5

MMR

As the pertussis crisis faded into memory, it appeared that Britain had once again bought into the vaccine narrative. Immunisation rates increased over the 1980s, and new vaccines offered the British public even greater protection from infectious disease. Parents were well aware of the vaccines on offer, and broadly considered these to be safe and effective.[1] The iconic new public health threat, HIV, did not yet have a vaccine; but there was great optimism that one would eventually be found.[2] Then, in the late 1990s, another crisis threatened to dent confidence yet again. This time, the culprit was another trivalent vaccine – MMR. In 1998, Andrew Wakefield and colleagues published a paper in the medical journal *The Lancet* which alleged a possible link between MMR and a rare form of autism. While the journal itself took the unusual step of printing a repudiation alongside the paper, Wakefield used the press conference to launch the edition to claim that MMR was dangerous and parents should immediately seek separate measles, mumps and rubella vaccines until further safety testing had been completed. Medical consensus was always against Wakefield and his small group of allies – but the controversy made for a great media story. Over the following years, uptake of MMR dropped. Multiple studies showed that there was no evidence for a link between MMR and autism, and in 2004 ethical violations and poor research practices were exposed in Wakefield's work. After that point, vaccination rates recovered once more. But the crisis has become infamous as an example of how public health authorities can struggle in the modern, digital world to overcome misinformation.

MMR led to a reappraisal of public health researchers' and practitioners' approaches to parents who refused vaccination for their

children. It had been traditional to reassert the facts, relying on scientific authority and health statistics to prove the worth of vaccination and the errors of its opponents. This approach did not die in the early years of the twenty-first century, but there was a more concerted effort to borrow from the research of those engaging with sociological conceptions of risk and health. Just as new technologies, such as the internet and twenty-four-hour news networks, changed the way that members of the public received, consumed and interpreted information about health risks, the authorities began to make use of those same media to communicate with the public in different ways. By the 2010s, the memory of the MMR crisis and similar concerns about the progress of vaccination schemes in other countries led researchers not just to focus on parents who refused vaccines, but to begin to investigate the various trends in society that affected decision making, either pro- or anti-vaccine.

This chapter is about the concept of hesitancy within the MMR crisis. The concept of hesitancy used by the WHO in the 2010s argues that parents' choices are affected by confidence, convenience and complacency.[3] As the British experience shows, confidence was rocked by reports that MMR might have caused autism in some children. Yet major reforms in public health over the 1980s and early 1990s meant that vaccination was more convenient than ever for both parents and administrators. Similarly, while there had been some complacency about whether measles, mumps or rubella were serious diseases, the immunisation rates against all three dropped nowhere near as significantly as pertussis had done in the 1970s.[4] Instead, British parents appeared to be unsure about what to do for their children at the turn of the millennium. Despite the popular conception of British parents during the MMR crisis, they were not, for the most part, anti-vaccine.[5] Average uptake of MMR in England fell from 91.8 per cent in 1996 to 79.9 per cent in 2004; but it dropped below 80 per cent in only three English regions, and rates remained robust elsewhere in the United Kingdom (Figure 5.1).[6] There was instead a public debate about whether MMR was specifically the right vaccine to be giving to children. Potential alternatives such as separate measles, mumps and rubella vaccines offered compromise solutions that were shut down by the government, leading to disquiet. To follow the WHO model, parents were hesitant primarily because confidence in MMR had been substantially

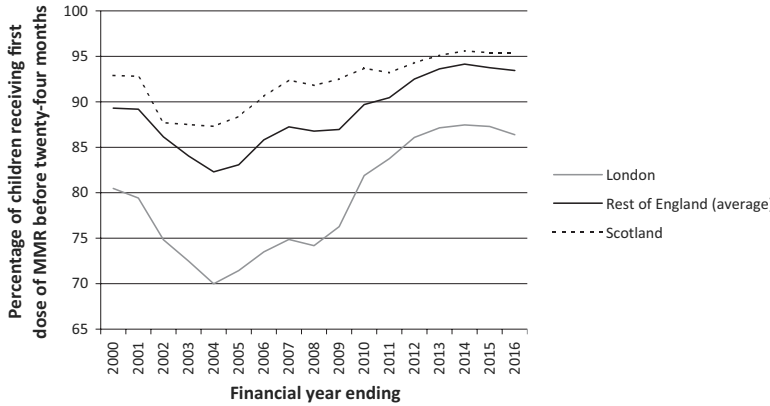

Figure 5.1 Percentage of children receiving first dose of MMR before 24 months in London, rest of England and Scotland, 1999–2000, 2015–16. *Source*: England 1999–2000 to 2004–5: Health and Social Care Information Centre, 'NHS Immunisation Statistics: England, 2004–05' http://content.digital.nhs.uk/catalogue/PUB00176 (accessed 23 August 2017); England 2006–16: NHS Digital, 'NHS Immunisation Statistics: England, 2015–16' (London, September 2016). Scotland: Information Services Division Scotland, 'Trends in immunisation uptake by quarter, calendar and financial year – Scotland' (Edinburgh, June 2016).

weakened. This chapter examines why that was the case by looking at the crisis in the wider historical context of the events discussed elsewhere in this book. British public health authorities had engendered broad support for vaccination, overcoming apathy, protecting the nation from outside threats, sating demand for protection from infectious disease and managing the risks to individuals and the nation as a whole. The MMR crisis was significant not because of how widely confidence was dented, but in the depth of the damage done to those who were unsure of the best way to protect their children.

First, this chapter explains how MMR came to be used in Britain. The trivalent vaccine was part of a number of reforms to health care in Britain in the late 1980s. The DHSS was split into two separate departments, and greater emphasis was placed on preventative health. Better monitoring systems, WHO targets and remuneration for general

practitioners meant that vaccination rates improved significantly over this period, giving a greater degree of protection than hitherto enjoyed by the British population. Parents were placed under more extensive surveillance by local health authorities, allowing better follow-up, more convenient appointments and more successful vaccinations. Yet the nature of those reforms stored up potential political dilemmas that came to the fore during the MMR crisis. The chapter then goes on to describe the chronology of the crisis and explain the role of the major players. Focusing primarily on the years 1998 to 2004, it shows how and why the case against MMR was made by its opponents. This leads to a discussion of the main issues of the crisis and just how the MMR–autism link took hold. In short, it was believable. Faith in medical and political authorities in Britain had been rocked by a succession of crises, most notable the bovine spongiform encephalopathy (BSE) and variant Creutzfeldt-Jackob (vCJD) scare and subsequent investigation into what the government knew before the people. There was little concrete research into autism's causes and aetiology, and doubts about vaccine safety had been raised in other parts of the world. The government responded through traditional educational campaigns, but these did little to persuade parents. The chapter details how the government launched new websites to speak to the public through "risk communication". By outlining various choices and the potential impacts of those decisions, the government hoped that it could restore confidence. Finally, the chapter shows how public health researchers have used the memory of MMR as part of their analyses of how members of the public make decisions about vaccination. Rather than focusing solely on events where parents show hesitancy, there has been more focus on both a lack of and an adequate supply of confidence. It is just as instructive to ask why, as a nation, we usually *do* vaccinate our children as why we might not.

Vaccination policy in the 1980s

The late 1980s saw a shift in emphasis in vaccination policy, reflecting other trends in health care and public health.[7] The problems of low pertussis vaccine uptake faded over the course of the Thatcher administration.[8] As the decade wore on, the Conservative government looked to preventative health care as a way of managing the demands on the

health services, the financial costs of health care and lost productivity and to emphasise moral values surrounding personal and parental responsibility. For public health, the 1987 White Paper *Promoting Better Health* included government plans for how this might be achieved UK-wide, bolstered by the publication of the Acheson Report on the state of English public health a year later.[9] Personal responsibility and vaccination featured prominently in the White Paper. Among a list of key statistics to show the extent to which public health interventions might reduce the burden on other health services, it noted that there were 90,000 measles cases in 1986 and over 1,000 hospital admissions. Parents who did not present their children for measles vaccination were placed implicitly in the same category as people making poor dietary choices ('obesity: a quarter of young people are overweight'), smokers ('100,000 deaths a year … 50 million working days lost … £400 million in [NHS] treatment costs') and drug users ('the number of addicts newly notified in 1986 exceeded 5,000').[10] But while this responsibility rhetoric was a key part of managing the risk of measles and its attendant economic impacts, the report also recognised the government's obligation to make services available for individuals and to promote them properly so that people were able to make the "right choices". Vaccination was therefore also in the same category as cancer screening – citizens were expected to present themselves for medical surveillance so that symptoms could be caught early and treatment outcomes would be both more successful and cheaper in the long run.[11] These problems could be overcome by reforming primary care:

> The Government intends positively to encourage family doctors and primary health care teams to increase their contribution to the promotion of good health. These professional workers as well as dentists and pharmacists are in daily contact with large numbers of the public and represent the front line of health care; they are therefore very well placed to persuade individuals of the importance of protecting their health; of the simple steps needed to do so; and of accepting that prevention is indeed better than cure.[12]

In promoting health, the UK was not acting alone. Increased monitoring of health statistics from the 1970s, including the rise of health economics and related disciplines, had led to a greater understanding of Britain's place relative to other nations. Global public health was

firmly on the political agenda, as reflected in the Alma Ata conference and subsequent regional and worldwide programmes run by the WHO to achieve 'Health For All' by the year 2000.[13] International comparisons were nothing new. The British government had gathered information on the use of smallpox vaccine in other countries when deliberating over whether to cease routine vaccination. Similarly, the entry into the European Economic Community in the 1970s had led to the use of regular comparisons with other member states when considering policy on vaccination, vaccine compensation and other areas of DHSS activity. WHO goals and targets did, however, place a new political imperative to improve certain metrics and increased the overlaps between public health and foreign policy.[14]

The WHO's goal of 90 per cent immunisation in Europe against common childhood diseases was considered to be a challenge, but not an impossible one for the British programme.[15] Many Area Health Authorities had already achieved this by the late 1980s. Yet the national average still lagged some way behind, and rates varied between vaccine types.[16] To incentivise higher uptake, the Department of Health announced that it would begin to pay general practitioners a bonus if they achieved high vaccination rates in their area. This performance-related pay was part of a number of changes designed to shift the focus of general practice towards preventative medicine and to make primary health care run more efficiently, while also reflecting the increased marketisation within the NHS.[17] The new general practitioner contract faced significant opposition from the BMA, but Health Secretary Kenneth Clarke forced it through in 1990.[18] This was linked to the economic and social imperatives of what might broadly be called the New Right or Thatcherism during the 1980s and early 1990s.[19] Managerialism and the internal market in the NHS were designed to deliver efficiency savings and improve quality and choice.[20] Similarly, individuals partaking in healthy and responsible behaviours would decrease the demand on the system, aided by properly incentivised primary health care professionals to make those "correct" decisions. Vaccination was an ideal public health measure in this context. As Jennifer Stanton has argued, vaccines themselves are 'high-demand, low-cost' technologies, especially for common childhood diseases such as poliomyelitis or whooping cough.[21] During the late twentieth century they were also technologies that could be developed by private pharmaceutical

companies with public sector support, creating both supply from profit-making bodies and demand from public health programmes looking to reduce the financial burden of infectious disease.[22] But there were limits to what health departments would fund, based on the perceived gains relative to cost. Stanton shows that in the case of hepatitis B – a relatively rare disease associated with stigmatised groups and behaviours such as homosexual men and intravenous drug-taking communities – the government was not willing to fund and implement a routine childhood vaccination programme in the 1980s.[23]

Structural reforms to the general practitioner contract could go only so far. The other major innovation of the 1980s was the introduction of MMR. Measles vaccination had remained low in comparison to other countries, including some in the developing world. WHO targets, combined with a sense of embarrassment, led to a change of approach.[24] As with multivalent vaccines in previous decades – like DTwP – the hope was that the vaccine would be easier to administer for health authorities and more acceptable to parents because it reduced the number of injections their children had to endure and the number of trips needed to be made to the clinic.[25] Experiences in other countries appeared to bear this out. Indeed, in the trials in the United Kingdom, uptake had been much better than for the single measles vaccine even though participants had been inconvenienced by asking them to fill out a diary of any possible side-effects for three weeks afterwards.[26] The vaccine was given in two doses, one before the second birthday and the second before the child started school. Since around 90 per cent of MMR vaccinations confer immunity, two doses gave a 99 per cent chance of success.[27]

Authorities had reasons to be concerned by all three diseases. Measles was explicitly cited in *Promoting Better Health* because of its high morbidity and the number of hospital visits it necessitated. A vaccine had been recommended in Britain since 1968.[28] However, uptake had remained stubbornly low; and while the number of cases had dropped from 236,000 in 1968 to 86,000 in 1988, the Department of Health wished to go further. This was problematic, as measles is an unusually infectious disease. Herd immunity requires a vaccination rate upwards of 95 per cent. The disease itself can be relatively mild, resulting in a rash and a fever. In some cases symptoms can be much more severe, leading to swelling of the inner ear (1 in 11–14 cases) convulsions (1 in 200) and even death (1 in 5,000).[29] Because there were so

many cases of measles per year, even this small percentage led to a high number of complications. As discussed in the previous chapter, rubella vaccine was used to prevent CRS. Although CRS rates had declined, it remained a concern for the Department of Health, which hoped that MMR would increase the vaccination rate in females as well as interrupting disease transmission by creating a cohort of immune males.[30] Like measles, CRS was part of the WHO's immunisation targets.[31]

The final component, mumps, was not a specific WHO target but was still thought to be serious enough to be included in the overall programme.[32] Mumps could also be a mild disease – many who contract it do not realise they have done so – but when it presents it commonly results in hospitalisation, accompanied by painful swelling of the glands and, in boys, the potential for infertility. Deafness is another possible side-effect.[33] Uptake of mumps vaccine before MMR was poor, compounded by the perception that mumps was a boys' disease.[34] The trivalent vaccine was therefore not simply about reducing the number of visits and injections needed to make vaccination more convenient for parents. It was designed to increase the immunisation rates against the three diseases by protecting boys against rubella, girls against mumps and everyone against measles, despite the fact that parents might have previously expressed less enthusiasm for one vaccine over another.[35]

One final element of the changes during the Thatcher and Major governments concerns the measurement of vaccination levels. In order to remunerate general practitioners properly, authorities needed reliable and comparable measures of uptake. Moreover, the Department of Health had tried to learn lessons from the pertussis crisis. In 1987, Public Health Laboratory Services established Cover of Vaccination Evaluated Rapidly (COVER) to produce nation-wide statistics on a quarterly basis.[36] This replaced other forms of local reporting of vaccination numbers which had evolved since before the 1940s (see Part I). COVER was supplemented in 1991 by the creation of six-monthly surveys of parental knowledge and attitudes towards vaccination.[37] These tools were designed to be able to monitor if vaccination rates were dropping and/or if parents were expressing doubts about a particular vaccine at any given time. With the pertussis crisis, one of the major issues that the vaccine's opponents had been able to draw upon was the relative scarcity of hard evidence that there was no link between brain damage and the vaccine at the population level.[38] Therefore, research

had also begun on new, active monitoring systems for adverse events. The existing passive reporting system required general practitioners to submit information on possible reactions to vaccines on "yellow cards" to the health authorities. These could be unreliable, and tended towards under-reporting of incidents and damage to the credibility of drug safety administration.[39] Increasing computerisation during the 1980s and 1990s offered the possibility of monitoring indicators such as hospital admissions for certain conditions in children of specific ages and mapping these onto vaccination coverage in a particular area.[40]

Despite these top-down reforms in the late 1980s and early 1990s, the government did not simply impose vaccination on the population from above. As in the 1970s, it was clear that the vaccine narrative was broadly accepted and uptake was relatively high as compared to previous decades, albeit with the same problems of local variation as before. Vaccination had proved its worth. It had eradicated smallpox worldwide, and once-common childhood diseases had been virtually eliminated in high-income countries. All of these issues reflected the topics covered in previous chapters of this book. If apathy was a product of low engagement, the inconvenience for parents and lack of access to vaccines, then incentive payments and combination vaccines were designed to prompt local doctors to solve these issues.[41] The protection of the nation was to come not simply through vaccinating the population, but from regional cooperation with other European countries through the WHO.[42] The popularity of the MMR vaccine in the trial areas appeared to show demand for this new technology from some constituencies – in any event, increased surveillance and monitoring of parents would ensure compliance. All of this, however, was refracted through the lens of risk: the risk to the state of the costs and burdens of infectious disease, and the outlining of personal responsibility for ensuring that risky behaviours did not put the nation's health or finances at risk. Official and public confidence in the vaccine rested on whether it would be convenient for parents, protect children from disease and be more cost-effective than the public health measures that had preceded it.

The MMR crisis

These developments improved vaccination rates. It was now easier for local authorities to monitor and follow up on parents of unvaccinated

children, and doctors had a direct financial incentive to do so. The single vaccine, given in two doses, was also much more convenient. However, this system still required parents to choose to vaccinate. This caused problems during the MMR crisis itself. For while there was little counter information or other options available to parents, there was only one obvious choice. When the MMR–autism link became more widely talked about and an alternative action was considered possible – separate vaccinations – choice became a major issue. The rise of the rhetoric around choice and growing health consumerism meant that citizens were more likely to seek out and demand alternative forms of care.[43] This was compounded by the fact that the political context of the late 1990s and early 2000s made the claims of anti-government voices sound credible. It was because of this that confidence could be damaged and parents could become more hesitant.

For public health professionals and researchers, the MMR crisis refers to the period in which significant doubt was expressed over MMR's safety, leading to a drop in immunisation rates. While this decline was not as striking as it had been over the pertussis scandal in the 1970s, the level of coverage devoted to MMR in popular media, coupled with the circulation of vaccine-sceptic information through growing internet usage meant that convincing the public of the vaccine's safety was a much more difficult task. Most accounts of the crisis place its beginnings in the *Lancet* paper published by Wakefield and colleagues in 1998. This acts as a useful starting point for tracing the public debate about MMR, particularly in the popular and medical press. The most intense period of press activity began around 2001 (Figure 5.2).[44] By late 2004, the main crisis was over. Brian Deer's exposés were published in this year, and ten of the twelve co-authors of the Wakefield *Lancet* paper retracted their conclusions.[45] However, as with all historical periodisations, we should be aware that concerns with MMR permeate these clean boundaries. Immunisation rates had been falling for a couple of years before 1998, and Wakefield's research (as detailed below) exposed a number of concerns in a minority of parents, rather than simply appearing *ex nihilo*. Similarly, quoting an end date for the crisis is complicated by the fact that many of the debates of that time continued to be felt among some communities in the United Kingdom and elsewhere in the world.[46]

It is therefore worth briefly exploring this timeline. Wakefield was the key figure for MMR sceptics. A clinical researcher working at the

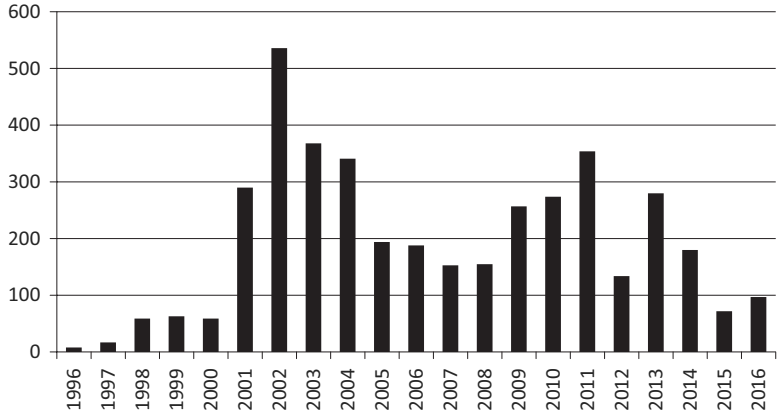

Figure 5.2 Mentions of MMR in major daily newspapers, 1996–2016. *Source*: Search for string 'MMR' in ProQuest European Newsstream on selected newspapers. Newspapers chosen were major dailies in the database with full text searchable from 1 January 1996 onwards: *The Times*, *Daily Mirror*, *Independent*, *Guardian* and *Sun* (accessed via Senate House Library, University of London, 28 June 2017).

Royal Free Hospital, University College London, he and his team had studied a particular form of autism which was associated with problems in the gut. The 1998 paper described this syndrome in twelve children, but also claimed a temporal link with the onset of their symptoms and MMR. While the article itself made it clear that the authors 'did not prove an association between measles, mumps, and rubella vaccine and the syndrome described', Wakefield himself was far less reserved.[47] At a press conference organised by *The Lancet* at the Royal Free Hospital to explain the paper and its wider context, Wakefield declared MMR to be dangerous and asserted that it would be safer to give separate vaccines until more was known about its effects. The media covered this as a potential medical scandal, but there were clear reservations.[48] The authors had failed to prove an association, as the critical commentary printed alongside the paper in *The Lancet* had argued.[49] And while the volume of newspaper stories on MMR for 1998 compared to subsequent years would suggest that the *Lancet* article was not hugely

significant in itself (Figure 5.2), it provided the basis for debate in the medical and popular press. The tabloid press was more sensationalist than the broadsheets, as might be expected. In particular, the *Sun*, *Daily Mail* and *Daily Express* gave the matter significant coverage – in the case of the latter two even after most had accepted that the MMR–autism link was unfounded.[50]

While co-authors John Walker-Smith and Simon Murch both continued to claim that MMR was still safe and recommended parents to vaccinate their children, Wakefield was more strident in his opposition.[51] In December 2000 he and Scott Montgomery published a critique of the testing procedures for the vaccine during its initial licensing stage.[52] The national media gave this new paper a new round of attention. To assuage doubts and combat declining vaccination rates, the Department of Health began a publicity campaign for MMR in January 2001.[53] In the meantime, epidemiological and public health studies continued to find no evidence of a link between MMR and autism.[54] It was in early 2002 that the crisis reached its peak, however. Over Christmas 2001 and the New Year, Prime Minister Tony Blair refused to answer questions from Members of Parliament or journalists about whether his young son Leo had received the vaccine.[55] The BBC's *Panorama* documentary series publicised the work of MMR-sceptic John O'Leary on 3 February 2002.[56] While it too did not prove an autism link, the media seized upon the story. Vaccination rates continued to drop, and measles cases were on the rise, including an outbreak in London.[57] The drip of newspaper articles questioning MMR became a flood, with the bulk of the torrent coming in February 2002. The government was again forced into a defensive campaign to restore faith in MMR.[58]

While the crisis rumbled on over 2003, newspaper mentions of MMR declined. Parents of autistic children had begun legal proceedings against the Department of Health, claiming that MMR had caused their children's conditions. Initially it had secured legal aid, but in September 2003 the Legal Services Commission withdrew its support. The weight of evidence suggested very little chance of success.[59] For the most part, the mainstream debate ended in 2004 following the work of investigative reporter Brian Deer. He had returned to the original 1998 *Lancet* paper to reassess Wakefield and colleagues' claims about the twelve children. He uncovered a number of issues which called into

question the integrity of the researchers and the scientific validity of their findings. The claims included: that ethics approval had not been given for some procedures (such as lumbar punctures and colonoscopies); that ethics approval had been sought for a different project to the one eventually carried out; that there was bias in the selection of cases for the study (including accusation that Wakefield had paid children for blood samples at a birthday party); that legal aid funding had been used for supposedly independent research; and that findings were used for legal cases prior to peer review and publication.[60] When these claims were aired in a Channel 4 *Dispatches* documentary and printed as a series of exposés in the *Sunday Times*, Wakefield's credibility was destroyed. Ten of the paper's twelve co-authors retracted their conclusions, stating:

> We wish to make it clear that in this paper no causal link was established between MMR vaccine and autism as the data were insufficient. However, the possibility of such a link was raised and consequent events have had major implications for public health. In view of this, we consider now is the appropriate time that we should together formally retract the interpretation placed upon these findings in the paper, according to precedent.[61]

Declining confidence

It is overly simplistic to attribute the MMR crisis solely to the *Lancet* paper. However, the debate it sparked raised a number of issues about the vaccine and vaccination that were difficult for the government to counter effectively. It was the interplay between these that chipped away at the public's confidence. It is worth highlighting five of these issues. First, autism rates had been increasing for some years with no definitive explanation. Second, Japan had banned MMR on safety grounds, leading to questions about the reliability of the UK's safety testing procedures. Third, the quality of the government's medical advice and the role of the medical profession were complicated further by other scandals reported at the same time as MMR, such as "mad cow disease" (BSE). Fourth, the changes to the general practitioner contract led to a debate over whether doctors were recommending MMR for the money or because they genuinely believed that it was in their patients' best interests. Fifth, and finally, the apparent compromise position of

administering separate measles, mumps and rubella vaccinations was attractive to parents but was denied out of hand by the government. These interrelated debates meant that the British public had every reason to be sceptical about MMR.

The first major issue, and the one with the longest life beyond the crisis, was the alleged link between MMR and autism. Autism, like brain damage in the pertussis crisis, was seen as the main potential hazard of MMR. Wakefield's work centred on establishing a connection between the two, while the majority of scientific evidence presented in favour of MMR mobilised to show that there was no provable statistical correlation.[62] One of the reasons why this debate was so potent was because so little was known about autism around the turn of the millennium. Even if there was no evidence of a link between MMR and the syndrome, there were also no clear answers about what did cause it. It was common knowledge that autism diagnoses had increased significantly over the previous twenty years. For concerned members of the public, any explanation was worth exploring. The *Daily Mail* was particularly interested in these questions.[63] 'It would be a gross insult to the intelligence of … parents', wrote David Goldberg, a doctor and the father of an autistic son, 'if their collective view was explained as an emotional response to media hyperbole.'[64] Parents of autistic children were a key part of Wakefield's campaign against the vaccine, just as parents of children damaged by the pertussis vaccine had been key to the 1970s campaign. The mother of an autistic child, Jackie Fletcher, had founded the group Justice Awareness and Basic Support (JABS) in the mid-1990s.[65] Fletcher eventually won vaccine damage payments for her son, albeit for severe epilepsy rather than autism.[66] The 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).[67] It and the Society for the Autistically Handicapped were involved in litigation against the Department of Health, and successfully secured legal aid to help them with the case.[68] For parents weighing up the risks of vaccination, the publicity given to the possibility of autism had an impact on their decision.

Although the weight of scientific evidence of MMR's safety eventually resulted in the withdrawal of legal aid funding in 2003, the existence of the case contributed to the debate's credibility.[69] Other evidence

further complicated this picture. Concerns had been raised about MMR's safety before. In Japan, MMR was withdrawn completely because the mumps component produced a higher-than-acceptable risk of meningitis. Britain responded to concerns about the Urabe strain of mumps vaccine by replacing it entirely with the more expensive but safer Jeryll-Lynn strain. Most other nations did likewise. In Japan, however, legislation meant that its public health system could use only Japanese-made vaccine. The vaccine had been withdrawn not because it was dangerous per se, but because no Japanese manufacturer was yet able to produce it.[70] To supporters of vaccination, this proved how robust testing systems were. It had caught a potential problem early, and the increased rate of measles in Japan following the withdrawal showed that the vaccine was effective.[71] To critics, it showed that even in a modern advanced nation potentially dangerous medications could slip through the cracks. Wakefield was keen to emphasise this point.[72] Again, however, medical consensus supported the testing procedure. *Adverse Drug Reactions and Toxicological Reviews* took the unusual step of publishing Wakefield and Montgomery's article alongside the peer review reports, emphasising the journal's support for freedom of scientific expression, but also its reservations about the legitimacy of Wakefield and Montgomery's conclusions.[73] Still, given the lack of information on autism and the Japanese withdrawal of the vaccine, the possibility of MMR being dangerous remained plausible. The British government said that it wanted to protect the nation from infectious disease – but was it capable of doing so?

For the public this was not the first time in recent memory that medical professionals had been wrong, had withheld information or had actively attempted to deceive. Just as the pertussis crisis occurred in the shadow of thalidomide, the BSE and vCJD scandal loomed heavily over discussions of MMR. As Tammy Speers and Justin Lewis have argued, it also served as a narrative framing for press coverage and public understanding of the crisis.[74] Even in the medical press, it was acknowledged that the fall-out of the BSE crisis meant that medical experts could not be seen to dismiss criticism of MMR out of hand.[75] Nevertheless, this was not the only example of government and medical establishment incompetence. In a 2003 study of the role of the media in attitudes towards science, 24 per cent said that their 'trust in science' had decreased as a result of BSE, the most-quoted single reason.[76] As

the autism lawsuit was building up, the victims of contaminated blood transfusions won their case against the Department of Health, using legal aid.[77] The reports of the inquiries into the Bristol heart scandal (in which a number of children had died unnecessarily due to a poorly staffed hospital department) and the Alder Hey scandal (where dead children's organs had been retained without parental consent) were also published at this time.[78] Trust was dented both in whether doctors could be believed in and whether, even if they were not trying to deceive, they were capable of finding the truth. In an article in the *British Medical Journal* radio journalist Sharon Alcock described a programme she had made with the Warburton family in 2002. The Warburtons were chosen as a "typical" family who were unsure about whether or not to vaccinate their children. The parents debated the issues surrounding MMR throughout the week with selected "experts", before declaring their decision on the Friday. The BSE issue had left the family feeling especially sceptical.[79]

While there were clearly reasons to distrust the official government line, confidence in general practitioners had also been shaken. It was well established that patients and parents were more predisposed to trust medical advice from general practitioners than from government advertising or other sources of information.[80] As we saw with the campaigns of the 1940s and 1950s, the government had long emphasised the role of face-to-face contact with medical professionals in convincing parents to have their children vaccinated. Changes to the NHS contract, however, meant that GPs now had a direct financial incentive to convince parents to accept MMR. The Warburtons found the relationship between GPs, money and the government problematic. 'They couldn't really decide where to draw the lines between government and medical professionals' advice,' wrote Alcock. 'They wanted to trust their doctor and health visitor, but felt they were being spun a political line.' The government had made vaccination policy decisions based on cost-benefit analyses before, notably over hepatitis B.[81] One correspondent to the *British Medical Journal* argued that there was an inherent conflict between offering the patient choice and following government evidence and guidelines.[82] Doctors insisted that they supported MMR regardless, and that the financial payments were simply to formalise actions that ought to be taken anyway.[83] Such was the strength of feeling on this point that the BMA recommended that performance-related

pay on vaccination should be abandoned.[84] By the time the new general practitioner contract was rolled out in 2004, other priorities had arisen and worries over MMR had faded.[85] The concern was not that doctors would favour cash over patient safety; indeed, since vaccination was an epidemiologically proven preventative health measure, it was clearly in both the doctor's and child's best interests. Rather, it was that physicians *could be perceived to be* compromised in their decision making. Certain sections of the public health profession, therefore, understood that building trust was also an exercise in presentation as well as hard numbers.

When taken together, there were clear reasons for parents to be cautious about MMR. For those worried both about the vaccine and about infectious disease, however, Wakefield had offered a solution. At the press conference to announce the 1998 *Lancet* paper, he had urged parents to seek out separate measles, mumps and rubella vaccines so as to reduce the risks to the child. As with the pertussis crisis and compensation, this appeared to be a compromise position between two entrenched viewpoints. It was known from a study in the United States that parents were more willing to take risks with errors of omission (i.e. the risks associated with not vaccinating) than with errors of commission (i.e. the risk that something could go wrong with their active decision to vaccinate).[86] Helen Bedford, a researcher into child health, lamented that 'natural infection is somehow thought of as being out of our control, but immunisation is something that parents have to decide to take up, so they feel more responsible'. One of the more-strident critics of Wakefield, a London GP and the father of an autistic son, Michael Fitzpatrick, also placed this debate in political context. The New Labour government had championed choice in public services, including health care.[87] While this was designed to begin to equalise the doctor–patient relationship, improve satisfaction and improve outcomes, vaccination was, paradoxically, an area in which the government offered very little choice.[88] It could not countenance separate vaccines. No individual immunisations were licensed for use in the United Kingdom – and, as the government repeatedly stated, no country which used MMR offered separate vaccines.[89] There was no evidence that the individual immunisations were safer. Indeed, pre-MMR experience in Britain suggested the opposite. Since child vaccination rates against the three diseases were lower before the trivalent vaccine became available,

separate vaccines (on the population level at least) placed the public at greater risk of infection.[90]

Again, while this was epidemiologically justifiable, it appeared to some to be too draconian. Private clinics began to offer separate vaccinations to concerned parents, drawing the ire of the Department of Health.[91] Separate vaccines were strictly forbidden on the NHS, and individual doses were technically not licensed for use in the United Kingdom. General practitioner Peter Mansfield offered this service to his patients through his private practice, leading the Director of Public Health in Worcestershire to refer him to the General Medical Council.[92] The case was eventually dropped, but the apparent lack of flexibility on the part of the government made some parents suspicious. The *Daily Mail*, a notable critic of the government throughout the crisis, published a series of letters about the decision. One nurse 'fully support[ed]' the 'right to choose' of the parents of her grandchildren. Another questioned whether this was a matter for the General Medical Council, which was surely 'supposed to be saving us from the Dr Shipmans[93] of this world not stopping us having the treatment that's right for us'. Many emphasised the choice element, concluding that it was better for children to get some protection through unconventional practice than receive no vaccination at all.[94] Back at Alcock's radio programme, the Warburtons were especially puzzled on this point. Having spoken to the "experts" in the BBC programme – including Wakefield and Mansfield – they opted for the separate vaccines. The head of the Public Health Laboratory Service, Elizabeth Miller, and Scope (previously called the Spastics Society) had convinced them that measles, mumps and rubella were dangerous and that vaccination would protect their child. But they still questioned whether MMR was the right solution. They told the BBC that their decision to vaccinate would have been much easier if separate injections were available on the NHS.[95]

Risk communication

As vaccination rates continued to decline and press interest remained, the government made attempts to re-establish confidence in MMR. The scientific position was much clearer than it had been with the pertussis crisis, and so the Department was quicker to begin a new publicity campaign. While some funds were directed into increased research

in autism to build a body of evidence for other causes for the syndrome, £3 million was set aside in 2001 to educate parents.[96] At the launch, Chief Medical Officer Liam Donaldson declared that 'on each occasion that these scares have been raised they have been thoroughly examined and on each occasion MMR has been given a clean bill of health.'[97] Yet it appeared to have little impact. The government was forced to re-launch the campaign in 2002 in the wake of yet more negative publicity, mostly stemming from the BBC *Panorama* documentary and Tony Blair's refusal to confirm his son Leo's vaccination status.[98] This was mainly an attempt to draw media attention to the campaign rather than a major change in tack, although it is clear that risk communication took a more central role from this point forward. Authorities had been accused of taking a 'patronising, high-handed and arrogant' approach to parents.[99] The medical press also criticised public health authorities' responses.[100] While organisations from the BMA to the Scottish Government produced guidance and reports on MMR and its safety, nothing appeared to be working.[101] The approach of giving information and answering questions was not enough on its own, as Richard Horton, editor of *The Lancet* later noted:

> Wider public trust is best fostered neither by referring to abstract evidence alone nor by official pronouncements of reassurance, but by explaining face-to-face in transparent, human, even anecdotal terms with personal stories, why a particular course of action is being advocated.
>
> Persuading the public to support vaccination is not only a matter of winning an argument. It is also about understanding the reasons why parents are and are not inclined to take their children for immunisation. The complexity of this decision demands a more nuanced response from the public-health community than it has so far received.[102]

In searching for alternative approaches, social science work on decision making and risk began to gain traction with public health professionals. This built on the growing professionalisation of health education, beginning in the 1980s.[103] The Medical Research and Economic and Social Research Councils funded a study into how the recent body of scholarly work on risk could help in public health. As the lead researchers noted, the education and persuasion approach:

> assumes that the target audience is made up of individuals who rationally review evidence to identify and choose the best course of action – that

> is, the one that will maximise health benefit. There is little evidence that these approaches have made a major impact, despite the investment in health promotion and public health targeted in particular 'at risk' groups.[104]

The authors identified five aspects that affected how publics receive public health messages. First, the extent to which the source of the information is trusted; second, 'the relevance of the information to everyday life'; third, 'the relation to other perceived risks'; fourth, 'the fit with previous knowledge and experience'; and fifth 'the difficulty and importance of the choices and decisions'. The authors were critical of medical authorities that had appeared slow to incorporate this approach into their attempts to change population behaviours.[105] In some ways this was justified. The government publicity campaign had been a traditional advertising affair, with regular pronouncements about the safety of the vaccine, backed by epidemiological studies. As the Alcock documentary demonstrated, however, there was a perception that "the Lady doth protest too much":

> Halfway through their journey, Darren and Carol [Warburton] said that the more insistent the government became, the more they distrusted its advice. So when Professor Liam Donaldson called a press conference to endorse MMR, flanked by the great and the good of the medical world, it was the last straw. If more measles outbreaks are to be avoided, parents have to feel as though the medical profession isn't pulling rank and dismissing their concerns.[106]

The Department of Health was acutely aware of criticisms. At the time of the 2002 relaunch, a spokesman explained that research had shown how anxious parents were, and so the government had continued to focus on facts and 'the message' of 'individual choice'.[107] But it could do more to communicate risk in the way advocated by contemporary researchers.

One way of doing this in a less 'highhanded' way was to make use of growing access to the internet. According to World Bank statistics, web usage among Britons increased dramatically in the early years of the twenty-first century. The United Kingdom had a number of internet users broadly comparable to the Organisation for Economic Co-operation and Development average, but significantly behind the United States, in the late 1990s. In 2001, 33.4 per cent of the UK

population was online, compared to 49.1 for the United States. By 2003, Britain had overtaken the United States.[108] Public health professionals noted how the internet had changed their interactions with certain sections of the public. Patients appeared to be armed with more knowledge – albeit the quality and relevance of this knowledge was contested – and the volume of vaccine-sceptic data available to parents raised questions that professionals found it difficult to answer without preparation.[109] Parents have always sought and received information from sources other than the government and medical professionals. Folk knowledge, self-care guides and informal networks had existed for centuries, and continued to do so even as the power of biomedicine increased.[110] What was different was the amount of information and the speed at which it could be delivered through this new communication network. Anti-MMR campaigners had used the internet to deliver previously obscure academic journal papers to journalists to help fuel the evidence for their cause and keep the debate in the popular press.[111] While we must be careful not to overstate the reach of the web – only 5 per cent of respondents in a 2003 study said that they got their science news mainly from the internet – this was undoubtedly a new issue for public health professionals to deal with.[112] It also offered a platform for solutions.

The government therefore sought to inform the public and communicate the risks and benefits of MMR through a new website called 'MMR The Facts'.[113] Hosted on the nhs.uk domain, it used an interactive map feature to show how MMR was used safely across the world. Britain's place as a modern nation in a global public health network was an important selling point. According to NHS information, only less-developed and obscure nations did not trust MMR. The map also provided ample statistics on MMR usage in different countries, and how many cases statistical modelling estimated could be prevented if non-adopting nations were to use the vaccine.[114] This type of risk communication extended to the 'myths and truths' section of the site, which used WHO data and published papers to dispel the 'Top 10 Myths about MMR'.[115] The main content of these static pages did not change over the course of the crisis. However, there was an element of interactivity in the 'Your questions answered' section. Site users could fill in a form, and a team of experts at the NHS would reply. The top questions were kept on the main 'questions' page. The Internet Archive has captured around forty of these questions, covering a wide range of topics from

specific enquiries about personal circumstances to broader requests for more data on vaccination and autism.[116] Although it was clearly curated and mediated through the form of the website, this did at least represent an attempt by central government to speak directly to parents on issues about vaccination in the same medium through which they consumed other information about health decisions.

However, it was not just parents who needed access to reliable information. Researchers had found that many health workers' knowledge about MMR was poor. For example, many did not understand the reasons for the second dose, believing it to be a booster to the first dose rather than an important element in ensuring herd immunity.[117] NHS staff themselves acknowledged that it was difficult when presented with vaccine-sceptic material for the first time to respond to parents in a meaningful and reassuring way.[118] And, as members of the public, medical professionals were affected by the scares too. Very few were experts in immunology, and clear information was difficult to obtain.[119] The government's main advice to practitioners, the 'Green Book' on immunisation, was a rather weighty document and could not be readily updated to reflect the ever-changing field of vaccination science and public debate. In Scotland, specific information was sent to general practitioners in 'discussion packs' so that they could speak to parents and 'explore related concerns together'.[120] In England, the Department of Health set up a sister site to 'MMR The Facts' to include up-to-date information on MMR and all the other childhood immunisations. The MMR section included a succinct explanation of why the government refuted the paper by Wakefield and colleagues, what extant literature there was on the link with autism and the statistical details on why the risks of not vaccinating far outweighed the risks of MMR. It then made the political case, refuting suggestions that it was simply looking to cut costs, "bully" parents or deny people choice. It concluded by setting out the moral case for the vaccine:

> There is no doubt that parents always face real dilemmas when it comes to protecting their children's health. All want to do what is right by their children. … However, it is the Government's responsibility to ensure that the care and treatment it makes available is the best possible. … All the experts advise that MMR is the safest and best option and that single vaccines are definitely second best. For this fundamental reason, the Government does not support the use of separate vaccines.[121]

Talking about risks was by no means new. In the 1940s the government's main defence of diphtheria immunisation was that children were twenty times more likely to die of diphtheria if they were not immunised.[122] But the focus on risk communication in this way was a product of its time. The growing popularity of risk as a category of sociological analysis was born out of and in turn influenced the rhetoric around health and society at the turn of the millennium.[123] The venue for the communication outlined here, the World Wide Web, was certainly new, reflecting the growing access to the technology and its increasing influence on parents' decision making. The major turning point in the MMR narrative, however, was the detective work and subsequent publications of Brian Deer, the freelance investigative journalist. He published damning reports on Wakefield and his work in the *Sunday Times*, *British Medical Journal* and Channel 4's *Dispatches* documentary series. After this point, the public debate on the MMR–autism link appeared to be relatively settled. While some publications, including the *Daily Mail* and the satirical/investigative magazine *Private Eye*, ran pieces questioning this new consensus, the number of references to the subject dropped significantly in both the medical and popular press (see Figure 5.2).[124] It was also after this point that MMR vaccination began to recover to pre-crisis levels.

Conclusion

While the MMR vaccination rate dropped across Britain until 2004, the Department of Health saw nothing like the extremes experienced with pertussis. There, rates fell from 79 per cent to 37 per cent in three years.[125] With MMR, uptake in England fell from 92 per cent in 1996 to 80 per cent in 2004. Based on the aetiology of measles and the expectations and successes of the WHO and Department of Health over the early 1990s, this was a public health problem; but in historical context, it was relatively mild. Figure 5.3 shows that measles notifications did indeed increase, but the aggregate number of cases remained moderate by 1980s standards. In Scotland, MMR uptake remained above 87 per cent throughout the crisis. Indeed, when London is factored out of the national figures for England, it is clear that regional variation remained part of the story of vaccination rates in British public

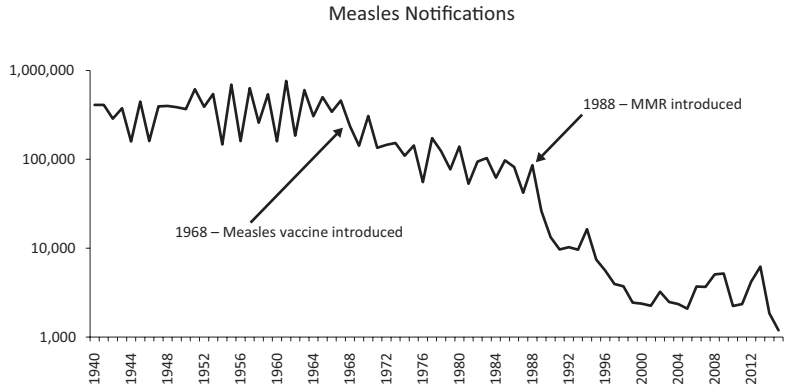

Figure 5.3 Notifications of measles in England and Wales, 1940–2015. Logarithmic scale.
Source: Public Health England, 'Measles notifications and deaths in England and Wales: 1940 to 2016', www.gov.uk/government/publications/measles-deaths-by-age-group-from-1980-to-2013-ons-data/measles-notifications-and-deaths-in-england-and-wales-1940-to-2013 (accessed 2 August 2017).

health (see Figure 5.1). It was also evident that the public had not lost its faith in vaccination. The clamour for the separate vaccines, even in MMR-sceptic newspapers such as the *Daily Mail*, indicated that even parents who wanted to avoid the trivalent vaccine were willing to go to great lengths to ensure that their children remained protected against infectious disease. However, outbreaks of measles in London at the time of the crisis, and in Swansea in 2012, showed that even these relatively small changes could have disastrous consequences.[126] In the latter case, the fear of MMR had largely dissipated, but many parents had not taken steps in the years following the crisis to ensure that their children were protected. Much like with the smallpox outbreaks seen in Chapter 2, there was a lingering problem for public health authorities in convincing parents to use vaccination as a preventative rather than epidemic control tool. As a result, when measles broke out in the Swansea area during the winter of 2012/13 there were large

queues outside doctors' offices as parents sought to have their children vaccinated.[127]

MMR, then, lives on. It is a cautionary tale for public health workers, just as the generation fighting the crisis at the time looked back on pertussis.[128] As the rise in online anti-vaccination activity and growing mistrust of political authorities threaten once again to reduce uptake of vaccination among certain groups, the MMR crisis is held up as an example of how people can be misled by misinformation and how public health professionals must remain ever vigilant.[129] It even formed part of the 2011–12 Leveson Inquiry into the conduct of the press.[130]

Public health researchers' concerns have changed since the beginning of the century. MMR is not simply being used here, therefore, as a lesson from history from which direct predictions of future action can be gleaned.[131] Vaccine crises in other countries led the WHO and the Global Alliance for Vaccines and Immunization to create a Strategic Advisory Group of Experts (SAGE) to investigate how such drops in confidence could be avoided in the future. In some countries, progress towards world vaccination goals had stalled. In high-income countries, pockets of non-vaccinators caused health authorities to worry about high-risk, geographically concentrated areas with poor herd immunity.[132] SAGE identified that the main reason for these problems was vaccine hesitancy. The MMR crisis in the United Kingdom and subsequent debates in other high-income countries formed part of this analysis – especially the difficulties around convincing populations to take the vaccine against the swine flu H1N1 virus.[133]

Yet hesitancy as a concept grew out of changing ways of seeing non-vaccinators in the wake of MMR and emphases on risk communication in the previous decade. As Heidi Larson's work showed, few parents are completely pro- or anti-vaccine; rather, their attitudes towards specific vaccines at specific times can be changed. By focusing solely on individuals when they become a problem for public health authorities, this fluid state can be obscured.[134] This is a story borne out by the history of vaccination in Britain since the Second World War. Parents did not abandon or adopt vaccination as a technology wholesale. Enthusiasm for diphtheria immunisations waxed and waned over the 1940s. Smallpox vaccination was embraced as a form of epidemic control, but treated with indifference by the majority of the population in the 1950s

and 1960s. Polio vaccine was hailed a modern marvel; and yet both the government and the public had an awkward relationship with it until the oral vaccine became widely available. And even at the height of the pertussis vaccine crisis, immunisation rates for other diseases remained relatively robust.

While this chapter has used the language and framework of hesitancy, this concept has been developed by researchers for investigating present-day public health problems. It must be historicised. It is itself born out of the historical period covering MMR. Convenience did not appear to be a great issue. The reforms to the general practitioner contract and the introduction of MMR meant that access to the vaccine was straightforward, and there were incentives throughout the system for following up on defaulters. While there were still issues of monitoring and access in some inner-city areas and amongst some populations,[135] public health officials did not face the same hurdles as those explored in the first section of this book. Confidence was a different matter. Declining trust in state authorities meant that anti-government voices carried an air of legitimacy. With a hostile press, the growth of twenty-four-hour news channels and increasing access to the internet, some parents' confidence shifted towards other sources of expertise.[136] Contemporaries also pointed to increased complacency and the idea that vaccination had, ironically, become a victim of its own success. As the threat of measles and other infectious diseases receded (Figure 5.3), some parents became less motivated to seek out vaccination, or felt that they could afford to wait and try out alternative vaccines and vaccination schedules.[137] This was, in some ways, the language of apathy reconstituted in a different era – albeit one that was more grounded in the sociology of risk and wider qualitative studies of parental attitudes through surveys and systematic literature reviews.

This is not to say that qualitative investigations into the issues surrounding hesitancy had not been conducted before the crisis and its aftermath. Questions about parental attitudes were being asked of pertussis vaccine and MMR going back to at least the 1980s.[138] The ways in which they are now being used to explain and measure vaccine confidence as an indicator is, however, historically intriguing.[139] SAGE has done so through breaking hesitancy into three constituent parts: confidence in a vaccine and vaccination authorities; convenience of access to vaccination; and complacency about the risks of inaction.[140] What

history shows is that confidence, convenience and complacency have manifested in different ways at different times. They have not been universal, either within populations or across all types of vaccine. Moreover, the fact that imperfect levels of these three qualities have still resulted in the general public following government guidelines says much about how well established and accepted vaccination was in the post-war period.

Notes

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