of how unlikely it is that the risk will materialise.

More generally, as already mentioned in the introductory chapter, the three main 'macro-areas' of conceptual domains to which my codes refer (i.e. 'Causal Knowledge', 'Normative Principles and Advocacy', and 'Collective Identity') were informed by two main theoretical frameworks, that is 'counterpublics theory' (see particularly Foust, Pason and Rogness 2017) and the 'epistemic communities approach' (see Haas 1992; Akrich 2010). I will elaborate more on their relevance for vaccine counterpublics in the course of the 'data chapters' of the thesis. For the moment, I just wanted to note that while theory has played an important role in my analysis, it was not 'applied' a priori to the data as in a 'codebook' thematic analysis model. Rather, different theoretical frameworks became relevant as the analysis and coding of the data went on, with an interactive relation emerging between data and theory, in which I would not only read the data in light of the theory, but also look back at (and, sometimes, rethink) theory in light of what I found through the data.[75]

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[75] Even counterpublic theory, which is a framework I have originally become interested in while researching the history of vaccine-critical activism (and therefore prior to the beginning of the data analysis process – see Chapter 2), has not simply been 'applied' to the data, but allowed to interact with it, which has led me to combine the theory in conjunction with the epistemic community framework (Haas 1992; Akrich 2010 – see Chapter 4) to best understand the online practices of vaccine critics.

The rather linear discussion carried out so far, however, should not be interpreted as meaning that the analysis process has been free of complications, uncertainty, and indeed 'messiness'. As an activity involving interpretation of meanings conveyed by people, coding is arguably not a logical process, but rather something which involves the use of intuition and instinct, as well as much trial and error.[76] Determining what is the 'meaning' of the data is not simple, and initial interpretations will evolve and change as individual codes are related to each other, as well as to further analysed data.[77] A related issue I have encountered in the course of the research process is that of having 'too much data' to incorporate in a single research project. This is a familiar issue for internet ethnographers (see e.g. Markham 2013; de Seta 2020), and involves having to make some important decisions about which threads to follow and which ones to leave for future research projects. As Gabriele de Seta (2020) has put it:

> ...in order to decide what does or doesn't belongs in one's research project and to produce a viable written report, the ethnographer continuously prunes down networks as they proliferate, constructing a skeletal 'field as network' that eventually feels more like a crooked bonsai tree than an expanse of thick experiential wilderness.
> (2020, 84)

I have attempted to deal with this 'too much data to prune down' issue in different ways. For example, I have decided not to pursue a line-by-line coding strategy (as is for instance common in grounded theory approaches), as this might have broken down the data too much, running the risk of 'over-coding' (see Smith 2016). Instead, vaccine-critical texts have been read more holistically until patterns emerged, making it possible to identify themes that were then considered in relation to each other, in order to identify areas of connection and difference – not too dissimilarly from the process of 'theme-ing' in 'narrative analysis' approaches (2016, 217). Some networks of related themes which were

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[76] This process would have looked very different had I chosen to use a software to automatically perform data analysis, for instance adopting an approach to analysis involving the use of a machine learning model to 'extract' topics from the data. However, in this research I have decided to manually code the data. This is because, especially in the type of 'sub-cultural' environment found among online vaccine-critical groups, I was concerned that a software would not have been able to pick up the nuance and context needed to accurately capture the meaning of what vaccine critics were talking about and doing online (see Mulcahy and Wheeler 2020; Arango Olaya 2021). Learning more about the contexts in which texts are created and conversations take place is indeed crucial for research approaches informed by ethnographic methodologies such as the present one (see Uberti 2021). Additionally, the idea of 'extracting' codes from the data would have been at odds with my interpretive epistemological commitments and reflexive approach to thematic analysis, in which the role of the researcher as she interacts with the data is foregrounded, and codes and themes are not seen as 'emerging' from the data, but rather as actively constructed by the researcher in the course of the analysis process.

[77] The use of NVivo has been particularly helpful in this respect, as it allows for the easy retrieval, modification and merging together of individual codes. In addition, while the coding of the data was done manually, the 'Text Search' and 'Word Frequency' functions available on this software have given me the opportunity to more conveniently double-check the prevalence of certain themes and ideas across the different blogs considered in the study.

considered particularly significant in relation to my main research aim – that is, how to interpret and understand internet-mediated vaccine-critical activism – were then used to guide the coding of further data, in a more advanced stage of data analysis akin to what Strauss and Corbin (1998) have called 'selective coding' (see also Benaquisto 2008, 87-88).

Conceptual maps have also been created using a dedicated analysis tool NVivo, which has been particularly helpful as it translated into a more intuitive visual form the emerging networks of relationships between different codes (see Appendix D). All these processes and tools have helped to make the vast amount of information available online more manageable, allowing me to address the issue of having 'too much data'. It should be acknowledged, however, that even the best techniques and strategies cannot completely remove the complexity and 'messiness' experienced during the actual research process. My discussion here, therefore, should be read not as a 'guide' describing how I have 'sorted out' problems encountered during the research but rather as an account of why I made certain choices and followed certain paths, so that while my research journey could not be perfect, it could be at least appropriately traced and examined. This point also applies to addressing the ethical issues raised by this study, as considered in the next and final section of this chapter.

Ethical considerations for an online-based research study

Ethical considerations have played an important role in how I have gone about data collection and analysis, as well as to how I have approached writing up the research findings. Ethical approval was sought and obtained from the LSE Research Ethics Committee for the stage of the research involving the analysis of comments posted by users in the comment sections of the blogs and social media pages, while LSE's departmental self-certification was carried out with respect to the analysis of the content published by bloggers.[78] It should be noted, however, that the ethical issues involved in research are not 'solved' once approval has been obtained from the appropriate research ethics body – rather, it is important to keep considering emerging problematic issues and questions throughout the research process. For the present study, I had to address some interrelated ethical issues linked primarily to the fact that I sought to work with online data while not making myself 'visible' on the blogs or Facebook pages by actively interacting with the bloggers or commenters whose texts I was reading and analysing.

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[78] The LSE Research Ethics Committee approval was received on April 5, 2019 (REC ref. 000879).

As with all internet-mediated research, this study has required a flexible approach to deal with scenarios and situations that are different from those that may be encountered offline. A particular area of ethical concern for internet-mediated research lies in the blurring of the line between what is in the public domain and what is being shared privately, engendering expectations of privacy among internet users.[79] What constitutes covert research, and what does not, is not an objective determination with only one 'true' or valid answer, but instead depends on participants' individual perceptions of what constitutes a public space. In certain online settings, such perceptions might not be so clear-cut, and there might be uncertainty on the part of the researcher and internet users alike. Expectations of privacy online are also likely to differ from community to community, and even from individual to individual within the same online groups.

Additionally, it needs to be acknowledged that while many online spaces, particularly on social media platforms, are easily accessible by anyone just by creating an account on the platform, these spaces occupy a 'grey area' and may constitute uncertain territory for researchers (as well as for participants). At the same time, active intervention by researchers to obtain informed consent in these publicly-accessible digital settings may in certain cases be disruptive for online group members, by asking participants to disclose more details about themselves (e.g. contact information, signatures) than they were originally willing to share online (see Johns 2013). Furthermore, as stated by Townsend and Wallace (2018), it may not be 'straightforward to ask for consent' both for the safety of the researcher and 'to ensure that social media research ethics does not result in indirect censorship of critical research' (11-12).

Ethical decisions in online research settings therefore involve a context-specific balancing exercise, which makes it hard to create universal 'best practice' guidelines. This means ethical assessments relevant to mediated research are arguably best conducted on a case-by-case basis. This is also the position of the Association of Internet Researchers, which in its guidelines recognises that 'internet research involves a number of dialectical tensions that are best addressed and resolved at the stages they arise in the course of a research study', through a 'casuistic or case-based approach'. (Markham and Buchanan 2012, 7). Anonymising online data in 'grey area' or higher privacy scenarios might be a solution when asking for informed consent is either too impractical or not the best solution from an ethical standpoint. However, attempts to provide anonymity in online contexts might be ineffective if individual quotes can be searched for in social media archives or search engines such as Google.

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[79] During the first year of my doctoral project I have attended a research ethics seminar offered by the LSE PhD Academy to become more aware of the issues linked to research involving the use of online data and social media-based research more specifically.

Much of the data considered in the present research has been sourced from publicly-available blogs with a focus on vaccine issues. These blogs include articles that anyone with an internet connection can have access to and read, without the need for a subscription or any additional steps. Indeed, as became clear in the course of my analysis, all bloggers made efforts to reach as many readers as possible, for example by publicly sharing their articles on the biggest commercial social networking platforms, such as Facebook, Twitter and Pinterest. Blogs also appear to accept that, with publicity, may come critical interpretations or reactions to their content, with most of the blogs containing either references to external criticism or even direct negative reactions from some users in the comment sections. I therefore considered that bloggers are generally aware that a diverse range of readers might be looking at their content, including readers who are opposed to vaccines, pro-vaccine advocates and people who are just curious about vaccine-related controversies.

Additionally, looking at the entities who own and manage the blogs (see Appendix B), as well as the content of the blogs themselves, it is possible to deduce that these are published for public advocacy and/or commercial purposes. In these circumstances, it was considered that no reasonable expectation of privacy should exist on the part of the bloggers selected for the study, as they are willingly choosing to publicly share their ideas and personal experiences, thereby making their articles part of the public domain. Therefore, in so far as the study referred to the analysis of materials published online by bloggers, it was not deemed as involving covert observation or intrusion into private aspects of the participants' lives.

Establishing where the public/private line lies became more complex when it came to the content shared by users in comment sections. While there might be an argument that commenters should expect that what they share will end up in the public domain, I was not convinced that all users could have anticipated that their comments would become the subject of an academic study. To err on the side of caution, and respect the principles of beneficence, non-maleficence and confidentiality in research ethics set out by Association of Research Ethics Committees (AREC 2013), it was decided to provide added anonymity safeguards to commenters by paraphrasing their posts (as well as anonymising their identities), to reduce to a minimum the risk that a comment could be traced back to a particular commenter through the use of an online search engine.[80]

Finally, it has been acknowledged that internet-mediated research of any kind may pose a risk of unwillingly interacting with participants who may lack capacity, as it is often practically impossible to

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[80] It is acknowledged that paraphrasing comments may mean that something is 'lost in translation' – however, on balance, I considered that confidentiality had to take priority.

ascertain the identity and particularly the age of those involved. However, because of both the complexity and type of topic involved in this research (critical views on childhood vaccinations) and the 'terms of service' of the blogging platforms which specify that their services are not directed at children and that in order to register users must 'possess the legal authority, right and freedom [...] to form a binding agreement' (see e.g. Wix 2021), it was considered that such risks were sufficiently mitigated so as not to raise particular ethical issues. The unobtrusive nature of this study arguably further minimised the already unlikely possibility of this research negatively impacting children or people lacking legal capacity.

Conclusions

In this chapter, I have offered reflections on the design of this research project and discussed my choice of a qualitative methodological approach, informed by internet ethnography. I have also elaborated on my methods, and particularly on matters of sampling, data collection, and data analysis. In the final section, I explored the ethical questions raised by the study (which include issues common to much qualitative internet-based research) and how I addressed issues emerging in the course of the research process. While my account here has presented the research process as made up of a series of self-contained, consecutive steps, my approach to research has, in practice, been more intuitive and exploratory than this. My research experience has led me to accept what palaeontologist Neil Shubin (2008), who was quoted at the beginning of the chapter, has said about '[f]acts on the ground' being able to challenge 'our best laid plans'. Research choices are not made in a vacuum, but they are always shaped by what is found 'on the ground' or 'in the field' by the researcher – and what is found in the field may not always be what was expected at the outset of a study. In the case of vaccine critics, few things were quite as unexpected as their way in which they engage with science and scientific knowledge, as will be seen in the following chapter.

4

DIY SCIENCE, MISINFORMATION AND FREE SPEECH AMONG VACCINE COUNTERPUBLICS

Introduction

Knowledge-making and knowledge-sharing practices lie at the heart of what vaccine counterpublics do online, making up a key part of the everyday workings of their members' internet-mediated lives. In this chapter, I am going to take an in-depth look into one significant area within which counterpublics collaborate to create vaccine-critical knowledge. This area encompasses what I refer to as sets of 'shared causal beliefs', or 'causal ideas' drawing on Peter M. Haas's notion of the expert 'epistemic communities' (Haas 1992; 2001).

In Haas's framework, epistemic communities are constituted by 'professional' experts, or – as he puts it – '[a] network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area' (1992, 3). However, as I found in my analysis of the blogs, the articulation of causal beliefs also plays a prominent role in the context of day-to-day conversations across the different vaccine counterpublics researched in this study. The special attention paid to issues of *causation* among vaccine counterpublics resembles an epistemic community model in that this shared causal 'knowledge' becomes one of the crucial dimensions orienting vaccine critics' advocacy action. However, the nature of vaccine-critical causal 'knowledge', as well as the practices and values underlying its creation and circulation are unique to vaccine counterpublics, differentiating them from 'expert' epistemic communities, as I will contend in this chapter.[81]

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[81] It should be noted that some authors, such as Peterson (1992) and Akrich (2010), have built on Haas's notion of the 'epistemic community', expanding its meaning to include groups largely made up of non-professional members without an 'a-priori [...] recognised expertise' (see Akrich 2010), such as environmental activists or online-based groups campaigning around childbirth issues. As previously discussed, in this study I have adopted the lens of 'counterpublic' to analyse the activities of internet-mediated vaccine critics, therefore maintaining a conceptual distinction between 'counterpublics' and 'epistemic communities'. I decided to do so because while vaccine counterpublics arguably display an 'epistemic' character and share common 'normative beliefs' based on which they advocate for policy change, they differ from epistemic communities in a number of other significant ways, as will be shown in the course of this work. This chapter specifically explores how (non-professional) vaccine critics have to carry out their knowledge-making activities on alternative media fora, and the unique issues they face because of their reliance of such fora as counterpublics opposing institutional discourses around immunizations.

As I emphasise in the chapter, the special character of online vaccine-critical groups as 'outliar' counterpublics opposing official expert and public health discourses gives rise to novel and unexpected interactions with law and regulation. Because of this, I found counterpublic epistemic activities deserving of in-depth examination in their own right, rather than merely as a way to account for vaccine critics' policy demands and advocacy around issues such as mandatory vaccination. Vaccine counterpublics' special ways of making and sharing 'knowledge', along with the way in which counterpublics react to emerging regulatory restrictions to these epistemic activities will therefore make up the main subject of investigation in this chapter.

But what does it mean exactly to talk about the 'shared causal beliefs' of vaccine counterpublics? To recall Haas's (1992) original definition, shared causal beliefs 'are derived from [epistemic communities'] analyses of practices leading or contributing to a central set of problems in their domain and [...] serve as the basis for elucidating the multiple linkages between possible policy actions and desired outcomes' (1992, 3). For our vaccination critics, the shared causal beliefs grounding their activism and policy demands are represented by a range of alleged cause-effect links between vaccines and a number of severe adverse reactions which they view as having a profoundly negative impact on children's health. Claims that childhood vaccines are the underlying cause of autism, neurodevelopmental disorders, chronic conditions such as asthma or eczema, and even cases of unexplained deaths in children indeed appear in some shape or form across all the blogs analysed in this study.[82] The widespread recurrence and relevance of causal links in vaccine critical talk led me to introduce the general-level code '*causal knowledge*', which encapsulates data relating to the multiple ways in which vaccine critics attempt to assert the existence of a causal link between vaccines and serious harm to children's health.

Previous research looking into vaccine-critical websites has pointed to alleged links between vaccinations and a number of severe adverse events as the most common concern raised by online vaccine-critical groups (see e.g. Zimmerman et al. 2005). The existing literature has also revealed that questions around vaccine 'safety and effectiveness' (Bean 2011) and allegations that vaccines are toxic or unsafe (Kata 2012; Hoffman et al. 2019) are of primary concern for these groups. However, this literature remains exploratory and descriptive, focusing primarily on the content that is being talked about on vaccine-critical websites. In this chapter, I take a different approach. My main aim is to provide an insight into vaccine-critical activism by examining *how* vaccine-related causal claims are

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[82] Text frequency queries conducted on NVivo also seemed to confirm this point, with terms directly (e.g. 'cause', 'caused' or 'causing') and indirectly (e.g. 'research', 'study', 'information', 'effect', 'association') relating to causal knowledge appearing among the most used words in all individual blogs sampled. Searches for the 100 most used words (composed of four letters or longer, with the exclusion of few generic words such as connectors) were conducted for each blog and the results then compared to each other to confirm what had originally emerged as a recurrent theme during the 'manual' coding stage of analysis.

constructed in online talk. In other words, I am interested in looking into what I call the 'epistemic practices' of vaccine counterpublics: the strategies and ideas deployed by vaccine counterpublics to make, support and share their causal beliefs. I believe this type of approach – focused on the dynamics of how critical claims about vaccines are actively constructed, learned and circulated, rather than on the 'static' claims themselves – offers an original contribution to the current literature on vaccine opposition.

In trying to make sense of how vaccine counterpublics construct and share causal knowledge, and the social and legal implications of these knowledge-making processes, the chapter will be organised in four parts. In the first part, I explore how scientific knowledge and narratives of science are framed in online vaccine-critical talk. My preliminary goal here is to challenge pre-conceptions of vaccine critics as an 'anti-science' force by showing that these counterpublics are not merely resisting or opposing science, but rather they treasure it as a precious body of knowledge that they believe can be employed to justify their vaccine-critical causal claims. In the second and third parts of the chapter, I move to analyse the actual epistemic practices of vaccine counterpublics – including the 'DIY' strategies they employ to construct vaccine-critical knowledge in online spaces as well as their 'self-reliance' learning ethos. In the fourth part of the chapter, I focus on how counterpublics are responding to attempts to curb their vaccine-critical epistemic activities on social media platforms through the mobilisation of an expansively re-defined right to 'free speech'. In highlighting how vaccine counterpublics are invoking and recasting the legal notion of free speech to resist the 'health misinformation' policies of social media companies, I hope to bring to light an emerging tension between attempts to regulate online misinformation and the epistemic practices of counterpublic members. It is suggested that such tension may result in the further alienation of vaccine critics, aggravating an already difficult relationship with the state and public institutions.

Vaccine counterpublics as 'pro-science' counterpublics

> Doors opened at 7:30 a.m. and the eager crowd entered the warmth of the building, complied with security screening, and rushed to the fourth floor to line up for the long wait until the 10:00 a.m. hearing. First ten, then fifty, then a hundred, then several hundreds of parents, buoyed by the feeling of fellowship, streamed in to take their place in line, sharing their personal journeys of vaccine injury, healing, recovery, and loss. Those early in line peeked into the hearing room and saw it was set for around 60 people. The first in line were excited to see they would, indeed, be

> upfront and close, able to observe testimony, and also be seen on C-SPAN as bearing witness on behalf of so many who have been harmed by current vaccine policies.
> (Age of Autism (AoA), 11 March 2019).

On March 5th 2019, the U.S. Senate Committee for Health, Education, Labour and Pensions held a hearing entitled 'Vaccines Save Lives: What Is Driving Preventable Disease Outbreaks?' It was a well-attended hearing, with a live recording showing multiple full rows of seats in an ample room.[83] Some audience members can be seen standing up at the back of the room. The hearing opened with remarks given by the Republican Senator Lamar Alexander, who expressed the Committee's concerns about dwindling vaccination rates in certain areas of the country driving local outbreaks of vaccine-preventable diseases. After his speech, the Committee moved to hear the testimonies of a diverse range of witnesses, including the former U.S. Health Secretary John Wiesman, two epidemiology and paediatrics university professors, and the president of the NGO 'Immune Deficiency Foundation', representing immune-compromised patients who are particularly vulnerable to outbreaks of vaccine-preventable diseases.

No vaccine-critical campaigner was invited to testify at this hearing. However, as it emerges from a lengthy account of the event published on the blog *AoA* a few days after it had taken place, the fact that the hearing was being held at all represented an important opportunity for many vaccine-critical parents. Even if they could not have their voices heard by the Committee, they could at least have their presence recorded by the cameras, 'bearing witness' to the broader public on behalf of those who they describe as having been 'harmed' by 'the current vaccine policies'.

The evocation of a stream or a 'crowd' of sympathetic vaccine-critical supporters ('several hundreds of parents') and the reference to 'bearing witness' in the *AoA* blog post quoted above resonate with what social movement scholars della Porta and Diani (2020) have called the activist 'logic of numbers' and 'logic of bearing witness'. From this social movement perspective, the vaccine-critical parents queuing up to attend the Senate Committee hearing may be seen as attempting to seize an opportunity to offer a 'spectacle of numbers' (see Cammaerts 2012), while promoting an alternative, critical reading of the hearing itself. However, according to the *AoA* account, the parent-activists were soon disappointed as they learned that most of the seats in the room had already been 'reserved', and only some fifteen seats 'behind the cameras' remained available for them. As the blog puts it:

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[83] A video recording of the full hearing described by the *AoA* blog is available at: https://www.help.senate.gov/hearings/vaccines-save-lives-what-is-driving-preventable-disease-outbreaks.

> [w]ord quickly spread down the line and the mood began to change. Moms and dads who thought their place in the room was assured by their early arrival realized they would be relegated to an overflow room. Shut out.
> (AoA, 11 March 2019).

This double exclusion from the hearing as well as its video broadcast did not however make the vaccine critics' journey to Washington completely pointless. As the *AoA* post explains, some of the parents were approached by journalists for interviews outside of the hearing room. And as we hear more about these vaccine-critical parents' perspectives, things become particularly interesting for the purposes of this chapter. Indeed, the blog emphasises how:

> [The m]edia approached parents and were given thoughtful interviews which included *peerreviewed* [sic] *scientific data and references to public health's own information*. As parents *thoughtfully and intelligently articulated their reasons* for being there, the reasons for current outbreaks, and their concerns with vaccine safety learned through real life injury of their own children, they wondered if the interviews were in vain. Would the *data and science* be included in coverage of the event? Or would it once again be one-sided coverage spouting the *CDC rhetoric* that vaccines are "safe and effective", "vaccines save lives", and would these concerned parents' words be spliced and diced in an effort to make them look like "*crazy anti-vaxxers*"? The experienced among them had been in this fight too long and suspected the outcome. Still, brave parents approached media and tried to register their concerns and *educate*.
> (AoA, 11 March 2019, emphases added).

This passage is particularly relevant here, I would suggest, as it offers an important insight into vaccine counterpublics and their relation to and framings of scientific knowledge. As is apparent from the post, parent-activists did not head to Washington to merely testify through their presence, or even to share narratives of their children's experiences of 'vaccine injury'. 'Parents', we learn, were there to offer 'peer-reviewed scientific data' and bring up 'public health's own information', to 'thoughtfully and intelligently' raise their own concerns about vaccines and articulate their views of the current outbreaks. In other words, vaccine counterpublics were there to bring '*data and science*' to the table. Nevertheless, *AoA* appears pessimistic about the possibility of journalists taking the 'data and science' offered by parents seriously ('would it once again be one-sided coverage spouting the *CDC rhetoric* that vaccines are "safe and effective...'). Further, the blog's author worries that media coverage would actively distort what was said by parents ('(...)would these concerned parents' words be spliced and diced in an effort to make them look like "crazy anti-vaxxers"?).

In the paragraphs that follow, I would like to shed light on and discuss in greater detail what I see as two key, interrelated dichotomies drawn by vaccine counterpublics which emerge from this vaccine-critical blog passage. The first dichotomy is related to the image (supported by *AoA*) of vaccine critics as parents who are able to reason 'intelligently and thoughtfully' about vaccines by referring to peer-reviewed studies and 'public health information'. This image may be opposed to that of the 'crazy anti-vaxxers' which the blogger fears will be employed by the mainstream media to portray vaccine-critical activists. The second is a dichotomy between the 'data and science' counterpublics rely upon and wish to share with the public and the 'rhetoric' that vaccine critics say is propagated by public health agencies such as the US Centers for Disease Control and Prevention ('CDC').

To better understand these two dichotomies, it should be noted that research on vaccine opposition has tended to assume an underlying ignorance of immunisation science on the part of parents choosing not to vaccinate their children. In doing so, this research espoused the so-called 'deficit model' of science communication.[84] This model has been challenged by other voices in the literature, which adopt the alternative position that 'more information may not prevent vaccine hesitancy' among those who are opposed to vaccines (Getman et al. 2018; see also Mitra, Counts and Pennebaker 2016; Browne et al. 2015). Nonetheless, the 'science deficit' model still enjoys widespread support and is relied upon by some scholarship on vaccine opposition which concentrates on improving the ways in which vaccine information is communicated to the public (see e.g. Hoffman et al. 2019; Gunaratne, Coomes and Haghbayan 2019; Blankenship et al. 2018; Smith 2017). Significantly, this model also dovetails with media reports depicting parents as easy victims of the misleading and 'debunked' information peddled by the 'anti-vaccination movement', particularly on social media. For example, a recent article on *Forbes* titled 'Measles Is Back. Blame The Anti-Vax Movement', pins down parental refusal to vaccinate their children to 'the highly vocal, supremely confident, and utterly misinformed anti-vaccine movement... [spreading] their message daily on Facebook, Twitter, websites, and other media outlets' (Salzberg 2019).

If we return to the above quote by the *AoA* blogger, we can now put in context her emphasis on the intelligence and thoughtfulness of the vaccine-critical activists interviewed outside the hearing room, and on their familiarity with both public health data and scientific articles on immunisation published in

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[84] See Miller (1983) for an early exemplification of this general approach in science communication. The corollary of the deficit model is a top-down, educational style of intervention in cases of 'scientific controversies', in order to close the perceived gap of scientific understanding between 'experts' and 'lay public'. In practice, applied to childhood immunization 'hesitancy', this approach would imply public health institutions becoming more proactive and effective in communicating vaccine science to the public as the main response to vaccine hesitancy.

peer-reviewed journals. This emphasis may be read as a straightforward challenge to media framings of vaccine counterpublics as ignorant and relying on unreliable information casually encountered online. Instead, the blogger asserts that counterpublic members are knowledgeable, and able to read and use credible scientific and institutional sources to justify their claims. At the same time, the blog's concern about activists being represented as 'crazy antivaxxers' can be seen as an indirect challenge of another image often found in media accounts – that of the anti-vaccination movement as radically anti-science.[85]

The media narrative of 'anti-vaxxers against science' that the blog is attempting to challenge is echoed by accounts of the 'anti-vaccination movement' found in medical journals. For instance, in a widely cited article Poland and Jacobson (2011) speak of a 'radical fringe element' of vaccine critics '...who use deliberate mistruths, intimidation, falsified data, and threats of violence in efforts to prevent the use of vaccines and to silence critics' (98). Other voices in the literature place an emphasis on the 'cognitive errors in reasoning, wishful thinking and distortion of reality' which would be expressed in the propaganda produced by a number of anti-vaccine websites (MacDonald et al. 2013, 385). Additionally, Marshall (2013) argues that 'there is a very small minority [of parents] who are absolutely unreachable' by attempts to convince them to vaccinate their children. This picture of 'unreachability' of individuals who are strongly critical of vaccinations ties in with some of the social psychology literature on vaccine opposition, which focuses on personal cognitive 'defects' such as confirmation bias, and concepts such as the 'backlash effect'[86] and 'motivated reasoning'.[87] According to this literature, cognitive biases act as powerful internal forces distorting individual reasoning, and therefore preventing vaccine critics from properly understanding the immunisation science that is being communicated to them.

While these psychology-grounded framings of vaccine opposition are arguably richer and more complex than the ones underlying the 'science deficit' approach, they still imply the existence of an objective gap between 'proper' understanding of scientific evidence on the part of experts and the flawed reasoning processes of vaccine critics. Framings of this kind are vigorously opposed by vaccine counterpublics themselves. Indeed, the contrast drawn by *AoA* between the scientific knowledge possessed by vaccine-critical campaigners and the 'CDC rhetoric' depicting vaccines as safe and effective ('vaccines save lives') turns these framings on their head by painting a picture of vaccine critics as well-informed and intelligent actors facing institutions which are not willing to engage in a

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[85] Vaccine critics have been variously called fanatic (Hiltzik 2014b), irrational (Mooney 2014; Hanley 2017), and anti-science propagandists (Tran 2019) by the media in recent years. The 'anti-vaxxer parent' has also been much parodied in recent public commentary, for example through portrayals of 'anti-vaccination' mothers as – among other things – entitled, anti-science, and 'essential-oil using' (see Romano 2020; Bhuyan 2020).

[86] On the 'backlash effect' in a vaccination context, see Nyhan et al. (2014).

[87] For a concise synthesis of the literature on misinformation and 'identity-protective cognition' see Kahan (2017).

conversation about the 'science', and are instead resorting to 'rhetoric' to shut down opposing voices. In this sense, there appears to be an attempt by vaccine counterpublics to turn the tables on media and public health representations by portraying activists as the ones who are rational and embracing science, and expert institutions as illogical and misguided. This picture is summarised and further supported by this concluding episode narrated in a vividly dramatic tone:

> The gavel dropped and the meeting was brought to an end. The few parents packed in to the back row stood up in a daze, incredulous at what they had just witnessed. While being closely followed by Capitol police as a potential threat, a petite mom from Washington State attempted to talk with Secretary of Health Wiesman about why he had not mentioned the failure of the DTaP vaccine, or the mumps vaccine, or that the flu vaccine does not prevent mucosal infection and so cannot contribute to herd immunity. *She brought up science*, *not hyperbole*, but Wiesman ignored her and was ushered out a side door. She was shut down and shut out. Several moms approached media who lined the rooms and offered to be interviewed, to provide *scientific reasons* for infection outbreaks and vaccine hesitancy. They were met with bowed heads and ignored. Shut out.
> (AoA, 11 March 2019, emphases added)

Vaccine critical parents – 'petite moms', not 'crazy anti-vaxxers' – are therefore described as providing valid reasons, and specifically '*scientific reasons'* to ground their explanations of 'infection outbreaks and vaccine hesitancy'. Yet, the blogger states, despite activists 'bringing up *science*, not *hyperbole*', they are being 'shut down and shut out' by public institutions and the media.

Scientific knowledge is emphasised multiple times throughout the text as the true driver of vaccination hesitancy and opposition. But is this emphasis on scientific knowledge shared across different vaccine counterpublics? As I delved into vaccine-critical talk online, I came across multiple invocations of 'science' and 'scientific evidence' to back up what is considered by activists as a science-based critique of childhood vaccines and vaccination programmes. Compared to appeals to direct experiential knowledge, which are mostly found in posts on *AoA* (the only vaccine-injury advocacy blog in my sample), scientific knowledge is evoked across the spectrum of vaccine counterpublics as a basis – in some cases, the most important one – to support vaccine-critical claims. For example, in an open letter directed to New Jersey governor Phil Murphy, a *Fearless Parent* (*FP*) blogger underscores how, as a vaccine-critical advocate, she spent thousands of hours studying the issue of childhood vaccine safety, including the 'peer-reviewed scientific research':

> [As someone] with an Amazon bestselling vaccine book (and a second book on its way) who spent over 10,000 hours studying this issue and interviewing experts as if my children's lives depended on it — because they did — I can tell you that there is both *ample peer-reviewed scientific research* and substantial clinical experience raising grave questions about the wisdom of the US childhood vaccine program and offering insights into biological mechanisms of vaccine injury and the link to the devastating chronic, autoimmune, and neurodevelopmental disorders plaguing our children. Yes, autism. Also yes, ADHD, allergies, asthma, arthritis, and that's just the A's. There's a lot more.
> (FP, 11 June 2018, emphasis added)

This extract has similarities with the *AoA* blog post referred to above, as in both cases the bloggers appear to claim a form of 'lay expertise' (see Epstein 1995) on vaccines, either for themselves or for other vaccine critical activists. Crucially, it is claimed that this 'lay expertise' has been developed through close and thorough reading of the relevant scientific literature.

As previously mentioned, all of the blogs analysed in this work contain references to scientific knowledge and, in one way or another, they all contend that science ultimately supports their causal beliefs around vaccine injuries. A comment on *AoA* synthethises this idea well by stressing that vaccine critics have 'facts' and 'science' on their side. But perhaps the strongest endorsement of science as the single most important tool in the hands of vaccine critics comes from the blog *Vaccine Papers* (*VP*), which curates a digital library of vaccine-critical research which is stated to provide 'detailed, science-based and objective information about the dangers of vaccines' (VP ('About'), n.d.). Not only does this blog rely on scientific research to make its claims about vaccines (something I will discuss in further detail in the following section of the chapter), but it explicitly defends an ideal of scientific ethos which is reminiscent of 'traditional' Mertonian norms.[88] In its 'About' page, *VP* highlights, for instance, the importance of respecting the norm of universalism in science – that is the principle that scientific validity should be determined independently of the personal attributes of the individual making a claim (Merton 1973, 270). In fact, while defending the decision to keep the blog anonymous, *VP* condemn the 'lazy, intellectually vapid practice of "argument by authority"' they view as widespread among 'vaccine advocates', and emphasise that 'all that matters' is 'the science and the evidence', regardless of who is speaking:

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[88] The Mertonian norms are 'four sets of institutional imperatives' which, according to sociologist Robert K. Merton (1973), 'are taken to comprise the ethos of modern science': these are 'universalism, communism, disinterestedness and organized skepticism' (270).

> Scientific ideas and opinions must be judged by the evidence, not according to whether the source is perceived as an "authority". All that really matters is the science and the evidence. To determine if VP is trustworthy, all you have to do is consider the opinions on these pages in view of what the science says. Then do the same for the CDC, WHO, AAP and other so-called "authorities".
> (VP, 'About', n.d.)

Similarly to the views expressed on *AoA* and *FP*, for *VP* it is not vaccine critics who are ignorant of science or ideologically opposed to scientific knowledge, rather it is medical institutions and 'the mainstream media' which are ignoring existing scientific evidence pointing towards the injuries caused by vaccines. A different position on this point might be expected from the alternative health blogs, as certain complementary and alternative medicine (CAM) perspectives are known to disavow the scientific paradigm of 'evidence-based medicine' (EBM), and instead rely on systems of 'knowledge' developed by 'alternative' health traditions and philosophies. Indeed, it has been argued that it might be inappropriate to expect alternative medical practices to conform to the epistemological standards of EBM. As Tonelli and Callahan (2001) have put it '[t]he epidemiologic epistemology of EBM fits relatively well with the biophysiologic theory of disease associated with orthodox medicine, but may not be coherent with other theories of disease and healing' (1214).

Interestingly, however, even the blogs focused on alternative health and alternative medical discourses in my sample regularly make claims that their vaccine critical stances are based on scientific, evidence-informed grounds. For example, the blog *Living Whole* (*LW*), whose founder is a certified naturopath, maintains that it would be an error to think of vaccine critics as opposed to modern medicine as a matter of principle:

> It is flat-out false that parents who don't vaccinate have an aversion to modern medicine. [...] Parents who don't vaccinate opt out because they only believe in *sound medicine* that *has been proven* to be safe or effective. Vaccines have not been proven to be safe and effective and fail to meet the standards for *evidenced-based medicine*. It's really THAT simple.
> (LW, 5 November 2018, emphases added)

Along the same lines, the multi-author blog *Alliance for Natural Health International* (*ANHI*) – which has ties to the nutraceutical, supplements and 'natural health' sectors – defines its mission in relation to the production and circulation of scientific knowledge. This may be glimpsed, for example, in the (undated) 'Research' section of the blog, which explains how as a '[a]s a non-profit, [ANHI] continually engage in research that helps us to understand the science and law that underpins natural and sustainable approaches to health care and health creation' (ANHI 'Research', n.d.). In the same 'Research' page, the blog lists a number of reports and scientific articles by ANHI-affiliated authors which emphasises how these had been 'published in the peer reviewed literature'.

On the other hand, an overview of ANHI's positions on issues of evidential standards reveals a more conflicted relationship with science than other blogs in the sample. Compared to other blogs, on ANHI contains more critical views of scientific standards of evidence. This may be seen, for example, in occasional critiques of the evidential 'golden standards' of EBM – that is large epidemiological studies and randomized controlled trials – particularly in the field of nutrition, highlighting how these kinds of studies suit 'the likes of Big Food and Big Pharma' (ANHI, 20 June 2018). According to this perspective, clinical experience is preferable to randomised controlled trials and epidemiological studies in supporting claims about health. This perceived opposition between the 'evidence-based' model of medicine and clinical experience is a theme that appears on ANHI but is not prominent in other blogs.

Among all of the blogs I sampled, *AoA* is arguably the one which places the greatest value on direct experiential knowledge of vaccine injury, and specifically parental experience (which is unsurprising given that most of its bloggers identify as parents of children harmed by vaccines). The general perspective embraced by *AoA* is that the individual experiences of parents with their children's health should be considered an important source of causal knowledge on vaccines and their effects. As one blogger puts it,

> Facts about vaccines can't just come from a scientific book, journal, or study. While professional input has its place, credible information can also come from those who didn't make it on the panel of vaccine experts that your medical provider is telling you to listen to. Information could very well come from a human, including from the parent of a child who was injured post-vaccination.
> (AoA, 20 May 2018)

However, scientific 'evidence-based' knowledge is generally presented by *AoA* bloggers not as in opposition to, but rather as supporting parental experience. This perceived consistency between scientific and experiential knowledge may be glimpsed in the extracts of the blog post cited at the beginning of this section, which referred to both 'concerns with vaccine safety learned through real life injury of [...] children' and 'peer-reviewed scientific data and references to public health's own information' as valid sources of information on vaccine dangers (AoA, 11 March 2019). In about a dozen posts on the same blog, bloggers and commenters also defend their vaccine-critical position as the one that is actually consistent with the available 'science' about vaccine injuries, and in an interesting reversal of dominant public discourses, they do so by framing their opponents as the true science 'denialists'. Other posts, especially on *AoA*, support the idea that official claims about vaccine safety are not 'real science'. In particular, comments on *AoA* challenge the notion of 'scientific consensus' in relation to vaccine safety, claiming that invocations of this consensus are in reality an example of 'scientism' or 'totalitarian pseudoscience'. Bloggers contrast this official 'pseudoscience' with their more 'sophisticated' and 'accurate' conceptualisations of scientific knowledge as something which is constantly evolving. As a blogger puts it while talking about vaccine debates: '[n]o scientific matter is ever closed, and particularly not this one' (AoA, 18 February 2019). A post on the *LW* Facebook page also invokes this framing of 'real' science as an ever-evolving process, referring to changing medical opinions on the use of aspirin for the prevention of cardiovascular issues in order to make the point that 'the science is never settled'.

In addition to this, as will be discussed in more detail in the next section of the chapter, one of the main functions of the vaccine-critical blogs sampled in this study is to provide counterpublic members with the 'research' necessary to publicly support claims that vaccines are harmful. Indeed, even for vaccine-critical parents who already 'know' that vaccines are harmful through their personal experiences, references to 'hard' scientific evidence may be helpful in certain circumstances, for example if challenged about their family vaccination choices during a doctor's appointment. In an *AoA* post, for example, a blogger speaks about an occasion when she ended up having to 'educate' a 'young medical professional who grew up outside of the United States' in order to try to change her mind on vaccine safety (AoA, 24 June 2018). Having references to 'the science' ready to use may also prove useful in the event of a vaccine debate with an online stranger – or an internet 'troll', to use a term from another *AoA* post – who might cast a doubt on the truth of the claims made by vaccine-critical parents. As this blogger puts it,

> When you engage [in an online debate], you're already armed with enough facts the most important one being your and your child's first-hand experience. Having citations and some literature to reference seems to carry some weight when someone demands you to "Prove It!" [...]
> (AoA, 3 February 2019)

The scientific literature can therefore become a key resource drawn upon by vaccine critics to outwardly validate their personal experiences of vaccine injury. The role of experiential knowledge in orienting counterpublics' judgments about the reliability of particular sources of vaccine-related information is something that will be explored in-depth in a later chapter of this thesis. For current purposes, it is sufficient to note that even when vaccine counterpublics place considerable importance on experiential knowledge, their members do not outright reject scientific, expert evidence as a matter of principle, but instead value and refer to it regularly in their own online talk in order to justify their claims.

In the 'alternative health' blogs, as discussed above *ANHI* in particular does seem to frame EBM as less reliable than clinical experience. On the other hand, *ANHI* bloggers routinely refer to scientific research (including epidemiological studies) in order to support a range of claims, from ones relating to their main focus on nutrition and health optimisation, to those supporting vaccine-critical positions. For instance, a document containing 'selected references' linked to a 2017 post in support of *ANHI*'s recommended dietary guidelines lists almost one hundred articles from a number of peer-reviewed scientific journals. In another instance, *ANHI* bloggers argue that '[h]ealth authorities are misleading the public when they imply that HPV [Human Papilloma Virus] vaccine confers protection against cervical cancer' (ANHI, 8 November 2017). This argument relies, among other things, on the bloggers' claim that HPV does not represent a major risk factor for cervical cancer. 'HPV,' *ANHI* bloggers write, 'is a transient infection and 90% of HPV infections resolve naturally within 2 years without vaccines or other medical interventions' (8 November 2017).

To support this latter claim, the blog article links to a study published in the scientific journal *PLoS One* which uses the results of a large, randomized clinical trial funded by the pharmaceutical company GlaxoSmithKline (GSK) to investigate the risk of developing cervical intraepithelial neoplasia (or 'CIN', which is a possible precursor to cervical cancer) following cervical HPV infection (see Jaisamrarn et al. 2013). While this study found that cervical HPV infection increases the risk of developing certain types of pre-cancerous lesions, it does indeed include a statement that 'HPV infections are usually transient, and even those that persist for a few months are usually cleared naturally' (2013, 2). As Smith (2019) points out, on the other hand, infection with HPV is very widespread in the population (more than 80% of sexually active individuals are estimated to acquire an infection in the course of their lives), which means that many individuals will still develop persistent HPV infections which can lead to pre-cancerous cervical lesions.[89] By preventing the formation of pre-cancerous lesions, the HPV vaccine reduces the need for the more painful and stressful surgical procedures used to remove these lesions (2019). What I would like to emphasise here, however, is not the validity of vaccine-critical argument itself, but the fact that the bloggers have decided to use science

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[89] For a recent systematic review and meta-analysis on the population-level impact of HPV vaccination programmes see Drolet et al. (2019).

– and, perhaps even more surprisingly, a study based on the results of a clinical trial sponsored by a major pharmaceutical company – to support their claims.

This strategic use of scientific research to challenge the need for childhood immunisations can also be found in the UK-based blog *Vaccination.co.uk* (*VCUK*). In the same way as *ANHI* bloggers challenge the usefulness of the HPV vaccine by downplaying the risk of developing cervical cancer following HPV infection, *VCUK* represents measles – another vaccine-preventable disease – as a 'mild infection', which poses little risk to children. Writing about his personal experience appearing on a TV talk-show with a medical doctor, the blogger recalls anticipating that he could be challenged about his personal views on measles in the course of the show. In a blog post, he recounts how he came prepared to back up his views by carrying with him two pages from a British Medical Journal article:

> [...] I had brought 2 pages from the British Medical Journal from February 1959 and pulled them out of my pocket. [The guest doctor] knew where I was going with this and dismissed my reference as "out of date", which got a laugh. The point being; this Journal was published during a massive measles epidemic, there had been 41,000 cases reported in January and no fatalities or serious adverse events reported, just kids getting measles, as [the doctor] and I had it in the 50s. (VCUK, 21 August 2018)

Although this blogger's strategy did not appear to play out particularly well during the televised debate, it is illustrative of the style of argumentation vaccine counterpublics pursue online. This involves the re-use and re-purposing of scientific research – with particular value placed on 'peer-reviewed' publications – to support vaccine-critical points. The re-purposing of scientific knowledge in vaccine-critical talk is then the expression of a trend not just limited to specific blogs such as *ANHI* and *VCUK*, but cutting across all of the vaccine counterpublics researched in this study. Along with the positive attitudes towards science and the scientific method encountered in previously quoted extracts, this suggests that scientific knowledge – especially research published in scientific journals, but also information found on the institutional websites of public health organisations and health agencies, clinical practice and health professionals' opinions – is not reviled or rejected *per se* by vaccine counterpublics. On the contrary, the general feeling that resonates throughout the counterpublics is that '*real* science is on our side'; that *if only* institutions, the media and the general public were willing to listen to the scientific evidence carefully collected and shared by counterpublics they would realise vaccine critics have been right all along. In a way, this perspective looks like the mirror image of the 'science deficit' model – which is perceived by vaccine counterpublics to affect policy-makers and the broader 'mainstream' public.

The use of technical-scientific knowledge as a way to challenge expert and medical establishments is not a new phenomenon. In his seminal work discussing different kinds of activism challenging scientific authority, sociologist Steven Epstein (1996, 12-13) has distinguished between four typologies of movements. The first typology is essentially negative in character and confined to the expression of distrust towards expert knowledge – Epstein here gives the example of anti-fluoridation movements: ‘we don't believe you when you claim that fluoridation is harmless’ (13). The second type of movement is more active in identifying and promoting the views of experts who support their particular political or ideological stances. Epstein here refers to movements underestimating the threat of greenhouse gases, but other examples could be interest groups denying man-made climate change and pro-tobacco ‘astroturf’ organisations (see Oreskes and Conway 2010; Russell 2019, 211). The third typology is perhaps the most radical, comprising movements which outright reject that ‘scientific ways of knowing’ give rise to a superior form of expertise, and favour other modes of knowledge or ‘epistemic standpoints’ – this could be the case with certain advocates of ‘New Age’ philosophy or mysticism (see Epstein 1996, 13). The fourth typology consists of movements which are not simply distrustful, cynical or ‘anti-science’ but, as Epstein puts it, ‘try to stake out some ground on the scientists' own terrain’, seeking ‘to perform science by locating themselves on the inside’.

The activists in this latter kind of movement undergo a process of ‘expertification’: ‘[m]ost fundamentally,’ Epstein writes, ‘they claim to speak credibly as experts in their own right—as people who know about things scientific and who can partake of this special and powerful discourse of truth’ (1996, 13). Among these activists, we can include citizen-scientists assessing environmental health risks and involved in what Brown (1992; 1997) has called ‘popular epidemiology’, as well as the AIDS activist groups researched by Steven Epstein himself (1995; 1996). While acknowledging that the boundaries between these categories may sometimes be blurred in practice (for example, vaccine counterpublic members on a blog like *AoA* value both epidemiological studies *and* individual parents’ experiences), it could be argued that vaccine-critical activists mainly belong to this latter category of activism. Their use of knowledge is not limited to appeals to a few sympathetic experts, or anti-vaccine ‘champions’, as is sometimes implied by the literature (see e.g. Marshall 2013). Rather, in the process of navigating immunisation science and evidence, vaccine counterpublic members become active participants in the making (and sharing) of vaccine-related ‘knowledge’.

Vaccine counterpublics’ epistemic practices position them somewhere in-between ‘professional’ experts and the lay public, involving counterpublic members claiming credibility and legitimacy as kinds of ‘quasi-experts’. In this regard, a commenter on *AoA* draws a parallel between vaccine-critical groups and ‘citizen scientists’ in fields like astronomy and ornithology who, the commenter argues, have had a key role in the ‘advancement of knowledge’. By referring to vaccine-critical collectives as ‘citizen scientists’, this counterpublic member is effectively identifying vaccine critics as part of a long tradition of individuals who, despite not having received formal education and training in a particular scientific discipline, have nevertheless made important contributions to that discipline.

This framing of the epistemic role played by counterpublics as beneficial to society is not confined to *AoA*, but can be found across the spectrum of sampled blogs. I have already mentioned how *ANHI* present themselves as a non-profit whose mission involves engaging in ‘research’ focused on ‘sustainable approaches to health care and health creation’ (see ANHI ‘Research’, n.d.). *VP* also seem to conceptualise their role as actors bridging the gap between vaccine critics and the general public by making (vaccine-critical) ‘scientific knowledge’ accessible to a wider audience:

> What’s needed today is an explanation of the science for intelligent non-specialists, showing how the scientific results together to tell a story [sic]. We reach a much larger audience this way. Also, a blog allows instant updating as the science progresses. And a blog can include a diversity of topics and connect them in ways impossible to do in a scientific paper.
> (Vaccine Papers, ‘About’, n.d.)

It is important to note that, as it emerges from the above extract, vaccine counterpublics do not imagine themselves as a direct alternative to scientific publications, but more as intermediaries engaged in the task of collating, explaining and circulating expert knowledge among the lay public. Of particular significance is how *VP* here differentiate between the kind of hyper-specialised knowledge offered by ‘scientific papers’, and the ‘story’ that can be told in vaccine-critical blogs by finding connections and threading together multiple scientific ‘topics’ and research findings. This ‘quasi-expert’ role claimed by counterpublics has to be constantly defended and justified, especially in light of the weight of scientific research which establishes that there are no connections between vaccines and the chronic health conditions counterpublics causally link to immunisations.[90] This raises further questions around the precise nature of the kind of ‘scientific knowledge’ that counterpublics are referring to in their online

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[90] In ‘Pediatric Infectious Diseases Revisited’, for example, Dittmann (2007, 80) states that adverse events linked to vaccinations are so rare that vaccines are considered ‘among the safest tools of modern medicine’ (see also Smith and Woods 2010; Institute for Vaccine Safety at John Hopkins Bloomberg School of Public Health (IVS) 2018; Klein et al. 2015). In 2012, the Institute of Medicine (IoM) has published a review with a comprehensive list of vaccine-related adverse events (see IoM 2012). Aside from anaphylaxis (a severe allergic reaction) the most serious neurological adverse events with enough evidence supporting a link to vaccines mentioned in the review are measles inclusion body encephalitis – a rare form of encephalitis linked to the measles virus – only for immunodeficient individuals receiving the MMR vaccine (which is why the MMR vaccine is not recommended for patients with certain forms of immunodeficiency), and viral meningitis for the varicella vaccine. These conditions do not seem to form a specific focus of the vaccine-critical talk analysed in this study.

talk as supportive of their claims, and the ways in which this knowledge is both constructed and circulated. I will attempt to deal with these questions in the following two sections of the chapter.

Constructing 'DIY science': the knowledge-making praxis of vaccine counterpublics

Media discourse on vaccine controversies in recent years has paid considerable attention to a study conducted by the former London Royal Free Hospital gastroenterologist Andrew Wakefield and his colleagues (Wakefield et al. 1998). In the study, a small-size case report published in *The Lancet*, Wakefield et al. had hypothesised a link between the combined MMR vaccine and a 'new syndrome', a form of 'regressive autism' accompanied by gastrointestinal symptoms. The study had a tumultuous history, receiving wide media attention after publication and leading to a sharp decrease in MMR vaccination rates (De Stefano and Chen 1999), as well as to subsequent measles outbreaks in the UK and the US in the late 2000s (Eggertson 2010). Once published, the study also triggered an almost immediate response on the part of the scientific community, as multiple epidemiological studies were conducted and published in short succession refuting the alleged connection between MMR and autism (see Rao and Andrade 2011). Eventually, in 2010, the Wakefield study was retracted from *The Lancet*.

Shortly before the retraction Wakefield, alongside two of his co-authors, had been found guilty of serious professional misconduct and struck off the medical register by the General Medical Council (GMC) for reasons relating to research ethics (including conducting clinically unnecessary examinations on some of the *Lancet* study children) and financial conflicts of interest (see GMC 2010). Despite this, Andrew Wakefield remains to this day a credible epistemic authority for at least some vaccine counterpublics. *AoA*, for example, has come out in defence of Wakefield on multiple occasions. Particular attention has been devoted to a 2012 High Court judgment reversing the original GMC decision with respect to one of Wakefield's colleagues.[91] This decision is referred to by *AoA* bloggers in order to depict Wakefield as a victim of injustice by the GMC:

> The findings of the GMC in respect of the paper were rejected by the High Court in 2012 in the appeal of Wakefield's senior colleague, Prof John Walker-Smith [...] This decision were not appealed by the GMC [sic], which remained party to injustice by not amending the findings against Wakefield or his other accused colleague Prof Simon Murch.

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[91] [2012] EWHC 503 (Admin).

> (AoA, 30 July 2018)

This ongoing, strenuous defence of Wakefield and the *Lancet* study years after the retraction of the article and the GMC decision to strike its authors off the medical register reveals how the publication of this study constituted a crucial moment for vaccine counterpublics aiming to achieve institutional-expert validation. This is especially true for those counterpublics which, like *AoA*, are linked to parental organisations which frame autism as a 'vaccine injury' (see also Baker 2008). Since Wakefield et al. (1998), a few other studies alleging links between vaccines and neurodevelopmental disorders have been published in peer-reviewed journals (see e.g., Geier and Geier 2003; Tomljenovic and Shaw 2011; Mold et al. 2018). None of these studies have enjoyed the same public resonance as Wakefield's 1998 study, and none have been published in major generalist medical journals such as *The Lancet*. Nonetheless, scientific research of the 'Wakefield' kind – that is, research *directly* concerned with connecting vaccines to chronic health conditions (and, most frequently, neurodevelopmental disorders) represents perhaps the most valued form of scientific evidence among vaccine counterpublics.

The most prominent post-Wakefield example of this type of research is perhaps represented by the work of Professor Christopher Exley (a co-author of the Mold et al. 2018 study mentioned above). A professor of bioinorganic chemistry at Keele University, Exley is a strong proponent of the hypothesis that aluminium salts present in certain vaccines as adjuvants (a category of ingredients used to increase the immune response produced by vaccines) may cause brain injury. Exley's work linking aluminium in vaccines to injury is a major epistemic source informing the vaccine-critical claims set out in *VP*. As noted in the 'About' page of the blog:

> Vaccinepapers.org provides detailed, science-based and objective information about the dangers of vaccines. We are most concerned about aluminum adjuvant toxicity and immune activation-mediated brain injury. Vaccinepapers.org is the first to make this hugely important scientific research accessible to the public.
> (VP, 'About', n.d.)

Studies by vaccine-critical researchers (who tend to be marginal, 'outlier' voices in the field of vaccination research) linking certain vaccinations to specific conditions are of particular importance for counterpublics as they can be cited directly as 'evidence' that vaccines are harmful. However, the largest section of 'scientific evidence' incorporated in vaccine-critical talk (with the exception of *VP*, which deals almost exclusively with Exley's research) is not represented by this kind of 'direct' vaccine harm research, but rather consists of *indirectly* relevant research, that is non-vaccine-specific research. This includes studies that do not mention vaccines at all, but then are recontextualised by counterpublics in order to make claims regarding links between vaccines and chronic health conditions appear more plausible. An example of research used to *indirectly* suggest that vaccines are unsafe is general research about metal toxicity or poisoning, which features heavily in 'alternative health' counterpublic talk. For instance, in their 'Vaccine Choice Campaign' page, *ANHI* argue that:

> A reasonable guesstimate of the truth that will no doubt eventually emerge is that MMR is a minor factor in precipitating autism, or perhaps just a common "last straw", but that toxins, particularly but not only *mercury preservatives* in vaccines, are a major factor.
> (ANHI, 'Vaccine Choice Campaign', n.d., emphasis added)

While there are no direct references to any peer-reviewed articles in this passage, the page ends with a series of links which the *ANHI* author indicates will show 'just what mercury can do to nerve cells, and at minute dosages'. One of the (now broken) links on the page used to direct readers to a webpage from the University of Calgary which contained references to research and media resources on mercury toxicity. The link between mercury, autism and vaccines has historical roots in the hypothesis that autism can be etiologically explained as a form of poisoning from thimerosal (or thiomersal), a mercury-based preservative compound contained in very small doses in certain vaccines.[92] Interestingly, the thimerosal/mercury-autism hypothesis originally came from early autism parental-support groups, and not from 'divergent' medical researchers such as Wakefield. As Baker (2008) explains:

> It was in fact a group of parents of autistic children [...] who first seized upon thimerosal as an explanation for the autism epidemic. In keeping with their identity as participants in shaping research, some spent long hours on the computer or in libraries researching studies on mercury. Eventually, their efforts led to a published study in *Medical Hypotheses* that compared the features of autism to various signs reported in past studies and case reports of mercury exposure.
> (2008, 250)

We have encountered these parental groups before in Chapter 2, and I will come back to them again when dealing with issues of epistemic trust and accountability in Chapter 7. For our purposes here, these groups could be considered as important precursors to current counterpublics. The practice and outputs of these early 'lay researchers' still reverberate in the work of current online vaccine critics.

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[92] It has to be pointed out that ethylmercury – the form of mercury contained in thimerosal – is a different chemical compound than methylmercury which is found, for example, in fish, and that is considered toxic at lower doses. In a statement on thiomersal, the WHO has declared that there is 'no reason on grounds of safety to change current immunization practices with thiomersal-containing vaccines, as the risks are unproven' (WHO 2006).

Indeed, despite having been comprehensively refuted by evidence-based research, the mercury-thimerosal-autism hypothesis developed by parental groups is still influential among some counterpublics, especially those in the 'vaccine injury' community.[93] For example, *AoA* bloggers have put together a list of more than one hundred studies purportedly supporting the existence of a causal link between vaccines and autism. Many of these studies consist in environmental science or biological research on the toxic effects of mercury. However, this research mostly refers to elemental mercury or methylmercury, as opposed to ethylmercury, which is the actual compound used as a preservative in vaccines.

Rather than evidence that vaccines critics are confused or ignorant, I view the inclusion of this kind of indirect, 'peripheral' research among the scientific resources and in commentary found on blogs as indicative of how vaccine counterpublics generally approach scientific knowledge. As previously discussed, the counterpublics researched in this study consist, by and large, of non-experts. Their members do not claim to be engaging in laboratory or clinical research. Furthermore, they are not involved in clinical trials as patients - as opposed, for example, to the AIDS activists described in Steven Epstein's work as 'lay experts'. Vaccine counterpublic activities instead mainly involve collating, discussing, interpreting, commenting on, sharing, critiquing and circulating research – simultaneously consuming what they consider to be valid scientific evidence of a causal link between vaccines and chronic health conditions, and reproducing a collective vaccine-critical knowledge shared across different counterpublics.

What I am suggesting here is that *ANHI*'s links to academic materials or *AoA*'s collection of scientific studies on the toxicity of different forms of mercury may be understood as an appropriation of pre-existing research, which is introduced into a completely different context from that envisaged by the original authors. This attitude towards not just passively consuming, but actively remaking existing resources which are found, 're-purposed' and re-circulated by counterpublics may be recognised as a familiar form of agency by scholars of internet publics. Media scholar Mizuko Ito (2008), for example, has provided a well-known definition of publics as 'reactors, (re)makers and (re)distributors, engaging in shared culture and knowledge through discourse and social exchange as well as through acts of media reception' (3). Similarly, according to Atton (2004):

Alternative media have been powerfully characterised by their potential for participation. [...] Producers of alternative media can be thought of as re-positioning themselves from a more or less passive

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[93] It is worth noting that some *AoA* bloggers, including one of the blog's founders, were involved in these early parental autism support groups.

audience (pace Fiske), consuming the output of mainstream media, to become media producers themselves. (9)

Production of alternative media is not restricted to critical or radical publics. In fact, 'participation' ties in with the more general notions of 'prosumer' (Toffler 1980) and 'value co-creation' (see, e.g., Humphreys and Greyson 2008). These in turn have been linked to broader, socio-economic processes through which 'the consumer becomes the producer' (Nevitt and McLuhann 1972, 4 quoted in Ritzer, Dean and Jurgenson 2012). As 'immaterial' labour and the production of 'immaterial' resources has increased in prominence, so have the industries which George Ritzer, Paul Dean and Nathan Jurgenson (2012) have defined as 'primarily about the production of ideas' – such as software, marketing and advertising. 'Since immaterial production takes place in the realm of ideas,' Ritzer, Dean and Jurgenson argue, 'and these ideas are part of what is called the "general intellect," it becomes increasingly possible [...] for consumers to draw on this general fund of knowledge and information. As they draw upon—or consume—this knowledge, they produce and further contribute to it' (383).

Research done on this kind of 'production by consumers' has often focused on commercial phenomena such as consumers creating meanings and value around brands (see for example Ardvisson 2005). However, this process is, I would argue, also what lies at the heart of vaccine counterpublics' relationship with scientific knowledge. Real immaterial labour goes on behind the scenes across all of the sampled blogs in the making of 'science-based' knowledge from the 'raw materials' of peer-reviewed studies, science reports in the media and institutional websites of public health organisations and universities. All the blogs in my sample contain links to at least some peer-reviewed studies found in online repositories such as PubMed or online publisher websites. These studies are in a few cases conducted by vaccine-critical scientists, such as the Wakefield and Exley studies (which are both cited in the *AoA* 'scientific resources' list). To provide another example, a *Living Whole* post contains a link to a study titled 'Pilot comparative study on the health of vaccinated and unvaccinated 6- to 12- year old U.S. children' (Mawson et al. 2017). This study was retracted from two different scientific journals before a version of it was republished by the open access publisher OA Text (OAT). The *Living Whole* reference to the Mawson study is included in the following paragraph (the link is underlined in-text):

> ...the data shows that unvaccinated children are healthier and have a lower incidence of chronic disease than vaccinated children. They require less medical care, prescription medications, and antibiotics, have lower incidences of ear infections, seizures, autism, neurodevelopment disorders, eczema, and ADHD, and have more robust immune systems.
> (Living Whole, 5 November 2018)

Where the blogger is referring to research that is directly critical of vaccines, the counterpublics' immaterial labour is minimal, as they simply provide a link to an article that can be used to support a vaccine critical claim. However, as seen above, most of the analysed blogs also refer and link to scientific research which is not directly relevant to or critical of vaccines, and has to be more or less reworked by counterpublics as part of their epistemic activities. From a counterpublic member's perspective, this is still legitimate scientific knowledge, '...only often viewed from a different critical angle or simply just highlighted in a different context', as an *AoA* blogger puts it.[94] An example of this could be the re-purposing of research relating to mercury toxicity examined above. In other cases, counterpublics re-work research even more comprehensively, producing their own original 'research' in the process. This is the case with *VP*, which uses the research on aluminium and autism conducted by Exley and, as it were, 'remixes' it, combining it with other scientific studies to reinforce its own belief that levels of aluminium 'in autistic brains' are likely to be significantly higher than in the average population:

> If Al adjuvant is responsible for much of the rise in autism, then autistics should have elevated brain aluminum levels. A new study (Mold et al 2017) by Dr Chris Exley's research group provides the first-ever measurements of aluminum in autistic brains. *In this article I show that the aluminum levels in autistic brains are abnormally high.* Brain aluminum concentration is highly nonuniform, whether the brain is healthy or diseased. Adjacent brain regions can have dramatically different Al concentrations. Consequently, many measurements and statistical methods are necessary to determine if aluminum is elevated or normal...
> (VP, 10 April 2018, emphasis added)

In the examples shown in this section, we can therefore observe a 'spectrum' of vaccine counterpublic epistemic activities involving scientific knowledge, from simply providing links to existing vaccine-critical studies, to more intensive 'DIY science' reworkings involving research not directly related to vaccines. The term 'DIY' is used purposefully here, as I would like to shed light on what I view as an important area of overlap between vaccine opposition and DIY cultures, particularly those involving the production of alternative media. Specifically, when I describe vaccine counterpublic members as engaged in the 'remaking' of scientific knowledge my aim is to draw a connection with what have been defined as 'maker cultures'. These cultures can be seen, Chidgey (2014) suggests, as 'strategic processes

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[94] The quote is from a statement submitted by *AoA* as evidence to the House of Commons Select Digital, Culture, Media and Sport Committee 2017 inquiry into disinformation and 'fake news'. The statement is available online at: http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/digital-culture-media-and-sport-committee/fake-news/written/73097.html (last accessed on April 11, 2022).

through which people reclaim power in their everyday lives' (104). Maker identities, she contends, are not necessarily subcultural and are 'in ascendance more broadly in recent times, with the emergence of ICT technologies and Web 2.0 platforms' (104).

Empirical research on DIY practices has found how achieving a sense of empowerment is an important source of motivation for people who become makers (see Wolf and McQuitty 2011). This also seems to be the case for vaccine counterpublic members. As a regular *AoA* blogger explains:

> Years ago, we didn't so much create attitudes about vaccines, we paved a new path for our children and their health. That included knowing how to make rock-solid informed medical decisions. It also gave us strength to create a more public platform about vaccines where parents were invited to ask more, share more, and speak up more.
> (AoA, 2 May 2018)

Calls for making 'informed medical decisions' are intertwined with appeals for their members to get actively involved in the management and optimisation of their health, as can be observed especially on the alternative health blogs. This call to actively 'educate oneself' in order to achieve empowerment is also a crucial aspect of the learning ethos of vaccine counterpublics, as I will discuss in further detail in the following section.

'Do your *own* research!': Defining a vaccine-critical learning ethos

In response to a comment lamenting how medical and regulatory experts' narrow views would not allow for the proper evaluation and understanding of 'lifestyle and diet' interventions on health, an *ANHI* blogger notes that:

> [...] it's so helpful for people to see how much is being done constantly behind the scenes to move effective, sustainable and cheap preventative healthcare forward and how strong the resistance is. It's not conspiracy theory or thinking, it's just stark reality. But that's why it's imperative *for everyone to empower themselves with education and information on how to support their own health, and the health of their families*. It doesn't really matter where the resistance is coming from, the point is that radical change is not going to come from the top down. We need to drive that change. It's what our blueprint for

> a sustainable health system [...] is all about - placing the *locus of control for one's health back where it belongs, in the hands of the individual...*
> (ANHI, 2 August 2018, emphases added)

This appeal 'for everyone to empower themselves through education' represents a recurrent theme among different vaccine counterpublics – and it is a defining aspect of a common 'learning ethos' shared by counterpublics based on the ideals of self-reliance and individual empowerment. This ethos is also nicely summed up in the following extract from *LW*:

> Dear parents, I urge you not to check your brains at the door because someone else *did their research for you*. I urge you to continue to *educate yourself, inform others, stand for what you believe in*, *and make the decision that you feel is best for you and your family*. I also urge you to avoid any medical practice, practitioner, or hospital that doesn't value the opinions and beliefs you hold. We simply shouldn't tolerate anything less.
> (LW, 5 November 2018)

The comments on this blog post are largely supportive of the blogger's self-reliance ideals, with one commenter stressing that a crucial difference between 'pro-vaccines professionals' and 'anti-' or 'ex-' vaccinators is that only the vaccine critics are endeavoring to empower the public by encouraging them to 'think for themselves', pointing to appropriate sources of information and letting everyone draw their own conclusions on vaccine safety. Significantly, the post suggests that by inviting parents to 'conduct their own research', counterpublics are treating their members like adults, while professionals adopt a patronising approach which infantilises their audiences. The idea of vaccine critics as independent learners, who refuse to 'blindly trust' medical authorities has been previously emphasised by Hobson-West (2007) with regards to UK-based vaccine-critical organisations, while Reich (2016) and Kaufman (2010) have remarked on the importance of information-seeking and-self empowerment for parents in the US. For these authors, this emphasis upon self-education does not exist in a vacuum, but are rather is drawn from broader discourses involving individual responsibilisation towards health.

Reich (2016), for example, has highlighted how contradictory public health messages reinforce the idea that parents - and mothers particularly - are vested with the responsibility of protecting their children against health risks and exercising 'precautionary consumption' (124), while simultaneously they are 'pushed toward' vaccination on the 'pretence' of aiding collective wellbeing. Kaufman (2010) has paid attention to the notion of parental responsibility in the field of healthcare, framing it in the language of the informed consumer. For her, the 'freedom to pursue information, therapies and theories' becomes a burden, hanging over parents 'as it hangs over all health consumers' (27). More generally, the frame of the 'responsible consumer' has been theorised by Giesler and Veresiu (2010) with reference to Foucauldian theories of governmentality and 'technologies of the self', which are defined as 'specific techniques that human beings use to understand themselves', operating through 'certain modes of training and modification of individuals, not only in the obvious sense of acquiring certain skills but also in the sense of acquiring certain attitudes' (see Foucault 1988, 18). Drawing partly on the work of Shamir (2008) on 'responsabilisation' as a kind of 'technology of the self' based upon individual self-reliance, Giesler and Veresiu (2010) have focused on how this is employed to create the 'health-conscious' consumer. The genealogy of the 'health-conscious consumer', they suggest, may be traced to official discourses critiquing the welfare-based model of healthcare as fundamentally '...immoral because it ultimately produces passive, uninspired, egocentric, and fatigued citizens who, in their total inability to realize their full potential, will automatically become sick' (2010, 850). These discourses, in their view, have been shaped in a significant way by non-public health institutions such as the World Economic Forum. As they explain:

> Around 2007, the WEF began propagating that health care should never be redistributive and collective per se, as this would invariably foster passive consumer-citizens who are not actively contributing to their own well-being. It should rather be individualized, taking individual consumers' health ambitions into account. This solution ethos not only seemed to end the dreaded democratic debate but also fundamentally redefined the roles of health activists, medical and technological experts, gerontologists, health sociologists, and critical celebrities. Representing their traditional democratic interests would be a way to demonstrate inflexibility and lack of vision and thus not present a contribution to ending chronic illness. Good conduct, in turn, would entail the prioritization of the general interest in consumer values of hard work, discipline, and can-do spirit. (Giesler and Veresiu 2010, 849)

This 'can-do' spirit is well represented by *ANHI*'s self-assumed role as an enabler of well-informed, responsible health-consumers working towards, as in a post quoted above, '...placing the *locus of control for one's health back where it belongs, in the hands of the individual*'. These references to 'self-empowerment' might be read in conjunction with counterpublics' epistemic activities involving the use and reworking of scientific knowledge as suggesting that vaccine critics are embracing dominant discourses of scientific expertise and individual responsibilisation.

However, I would argue that it would be reductive to view vaccine critics' use of scientific knowledge and their adoption of a 'self-reliance' learning ethos merely as a sign of 'subjection' to powerful institutional discourses. Rather, I suggest, vaccine critics' epistemic practices – including their self-reliance ethos – are essential for the constitution of counterpublics as sites of resistance to power. In this sense, the remaking of scientific knowledge among vaccine counterpublics can be seen as a key process within what social movement scholars call 'repertoires of contentious action'. Repertoires of contentious action can be described as combinations of different forms of collective action employed to pursue social and political change (see e.g. Tilly 1979; 2004). Viewed through this 'social movements' lens, invocations of scientific evidence among online vaccine critics are a way to acquire agency by forging a credible form of 'counter-expertise'. This is intended to enable counterpublics' claims to be heard and recognised as legitimate in a world in which scientific and technical expertise and professional status give access to social influence and power. Indeed, as Akrich (2010) notes, 'the 'scientifization' of politics, which occurs through recourse to scientific expertise, is often accompanied by a movement towards the 'politicizing' of science: where political positions appear to rely strongly on the mobilization of experts, their opponents aim to constitute a counter-expertise' (14).

However, I would argue that the ties that link vaccine counterpublics to scientific knowledge go even counterpublics' goal of being taken seriously by experts and policy-makers. By reusing and circulating scientific knowledge online, counterpublics are simultaneously constructing novel sites of connection, engagement and sharing, which are distinguished from official or professional sites, where expert knowledge is merely consumed rather than actively engaged with. As stated in an *AoA* blog post, in which the author refers to her previous experience on early 'Yahoo! Groups' discussion boards:

> Those *Yahoo! Groups* might be considered prehistoric now, but that sort of social media, which dictionary.com states as *websites and other online means of communication that are used by large groups of people to share information and to develop social and professional contacts*, gave many of us exactly what we needed: the confidence to keep educating ourselves. Those early days gave us a chance to sort through valuable information that our doctors wouldn't discuss. Not only that, it gave us much-needed support and the chance for friendships that, for some, are still going strong.
> (AoA, 20 May 2018, emphasis in original)

What social media provides, according to this blogger, is therefore a novel and welcoming social space in which pursuing knowledge independently is actively encouraged and rewarded, crucially giving counterpublic members 'the confidence to keep *educating ourselves*' (emphasis added). This attitude is shared across the sampled blogs. For example, according to *VCUK*, vaccine hesitancy is something which derives from a positive 'growth in knowledge of what makes children healthy'. Furthermore, it is a reaction to what the blog depicts as the 'obvious propaganda' surrounding vaccines among mainstream publics:

> Many of these discussions are taking place on social media and as more people refuse vaccines the view of mainstream media is that socialmedia [...] has paved the way for a new era of "anti vaxxing", but not for the reasons being reported; 'ignorance", "stupid", a belief in "conspiracy theories". In my opinion, the reason for increased vaccine hesitancy is a growth in knowledge of, what makes children healthy and the obvious overt propaganda surrounding vaccines from an industry happy to present PR as science and not explain what "safe" really means. These parents have heard "safe" before in relation to nuclear tests or smoking, or Thalidomide, or Vioxx, or blood contamination, or asbestos, or diesel omissions or Monsanto's Herbicide Roundup.
> (VCUK, April 2019)

This explicitly critical outlook is centred around the belief that experts learn in closed, 'manipulated' epistemic spaces and are therefore not appropriately equipped to learn about the 'real risks' posed by vaccines. Criticism of 'industry science' is common among counterpublics, and might be understood, along with the 'citizens media' and 'DIY' practices embraced by counterpublics, as a way to build communities of resistance. As Chidgey (2014) writes, 'DIY media offer possibilities of engaging with social change; they also encourage readers to become participants by putting thought into action' (109). There is an underlying tension here between a centralised model of information provided by officially-sanctioned institutions, and a decentralized picture where information is independently shared among networks of 'credible' quasi-experts and 'empowered' peers. This tension is intrinsically connected to the theme of (epistemic) trust in public and political institutions and the relation between collective identity, accountability and symbolic change in our information society, which will be explored later on in this thesis.

In the remaining part of this chapter, I would instead like to focus my attention on how this construction of new, critical epistemic spaces by counterpublics relates to the political and legal contexts surrounding the creation and circulation of vaccine-relevant information. The aim of this last section is to better understand internet-mediated counterpublics' opposition to strategies aimed at regulating their epistemic practices, which involves a critical assessment of the approach taken by certain social media corporations in regulating 'vaccine misinformation'.

Misinformation, corporate power and invocations of an ‘expanded’ right to freedom of expression

In the first section of this chapter, I provided a critique of both ‘deficit’ approaches to science communication focusing on the supposed ignorance of science on the part of vaccine-critical activists, and views that depict online vaccine critics as ‘anti-science’. I then provided an account of the key role that ‘DIY’ science-making activities and a learning ethos of self-reliance play in vaccine counterpublic epistemic practices. In this final section, I build on this understanding of vaccine counterpublics as independent, self-reliant ‘makers’ of scientific knowledge engaged in ‘DIY’ epistemic activities in order to critically assess the emerging regulation of vaccine-critical information by social media corporations. My specific focus here is on Facebook – mainly because of its size and popularity among vaccine counterpublics. However, my arguments have been developed to be applicable as far as possible also to other social media platforms which have attempted to regulate ‘medical misinformation’.

To begin with, it is important to understand why social media platforms have become such an important resource for vaccine counterpublics. In this regard, some valuable insight can be found in recent literature on social movements and the internet, which highlights different issues which hinder the success of online-based activism. For example, in *Net Delusions*, Evgeny Morozov (2011) has criticised the tendency of online activism to manifest as so-called ‘slacktivism’, evidencing a lack of commitment among most online-only campaigners. Another important issue raised by activists is the feeling that they are only ‘preaching to the converted’. In other words, activists struggle to reach non-activists. This sense of insularity has been highlighted by research on different internet-based activist groups (see e.g. Hestres 2014; Craddock 2020, 157). While a will to reach out to wider audiences is mostly implicit in vaccine counterpublic activities – such as the invitations often found on vaccine-critical blogs for their readers to share blog content with their own personal contacts – on occasion concerns that they are not being heard enough by ‘outsiders’ are aired explicitly, especially by bloggers. This may be seen, for instance, in the following extract from an *AoA* blog post lamenting the consequences of vaccine critics being ‘ignored’:

> The more we’ve been ignored, the higher that autism rate rises. The higher other childhood disorders rise as well. What can we old timers do? Share more? Talk more? Write more? We’ve covered every single topic out there already!
> (AoA, 20 April 2018)

It is clear that, at least in some cases, vaccine critics feel that blogging platforms are not enough to achieve the level of public engagement to which they aspire. *AoA* bloggers are reflexive about their readership, and acknowledge that the public includes steadfast vaccine supporters whom they will probably never be able to convert to their cause. Their focus should instead be on the 'movable middle', as this blogger puts it:

> Good morning family and friends. [Generation Rescue] founder and Age of Autism founding Editor JB Handley has written a striking book called "How to End the Autism Epidemic," that we think will reach will reach [sic] the moveable middle - those parents, grandparents, providers who have a niggling feeling "something" is going with our children, but haven't yet come to terms with possibility of vaccination as a cause.
> (AoA, 27 August 2018)

While trying to bridge this perceived gap between full-blown vaccine critics and the 'movable middle', counterpublics seek to make use of the opportunities that wider social media platforms afford them in order to increase their visibility and have their voices heard beyond the limited, arguably insular, confines of their blogs. Among social media platforms, social networking websites in particular appear to represent an invaluable tool for counterpublics to reach out to vaccine hesitant parents who, for a number of reasons, might decide to delay or refuse vaccinations, but are not already involved with vaccine-critical activism. Sharing blog articles, media and producing commentary on the most popular social networking platforms – such as Facebook, Pinterest, Instagram and Twitter – may seem to be an ideal approach for vaccine critics in order to avoid the insularity pitfalls encountered by online activists whose blogs may be lost in a vast ocean of internet content. For example, vaccine-critical posts on Facebook pages can easily receive several hundred 'likes' and comments, and be shared by each 'fan' of the page across their networks of friends, helping to reach people beyond the small, recurring base of users that – as observed in even in bigger, multi-authored blogs such as *AoA* – tend to regularly comment on the original blogs.

Considering the significant role social networking sites play for counterpublics, and the self-defined roles of counterpublic members as producers and circulators of 'quasi-expert' knowledge explored earlier on in the chapter, it is hardly surprising that they have responded vocally and critically to emerging restrictions to their social media activities. For instance, after finding out that their account had been deleted from the image-sharing platform Pinterest for violating their 'misinformation' policies, an *AoA* blogger writes:

> Pinterest was never one of my favorite websites to visit. But with readers all over the world using all manner of social media platforms including Pinterest, I created an account for Age of Autism there several years ago. Once in a while, when I'd remember to, I'd pin something under our Great Reads, Good Movies, or Friends of AofA boards. A new book to check out, a documentary of interest, or an infographic that was making the rounds on other people's advocacy pages were what I'd typically pin. Never more than an afterthought though, I'd spend more time adding links and reading material to our AofA Facebook fan page. With a much larger audience, FB was the place to be.
> (AoA, 11 February 2019)

While the blogger expresses her discontent at the blog's material being cancelled on Pinterest, she emphasises how much more time and effort she had spent on 'adding links and reading material to our AofA Facebook fan page'. It is easy to see why Facebook's almost 2.5 billion user profiles active each month constitutes an invaluable resource for counterpublics. But, like Pinterest, Facebook has also implemented measures to tackle the proliferation of what it calls 'vaccine' or 'medical misinformation'. Among the measures taken by Facebook are a reduction of 'the ranking of groups and Pages that spread misinformation about vaccinations in News Feed and Search', the rejection of 'anti-vaccine ads', and the provision of 'authoritative information about vaccines' (Meta 2020). The latter has been implemented through an official notice posted in vaccine-critical pages inviting the reader to learn more about vaccines from the World Health Organisation (WHO), and linking to the WHO's institutional website, which I observed in some (but not all) of the pages analysed in this research.[95]

As I have shown in this chapter, people who choose to join vaccine counterpublics become part of 'epistemic counterpublics' involved in the creation of causal knowledge about vaccine harms, built around a learning ethos of self-reliance and a DIY science-making praxis. This means that vaccine counterpublic members are involved in a process of knowledge construction and sharing from sources they have personally selected as being trustworthy or authoritative. Therefore, concealing vaccine-critical pages on Facebook, or linking to the WHO or other institutional websites, is unlikely to deter people who are intent on finding 'the real truth' about vaccines.

In addition, what has been framed by Facebook and other social media corporations as a fight against misinformation has been perceived by counterpublics as a violation of their 'free speech rights' – in

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[95] It should be pointed out that, as of the time of writing, these measures have been tightened up even further as a result of the Covid-19 health crisis. Some of the newly introduced measures include limiting the distribution of posts marked as false by a team of 'fact checkers' and adding warning labels to stories that have been flagged as misinformation. See https://about.fb.com/news/2020/04/covid-19-misinfo-update/ (last accessed on April 11, 2022).

other words, as unfair and politically-motivated ‘censorship’. Alternative health blogs have specifically contested Facebook misinformation policies, depicting these as a form of political manipulation. For example, *LW* has shared a post on their Facebook page arguing that the social networking site has turned into a ‘huge problem’, and that the public does not fully understand the implications of Facebook’s ‘new censorship policies’. According to the blogger, these policies are actually designed to ‘manipulate’ under the pretense of helping users ‘sift through misinformation’. Further, *LW* insists that misinformation policies are bad for users, businesses and ‘content creators’, lamenting the fact that a business might spend ‘years’ trying to build a platform only to have it ‘wiped out overnight’ because Facebook does not like what is being posted.

For a relatively small, individual blog such as *LW*, reliance on ‘platforms’ like Facebook to connect to a potential audience is crucial, and the ‘wiping away overnight’ of a platform ‘they spent years building’ might have serious effects when the blog is used as part of the blogger’s business. But even a bigger blog, with links to alternative health interest groups, such as *ANHI* fears the impact of Facebook misinformation policies:

> ...[a]s a result of recent mass purges, Facebook is alleged to have deleted over 80 pages dedicated to natural/alternative health and nature. Most of these pages contain views that oppose mainstream narratives. Severed from their millions of followers, the censored groups were by no means small, insignificant deviants. Unsurprisingly, the affected natural health community was quick to respond, contesting what was perceived to be a concerted attack and censorship on important viewpoints that are largely intended to facilitate more informed decisions over healthcare choices.
> (ANHI, 5 August 2018)

Significantly, *ANHI* tries to stress the injustice of Facebook actions by pointing to the fact that the cancelled groups ‘were by no means small, insignificant deviants’, but had ‘millions of followers’. This is an interesting point because it may suggest that – in line with my earlier discussion of the ‘informed consumer’ – vaccine critics find themselves at the centre of conflicting messages by powerful actors who are simultaneously legitimate vaccine critics’ roles as social media ‘content creators’. Indeed, Facebook provides all the tools for vaccine counterpublics to succeed as ‘businesses’ advertising their ‘brands’ and messages throughout the platform. It is notable that ‘Facebook pages’ are deliberately included among Facebook’s tools for business.[96] They enable the setting up of private digital spaces in which counterpublics can share their ‘content’ and engage with their ‘fans’, who are requested by

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[96] See for example https://www.facebook.com/business/pages/set-up, explaining how to set up a ‘free business page in minutes’ (last accessed on April 11, 2022).

Facebook to use their real names when registering, and who can react to posts in a number of ways, mostly positive (the default choice is a 'like'). Furthermore 'business page' managers can delete or hide comments they do not agree with, through Facebook page moderation tools. These features of the platform may be among the most attractive for businesses and counterpublics alike, as they can potentially discourage critique in favour of expressions of support for the claims presented on the pages.

By obtaining high engagement levels and constructing larger platforms for their epistemic activities, counterpublics are taking the opportunities that Facebook offers them to become successful 'content creators'. Facebook is not and has never been conceived as a platform dedicated to the collaborative construction of 'high quality' knowledge. It lacks the more sophisticated systems of distributed peer-review and dispute resolution found in other websites that have been described as being primarily 'epistemic social software', such as Wikipedia (see Simon 2010). Indeed, it is probably not possible for these kinds of system to be implemented without Facebook renouncing its identity as a 'tool for business'. However, Facebook has intervened to change its algorithms so that counterpublics' pages are downgraded and demoted for violating 'misinformation' policies (although the core features described above are still available to vaccine-critical pages). This creates a paradoxical situation, as also noted by the vaccine-critical bloggers cited above, with a tension between the design of Facebook – which rewards counterpublics for acting as businesses looking to build a following of like-minded users – and the new misinformation policies which punish vaccine-critical pages for promoting their messages in a business-like way.

These policies have followed a period of media scrutiny of the information circulating on social media, particularly since major political events such as the 2016 US presidential elections and Brexit, which brought to the forefront the circulation of 'fake news' on social media platforms as a new, major social and political issue. As *ANHI* pondered in a 2018 blog post:

> Can we be so quick to point the finger at a social media giant's potential agenda, or should we look a little closer at the online elephant in the room: collateral damage in the regulatory battle against 'fake' news?
> (ANHI, 5 August 2018)

The 'regulatory battle against fake news' is presented here as a fundamentally political battle that is harming vaccine counterpublics as its 'collateral damage'. Other blogs, however, describe a political battle in which vaccine critics are not merely ‘collateral damage’, but direct targets. For example, while lamenting the ‘censorship’ of a vaccine-critical documentary on Amazon, a *FP* blogger writes:

> I was appalled to read Adam Schiff’s recent letter to Jeff Bezos. Schiff touts the importance of a free press, yet called for censorship of “anti-vaccine information.” More alarmingly, Bezos complied. Amazon removed documentaries raising questions about vaccine safety from Prime Video.
> (FP, 4 March 2019)

Adam Schiff is a US Congressman who in 2019 wrote to the CEOs of a number of social media corporations to encourage them to intervene directly to ‘distinguish quality information from misinformation or misleading information’ on their platforms. An extract from Schiff’s letter to Facebook mentioned by *FP* reads:

> I acknowledge that it may not always be a simple matter to determine when information is medically accurate, nor do we ask that your platform engage in the practice of medicine, but if a concerned parent consistently sees information in their Newsfeed that casts doubt on the safety or efficacy of vaccines, it could cause them to disregard the advice of their children’s physicians and public health experts and decline to follow the recommended vaccination schedule. Repetition of information, even if false, can often be mistaken for accuracy, and exposure to anti-vaccine content via social media may negatively shape user attitudes towards vaccination.
> (Schiff 2019)

Bloggers at *AoA* have also mentioned and discussed Schiff’s 2019 letter:

> Representative Adam Schiff wrote a letter to the Chief Executive Officers of Google and Facebook calling on them to shutdown vaccine risk aware groups and postings on the company’s platforms including YouTube, Facebook and Instagram. He called for a *modern-day book burning*. In the days leading up to the Senate hearing, there was already evidence of a shift as people found it difficult to find previously available information missing from these sources and others.
> (AoA, 12 March 2019, emphasis added)

By redefining ‘vaccine misinformation’ as the ‘postings’ of ‘vaccine risk aware groups’, and using highly charged expressions such as ‘modern day book burning’, the blogger here is challenging the neutral framework implied by the wording of the Congressman’s letter. The point made by the blogger is that choices around the circulation of information on social media platforms are necessarily political in nature. The blogger's argument is not just a normative argument about specific kinds of online speech and whether they should or should not be restricted. Rather, the response of vaccine counterpublics to the emerging attempts to regulate misinformation (or imposing censorship, from the counterpublics' perspective) could be seen as an attempt to shed light on the political nature of decision-making about not only which kinds of talk is allowed or disallowed online, but also *who* gets to make the call about such decisions.

In our current media landscape, such decisions are the product of an interplay between national governments, national expert bodies, international organisations (in this case, the WHO) and the new corporate power of dominant social media corporations. This interplay of 'old' and 'new' powers in the identification and limiting of vaccine-critical talk may be helpfully understood in the context of 'network society'. This has been famously defined by sociologist Manuel Castells as a society 'characterized by the pervasiveness of communication networks in a multimodal hypertext' (2007, 239). In a network society, both power and resistance to power are crucially reliant on electronic-based communication technologies. As put by Castells, 'power relations, that is the relations that constitute the foundation of all societies, as well as the processes challenging institutionalized power relations are increasingly shaped and decided in the communication field' (239). The implications of network society for vaccine opposition are therefore ambivalent. Indeed, while internet-enabled 'mass-self communication' (Castells 2015, 6) has allowed for the emergence and shaping of vaccine counterpublics as 'knowledge making', epistemic agents, and allowed their voices to be more widely heard, it has also engendered the creation of new networks of power that are now threatening to limit the vaccine-critical talk they have originally enabled.

The resistance of vaccine counterpublics has manifested itself by framing social media regulation as 'censorship' or 'book burning', referring to a long-standing tradition of freedom of speech and freedom of expression in (American and European) legal cultures. Significantly, some blogs and their commenters mobilise legal rights to 'free speech' directly in their critiques of social media companies. These vaccine critics use rights-based discourses to defend their ability to make and circulate their vaccine-critical knowledge online unencumbered by the misinformation policies put in place by social media companies. *AoA* is particularly vocal on this issue, as may be glimpsed from previous comments and also evidenced by the following extract:

> Where is the level playing field in the USA? Can the "little guy or gal" survive any longer? We're fighting for our lives to speak out on social media while major media demands we be silenced.

> Amazon, YouTube, Pinterest - all ripping away free speech when it comes to vaccine safety. There are many seeking to destroy us where and how we make a living.
> (AoA, 12 March 2019)

In another post from August 2018, a blogger sympathises with the far-right alternative news website 'Infowars' (albeit acknowledging she is not particularly fond of its founder: '[y]es the man gets on my nerves. too'). Commenting on how the owner of Infowars had reportedly been 'banned' from using certain social media platforms following a court hearing, the blogger notes:

> For those of you who have not caught up with the news, after a court hearing yesterday, InfoWars/Alex Jones has been banned from YouTube, Facebook, Apple and Spottily for violating policies on "hate speech."
> (AoA, 8 August 2018)

The post shows how a common concern over online free speech might give rise to unexpected solidarities and alliances, between different counterpublics which might otherwise not have much in common. However, not every commenter under this blog post shares the blogger's more sympathetic stance towards this far-right website. For example, one commenter states that they did not feel sorry for Infowars, maintaining that 'freedom of speech' needs to be in all cases balanced with regard for 'truth'. Another commenter expresses a more nuanced view of freedom of speech, noting that limitations may be justified in the context of 'privately owned' platforms. This commenter draws a distinction between private and public services (offering postal services as an example of the latter category) and their abilities to stop the circulation of information, while stating that ideally at some point 'some court' should identify social media platforms as public fora on which free speech cannot be 'shut down'.

Instead of merely opposing the law or legal authority, in this case vaccine critics are transposing a concept drawn from their own legal cultures (freedom of expression or 'free speech'), redefining its meaning in an expansive way to apply not only to state interference, but also to the private regulatory power of media corporations they are resisting. The peculiar aspect of this situation is that this corporate-political alliance to 'limit misinformation' on vaccines – which is, it must be remembered, done through media corporations' self-regulation rather than legislation – is awkward for social media companies. Returning to Facebook, the conflict between what Facebook is – an advertising platform – and what it has been asked to do – regulate online information – pushes it towards doing something it would rather not, namely deciding what kind of misleading information its clients are able to publish, or are barred from publishing on its platform. This may help explain why Facebook has decided not to ban vaccine counterpublics outright, and instead has adopted softer measures to 'conceal' vaccine critical talk.

Having to negotiate their way around questions of free speech may nevertheless be more appealing for many social media companies than having to consider the social effects which arise from the intrinsic structure and design of their platforms. The framing of the matter as a question of 'free speech', however, allows vaccine counterpublics to claim the moral high ground when complaining about misinformation restrictions. Additionally, it may create further mistrust in the already fragile relationship between counterpublics and state institutions. This relationship will be looked at in further detail in the following chapters of the thesis.

Conclusions

This chapter offers an insight into the emerging landscape of knowledge-making and sharing among online-based vaccine critical activists. Drawing on scholarship in the field of media and internet studies (see e.g. Ito 2008; Atton 2004; Chidgey 2014) as well as sociologist Manuel Castells' notion of the 'network society' (2007; 2015), I have shown how vaccine critics' knowledge-making practices are founded upon an appreciation and (re)use of scientific evidence according to a 'DIY' praxis, alongside a learning ethos based on individual self-reliance. In addition, I have suggested that these practices of vaccine counterpublics can help us to understand their antagonistic responses to moves made by social media corporations to regulate 'medical misinformation' on their platforms. I have looked in particular at the self-regulation measures adopted by Facebook, because many of the counterpublics encountered in this study have a presence on the platform through individualised 'business pages'.

Because of the 'DIY' nature of counterpublics' online knowledge practices and the strong emphasis on the values of self-reliance and independent learning, it has been argued that measures aimed at concealing vaccine-critical pages and directing the readers to official information-providers, such as the WHO, are unlikely to be effective in deterring counterpublic members from engaging with vaccine-critical pages. From a more critical perspective, I have also suggested that vaccine counterpublics can be found at the intersection of conflicting dominant discourses. On the one hand, social media platforms such as Facebook provide them with tools to effectively disseminate vaccine-critical knowledge and metrics to evaluate their success in doing so. On the other hand, Facebook is pursuing punitive measures, such as algorithmically downgrading vaccine-critical content, which are perceived to be unfair and unjust by counterpublics. This in turn feeds into narratives about counterpublics being involved in a righteous fight against perceived 'censorship' and violation of their 'free speech' rights. Crucially, the meaning of the right to freedom of expression is actively expanded by counterpublics to cover not only interference from the state, but also that from powerful private actors such as social media companies. This point is significant as it reveals a novel way in which online vaccine counterpublics are 'bumping up against' and actively engaging with the legal system, which resonates with the interactive, 'DIY' approach they adopt towards scientific knowledge. This reinterpretation of 'free speech' in vaccine-critical talk sheds a light upon the nature and limits of power in our network society as resulting from an interplay between 'traditional' state institutions and novel, increasingly influential media-corporate actors. Finally, this interplay can reinforce a set of pre-existing negative framings of political, legal, and public health institutions by counterpublics, causing further damage to what is arguably an already difficult relationship between the counterpublics and the state. Different aspects of this complex relationship will be further unpacked in the following chapters of the thesis.

5

A MATTER OF CHOICE: THE 'HIJACKING' OF INFORMED CONSENT RIGHTS IN VACCINE-CRITICAL ADVOCACY

Introduction

In Chapter 4, I discussed and challenged certain portrayals of vaccine critics found in the media as well as in some medical journal commentaries, which have tended to paint 'anti-vaxxers' in broad brushstrokes, as either ignorant of science, or generically opposed to scientific knowledge and scientific methodologies. In this chapter, my focus is less on how vaccine critics construct causal knowledge and scientific evidence, and more upon the ways in which counterpublics frame the harms they believe to be connected to childhood vaccinations, and how they resist state policy and legal pressures to vaccinate. More precisely, this chapter will examine the normative beliefs around vaccine decision-making which orient online vaccine-critical advocacy, exploring how these beliefs relate to the kind of policy changes pursued by counterpublics. In the chapter, I argue that the beliefs and policy demands of vaccine-critical activists are not merely the result of irrational fears, individualistic political worldviews or selfishness, but emerge from notions of vaccine decision-making that are not incompatible with official and expert discourses on immunizations.

Drawing on Peter M. Haas's (1992) 'epistemic community' approach, the idea of 'normative beliefs' is used here to indicate vaccine counterpublics' shared values, which ground their advocacy and policy demands. The idea of using the concept of normative beliefs and linking this to vaccine-critical advocacy around 'vaccine choice' arose at a relatively advanced stage of data analysis. Originally, the vaccine-critical arguments about parental vaccine decision-making identified in this research were all coded under a single 'advocacy against mandatory vaccines' code. However, it soon became clear that the label 'mandatory vaccines' was too limiting, as new data emerged showing that the ways in which vaccine choice is promoted by vaccine counterpublics goes beyond merely advocating against compulsory vaccination.

For this reason, the original 'mandatory vaccines' code was subsumed under the more general category 'normative beliefs and advocacy', and includes the way in which vaccine critics appropriate and 'hijack' the legal notion of informed consent in order to support a two-pronged approach to 'vaccine choice' advocacy.[97] This approach involves, on the one hand, insisting that families are the only legitimate locus of vaccine decision-making and that childhood vaccination choices are exclusively for parents to make. On the other hand, vaccine critics contend that in order that parents are able to give 'fully' informed consent, they should be provided with vaccine-critical information about ostensible 'vaccination dangers'. This encounter between the shared normative beliefs of vaccine counterpublics and the policy change they seek through 'vaccine choice' advocacy is mediated by 'personalised' framings of the right to informed consent. Specifically, vaccine-critical framings of informed consent are invoked in counterpublic talk to advance a shared policy agenda of free and ample vaccine choice.[98]

Based on the coding structure outlined above, the chapter has been divided in two main parts. The first part looks at the normative beliefs or values shared by counterpublic members about vaccine decision-making. This begins with a brief overview of the notion of 'risk', which has been both adopted and critiqued by public health scholars and social scientists in order to understand vaccine opposition and hesitancy (see Hobson-West 2007; Leach and Fairhead 2007; Sobo 2015; Sobo et al. 2016). The analysis then moves to consider how narratives of rational decision-making and risk assessment actually play out in vaccine-critical talk. The other normative belief discussed in the first part of the chapter is the relationship between individual-family and broader community concerns in vaccine-related choices. In contrast to the view of vaccine critics as primarily self-interested, I contend that there is a strong community-oriented side to vaccine-critical advocacy, which manifests itself in the framing of vaccine-related dangers as a significant public concern. In addition, based upon the data collected from blogs across all sampled categories, I show how 'public' and 'private' interests are not always depicted as conflicting by counterpublic members. Indeed, at times, the binary private/public seems to lose importance, as advocating the rejection of vaccines becomes a way of protecting at the same time the individual health of one's children and the health of all children in a community.

The second part of the chapter uses the vaccine-critical beliefs introduced above to better understand the ways in which critics pursue their policy demand of 'truly free and informed' vaccination choice. In

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[97] In addition to how vaccine choice is being advocated for by vaccine critics, the macro-area or domain 'normative beliefs and advocacy' adopted in this study includes another main theme, which is represented by how vaccine critics are recasting certain aspects of vaccine regulatory frameworks to support their beliefs around the (un)safety of vaccinations (see Annex C for conceptual maps of the main codes of this study). This theme linking vaccine regulation to vaccine-critical framings of vaccine safety is explored in detail in Chapter 6.

[98] Informed consent is a broad concept which has attracted a vast amount of scholarship in the regulatory, legal, medical ethics, and public health literatures. It should be clarified from the outset that this chapter does not aim to provide a comprehensive synthesis or review of these very diverse literatures. Rather, as mentioned above, the chapter seeks to shed a novel light on how this legal concept is understood, represented, and strategically re-deployed by vaccine critics as a means to achieve policy change.

this second part, I analyse how vaccine counterpublics reframe the legal concept of 'informed consent' in order to support of their advocacy for vaccine choice. In doing so, counterpublics refer to both the individual-family and the community-oriented aspects of vaccine-related decisions, managing to use 'informed consent' as a vessel to simultaneously emphasise the sanctity of individual parental rights to make medical decisions for their children, and a more collective right to give 'fully informed consent'. Significantly, this latter way of framing informed consent involves counterpublics' input in identifying what kind of information needs to be given to parents in order to obtain valid consent to vaccination. The chapter ends with reflections on how new information and communication technologies have paved the way for novel strategies of resistance, in which counterpublics appropriate and reinvent legal concepts in order to advance their desired policy outcomes.

Vaccine decision-making, uncertainty and the (mis)perception of risk

In this part of the chapter I consider how online vaccine critics understand and speak about vaccine choice. Questions around the possibility of harm and damage following the administration of vaccines are frequently framed in academic, policy and media discussions as matters of risk and risk perception. It should be noted that some scholars have previously cautioned against using 'risk' as a single lens to analyse all issues of uncertainty leading to public reluctance to accept particular scientific findings or novel technologies (see e.g. Leach and Fairhead 2007). Despite this, risk and risk perception have remained popular concepts in sections of the literature researching resistance to science and technology in general, and to vaccinations more specifically. This is particularly true for the social-psychological literature, in which there have been multiple empirical studies trying to identify reasons for the risk 'perception gap' (Ropeik 2010; 2012) between experts and lay publics in a number of contested policy areas, including water fluoridation, nuclear energy, climate change and, indeed, vaccines.

As Hobson-West (2005, 15) has pointed out, this scholarship is grounded in what is referred to in the sociological literature as the 'realist approach' to risk. According to this approach, risks are real objective entities that can be quantified, measured and compared to each other. As a consequence, in a realist perspective it is possible to perform objective risk-benefit calculations, thus allowing for a rational determination of the best course of action in any given situation of uncertainty. The existence of objective, quantifiable risks in the realist approach also implies that any deviations from their correct, rational assessment are the result of individual mistakes in judgement. These mistakes are the result either of inaccurate or insufficient information, or lay public 'misperceptions of risk'. The latter tend to be 'diagnosed' in the literature as resulting from 'deficits in non-expert reasoning', as argued by Martin Bauer (Bauer 1995, 396, cit. in Hobson-West 2005, 15). It is this view of risk misperceptions resulting from laypeople straying away from 'rational' expert assessment of risks that has led to the emergence of empirical work trying to explain how and why non-experts reason 'differently' from experts.[99]

Some empirical studies in this field also approach certain risk misperceptions, which are particularly problematic in terms of their public policy implications, and which therefore necessitate correction through appropriate 'risk communication' strategies, which take into account the psychological, moral, or social factors that distort lay reasoning about risk. For example, a research article recently published in *Nature Human Behaviour* links vaccine hesitancy to individually-held moral values – specifically those of 'liberty' and 'purity'. It also suggests taking these 'moral foundations' into account when addressing the public, incorporating appropriate messages (such as 'keep your child pure of infections' or 'take personal control of your child's health') in public health communications about immunisation (Amin et al. 2017). Much of the public health literature on vaccine refusal and hesitancy relies on this realist approach. It is common for vaccine opposition to be portrayed as an example of communication breakdown between experts and lay people, where true, objectively-existing vaccine risks are misperceived and misrepresented by individuals who reject vaccines (see e.g. MacDonald et al. 2012; WHO 2017).[100]

However, as the findings presented here suggest, this picture of lay 'misperception of risk' does not always accurately reflect how matters of vaccine choice are actually articulated in counterpublic talk. In some cases, as we will see later on, individual risk might not be the best way to explain how counterpublics think about vaccine decision-making.[101] But even when individual risk assessment is part of online vaccine-critical commentary, there may be less difference between lay and expert ways of describing vaccine risks than previous psychological and public health scholarship has tended to suggest.

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[99] It has to be noted that 'objective risk' and expert assessment of risk are not universally equated to each other by the literature. Some commentators have acknowledged that experts may have their own biases, which can be based on their individual attitudes, values and beliefs, on their belonging to organisations with particular interests and goals, or on their professional training and the 'mental models' they recur to in their respective areas of expertise (see Evans et al. 1997, 9). However, the distinction between expert and lay risk perception is still arguably a rather prevalent one, particularly in the risk communication and cognitive psychology literatures.

[100] For a rich historical account on the notion of risk and the developing theoretical lenses used to understand the concept see Luhmann (1993), esp. Chapter 1.

[101] Some very valuable theoretical insights and critical perspectives in relation to the use of 'risk' as a category to understand vaccine-sceptical views have been offered by Leach and Fairhead (2007) and Hobson-West (2007). Although this chapter does not have a primary focus on the concept of risk, some of the findings presented here on counterpublic members' framings of parental vaccine decision-making appear to resonate with the discussions on risk present in this previous social-scientific scholarship.

Rationality and individual risk assessment in vaccine decision-making

First, it is important to note that counterpublic members do not just 'perceive' vaccine-related risks in a passive or purely emotive way. Rather, they use their knowledge about vaccines and medical research in general to reason about risk, justify their opinions around vaccine hazards and defend their vaccine assessments and decisions. Indeed, different counterpublics stress the importance of actively researching 'what goes in your child's body', representing this as their duty as both parents and consumers. This is particularly visible in the 'vaccine injury activism' blog *AoA*, whose bloggers often write posts based on their personal experiences as parents. Their approach to vaccination choice as something to research and become educated about, as well as a matter best left to parents' individual responsibility is well exemplified by the following exhortation to other parent-readers:

> You decide what goes in and on your child's body. You get to pick what he eats, what she drinks, what hair care and hygiene products he needs, and which vaccines she will get.
>
> That last product, which comes with no money-back guarantee, deserves as much research time as your baby's crib, car seat and which type of paint you're going to put in the nursery. Should you opt for vaccines, just remember that.
> (AoA, 15 April 2018)

In this post, vaccine choices are regarded as one among the many sets of choices responsible parents have to make on a regular basis on behalf of their children, and which may have an impact on their children's development and well-being. It is any responsible parent's duty, according to this perspective, to thoroughly research a product and evaluate whether it might be 'a good fit' for one's child. This inclusion of responsible consumption as a requirement of good parenting – and particularly crucial to the construction of the identity of the 'good mother' – is something that has been previously discussed in the literature on vaccine refusal as a key feature of 'neoliberal parenting' (see e.g. Reich 2016).

In the context of online vaccine-critical activism and vaccine decision-making, it is important to note how narratives emphasising the interconnection between risk, responsibility, education and choice are found across the board among all counterpublics investigated in this research. Such narratives are significant in that they contribute to the unfolding of discourses of risk as rationally determined by individuals based on the diligent assessment of available information. For example, the natural health blog *ANHI* encourages its readers to become 'empowered citizens' and 'take an active part' in the management of their health by asking their health providers to answer a number of questions about any recommended treatments, including what benefits would result from the treatment, an assessment of any risks or harms connected to different potential treatments and how these treatments would 'compare with doing nothing' (ANHI, 29 March 2019). This post points towards a general view of health choices as a rational balancing exercise, in which the risks and benefits connected to various medical treatments can be measured and compared, in order to identify the optimal alternative.

Referring more specifically to vaccines, the blog VP clearly states in its 'about' page that vaccine decision-making should be based on an 'objective risk/benefit analysis':

> Like any other medical treatment, vaccination must be justified in view of an objective risk/benefit analysis. All risks and benefits must be considered. Any rational medical treatment must do more good than harm. This is universally accepted.
> (VP, n.d.)

A different blog, *VCUK*, includes an account of how the blogger came to the decision not to give the HPV vaccine to his children. In one post, he starts by stating that 'when assessing any medical intervention you weigh up the benefits against the risks', and then goes on to estimate that as a 12-year old, his child would have benefited 'zero' from the vaccine, while having a risk of adverse events of 'about 3%', as well as a 'small risk of death' (VCUK, 5 March 2019). The post continues by stating that even if one contracts HPV, there are other 'effective ways' to manage the risk of developing cervical cancer, including 'not to smoke, not to become obese, adopt a healthy active lifestyle and develop an effective immune system'. In the same post, the blogger also recounts a personal interaction with a well-known science writer on Twitter, in which he ended up criticising the writer for stating that there are 'virtually no side effects' and 'no risks' associated with the HPV vaccine.

This critical perspective appears to be shared by at least some *VCUK* readers. One commenter, for example, expresses approval of the blogger's risk-benefit comparison approach, and insists that the expert insistence on 'zero risk' is negligent and inaccurate. Regardless of the accuracy of the particular risk-benefit considerations offered by *VCUK*, what is interesting to note here is how the blogger's reasoning in relation to issues of vaccine decision-making has been couched in the language of realist and rational risk assessment. In justifying the parental decision to reject a particular vaccine, the *VCUK* blogger does not mention 'extra-rational' factors such as emotions, moral values and political or ideological beliefs, as might have been expected based on the 'risk misperception' perspective outlined above.

Other blogs also include attempts by bloggers and commenters alike to justify their childhood immunization-related choices by recourse to 'rational' risk discourses. On *LW*, a commenter notes that because her daughter has suffered from 'severe' allergies to certain foods and mould, among other things, her 'chances' of harm would be greater should she receive a particular vaccine. Another commenter on *VP* states that because there are many cases of autism in their family, including the mother of his children, he has decided to refuse certain vaccines for his last-born child, explaining how they were avoiding one vaccine specifically as they believed this could interfere with their children's immune system by interfering with a particular immune-regulating protein found in the body.

Although 'rationally assessing' individual risk is not the only way in which counterpublics approach vaccine decision-making, its recurrence across different types of blogs is significant, particularly since it is often assumed that 'fact-resistant' vaccine opposition derives from lay perceptions of risk which eschew rational considerations and logical reasoning. Sometimes vaccine counterpublics (and particularly counterpublic members identifying as parents) are aware of this assumption and challenge it directly. In an *AoA* post which reveals that some vaccine critics are aware of scholarly research on vaccine refusal, a blogger mocks a psychological study which claimed that anti-vaccine attitudes are more frequent in individuals with a general propensity to believe in 'conspiracy theories':

> This study says that the push to "educate" us into believing vaccines are as magical as fairy dust, as safe as a mother's hug and as necessary as air via "intervention programs" is a failure. Well, lah de dah. Imagine that. Bullying fails. We believe what we see with our own two eyes. The study says that we tend to believe "conspiracy theories." You can't color me and most of my colleagues with this broad "conspiracy nut" brush. The more injured kids, teens and adults, the more the bubble is bursting on the Vaccines Are God industry. Do I like this? Not really. It would be very nice if vaccines could safely protect from disease with ZERO harm. So would finding the Giant Pink Sea Snail with Dr. Dolittle.
> (AoA, 7 May 2018)

Here the blogger draws a contrast between how vaccine critics are being represented (as 'conspiracy nuts') and her wish that 'vaccines could safely protect from disease', 'with zero harm' involved. She also emphasises that her assessment that vaccines are unsafe is based on her personal, 'factual' knowledge and compares authorities' attempts to communicate with parents about vaccine risks as 'bullying'. Some users commenting under this post have also felt the need to point out that they are not 'conspiracy theorists'; noting, for instance, that they do not believe that 'yetis' are real, or that the moon landing was a hoax. Other commenters have observed that governments and corporations sometimes do misrepresent facts to the public, citing the non-existence of weapons of mass destruction in Iraq at the time of the 2003 US invasion, or the health-endangering tactics of 'Big Tobacco'. For our purposes it is interesting to note how most of the comments – consistently with counterpublics' emphasis upon researching and 'educating oneself'– imply that opposition to vaccines is based on 'facts', rather than irrational thinking.

Despite this, in recent years more research – as well as media commentary – has emerged supporting a correlation between the holding of anti-vaccine views, believing in conspiracy theories and sharing particular ideological tendencies, such as a preference for individualism (see e.g. Goldberg and Richey 2020; Hornsey, Harris and Fielding 2018). It could be argued that counterpublic members' self-representation as rational risk-assessing agents does not necessarily mean that their immunisation choices are actually taken 'rationally'. However, I would suggest that the recourse to realist risk discourses and particularly the stress placed upon rational decision-making by vaccine counterpublics are findings that necessitate more careful analysis. In particular, vaccine critics' views on vaccine decision-making and rationality raise a different sort of question than those previously considered by the literature on vaccine refusal and risk perception: why is it so important for vaccine critics to represent themselves as rational decision-makers?

The way parent-bloggers and commenters try to relate what they know about vaccines (which they regard as their carefully researched causal 'knowledge') to particular 'risk factors' they identify in their children points towards the significance of individual risk discourses as technologies of self-regulation (or 'techniques of the self'). Indeed, the explicit use and inclusion of risk considerations in these parents' reflections and comments is something that could be expected in a 'governmentality' approach to risk (see e.g. O'Malley 1992; Dean 1999; Weir 1996; Rose 1999). In a governmentality framework, according to the definition offered by Dean (1999), risk is seen as 'calculative rationality that is tethered to assorted techniques of regulation, management, and shaping of human conduct in the service ends and with definite, but to some extent unforeseen, effects' (206). As opposed to realist approaches to risk, a governmentality approach does not deal with risks as objectively existing entities, but rather stresses the role of risk as a key modality through which the modern state can govern human behaviour.

Governance through risk may manifest itself in a multiplicity of ways. Lorna Weir (1996) has focused upon the use of 'clinical risk' in the context of pregnancy, noting how the framing of pregnant women as an 'at risk' category allows them to be subjected to a series of 'risk management duties', in order to maintain their own health as well as the health of their foetuses. Along similar lines, Novas and Rose (2000) have discussed the implications of genetic screening technologies and their use in the identification of individuals who are 'genetically at risk', noting how rather than fatalism and resignation, identification of risk leads to a form of active 'genetic responsibility' among patients, who become subjects of 'self-actualization, responsibility, choice and prudence' (502).

An emphasis on individual responsibility and the privatisation of risk has also been associated with 'neo-liberal societies' and the rise of 'neo-prudentialist approaches', in which the 'entrepreneurial subject' is expected to make her own health choices to minimise risk, rather than relying on state support (Lupton 2006, 96; see also O'Malley 1992; Dean 1997). By categorising their children as being 'at risk' of vaccine adverse reactions, and presenting this risk status as a reason to refuse childhood immunisations, counterpublic members could be regarded as paying attention to their risk management duties. In short, even if their chosen course of action – refusing vaccines – is not desirable in terms of public health (which is consistent with Dean's (1997) idea that the effects of risk are not always foreseeable), counterpublic talk demonstrates how vaccine critics generally accept the importance of rational risk assessments as a way to navigate health decisions which are carefully presented, justified and defended against mainstream vaccine recommendations.

There is, however, another context in which appeals to rational cost/benefit analysis seem to recur, at least in a section of the sampled vaccine-critical blogs. This is when counterpublic members are advocating for their parental 'right to choose', that is their 'right' to opt out of vaccines when they believe these would be unsafe for their children. The 'medical choice' blog *FP*, for example, in an open letter to a local politician advocating for the maintenance of religious vaccine exemptions argues that we should 'empower parents to make their decisions', to 'help make them aware of risks and benefits', rather than restricting the scope of vaccine choice through legislation (FP, 11 June 2018). *AoA* bloggers equally link parental duties to be informed about possible vaccine adverse reactions to a corresponding 'freedom' to reject some or all vaccinations. For example, an undated post detailing the blog's nine 'core beliefs' includes the point that:

> [p]arents should find ways to educate themselves and each other about the risks. They also must be free to choose which vaccinations they want their child to receive and when, and they must be free to reject vaccination entirely.
> (AoA, n.d.).

The idea that informed risk assessment and vaccine choice are linked to each other has even been turned into a slogan - 'where there is risk, there must be choice' – which is used by bloggers and commenters on *AoA* and *FP* to oppose vaccine mandates.[102] Other blogs represent themselves as advocating for 'informed choice', which would involve individual assessment of the evidence about vaccine risks and benefits. For example, *ANHI* claim to have 'long campaigned for informed choice when it comes to vaccines so that any decision is based on sufficient evidence of both risk and benefit' (ANHI, 24 January 2019). In its main homepage, the blog *VCUK* includes the caption: '[v]accinations; are your choice, make an informed one' (sic). While – presumably because of stricter legal provisions requiring specific vaccinations for school attendance – US-based blogs are more explicitly concerned with pushing back against vaccine mandates, both UK and US blogs seem to understand rational, informed assessment of risks as a precondition to (free) vaccine choice, or the right to choose to accept or reject vaccines.

I will come back to 'vaccine choice' campaigning and its interaction with human rights discourses further on in the chapter. For now, I would like to emphasise that risk assessment and rational choice discourses are not just passively accepted and applied by counterpublic members in ways which might be expected. Rather than being taken as given, what constitutes a 'rational' vaccine decision becomes a contested field – and the symbolic power of rational, informed risk assessment is yielded against the state and its attempts to limit vaccine choice. In this sense, risk discourses appear to be reinvented by vaccine counterpublics as tools of resistance. At the same time, the fact that activists present themselves as empowered to make their own 'informed', rational decisions could be viewed as showing how the 'right to choose' on matters of family life and health is perceived to be dependent on being a rational decision-maker.[103] Being a rational decision-maker, however, is not always associated by counterpublics with balancing risks and benefits in a quantitative way, as will be seen in the following section.

Toxic vaccines and the 'disaster threshold'

Although counterpublic talk often encourages parents to engage in well-informed, rational reasoning in order to make good vaccine decisions, in many instances bloggers just seem to take for granted that

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[102] In the blog posts analysed in this work, this slogan recurs twelve times.

[103] Cf. Sunstein (2005), for a detailed exposition of the argument that risk regulation should be left to experts who are the best suited to rationally assess the available evidence on a specific matter.

vaccines are unsafe and should not be given to children. In these kinds of posts, references to vaccine decision-making emphasise how disastrous, unpredictable, and – in some cases – widespread side effects resulting from immunisations can be. As a consequence, in these vaccine-critical accounts not vaccinating is frequently presented as the *only* choice a reasonable parent could make in order to protect their children's health and wellbeing. This suggests that critics do not always deem it necessary to quantitatively estimate and balance all relevant risks and benefits before deciding to refuse a vaccine, but rather oppose vaccines as a whole.

To support this sort of blanket opposition to vaccination, they make a number of points all directed towards the limitations of a quantitative risk assessment approach for medical decisions generally – and vaccine-related choices in particular. *ANHI*, for example, suggests that it is generally 'difficult for patients to assess risk of harm or potential benefits of a treatment', because of the media and 'pharma spin doctors' misrepresenting risk and misleading the public (29 March 2019). An *AoA* commenter, referring to a study on the safety of the oral polio vaccine describes the vaccine safety data presented in the study as a mere 'fiction' that only looks good on paper, and which people trust only because it has the World Health Organisation logo on it. *VCUK* also raise the problem of the uncertainty which they claim surrounds the determination of actual vaccine risks:

> In the US when you consent to the first vaccine for your baby, you sign a "Vaccine Information Statement"; which states "As with any medicine, there is a very small chance of a vaccine causing a serious injury or death"? How "small" those risks are is not clear.
> (VCUK, August 2018)

In addition, *VP* raise the presumed unreliability of available data on vaccine risks and benefits, noting in particular how vaccine risks have been 'underestimated' and benefits 'overestimated':

> The problem with vaccines is that risks have been underestimated, and the benefits overestimated. In particular, the risk of brain injury from vaccines is much higher than commonly believed. Brain injury can be devastating to the life of a child, and the child's family. The personal and financial costs of vaccine injury are often enormous. Therefore, even a small risk of brain injury must be considered seriously. And the science strongly suggests that the risk is not small.
> (VP, n.d.)

Based on this commentary, it is possible to delineate two main reasons why an approach based on the measurement and comparison of known risks and benefits is sometimes seen as of limited assistance to parents wishing to make informed vaccine choices for their children. First, the available information is perceived by counterpublics as either insufficient – as in the *VP* extract above, which continues by listing a series of 'contributors' to vaccine risks, stating that '...[t]here is not nearly enough science available to accurately estimate these contributors to risk' – or, in the worst case, wilfully misleading (as in the above *ANHI* quote mentioning 'pharma spin doctors'). As the blog *FP* observes, people are aware 'vaccines can and do harm [...] [t]he problem is that we don't know how it happens, how often it happens, and who is susceptible. All three are vital pieces of information' (March 4, 2019). The uncertainty around 'how', 'how often' and 'to whom' harm can happen is particularly problematic, for vaccine critics, because of the severe and life-long repercussions they attribute to childhood vaccine injuries. This uncertainty and fear of a potential incoming 'disaster' is very well encapsulated in a comment posted on *LW* comparing vaccine adverse reactions to peanut allergies, reasoning that even though peanuts are safe to consume for most, they can still be deadly for some people. The author of this comment also notes that while she does not know whether her child is actually among those at risk of significant harm, she would not want to take the chance in order to find out.

As has been previously discussed, all the blogs analysed in this study causally link vaccines to disastrous, life-changing adverse reactions (see Chapter 4). Some bloggers and commenters, such the one just cited, hold the position that serious adverse reactions to childhood vaccinations are rare, but as it is impossible to predict whose children will suffer a serious reaction, vaccines cannot be considered a 'safe product', and should therefore be avoided by parents. Some bloggers and commenters on *AoA* likens the practice of vaccination to 'Russian roulette' (a metaphor which appears in four different posts on the blog), which is intended to capture the notion that the damage that could result from immunisation is considered to be both extreme and unpredictable.[104] Attempts to promote vaccines as one of the safest medical interventions are criticised by another commenter on *AoA* as 'sickeningly patronising'. The blog *VCUK* also appears to accept that injuries caused by childhood vaccines are rare, but because the consequences of such injuries may be disastrous, and they could affect one's own children, the risks involved are still perceived to be unacceptable:

> I accept lots of children are vaccinated with out problem [sic], but how does one tell which children are at risk. Even if the risk is only one in a million, if thats your only child its 100%,

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[104] The expression 'Russian roulette' also links back to the US documentary by the same name which has been indicated as one of the main 'triggers' of the DTP vaccine crisis emerging in the country in 1980s (see Chapter 2).

> Bearing in mind the advice is; “some children should not be vaccinated”, how do we identify who they are [...]
> (VCUK, May 2019)

In these posts, the challenge to public health messages which present vaccines as safe rests not on the frequency of vaccine adverse reactions, but on their potentially ‘devastating’ nature. It should be noted, however, that vaccine-critical talk on US-based blogs often embraces an alternative view that ‘vaccine damage’ is much more common than is represented by public health institutions, the media, and expert commentary. These more radical narratives often paint vaccines as ‘dangerous’ and ‘toxic’ products, or even as ‘poison’. In the context of offering guidance on ‘how to get a vaccine religious exemption’, for example, a blog post on *LW* lists a series of harmful ‘contaminants’ supposedly contained in vaccines: ‘[v]accines contain neurotoxins, hazardous substances, attenuated viruses, animal parts, foreign DNA, albumin from human blood, carcinogens, and chemical wastes that are proven harmful to the human body...’ (LW, 29 June 2019). Commenters on *FP* and *AoA* also frequently make reference to the toxicity of vaccines. On *FP*, a commenter identifying as a healthcare worker speaks of children and adults being ‘killed’ and ‘maimed’ by vaccines. Another commenter expresses concerns about ‘most’ vaccines being manufactured in China, where producers allegedly employ ‘unsafe heavy metals’ in their manufacturing processes. Yet another comment suggests vaccines may be at the root of a rise in ‘autism’, along with ‘other debilitating conditions’, or even death. On *AoA*, I identified more than thirty blog posts containing references to the toxicity of vaccines (for example, one blogger refers to them as ‘dastardly and toxic concoctions’). A commenter suggests extreme reactions to vaccines, including ‘autoimmune encephalitis’, ‘food anaphylaxis’, ‘headbanging’, and even death are not ‘one in a million’, but actually quite common. Another speaks of vaccinations as a ‘mass poisoning’ of children, and a ‘crime against humanity’.

In general, the idea of vaccination as a form of population-wide poisoning is a recurring one among US-based counterpublics, with the word ‘poison’ (or words with the same root, such as ‘poisonous’, ‘poisoning’, or ‘poisoned’) appearing alongside the word ‘vaccines’ in more than one hundred blog posts across the blogs *LW* and *AoA*. *AoA* is notable among blogs for explicitly embracing the existence of an ‘autism epidemic’ or ‘special education epidemic’ (on which the blog has a dedicated series of posts). Some posters (mostly commenters) even write about what they describe as the ‘Vaccine Holocaust’. This expression appears in more than thirty posts on *AoA*, and is used to indicate an ‘expression of medical tyranny’, ‘something destroying our children’, with childhood vaccinations being perceived to be at the root of a growing range of severe conditions affecting the whole population (including autism and the ‘autism epidemic’). The use of these charged expressions and the contexts in which they are employed point to a collective- or publicly-oriented side of counterpublic concerns, which seems to counteract the idea that vaccine critics are 'freeriders' moved by purely self-interested reasoning.[105]

Even in the blogs which depict vaccine injuries as widespread, however, counterpublic talk seems to pay less attention to probabilistic, quantitative risk-related considerations – such as the frequency of adverse events, their distribution in a population, and factors which might contribute to risk in individuals – and more on the qualitative aspects, or the *nature* of the dangers attributed to vaccines. Neurodevelopmental conditions such as autism, commonly seen by vaccine critics as the result of 'brain injuries' or 'autoimmune encephalitis' caused by vaccinations, are particularly feared as 'irreparable harm', having a life-long and life-changing impact not just on the particular children, but on their entire families. As one *AoA* commenter puts it while encouraging parents to exercise their 'medical freedom of choice', you can always decline or delay vaccinations, but you can never 'undo' them. This sense of finality linked to vaccine decisions and their consequences may be taken to indicate that the risk of vaccine harm surpasses what could be described as a counterpublic-specific 'disaster threshold'.

'Disaster threshold' is a concept developed by German sociologist Niklas Luhmann (1993) to point towards a particular limitation of quantitative risk assessment models. For Luhmann, people are willing to perform risk-benefit calculations and accept the result of such calculations as a basis for their decisions 'only when [these calculations do] not touch the threshold beyond which a (however unlikely) misfortune would be experienced as a disaster' (1993, 2). Crucially, what constitutes a disaster cannot be established through objective criteria. As Luhmann argues:

> [the] disaster threshold is set in very different ways by the politically relevant population and above all by the mass media, and it will prove difficult to obtain agreement even on borderline cases because it is precisely here that the exact delimitation of the loss falls within the zone of the uncertain. This means that politics cannot rely on the quantitative calculation of a risk and that it cannot be expected to do so. Instead it has to make do with informal guesses on the effects and above all on the acceptability of its own decisions.
> (1993, 150-151)

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[105] It has to be reminded that parents who refuse vaccination are frequently portrayed as 'selfish' in journalistic reports: see e.g. Siegel and Berezow (2019); Gaskin (2015); Turner (2018).

While Luhmann focuses on the power of the mass media to influence where the 'disaster threshold' is placed in particular cases, this power may extend to new information and communication technologies – particularly the internet and the new forms of agency and collaboration enabled by social media. In their online discussions, vaccine counterpublics set and affirm their own disaster threshold for vaccine-related decisions. The threshold is established by linking particular conditions which can lead to life-long disability (or even death) to vaccines, while framing these conditions as catastrophic for parents making vaccine choices for their children. Seen through this lens, it might easier to explain why messages emphasising the extreme rarity of severe vaccine adverse reactions generally fail to persuade vaccine sceptics about the safety of immunisations. If the 'disaster threshold' has been met, so that an alleged adverse reaction is considered to be catastrophically harmful, pointing to the quantitative aspect of how 'unlikely' it is to happen will not make it any more acceptable to parents. In other words, the extreme severity of perceived vaccine hazards put these beyond the realm of risk/benefit calculations.

In fact, public health or mainstream media messages emphasising the rarity of severe reactions to vaccines may even unwittingly perpetuate vaccine-critical framings of vaccinations as fundamentally unsafe medical procedures which should in all cases be rejected by parents. In the absence of any qualifications regarding the *nature* or quality of the adverse events being discussed, these messages are interpreted by vaccine counterpublics as confirmation of the reality of what they see as specific, 'disastrous' outcomes of vaccinations – including autism and death. Viewing the notions of risk and disaster from Luhmann's subjectivist perspective, a refusal to engage in quantitative risk analysis does not make counterpublic normative beliefs around vaccine decision-making 'irrational'. What it shows is instead a move by some counterpublic members to assert their own vision of vaccine risks as beyond acceptability, and thus impervious to public health discourses which stress the positive risk-benefit profile of vaccines. What this implies in terms of vaccine-critical activist mobilisation and advocacy is a question which will be explored in the next part of the chapter.

Informed consent and parental 'vaccine choice' advocacy

This section moves from the findings presented in the previous part of the chapter about vaccine-critical normative beliefs and vaccination decision-making to explore the ways in which counterpublics construct and advocate for parental 'vaccine choice' rights. An analysis of the data collected on bloggers' advocacy activities revealed that the legal concept of 'informed consent' has a very significant role in counterpublic talk opposing any restrictions upon vaccine choice. In bioethical scholarship, informed consent is often represented as an applied expression of the principle of autonomy in the realm of health care (see Kukla 2005). According to Rebecca Kukla, in traditional medical ethics, patients 'can exercise their autonomy only through the act of choosing once they are already informed' (Kukla 2007, 27). This traditional view of informed consent regards the patient as a 'passive' recipient of expert medical information communicated to her by healthcare professionals. When discussing informed consent, medical ethicists tend to focus on how to ensure patients understand the information they receive from medical professionals, rather than what happens before consent is (or is not) given, including the information-gathering that many patients engage in independently of their doctors or healthcare providers (2007, 28-29)

The way online vaccine-critical talk engages with the notion of informed consent lends support to Kukla's critique of the narrow scope of traditional bioethical approaches to informed consent. References to 'informed consent' are present across all sampled blogs except for *VP*, for a total of more than eighty posts across *AoA*, *LW*, *FP*, and *ANHI*. In these blogs, informed consent is generally constructed by counterpublic members as an 'ideal', which has been 'betrayed' by the state and medical professionals, and which they have to actively fight to restore. As the blog *FP* notes:

> If our government feels compelled to recommend vaccines for public health reasons, so be it. But it must give parents informed consent: Information on the risks and benefits plus the opportunity to consent or decline. This happens to be the *international human rights standard* (see Article 6) and a requirement in the practice of ethical medicine. This is not what's happening, however. "There is no federal requirement for informed consent related to immunization," says the CDC.
> (FP, 11 June 2018, emphasis added)

The above quote is interesting in that it contrasts what are seen as the ideals of an 'international human rights standard' of informed consent (for which the blogger refers to Article 6 of the UNESCO Declaration of Bioethics and Human Rights) to the reality of the blogger's legal system which is said to fall short of such ideals.[106] Discourses surrounding 'human rights', 'constitutional rights', 'individual rights and freedoms', 'civil rights' and 'parental rights' are often invoked by counterpublics in the context of appeals to informed consent – with the word 'rights' appearing alongside 'informed consent' in more than fifty posts across all above-mentioned blogs. Such discourses are especially relevant to

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[106] While it is true that in the US there is no Federal Government requirement to provide informed consent for immunizations, some state-level and local regulations have set out their particular informed consent requirements for vaccination. In addition, the NCVIA 1986 provides that vaccine recipients, or their parents or legal guardians, should be given a Vaccine Information Statement (or 'VIS') setting out risks and benefits for each vaccine. For more detailed expositions of informed consent laws in the context of vaccination see Parmet (2005); Reiss and Karako-Eyal (2019).

vaccine-critical talk in which such 'rights' are perceived to be, and are represented as being constantly 'violated', 'impinged upon', 'restricted', 'twisted', 'denied access to', 'interfered with', 'trampled on' and 'taken away'. Parents are encouraged to, among other things, 'not give up', 'exercise' and 'fight to protect' their 'vaccine rights', appealing to broader, rights-based legal discourses to ground their advocacy for medical and vaccine choice.

The contexts in which vaccine counterpublic members speak about informed consent sheds further light on the complex relationship between lay and expert medical knowledge discussed above. For vaccine critics, the right to informed consent is about more than being able to understand the information given to them by a doctor. Rather, informed consent takes on a markedly political dimension in counterpublic talk, in so far as it is framed as being about laypeople having a stake in shaping the relationship between expert knowledge, the state, and individual parents.[107] This can be seen in the two main ways in which the legal concept of informed consent is 'hijacked' and modulated by counterpublics, based upon whether they are opposing governmental restrictions to vaccine choice, or actively trying to influence other parents' vaccination decisions.

When discussing existing or proposed 'vaccination mandates', usually in the form of restrictions on vaccination exemptions in the US, counterpublics often invoke 'informed consent' as an expression of their 'parental rights', interpreting it as if it conferred upon parents the *exclusive* right to make medical decisions (including vaccine-related decisions) for their children. While advocating for 'informed consent' in this sense, counterpublics often depict 'the parents' and 'the state' as in fundamental opposition to each other, arguing that only the former have the best interest of children at heart. The transcript of a public presentation by an *AoA* blogger for an organisation called 'Your Health Freedom' includes a good example of this:

> Why is it legal to restrict and eliminate parental rights with regard to medical decision making for their children? *Children belong to their parents, not to the state. Parents know their children best.* They know their family medical history best. *They will personally bear the responsibility for any and all health-related decisions they make on behalf of their children, and therefore, the decisions are theirs alone to make.* (AoA, 8 November 2018)

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[107] It has to be noted that this 'politicisation' of the language of informed consent is not unique to vaccine-critical activism but is rather shared by other groups in different domains, such as abortion and end-of-life decision-making, as will be seen later on in this section.

The idea that 'parents know best' seems to be shared by multiple commenters on the blog *AoA*. One comment, for example, claims that it would be easy for the state to 'manufacture' a health emergency if they wanted to, while ignoring real emergencies such as the 'autism epidemic' or other damage which they claim is caused by 'forced vaccination'. This is why, the commenter argues, people should be advocating for 'full' implementation of 'individual and parental rights' to make all medical decisions for children, which is seen as the only way to prevent medical and vaccine-related harm. Another comment claims that childhood vaccinations represent an attempt by the state to 'centrally plan' people's healthcare, while claiming vaccination programmes are based on 'fraud' and 'coercion'. Because of this, the comment continues, there should be a 'separation' of vaccination and the state, and 'parents and individuals' should be able to determine how best to safeguard themselves and their children against diseases, 'on the basis of informed consent'. The same commenter in another post also refers to the idea of parents having to use their 'medical freedom' in order to protect their children, stating that without this kind of freedom it is not possible to effectively defend children from 'vaccine dangers'. The main enemy of medical freedom and parental rights, another commenter writes, is 'mandated medicine', as this would violate a 'most fundamental human right', that is the right of a person to determine what is and what is not done to one's own body, as well as to the body of one's children. The commenter concludes that vaccine mandates shouldn't be allowed in a 'free' and 'ethical' society.

In these blog posts and comments which set 'parents' against 'the state' in medical decision-making, two main points are generally raised. First, reflecting the beliefs presented earlier on in this chapter, it is a parent's duty to ensure children's health is protected by taking an active part in all of the medical choices that could affect their wellbeing. Second, and related to this, it is claimed that the state does not actually have children's health and wellbeing at heart.

The fact that vaccine critics who identify as parents see it as their responsibility to exercise 'vaccine choice' for their children may be directly observed among US-based counterpublics in the work and research they put into crafting legalistic arguments for 'vaccine exemption' applications. *LW*, in particular, has a dedicated blog post and lengthy comment thread on the subject of religious vaccine exemptions. This post has become a site of practical advice and support in which the blogger, as well as individual 'well-researched' commenters, offer recommendations on how to draft applications for vaccine exemptions on religious grounds. Religious exemptions are provided for in many US states in which immunisation is otherwise a required condition for school enrolment. While explaining to her readers how to articulate the purely 'religious' grounds which will enable them to successfully 'get an exemption', *LW* warns against including 'too much story and not enough facts' in one's application, stressing that an exemption application is not the place 'to tell an emotional story' ('[y]ou want an exemption, not for someone to hand you a box of Kleenex'). Should a parent get carried away and 'talk too much' they might have their application rejected: '[t]he next thing you know, you've argued for a philosophic exemption that your state doesn't even offer and your religious exemption is denied' (LW, 23 June 2019).

By referring to philosophical exemptions and advising parents not to 'mix up' their religious arguments with 'external' concerns, the blogger is implying that there are a multiplicity of reasons to reject vaccines, and parents need to be careful to select the 'right reasons' in order to succeed in their legal applications. This should be done even when parents may have other reasons for refusal, such as their concerns about the severe adverse reactions they attribute to vaccines. 'Philosophical' exemptions might allow these health concerns to be expressed more freely by parents: the above-mentioned *LW* blog post specifically mentions not wanting one's child 'to live the rest of their life with a catastrophic medical condition' as a possible 'philosophical' (but not 'religious') ground for exemption. However, as philosophical (or 'personal belief') exemptions are not as largely available as religious exemptions on a state level, the latter are often the only available route for some US parents who wish to decline childhood vaccinations.[108] This means that many vaccine critics put considerable time and resources into exemption applications in order to exercise their 'parental rights'. And they are encouraged to do so by counterpublics: as the *LW* blogger writes, addressing other parents, '[y]ou are never too old for homework, and we are saving rights ~~lives~~ [sic] here'.

In certain US states, religious exemptions are especially difficult to obtain, requiring official certification of the relevant religious beliefs from a doctor, religious leader or government official. *LW* is critical of more demanding and bureaucratic exemption procedures, claiming that their purpose is to 'trip [parents] up with tricky questions designed by vaccine enthusiasts to rob people of their rights'. Despite this, counterpublic members still put in considerable effort in order to draft good applications, sometimes engaging with complex debates about the legal definition of 'religious belief', the constitutionality of state exemption application processes, and their compatibility with 'informed consent'. The intensity of such efforts suggests that vaccine critics see themselves as having to 'fight' against the state to protect their children's health, and to champion their 'rights'. In addition, it shows that applying for exemptions is perceived to belong to the sphere of risk-management responsibilities and duties which – as previously mentioned in the chapter – counterpublics link to good parenthood.

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[108] Medical exemptions are also a possibility, as they are provided in all US states, but arguably much harder to obtain in that they require the presence of a 'recognised medical condition' for which there is evidence of heightened health risks resulting from certain vaccines.

This once again reflects the normative belief that vaccine decisions should be actively researched, assessed and independently managed by individual parents.

The second, and related point made by counterpublics on vaccine choice is that the state can never be trusted to prioritise children's health. On this point, an *AoA* blogger warns against complying with governmental vaccination policies, referring to the 'Alfie Evans case' (in which a UK court had supported the medical decision to withdraw life support from an infant boy suffering from a devastating neurodegenerative disease) as an instance where 'parents rights were ignored'. The blogger then proceeds to recommend readers not to 'hand over your parental rights or bodily autonomy' to anyone else. In the same post, it is maintained that long-standing principles of medical ethics are no longer followed in 'our very fragile world', in which the '[p]harmaceutical [l]obby ... manipulate our Government into destroying our health for profit' (11 May 2018).

Another comment describes proponents of mandatory vaccinations as supporters of 'forced injections of dangerous products', which disregard informed consent and other protections afforded by the law. In an 'open letter' shared on *AoA* opposing a government bill aimed at restricting vaccine exemptions in one US state, restrictive vaccination policies are even compared to sexual assault. More specifically, the letter contends that a 'medical rape culture' exists in the US, in which '[i]nstead of respecting your personal space, we say "we'll come at you because we're bigger than you and we can take away your privileges to get you to do what we want you to do"'. Yet other *AoA* commenters complain about 'governmental coercion', and a supposed generalised violation by the state of people's 'humanitarian right to informed consent'. The nature of the relationships between counterpublics, the state, and other actors involved in vaccination policy and communication is further explored in the following two chapters of this work. For now, it is sufficient to note that counterpublic members wishing to assert authority over their children's vaccine decisions, and their mobilisation of the concept of informed consent to oppose 'vaccine mandates' is related to a desire to protect children against a system perceived to have priorities other than safeguarding individual children's health.

Other blogs beyond *AoA* discuss 'medical freedom' in the context of a general distrust of the state and its institutions. *ANHI*, for example, claims that the US Department of Health and Human Services has failed to submit specific 'vaccine safety reports' which are required under the National Childhood Vaccine Injury Act of 1986, and refers to this as 'clear proof why parents need to make their own informed choices about vaccination rather than relying on the authorities' (26 July 2018). *FP* commenters also question the motives of public health policy, with one comment on the blog stating that vaccine policies are about 'control' rather than public health and 'children's safety'.

The blog *FP* is generally very active in advocating for parents to be able to make independent decisions on childhood vaccines, and it also refers to informed consent as something that parents should 'use' in order to make choices about vaccination. For instance, a *FP* blog post argues that '[p]arents have a fundamental right to use informed consent to determine if the benefits [of vaccines] outweigh the risks for their child', adding that '[i]t is not the role of government to make health care decisions for people and especially children' (11 June 2018).

The idea that parents are generally best placed to make medical decisions for their children, as they care the most about them and want the best for them, resonate with certain medical ethics arguments in favour of a high threshold for state interference with parental autonomy (see e.g. Diekema 2004). However, these arguments rest upon the assumption that there is a point beyond which parental medical decisions should not be accepted by the state. Douglas Diekema (2004), for example, argues in favour of a 'significant harm threshold' in order to determine whether a parent's choice should be overruled. Vaccine counterpublics, in contrast, hold different views around the role of the state and parents in medical decision-making and risk assessment, and – as will be discussed in further detail in Chapter 6 – they view the state as uncaring towards the wellbeing of individual children, and therefore untrustworthy when it comes to children's medical decisions. These beliefs arguably lie at the basis of vaccine critics' more absolutist position that parents should have exclusive responsibility over their children's health choices. They also shape counterpublic framings of 'informed consent' as linked to 'parental rights' and 'individual freedoms', and as incompatible with any governmental restriction of parental vaccination choices.

In the first part of the chapter, I also discussed how counterpublics depict vaccines as being so dangerous that no reasonable parent would ever accept them for their children. Given this fact, it might seem surprising that blogs campaign for the freedom to refuse vaccines, rather than advocating instead for more substantial public health changes, such as the banning or recall of some or all vaccines. This focus on individual and 'negative rights' in counterpublic advocacy activities might at first appear to be in tension with the concern for the health of all children which is expressed across the sampled blogs. However, I do not see this particular interpretation of informed consent as a 'negative right' to refuse vaccines as indicating that counterpublics adopt a broadly individualistic worldview. In fact, while some counterpublic members espouse libertarian-leaning views (particularly among US-based blogs and their comment sections), such views are far from universally accepted by all vaccine critics. Instead of using ideological lenses such as libertarianism or individualism to define vaccine-critical activists, I would argue that invocations of 'informed consent' to affirm parental choice against the threat of vaccine mandates are, at least partly, an example of pragmatism. Eliminating 'vaccine mandates', or extending exemptions, is a more realistic and attainable outcome than an outright 'ban' on all vaccines. Talk about banning all vaccines is rare and not 'mainstream' even across vaccine counterpublics. However, at least some counterpublic members (particularly on *AoA*) do expressly support the idea of banning or imposing a 'moratorium' on vaccines – with one commenter putting this in terms of fighting to end 'child abuse' and protecting children's 'human rights'.

There is, moreover, a second way in which the concept of 'informed consent' appears in vaccine critical talk, which follows more straightforwardly from the 'communitarian' dimension of vaccine-critical activism, discussed earlier in this chapter. This idea manifests itself in what counterpublics refer to as 'truly' or 'fully informed consent'. The implication is that even when parents actively enquire about the safety of vaccines, they are not told the full story, which results in ill-informed parents underestimating the 'real' risks posed by vaccinations. An *AoA* blogger, for example, laments how even in a country without any direct legislative restrictions on parents' vaccination choice, such as the UK, vaccine compliance is still 'very high', and 'informed consent' is weak. 'The compulsion', the blogger argues, is to be traced to societal rather than legislative pressures, coming mainly from 'the media' and 'some voices inside the [medical] profession'.

A commenter on *LW* also blames the media for what they see as a lack of informed consent in society, claiming it would be 'naïve' to expect mainstream media to seriously investigate reports of vaccine injury. The commenter adds that although there are 'self-funded YouTube videos' and 'blogs' providing 'more accurate' vaccine information, they cannot guarantee the 'truly informed consent' that, they argue, should be the right of every parent. 'Believing everything mainstream media tells you', is something that tends to be associated in these kinds of comments to 'unthinking' parenthood. According to counterpublics' perspective, this does not mean that most parents are careless, but rather that they have been kept in ignorance about the 'true dangers' allegedly posed by vaccines. In the words of another commenter, vaccine compliance is generally 'best served by ignorance', when parents 'unthinkingly' vaccinate their children while believing that they are doing 'the right thing'. Vaccine injury is therefore, according to these views, enabled by a lack of informed consent caused by widespread 'ignorance' of vaccine-critical information.

In opposition to this, vaccine counterpublics suggest that it is only by looking beyond professional claims that vaccines are safe, and researching alternative vaccine-critical materials, that parents become able to give 'fully informed consent'. As put in an *AoA* introductory post, '[p]arents should find ways to educate themselves *and each other* about the risks' (AoA, n.d., emphasis added). This philosophy of direct involvement in other parents' assessment of vaccine-related risks is shared by UK-based blogs. According to *VCUK*, the '[p]harmaceutical industry gloss over side effects in UK (sic) when advising parents to vaccinate.' The blog also states that new parents will not be informed about vaccine side effects by the 'red book' – that is the 'Personal Child Health Record' that is given to all UK parents at a child's birth in order to track their development. Blog readers are instead invited to link to the US Vaccine Information Statement which, as stated in the blog, does warn patients about 'actual risks' of 'serious injury' and 'death'.

Another UK-based blog, *ANHI*, also invokes the idea of 'fully informed consent' as requiring access to information constructed and shared by 'alternative' health sources. For example, in a blog post discussing the introduction of the HPV vaccine in Senegal, with the support of the non-governmental organisation Gavi, the Vaccine Alliance ('GAVI') *ANHI* bloggers express their hope that Senegalese parents 'will be party to a *fully informed consent* process', and 'given unbiased information about the vaccine, including its potential to cause harm, before their child is vaccinated' (ANHI, 7 November 2018, emphasis added).[109] In addition, *ANHI* invites all its parent-readers to consult their website prior to deciding whether to accept the HPV vaccine for their children, emphasising that this will enable them to make a 'fully informed decision':

> Before you make a decision whether or not to allow your child to be given the HPV vaccine, take a look at our HPV vaccine campaign page so you can make a *fully informed decision*. If you haven't already done so, please consider signing (and sharing) our petition calling on health authorities to stop claiming vaccines are 'safe' to *safeguard informed choice and consent over vaccination*. (ANHI, 7 November 2018, emphases added)

As seen in the quote above, the act of signing a petition in order to stop authorities from claiming vaccines are safe is also represented as helping to 'safeguard' informed consent. That being said, different counterpublic members have different ideas about what exactly 'truly informed consent' entails. An *AoA* commenter, for example, argues that all paediatricians should be required to have posters in their waiting rooms stating that no one can be held liable in case of adverse reactions to vaccination, that vaccines have not been sufficiently tested, and that sudden infant death syndrome (SIDS) might be caused by vaccines. What emerges more generally across the sampled counterpublics is the idea that the critical information counterpublic members are involved in constructing and sharing should somehow form part of the informed consent process for childhood vaccines.

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[109] GAVI (officially 'Gavi, the Vaccine Alliance') is an international organisation focused on access to vaccination in developing countries, which was set up in 2000 by the Bill & Melinda Gates Foundation.

Furthermore, as will be seen in further detail in Chapter 6, counterpublics derive some of the 'evidence' supporting their beliefs that vaccines are fundamentally unsafe from certain aspects of the regulatory and legal frameworks surrounding vaccination. For example, an *AoA* blog post describes how, in response to a number of governmental bills that would have restricted vaccine exemptions in a particular US state, the blogger's local vaccine-critical advocacy group presented their own 'Vaccine Consumer Protection' bill. The post goes on to explain how this proposed bill '...would, among other things, require that physicians and medical professionals be mandated an education on vaccine risk, injuries, contraindications and adverse outcomes via the vaccine package insert and the HRSA Vaccine Injury Compensation Program Table' (12 November 2018). The same blogger is also strongly critical of health professionals, claiming they opposed the vaccine critics' Bill while not knowing anything about 'federal vaccine safety guidelines'. This implies a belief that counterpublics are better informed than experts in relation to issues of vaccine safety.

It is interesting to note how this kind of counterpublic talk again departs from a view of informed consent which depicts patients as passively receiving information from their healthcare providers. As Kukla (2007) has put it, '[b]ioethics literature depicts "informing the patient" as something that clinicians do to patients and assumes that patients accept their doctors as authoritative experts'. As discussed in Chapter 4, vaccine counterpublics claim a sort of 'quasi-expertise' over vaccine-related matters, and have their own selected sources of information which they rely on and regard as superior to 'mainstream' or official expert knowledge.[110] But counterpublic members go beyond being 'autonomous patients' who actively seek and use information without relying on expert medical professionals. By advocating for 'fully informed consent' for everyone, counterpublics aim to directly influence parental vaccine decision-making, by shaping the information which is provided to parents before they vaccinate their children. In other words, counterpublics' 'informed consent' advocacy is not limited to opposing vaccination mandates in a negative fashion –they also perceive it to be their duty to actively 'educate' parents about the 'real risks' supposedly presented by vaccination.

It should be pointed out that this use of the legal language of informed consent, and particularly the framing of 'fully' or 'truly' informed consent is not unique to vaccine-critical activists. Rather, it belongs to a broader context of social movement tactics and advocacy strategies which are shared across different groups campaigning around health-related issues. For example, a comparison may be drawn between vaccine critics' invocations of informed consent to justify conveying their 'alternative'

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[110] The link between vaccine critics' selection of specific sources of information on vaccinations and the construction of vaccine-critical collective identities by counterpublics is further discussed in Chapter 7.

information on vaccination to parents and the deployment of the same discourses of informed consent to ground the introduction of mandatory ultrasound legislation in several US states (Sanger 2008; see also Sanger 2016; Suter 2013). Mandatory ultrasound laws provide that women should undergo ultrasound scans and receive images of their foetuses before being allowed to consent to abortion. These laws have been justified through the argument that, without the ultrasound, a woman's consent to abortion would not be 'fully informed' (Sanger 2008). Legal scholar Carol Sanger (2008; 2016) has written critically about such legislation, contending that the mandatory ultrasound requirement represents an attempt to 'bend a woman's will once she has already made up her mind to seek an abortion' (2008, 362). 'Mandatory ultrasound statutes', she notes, 'interfere with the profoundly personal considerations that go into reaching an abortion decision' (2008, 363). In doing so, the legislation transcends the scope of 'medically informed consent' and enters that of what Sanger terms 'morally informed consent' (351; see also 2016, 660).

Sonia M. Suter (2013) has also highlighted the contentious nature of mandatory disclosure in the context of abortion, while additionally noting how, in the US, prescriptive 'informed consent' statutes have similarly been adopted in the realm of end-of-life care. In relation to end-of-life care, state informed consent legislation has been opposed by religious conservative campaigners – a political inversion of roles compared with the case of mandatory ultrasound laws. Despite these differences, Suter argues, in both contexts taking patients' decision-making processes seriously requires more than simply mandating that a patient receives particular pieces of information – rather, the possibility of 'supportive dialogue' should be offered to help patients better understand the information 'in light of [their] circumstances and beliefs' (2013, 60). Of course, the issues raised by abortion and end-of life care decisions are distinct from those raised by vaccination. However, the fact that appeals to 'fully' informed consent are shared by advocates across different health-related domains is still worthy of note and further investigation, as it reveals a broader trend through which 'informed consent' has become part of the legal rhetoric deployed in multiple (and often controversial) ways to achieve diverse political objectives.

In the case of vaccine-critical activism, providing a picture of vaccine-related 'risks' consistent with counterpublics' beliefs would result in dissuading parents from vaccinating, which is why this way of intending informed consent makes up a crucial part of how counterpublics seek to achieve 'vaccine choice' in a more 'collectivist', public-oriented sense. This, again, challenges the idea that vaccine critics and their demands can be neatly accounted for by referring to individualist ideologies, or to the notion of 'anti-vaxxers' being driven only by self-interest. Rather than seeing a contradiction between individual and collective interests, and portraying vaccine-critical activism as embracing the former, I would argue that counterpublic members' explicit expressions of concern and advocacy for the health of 'all children' and their families is consistent with their beliefs about exclusive parental responsibility over children's medical decisions. Indeed, the kind of opposition most commonly drawn in vaccine-critical talk across blogs is not between the interests of individuals/families and broader society, but instead between an uncaring state and children's health. Parents are seen as the sole champions of children's health, and they can only safeguard children against external 'dangers' (such as the ones ostensibly posed by vaccines) through the exercise of their 'true' and 'full' informed consent rights.

The two main ways in which vaccine counterpublics deploy the notion of informed consent to advocate for vaccine choice differ in the emphasis they put on individual 'parental rights' and 'fully informed consent' for everyone. This apparent conflict, however, disappears by abandoning the idea of vaccine critics as fundamentally individualist and self-interested, and instead recognising that for counterpublics there is no incompatibility between family responsibilities and broader community concerns. At the same time, both ways of advocating for vaccine choice involve the strategy of 'hijacking' a pre-existing legal framework (here, the right to informed consent) in order to pursue their advocacy objectives.

Conclusions

Vaccine critics are often assumed to be irrational, making decisions based on emotions and feelings. Alternatively, they are regarded as selfish and self-interested, their risk judgment coloured by a highly individualistic libertarian ideology. This chapter shows these assumptions to be inaccurate, at least in relation to some online vaccine counterpublics. Indeed, vaccine counterpublic members have been shown not to be intrinsically opposed to cost-benefit analysis and rational risk assessment, with some vaccine critics explicitly claiming to be engaging in a rational calculation when making vaccine-related decisions for their children. At the same time, many counterpublic members argue that the risks associated with vaccines are so severe that no reasonable parent aware of these risks would agree to have their children vaccinated. This latter framing highlights the emphasis vaccine critics put into qualitative rather than quantitative aspects of risk, such as the severity of vaccine risks and the fact they can affect one's own children. Looking into critical beliefs on vaccine decision-making also revealed that counterpublic members do not just care about the wellbeing of their own families. Rather, there is a clear communitarian or public-oriented dimension to vaccine critical activism.

In the second part of the chapter, I discussed how vaccine counterpublics' normative beliefs around vaccine decision-making are reflected in their advocacy activities and in how they articulate their demands for 'vaccine choice'. Vaccine-critical advocacy not only involves resistance to vaccine mandates, but also seeks to discourage other (non-counterpublic) parents from vaccinating their children. In this context, a key role is played by the notion of 'informed consent', which is 'hijacked' and reframed by vaccine critics to mean, in the first instance, *exclusive* parental authority over children's vaccine decisions and, second, being 'fully' informed by consulting alternative sources of information about vaccine risks. While not exclusive to vaccine-critical activism, the idea of a 'fully' or 'truly' informed consent is a recurrent one among vaccine counterpublics. It emerges in order to support counterpublic members' active involvement in providing vaccine-critical information to parents. At a micro level, counterpublic involvement in information-provision is intended to dissuade parents from consenting to vaccination, while at the same time, it is an example of the more public-oriented and 'communitarian' side of vaccine-critical activism and advocacy. But 'vaccine choice' advocacy also relies on the sharing of particular vaccine-critical framings of issues of vaccine safety, including the role of the state in managing vaccine-related risks across the population. How such beliefs are constructed and justified will be the subject of the next chapter.

6

THE UNWITTING CONTRIBUTION OF REGULATION TO CRITICAL BELIEFS ON VACCINE SAFETY

Introduction

According to the normative beliefs around parental vaccine decision-making examined in the previous chapter, which are also reflected in the interpretations of 'informed consent' proposed by counterpublics, parents should assume personal responsibility to educate themselves about the 'real' risks and dangers posed by vaccines. This is consistent with the way in which counterpublics invite their members and readers to 'do their own research' on vaccines, with the goal of becoming 'informed' or 'educated' enough to be able to make the best possible decisions for their children, and turning themselves into independent and self-reliant learners in the process. In the context of their knowledge-making and sharing activities, vaccine critics commonly refer to the 'peer-reviewed science' as 'evidence' purportedly proving the existence of causal links between vaccinations and certain severe conditions (see Chapter 4). However, beyond the reworking and sharing of scientific sources, the advocacy activities of vaccine counterpublics, and particularly their campaigning for 'vaccine choice' relies on other aspects of the state's role in the implementation of policies intended to ensure public confidence in national immunisation programmes. This chapter looks at how reinterpretations of information coming from official regulatory and legal sources play a key role in counterpublic justifications of their beliefs about vaccine safety.

More specifically, the chapter focuses on how patient information leaflets (PILs, also known as 'package inserts' in the US), 'passive' post-licensing surveillance systems (particularly the US Vaccine Adverse Events Reporting System, or VAERS, and the UK Yellow Card Scheme) and vaccine injury compensation schemes are reinterpreted in order to be invoked in support of three main counterpublic narratives about vaccine dangers. The first narrative is that official messages about vaccine safety are masking their 'hidden' risks, which parents will only discover by researching the 'fine print' information drawn from vaccine PILs/package inserts. A second narrative based on the VAERS and the Yellow Card Scheme depicts vaccine risks as being grossly underestimated by authorities. Third, the existence of compensation schemes is used to claim that the state and public health institutions are concerned only with population-level statistics, and that they are indifferent towards the wellbeing of individual children and their families. Counterpublics believe that vaccines cause injuries which are too severe to be acceptable, let alone adequately compensated through a monetary award, thus leaving parents as the only true 'champions' of their children's health. This claim is used to further justify the argument that families are the only legitimate locus of vaccine choice (see Chapter 5), as well as to promote representations of the state as fundamentally incapable of guaranteeing adequate safeguards in its immunization programmes.

The chapter begins with a brief overview of the regulation of medicinal products, including vaccines, in the UK and the US national legal systems, and of the relation between these national systems and surrounding international frameworks. In this first section, a particular focus is on how pharmaceutical regulation applies in relation to vaccines, and how it is intended to reassure citizens about the high safety standards of national immunisation programmes (which might reasonably be expected to build public trust and confidence in vaccine safety). In the following sections of the chapter I look at how counterpublic members interact with the regulatory and legal frameworks surrounding the production and delivery of vaccines. My aim here is twofold. First, I want to show that the normative beliefs espoused by online vaccine critics around vaccine safety and parental responsibilities have an impact upon how they perceive regulatory institutions. Second, I put forward the argument that the representations of vaccine safety and critiques of state immunisation policies embraced by counterpublics are sometimes pursued by appropriating and reworking certain elements of the existing regulatory-legal frameworks surrounding vaccination.

Biological medical products and vaccine regulatory frameworks

Vaccines, as medicinal products, are embedded in the complex web of rules, regulations and guidance set out by national and international authorities to govern the development, licensing and surveillance ('pharmacovigilance') of medicines. The regulatory frameworks for medicines are established at the national level by national regulatory authorities (also referred to as NRAs), which in turn refer to guidance from the World Health Organisation on scientific, regulatory and methodological questions. In the UK, matters related to medicinal products in general, including their manufacture, distribution, sale, supply, import, marketing, and surveillance, are regulated by the regime set out in the Human Medicines Regulations 2012 (HMRs 2012). Prior to Brexit, EU legislation required 'biotechnological medicines' to obtain marketing authorisations from a supra-national authority, the European Medicines

Agency (EMA).[111] The EMA is an expert body tasked with the scientific evaluation of medicines in the EU, and responsible for the post-marketing surveillance of vaccines. However, following Brexit, the UK vaccine regulatory picture has transformed, with the London-based Medicines and Healthcare Products Regulatory Agency (MHRA) becoming the standalone UK authority responsible for marketing authorisations for medicinal products and also for pharmacovigilance across the UK.[112] In addition to this, in relation to vaccines specifically, the UK follows guidance from a national independent advisory body, the Joint Committee on Vaccination and Immunisation (JCVI), which is made up of expert members and issues recommendations to the government regarding immunisation schedules and questions of vaccine safety.

In the United States, the Food and Drug Administration's Center for Biologics and Evaluation Research (the FDA's CBER) is the authority responsible for regulating biological medical products, including vaccines. The FDA also grants approval for the marketing of individual vaccines, following three phases of clinical trials,[113] an official inspection of the proposed manufacturing facilities for the relevant vaccine, and the presentation of preliminary findings to a specialised committee of non-FDA experts (the Vaccines and Related Biological Products Advisory Committee), which advises the FDA on the safety and effectiveness of vaccines for their intended use.[114] During this stage, the proposed drug labelling (which includes packaging and information leaflets) is also reviewed. If a vaccine is approved and licensed by the FDA, it may be added to the US Recommended Immunization Schedule through a separate procedure involving a review from another expert body, the Advisory Committee on Immunization Practices (ACIP), whose recommendations have to be approved by the Director of the US Centers for Disease Control and Prevention (CDC). Further studies are conducted after a vaccine is approved, in order to monitor its safety in the general population. In many cases, manufacturers will have so-called 'phase four', or formal post-licensing studies conducted on their marketed vaccines. The FDA, in conjunction with the CDC, is also responsible for post-licensing vaccine surveillance in the US, which continues for as long as a specific vaccine is in production.

The intricacies of the US and UK frameworks outlined above, and the multi-layered nature of vaccine regulation, which relies on the collaboration of a multiplicity of actors – private companies,

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[111] See particularly Directive 2001/83/EC (as amended by Directive 2003/63/EC).

[112] The new MHRA guidance covering pharmaceutical-related issues such as clinical trials, licensing, importing and exporting medicinal products and pharmacovigilance, have been implemented through the Human Medicines Regulations (Amendment etc.) (EU Exit) Regulations 2019. It should be noted that Northern Ireland follows a different regime than the rest of the UK, and while its national competent authority remains the MHRA, the EU regulatory regime still applies to medicines and medical devices in Northern Ireland (see Kerr-Peterson and Summerfield 2020).

[113] The start of human clinical trials is also subject to authorisation based on the results of a previous phase of animal testing.

[114] For further information on the role of the Committee, see https://www.fda.gov/advisory-committees/blood-vaccines-and-other-biologics/vaccines-and-related-biological-products-advisory-committee.

governmental authorities, committees of experts, and international bodies – may reasonably be seen as offering powerful evidence of the stringency of controls to which vaccines are subject both prior to and following licensing. However, the strict processes in place to approve vaccines and to monitor their effectiveness and safety after approval, do not appear to positively affect counterpublic members' views about the safety of vaccines. In fact, as will be observed, some aspects of the regulatory systems underlying national immunisation programmes are referred to and 'recast' by critics in order to consolidate and justify their beliefs regarding the general unsafety of vaccinations. There are three components of the UK and US vaccine regulatory frameworks, in particular, which often recur in vaccine critical talk: vaccine package inserts (or patient information leaflets – PILs – as they are also known in the UK), adverse events reporting systems, and vaccine injury compensation (or payment) schemes. These three components of the UK and US national vaccine regulatory and legislative regimes, and specifically how they are being recast in vaccine-critical talk to support critical views of vaccination safety, will be the main subject of focus in the following three sections of the chapter.

The legal construction of vaccine dangers: vaccine patient information leaflets/vaccine package inserts

As previously discussed, vaccine counterpublics use information drawn from different reputable or 'official' sources to support claims that vaccines cause certain severe and irreversible health conditions. Regulatory sources, however, also feature in a prominent way in broader counterpublic narratives justifying vaccine-critical beliefs around vaccine safety and the roles played by the state and parents respectively in managing vaccine-related risks. Vaccine patient information leaflets (PILs) or vaccine package inserts (as they are known in the US) are among the sources offered by critics in support of their beliefs. Vaccine package inserts are considered as part of the 'labelling' of vaccines. They are therefore subject to approval during the vaccine licensing process. Package inserts/PILs are highly regulated, standardised technical documents included in all medicine packaging, and their purpose is to convey to patients (or their parents/guardians) information about the administration and risks of medications. This information is drawn from different sources, including clinical trials and post-licensing pharmacovigilance studies. By recasting PILs in such a way, counterpublic members are particularly attempting to redefine and justify a more active role for parents in making risk assessments in order to make the best vaccine decisions for their children.

More specifically, rather than passively accepting regulatory frameworks as external guarantors of vaccine safety, counterpublic members approach these frameworks critically, and evaluate them as they would any other sources of information about vaccines, while reclaiming their authority to actively decide what is (and what is not) a safe product for their children. For example, in the context of vaccine critics' exhortations to 'educate oneself', reading vaccine inserts is presented as one of many things diligent parents need to do before deciding whether to vaccinate their children. As stated in a comment on *LW*, it is not enough for a parent to be given a 'Vaccine Information Statement' (a document summarising the risks and benefits of particular vaccines to US patients) to quickly read and approve at their doctor's appointment. In order to be 'fully informed', they write, parents should ask their doctors to provide them with 'the actual [vaccine] insert in [the] box'. Another commenter, this time on *AoA*, questions the assumption that parents are allowed to properly 'weigh up' immunisation risks and benefits at their medical appointments, arguing that they are not 'even' shown copies of the 'vaccine inserts'. This is particularly true, they continue, in a context in which the pressure to vaccinate is 'huge [...] regardless of parental wishes'.

Of particular concern, for counterpublics, are the lists of possible 'adverse reactions' contained in vaccine information leaflets. For instance, in a blog post aimed at highlighting contradictory governmental positions on the question of whether vaccines cause autism, a blogger on *AoA* cites the 'adverse events' listed in a 2005 version of the package insert for a particular brand of diphteria, tetanus, and acellular pertussis (DTaP) vaccine:

> Adverse events reported during post-approval use of Tripedia vaccine include idiopathic thrombocytopenic purpura, SIDS, anaphylactic reaction, cellulitis, *autism*, convulsion/grand mal convulsion, encephalopathy, hypotonia, neuropathy, somnolence and apnea. Events were included in this list because of the seriousness or frequency of reporting. Because these events are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequencies or to establish a causal relationship to components of Tripedia vaccine.
> (AoA, 12 November 2018, emphasis added)

It is important to note that the caveat included in the package insert text that it is 'not always possible [...] to establish a causal relationship' between the vaccine and the adverse events listed does not deter this blogger from using the 'possible adverse events' list on the insert to support their claim that vaccines are dangerous and cause autism, along with other severe reactions. References to the same 2005 DTaP vaccine package insert appear in two other blogs, including a UK-based one. Other bloggers and commenters on *AoA* refer to other unspecified vaccine inserts as a source of information on a range of purported immunisation adverse reactions. These include a commenter alleging that patient information leaflets for vaccines contain warnings that immunisations cause, among other things, 'death', 'encephalopathy', 'internal bleeding', 'skin problems' and 'food allergies'. Similarly, a blog post maintains that '[d]ocumented side effects and adverse events, including death, are listed on package inserts of vaccines produced, sold, and administered in the United States' (Age of Autism, 17 March 2019). Yet another blogger contrasts the information contained in vaccine package inserts to media content promoted by governments and manufacturers with the specific purpose of promoting vaccinations:

> Over the airwaves, in magazine advertisements, and across all sorts of social media platforms, it's what the manufactures and our government hope consumers would continue to believe, "Vaccines are safe. Vaccines are effective." Yet, *according to the CDC and the vaccine package inserts published by the FDA*, all vaccines come with risk. In fact, all medical procedures come with risk. (Age of Autism, 10 March 2019, emphasis added)

Here, vaccine counterpublics are highlighting an apparent contradiction between what is communicated to the public about vaccines in the media, and what can be found by individuals and parents by autonomously researching other reputable sources, such as the CDC and 'the vaccine package inserts published by the FDA'. The main blogger at *VCUK* also draws a contrast between 'what they want you to know' (where 'they' refers to public health authorities) and the 'real side effects' caused by vaccines, which can be found by looking into other, more specific 'official' sources.

Specifically, in a blog post already encountered in Chapter 5, *VCUK* critically refers to the so-called 'Red Book' – officially known as the 'personal child health record', or 'PCHR', a document given to new parents in the UK to track information related to their child's development, including weight, height and vaccination status. The blogger argues that the only vaccine adverse reactions mentioned in the book are 'soreness at site of injection and possible fever', leading parents (and journalists) to believe that when receiving a vaccine 'the worst that might happen, is no worse than catching a cold' (VCUK, 19 May 2019). He then compares the Red Book information to what he sees as the more accurate warnings contained in US 'Vaccine Information Statements' (VISs) including one purportedly stating that '[a]s with any medicine, there is a very remote chance of a vaccine causing a serious injury or death'. US 'VIS' documents are also mentioned in two other blog posts on *VCUK*, always in the context of vaccines having the potential to cause catastrophic injury. The difference in the vaccine risk information presented to US and UK parents is put down by the blogger to the US being a 'more litigious society'. Ironically, VISs are also sometimes criticised by American counterpublic members for not being informative enough about vaccine adverse reactions, and discounted in favour of 'package inserts', as in the case of the *LW* commenter mentioned earlier on in this section.

The comments and posts discussed here support the notion that individual patients and parents should actively seek to acquire valuable information about potential vaccine risks, instead of 'passively' receiving this information from health authorities and the media. In doing so, counterpublic members present vaccine package inserts (or PILs) as important tools empowering parents to make 'informed' and 'rational' vaccine decisions for their children. As we have seen, researching vaccinations as a requirement of responsible parenthood is a recurrent theme in vaccine counterpublics' normative beliefs around vaccine decision-making. Narratives about 'empowering parents' to make responsible decisions to protect their children's health could even be said to resonate with perspectives within the medical profession which frame PILs as patient-oriented 'means of democratisation' (see Dixon-Woods 2001). Arguably, they also resonate with the broader institutional discourses of individual patient responsibility and self-actualisation discussed in the previous chapter, again showing a possible connection (rather than a rift) between risk talk among vaccine counterpublics and the wider health policy landscape. In addition, the conflict between what is written in vaccine PILs/package inserts and more 'reader-friendly' attempts to communicate about vaccine risks, from medical sources and the media further reinforces the idea that authorities are 'hiding something', and that it is counterpublics' duty as responsible health consumers and parents to 'read the fine print' in order to become aware of the 'true risks'.

Vaccine package inserts are also cited by bloggers in a different context, specifically to support claims that vaccines have been insufficiently tested for safety prior to their approval and licensing for use in patients. For instance, a blog post on *LW* mentions package inserts in order to argue that vaccines have not been properly tested against a 'placebo' (5 November 2018) – referring presumably to the fact that certain vaccines are not tested against a 'saline placebo' in clinical trials (they may be tested, for example, against another previously-approved vaccine). A commenter on the same blog claims that, according to 'every single' vaccine package inserts, vaccines have not been evaluated for 'carcinogenic' or 'mutagenic' effects, or for their potential impact on fertility.[115] On *AoA*, a blogger puts forward a similar claim that package inserts reveal the insufficient testing of vaccines, inviting the reader to '[p]ick

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[115] This observation seems to refer to a particular section of package inserts called 'Nonclinical Toxicology'. For many vaccines, such as MMR, this section states that the vaccine 'has not been evaluated for carcinogenic or mutagenic potential or impairment of fertility'. However, it has been noted that the language contained in these package inserts has been misinterpreted as meaning there has been no testing at all for certain potential vaccine-related adverse events, whereas the statement should be intended to mean that no further testing was needed in these areas as 'toxicology studies conducted at the preclinical phase showed no signs of adverse effects from the vaccine or its individual components' (Lunan 2020).

any vaccine's package insert,' to show that 'vaccines are not tested for cancer-causing capabilities, or for their ability to alter, damage, and destroy both RNA and DNA, or for their ability to impair fertility or cause permanent sterility' (AoA, 8 November 2018).

These claims echo the framings of vaccination-related risks as 'unknown', which Hobson-West (2007) has previously identified among UK-based vaccine-critical organisations. However, in the blog posts just referenced, while highlighting the uncertainties related to possible vaccine harms, counterpublic members simultaneously insist that vaccines are 'invasive medical procedures where all types of toxic, heinous ingredients that have no business in any human are being injected by the score' (AoA, 8 November 2018). They depict non-vaccinated children as needing 'less medical care, prescription medications, and antibiotics', and presenting lower incidences of, among other things, 'seizures', 'autism', and 'neurodevelopment disorders' than vaccinated children (LW, 5 November 2018). Claims about the lack of information on long-term vaccine risks in package inserts are thus being used by counterpublics in order to paint a broader overall picture of vaccination as an unsafe medical practice.

By using 'official' inserts as evidence of the alleged unsafety of vaccines, counterpublics are also seeking to reject the 'irrational antivaxxers' label assigned to them, and instead portray themselves and vaccine-refusing parents more generally as rational decision-makers. These appeals to their own rationality (and the rejection of the 'anti-vaxxer' image found in media representations of vaccine opposition) are a key strategy which counterpublics have adopted in order to oppose mandatory vaccination and vaccine choice restrictions, as has been discussed in Chapter 6. As a guest blogger on *AoA* laments:

> When people like me speak up to warn that vaccines, like any other drugs, have side effects (just look at the vaccine inserts!), we are labeled "ANTIVAXXERS," "ANTI-SCIENCE," and "DISEASE SPREADERS." Somehow, we have been made to look like the bad guys...
> (AoA, 14 March 2019)

Instead of the term 'anti vaxxers' (which implies that they are 'the bad guys'), *AoA* bloggers sometimes refer to themselves and to other counterpublic members as 'vaccine risk aware'. References to the 'vaccine risk aware' community, 'vaccine risk aware groups' or the 'vaccine risk aware movement' are common on *AoA*, appearing in nine different posts on the blog. In addition, in a letter from the British vaccine-critical chemist Christopher Exley published on the same blog, reference is made to an episode of 'Newsnight' – a UK news programme broadcast by the BBC – in which vaccine opposition was depicted as an expression of 'irrational fears'. In the blog post, this view is critiqued on the basis that vaccine opposition is supported by vaccine producers' 'own data':

> [y]ou are suggesting that all vaccines are 100% safe in all recipients. However, many individuals, approximately 2.5% using vaccine manufacturer's own data, suffer a serious adverse event following vaccination...
> (AoA, 15 November 2018)

'Adverse events following vaccination', the post goes on, 'include everything from a sore arm to death. Is this an 'irrational fear'?...'. In blog posts about package inserts, vaccine opposition is framed as an instance of rational, respectable and well-informed actors relying on institutional sources, rather than as the product of radical, unorthodox views.

Nonetheless, a certain degree of manipulation and reworking of official sources of risk information is needed to accomplish this. [116] Indeed, while it is true that vaccine package inserts and PILs contain lengthy lists of various medical conditions in their 'adverse reactions' or 'undesirable effects' sections, it has to be emphasised that the reactions counterpublics appear to be mostly concerned with - including autism and SIDS - have not been causally linked to childhood vaccines.[117] When mentioned, these events are generally listed in a part of the vaccine insert referring to 'post-marketing experience', which includes public reports from post-marketing vaccine surveillance programmes. This part of the insert, in the US, carries the explicit warning that '[b]ecause these events are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequencies *or to establish a causal relationship* to components of [the] vaccine' (emphasis added).[118] Therefore, while they may be included in a vaccine insert, these events have not been proven to be causally linked to vaccines. It should be noted that the inclusion of patient-generated reports of adverse events in package inserts, even if they cannot establish a causal relationship between a vaccine and a particular condition is actually mandated by both US and EU regulatory frameworks on drug labelling.[119] These kinds of

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[116] It should be pointed out that 'autism' specifically does not seem to be included in the latest versions of any childhood vaccine inserts. See the Institute for Vaccine Safety (IVS) at John Hopkins Bloomberg School of Public Health online website for a helpful and recently updated list of U.S. vaccine inserts: https://www.vaccinesafety.edu/package_inserts.htm.

[117] According to the Institute of Medicine (now known as National Academy of Medicine, or NAM) review on the 'Adverse Effects of Vaccines' (IoM, 2012), there is insufficient evidence in the literature to support childhood vaccines may be a contributing cause of SIDS, autism or encephalopathy. There is some evidence to support an association between measles body inclusion encephalitis (MIBE) and MMR vaccine in individuals with demonstrated immunodeficiencies, and between the Varicella vaccine and 'Vaccine Strain Viral Reactivation with Subsequent Infection resulting in Meningitis or Encephalitis' (i.e., rare varicella infection caused by vaccination which in very rare cases may result in encephalitis). According to the IVS website, '[n]atural infections with measles, mumps, rubella and varicella viruses can cause encephalitis and meningitis. Thus, measles, mumps, rubella and varicella vaccines protect against encephalitis and meningitis caused by these agents' (see IVS 2018, available online at: http://www.vaccinesafety.edu/vs-mening.ht).

[118] It is also possible to read this statement in the extract from the (now outdated) vaccine package insert cited by the *AoA* blogger quoted above.

[119] See the US Code of Federal Regulations Title 21 (21 CFR 201.57), and particularly 21 CFR 201.57 (c)(7)(ii)(B): 'Postmarketing experience. This section of the labeling must list the adverse reactions, as defined in paragraph (c)(7) of this section, that are identified from domestic and foreign spontaneous reports. This listing must be separate from the listing of adverse reactions identified in clinical trials.' For the European context, see Directive 2001/83/EC, Article 11 and European Commission's guideline on SmPC (2009), section 4.8, stating that in order for adverse reactions recorded by post-marketing surveillance to be included in the 'Undesirable Effects' section

'patient-generated reports' of presumed adverse reactions to vaccines constitute another aspect of vaccine regulation which is directly incorporated in vaccine-critical talk, as discussed in the following section.

Regulation, patient experience, and vaccine injuries: post-licensure surveillance systems in vaccine-critical talk

The regulatory frameworks for pharmaceutical products marketed in the US and UK also govern post-licensing surveillance (or 'pharmacovigilance'), from which some of the 'adverse reactions' included in package inserts are derived. Formal adverse event reporting schemes (such as VAERS in the US and the Yellow Card Scheme in the UK) are part of the post-licensing pharmacovigilance system. They exist to enable authorities and manufacturers to identify and quantify possible drug reactions – including vaccine reactions, sometimes referred to as 'adverse events following immunisations' (AEFIs). As stated in a 2004 report on vaccine surveillance in Europe, '[t]he system should be able to recognize any potential increase in the incidence of previously known adverse reactions, and also be able to detect novel, rare adverse events that may be causally related to immunization' (Lankinen et al. 2004).

As with vaccine package inserts and PILs, the information from these systems plays an important role in supporting claims about alleged vaccine injuries put forward by counterpublics, as well as justifying wider arguments about the fundamental unsafety of vaccines. One example of a pharmacovigilance programme which is mentioned on a number of occasions by counterpublics is the 'Yellow Card scheme', which is used to collect information on potential adverse reactions to medicines and vaccines marketed in the UK, and which was established in 1964 as a response to the thalidomide scandal.[120] The Yellow Card Scheme has been referred to in vaccine-critical talk to suggest that certain vaccines are particularly dangerous in comparison to others – a comment left on an *ANHI* blog post, for example, defines the number of adverse event reports submitted to the UK Medicine and Healthcare products Regulatory Agency (MHRA) in relation to the HPV vaccine as 'worrying' and 'disproportionally higher' than any other vaccine. On *AoA*, a blogger further insists that the Yellow Card scheme 'would be incapable picking up long term neurological effects of vaccination' (7 March 2019). In addition, a

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of a medicinal summary of products characteristics (or 'SmPC', a legal document whose content dictates what is included in the PIL) 'a causal relationship between the medicinal product and the adverse event' has to be 'at least a reasonable possibility'.

[120] References to this UK scheme appear in five different blog posts across two blogs (*AoA* and *ANHI*). For further information on the creation of the Yellow Card Scheme following the thalidomide scandal in the UK, see the Royal Pharmaceutical Society website at: https://www.rpharms.com/resources/quick-reference-guides/yellow-card-scheme-advice-for-pharmacists.

comment on the same blog laments that this pharmacovigilance scheme is 'not mandatory', which results in a severe underestimation of vaccine adverse reactions; the 'Yellow Card' scheme should therefore be 'mandatory' for everyone, the commenter contends.

Among the existing pharmacovigilance systems for vaccines, however, the 'VAERS' (or 'Vaccine Adverse Events Reporting System'), run jointly in the US by the FDA and CDC, is probably the one mentioned most frequently by vaccine critics – both in US- and UK-focused blogs. According to a comment on *LW*, the VAERS website displays reports of almost 100 deaths and 700 'disabilities' in a ten-year time frame. On *AoA*, a commenter notes that one does not have to 'to look very hard' to find evidence that vaccines are harmful – the first place to look, they write, is the US Vaccine Adverse Events Reporting System. VAERS, they claim, receive tens of thousands reports every year about 'vaccine injuries and deaths'. Another *AoA* blogger writes that 'people have reported over 450 deaths and over 61,000 serious medical conditions from HPV vaccines to the government's Vaccine Adverse Event Reporting System (VAERS)' since the vaccine was introduced in 2006 (28 February 2019). A comment on the same blog refers to VAERS reports to claim there have been almost one-hundred cases of 'premature menopause' following HPV vaccination in one year. Another commenter mentions VAERS on *ANHI* (a UK-based blog) inviting readers to ask their doctors whether they are aware of the US scheme and if they 'use it' in their practices. In total, references to VAERS appear in 24 different posts across the sampled blog posts on *AoA*, *LW*, *FP* and *ANHI*.

As well as being referred to and recast as 'evidence' of the existence of specific vaccine injuries, VAERS and the Yellow Card scheme are discussed among counterpublics in relation to their limitations – and by extension, the limitations of state regulatory frameworks to provide adequate guarantees about the safety of national immunisation programmes. Some limitations seen by vaccine critics as negatively affecting the ability of the UK Yellow Card scheme to detect all adverse reactions have been mentioned earlier on in this section. Similarly, in relation to the VAERS, discussions of report numbers are often accompanied by the qualification that adverse events are 'grossly underreported'. As an *AoA* blogger argues, '[t]he reality at the present time is that the US Vaccine Adverse Events Reporting Database has reported more than 650,000 events since 1990 and being a passive reporting database this is likely no more than 1% of cases, many of which may include irreparable harm' (AoA, 24 July 2018).

The idea that VAERS captures just a tiny fraction of vaccine-related adverse events is a recurrent one among counterpublics. According to another *AoA* comment 'everyone knows' that the reports submitted through VAERS miss '99% of cases'. The same commenter adds that, as a consequence of this, available 'vaccine safety numbers' are pure 'fiction'. The blog *FP* offers slightly different statistics, stating that '[f]ormer FDA Commissioner and paediatrician David Kessler, MD and others estimate that the voluntary VAERS system of reporting misses more than 90% of serious adverse events' (FP, 4 March 2019). Along the same lines, a comment on *AoA* laments the alleged shortfalls of both vaccine pre-licensing trials and post-licensing adverse event surveillance systems, claiming that UK reports are not followed up by the relevant authorities. A blogger, in a post on the same platform, also argues that '[n]either short term nor long term follow up is performed or required when it comes to vaccine studies, despite the fact that many vaccine injuries take weeks, months, or years to fully manifest...' (AoA, 8 November 2018). Yet another maintains that '[t]here is almost no long-term safety testing of vaccines, and no safety testing of the overloaded schedule as a whole' (AoA, 21 January 2019). These messages around the unreliability of surveillance statistics tie in with the idea that the ability of parents to make informed decisions about childhood vaccines is compromised by the lack of, or unreliability of safety information (which was also observed in relation to vaccine-critical framings of vaccine package inserts).

Dealing with vaccine injuries: the US National Vaccine Injury Compensation Program and the UK Vaccine Damage Payment Scheme

As seen in the previous sections, vaccine package inserts/PILs and post-licensing surveillance systems are 'recast' by counterpublics in a way that is consistent with their normative beliefs both that vaccine risk assessment is the responsibility of individual parents, and at the same time that there are serious limitations to what parents can find out about vaccine risks. This latter observation is also invoked more broadly to suggest that vaccines are unsafe and that parents who refuse them are therefore acting 'rationally', as vaccine regulatory frameworks are deemed unable to prevent or even properly account for vaccine-related risks. In other words, according to online vaccine critics, despite rules and systems having been put in place to guarantee the safety of national immunisation programmes, parents are still not in a position to be able to properly identify all the dangers presented by the vaccinations recommended for their children.

There is, however, an additional narrative shared by counterpublics around issues of vaccine safety in which they draw affirmation from legal sources, and particularly from critical framings of national vaccine injury compensation schemes. Both the UK and the US have governmental programmes tasked with the assessment of vaccine injury claims and their compensation under a strict liability regime: the Vaccine Damage Payment (VDP) scheme in the UK and the National Vaccine Injury Compensation

Program (NVICP or VICP) in the US. The existence of specialised compensation schemes such as the NVICP in the US and VPD scheme in the UK are used by vaccine critics to reinforce the idea that the state is prepared to accept all vaccine adverse reactions – even those with 'catastrophic' consequences – preferring to offer monetary compensation to some parents, rather than attempting to make childhood vaccines 'safe'.[121] As previously discussed, that catastrophic events may result from vaccines is something claimed by counterpublics on the basis of a number of 'official' sources – including vaccine package inserts, and post-licensing surveillance systems such as VAERS and the Yellow Card scheme. However, it is vaccine injury compensation schemes which are specifically referred to by counterpublics to defend the idea that vaccines are overall too unsafe to be acceptable, and to represent the state response to vaccine safety as uncaring towards individual children and their families.

In the first place, the petitions or applications filed with vaccine injury compensation schemes and the payments awarded through these schemes are referred to by vaccine critics to show that catastrophic adverse reactions to immunisations do happen. The existence of widespread and severe vaccine damage is why – according to vaccine counterpublics – special, governmentally-sanctioned monetary compensation schemes for the 'vaccine injured' have been introduced. As *FP* put it,

> The crux of the issue is that vaccines can and do harm. This is why there's a vaccine program, which tracks and compensates for death and catastrophic injuries caused by vaccines, with $4 billion paid out to 6,000+ petitioners to-date. Many more have seen their children slip away following vaccination. The House report on the 1986 National Childhood Vaccine Injury Act states: "… information has become available about the potential hazards of these vaccines and about the serious — and sometimes deadly — consequences they can have."
> (FP, 4 March 2019)

In another post, the same blog again mentions the '$4 billion' paid through the NVICP to compensate thousands of 'catastrophically injured and deceased individuals', stating that this constitutes 'the government's explicit admission that vaccines do fatefully injure and cause death' (FP, 11 June 2018). *AoA* also refer to the NVICP as 'evidence' of severe vaccine damage in children. In an *AoA* blog post, the existence of vaccine injury compensation schemes is seen as a rebuke to 'hit pieces' on social media which 'gloss over important information' on vaccine safety:

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[121] The use of the adjective 'catastrophic' to describe vaccine adverse reactions here refers to the notion of 'catastrophe' or 'disaster threshold' first articulated by Niklas Luhmann (1993), which has been drawn on in Chapter 5 to account for vaccine critics' emphasis on the nature or qualitative aspects of vaccine-related risks, and their framing of such risks as so severe that they should be considered as completely unacceptable by society, regardless of how unlikely they are to materialize in practice.

> [...] the hit pieces that make the rounds on social media tend to gloss over important information, like the fact that all vaccines come with risk, that adverse reactions do happen, and that our government has a vaccine injury compensation program set up for those who are harmed by vaccines.
> (AoA, 20 May 2018)

In a similar way, the existence of the VDP scheme in the UK is framed by vaccine critics as a justification for the decision to decline vaccinations for one's children. For example, in a *VCUK* blog post recounting the blogger's experience as a guest on a popular TV talk show, critical questions posed by the show presenters about why the blogger 'had not followed the crowd' with respect to childhood vaccinations are addressed by referring to the VDP:

> To have done as the presenters [...] would have liked, could have resulted in us having to make a claim to the "Vaccine Damage Payment" scheme an inconvenient truth in the entire vaccine programme.
> (VCUK, May 2019)

In the *VCUK* extract quoted above, the VDP scheme is presented as a sort of crack in the system, an 'inconvenient truth', revealing the reality of severe vaccine damage in a mainstream context which otherwise overlooks its existence. The role played by the VDP scheme and NVICP in legitimising the existence of certain severe vaccine injuries by making them 'officially recognised' in the eyes of the law is further reinforced through vaccine critics' references to individual stories of alleged injury and harm from families who have filed compensation claims through these schemes. While successful compensation cases are not presented in the blogs as 'science' (as opposed to the sources examined in Chapter 4), they are also used as 'evidence' of vaccine harm. The *VCUK* blog post quoted above, for instance, includes the story of a man who was awarded a substantial sum in compensation for injuries which, according to a VDP scheme decision, resulted from the MMR vaccine he was given as a child, which the blogger claims 'left [the man] unable to talk, stand unaided or feed himself'. According to the blogger, it took the man's family almost twenty years before they were granted compensation.

In the UK, the amount payable by the VPD scheme is currently capped at £120,000. This is a relatively small amount compared to the sums paid by the compensation programme in the US which – as opposed to the UK's administrative scheme – involves litigation before a specialised court, the Office of Special Masters of the US Court of Federal Claims (commonly known as the 'Vaccine Court').[122] For example, an *AoA* blog post from July 2018 reports on a settlement of more than 100 million dollars awarded to an 'infant that suffered brain injury', allegedly also as an adverse reaction to the MMR vaccine. A couple of posts of *VCUK* remark on the financial difference between the amounts awarded to successful petitioners in the UK and the US, noting that '[t]he UK taxpayer has paid out over £75,000,000 to vaccine damaged children over the years – a snip to the $3 billion been paid out in the US' (VCUK, August 2018).

It is not always clear from counterpublic members' accounts of vaccine injury what the exact conditions are for which compensation has been claimed, as is the case with the two stories mentioned above. In some instances, the adverse reactions discussed in blog posts are more precisely defined but still not included as recognised immunisation adverse events in the previously mentioned major review by the US Institute of Medicine (IoM 2012). For example, an *AoA* post states that two cases of heart attack following HPV vaccination have been compensated by the NVICP (18 October 2018); however, the existence of a link between HPV and heart attack is not supported by the IoM review. In yet other cases, such as autism, the available scientific evidence weighs against a connection between vaccines and a compensated 'injury' reported by bloggers. The blog *AoA* focuses on autism, and it sometimes refers to cases compensated by the US Vaccine Court to support the connection between autism and vaccines. For example, in one post challenging the 'vaccine safety statements' offered by government officials, a blogger writes that such statements would ignore:

> [...] a hundred research papers that demonstrate multiple links between vaccines and autism [...] as well as at least 83 documented *vaccine-induced encephalopathy with autism* claims paid by the *Vaccine Injury Compensation Program*
> (AoA, 12 November 2018, emphases added)

Other counterpublic members imply that the NVICP represents a governmental admission that vaccines cause autism, such as an *AoA* commenter insisting that all the epidemiological studies supporting vaccine safety are 'flawed', and that the link between vaccines and autism has been 'conceded' by the US government 'both scientifically and legally'. Yet another blogger recounts how she 'educates' peers who question her decision not to vaccinate by referring to 'the 1986 National Childhood Vaccine Injury Act', and to the 'Hannah Poling' case in particular. This is the case of a child

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[122] The legal-historical background of no-fault vaccine injury compensation schemes in the UK and the US, along with the main features of the compensation schemes available in relation to childhood vaccines in these two countries, have been explored in more detail in Chapter 2.

suffering from a rare mitochondrial depletion syndrome who developed autistic symptoms and received compensation from the NVICP on the basis that the vaccines had '"stressed" her already weakened system and worsened her developing autism' (see Eickhoff 2008).

The Poling case engendered significant controversy among medical commentators because by the time the Vaccine Court made its decision to offer an award, multiple studies finding no link between vaccines and autism had been published in the scientific literature. In addition, according to the CDC, symptoms of autism in children with underlying mitochondrial diseases can be exacerbated by certain vaccine-preventable infectious diseases, such as the flu, whereas there is no evidence that they can be made worse by vaccines (CDC 2019). Critics of the Vaccine Court decision attribute the success of the claim filed by the child's family to the particular standard of evidence adopted by the court. For example, according to Offit (2008), '[t]he Poling case is best understood in the context of the decision-making process of this unusual vaccine court'. He argues that the court has seemed in recent years 'to have turned its back on science' by adopting a 'plausibility' test that allows the finding of a causal link between vaccines and harm in the presence of a 'biologically plausible mechanism by which a vaccine could cause harm, as well as a logical sequence of cause and effect'. Because of this, the Vaccine Court has granted awards in the absence of a consolidated body of scientific evidence supporting a connection between specific vaccines and health conditions.

The compensation regime implemented in the US through the NCVIA 1986 may be more favourable to petitioners claiming damages for vaccine injury than its UK counterpart, reflecting the historical origins of the two schemes. As discussed in Chapter 2, the US NVICP and the UK VPD scheme emerged as the result of different compromises between the demands of parental advocacy organisations, national governments, and – particularly in the US – the pharmaceutical industry and vaccine manufacturers. While the rules of evidence and potential for higher compensation awards in the US compensation regime may be seen as favouring petitioners, it should be pointed out that with the introduction of the NVICP, vaccine manufacturers simultaneously gained substantial protections from liability in vaccine injury claims. For this reason, even when they refer to successful compensation cases in order to support claims that vaccines are unsafe, vaccine counterpublics remain ambivalent towards the compensation programme and the Vaccine Court. For example, on *LW* the NVICP is characterised as mainly beneficial to the pharmaceutical industry. In particular, a comment on the blog claims that many health care providers are 'shocked' when they learn that vaccine manufacturers have 'demanded' immunity from any legal liability resulting from vaccine injury. This is why, the commenter adds, the NVICP was created: to enable companies to continue making vaccines despite a growing number of previously 'completely healthy' individuals who have become 'chronically ill', 'severely disabled', or 'fatally injured', shortly after receiving routine vaccinations. In the commenter's account, because of this increasingly significant risk of legal liability and financial loss, the pharmaceutical industry 'threatened' to halt vaccine production, unless given full immunity against vaccine injury lawsuits.

Perhaps unexpectedly, considering the different legal context in which it was introduced and the lack of liability protection provisions for vaccine manufacturers in the Vaccine Damage Payments Act 1979, the UK VDP scheme has been similarly represented by UK-based counterpublic members as originally conceived to protect pharmaceutical companies from having to deal with the 'financial risks' involved in vaccine litigation. This framing is found on the UK-based blog *VCUK*:

> In the UK and US, the Government protects pharmaceutical companies from liability for vaccine injury, because its government policy to promote vaccination. The financial risks from "class actions" from vaccine injury became too great for the pharmaceutical industry to continue manufacturing vaccines, hence the Vaccine Damage Payment programme run by the HMRC in the UK and the Vaccine Injury Compensation Programme in the USA? (VCUK, May 2019)

In another blog post, *VCUK* also claims that despite an increase in the number of vaccines now administered in the UK, 'the vast majority of [VPD] money was paid out in the first ten years of the programme; £8,530,000 in initial payments and £56,000,000 in top ups'. The post challenges the idea that these figures are the result of vaccines now being 'safer'. 'Safe', the paragraph continues, 'is good enough for the less curious in the Main Stream Media who seem to rely on Press release's for their articles on vaccines [sic]' (VCUK, May 2019). In fact, as discussed in Chapter 2, the original awards made under the VDP scheme referred to claims related to the 'pertussis vaccine scare' of the 1970s, and the number of claims compensated started to decrease dramatically from the beginning of the 1980s, as public opinion shifted back in favour of vaccines (see Millward 2017).

In the UK, an important test case on vaccine brain damage, *Loveday v. Renton and the Wellcome Foundation* ended in 1988 with a High Court decision finding that the link between the pertussis component of the DPT vaccine and brain injury had not been proven on balance of probabilities.[123] In the US, a 1991 review from the US Institute of Medicine concluded that there was no evidence that the whole-cell pertussis vaccine could cause permanent brain injury (Baker 2003, 4006). These developments created

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[123] See *Loveday v. Renton and the Wellcome Foundation* [1990] 1 Med LR 117.

an apparent tension between scientific knowledge on vaccine safety and the decision-making of vaccine injury compensation institutions such as NVICP and VDP. This tension reignited after the publication of the Wakefield paper, but seemed to subside with the Vaccine Court decision in the 'Omnibus Autism' case (see Chapter 2), in which the NVICP adjudicated on more than 5000 claims by finding no association between vaccines and autism. However, as the blog posts and comments discussed in this section demonstrate, the awards made by vaccine injury compensation schemes are still referred to by counterpublics to argue about the dysfunctionality and unsafety of national vaccine immunization programmes.

The ambiguities engendered by compensation schemes about what conditions are 'officially' recognised as possibly resulting from vaccine damage have allowed counterpublics to draw on vaccine regulation to challenge the safety of vaccines. A comment on a *FP* blog post, for example, remarks on how more than four billion 'taxpayer dollars' have been awarded to the 'vaccine injured', while arguing that 98% of autism cases are 'man-made'. The commenter also contends that until it becomes possible to sue vaccine producers in 'an open court of law', everyone involved in the vaccination programme has 'blood on their hands'. Another commenter on a different post also insists that regardless of what one thinks about the benefits of vaccines, parents would have to be 'insane' to use the products of a profit-hungry company with 'no responsibility' to guarantee the safety or effectiveness of their products.

I will look in greater depth into issues relating to legal liability, blame and accountability – particularly in relation to the construction of vaccine-critical collective identities – in Chapter 7. In the context of the present chapter, what I would like to emphasise instead are the links between vaccine injury compensation schemes and counterpublic members' arguments that vaccines are fundamentally unsafe medical products. As I have previously argued, for counterpublics vaccines are so dangerous that they fall beyond the realm of acceptable risk-benefit calculations, so that any 'reasonable' parent should refuse to have their children vaccinated. As a commenter on *LW* puts it, while even one single injury would be 'too much', many vaccine-injured people have actually been 'paid out millions' in compensation. Drawing on Niklas Luhmann's (1993) reflections on risk, I have analysed this counterpublic normative belief through the theoretical lens of the 'catastrophe threshold' – referring to a socially-determined threshold beyond which a risk, no matter how unlikely, has consequences too severe to be acceptable (see Chapter 5). While counterpublics frame vaccine risks as falling beyond the 'catastrophe threshold', they perceive governments to be imposing these unreasonable risks on parents, offering monetary compensation to the 'vaccine injured' as a way to persuade them to vaccinate.

However, as counterpublic members across different blogs make clear, no monetary award would be sufficient to compensate these kinds of injury, nor to convince them to accept potentially 'catastrophic' risks for their families. For example, in a comment posted on *FP* about having to 'fight' against a doctor who wanted to convince them that vaccines are safe, the comment author states that if something were to happen to their child because of vaccines 'no amount of compensation' would be able to 'dull' their pain. Another comment on *FP* tells the story of a 'very lucky' family who were awarded compensation by the vaccine court, emphasising that despite being successful in litigation, parents 'do not feel victorious', but are 'still devastated'. Another commenter, this time on *AoA*, states that he does not 'want their compensation', that it is 'too late for any of that' – and that what he actually wishes for is to have everyone involved in vaccine injury 'held personally to account'. A blogger on *AoA*, while claiming that successful NVICP petitioners are subject to 'gag orders' in settled cases, also asks:

> Why is it legal to silence those who "win" in the VICP via gag orders as a requirement to receive their compensation settlement…*as though there is any compensation when vaccines destroy one's health and development, or take a life?* Why would those involved in public health *not want every potential vaccine recipient to know the real risks* of the invasive medical procedures they are considering, or being forced to permit? [...]
> (AoA, 8 November 2018, emphases added)

Similar views that 'no amount of compensation would ever be enough' to make vaccine injury acceptable are expressed on *VCUK* with reference to the VDP scheme. The UK-based blog emphasises how '[e]ven if liability is accepted the maximum payout is £120,000 and the child has to be 60% brain damaged', adding that:

> Any of the parents I have spoken to over the years with vaccine damaged children are *not after money, in fact the amount is an insult for the damage it has caused,* but it does represent an admission of guilt and these are parents who are angry because they believed in the vaccine programs, were never warned of the risks and they don't want it to happen to anyone else.
> (VCUK, May 2019)

These comments are all rooted in the idea that some vaccines injuries are just too severe to be adequately compensated through a monetary award. In short, by critiquing the very concept of vaccine injury compensation in this way, counterpublics are indicating that vaccine risks go beyond their threshold of acceptability (or 'catastrophe threshold'). The perceived 'catastrophic' character of vaccine risks are then drawn upon by counterpublics to remake official discourses around the safety of vaccines. More specifically, current vaccine injury schemes are used to reinforce the idea that the state is prepared to accept *all* serious vaccine reactions and that its preferred solution is to offer monetary compensation – ironically funded by the tax-payer, rather than vaccine manufacturers – instead of making vaccines 'safe'. Along these lines, VCUK paint a picture of national immunisation programmes as a 'cost-effective' way to improve public health at the expense of a 'few children' who are then 'thrown a bone' in the form of monetary compensation:

> I started to investigate vaccines in the mid 90s. What I found surprised me, as I picked at a very thin layer of veneer over a *cost effective* method of reducing childhood infections. *A "health" service does not need so many doctors and nurses if less children are ill* and if a few children are seriously injured by a vaccine in the UK and can prove it, *throw them a bone of £120,000*. The child must be 60% disabled and if the child dies before the age of two no need to pay anything under the Vaccine Damage Payment Scheme. One is reminded of China where a driver can be responsible for the medical bills of a pedestrian they injure for years its cost effective if the pedestrian dies at the scene.
> (VCUK, May 2019, emphasis added)

The language used in this post portrays the state and public institutions as uncaring and cynical, more interested in reducing health service costs than in the health of individuals. The blogger presents 'vaccine injured children' as a vulnerable group neglected by the state, drawing a comparison with 'China [...] where its cost effective if the pedestrian dies at the scene', attempting to support its depiction of an authoritarian-like state which regards its citizens as disposable. In various posts on *AoA*, commenters and bloggers also refer to the idea that vaccines have been deemed 'unavoidably unsafe' by the US legislator, referring to language contained in the NCVIA 1986 and in the 'Restatement Second of Torts', a scholarly treatise summarising the principles of the US common law of torts (American Law Institute 1965).

In the US, 'unavoidably unsafe' is a legal expression that is used to describe a product, such as a medical drug or device, which if 'properly prepared, and accompanied by proper directions and warnings, is not defective, nor is it unreasonably dangerous'.[124] These products are normally excluded from general rules establishing strict liability for manufacturers in cases of product design defects. Legal scholarship has explained this exception by arguing that 'though these products are dangerous, they are nonetheless of such benefit to society that strict liability is inappropriate' (Hoffman 1993, 55).

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[124] Restatement (Second) of Torts §402A, comment k (American Law Institute 1965).

However, *AoA* counterpublic members see the notion of 'unavoidably unsafe' products in a completely different light, as a literal affirmation that vaccines are dangerous and that the state accepts their unsafety as 'unavoidable', in order to achieve broader public health goals. A commenter on the blog even refers to Hoffman's article to claim that 'the entire industry' would 'parrot' that vaccine benefits outweigh the risks only to maintain this legal 'liability shield' in place for manufacturers.[125] Again, the state is represented as uncaring of, or at least not prioritising, individual health. This view is also well represented by another *AoA* post, in which a commenter argues that not much 'sympathy' is given to those who 'pay the price' of complying with vaccine policies. 'Individuals,' she laments, are casually disregarded as 'collateral damage' in a 'war for public health'.

In conclusion, counterpublic members' representations of vaccine injury compensation schemes are recast to justify vaccine-critical narratives which draw a binary between the 'state' as exclusively concerned with quantitative aspects of vaccine risk calculation across the population as a whole, and 'parents' whose focus is on the nature and consequences of vaccine adverse events for individual children. This may be argued to paint an oversimplified picture of the position of public health institutions around immunisation risks and their acceptability. For example, there are certain recognised categories of 'at risk' individuals who, according to public health guidelines, should not receive specific vaccines.[126]

Conclusions

Conventional representations of pharmaceutical regulatory frameworks usually draw attention to the stringency of the safety controls to which vaccines are subject, both before and after they are allowed onto the market (see CDC 2018; Oxford Vaccine Group 2021). The expectation is that strict legal and regulatory systems will enhance public confidence in national immunization programmes. However, the existence of stringent regulatory requirements does not appear to affect vaccine-critical views about the dangers posed by vaccines. On the contrary, counterpublic members subversively recast some features of these regulatory systems as official sanctioning of their claims about the unsafety of vaccinations. Far

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[125] It should be noted that the strict liability provisions contained in the Restatement (Second) of Torts are not the same thing as the more specific liability protections for vaccine manufacturers introduced by the NCVIA 1986. The latter protections and their interpretation by vaccine counterpublics will be further discussed in Chapter 7.

[126] For example, US Vaccine Information Statements (or VISs, which were discussed earlier on in the chapter) list some categories of patients who should not receive specific vaccines because of a heightened individual risk of adverse effects, for example because they are allergic to a vaccine component or have had a severe allergic reaction after a previous dose of a certain vaccine – see Reiss and Karako Eyal (2019).

from relying only on unorthodox sources of information, vaccine counterpublics incorporate aspects of existing vaccine safety regulations and laws in their online talk about vaccine safety issues.

According to vaccine-critical framings of these regulatory and legal frameworks, parents should actively educate themselves about the 'real' risks and dangers presented by vaccines by looking beyond what is seen as 'misleading' mainstream media messaging on vaccine safety. Instead, counterpublics argue, parents should do their research and read the 'fine print' hidden in official regulatory sources – such as vaccine package inserts, post-marketing surveillance programmes, and vaccine injury schemes – which reveal instead how the actual dangers posed by vaccinations are much greater than is admitted by the media and public health institutions. More broadly, this 'recasting' of official legal-regulatory sources is done by counterpublic members in order to support the view of vaccines as unsafe medical products, and depicting the state as fundamentally unconcerned with the health of individual children.

Of course, these narratives may seem partial, skewed and often inaccurate, but it is important to acknowledge that official sources, and particularly aspects of the frameworks regulating issues of vaccine safety, are being redeployed in vaccine-critical talk as 'proving' the unsafety of vaccines and as admissions of 'culpability' on the part of the state. State culpability for vaccine harm is a recurrent theme in vaccine-critical talk, resonating with broader counterpublic worldviews in which public institutions are seen as 'colluding' with corporate actors, by, for example, turning a blind eye to the reality of vaccine-related harm. These more symbolic aspects of vaccine-critical activism, which are intertwined with notions of truth, accountability and blame, and their role in the constitution of vaccine-critical collective identities, will make up the main subject of the following chapter.

7

THE ONLINE MAKING OF VACCINE-CRITICAL IDENTITIES: TRUTH, ACCOUNTABILITY AND THE 'WELL-INFORMED CITIZEN'

Introduction

In the previous three chapters, I have unpicked some of the threads which I considered most helpful in understanding the nature of online vaccine opposition, exploring some of its defining features. I have started by investigating what vaccine counterpublics *do* online, finding of particular interest how counterpublic members at once consume and produce informational or 'causal knowledge' resources regarding vaccines. I then moved to consider vaccine-critical advocacy activities, including what policy changes are being pursued by vaccine-critical activists, how they advocate for these changes, and what normative beliefs underpin and orient their advocacy work. Looking more closely into the role played by the law in these aspects of online vaccine opposition, I have noted how counterpublic members appear to be variously engaging with, rather than standing in opposition to their surrounding legal landscapes. In this chapter, I develop these ideas by addressing some outstanding questions raised by the findings presented in the previous chapters.

First of all, Chapter 4 has left open the conundrum of how counterpublics manage to ringfence 'acceptable' knowledge resources on vaccines while simultaneously claiming they are purely 'looking at the science' and advocating an approach to members' learning which emphasises independent thought and autonomous research. Second, vaccine counterpublic talk emerges from a variety of blogs, which have different backgrounds and include a range of areas of interest and focus, from alternative approaches to health and 'natural' lifestyles to particular forms of parent-led disability advocacy, and other forms of 'lay citizen' investigation. In what ways do these different counterpublics overcome this internal fragmentation and come to embrace common interpretations of scientific and legal knowledge? Finally, and related to this, how are the geographically dispersed members of online counterpublics able to foster a sufficient degree of group solidarity to build consensus and advocate around a number of shared concerns and policy demands?

The missing thread needed to address these questions lies, I argue in this chapter, in how counterpublics are able to make compelling narratives which resonate with their members, giving rise to vaccine-critical subjectivities or 'collective identities'. It should be noted at the outset that in line with counterpublic theory, 'identity' is not treated here as a pre-given, stable and immutable quality, but rather as something that is created and reproduced through a collective process of 'constitutive rhetorics' (Charland 1987), and which is therefore subject to being contested, renegotiated and remade in ever-evolving fashion (see Pason, Foust and Rogness 2017). As Polletta and Jasper (2001) have suggested, collective identity 'describes imagined as well as concrete communities, involves an act of perception and construction as well as the discovery of pre-existing bonds, interests, and boundaries' (298). The making and reproduction of a collective identity across critical counterpublics through discursive, narrative processes constitutes the main concern of this chapter.

More specifically, I explore here three sets of narratives which I have identified as shaping counterpublic identities across the sampled vaccine-critical blogs. The first set of narratives is concerned with the notion of 'truth', and it is linked to the construction of what I refer to as the collective identities of vaccine critics as 'courageous whistle-blowers'. While looking at how online vaccine critics define themselves and their opponents in relation to their pursuit (or obfuscation) of 'the truth', particularly regarding vaccine injury, I critically engage with recent theories of post-truth society. These theories, which I will challenge to the extent they are used as an explanatory framework for vaccine opposition, view the emergence of vaccine scepticism as consequential to a social landscape in which truth and expertise have lost their status as foundational forces which ground rational debate in the public sphere, with the internet acting as a sort of 'postmodern Pandora's box' enhancing these structural changes (Kata 2010; see also D'Ancona 2017; McIntyre 2018).

A second set of narratives deals with counterpublic members' internal representations – of themselves, and of other counterpublic members – in relation to their ability to discern 'reliable' information. To account for these internal representations, I refer to the notion of 'trust', particularly as captured by the philosophical concepts of 'epistemic trust' and 'epistemic self-trust' (see Zagzebski 2012; Dormandy 2020). These terms refer specifically to the relationships of trust involved in processes of learning and knowing. The chapter considers narratives demarcating which sources of knowledge are accepted and valued among vaccine counterpublics, along with narratives which feed counterpublic members' confidence in their own abilities as learners and knowers. This 'internal' aspect of trust is important, I suggest, because it facilitates the construction and reproduction of shared identities of vaccine critics as intelligent and reliable investigators, able to assess, discern and select among diverging expert claims on vaccine safety matters. Here, I found a close resonance with the model of the 'well-informed citizen' developed by Alfred Schütz (1946), from which I will draw below.

The third and last set of narratives relates to counterpublic members' representations of authorities involved in vaccination policymaking, including pharmaceutical companies, state institutions, and public health organisations. I look at these externally-oriented narratives through the lenses of 'blame' and 'accountability', which encompass vaccine-critical narratives relating to 'conflict of interests' and 'systemic collusion' which are recurrent across a wide range of different counterpublics. These narratives support the vaccine-critical idea that official vaccine safety research is 'tainted research', produced only to advance the financial interests of pharmaceutical companies. In this context, the existence of legal provisions offering liability protection to vaccine manufacturers against claims for vaccine-related damages is presented by vaccine critics as proof that 'the system' is designed to advantage pharmaceutical companies, and that the state is on the side of 'Big Pharma'. The collective identities of vaccine critics as 'whistleblowers' and 'well-informed citizens', coupled with representations of systemic collusion among private and public institutions can be seen as two sides of the same coin, supported by alternative interpretations of current laws.

In the conclusions, I will bring together these different narrative threads to show how, rather than an expression of the muddy politics of post-truth, or of pervasive uncertainty in late-modern societies, vaccine counterpublics create confident, self-assured members who see themselves as brave 'whistleblowers', who are 'fighting for the truth' in the face of what they frame as lying and corrupted institutions, guilty of causing childhood vaccine injuries and therefore worthy of blame. As a whole, I suggest these narratives should shift our attention from the posited cognitive deficits of vaccine critics to some of the broader, 'inaccessible' dynamics of power underlying the making of vaccination policies.

Uncovering lies, fighting for the truth: vaccine critics as 'courageous whistleblowers'

'We live in an Orwellian world...'

This remark was posted in 2019 by a vaccine-critical commenter dismayed at the news that Peter Gøtzsche, a Danish physician, had been expelled from the influential Cochrane Collaboration – a not-for-profit organisation producing reviews of medical evidence of which Gøtzsche himself was a co-founder. According to the blog *ANHI*, 'Gøtzsche dared scrutinise available data on vaccines', while critiquing '...Cochrane's own deficient review of the HPV vaccine showing it was both incomplete and ignored important evidence of bias' (ANHI, 13 March 2019). For the blog, the 'Gøtzsche case' is a clear instance of how propaganda has taken over from 'the truth', and is uncritically consumed by the public as '*fake news*'.

During the timeframe considered in this research, references to 'fake news' are found quite frequently among counterpublics, appearing in 51 posts across three of the sampled blogs.[127] On *AoA*, these references are usually made by bloggers and commenters lamenting the public being 'peddled fake news' by pharmaceutical companies, the media and public institutions. For example, a post from March 2018 expresses the belief that the media will not report on a story unless this has a 'sponsor' pushing it:

> Investigative journalism - unless it supports the views (pro-Trump or anti-Trump) that drive viewers to the network they work for - simply won't touch the pharmaceutical industry. It's not that we are being shown "fake news." We are, however, only seeing "sponsored news." [...]
> The true cause of the opioid crisis and the autism crisis is not being covered on the major news outlets because it simply doesn't have a powerful sponsor. The industry pays too many of the network's bills.
> (AoA, 4 May 2018)

In addition to mainstream media, commenters on the blog also tend to blame the 'vaccine industry' and the World Health Organisation ('WHO') for spreading 'false' information about vaccines. One commenter for example specifically challenges official figures on measles mortality, suggesting these have been artificially inflated, and even refers to the WHO as the 'propaganda arm' of 'Big Pharma'. Some posts expressing similar views show a degree of self-awareness among counterpublic members, conscious of their public portrayal as suppliers of misinformation. Reacting to these portrayals, which they perceive to be unfair, vaccine critics try to turn the tables on who is *actually* responsible for the spreading of fake news in society.

An instance of this is an *AoA* post accusing a US-based political news organisation of hypocrisy for allegedly supporting a pharmaceutical 'lobby group' masquerading as a public body, while 'attacking vaccine critics for spreading fake news' (30 November 2018). Another post on the same blog accuses the UK Department of Health of having played 'a dirty game' for many years in order to inflate the

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[127] References to 'fake news' are present in 51 posts across the three blogs *AoA*, *ANHI* and *LW* (it should be noted that these are the blogs with the highest amount of posts among those sampled in this research).

numbers of flu-related deaths in the winter, over-estimating the incidence of flu mortality and providing a 'fraudulent narrative' around the relevant figures, which are then further propagated by the news media. 'Yet,' writes the blogger, '[the BBC and the British government] are the first to accuse others of purveying FAKE NEWS'. They are debasing the currency' (3 December 2018).

For an *AoA* commenter the issue goes beyond vaccines, as they condemn the 'UK media' for allegedly peddling false news on 'worthless cancer drugs'. In a different post, the same commenter also depicts this kind of top-down obfuscation of truth as a long-standing issue, citing the 1919 'Spanish flu' pandemic as a sinister precedent of 'fake news'. Specifically, the commenter maintains that the Spanish flu was a made-up disease introduced to conceal the damage done to WWI troops by some 'experimental vaccines' they received at the end of the war. *ANHI* also view 'misinformation' and 'fake news' as broader problems affecting both the media and the scientific world. In one post, the blog questions whether terms such as 'fake news' and 'deniers' represent a novel inflection of the notion of 'conspiracy theory', used to silence critics of the establishment:

> 'Fake news' and 'deniers' are two terms we now hear every day. They've largely replaced the term 'conspiracy theorist' that was long used as a smokescreen intended to stop people distinguishing those who had no evidence of conspiracy, say between governments and corporations, as compared with those whose evidence would be better ignored by the establishment as and when it was advantageous for the conspirators. No surprise this is generally at the public's or the natural environment's expense. Did you ever meet a 'conspiracy theorist' who was subsequently revered as a 'conspiracy realist'?
> (ANHI, 6 March 2019)

Other takes on vaccine-critical blogs include the idea that governments push alarmistic framings of 'fake news' being spread on social media by 'anti-vaxxers', in order to deflect the public's attention from the real dangers of vaccines, or from parents' experiences of vaccine injury in their own children. Along these lines, one comment on *AoA* compares 'the ongoing fight against fake news' to an outright ban on any form of personal research on vaccinations and vaccine safety.

These comments also resonate with the one reference to 'fake news' found on *LW*, made by a commenter reflecting more specifically on what is seen as lack of vaccine-critical information in the 'mainstream' media. Comparing our society to 'Babylon' and remarking on the 'strange times' we are currently living in, this commenter expresses agreement with former US President Donald Trump about the issue of 'fake news', implying a view of journalists as unreliable if not wilfully misleading.[128] Elaborating on this statement, the comment points towards a case in which an American television network was accused of digitally manipulating a picture of a baby in a news segment in order to encourage the use of the MMR vaccine in children. More specifically, the comment claims, the show made it appear that the baby in the picture had a measles rash, when it was claimed that the original picture showed a baby with clear skin and no signs of measles.[129] After having looked further into the issue, this commenter discovered that the TV channel received funding from a multinational pharmaceutical company. This led to their realisation that what they had thought was 'news' was actually an 'infomercial', that is advertisement masquerading as news reporting. Further, the comment argues that 'news', in general, can be controlled by an all-too-powerful pharmaceutical industry which public institutions fail to keep in check, to the detriment of the 'medical community' and public health.

Considering how unstable, unreliable and biased vaccine counterpublics perceive their surrounding information ecosystems to be, it is not surprising that they embrace a circumspect approach to how they research vaccination issues. The almost ubiquitous appeals for individuals to 'educate themselves' about vaccines which are found across the blogs (see Chapter 4) are then carefully qualified, as truthful information may be difficult to identify in an ocean of 'biased' voices. This is why, for instance, *ANHI* warns its readers about 'online bias and manipulation', inviting them (and their children) to avoid 'fake news': '[q]uestion what you read and where it's coming from. Manipulation and censorship is rampant and may come from widely trusted sources such as Wikipedia. It may also come in the form of information purging on social media' (9 January 2019). By seeding doubts about the reliability of Wikipedia and representing social media misinformation policies as 'information purging', *ANHI* is attempting to 'correct' their position, so that they are no longer seen as potential contributors to disinformation, but instead as victims and even correctors of a distorted media ecosystem.

These interrelated representations of 'fake news' among counterpublics are significant as they start shedding light on how online vaccine critics conceptualise notions of 'truth' and 'truth-seeking' in their collective identity narratives. This includes how counterpublic members frame themselves as involved in the pursuit of 'vaccine truths', which can be uncovered through personal research by intelligent, motivated lay citizens despite being hidden behind curtains of lies propagated by various public authorities, 'Big Pharma' and the media. Self-portraits of vaccine critical identities as requiring some

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[128] This comment appears to be referring to the former US President's numerous attacks on journalists and the 'mainstream' news media during his presidency, in which he had frequently used the expression 'fake news' to dismiss media criticism (see Woodward 2020).

[129] Other sources have since noted how NBC did not manipulate the image, but rather used a stock picture that had two versions, one showing baby with a rash, one without. See https://debunkingdenialism.com/2019/05/14/nbc-did-not-fake-image-of-baby-with-measles/.

sort of 'fighting for the truth' recur across different blogs. *VP*'s 'About' page, for example, describes the mission of the blog as 'provid[ing] detailed, science-based and *objective* information about the dangers of vaccines', while justifying the need for these knowledge-making and sharing activities by reference to how 'the media, and [...] medical institutions that are supposedly guided by science' in fact 'ignore' any scientific evidence suggesting vaccines are dangerous (n.d., emphasis added).

On *AoA*, bloggers speak of the need to 'fight' for 'the truth' about vaccines to be uncovered and revealed to the broader public. For example, in a review of a book by one of the blog's founders, another vaccine-critical blogger refers to the book as 'unadulterated truth' and frames its contents in opposition to '[...]blind belief in the CDC and AAP, government, and the media'. The *AoA* book's author is also depicted in a reposted review by vaccine critic Robert F. Kennedy Jr as leading 'the *big fist fight* against the Pharma Cartel to force the issue, broadcast the science, and *expose the lies* behind the vaccine policies that have created an epidemic of chronic disease among our children' (19 July 2018, emphases added).

In other *AoA* posts, 'the truth' offered by vaccine-critical activists about vaccine injury is variously described as 'unadulterated', 'unfiltered', 'undeniable', 'whole', 'real' and 'full'. But truth is also described as 'ugly', 'bitter' and 'sordid'. 'Ugly truths' need to be 'exposed' by vaccine counterpublics, because they are otherwise distorted by the media and governments which, being in the hands of 'special interest lobbying groups', are not able to 'handle' them. In a poignant image, an *AoA* commenter talks of truth as an 'irresistible force' finally starting to approach an 'immovable object', represented by established authority: it is only a matter of time until a collision will happen. Another *AoA* commenter, in a similar way, speaks about a 'dam' that is 'beginning to crack', leaving the 'filth' (that is, the truth about the dangers posed by the pharmaceutical industry) ready to overflow.

The 'inaction' of institutions in the face of emergent 'vaccine truths' is also subject of discussion on *FP*. In one of their posts, the blog makes a point of remarking on how '[o]ver the past 14 years, we've been reporting about skyrocketing autism rates', despite a 'concerning media silence', and inaction on the part of public health and political authorities over what they frame as a massive 'public health crisis' (11 June 2018). In the widely supportive and appreciative comment section of this post – which is structured as an open letter directed to New Jersey Governor Phil Murphy - readers of the blog invite the politician to 'stand up' and 'do the right thing', educate himself on the reality of the 'autism epidemic', 'protect the children' from vaccines and 'stop fearing' pharmaceutical corporations. One commenter argues that citizens are gaining more awareness about vaccines as more information (on vaccination dangers) becomes available, even anticipating a 'turning point' in the near future and asking

Governor Murphy to be on the 'right side of history'. Another comment implores him not to let the media 'silence' him, maintaining that his intervention is needed by the whole country, and especially 'innocent children' who would otherwise 'not have a voice'. Framing themselves as being involved in a mission to find out and share the truth about vaccine dangers against what they see as an institutional wall of silence, *FP* counterpublic members try to 'evangelise' political figures by rhetorically constituting (Charland 1987) the vaccine-critical advocate as a sort of heroic 'fighter for truth', or 'courageous whistle-blower', who defies powerful elites in defence of the rights of children and their families.

This sort of 'whistle-blower' identity claimed by vaccine counterpublics is furthermore projected onto figures in the scientific-medical world who are seen as bravely opposing the mainstream consensus on vaccine safety. One of these figures, as mentioned above, is that of Peter Gøtzsche, portrayed as an expert voice challenging the consensus on HPV vaccine safety. A second example is Christopher Exley, a professor of inorganic chemistry at Keele university in England whose controversial research claiming a link between aluminium adjuvants in vaccines and autism is a key resource for the vaccine-critical blog *VP*. Exley's work is also referred to on *VCUK*, and he is hailed as a 'brillant' and 'ethical' researcher, a 'true hero' and even a 'rock star of science' on *AoA*. But perhaps the most well-known among the vaccine-critical researchers mentioned in the blogs is former physician Andrew Wakefield.

Wakefield's work is defended particularly on *AoA* – which is consistent with the blog's focus on the autism-vaccines 'link'.[130] According to *AoA*, Wakefield has been unfairly targeted by the media and wrongly struck off the medical register in the UK by the General Medical Council (GMC) – whose decision on Wakefield's misconduct was followed by the retraction of his paper positing a link between autism and the MMR vaccine by the medical journal *The Lancet*.[131] In a complaint sent by an *AoA* blogger to the Independent Press Standards Organisation (a UK news media regulatory body) about an article published in *The Telegraph* newspaper, Wakefield is depicted as having been fully exonerated of professional misconduct by a 2012 High Court ruling on an appeal by one of his MMR paper co-authors, Professor John Walker-Smith, which reinstated the latter's medical licence (AoA, 30 July 2018).[132] While Wakefield was not a party to the appeal, and claims that the High Court decision has any relevance for his case have been contested (see e.g. Harrison 2016), for our purposes the significant

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[130] The name 'Exley' is mentioned in 42 blog posts across the Blogs *AoA*, *VP*, and *VCUK*, whereas Wakefield is mentioned in 12 posts, all on *AoA* except for one on *VCUK*.

[131] See General Medical Council, Fitness to Practise Panel (2010). As Jacob (2016) notes, the General Medical Council decision on the Wakefield case was not about whether the findings presented in the *Lancet* study were right or wrong, but rather whether the research was 'ethical and genuine to begin with' – in other words the case did not involve 'technical errors', but 'normative' ones (504). The distinction between 'technical' and 'normative' errors, originally proposed by Bosk (1979), is significant as it only normative errors which 'might impair the fitness to practise of the individual medical professional, while bringing the profession into disrepute' (Jacob 2016, 505). The impact of the GMC decision on Wakefield's personal reputation contextualises *AoA*'s efforts to defend his MMR research.

[132] *Professor John Walker Smith v General medical Council* [2012] EWHC 503 (Admin).

point made on *AoA* is that the media has used the 'innocent' Wakefield as a 'scapegoat' in a 'deliberate attempt to distract from the real issues'. The stories about him are then presented as nothing but 'FAKE NEWS [...] being outrageously blown up' (AoA, 30 July 2018). 'It is terrifying', it is stated on the same blogpost, 'the extent to which mainstream journalism has *abandoned the objective reporting of complex reality*, and turned on many responsible communities across the world wide web, who are actually often well-informed and trying to do their best for their fellow citizens' (emphasis added).

There are three levels, then, at which the idea of 'whistleblowing', can be found among critical communities. The first is represented by counterpublics who see themselves as 'speaking the truth' about both the 'science' behind vaccine-related risks and – in the case of parent-activists – the reality of their children's vaccine injuries. Counterpublic members' 'fight for truth' is sometimes depicted as a sort of personal life mission for the benefit of society, as encapsulated in the following extract from an *AoA* blogpost:

> We will not stop fighting. We will not stop educating. We will not stop shouting the truth one person, one conversation, one study at a time. Our message is too important. It is vital that we continue our mission. The health and future of our nation depend upon it.
> (AoA, 11 March 2019)

The second level consists of those 'potential political allies' (such as the addressees of the open letters published on *FP*) who are not yet on counterpublics' side but who are invited to embrace their cause through carefully crafted rhetorical appeals. These create an opposition between, on the one hand, morally upstanding vaccine-critical subjectivities and, on the other, powerful lobbies and elites who are seen as suppressing information on 'vaccine dangers' and punishing those who 'dare to speak the truth' about vaccine safety issues. However, some blogs appear more pessimistic than others about the possibility that mainstream politics will ever acknowledge their claims about vaccinations. On *AoA*, hopes that politicians will pay attention and listen to vaccine critics are seen as frustrated by the intermingling of politics and corporate interests. A comment on the blog for instance argues that what vaccine critics 'need' from politicians, regardless of party allegiance, is 'the truth'. However, the commenter laments, nobody is interested in the truth anymore, as 'truth' represents the most 'dangerous' threat for profit-making companies.

The third, more widespread level at which the notion of 'fighting for truth' appears in counterpublic talk is that involving the heroic, anti-establishment 'vaccine-critical expert'. Vaccine-critical experts represent an actualisation of the figure of the potential political ally – they are celebrated as heroes among counterpublics for 'speaking up' about vaccine safety issues, but they pay a price for sharing the 'truth' in terms of marginalisation or even exclusion (as in the case of Wakefield) from mainstream science, suffering as a result the reputational damage caused by what counterpublics frame as unfair media reporting.

In addition, in certain cases the figures of the 'whistleblowing' counterpublic member and critical expert may overlap. *VP*, for example, refers to the story of 19th-century Hungarian physician Ignaz Semmelweis, who while working at Vienna General Hospital discovered that hand disinfection could reduce the occurrence of often deadly puerperal fever in pregnant patients. Because Semmelweis' discovery meant physicians were responsible for causing the higher rates of infections in women by not washing their hands (particularly as the same physicians working in the obstetrics' clinic also routinely performed post-mortems in the hospital's autopsy room), he was, as *VP* recounts, '...ridiculed, viciously attacked and hounded out of medicine'. Semmelweis' contributions to medicine were indeed only acknowledged after his death – which tragically occurred at an asylum in Vienna to which he was committed following a prolonged period of mental decline, and after his hypothesis on puerperal fever had been widely rejected by his colleagues and the surrounding medical community (see Lane, Blum and Fee 2010).

The reference to Semmelweis in this blog post arguably represents more than a casual anecdote. In the same post, *VP* complains twice about the threats of 'ad hominem personal attacks' and 'harassment', which it maintains are 'commonplace in the vaccine debate'. 'There are considerable personal and professional risks', the blog claims, 'in being associated with vaccine criticism' (n.d.). It should also be noted that *VP* mentions Semmelweis' story in the context of advising readers not to trust the advice of health professionals on vaccines (implying they should instead listen to the alternative claims set out in the blog), referring to the 'corruption' of medical science and the 'motivated reasoning' of medical doctors refusing to acknowledge the 'iatrogenic' (or doctor-induced) damage caused to their patients. By emphasising the risks of publicly fighting for truth and the resistance even true claims supported by evidence may encounter from the scientific mainstream, *VP* is drawing a parallel between Semmelweis' courageous defence of his findings and the blog's own efforts to share the 'truth' on vaccine dangers. Through this parallel, *VP* is then able to offer a compelling explanation as to why vaccine-critical claims are not being taken seriously by the vast majority of the scientific community, while comparing its activities as a producer and sharer of information countering consensus views on vaccine safety to those of a 'brave scientist' persecuted for telling the truth even if this means challenging the establishment.

It should be noted how these kinds of 'whistleblower' vaccine-critical subjectivities are not unique to *VP*. In parallel, a blog post on *LW* (5 November 2018) and an *AoA* comment refer to 'Galileo' and the historical events surrounding his forced recanting of heliocentrism – the former noting how the astronomer was once considered a 'heretic', and the latter pointing out that although today there are many monuments to Galileo (and none to those who persecuted him), 'scientific reasoning' is still 'time and again' sacrificed to 'ideology'. Rather than being 'outsiders' to the scientific world and its history, then, counterpublics frame themselves as following a respectable tradition of 'pure', evidence-driven experts who for a period of time are disbelieved within their research communities and broader society, but who eventually become acknowledged and celebrated for having stood up for the 'truth' in the face of great personal cost and adversity.

Whistleblowing identities and post-truth

As can be evinced from the data analysed above, matters of truth – particularly recurrent distinctions between truth and lies (including the 'fake news' on vaccines seen as being propagated by the media) play an important role in counterpublic talk and identity-making narratives. The implications of these findings should be considered carefully, especially in relation to recent theoretical accounts which situate vaccine opposition in a broader historical context in which – it is claimed – 'facts' and 'truth' have lost their status as guiding principles of social life. In such accounts, vaccine-critical activism is seen as exemplifying 'facts denial' phenomena emerging from a 'post-truth era', or 'post-truth society'. According to an *Oxford English dictionary* definition often quoted by commentators (see e.g. Speed and Mannion 2017; De Cleen 2018), 'post-truth' is an adjective 'relating to or denoting circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief'. 'Post-truth' has also been argued to have become a prevalent condition across the western world in the past decade, finding expression in various phenomena and events such as a rise in populism in liberal democracies, Brexit, and the American presidential election of 2016 (see Rose 2017; Speed and Mannion 2017; Kakutani 2018).

Philosopher Lee McIntyre has argued that 'post-truth' is connected to science denialism, and that scientific controversies on issues such as climate change and vaccines have been artificially generated by groups with 'something financial or political at stake' (2018, 77-78). He claims that these groups have been successful in hijacking the media to make it seem as if the scientific community is divided on topics such as vaccinations – even when a clear scientific consensus on these topics already exists.

Matthew D'Ancona (2017) has also specifically discussed vaccine opposition as an expression of post-truth society, even defining the 'modern campaign against vaccination' as a 'case study in Post-Truth' (70). In his view, an array of actors, TV personalities and public figures has reinforced the 'anti-vaccination' cause by conferring it with credibility and 'glamour'. Therefore, even though 'it was beyond rational dispute that vaccination had eliminated a number of vaccine-preventable diseases,' D'Ancona writes, '...scientific evidence proved no match to the charisma of celebrity' (2017, 71).

'Post-truth' framings of vaccine opposition generally tend to assume that vaccine critics are either opportunists with a hidden political or financial agenda, or gullible people fooled by charismatic and manipulative activist-leaders. Crucially, the success of these vaccine-critical leaders in manipulating their 'publics' is presented as if it were made possible by facts and evidence losing their foundational status as the basis for rational debate in the wider public sphere.[133] This point links back to arguments that vaccine-critical claims have their roots in 'postmodern society', or bear an affinity with certain philosophical approaches broadly defined as 'post-modern'. These arguments are well exemplified by Kata's (2010) influential discussion of the internet as a 'postmodern Pandora's box' of misinformation. In her analysis, vaccine-critical claims diffused online have become particularly difficult to challenge, from a 'postmodern perspective', which, Kata elaborates, 'questions the legitimacy of science and authority', redefining the notion of expertise so that '[...]even the most respected vaccine authority's advice becomes just another opinion' (1715). Postmodern philosophy is also framed as one of the roots of 'post-truth' by McIntyre (2018), who argues that both share a philosophical perspective averse to universal, objective truths and facts. As he puts it, '[t]he postmodernist approach is one in which everything is questioned and little is taken at face value. There is no right answer, only narrative' (2018, 125). This suspicion of truth and facts in turn flows from a broader belief that any truth claim should be seen as a mere expression of the political ideology of whoever is making that particular claim (126).

Here, I do not wish to make any general claims regarding 'post-truth' and its accuracy in capturing our contemporary social landscape.[134] What I would like to focus on instead is the paradoxical co-opting by vaccine counterpublics of something akin to 'post-truth' as a lens through which to view certain institutions and power relationships within society. Crucially, in the vaccine-critical talk carried out on the blogs not everything is treated like 'just another opinion'. The existence of objective, universal truths is not questioned: on the contrary, 'vaccine injury' is often talked about as a firm 'reality' and a 'fact'. In addition, counterpublic members adopt language bearing a similarity to critiques of 'post-

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[133] For an exposition and critique of this 'popular post-truth narrative', see Ashton and Cruft (2021).

[134] It should be pointed out nevertheless that the connection between postmodern epistemologies and post-truth is not accepted uncritically by all commentators (see Biesecker 2018; cf. Prado 2018).

truth', when they lament the dismissal of those who speak the truth, and the fact that economic interest often prevails over scientific knowledge.

Counterpublics do not seek to challenge scientific discourse itself as a basis for truth (see also Chapter 4). Rather, they frame themselves as part of a cyclical narrative of scientific progress in which new discoveries may initially be opposed by the mainstream and defended by only a minority of 'enlightened' researchers, but as time passes, and the evidence accumulates, they eventually become accepted as 'true science'. Evocations of the 'heroic' but marginalised expert opposing mainstream opinion, but ultimately being proven right implies a belief in truth, as well as a hope that this will at some point prevail and be universally recognised as a new consensus is established.

This belief in a clear, black-and-white dichotomy between truth and lies (or true and false claims) may also be glimpsed in references to instances of corporate denial of science: 'Cigarettes Don't Cause Lung Cancer and Vaccines Don't Cause Autism', reads the headline of an *AoA* post (13 October 2018). The notion of 'denial' is used to frame critiques of vaccine-critical claims, with more than 70 blog posts mentioning the term.[135] Tobacco harm, asbestos litigation and the Thalidomide scandal are all presented as historical precedents comparable to 'vaccine injury denial' in multiple posts across four of the six sampled blogs. Additionally, a book co-written by the late founder of *AoA* includes 'denial' in its title (see Blaxill and Olmsted 2017), with a blogger arguing the book should be 'required reading' during what they call 'National Vaccine Injury Denial Month' (7 April 2018).[136]

Counterpublics' views of the social and economic dynamics of truth may therefore be seen as a sort of mirror of 'post-truth' perspectives, with vaccine critics lamenting how powerful elites are lying and obfuscating the truth, while they portray themselves as the only stewards of the 'real' truth about vaccine dangers, bravely opposing their own silencing. This is very different from the 'postmodern' epistemologies discussed above. As seen above, some counterpublics even think that there is a chance some politicians may become involved in their fight for 'vaccine truth'. It is notable how vaccine-critical counterpublics, which have been portrayed as a sort of textbook example of 'post-truth', actually see themselves as fighting courageously against it.

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[135] Some references to 'denial' include other claims made critical blogs about 'hidden', yet to be exposed purported threats to human health, such as 5G and statin drugs.

[136] The complete title of the book by Blaxill and Olmsted (2017) is 'Denial: How Refusing to Face the Facts about Our Autism Epidemic Hurts Children, Families, and Our Future'. The blogger's mention of a 'National Vaccine Injury Denial Month' is likely a sarcastic reference to the 'World Autism Awareness Day', an internationally recognized day about autism and autistic people, which falls on April 2 each year (see United Nations General Assembly 2007).

Analysing the 'truth-talk' circulating among online vaccine critics sheds light on some important aspects of vaccine-critical identity-making, but it also raises further questions about counterpublics and their activities. How do counterpublic members become confident about deciding who is telling the truth and who is lying about vaccines? How do they frame those actors and institutions they see as lying about vaccine harm, and how do they conceptualise their own relationship with 'mainstream' expert authorities? These different aspects of online vaccine opposition will be explored in the following sections.

Epistemic trust and the 'well-informed counterpublics'

> I decided not to vaccinate my children because I was concerned about vaccine side effects. However, sometimes I doubt myself and question if I have made the right choice [...] As much as I strive to be educated or well-informed, as I am not a doctor or a scientist, I feel that my choice may not be the right choice...
> (commenter [reworded], VCUK)

This commenter's expression of self-doubt about making the 'right' decision on whether or not to vaccinate their children, which appears on the blog *VCUK*, is a rare find on our vaccine-critical blogs. Specifically, the comment above is one of the few instances in which the choice not to vaccinate is presented by a counterpublic member as the result of an individual dilemma, rather than a clear-cut decision which has already been taken. One of the other rare examples of a more nuanced approach to vaccine choices which was found in the blogs' comment sections is represented by a recurrent commenter on *AoA* who in multiple interventions expresses cautious support for certain vaccines (including polio and HiB).[137] According to this more 'moderate' commenter, the suffering and death caused by vaccine-preventable diseases and 'diseases for which there is no vaccine now' should be acknowledged, and the choice to vaccinate or not should come down to a 'judgment call' by parents, involving a careful balancing of risks and benefits.

The commenter's 'support' of vaccines is still quite limited – just extending to some diseases they consider particularly dangerous, and seen as a last resort when lifestyle changes (for example raising a toddler at home rather than sending them to nursery to decrease the risk of potential infections) are not

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[137] This commenter's (relatively) more nuanced approach to vaccinations appears in the comment sections of 27 different blog posts on *AoA*.

possible, or homeopathic alternatives to vaccines are not available. Nonetheless these more nuanced comments are the object of criticism by other commenters on the site, some of which particularly challenge the use of the terms 'vaccine-preventable diseases' or 'VPDs' ('you are the only one here who mentions VPDs!'; 'there is no such thing as a vaccine preventable disease'; 'there is always a vaccine apologist bringing up the boogeyman of vaccine preventable disease'; 'go post on a pro-vaccine site instead'), as well as the idea that vaccines are effective and beneficial in certain circumstances.[138]

Like the majority of commenters on *AoA*, the blogger at *VCUK* tends to present the decision not to vaccinate one's children as an obvious one. For example, explaining the decision to reject HPV vaccines for young teens he writes: '[a] twelve year old has zero risk of cervical cancer and a small risk of death. The decision is a *no brainer*' (March 2019, emphasis added). Regarding the DTP vaccine, he states that:

> As it would appear the vaccine is not very effective and as there are risks associated with the vaccine, not giving it to our children *was not a difficult decision for us*. I would not say adverse events from vaccines are common, but they are there and are glossed over in the UK when the appointments are made.
> (VCUK, August 2018, emphasis added)

The expression 'no brainer', referring to the claim that vaccines are dangerous for children (and should therefore be avoided) also appears in a comment on *FP* claiming that even the US Supreme Court has 'ruled' that vaccines are 'unavoidably unsafe'. HPV vaccines are also presented as especially dangerous on *ANHI*, whose bloggers even invite readers to sign and circulate a petition '...calling on health authorities to stop claiming vaccines are "safe" to safeguard informed choice and consent over vaccination' (16 May 2018). *LW*'s approach to immunisation decisions and vaccine safety matters is similarly straightforward. In a critical blog responding to a pro-vaccination post by a user identifying as a nurse which was widely circulated on Facebook, *LW* contends that vaccine-refusing parents are not rejecting modern medicine as a whole, but rather are justifiably concerned about safety issues as (according to them) vaccines do not represent 'sound medicine' and there is no evidence supporting their safety and the effectiveness:

> It is flat-out false that parents who don't vaccinate have an aversion to modern medicine. Allow me to (once again) educate you: Parents who don't vaccinate opt out because they only believe

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[138] These commenters' reactions have been reworded to further protect their anonymity.

> in sound medicine that has been proven to be safe or effective. Vaccines have not been proven to be safe and effective and fail to meet the standards for evidenced-based medicine.
> (LW, 5 November 2018)

Along similar lines, *VP*'s 'About' page includes the blog author(s)' general perspective on childhood vaccines:

> Vaccinepapers.org is not ideologically opposed to all vaccines, but we are unaware of any specific vaccine that has an acceptable level of proven safety, especially for infants, and especially if it contains aluminum adjuvant.
> (VP, n.d.)

While *VP* might seem to have a more nuanced approach to vaccine choice at first glance (earlier on in the same page, they maintain that '[l]ike any other medical treatment, vaccination must be justified in view of an objective risk/benefit analysis'), the statement quoted above effectively amounts to a recommendation not to vaccinate, claiming that no currently available vaccines have been proved to be 'safe' enough for use in young children. A similar rhetorical appeal to 'vaccine choice' in conjunction to substantial nudging towards not vaccinating appears on *ANHI*. *ANHI* seems to embrace a 'moderate' position (in comparison to *VP* and *VCUK*) regarding the effectiveness of particular vaccines, explicitly acknowledging the dangerousness of at least certain vaccine-preventable diseases. For example, the blog's MMR 'Vaccine Choice' campaign webpage states that:

> ...There is no question that vaccines have been shown to work in specific situations and among particular population groups, and there are some diseases that are sufficiently dangerous that it's a reasonable choice to go for the vaccination; the obvious example is tetanus.
> (ANHI n.d.)

In the same page, however, the blog strongly discourages readers from immunizing their children while young:

> But the real question is: do all these vaccines have to be given to babies and toddlers? In my opinion, and that of a growing group of my medical colleagues, their immune systems are just not geared up to handle this onslaught.
> (ANHI n.d.).

While advocating for 'vaccine choice', therefore, the blog simultaneously provides reasons why someone should delay or avoid childhood vaccines altogether. It might not be surprising to find confident claims about purported vaccine dangers and statements advising against vaccinating children coming from vaccine-critical bloggers. However, one might reasonably expect to find requests for advice on vaccination, or at least some expressions of doubt and hesitancy in the comment sections of the blogs.

Looking at the existing public health research on vaccine-related behaviours and attitudes, parents' refusal or delay of childhood vaccinations are often framed in terms of 'vaccine hesitancy', and in the literature there are recurrent references to 'vaccination doubts' and 'concerns' within populations (see e.g. Larson et al. 2014; Siddiqui, Salmon and Omer 2013; Dubé et al. 2013). In addition, previous interpretations of vaccine opposition have approached this through the theoretical prism of Anthony Giddens' (1990; 1991) and Ulrich Beck's (1992) work, which emphasise the role played by pervasive sentiments of *doubt* and *uncertainty* as prominent features of late modern societies, and as the basis of increasing distrust towards public institutions (see Leach and Fairhead 2007, 30-31).

As Leach and Fairhead (2007) note, this view of society has been framed either in a negative sense, as the ushering in of a new 'era of insecurity' (see Bauman 1999) and 'anxiety', or in a more nuanced and positive way, as the expression of an emergent 'active scientific and technological citizenship', displaying 'a reflexively organised dialectic of trust and doubt' (Williams and Calnan 1996, cited in Leach and Fairhead 2007, 31). Either way, these interpretations regard feelings of 'doubt' (or more precisely collective, institutionalised doubt as a societal condition) as a force which undermines 'trust' in expert institutions and their representatives). As Giddens (1990) puts it, '[w]e are abroad in a world which is thoroughly constituted through reflexively applied knowledge, but where at the same time we can never be sure that any given element of that knowledge will not be revised' (39).

With this existing scholarship and previous interpretations of vaccine scepticism and opposition in mind, as I analysed my data and created codes related to the broader areas of 'vaccine-critical identities' and 'trust', I was puzzled by the lack of genuine questions about vaccines, or any expressions of uncertainty and doubt among blog commenters – some of whom, I assumed, might have shown something more akin to 'hesitancy', rather than outright rejection of vaccination. Instead, commenters on these vaccine-critical blogs and their social media pages appear by and large to have already 'taken sides', yielding secure, taken-for-granted negative views on vaccines which are expressed and become reinforced through online interaction. In contrast, the many appeals to 'educating oneself' and independently learning about vaccine safety issues found across all the blogs sampled in this study –

which I discuss in more detail in Chapter 4 – might lead us to expect if not challenging questions and reservations, at least a degree of nuance in the discussions about vaccines in these comment sections. Surely, while doing their own independent research, these counterpublic members will have come across some of the abundant 'mainstream' scientific literature on vaccine safety, much of which is accessible online?

A clue to explaining this apparent tension between the recurrent invocations of independent research and critical thinking, and the simultaneous lack of expressions of doubt among counterpublics may be found in the comment quoted at the beginning of this section – which is unique in the way it signals uncertainty about vaccine decisions by a blog reader identifying as a parent. As seen above, the author of this comment unusually (for a counterpublic member) admits to not feeling qualified enough to be confident about making the 'right' decision on vaccines, not being a 'doctor' or 'scientist'. The full comment shows that its author is aware of the possible complications of vaccine-preventable diseases – the author mentions having independently read 'other sources', as well as being 'bombarded' with letters from their children's doctors and school about the dangers associated with such diseases. However, what the commenter seems to be mostly interested in is the *VCUK* blogger's own lived experience as a parent. How did the *VCUK* blogger come to the decision not to vaccinate his children, the commenter wonders, and manage to be 'peaceful' about it? Would he consider vaccinating at least against tetanus? In the comment, it is also stated that the *VCUK* blogger's recounting of how his teen daughters had received certain vaccines in order to be able to travel abroad had made a 'big impression' on the commenter, who notes they would not want to find themselves in the same position of allowing their children to be immunised with many shots 'in such a short span of time'.

While the *VCUK* blogger did not respond to this particular comment, the commenter's questions reveal a common trend among counterpublic members – namely reliance on experiential knowledge as an important resource grounding health decision-making, including the choice to reject vaccines. The experiences conveyed in blog posts and comment sections often consist in personal accounts of 'vaccine harm' or 'injury'. Multiple commenters and bloggers, across different counterpublics, share stories about and relay their experiences of vaccinations resulting in severe, 'life-changing' injuries for their children.[139] A recurrent narrative emerging from all these stories is how counterpublic members used to be unquestioningly accepting of vaccines, before a tragic 'vaccine reaction' hit them and their families, unsettling their realities and leading them to *research* immunisations further and become aware

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[139] Occasionally, counterpublic members claim other family members and acquaintances have been harmed by vaccines, or that they have suffered vaccine injury themselves.

of the 'true dangers' vaccines would pose. Multiple reiterations of this narrative are found on *AoA*, as may be exemplified from the following blogpost extracts:

> Some of us come at vaccines at a different angle. Those of us whose child suffered greatly post vaccination were with the pro-vaccine crowd at one time. Lots of pro-vaxxers tend to forget that. At one point, we were with you 100%. But when our child was left with a host of medical problems, to include autism, our lives were flipped upside down and we were forced to rethink everything we were taught, told, and believed. That's shaped me into the person I am today...
> (AoA, 15 April 2018)

> I can't speak for all "anti-vaxxers" who choose not to vaccinate, but I can share a bit of our story. I was once pro-vaccine. 100% for them. It wasn't until after my child suffered an adverse event that I changed my outlook on them. What I was told couldn't happen to my son happened: he was injured by a vaccine. After that discovery, I started to finally read about vaccines instead of taking what our providers were saying as gospel truth. Believe me, I did not want to walk away from them or from what I'd been told my whole life, that vaccines were only safe and only effective. But the more I read, the more I learned. I learned that all vaccines come with risk, that they were not studied as the CDC says they've been, and that for some people like my son, they can do more harm than good. Side effects and adverse events were our reality - not better health or protection from diseases (yes, we've tested this and know that the vaccines did not work).
> (AoA, 24 March 2019)

In another blogpost, the same author of the posts quoted above describes going 'from being 100% pro-vaccine to somewhat vaccine cautious to advocating for informed choice and for vaccine choice', following her son's vaccine injury (AoA, 14 October 2018). In yet another she maintains that knowing what she has learned since the vaccine injury, she would 'skip all the shots completely [...] in a heartbeat'. On their Facebook page, *AoA* also posted memes and other visual content conveying the same message of personal experience lying at the root of vaccine opposition. 'If I had children who escaped vaccine injury the last f***ing place you would find me is social media' reads one image posted in 2019, which received more than 200 likes. A similar vaccine meme posted on the *AoA* Facebook page in March 2019 (totalling about 100 likes) offers the following answer to the question of who are the 'anti-vaxxers' (the text of the meme is quoted below):

> Who exactly are the 'anti-vaxxers'? We're people who believed in vaccines. We're citizens who trusted the government. We're mothers. We're fathers. We're parents who regret not knowing enough, reading enough or asking enough before it was too late. We're the ones who took one for the herd. We're the ones who know too much to be silent. We're driven, educated and vocal. Call us what you want. But calling us 'anti-vax' won't stop us. It hasn't yet. We're parents who think to question vaccines.
> (AoA FB page, March 2019)

This meme conveys a deep sense of regret for '...not knowing enough, reading enough, or asking enough before it was too late', emphasising how it is only following negative personal experiences that these counterpublic members have started to 'think to question vaccines'. While some *AoA* bloggers go in-depth into the circumstances leading them to challenge expert authorities and institutions about vaccine safety, they are not alone among counterpublic members in presenting their own *lived experiences* or *experiential knowledge* as reasons for being opposed to vaccines. Among blog commenters, three posts, one on *FP* and two on *AoA* refer to vaccine critics not as 'anti-vaxxers' but as 'ex-vaxxers', having been people who were once 'pro-vaccine'. On *FP*, three commenters claim their children have been vaccine-injured; they appeal for the 'truth' about vaccine safety to be disseminated and predict that more families will find out about vaccine dangers 'the hard way'. This latter expression is also used by another commenter on the same blog, who argues that vaccine critics are 'intelligent, educated people' who have 'learned the hard way' that vaccines may be harmful to certain individuals.

On *AoA*, a commenter writes that they used to have 'great faith' in vaccination programmes, before their children and spouse suffered multiple adverse reactions following immunisations. Another commenter recounts how it was witnessing vaccine injury in their dog which led them to 'the world of conspiracy'. Yet another argues that the 'only difference' between someone supporting vaccinations and someone against them is having experienced an 'adverse reaction to a vaccine'. On *LW*, a commenter claims to have experienced vaccine injury themselves decades before, after receiving the smallpox and polio vaccines in the 1950s. The author of a comment on *ANHI* also claims to have experienced vaccine injury, alongside their partner and a close relative. On *VP*, one commenter hypothesises a connection between their children's autism and vaccines, stating they are avoiding certain vaccines 'like the plague', and are even considering moving to a different US state with less strict vaccine requirements to protect their youngest child from vaccine harm. Even though *VP*, as a blog, does not rely on experiential knowledge to support claims of vaccine unsafety – stating instead that it provides an 'objective, science-based analysis of vaccine dangers' – references to personal experience are not completely absent within *VP* counterpublic talk.

It should be pointed out how not all counterpublic members who appeal to experiential knowledge claim direct experience of vaccine injury. Blogposts and comments also refer to reports or accounts of others' negative experiences with immunizations, or write more generally about large numbers of parents who purportedly have witnessed their children being harmed by vaccines. For example, in response to a comment arguing that vaccines do not cause autism, a counterpublic member states that such claims do not sway parents who have witnessed a reaction 'immediately' after immunizing, and claims that 'hundreds of thousands' of parents have 'seen' vaccine injury. In a *FP* post, the blogger, after identifying as a parent of 'two children who sustained serious injuries after vaccination', also refers to how the (US) government is ignoring '...the eerily similar experiences of hundreds of thousands of parents whose children were never the same (and then diagnosed with autism) following childhood vaccines ' (4 March 2019). On *LW*, a commenter speaks of 'millions' of parents worldwide who have 'trusted' vaccinations and followed immunisation guidelines, before 'something happened' making them reconsider their views on vaccine safety.

Some blogs provide specific accounts of vaccine injuries occurring to other people's children. *ANHI* refer for instance to the tragic case of a 14-year-old boy who died following complications from a rare neurological disease, acute dissemination encephalomyelitis (ADEM), three weeks after receiving a dose of Gardasil (a brand of HPV vaccine).[140] After expressing their condolences to the boy's family, *ANHI* invite their readers to read their 'Vaccine Choice campaign' page in order to 'find more information about this *controversial* vaccine', and be able to make an 'informed decision' on whether 'your child should receive HPV vaccine' (19 September 2018, emphasis added). It is important to note here how references to others' experiences are used by *ANHI* as a way to introduce readers to vaccine-critical views and flag their own content about vaccine safety. *VCUK* also make references to other parents' experiences, citing in particular the highly publicised accounts of two mothers – Rosemary Fox and Vera Duffy – both of whom published books alleging their children had been injured (by the polio vaccine in the early 1960s in the case of Fox's daughter, and the DTP vaccine about a decade later for Duffy's son) (May 2019).[141] For *VCUK*, there is no doubt about the veracity of these experiential accounts, and further 'expert' investigation into vaccine injury is not seen as necessary to confirm these accounts. As the blogger puts it: '[i]f you have a black eye after being punched. you don't need a "scientist" to prove what caused the black eye'.

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[140] It should be pointed out that a recent review involving almost 64 million vaccine doses found no association between receiving the HPV vaccine and developing ADEM (see Baxter et al. 2016).

[141] See Fox 2006; Duffy 2012. Fox's role in the vaccine-critical movement against the DTP vaccine which emerged in the UK in the 1970s has been discussed in Chapter 2.

This statement's defence of experience as a source of valid knowledge, along with the multiple references to personal accounts of vaccine injury found (albeit to different degrees and in diverse forms) across blogs, make a strong case for experiential knowledge playing an important role in counterpublic collective identities.[142] This would seem consistent with certain interpretations of vaccine opposition, such as the ones discussed in the previous section, seeing this as a 'postmodern' phenomenon involving the spread of a 'rhetoric of doubt' within society, combined with the increased ability to share personal experiences online, and a dilution of expertise such that 'everybody can be considered an expert to some extent' (see Kata 2010). However, vaccine counterpublics appear to adopt a more subtle stance towards expert knowledge than these kinds of interpretation allow for. This nuance emerges when interrogating the contexts in which personal experience and experiential knowledge are invoked. In addition to the way in which counterpublics use scientific knowledge in order to support vaccine critical claims (see Chapter 4) and celebrate certain medical 'experts' and researchers for 'fighting for the truth' about vaccines (as seen in the previous section of this chapter), it is possible to find various statements on blogs presenting experiential knowledge as compatible with, and complementary to expert knowledge, rather than opposed to it.

Therefore, rather than vaccine-critical bloggers and commenters embarking on abstract critiques of science as a system of knowledge, it is common to find them attacking scientific claims of vaccine safety as 'pseudo-science', and defending vaccine-critical research as scientifically sound. For example, immediately after referring to Fox and Duffy's vaccine injury accounts, *VCUK* moves on to discuss Wakefield's 1998 MMR paper, defending the paper's methodology and the soundness of its claims, and arguing that the reason the paper later became controversial was that '*scientifically illiterate*' journalists and their '*sensationalist reporting*' misrepresented Wakefield's research to the public. Along the same lines, the *LW* commenter who said that 'millions' of parents changed their minds about vaccine safety after negative experiences with immunisations also maintains in the same comment that there is a growing number of 'doctors and scientists' ready to come out against vaccines as 'whistle-blowers'. Another commenter on this blog highlights the validity of 'thousands and thousands' of parents' testimonies about vaccine injury, while defending *LW*'s use of just one 'pilot study' to make a point about unvaccinated children being healthier than vaccinated children, stating that the blog could have cited 'dozens more' scientific studies to prove the point.

AoA posts also place 'scientific evidence' and 'personal testimony' side by side when referring to knowledge capable of challenging the vaccine 'industry', and refer to people 'who are not poorly

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[142] References to experiential knowledge as basis to reject vaccines were coded on 54 blog (including comment sections) and social media posts across all blogs sampled in this study.

informed, malicious or engaging in irresponsible talk', but who want to discuss vaccine risk by looking at both 'published science' and 'personal experience' (12 April 2018). In the comment section of another *AoA* post, a one-off commenter arguing autism is a genetic condition and not something caused by vaccines is accused of making 'unscientific statements' and believing in 'fairy tales' and 'misinformation' by counterpublic members (one of whom also refers to the many 'peer reviewed scientific studies' on the subject which support vaccine-critical claims). In the same thread a commenter states that readers who have experienced vaccine injury happening to their family members consult *AoA* posts because of the 'scientific information' offered by the blog. Moreover, in a post promoting the release of a vaccine-critical documentary titled 'The Greater Good' about the lives of families affected by vaccine injury, a blogger remarks on how the documentary 'features vaccine advocates and *experts* from medicine, science and advocacy', adding that:

> [a]s an accompaniment to the film, the team from The Greater Good has put together a host of resources for medical professionals and lay folks alike. If you are interested in learning more about the science that explores and documents adverse reactions to vaccines, check out the *Catalogue of Science* which contains links to over 200 papers and case reports published in *peer reviewed medical literature*.
> (AoA, 28 September 2018, emphases added)

As in the *ANHI* post analysed above, personal experience is here intertwined with scientific knowledge, and the former may be seen as a sort of entry point to vaccine-critical 'scientific' research. More *AoA* posts refer to '*peer reviewed scientific data*' as supporting parents' '...concerns with vaccine safety learned through *real life injury* of their own children' (March 2019, emphases added), or they claim that 'real science' cannot be used to deny the link between vaccines and autism. or that parents' vaccine injury experiences as a whole (especially as data collected in surveillance schemes such as the VAERS) themselves constitute scientific knowledge. *ANHI* also released their own vaccine-critical documentary focusing on the HPV vaccine and featuring what they describe as 'cases of severe, life-changing adverse reactions experienced by girls and young women following HPV vaccination'. In a post discussing the documentary release, *ANHI* again make a connection between experience and scientific evidence:

> Today sees the release of a new documentary film from the Alliance for Natural Health across the UK and Europe questioning claims made by health authorities that the HPV vaccine is both a safe and a guaranteed method of preventing cervical cancer. This comes at a time when – *flying in the face of independent science* – the UK announced its intention to extend the vaccine's use to include teenage boys and the US Food and Drug Administration (FDA) approved its use for

> adults aged 27-45 years [...] At ANH-Intl we encourage individuals to make informed choices when it comes to vaccinations, particularly when it involves a vaccine as controversial as the HPV vaccine.
> (ANHI, 14 November 2018, emphasis added)

A hyperlink included in the last sentence of this paragraph takes the reader to another *ANHI* webpage titled 'HPV vaccine — the risk of uninformed consent?', which includes references to vaccine-critical research and claims that there is not enough evidence to support the safety and effectiveness of HPV vaccines: '[h]ealth authorities like to make out that the science on cervical cancer, HPV and the HPV vaccine is a done deal. That couldn't be further from the truth'.[143] Similarly, another *ANHI* post contrasting 'consensus' science to the experiences of health 'influencers' refuses to acknowledge the former as 'true' science, arguing it would be more accurate to refer to it as 'conspiracy science'. Interestingly, in the same post the blogger praises a mainstream expert (a 'top-level cardiologist and clinical researcher') for critiquing pharmaceutical companies over prioritizing profits over people's health in an article published on a health-related news website.[144] The expertise of this researcher is then effectively relied on by *ANHI* to make a case for 'personal empowerment' through the use of alternative medical approaches:

> Let's not leave it in the hands of the mainstream healthcare system. When a doctor with Milton Packer's background and pedigree says there's a problem relying on the drugs mainstream healthcare provides – there's no doubt that a big problem is afoot.
> Take things into your own hands – become empowered, fully informed and take the natural route as far as it will take you. For most of the common diseases today – that's all you'll ever need. Not that you'll hear that from the mainstream healthcare (pay and deliver) system.
> (ANHI, 25 April 2018)

These extracts from different blog posts and comment sections show that counterpublics are not outright rejecting expertise or 'professional knowledge'; nor is it accurate to say that counterpublic members see themselves as 'experts' as such. Instead, they have developed a degree of self-confidence in their epistemic abilities sufficient to discern 'good science' from bad 'science' – or to determine which 'experts' can be considered reliable and trustworthy, and which instead are either incompetent or even maliciously lying for personal gain (as examined in the previous section). I argue that this stance closely resonates with Alfred Schütz's social epistemological reflections, and particularly his seminal

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[143] See https://www.anhinternational.org/2017/07/12/hpv-vaccine-risk-uninformed-consent/ (ANHI, 12 July 2017).
[144] See https://www.medpagetoday.com/opinion/revolutionandrevelation/72407.

essay on 'The Well-Informed Citizen' (1946). Schütz's essay, which investigates how people 'accept unquestioningly *some* parts of the relatively natural concept of the world handed down to them and to subject *other* parts to question' (465) distinguishes three ideal-types: the 'expert', the 'man on the street', and the 'well-informed citizen'. These types (which, as Schütz clarifies, individuals can embody simultaneously with respect to different fields of knowledge) each represent a different approach to knowing. In Schütz's words:

> ...for the man on the street it is sufficient to know that there are experts available for consultation should he need their advice in achieving his practical purpose in hand. His recipes tell him when to see a doctor or a lawyer, where to get needed information and the like. The expert, on the other hand, knows very well that only a fellow expert will understand all the technicalities and implications of a problem in his field and he will never accept a layman or dilettante as a competent judge of his performances. *But it is the well-informed citizen who considers himself perfectly qualified to decide who is a competent expert and even to make up his mind after having listened to opposing expert opinions.*
> (1946, 466 emphasis added)

Unlike the expert, whose '...knowledge is restricted to a limited field but therein it is clear and distinct', and the 'man' (or person) on the street, who just trusts pre-existing procedures - even if not understood - to bring about certain outcomes, the well-informed citizen: '[o]ne the one hand [...] neither is, nor aims at being, possessed of expert knowledge; on the other, he does not acquiesce in the fundamental vagueness of a mere recipe knowledge or in the irrationality of his unclarified passions and sentiments' (466). The well-informed citizen, as an ideal-type, therefore lies in between the expert and the person on the street (465). Likewise, vaccine counterpublic members actively choose which experts they can rely on and, importantly, see themselves as qualified to do so. Conversely, they often explain away others' disbelief of vaccine-critical claims as the result of mere unthinking subservience and deference to authority, 'brainwashing', 'ignorance', 'fear', 'not being smart enough' or even a religious-like faith.[145] A good exemplification of this reliance on the 'well-informed citizen' mindset in a health (even if not vaccine-related) context is again found on the alternative health blog *ANHI*:

> Receiving a cancer diagnosis is an overwhelming experience for most of us. As you struggle to come to terms with the news you're often fast-tracked into a system of orthodox treatments over which you have little or no control, or have you? For many, scared by their diagnosis, they trust the path laid out by their oncologist, not knowing there are other, often safer, diagnostic

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[145] This is consistent with the findings on UK vaccine-critical groups presented in Hobson-West (2007).

> and treatment options open to them. As knowledge grows, many cancer patients are now turning to non-standard treatments seeking a gentler, more natural way to beat their illness. They also recognise that these approaches help strengthen the body in ways that allow it to better handle both the treatments being given as well as supporting the body's self-healing mechanisms.
> (ANHI, 16 May 2018)

Schütz (1946) views citizens as 'aiming to become self-informed' in areas of knowledge (or 'relevances') which have a bearing on their lives and in which they have developed an 'interest', either out of an independent choice (referred to as 'intrinsic relevances') or alternatively because of external events beyond the citizens' control ('imposed relevances'). Among these external events ('imposing' relevances'), Schütz mentions 'disease' – experiences of which, as seen above, are claimed to ground counterpublic members' quest for knowledge and truth about vaccine injury (or the seeking of 'non-standard' cancer treatments in the *ANHI* post quoted above). This link between 'interest' and knowledge is consistent with the emphasis that scholarship on patient groups and health-related social movements places on the role of experiential knowledge (usually in the form of embodied experience), and particularly how this is 'translated and mobilized in encounters between individuals, citizens' groups, researchers and experts or policy makers' and involved in the development of 'lay' forms of expertise (Akrich 2010, §1.4; see also Arksey 1994; Epstein 1995; 1996; Brown et al. 2004).

Experiential knowledge does not threaten or directly compete with expert knowledge, but features in narratives of personal empowerment as triggering a need for individual learning and research in order to become 'well-informed' – or, to use counterpublic terminology, 'vaccine-educated'. The experiential knowledge invoked by counterpublic members may not involve their own illness – as in the patient groups which were the subject of previous studies (e.g. Epstein 1996) – but it is still powerful enough to start this process of questioning and information-gathering. The research and learning process may at times be uncomfortable, but it is still necessary, as an *AoA* blogger argues while drawing a connection between the concern with one's child's health and the need to 'know more' about vaccines:

> It can be awkward, but it's okay to know more. It's also okay to to look up the information on your own. Your health and your child's health is worth it. Even if you sound like a crazy person when you share what you've learned. Honestly, I'd rather be crazy than ill informed, especially when it comes to knowing what to do for my child.
> (AoA, 15 April 2018)

In a different post, this *AoA* blogger also gives a particularly detailed account of her path from 'naiveté' to 'well-informed', or 'educated' parenthood:

> Before I had kids, and even after having them, I would never have said that I had an attitude about vaccines. Back then, I honestly never thought too long about them. I just knew I wanted them without any sort of hesitation. But, after observing my son fall ill post-vaccination, I started having doubts. As I began to question them, I realized that I didn't have enough information beyond what the doctor was telling me. Since she only offered positive vaccine thoughts and a very strong opinion supporting them, I set out to find the facts I wanted and needed. Like parents today who also have questions, I had to learn how to look for unbiased information. I had to learn how to discern what I heard from other people. Putting emotions aside, I had to learn how to weigh what I was being told by the pediatrician and also factor in what my gut was telling me. [...] I needed more help. But from where? I needed rock-solid Science. Surely, that could help me.
> (AoA, 20 May 2018)

The blogger continues recounting how her researching the 'science' behind vaccine safety first took her to physical libraries, then to the internet ('[u]nsure of how to navigate it like I can today, I wasn't always confident in what to look for'), and, finally, to online discussion boards which could be 'overwhelming' but on which she was 'glad' to find other parents asking 'the very same questions' about vaccines as her:

> Thank God for those early Yahoo! Group days. From what I remember from those groups, parents shared *experiences* and *facts*. They posted providers' input, recommendations, and credentials. Existing research was distributed, dissected, and debated, too. Those Yahoo! Groups might be considered prehistoric now, but that sort of social media, which dictionary.com states as websites and other online means of communication that are used by large groups of people to share information and to develop social and professional contacts, gave many of us exactly what we needed: the *confidence to keep educating ourselves*.
> Those early days gave us a chance to sort through valuable information that our doctors wouldn't discuss. Not only that, it gave us much-needed support and the chance for friendships that, for some, are still going strong.
> (AoA, 20 May 2018, emphasis added)

Commenting under this post, a prolific *AoA* counterpublic member shares a very similar experience to the blogger's, recounting their visit to the United States National Library of Medicine to search its vast medical archives. They also recall how in the early 2000s many medical journal articles revealing the 'extreme dangers' of vaccines were made available online for motivated and persistent parents to consult – alongside what they claim are the 'extremely biased' pro-vaccine papers written by 'corrupted' government officials, 'pharma doctors' and 'so-called scientists' with a religious-like faith in vaccines.

Appeals to direct personal experience are not present to the same extent throughout the blogs (unlike the almost ubiquitous references to 'science' and 'scientific' evidence in relation to vaccine injury). It is also not the purpose of this online-based study to make general claims about what motivates individuals to join vaccine counterpublics – the data collected shows some counterpublic members identify as parents of vaccine-injured children, but not all of them do. However, I would argue that the experiential knowledge that features prominently on most of the vaccine-critical blogs analysed here offers an insight into the dynamics and processes through which trust is established among counterpublic members, and also contributes to explaining how feelings of self-empowerment, certainty and confidence, rather than doubt, are prevalent in the blogs' comment sections. This creates a point of connection between bloggers and their readers, as sharing a common interest in children's (and more generally people's) health and wellbeing. In other words, through the sharing of their own or others' experiences, bloggers are able to enhance what Kelty and Panofsky (2014) have called the 'affective' or 'communicative' aspect of online participation, linking back to the Durkheimian concept of 'collective effervescence' (see Durkheim 1915). This affective aspect emerges when participants in internet-mediated platforms '...have opportunities to communicate amongst themselves to produce affect, affiliation, and sociability' (Kelty and Panofsky 2014, 8). The 'classic' example given is that of online patient support sites such as 'Patients Like Me', in which '[t]he value for patients is clearly in the creation of new relationships, knowledge sharing and learning about treatment and the experience of a disease' (2014, 10). Similarly, counterpublics share stories for (current and potential) members who might be going through similar 'journeys' or harbour similar questions about childhood vaccines. As an *AoA* blogger remarks, 'stories' about personal experiences may constitute a powerful force which could persuade other parents not to vaccinate: '[w]hen people wake up and hear stories from people they trust, including their own doctors, they stop vaccinating' (AoA, 30 October 2018).

Seen in this context, appeals to become educated, to 'do one's own research' and become empowered to 'optimise' one's and one's children's health found across blogs assume a different meaning – as it becomes clear that only the 'scientific knowledge' approved by trustworthy counterpublics can effectively constitute 'acceptable' research by counterpublic members. While commenting on an awkward interaction with a health professional offering information on a dental procedure for her child after she said that she would 'look it up' before agreeing to it, an *AoA* blogger puts it quite clearly: 'I meant I would go home and look up MY side's data, not rely on HERS' (AoA, 21 June 2018). This selectivity may also be seen in how *LW* refers to 'research' (in inverted commas) when talking about a pro-vaccine opponent's scientific sources, and how *ANHI* cautions readers against 'conspiracy science' in a previously quoted extract.

For *VP*, what is generally followed by doctors is not science, but rather interpretations by 'authorities' (in inverted commas) such as public health organisations or 'recommendations' by 'industry funded trade groups' (see VP 'about page', n.d.), while *VCUK* writes about the 'vaccine industry' presenting 'PR as science'. It is interesting to note how counterpublics, through easy access to informational resources and peer support online, and by selecting what counts as valid expertise based on their own specific interests, do not fall into a condition of doubt or even 'existential angst' or 'dread' – the latter of which, according to Giddens (1990), represents the 'antithesis of trust' (100). Trust towards physicians, and the expert systems they represent, is instead substituted by self-empowerment and epistemic trust in other 'well-informed' counterpublic members. This 'internal' form of trust is further reinforced by the allegations of systemic collusion among political institutions and industry which are widespread among counterpublics, as will be seen in the following section.

Narratives of blame, victimhood and accountability

References to experiential knowledge do not just appear in counterpublic talk as 'triggers' for research or points of connection and solidarity which build their readers' confidence in their own epistemic abilities. They also represent an important way for counterpublics to differentiate themselves from competing epistemic authorities who are motivated by the desire for financial profit or personal gain, rather than a genuine need to find out the 'truth' about vaccines. For example, an *AoA* blogpost contrasts the motives underlying 'parents'' sharing information and those of the 'vaccine industry' as follows: '[n]ew parents need to be empowered with truth, not distracted by spokespeople backed by the vaccine industry. The industry's goal is to make a profit. Truth is the only thing they'll get from parents like me' (20 January 2019). In a page dedicated to the MMR vaccine ANHI also links trustworthiness to the absence of a profit motive:

> [h]ow do you decide when you don't know who to trust? You do your own research and make up your own mind. You know that when people or websites are selling something they may not be offering completely unbiased information — and that goes for governments and companies as well as individuals of course. You know that medical research isn't always pure and unbiased (see link on this website on how pharmaceutical advertising biases what journals publish). You know that you have to form your own judgment even about what we say — and we wouldn't have it otherwise. So listen to what we say, then look at some of the links we provide, then exercise your vaccine choice.
> (ANHI, n.d.)

While the author of this post appears to be inviting the readers to make up their own minds about vaccine-critical claims, reminders that medical research is not 'always pure and unbiased' and that 'pharmaceutical advertising' has an undue influence on medical publishing serve as a way to dissuade counterpublic members from relying on 'mainstream' expert sources. This is similar to the way in which *VP* asks readers not to 'take our word for the claims made here' and to 'read the evidence for yourself' while claiming in the same webpage that '[t]he vaccine industry writes the vaccine recommendations' (n.d.). The main issue with vaccine safety evidence, according to counterpublics, is that this is intrinsically linked to the pharmaceutical industry, which is driven by profit and is not trustworthy. Like *ANHI*, *AoA* note that pharmaceutical companies' objective is 'selling' and turning in a profit. Conversely, parents are framed as consumers assessing the 'pros and cons of vaccines' and seeking honest 'consumer reviews' from other parents before making their choice about immunisations:

> For those who are currently weighing the pros and cons of vaccines and who want a consumer's review of vaccines, watch that trailer again. Listen to the parents and to the anguish in their voices. Listen to the warning the medical doctors are sharing, too. Know that many more stories were collected. Know that stories are still being told of problems stemming from all liability-free vaccines given today. Mainstream media and medical professionals may not want to share those stories, but that doesn't mean they didn't happen. They benefit from the products they can postively promote and sell. The benefit of listening to a parent of a vaccine-injured child is that you get the truth. It might be a painful truth filled with emotion, but it's a truth nonetheless.
> (AoA, 13 January 2019)

This framing of parents (and sometimes their children) as consumers can be found on other *AoA* posts, with nine blogs in total including mentions of the word 'customer'. These references are found either within comment sections, in claims that vaccines will make children 'dependant' on medication to treat auto-immune conditions, thereby creating 'a customer for life of the industry', or in blog articles stating that pharmaceutical companies dislike 'educated consumers' ('an educated consumer is the vaccine industry's worst customer', AoA 5 January 2019). In one instance, a blogger contrasts how 'customers' are normally treated to the way in which the healthcare system responds to parents who raise issues about vaccines, comparing it to her experience filing a claim with her car insurance company:

> Once the claim was filed, the insurance company promised to cover the repairs, compensate the fee of the rental car we'd need while our vehicle was in the shop, and they'd promise to make sure to keep in touch with us during the lengthy repair process. The body shop that conducted the repairs even offered us a lifetime warranty on their work. For the time we own the vehicle, all paint and body repairs are guaranteed. I wish I could say we had the same customer service and product warranty for the liability-free vaccines my son received when he was younger. Instead of top notch customer service, we got confused looks from medical staff when we mentioned that we thought the vaccines hurt him. [...] They'd known [my son] since birth. They'd seen him grow and develop typically to a point in time. But instead of jumping to assist us or to affirm that our hunch, that something happened to our once typically developing child, we were left on our own.
> (AoA, 10 March 2019)

As can be seen from this post, parents (and their children) are not only framed as 'customers' in relation to pharmaceutical companies, but also in their interactions with healthcare professionals. The latter are said by counterpublic members to just not know enough about vaccines to subject their 'pushing' by pharmaceutical companies to critical scrutiny. In this counterpublic perspective, the 'well-informed' parent or patient is better positioned to evaluate vaccine safety research than their physicians. According to *LW*, on top of being highly educated, vaccine-critical parents (many of whom, they say '...have worked for pharmaceutical companies, have been educated by firsthand experience with court cases and politics, and have vaccine-injured children.') are able to 'understand the lack of education and/or biased manner in which medical professionals are taught about vaccines' (5 November 2018).

In another example, the author of a review of a vaccine-critical book posted on *AoA* invites the readers to adopt a firm 'consumer-like' stance towards doctors: '[i]f your pediatrician has not yet done his or her own research and is just parroting the 'vaccines are safe and effective' marketing phrase, it is time for you to get a new pediatrician' (19 July 2018). *VCUK* also seems to support this critical view of doctors, whose 'narrow' perspective on health is constrained by the interests of pharmaceutical companies. 'Doctors', they write, 'are trained to provide interventions that make symptoms go away and most of these interventions are provided by the pharmaceutical industry whose aim is to make a profit from what the company is selling' (VCUK, July 2018). Similarly, *VP* states that '[d]octors and most medical professionals are not independent thinkers. They don't have the time or interest. Most simply follow the conventional recommendations and don't question them' ('about page', n.d.). Doctors and other health workers are understood to be 'pushing' vaccines because they have been indoctrinated to do so by pharmaceutical companies. Some counterpublics members even claim to have 'educated' their healthcare professionals themselves, as seen in the following extract from *VCUK*: '[w]e got some grief from health workers after the children were born, but they soon realised they had more to learn from me than they had to teach me and I am still friends with one of them' (May 2019). In another significant example, an *AoA* blogger recounts how she 'had to' educate a nurse who, in her account, was wrongly questioning her child's vaccination status:

> In her broken English, [the nurse] stammered, "But this date, it's…."
> While there is one question about one vaccine on this particular form, vaccines are not a requirement for why we were at the clinic that day. The nurse, who over time must see thousands of patients requesting this exam, should know that. *But I ended up being the one to educate her*. Just like I had to several years ago with another young medical professional who grew up outside of the United States. Relying on third-world facts and fear tactics, he, too, tried to change my mind about vaccines. After a lengthy convo, he respectfully came around. But this gal didn't seem to want to budge. *She'd need a longer lesson on knowing when to stop badgering a parent who obviously knew more about vaccines and parents' rights than she did.*
> (AoA, 24 June 2018)

By dismissing the nurse's knowledge as what she calls 'third-world facts', this counterpublic member is attempting to assert her own epistemic superiority, and at the same time represents the medical worker's position as one of ignorance, rather than bad faith and self-interest. While there is no doubt that these extracts from the blogs signify disillusion with, and distrust of the medical profession, their framing of government authorities, the media and the pharmaceutical industry go beyond simple distrust. Narratives of systematic, widespread collusion abound within counterpublics. For example, in a social media post linking to an article about a surge in measles vaccine sales leading to increased profits for the pharmaceutical company Merck, *LW* comments:

> This is what the propaganda, mass hysteria over a rash (literally), data manipulation, and the big push for mandates is all about ... money. It's not about you, your child, science, or even 'herd immunity'
> (LW, 1 May 2019)

Another social media post, this time by *FP*, goes even further, using a meme to quote vaccine-critical activist Robert F. Kennedy Jr. on how the pharmaceutical companies who produce vaccines have had to pay collectively billons of dollars 'in penalties, fine, and damage for their criminal behaviour' in the recent past. 'Every one of them', according to the posted quote 'is a convicted felon'.

A similar quote (or another version of the same quote) by Kennedy is utilized in a different meme posted on the *AoA* Facebook page, whose text reads:

> What kind of cognitive dissonance does it require to understand that this company [Merck] is lying and cheating and killing with every other medical product and pharmaceutical product it makes but it has found Jesus when it comes to vaccines...
> (AoA FB page, May 2019)

The 'criminality' of the pharmaceutical industry is a recurrent theme across blogs, with the combination of terms 'criminal' and 'pharmaceutical companies/industry' appearing in nearly 50 posts across the blogs *AoA*, *ANHI*, and *FP*. Around 20 posts on *AoA* also contain references to 'murder' in connection with the activities of pharmaceutical companies, and *AoA*, *FP*, *LW*, *VP* and *ANHI* use the term 'fraud' in nearly 60 posts. The term 'corruption', in conjunction with public institutions, vaccines and the pharmaceutical industry is further mentioned in more than 40 post across *AoA*, *ANHI*, *FP* and *VP*.

On *ANHI*, a commenter refers to the UK National Health System as a profitable 'disease management cabal', run by doctors, charities, and 'especially' drug companies, amounting in their view in a sort of criminal 'medical mafia'. A *FP* commenter refers to the pharmaceutical industry as 'corporate criminals' committing 'crimes against humanity' as well as engaging in 'fraud'. More than 30 comments on *AoA* mention either the 'Nuremberg Trials' or the 'Nuremberg Code' to frame vaccination as a practice violating fundamental human rights, with one commenter even claiming it is 'time for a new Nuremberg trial'. Another *AoA* commenter, while blaming the pharmaceutical industry for 'getting away with murder' regarding vaccines, also accuses health institutions, including the CDC, WHO, and AAP (American Academy of Pediatrics), of being the 'greater criminals', whose executives are compared to Nazi Germany officials.

As far as not-for-profit organisations are concerned, a frequent subject of critique across counterpublics is the Bill and Melinda Gates Foundation. Mentions of the 'Gates Foundation', or 'Bill Gates' specifically, appear on more than 70 posts on *AoA*, *ANHI* and *VCUK*. *AoA* refer to what they call the 'Gates agenda' having a sinister influence on other organisations and governments. For example, in an article reposted on *AoA* entitled 'Gates Foundation Buys Cochrane Collaboration Group' it is maintained that a donation from the Gates Foundation to the Cochrane Collaboration will have biased its scientific review of the safety of the HPV vaccine:

> For those of you who are under the illusion that the purpose of the Bill and Melinda Gates Foundation, and its financial "donations" is about philanthropy and the good of society, please, examine some of the empirical evidence that I have gathered [...]
> The insidious influence of the Gates agenda is in evidence. For example, the just released purported "systemic review" of the HPV vaccine by the Cochrane [...]
> The authors claim [sic] "We judged most included trials to be at low risk of bias" – is an oxymoronic statement, inasmuch as they concede that "all but one [study was] funded by vaccine manufacturers".
> ALL industry funded studies are designed to protect the company's financial investment. That is THE overriding primary bias
> (AoA, 11 May 2018; originally published on ahrp.org)

I would like to emphasise two points made by the author of the above extract. First, consistently with previously analysed counterpublic arguments, all scientific studies involving funding from the pharmaceutical industry are considered 'biased' because of the industry's profit motive. Second, charities and philantrophic foundations such as the Gates Foundation are considered suspicious and 'complicit' in a scheme which corrupts scientific research in order to enable pharmaceutical companies to sell more vaccines. This latter point is sometimes taken to more conspiratorial extremes, especially on *AoA*, where a post refers to pharmaceutical companies along with the Bill and Melinda Gates Foundation as 'taking over the world' (3 November 2018). A commenter on the same blog talks about multiple 'ultra coordinated efforts' by the Gates Foundation and 'pharma' to 'push their agenda' choosing 'money over ethics'. Another commenter describes Bill Gates himself as an 'evil man', and public health officials as his 'cronies', and yet another calls him a 'vaccine murderer'.[146] Some of the most deeply conspiratorial posts found in comment sections refer to what appears to be a sinister plot

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[146] It should be noted that Bill Gates has also been a particular focus of anti- COVID vaccines conspiracy theories (see e.g. Place 2022).

by 'globalist elites' to use vaccines as a way of artificially reducing world population and introduce what they call a 'New World Order'.

It should be pointed out that not all counterpublic members adopt such extreme perspectives, nor do all counterpublics accuse the pharmaceutical industry of criminal behaviour. However, counterpublics do uniformly represent 'Big Pharma' as an entity geared towards profit-making at all costs, even if this this means disregarding people's health needs. For example, *VP*, who claims not to want to demonise the 'other side' on vaccine issues, singles out pharmaceutical companies for their 'disturbing' motives:

> We assume that both sides in this debate share the same goal: a medical system that maximizes health. We do not demonize people of the opposition as monsters intending to harm (however, pharmaceutical companies appear to have deeply disturbing motivations, since they profit greatly from chronic illnesses).
> (VP, n.d.)

This view of pharmaceutical companies is also well-summarised by this extract from an opinion piece originally published on a US-based news website and shared on the *AoA* Facebook page, which compares vaccines to the case of Vioxx, a nonsteroidal anti-inflammatory drug which was withdrawn from the market after evidence emerged linking its use to an increased risk of heart attack and stroke:

> Five and a half years after it was licensed, Merck was forced to withdraw Vioxx. A total of 80 million patients had taken it, and annual sales had topped $2.5 billion. Merck agreed to pay $4.85 billion to settle 27,000 injury claims. A University of Michigan professor commented that this was the cost of doing business. Merck moved on. It had already found a less risky business model to expand into: no-fault vaccines. Since 1988, there has been no industry liability for injuries related to vaccines approved by the Centers for Disease Control and Prevention for the childhood schedule.
> (AoA FB page (extract quoted from from bangordailynews.com), 1 April 2019)

The narratives emerging from these posts do not merely convey sentiments of broken trust towards the pharmaceutical industry, and the regulators viewed as failing to keep it in check. Instead they invoke frames of blame and victimhood, in which corporations are primarily responsible for the harm and injury caused to vaccine 'victims'. In this worldview, pharmaceutical companies do not have any desire to make people healthier, but only see individuals as potential sources of profits and losses. This is a framing which, as discussed in the previous chapter, is reinforced through counterpublics' constructions of certain aspect of vaccine regulation. Vaccine injury compensation schemes (VICS), as previously seen, are particularly important to counterpublic talk, supporting claims of vaccine unsafety, as well as being interpreted by counterpublic members as tools to achieve public health goals regardless of the cost to individual children's health. There is, however, an aspect of the legal frameworks around the compensation for vaccine-related damage which deserves further discussion in the context of these the narratives of blame shared by counterpublics. This is represented by the liability protections afforded to vaccine manufacturers in the context of VICS as 'no-fault' liability schemes.

In the medico-legal field, the notion of 'no-fault liability' normally refers to compensation schemes where claimants have to prove that medical error caused their injury, without additionally having to prove negligence, or fault, on the part of the defendant (see Gaine 2003). For vaccine counterpublics, the concept of 'no-fault' is entangled with that of 'liability free vaccines', referring specifically to the liability protections afforded to vaccine manufacturers under the 1986 National Childhood Vaccine Injury Act (NCVIA), which created the US National Vaccine Injury Program (NVICP). The NCVIA prevented potential claimants from suing manufacturers directly. Instead, since the passing of the Act people wanting to claim compensation for vaccine injury (including parents claiming for their children) have been required to first file a petition with the US Court of Federal Claims to which the respondent is the US Department of Health and Human Services (see US Department of Health and Human Services 2021).[147] Only once they have exhausted this route, a claimant can appeal against the rejection of their application by filing a civil court claim against the vaccine manufacturer or healthcare professional who administered the vaccine.

Considering the lens of blameworthiness through which counterpublics see pharmaceutical companies, and the identification of the vaccine-injured as 'victims', it might not be surprising that, although on the one hand counterpublic members rely on NVICP to 'prove' the reality of vaccine injury, on the other they do not consider it an appropriate tool to deal with vaccine dangers and their consequences. According to *FP*'s libertarian perspective, NVICP constitutes a sort of market distortion by removing the incentive for pharmaceutical companies to make their vaccines safer:

> The second crux of the issue is that we don't allow our system of checks and balances to work. Vaccine manufacturers and those who administer vaccines, including physicians, have virtual blanket liability protection. The 1986 Act transferred responsibility to the federal government.

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[147] For a detailed account of the context surrounding the passing of the NCVIA 1986 see Kirkland (2016). Further historical background to the creation of both the US NVICP and the UK VDP is also offered in Chapter 2 of this work.

> When we removed the most important consumer protection — the right to sue — we eliminated the singular motivation that vaccine manufacturers have to make better vaccines. (FP, 4 March 2019)

In the same post, 'no-fault' liability is also seen as a way, alongside mandatory vaccination policies, to increase the profits of pharmaceutical companies at a time when their profits are put at risk by the patents expiring on certain blockbuster drugs:

> It is logical that Pharma would turn to vaccines to smooth the ride. Vaccines have become a substantial and reliable component of profitability. The federal government recommends them. State governments mandate them. Virtually all children get them. There's essentially no liability. (FP, 4 March 2019)

This reading of liability is shared by multiple commenters on the blog. One commenter defines vaccines as a 'money-maker' without liability; another speaks of 'unscrupulous manufacturers', who without liability are 'killing and maiming millions'. Yet another argues that until corporations can be sued in an 'open court of law', anyone supporting vaccination policies has 'blood on their hands'. Along similar lines, a commenter on *LW* argues that the pharmaceutical industry does not have any incentive to conduct 'reasonable safety studies' when developing vaccinations, as the NCVIA allows them to avoid being held 'legally, criminally, or financially accountable' for the 'devastation' they claim vaccines are causing. Claims about the negative impact limitations on manufacturers' liability has for vaccine safety are also found on *AoA*. For example, a blogger states that 'the "liability-free vaccines" produced and distributed in the US and elsewhere carry no incentive to improve safety' (AoA, 17 January 2019).

Despite the Vaccine Damage Payments Act 1979 not containing a similar provision preventing claimants from directly pursuing tort litigation against manufacturers, UK-based blog *VCUK* also claims that manufacturers are free from liability for vaccine injuries in the UK. According to the blog, pharmaceutical companies should make it clear that '...those manufacturing the products will not be held liable for adverse events associated with the products (vaccines)' (March 2019). The same blogger also makes the point that vaccine damages are not primarily sought by claimants for the financial reward, but rather for their symbolic value in pinpointing the 'guilt' of the pharmaceutical companies who are 'responsible' for their children's vaccine injuries:

> Any of the parents I have spoken to over the years with vaccine damaged children are not after money, in fact the amount is an insult for the damage it has caused, but it does represent an *admission of guilt* and these are parents who are angry because they believed in the vaccine programs, were never warned of the risks and they don't want it to happen to anyone else.
> (VCUK, May 2019)

If, on the one hand, framings of vaccine injury compensation frameworks are relied on by vaccine critics to show that vaccines are unsafe medical products, on the other hand these same frameworks are seen by counterpublics as part of the systemic failure to make vaccines safe. By emphasizing how vaccine manufacturers can 'avoid liability' through legislation, counterpublic narratives of corrupted institutions and blameworthy, or even 'criminal' pharmaceutical companies are bolstered. Instead of achieving the objective of 'reconciling' vaccine-critical parents and public health, the way some VICS are structured gives rise to more distrust and blame, reinforcing counterpublic claims about 'lying' institutions and their worldview in which these public bodies become the allies of greedy pharmaceutical companies, aligning themselves with their profit motives rather than with parents' goals of keeping their children healthy.

Although they may seem far-fetched to a reader not sharing such a worldview, the 'conspiratorial' lenses through which counterpublics see institutions and powerful social actors are significant for the understanding of vaccine critics' collective identities. This is not because they constitute an accurate representation of reality, but rather as they bring to light some discrepancy between counterpublics' shared priorities – a common interest in individual health and wellbeing – and those of distant institutions, which are inaccessible and the object of suspicion, concern and speculation. While vaccine opposition has been interpreted (as seen in the 'post-truth' literature encountered at the beginning of this chapter) as a result of individual cognitive biases, or as the rejection of logic and reason in favor of emotion, counterpublic narratives reveal how the construction of vaccine-critical knowledge takes place within its particular socio-legal context. It is in this social world that counterpublic members determine and make claims about who is lying and who is telling the truth, which research can be trusted and which instead should be disregarded – and, perhaps most importantly, that 'vaccine injury' exists and someone is to be blamed for it.

Conclusions

In this chapter, I have challenged the ‘post-truth’ framings which explain vaccine opposition in terms of individual cognitive bias, a reliance on emotion rather than facts, the embracing of a ‘postmodern perspective’, and scepticism about the existence of universal ‘truths’ or ‘facts’. In the first part of the chapter, counterpublic identity narratives around the notion of ‘truth’ were analysed, showing that rather than ‘postmodern’ scepticism towards facts, science and objectivity, counterpublics frame themselves as somehow ‘ahead of the curve’ of scientific knowledge, ‘fighting’ to defend and spread ‘facts’ about vaccine dangers which will one day be proven true and which will eventually be acknowledged by the scientific establishment and mainstream public. In the second part of the chapter, narratives about ‘trust’, and in particular counterpublic members’ epistemic abilities were analysed. Contrary to explanations of vaccine scepticism as a manifestation of pervasive sentiments of uncertainty and doubt in late-modern societies, the data from our blogs suggests that vaccine counterpublics are able to create confident members who are self-assured about their epistemic competence, and who create bonds of trust and epistemic solidarity through the sharing of experiential knowledge.

Finally, looking at how counterpublics portray the actors involved in vaccination policies demonstrates that such actors are not merely ‘distrusted’, but also actively blamed as guilty of causing childhood vaccine injuries. Rather than resolving tensions between vaccine manufacturers and vaccine-critical parents, vaccine injury compensation schemes are believed to reinforce this systematic collusion, in which pharmaceutical companies are allowed to avoid responsibility for the damage caused by their products. I suggest the narratives encountered in this chapter, taken together, should shift our attention from the posited cognitive deficits and ideological commitments of vaccine critics to the broader social and legal contexts which ground vaccine critics’ epistemic activities and their negative representations of public institutions.

8

CONCLUSIONS

Looking back at how this research began – by offering some historical background on the emergence of vaccine resistance in the 19th century – it cannot conclude without pointing out that the history of vaccine-critical activism does not end here, and has kept evolving since I started my investigation of vaccine counterpublics on the internet. Data collection for this project began in April 2019 and finished in December 2019, while the social media posts collected refer to a period ranging from April 2018 to the June 2019. In the first few months of 2020, the advent of a global pandemic involving a new viral disease – COVID-19 – has once again significantly changed the landscape in which vaccine-critical activism unfolds. Among a wide range of social and political developments, some of the governmental measures that have been implemented in response to the pandemic, such as lockdowns, the use of protective face masks in public spaces, quarantines and travel restrictions have encountered strenuous opposition by some sections of the population. Opposition to vaccines has become intertwined with protests against these other types of governmental restrictions (see e.g. Drury 2020), conferring a unique character to what might be considered a 'fourth wave' of collective vaccine opposition (following previous instances of campaigning against smallpox, DTP and MMR/thimerosal-containing vaccines).

The data analysed in this study refers to the years 2018 and 2019, before the emergence of the SARS-CoV-2 pandemic, and covers specifically opposition to childhood vaccines, most of which have been around for decades, as opposed to the newly developed COVID-19 vaccines. However, I would contend that the broader question addressed by this research, that is how to interpret and understand mediated vaccine-critical activism in our information age, is relevant to this altered social and public health environment, involving mass vaccination programmes to fight back against the pandemic. This is for at least three reasons. First, the media ecosystem in which resistance to vaccination takes place has largely remained the same since the advent of COVID-19, with a prominent role still being played by social media platforms which allow for interactivity and enhanced user participation (see Burki 2020). More specifically, while the scope and the scale of mediated vaccine-critical networks has expanded since the introduction of mass COVID-19 vaccination campaigns across the world and the adoption of new measures restrictive of individual freedoms such as vaccine mandates and 'Covid passports', the online platforms through which vaccine-critical conversations are carried out have not substantially changed. The findings presented here regarding the use of social media by activists to construct and circulate vaccine-critical knowledge are therefore also relevant to the newly emerging collectives of anti-vaxxers and 'COVID vaccine resistant groups'.

A second line of continuity between childhood and COVID vaccination resistance is represented by the difficult relationship between vaccine critics and the state, as well as the often pessimistic, cynical and bleak outlook on society shared by these counterpublics. As discussed in the previous chapter, vaccine resistance is framed by counterpublics as a sort of courageous 'whistleblowing' activity against powerful corporations which are willing to sacrifice children's health for the sake of profit. They do this – according to these counterpublics – with the support of irredeemably corrupted governments and public health institutions, along with the vast majority of the medical profession, which is said to be unable to acknowledge the 'true dangers' of vaccines. Worldviews which emphasise conspiracy, collusion and manipulation of the truth by 'elite' actors also resonate with 'COVID sceptics' and 'anti-lockdowners' (see Shackle 2021).

Third, there is at least some overlap between previously active vaccine counterpublics and COVID sceptics. Even among the sample of blogs and social media pages analysed in this study, while some appear to have gone offline or not to have been updated since the start of the pandemic, others have gone on to expand their vaccine-critical arguments to cover COVID vaccination as well. I would therefore suggest that the present research findings on vaccine-critical collective identities and worldviews may also be relevant to this latest wave of vaccine opposition, despite the novel character and specificities of COVID scepticism.

As I have previously argued, gaining a better understanding of the epistemic practices, collective self-representations and worldviews of vaccine counterpublics may be helpful in order to inform future communications with parents and other individuals who might be 'vaccine hesitant' and come into contact with vaccine-critical content. Knowing more about what these internet-mediated counterpublics say and do in practice, including how they construct, justify and share their claims, may help a broader public of 'vaccine hesitant' people to be able to identify and contextualise vaccine-critical information which they encounter online. In addition, while offering a more in-depth picture of mediated vaccine-critical activism will likely not change vaccine critics' minds on vaccine safety (nor was it intended to do so), it might at least help prevent their further alienation which may be exacerbated by over-simplistic framings of vaccine opposition as merely expressions of ignorance, anti-science sentiment, irrational thinking, selfishness or a radical 'post-truth' scepticism. As I have aimed to show throughout this thesis, vaccine counterpublics reject these framings, which they believe to be an inaccurate representation of their beliefs and activities.

The overarching objective of this research is therefore to offer a more sophisticated and accurate picture (albeit not a 'neutral' one, as I explain in more detail in my methodology chapter) of mediated vaccine counterpublics, capturing the complexity of their epistemic practices and their relationship with their surrounding social and legal landscapes. In pursuit of this broader objective, I gradually narrowed down my focus and formulated the following research questions: how do online vaccine critics construct causal beliefs and knowledge that feed into vaccination controversies? What kind of values underlie vaccine critics' policy demands, and how are these demands advocated for? How do critics understand and represent their collective identities in ways that assert their own perceived 'credibility' over 'official' expert institutions and actors? More generally, how do online vaccine-critical activists engage with the law?

To address these issues, I have drawn on insights from different bodies of literature and disciplines, including socio-legal theory, media and communication studies, sociology and social theory. While I did not *a priori* settle upon any existing theoretical frameworks to guide my data collection and analysis at the outset of the research process, instead opting for an inductive approach consistent with internet-ethnographic methodologies, in the course of my work I decided to rely on counterpublic theory as the main analytical lens to inform my overall understanding of online vaccine-critical activism. More specifically, counterpublic theory has shaped my analysis of mediated vaccine opposition as a form of resistance or counter-power, finding its expression through 'parallel discursive arenas' (see Fraser 1990) in which vaccine critics formulate 'counterdiscourses' distinct from and opposed to 'official' governmental, public health and corporate discourses and policies.[148]

Compared to other counterpublics, however, I found that vaccine counterpublics also display a special concern with issues of causation and causal knowledge, particularly in relation to the links they believe exist between vaccination and chronic forms of harm to children's health. In this regard, looking into the online activities of the different counterpublics considered in this research revealed how, beyond their different backgrounds and interests, all are engaging in epistemic practices to construct, support and circulate knowledge around such alleged links, in order to support their claim that severe 'vaccine-

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[148] Counterpublic theory was considered as a possible theoretical lens through which to understand internet-age vaccine opposition while researching the history of vaccine-critical activism and noting particularly the significance of mediated forms of communication for past vaccine critics, as discussed in Chapter 2. The relevance of the notion of counterpublicity to present vaccine-critical activism however has not been given for granted, but has been further interrogated and 'personalised' in the course of this research.

induced injuries' exist beyond those acknowledged by the scientific 'mainstream'. These distinctive concerns and practices dovetail with another theoretical framework, that of the 'epistemic community', to which I also refer in my analysis. Originally elaborated by the international relations scholar Peter M. Haas to account for political coordination and policy change in conditions of technical and scientific uncertainty, the concept of epistemic community indicates networks of professional experts who create (causal) knowledge to push for policy change by influencing decision-makers in a particular policy domain or 'issue-area' (Haas 1992, 3; see also Dunlop 2012).

While in Haas' original formulation epistemic communities are made up of professionals with an authoritative claim to knowledge in a particular domain of expertise, other authors have favoured a broader interpretation of this concept. For instance, sociologist Madeleine Akrich has redeployed the notion to frame online groups formed by non-professionals making and sharing knowledge around childbirth issues, which are described as also 'playing a role in the elaboration of childbirth policies' (see Akrich 2010, 7.5). There are undoubtedly some overlaps between the notions of counterpublics (and activist groups more generally) and epistemic communities, especially in relation to their expression of a political dimension through a shared set of 'normative beliefs' or values orienting demands for policy change. As Akrich (2010) puts it, referring to Haas' work, '...epistemic communities and social movements demonstrate certain similarities, particularly because both are based on "normative beliefs" that guide and give a meaning to their political action' (11.2). The normative beliefs expressed by online vaccine-critical activists, along with how such beliefs are supported and justified by activists, have been discussed in Chapters 5 and 6 of this thesis.

However, in this research I have decided to rely primarily on counterpublic theory as a framework to understand mediated vaccine opposition and treat 'counterpublicity' as an analytical lens distinct from the epistemic community approach. This is because, as suggested throughout this work, vaccine counterpublics face specific challenges and act in ways that distinguish them from professional epistemic communities. For example, not having access to institutional channels of communication, counterpublics have had to actively defend their knowledge-making practices against what they frame as the 'censorship' of major social media companies enforcing anti-misinformation policies which interfere with vaccine-critical content (see Chapter 4). In addition, in contrast to Haas' epistemic communities, online vaccine critics are not only concerned with influencing policy-making and legislation, but also with achieving broader symbolic social change and constructing shared collective identities.

Pason, Foust and Rogness (2017) acknowledge that there is a degree of 'blurriness' between how counterpublics pursue material and symbolic change, but they see the latter – which involves 'alterations in public opinion, worldviews, ideologies or subjectivities, manifest largely in the realm of discourse' – as an important 'end' of counterpublic activity (15). As they argue, symbolic discourses and material change are becoming increasingly interconnected in our 'information society' in which '...immaterial, intellectual and communicative labor dominates other forms of labor' (16). In addition, following Manuel Castells (2015), it may be argued that with the emergence of the internet in the information age the coercive power of the state has been surpassed by 'the construction of meaning in people's minds [as] a more decisive and more stable source of power' (5). In the case of vaccine counterpublics, the significance of this 'meaning-making' power may be seen in the remarkable efforts devoted by its members to the construction of 'positive' collective identities for themselves and, conversely, to their highly critical framings of the public institutions and corporate actors who are perceived to be their main opponents (as discussed in Chapter 7).

Drawing on these insights to analyse and interpret the data in this research, I understand mediated vaccine-critical activism as the expression of a special kind of counterpublicity involving the construction and circulation of causal knowledge around vaccines and vaccine-related injuries. Because of the importance and prevalence of epistemic practices among vaccine counterpublics and their members, I also refer to them as being 'epistemic counterpublics'. Considering the different dimensions of these counterpublics set out above, namely their engagement in knowledge-making practices, sharing of normative beliefs or values, pursuit of both policy and symbolic change and rhetorical construction of shared collective identities, has allowed me to formulate the more specific questions around internet-mediated vaccine-critical activism addressed in this research.

Additionally, using these dimensions as an analytical lens to understand online vaccine opposition has provided some fascinating insights into the importance of surrounding legal landscapes – including legal concepts, discourses and institutions – for vaccine counterpublics. More specifically, the research has highlighted the multiple, sometimes unexpected ways in which the law is 'bumped up against' by counterpublic members, coming into play in each of these domains of counterpublic activity. As seen while offering an historical perspective on vaccine-critical activism in Chapter 2, vaccine counterpublics and their members have always engaged with the legal system, albeit doing so in different ways throughout their history. Put concisely, the law has always been relevant to vaccine-critical activities, both as an external 'interference' to private and family life to be resisted, and as a resource to be redeployed in pursuit of vaccine-critical ends. The history of collective vaccine opposition explored in this early chapter revealed the recurrent significance of the law for vaccine critics, and pointed to this evolving relationship with the law as a fascinating (and under-explored) area in the study of vaccine opposition.

In the remaining part of these conclusions, I address my research questions on vaccine counterpublics and their relationship with the law by first synthesizing my findings on the different domains of counterpublic activism discussed above. I then move to consider the relationship between the law and internet-mediated, 'epistemic' vaccine counterpublics at a more general level, and to set out my observations on the implications of this research for policy and science communication. I conclude by proposing some possible avenues for future research which I suggest would further advance and enrich our understanding of vaccine opposition and its relation to vaccine hesitancy.

Vaccine-critical knowledge-making and the expansive interpretation of the right to 'free speech' by vaccine counterpublics opposing social media misinformation policies

Vaccine counterpublics spend considerable time and effort online in order to construct and circulate knowledge around alleged vaccine adverse reactions. In Chapter 4, I used the concept of 'causal knowledge' from Haas' epistemic community framework as a general-level theoretical code to capture this 'epistemic' character of internet-mediated vaccine counterpublics, encapsulating data relating to *how* counterpublic members make vaccine-critical content and share this content through digital platforms. I have referred to these knowledge-making efforts as the 'epistemic practices' of vaccine counterpublics. An important role in counterpublic epistemic practices was found to be played by scientific knowledge, which – perhaps surprisingly considering the widespread image of 'anti-vaxxers' as ignorant or anti-science – is framed in positive terms and sometimes even idealised in its 'pure', uncorrupted form by counterpublic members across different blogs, including those focusing on alternative, more 'natural' approaches to healthcare.

Alongside these positive framings of science, I have shown how the epistemic practices of vaccine counterpublics rely heavily on re-using, re-contextualising and re-interpreting 'scientific evidence' (including peer-reviewed articles and resources found on institutional websites such as those of public health organisations). I referred to this kind of activity as a 'DIY' praxis, borrowing from framings developed by authors in the fields of media, cultural and internet studies including Chris Atton, Mizuko Ito and Red Chidgey in order to conceptualise vaccine counterpublics as part of a tradition of participatory 'maker' or Do-It-Yourself cultures. The main feature of such cultures is represented by their engaging with, re-imagining and re-circulating information from 'mainstream' culture through alternative media outlets. Focusing specifically on public engagement with digital technologies, Mizuko Ito (2008) has offered a definition of 'networked publics' as 'reactors, (re)makers and (re)distributors, engaging in shared culture and knowledge through discourse and social exchange as well as through acts of media reception' (3). I have suggested that this definition also captures well the ways in which vaccine counterpublics actively 'remake' and 'redistribute' scientific knowledge on their blogs and other social media channels.

While engaging in these knowledge-making activities, vaccine counterpublics embrace a learning ethos based on individual (epistemic) self-reliance, as may be glimpsed by the recurrent appeals addressed to their readership to be independently minded and to 'educate themselves' and 'do their own research'. In advocating for epistemic self-reliance, I have argued that counterpublics are not just reproducing dominant discourses of self-empowerment and individual responsibility, but also giving rise to novel sites of resistance in which official knowledge is not merely consumed, but more actively engaged with through the opportunities offered by new media technologies. At the same, I have shown how counterpublics' epistemic practices in online spaces have created tensions with social media companies, which have in recent years introduced 'medical misinformation' policies which target much vaccine-critical content present on their platforms.

Focusing on the self-regulation measures adopted by Facebook, on which most of the counterpublics analysed in this research have personalised 'business pages', I have first considered measures which involve hiding vaccine-critical pages from search results and redirecting users to information provided by official public health organisations. I have suggested that such measures are unlikely to be effective in relation to vaccine counterpublic members who are used to a less passive approach to information-seeking, being engaged in DIY knowledge-making activities and valuing self-reliance and independent learning. Additionally, I have suggested that vaccine counterpublics encounter conflicting discourses articulated by social media companies which on the one hand invite the businesses using their services to be effective 'content creators', and on the other implement punitive measures to decrease the reach (and, consequently, the effectiveness) of vaccine-critical content. These measures are therefore generally perceived by counterpublics as unfair, and feed into their narratives about misinformation policies as 'censorship', akin to that imposed under totalitarian regimes, while reinforcing their representations of themselves as involved in a 'righteous' fight in defence of 'free speech' rights.

Interestingly, in invoking the right to freedom of expression, counterpublic members also actively engage with this right by expanding its meaning to cover not only interference from the state, but also from powerful private actors such as social media companies. This points towards an original way in which online vaccine counterpublics are 'bumping up against' the legal system which distinguishes them from past vaccine counterpublics. This new way of engaging with the law, in which misinformation policies on social media platforms are condemned as illegitimate censorship, resonates with counterpublics' interactive approach to knowledge-making more generally. Manual Castells (2007) has suggested how, in a 'network society' context 'power relations [...] as well as the processes challenging institutionalized power relations are increasingly shaped and decided in the communication field' (239). Seen in this context, the reinterpretation of 'free speech' in vaccine-critical talk also sheds a light upon an emerging power interplay between state institutions and increasingly influential media-corporate actors. This interplay is referred to as collusion which is intended to silence critical voices, further alienating counterpublic members and potentially attracting new followers among those who are already suspicious of the state and its institutions.

Vaccine-critical normative beliefs around vaccine decision-making and the 'hijacking' of informed consent in support of 'vaccine choice' advocacy

In assessing the beliefs about vaccines which underpin vaccine critics' advocacy activities, it is commonly assumed that these beliefs are either fundamentally 'irrational', or that they reflect a radical individualistic ideology, and that vaccine critics are fundamentally motivated by selfishness and self-interest. In Chapter 5 I offered a critique of these assumptions, showing how they do not adequately capture the values or principles of the online vaccine counterpublics studied in this research. None of these counterpublics expressed an a-priori aversion to cost-benefit analysis and 'rational' risk assessment of vaccine choices. In fact, as shown in the chapter, some counterpublic members defend and assert their status as rational decision-makers, invoking their ability to engage in rational analysis as the justification of their ability to make vaccine decisions for their children.

At the same time, counterpublics argue that the risks associated with vaccines are so severe that no reasonable parent who was aware of them would ever consent to having their children vaccinated. Vaccine critics are therefore especially concerned with the qualitative nature of vaccination risks, such as the severe and chronic nature of some of the conditions they claim to be linked to vaccination, as opposed to the quantitative aspect of risk frequency. To make sense of this approach to vaccination risks, I have drawn on sociologist Niklas Luhmann's (1993) notion of the 'catastrophe threshold'. Arguments which emphasise the rarity of adverse events associated with vaccines will therefore have little impact upon counterpublic members, as it is the quality, and not the frequency of risks which they believe exceeds their 'catastrophe threshold'. In counterpublic talk, the potential negative outcomes of vaccines are framed as so catastrophic that there is no threshold of risk that they would consider acceptable, either for their own or for other children. This emphasis upon the potential 'catastrophic' consequences of vaccination for society reveals that counterpublics do not just care about the wellbeing of their own families. There is instead a clear community-oriented dimension to vaccine-critical activism.

In the second part of Chapter 5, I have discussed how vaccine counterpublics' normative beliefs around vaccine decision-making are reflected in their advocacy activities and particularly in how they articulate their demands for 'vaccine choice'. Their campaigns for vaccine choice not only involve resistance to vaccine mandates, but they also seek actively to discourage other parents from vaccinating their children. In this context, a key role is played by the medico-legal concept of 'informed consent', which is re-interpreted and 'hijacked' by vaccine critics to mean, in the first instance, *exclusive* parental authority over children's vaccine decisions and, second, being 'fully' informed on the severe risks and dangers which critics attribute to vaccines. The idea of 'fully' or 'truly' informed consent is a recurrent one among counterpublics. It is a re-working of the legal notion of informed consent in order to justify their involvement in providing information to parents about vaccines. At a micro level, their involvement in information-provision is intended to dissuade parents from consenting to vaccination, while at the same time, it emphasises the more public-oriented and 'communitarian' side of vaccine-critical activism and of the policy goals pursued through the 'vaccine choice' advocacy activities of counterpublics.

The unwitting contribution of vaccination regulatory and legal frameworks to critical views on vaccine safety

According to the model of 'informed consent' proposed by counterpublics, parents should assume personal responsibility to educate themselves about the 'real' risks and dangers presented by vaccines. This is consistent with the way in which counterpublics invite their members to become involved in 'DIY' vaccine research, becoming independent and self-reliant learners in the process. In this context, as shown in Chapter 4, vaccine critics stress the importance of 'peer-reviewed science' as 'evidence' purportedly proving their claims regarding the existence of causal links between vaccination and certain severe adverse reactions. However, beyond the re-working and sharing of scientific sources, reinterpretations of information coming from official regulatory and legal sources also play a key role in supporting broader critical views on vaccine safety and the state's role in the implementation of vaccination policies.

Chapter 6 focuses on how patient information leaflets (PILs, also known as 'package inserts' in the US), passive surveillance systems and vaccine damage payment schemes in particular have become the object of critical interpretations which are used in support of three main counterpublic narratives about vaccine dangers. The first narrative is that official messages about vaccine safety are masking their 'hidden' risks, which parents will only discover by researching the 'fine print' information drawn from vaccine PILs/package inserts. A second narrative based on the US Vaccine Adverse Events Reporting System (VAERS) and the UK Yellow Card Scheme depicts vaccine risks as being grossly underestimated by authorities. Third, the existence of compensation schemes is used to claim that the state and public health institutions are concerned only with population-level statistics, and that they are indifferent towards the wellbeing of individual children and their families. Counterpublics instead believe that the risks they ascribe to vaccines cause injuries which are too severe to be acceptable, let alone adequately compensated through a monetary award, and this is invoked in order to argue that parents and families are the only legitimate locus of vaccine choice.

Conventional representations of the regulation of medicines usually emphasise the stringency of the safety controls to which vaccines are subject, both before and after they receive a marketing authorisation (see CDC 2018; Oxford Vaccine Group 2021). The expectation is that this strict system of regulation will enhance public trust in national immunisation programmes. However, the existence of stringent regulatory requirements does not appear to affect counterpublics' views about the dangers posed by vaccines. On the contrary, some of the features of these frameworks have enabled vaccine regulation itself to be invoked in order to challenge vaccination safety. Far from ignoring the regulation of vaccine safety, vaccine counterpublics incorporate aspects of regulation, such as the yellow card scheme, in their vaccine-critical talk. This is done in order to support their narrative that vaccines are unsafe medical products, and that the state is fundamentally unconcerned with individual children's health and families' wellbeing, and therefore not worthy of the public's trust.

Of course, these narratives are partial, skewed and often inaccurate, but it is important to acknowledge that vaccine-critical views on vaccine safety do not necessarily stem from anecdotes, rumours or 'fake news'. Rather it is official sources, and aspects of the regulation of vaccination which are often relied upon by vaccine-critical publics as 'proving' the unsafety of vaccines. It is therefore important for public health bodies and medicines regulators to understand that package inserts, post-licensing surveillance and compensation schemes are being redeployed among vaccine-critical online groups as admissions of 'culpability'. State culpability for vaccine harm is a recurrent theme in vaccine-critical talk, resonating with broader counterpublic worldviews in which public institutions 'collude' with corporate actors, by, for example, turning a blind eye to the 'reality' of vaccine-related harm.

Constructing vaccine-critical collective identities: truth, epistemic trust and legal accountability

In Chapter 7, I sought to understand what kind of vaccine-critical identities come to be constituted in online spaces, and also how these identities are rhetorically supported and justified by counterpublics. In the first part of the chapter, my analysis focused on counterpublics' collective identity narratives around the concept of 'truth', and related notions such as 'facts', 'reality' and 'objectivity'. I suggested that rather than a radical, all-encompassing 'postmodern' scepticism towards facts and objectivity, counterpublics frame themselves as somehow ahead of the curve of knowledge, fighting as courageous 'whistle-blowers', to defend and promote 'facts' about vaccine dangers which will one day be proven to be true and acknowledged by the scientific establishment and mainstream public. Counterpublic narratives appear to disprove 'post-truth' explanations for vaccine opposition which frame this as an expression of a more generalised and radical questioning of universal 'truths' or 'facts' by certain sections of society (see e.g. D'Ancona 2017; McIntyre 2018).

In the second part of the chapter, I analysed a second set of narratives, looking particularly at the ideas of epistemic trust and self-confidence, and how counterpublic members assess their abilities to learn and develop a reliable understanding of vaccine-related issues. Contrary to views explaining 'vaccine hesitancy' and scepticism with reference to pervasive sentiments of uncertainty and doubt in late-modern societies (see Giddens 1990; 1991; Beck 1992), including scepticism towards expert knowledge more generally, the narratives analysed in this research suggest that vaccine counterpublics create confident members who are self-assured about their epistemic competence, who create bonds of trust and epistemic solidarity with each other through the sharing of experiential knowledge. I also noted how the references to experiential knowledge made by counterpublic members do not signal disillusion with expert knowledge, or the belief that expertise is now so diluted that 'anyone can call themselves an expert'. Rather, drawing on Alfred Schütz's work on the sociology of knowledge, I contended that in their online narratives counterpublic members cast themselves as 'well-informed citizens' who, distinctively compared to both laypeople and fully-fledged experts in Schütz's ideal-typical framework, feel themselves qualified to appropriately discern which expert sources they can rely on.

In the final part of the chapter, I attempted to shed light on how online vaccine critics determine what expert sources they should consider reliable when researching vaccination issues. 'Outward-looking' counterpublic narratives become relevant here, particularly as they portray the pharmaceutical companies which manufacture and sell vaccines and those responsible for making policies on vaccination as colluding for the sake of profit, to the detriment of children's health. As a result of their belief that there is widespread and cynical collusion between institutions and corporate actors in order to promote vaccination, research which supports the use of vaccines or which demonstrates vaccine safety is perceived by counterpublics to be 'tainted research', produced only in order to promote the interests of 'Big Pharma'.

For counterpublics, this implies that pharmaceutical companies should not only be 'distrusted', but also actively blamed for causing childhood vaccine injuries. However, and crucially in vaccine-critical narratives, the state has intervened to protect vaccine manufactures, shielding them from being accountable for vaccine injuries through the introduction of 'no-fault' vaccine injury compensation schemes. More specifically, the liability protections accorded to vaccine manufactures under the US regime regulating childhood vaccine injury compensation (as set up by the 1986 National Childhood Vaccine Injury Act) are co-opted as proof that the system is set up in order to advantage pharmaceutical companies, with the state being on the side of corporations, rather than parents and children. In this regard, I have suggested that the collective identities of counterpublic members as 'whistleblowers' who care deeply about children's health (they may be parents of vaccine-injured children themselves, or be dedicated to sharing other parents' experiences) and the narratives of systemic collusion among public institutions may be seen as two sides of the same coin, supported by alternative interpretations of the law.

Vaccine counterpublics, law and citizen participation

Journalism and media scholar Michael Schudson (2003) has argued that in order to grasp the significance of digital media for democracy we should be looking first into what models of citizenship underpin our conceptions of democracy. As he sees it, '[i]f the new digital media are to be integrated into a new political democracy, they must be linked to a serious understanding of citizenship' (49). From this perspective, it makes sense to suggest that in order better appreciate and understand the influence of new media technologies, and particularly the internet, on the relationship between law and society we should investigate how citizens engage with the law in digital spaces, and what forms of citizenship are expressed through citizens' mediated legal activities. Looking at online vaccine critics and their relationship with the law, then, offers the opportunity to enrich previous scholarship on law and activism by focusing on the impact of new media on the legal agency of citizens.

When I started this research, I anticipated finding references to the law in vaccine-critical talk, but I expected these would consist mainly in negative reactions to mandatory vaccination measures and, perhaps, expressions of dissatisfaction with the current vaccine injury compensation regime. What I found, instead, is a much more complex picture in which vaccine counterpublics engage with different aspects of their surrounding legal landscapes. In relation to their construction of causal knowledge around alleged vaccine adverse reactions, for example, counterpublics invoke the right of freedom of expression, while expanding its meaning so that it applies not only to state interference, but also against private social media companies and their 'misinformation' policies curtailing vaccine-critical content. Vaccine counterpublics also 'hijack' the right to informed consent to argue that parents should be provided with vaccine-critical information in order to be able to give 'fully' informed consent to vaccination for their children. Certain aspects of the regulatory and legal frameworks surrounding vaccination – namely PILs, pharmacovigilance systems and vaccine injury compensation schemes – are reframed by vaccine counterpublics and presented as 'evidence' which supports critical views on vaccine safety. Finally, the liability protections afforded by law to pharmaceutical companies in the case of vaccine-related damage claims are co-opted by vaccine critics to reinforce their broader worldviews of systemic collusion, in which the state is seen as shielding corporations from being justly held accountable for vaccine damage. In all this, counterpublic members regard themselves as courageous whistleblowers fighting for the 'truth' – in the same way as people who first drew a connection between cigarettes and lung damage – who will in time be proved to have been right all along.

The legal system does not just offer counterpublics the opportunity for strategic litigation or lobbying for policy change, but it is also an important discursive resource which is used in order to advance vaccine-critical positions and, crucially, to construct vaccine-critical identities and worldviews. This resonates with what Gwendolyn Leachman (2013) calls the 'social constructionist model for legal framing research' (51). According to her, this model can contribute to social-scientific research on the legal dimensions of social movements, and particularly to a better understanding and theorisation of the ways in which participants to social movement activism:

> ...negotiate the symbolic meaning of legal language and generate new legal interpretations "in the shadow of social institutions" (Albiston, 2005), or how they construct law while taking into account the multiple arenas of social power that manifest both within movements and in the social environment.'
>
> (2013, 50, citation included in original)

Notwithstanding these affinities with the legal framing perspective in social movement studies, by adopting a counterpublicity approach to vaccine-critical activism, particularly as inflected by rhetoric and communication scholars (see e.g. Asen 2000; Palczewski 2001; Warner 2002; Foust, Pason and Rogness 2017), I wanted to further emphasise the rhetorical and mediated nature of vaccine critics' engagement with the law. What I suggest, more specifically, is that the alternative legal meanings emerging from the re-interpretations of legal concepts, discourses and institutions offered by online vaccine critics give rise to what Fraser (1990) has called 'parallel discursive arenas', allowing counterpublics to formulate and circulate their own counter-discourses which in turn enable them to reframe their 'identities, interests, and needs' (67). At the same time, the creation of novel, more interactive and connective discursive arenas made possible by the advent of digital media technologies has offered the opportunity for new bonds of solidarity to be forged among vaccine critics, reinforcing counterpublics' legal interpretations and meaning-making activities. Last but not least, the counterpublic approach adopted in this research highlights how courts, formal organisations and other official sites of legal discourse are not the only sites through which new legal interpretations and meanings can be asserted. Rather, in the information age, the internet is emerging as a powerful domain of 'legal' citizen participation and agency, in which law becomes another cultural resource which can be drawn upon, reframed and reimagined through these new processes of digital citizenship.

Researching internet-mediated vaccine counterpublics can therefore offer an insight into the emergence of a novel form of participatory legal citizenship in our information society, which is at once enabled and shaped by digital media. Of course, law is not only resource that can be drawn upon by digital citizens. As seen in the course of this work, for example, science is another very significant domain for vaccine counterpublics, who routinely invoke and reframe scientific knowledge in order to support their claims about vaccine injuries. In this regard, a broader connection might be drawn between counterpublic theory and the concept of 'DIY citizenship'. Media theorist John Hartley (1999) originally framed 'DIY citizenship' as about identity and particularly what he calls the 'right to semiotic self-determination' made possible by new media technologies. For him, DIY citizens are producers as well as consumers of media who are creating their own identities through the process of engaging with and reworking cultural resources. As he notes, therefore, the DIY citizen 'takes what she needs from the identities and differences available in the mediasphere and claims her rights of semiotic self-determination' (1999, 185). Building on Hartley's framework, Matt Ratto and Megan Boler (2014) have further suggested that DIY citizenship in an internet age can manifest as 'emergent communities of "critical makers" and political protestors that organise on- and offline' (5). In addition, they suggest that while DIY online activities initially were confined to youth subcultures – citing George McKay's (1998) influential edited volume on DIY culture as an example of this kind of original research – things have changed as ‘digitally mediated DIY practices have recently become more mainstream’ (Ratto and Boler 2014, 3).

As remodellers of knowledge from their surrounding scientific and legal cultures, I would suggest that it is possible to compare the activities of vaccine counterpublic members to those of DIY citizens ‘...who redeploy and repurpose corporately produced content or create novel properties of their own, often outside the standard systems of production and consumption’ (3). In drawing this connection between vaccine counterpublics and DIY citizenship, I would also like to emphasise how collective vaccine opposition is fundamentally political and cannot be easily explained away by referring to ignorance, irrationality, or susceptibility to ‘fake news’ or misinformation. Rather, I suggest, we should be looking beyond individual-centric approaches in order to understand vaccine counterpublics as an emergent form of political and legal agency enabled by digital media, expressing citizenship through the appropriation and reworking of mainstream culture and official discourses.

Implications of this research for science communication and policy

As suggested earlier on in these conclusions, while the present research has focused specifically on internet-mediated, collective opposition to childhood vaccines, it is possible to extend at least some of its findings to vaccine scepticism more generally, even in a developing context in which an emerging pandemic has brought with it also a new wave of vaccine-critical activism and vaccine hesitancy. The implications of this research for scientific communication around vaccination issues should perhaps be of interest to researchers, fact-checkers, journalists and educators considering how to best frame messaging around vaccination safety, as well as for decision-makers looking into ways to respond to vaccine hesitancy.

Reporting and messaging about vaccine safety has often relied on the so-called ‘deficit model’ of science communication, which focuses on ‘top-down’ education as a way to remedy an assumed lack of information on the part of the lay public on scientific matters (see Miller 1983). Challenging the applicability of the deficit model to vaccine controversies, some authors have instead suggested that ‘more information may not prevent vaccine hesitancy’ among those who are already opposed to vaccines (Getman et al. 2018; see also Mitra, Counts and Pennebaker 2016; Browne et al. 2015; Larson et al. 2011). In fact, as Heidi Larson and her colleagues have noted:

> Public decision making related to vaccine acceptance is not driven by scientific or economic evidence alone, but is also driven by a mix of scientific, economic, psychological, sociocultural, and political factors, all of which need to be understood and taken into account by policy and other decision makers.
> (Larson et al. 2011, 527)

Some of the critiques of the deficit model have specifically relied on recent research by social psychologists on vaccine safety communication. For example, a well-known experimental study published in the journal *Pediatrics* and looking at the effects of messaging about vaccines on parental attitudes towards vaccination found that public health communication may be ineffective in increasing intention to vaccinate, at least among some vaccine-sceptical sections of the population (see Nyhan et al. 2014). More specifically, the study tested the effects of four types of messages about the MMR vaccine. The first type of message consisted in information from the CDC about the lack of evidence that MMR causes autism. The second type was represented by information included in US Vaccine Information Statements emphasising the dangers of the diseases prevented by MMR, and the third by a visual-based message including images of children with diseases prevented by the MMR vaccine. Finally, the fourth message included a 'dramatic narrative about an infant who almost died of measles from a Centers for Disease Control and Prevention fact sheet' (2014). The types of messaging included in this survey-based experiment were consistent with previous approaches to communication, which emphasised the dangers to children's health, and used personal stories and images in order to elicit emotional responses. This study found that while some parents were persuaded by the information that the MMR vaccine does not cause autism, none of these interventions increased their intention to vaccinate, and they even decreased (self-reported) intention to vaccinate among parents who were opposed to vaccines to begin with.

Some of the findings presented in this thesis appear to support the results of this *Pediatrics* study, as well as challenging the science deficit model more generally. At the same time, the present research clarifies aspects of vaccine scepticism that remain quite opaque in this kind of experimental study, such as how vaccine critics are actually interacting with scientific information, engaging in knowledge-making activities, and responding to sources contradicting their beliefs in a real, situated environment. Specifically, this research has emphasised the importance of independent, self-reliant 'DIY' learning among vaccine counterpublics. This means that counterpublic members are not just passive consumers of information, but are actively engaged in the collection, study, reworking and sharing of vaccine-related knowledge. These epistemic practices reveal the particular significance of 'peer-reviewed science' for the reformulation of vaccine-critical claims. Additionally, they highlight the importance for vaccine critics of independently selecting one's sources of information, and carefully discerning between reliable and unreliable sources in a context in which lies and deceit for the sake of profit are perceived to be common, especially among institutional and commercial actors who have 'something to gain' by 'pushing' vaccination. In sum, it is not just the content of the information or how it is framed that matters for vaccine critics, but also where the information comes from and how one encounters it (e.g. through independent research rather than 'official', top-down communication).

On the other hand, some aspects of the counterpublic talk looked at in this research reveal that in order to address vaccine scepticism it is still crucial to conduct well-designed studies and circulate scientific findings on vaccine safety. First, thorough research on vaccine safety issues and proper communication of such research may signal to vaccine-hesitant parents and individuals who are not yet completely opposed to vaccines that the expert institutions care, and are deploying resources to ensure that vaccine-related concerns are adequately investigated, counteracting counterpublics' arguments about the purported disregard of such institutions for children and families' wellbeing. Second, vaccine counterpublic members may encounter vaccine safety studies organically while 'doing their own research'. In this regard, this research has shown that counterpublic members do not simply ignore scientific knowledge which contradicts their beliefs, but actively engage with this knowledge even as they critique it.[149] This does not mean more vaccine safety research will necessarily be effective in changing vaccine sceptics' minds, but at least it may focus their attention on the science surrounding vaccination, rather than more extreme ideological arguments and conspiratorial views.

The findings presented in this research also suggest that while communicating scientific evidence about vaccines to the broader public, it is important to adopt an approach that does not patronise one's audience, but rather relies upon and values the epistemic agency and independence of individuals and their abilities as learners, emphasising that by 'doing one's research' in an in-depth, thorough way, any member of the public can uncover the many well-designed studies conducted on vaccines and evidence pointing towards the safety of immunizations. Additionally, considering that counterpublics often refer to peer-reviewed studies and draw on scientific knowledge relating to very specific – and sometimes rather obscure, at least for the lay reader – aspects of medicine or related disciplines (such as chemistry or toxicology), science communication should also aim to include detailed in-depth analysis of scientific evidence, rather than offering over-simplistic answers on vaccine safety issues or trying to address vaccine concerns merely as the product of 'magical or superstitious thinking' (Bryden et al. 2018).

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[149] It should be pointed out that the science 'reworked' by vaccine counterpublics to advance their vaccine-critical arguments does not appear to include studies directly supporting claims of vaccine safety, so there should not be an issue about critics appropriating this kind of science to re-use in their epistemic activities.

Some of this kind of more thorough and in-depth communication, offering syntheses of the available scientific evidence and accessible but detailed analysis with references to the peer-reviewed literature on vaccine-related issues already exists. For instance, both the University of Oxford and the John Hopkins Bloomberg School of Public Health have ongoing projects dedicated to the communication of the science on vaccination safety, providing invaluable resources relevant to specific vaccines and offering detailed, well-referenced answers to a number of common vaccine concerns.[150] More effort to produce and reference these kinds of more in-depth resources may be a helpful way to address vaccine-related doubts, especially among those vaccine-hesitant parents or individuals who although not yet opposed to vaccination might question the information about vaccines offered by some mainstream sources as too generic and simplistic, especially compared to the hyper-specific arguments and detail found on vaccine-critical websites.

Perhaps most importantly, this research has shown the importance of legal contexts for vaccine-critical arguments and claims. Communication about vaccine safety should therefore pay particular attention to the ways in which vaccine PILs (or package inserts), pharmacovigilance systems and vaccine injury compensation schemes are referred to by vaccine counterpublics as 'evidence' that vaccines are unsafe medical products that should be rejected by parents. Making available more accessible information about the purpose of these regulatory measures, and how they work in practice may be helpful in order to provide a counterbalance to the misinformation about them which circulates online.

Additionally, the findings of this research on vaccine critics' advocacy for 'vaccine choice' may be seen as justifying caution in policy considerations regarding the introduction of mandatory vaccination measures. As seen in Chapter 5, such policies are represented by counterpublics as a violation of the human right to informed consent, and might unintentionally result in the reinforcement of vaccine-critical views depicting the state and public health institutions as 'pushing' vaccinations on children and their families, regardless of whether this is in the best interest of individual children. This research therefore lends support to arguments that '[vaccination] mandates can undermine public support, creating backlash and even reducing vaccine uptake' (Gostin, Salmon and Larson 2021, 533).

Last, but not least, this research has pointed towards the implications of liability protections for vaccine manufacturers in cases of claims for damages related to vaccine injuries. While protections for

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[150] The website of the Oxford Vaccine Group's Vaccination Knowledge Project is accessible through the following link: https://vk.ovg.ox.ac.uk/vk/vaccine-safety (last accessed 10-04-2022). The Institute for Vaccine Safety at the John Hopkins Bloomberg School of Public Health manages the website https://www.vaccinesafety.edu/ (last accessed 10-04-2022). Both websites also provide detailed information on the newer COVID-19 vaccines.

pharmaceutical companies producing vaccines may be an understandable policy choice in order to ensure adequate vaccine supply, especially in a US tort law context involving jury trials and the potential for hefty punitive damages, their adoption may have unforeseen effects beyond those envisaged by policy-makers. Specifically, liability protections may have negative implications for vaccine confidence, decreasing public trust by feeding into vaccine counterpublic claims about collusion and corporate greed.

Where next for vaccine opposition research?

The primary aim of this research has been to contribute to the existing literature on vaccine opposition by investigating internet-mediated vaccine-critical activism in our information age. In order to achieve this aim, I have adopted a qualitative research approach informed by internet ethnography and thematic analysis, looking at the online talk, interactions and activities taking place on six vaccine-critical blogs and some of their social media pages over the course of nine months of digital fieldwork. As the research period did not extend beyond 2019, my data did not cover the most recent developments in vaccine-critical activism following the advent of the COVID-19 pandemic. Although at least some of the findings of this research may be relevant to the emerging opposition to new COVID vaccines, as the data does not include vaccine critics' perspectives on these new vaccines, more research would be very useful in order to understand the impact of COVID-19 on vaccine opposition. This might include what alliances and divisions have formed within and outside existing vaccine-critical circles, as well as newer developments in vaccine critics' engagement with the legal system, for example, with the introduction of vaccine 'passes'. Additionally, because of the focus on the mediated, digital expression of collective vaccine opposition, and on the themes emerging from vaccine critics' online talk, this study has not sought to directly engage with vaccine critical individuals, neither on- nor offline. Although this approach has allowed me to offer an in-depth analysis of a rich body of online data in order to better understand how vaccine-critical activism in digital spaces works, future research could be undertaken to focus more on the offline lives of vaccine critics.

Finally, investigating the historical backdrop to vaccination resistance early on in this work has revealed important areas of connection and continuity among the successive waves of opposition which have rocked state vaccination policies since the introduction of the smallpox vaccine. An exploration of local historical or collective memories of 'vaccine crises' or an investigation of the family histories of vaccine critics, perhaps through an oral history lens might tell us more about how opposition to vaccinations has kept going, and become an ingrained, recursive phenomenon in our society. To be better equipped to deal with vaccine safety issues in the future we therefore need to understand vaccine opposition as a complex social phenomenon involving multiple dimensions – from the localised to the global, the individual and the collective, the digital and the physical. Above all, researching vaccine-critical activists – especially over the course of a prolonged period of time – should make one realise that there are no easy solutions or strategies that can be used to 'respond' to vaccine scepticism. On the other hand, learning more about what vaccine critics say, what they do and, indeed, how vaccine-critical activism works, may allow public discussions around vaccines to better contextualise vaccine opposition, helping to demystify what is sometimes portrayed as a puzzling or even incomprehensible resistance to one of the most successful interventions in the history of public health. Research on vaccine opposition may not change the minds of staunch critics or counterpublic members – however, taking their concerns seriously is arguably a step in the right direction.

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APPENDIX A

Vaccine-critical websites list

The following list includes vaccine-critical websites from previously compiled lists sourced from the website Vaxopedia (https://vaxopedia.org/2018/01/13/anti-vaccine-websites/), as well as previously published research articles, i.e. Bean (2011), Smith (2017) (supplementary material) and Hobson-West (2007). These sources were complemented by additional Google searches involving different combinations of terms, including 'vaccines information', 'anti-vaccine', 'pro-vaccine', 'vaccines dangerous', 'are vaccines safe', 'vaccines unsafe'. A snowball technique was also used to add vaccine-critical websites referred to in the 'references' or 'links' sections of the websites previously identified.

The listed anti-vaccination websites have been coded for national areas of interest, main thematic areas, type of website (individual/multi-author website, website with or without comment section, commercial/not-for-profit) following a preliminary review. Further comments have been included to some entries if needed for better categorisation. Those websites in the list without an active comment section, non-US or -UK focused websites, websites not concerned with routine childhood vaccinations more generally and more 'generalist' websites were excluded from the final sampling frame (see Chapter 3).

List of vaccine-critical websites

1. Age of Autism [https://www.ageofautism.com] [US based, vaccine injury (VI) activism, multi-author, comment section, NFP]
2. Alliance for Natural Health [https://www.anhinternational.org] [UK based, alternative health, multi-author, comment section, NFP (but commercial links)]
3. ~~Arnica [https://www.arnica.org.uk] [UK based, personal enquiry/other, not known, no comment section, NFP]~~
4. ~~Child Health Safety [https://childhealthsafety.wordpress.com] [N/A, personal enquiry/other, not known, no comment section, NFP]~~
5. ~~Children's Health Defense [https://childrenshealthdefense.org] [US based, personal enquiry/other, not known, no comment section, NFP].~~
6. ~~The Children's Medical Safety Research Institute [https://www.cmsri.org] [US based, personal enquiry/other, multi-author, no comment section, NFP]~~
7. ~~Collective Evolution [https://www.collective-evolution.com] [US based, personal enquiry/other (general conspiratorial), multi-author, no comment section, C]~~
8. ~~Colorado Coalition for Vaccine Choice [https://cohealthchoice.org] [US-based, medical choice advocacy, not known, no comment section, NFP]~~
9. ~~Daily Dose with Jack Harrison [https://jacksdailydose.com/] [US based, alternative health, not known, no comment section, C]~~
10. David Avocado Wolfe [https://www.davidwolfe.com] [US based, alternative health, multi-author, comment section, C (NB no strong focus on vaccines)]
11. ~~Educate Yourself [http://educate-yourself.org] [US based, general conspiratorial, no comment section, not known]~~
12. Fearless Parent [http://fearlessparent.org] [US based, medical choice advocacy, multi-author, comment section, NFP]
13. Focus for Health [https://www.focusforhealth.org] [US based, personal enquiry/other, multi-author, comment section, NFP]

14. ~~Generation Rescue [http://www.generationrescue.org] [US based, VI/autism/disability activism, not known, no comment section, NFP]~~
15. ~~Global Vaccine Awareness League [http://www.gval.com/] [US based, VI activism, not known, no comment section]~~
16. GreenMedInfo (the science of natural healing) [http://www.greenmedinfo.com] [US based, alternative health, multi-author, C]
17. ~~Green Health Watch [http://www.greenhealthwatch.com] [UK based, alternative health, not known, no comment section, not known]~~
18. ~~Healing Arts [http://www.healing-arts.org] [US based, alternative health, no comment section, not known, not known]~~
19. ~~Health Impact News [http://healthimpactnews.com/] [US based, alternative health, no comment section, multi-author, C (note: many internal links broken)]~~
20. The Healthy Home Economist [https://www.thehealthyhomeeconomist.com] [US based, alternative health, single author, C]
21. ~~The Informed Parent [https://www.informedparent.co.uk] [UK based, personal enquiry/other, comment section (note: no comments), not known, NFP]~~
22. ~~Immunity Education Group [http://immunityeducationgroup.org] [US based, personal enquiry/other, no comments section, not known, NFP]~~
23. ~~Immunity Resource Foundation [http://www.immunity.org.uk] [UK based, personal enquiry/other, no comment section, multi-author, NFP, note: mainly AIDS focussed]~~
24. ~~InfoWars [https://www.infowars.com] [US-based, general conspiratorial/right-wing political activism, comments section, multi-author, C]~~
25. ~~JABS [http://www.jabs.org.uk] [UK-based, VI/disability activism, no comment section, not known, NFP]~~
26. Kelly Brogan, MD [https://kellybroganmd.com/] [US based, alternative health, multi-author, comment section, C]
27. ~~Lew Rockwell [https://www.lewrockwell.com] [US based, personal enquiry/other, no comment section, multi author, C]~~
28. ~~Learn the Risk [https://www.learntherisk.org] [US based, personal enquiry/other, comment section, multi-author, NFP (NB: no comments)]~~
29. ~~The Liberty Beacon [https://www.thelibertybeacon.com] [US based, general conspiratorial/right-wing political activism, multi-author, comment section, C]~~
30. Living Whole [https://www.livingwhole.org] [US based, alternative health, single-author, comments section, C]
31. ~~Medicine No [links to 'New Jersey Spine Center', not anti-vaccine website]~~
32. Mercola [https://www.mercola.com] [US based, alternative health, multi-author, comments section, C]
33. ~~Mercury Madness [http://www.mercurymadness.org] [US based, alternative health, multi-author, no comment section]~~
34. Modern Alternative Mama [https://modernalternativemama.com] [US based, alternative health, single-author, comment section, C]
35. Moms Across America [https://www.momsacrossamerica.com] [US based, alternative health, NB mostly anti-GMO activism, multi-author, comment section, NFP]
36. ~~Moms Against Mercury [https://www.mercuryfreenow.com/mama/mama.html], NB not an anti vaccination website (dentistry focused website)~~
37. ~~National Vaccine Information Center (NVIC) [https://www.nvic.org] [US based, VI activism, multi-author, no comment section, NFP]~~
38. Natural News [https://www.naturalnews.com] [US based, alternative health (NB important right-wing political activism sub-theme), multi-author, comment section (NB there is a comment section, but very few comments below any blogs), C]
39. ~~Medical Academy of Pediatric Specials Needs [https://www.medmaps.org] [US-based, VI/disability/autism advocacy, multi-author, no comment section, NFP]~~

40. ~~Physicians for Informed Consent [https://physiciansforinformedconsent.org/leadership/] [US based, medical choice activism, no comment section, multi-author, NFP]~~
41. ~~safeMinds [https://safeminds.org/about/] [US based, VI/autism/disability activism, multi author, no comment section, NFP]~~
42. ~~SaneVax [https://sanevax.org] [N/A, VI activism (HPV only – no childhood vaccines), multi-author]~~
43. ~~Shirley's Wellness Café [http://www.shirleys-wellness-cafe.com] [US based, alternative health, not known, no comments section, C]~~
44. StopMandatoryVaccinations [https://www.stopmandatoryvaccination.com] [US based, alternative health, single author, comment section, not known]
45. ~~Talk About Curing Autism (TACA) [https://tacanow.org] [US-based, VI/autism advocacy, multi-author, no comment section, NFP]~~
46. The Thinking Moms' Revolution [https://thinkingmomsrevolution.com] [US based, autism advocacy, multi-author, comment section, C]
47. The Vaccine Reaction [https://thevaccinereaction.org] [US-based, VI advocacy, multi-author, comment section, NFP]
48. ~~Thinktwice Global Vaccine Institute [http://thinktwice.com/aboutus.htm] [US based, alternative health, no comment section, multi-author, C]~~
49. Vaccination.co.uk [http://vaccination.co.uk] [UK based, personal enquiry/other, single author, comment section, NFP]
50. ~~Vaccination Information Network [*NB impossible to navigate the website*]~~
51. ~~Vaccination Liberation [http://www.vaclib.org] [US based, personal enquiry/other, no comment section]~~
52. ~~Vaccination News [https://www.vaccinationnews.org] [US based, personal enquiry/other, no comment section]~~
53. ~~Vaccine Impact [https://www.vaccineimpact.org] [*NB not an anti-vaccine website*]~~
54. ~~Vaccine Victims Support Group [http://vvsg.co.uk] [UK based, VI activism, no comment section, not known, NFP]~~
55. Vaccinepapers.org [http://vaccinepapers.org] [US based, personal enquiry/other, single author, comment section, NFP]
56. ~~Vaccine Awareness Network [http://vaccineriskawareness.com] [UK based, personal enquiry/other, not known, no comment section, NFP]~~
57. ~~Vaccine Info & Choice Network [http://www.wellwithin1.com/vaccine.htm] [US based, alternative health, single author, no comment section, C]~~
58. ~~Vaccine Safety Website [http://www.vaccinesafety.edu] [*NB not an anti-vaccine website*]~~
59. Vactruth [https://vactruth.com] [US based, VI activism, multi-author, comment section, not known]
60. Vaxxter [https://vaxxter.com/] [US based, alternative health, multi-author, comment section, C]
61. Weston A. Price Foundation [https://www.westonaprice.org] [US based, alternative health, multi-author, comment section, NFP]
62. ~~WHALE [www.whale.to] [UK based, general conspiratorial, no comment section, multi-author, not known]~~
63. ~~World Mercury Project (Robert F Kennedy Jr.'s website) [https://worldmercuryproject.org] [US based, personal enquiry/other, no comment section, multi-author, NFP]~~

APPENDIX B

Sampling Frame (the sampled blogs have been highlighted)

No	URL	Relevant Country /ies	Main thematic areas of focus	Multi/ Single Author	Commercial/ Not-for-profit
1	https://www.ageofautism.com	US / UK (one UK-based editor)	Vaccine injury activism	Multi-author	Not-for-profit (Autism Age)
2	https://anhinternational.org	UK	Alternative health	Multi-author	Not-for-profit (Alliance for Natural Health International, but linked to commercial ANH Consultancy Ltd)
3	https://www.davidwolfe.com	US	Alternative health	Multi-author	Commercial (Chaga Inc)
4	http://fearlessparent.org	US	Medical choice Alternative health	Multi-author	Not-for-profit (Center for Personal Rights)
5	https://www.focusforhealth.org	US	Personal enquiry/ other	Multi-author	Not-for-profit (Focus For Health/Focus Autism)
6	http://www.greenmedinfo.com	US	Personal enquiry/ other	Multi-author	Commercial (Greenmedinfo LLC)
7	https://www.thehealthyhomeeconomist.com	US	Alternative health	Multi-author	Commercial (AustUS Media LLC)
8	https://kellybroganmd.com	US	Alternative health	Single-author	Commercial
9	https://www.livingwhole.org	US	Alternative health	Single-author	Commercial (Living Whole LLC)
10	https://www.mercola.com	US	Alternative health	Single-author	Commercial (Mercola Health Resources LLC)
11	https://modernalternativemama.com	US	Alternative health	Single-author	Commercial (Earthley)

12	https://www.momsacrossamerica.com	US	Alternative health	Multi-author	Not-for-profit (Moms Across America)
13	https://www.naturalnews.com	US	Alternative health	Multi-author	Commercial (Health Ranger Store LLC)
14	http://www.stopmandatoryvaccination.com	US	Alternative health Medical Choice	Multi-author	Commercial
15	https://thevaccinereaction.org	US	Vaccine injury activism	Multi-author	Not-for-profit (NVIC)
16	https://thinkingmomsrevolution.com	US	Vaccine injury activism	Multi-author	Commercial (TTMR LLC)
17	http://vaccination.co.uk	UK	Personal enquiry/ other	Multi-author	Not-for-profit (personal blog)
18	https://www.vaccinepapers.org	US	Personal enquiry/ other	Single-author	Not known (anonymous blogger)
19	https://vactruth.com	US	Vaccine injury activism	Multi-author	Not known
20	https://vaxxter.com	US	Personal enquiry/ other	Multi-author	Commercial (Choonadi LLC)
21	https://www.westonaprice.org	US	Alternative health	Multi-author	Not-for-profit (Weston A. Price Foundation)

APPENDIX C

Research Themes and Codes List

- I. Causal Knowledge
  - 'DIY science'
    - 'Scientific' evidence supporting vaccine injury claims
    - Linking specific health conditions to vaccination
    - Making and sharing knowledge claims
    - Promoting vaccine-critical content
    - Sharing information and resources through comment sections
    - Vaccine critics reading and commenting on vaccine research
  - 'Do your own research'
    - (Self-)education as individual responsibility
    - Health optimisation
    - Personal empowerment through research
    - Preaching to the converted
  - Supporting 'real' scientific knowledge
    - Challenging public representations of 'anti-vaxxers' as anti-science
    - Combining alternative approaches to health with scientific research
    - Critiques of vaccine-critical claims as science denialism
    - Mainstream science is not real science
  - VCPs as advocates for 'free speech'
- II. Normative Principles and Advocacy
  - Individual- and public-oriented vaccination concerns as compatible concerns
    - Individual risk concerns
      - Individual risk-benefit analysis
      - Limits to the pursuit of the 'common good'
      - Not enough information to adequately assess vaccine risks
      - Risk assessment and education on vaccine safety issues as personal responsibility
      - Risks posed by vaccine preventable diseases
      - The 'disaster threshold'
    - Public safety concerns
      - 'Autism epidemic'
      - 'Vaccine holocaust'
      - No such thing as a safe vaccine
      - Opposing vaccines to save others
      - Vaccines as a crime
      - Vaccines as toxic and poisonous
      - Vaccines should be 'as safe as humanly possible'

Research Themes and Codes List

- Informed consent rights 'hijacked' in support of 'vaccine choice'
  - 'Truly' Informed consent as parental right
    - Seeding doubt about 'true' vaccine dangers while advocating for personal choice
    - Supporting vaccine abolition
  - Parental choice and informed consent
    - Supporting 'medical choice' and 'freedom' (beyond vaccines)
    - Supporting parents applying for vaccine exemptions
    - Vaccine choice as basic human right
- Vaccine regulation recast to support views that vaccines are unsafe
  - Vaccine package inserts or PILs
  - VAERS, Yellow Card and AEs surveillance
  - VICS

III. Collective Identity

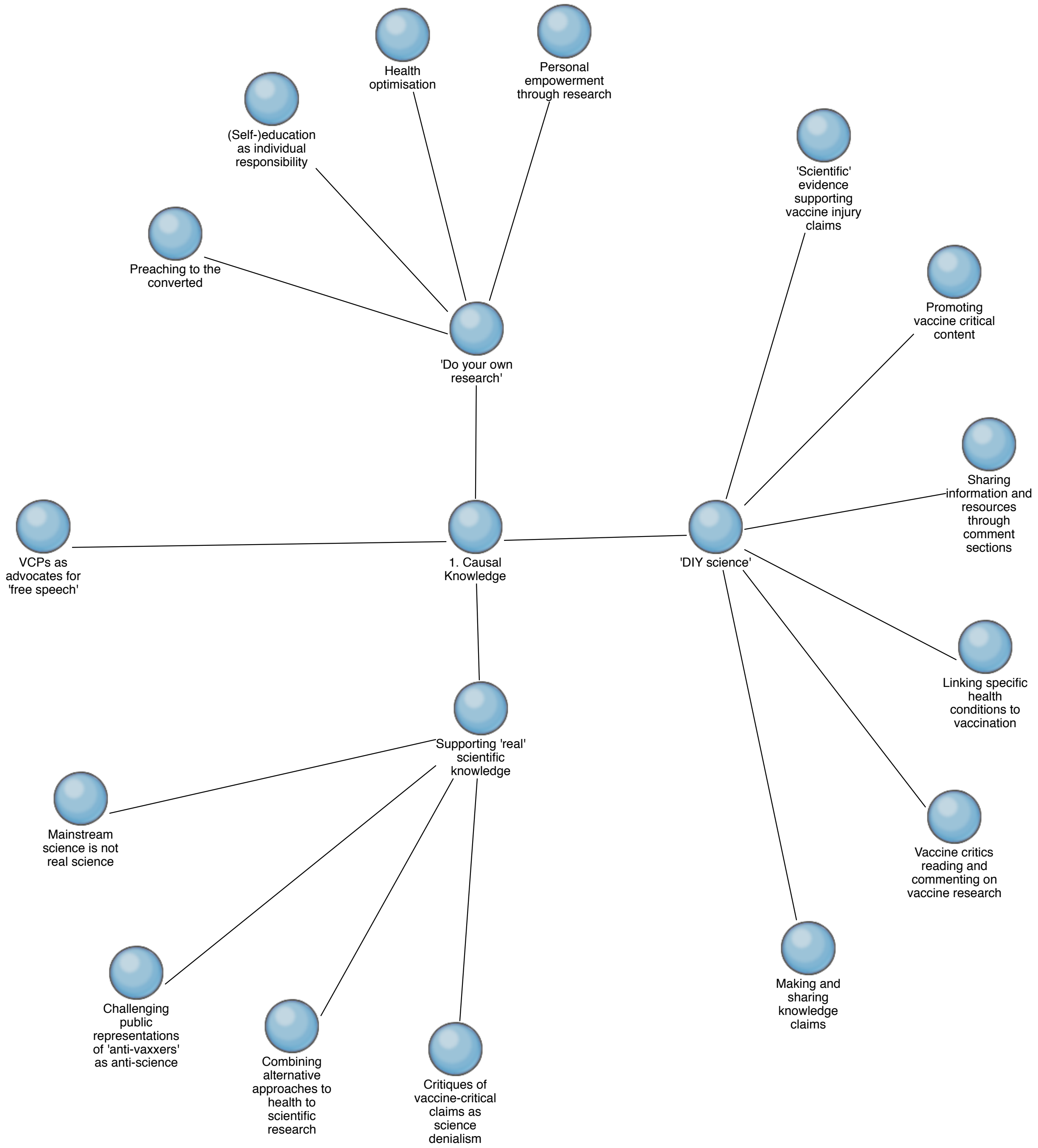
- 'Whistleblower' identities and search for truth as a mission
  - Fighting for the truth
    - Expressing scepticism towards the idea of scientific consensus
    - Questioning official narratives on vaccine safety
    - Uncovering the 'truth' about Wakefield
  - Lying and silencing the truth
    - 'Fake news' as a way to target vaccine critics and official institutions as the true propagators of false information
    - Being pro-vaccine as a kind of religious 'faith'
    - Mainstream media silencing vaccine critics
    - Revealing corporate bias in science
- Allocating blame and accountability for vaccine injury
  - Allocating blame through the legal system
  - Conflicts of interest in scientific research
  - Critiquing liability protections for vaccine manufacturers
  - Framing the 'vaccine injured' as victims
  - Systemic collusion among institutional actors and corporations
    - Legal and political institutions
    - Medical regulatory bodies
    - NGOs and charities
      - Bill Gates and GAVI
    - Pharmaceutical industry (and other related industries)
    - Public health organisations
    - Research organisations and scientific journals
      - 'Peer reviewed' scientific journals
- Experience and epistemic trust grounding 'well-informed citizen' identities

Research Themes and Codes List

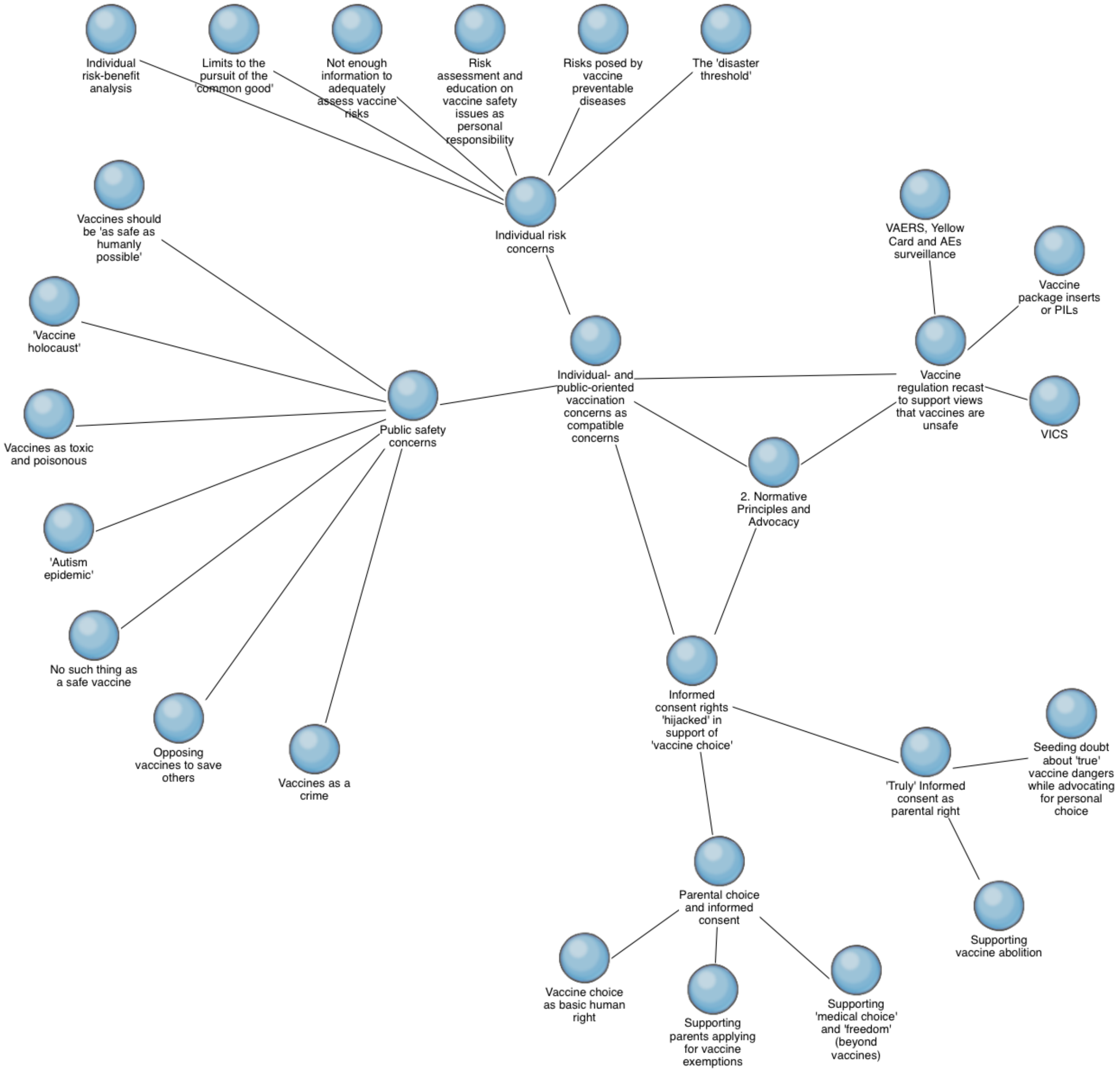
- (Rare) acknowlegments of the complexity of vaccine-related decisions
- Ambivalent relationship with healthcare professionals (HPs)
  - 'Good' doctors and helpful HPs
  - HPs are incompetent, or have less knowledge than vaccine counterpublics
  - HPs do not prioritise patients' best interests
  - HPs have also been vaccine injured
  - HPs pushing parents to accept vaccines or other medical treatments for their children
  - Vaccine-critical HPs
- Developing and displaying self-trust
  - Claims of trustworthiness
  - Experiential knowledge dismissed or valued outside a vaccination context
  - Explaining others' rejection of vaccine-critical ideas
  - Expressing encouragement and support
- Sharing experiential knowledge
  - Compatibility of experiential knowledge and scientific research
  - Experiential knowledge at the basis of vaccine-critical views
  - Experiential knowledge being dismissed by experts
  - Not acknowledging or rejecting others' (non-vaccine critical) experiential knowledge

APPENDIX D

Conceptual Map I: Causal Knowledge



Conceptual Map II: Normative beliefs and Advocacy



Conceptual Map III: Collective Identities