Risk conceptualisations, trust and decision-making in the face of contradictory information: the case of MMR

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RISK CONCEPTUALISATION, TRUST AND DECISION-MAKING IN THE FACE OF CONTRADICTORY INFORMATION: THE CASE OF MMR

Rachel E. Casiday

ABSTRACT

This thesis investigates the process by which parents evaluate contradictory information about risk in order to make the decision whether to have their children immunised with the measles, mumps and rubella (MMR) vaccine. Contested reports associating the MMR vaccine with autism have resulted in diminished confidence and uptake of the vaccine in the UK. Interviews and focus groups were used to develop an in-depth picture of parental notions of risk, trust and decision-making processes. Cultural consensus analysis was used to probe the areas of consensus and divergence of opinion, and a large-scale postal survey (N=996) assessed the level of agreement with the qualitative findings. Parental ambivalence to the safety of the vaccine reflected wider social concerns, and was crucially related to trust in governmental medical authority and medical practitioners. Trust was particularly damaged when practitioners and policy makers failed to recognise parents' concern for their children's health and their unique knowledge of their own children. A key tool for fostering trust is narrative: this played a central role in galvanising resistance to the vaccine, but was not well used to engender trust and cooperation between parents and medical practitioners. Three practical strategies to protect children from diseases and harmful vaccine side effects, to rebuild trust, and to cope successfully with similar controversies in the future emerged from this research: fully involving the public in framing scientific research agendas, streamlining the reporting procedures for suspected adverse reactions, and fostering trusting personal relationships between patients and health care practitioners.

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DECLARATION

The material in this thesis represents the original work of the author. A paper reporting the results of the survey described in Chapter 6 has been published (Casiday R, Cresswell T, Wilson D, Panter-Brick C. (2005). 'A survey of UK parental attitudes to the MMR Vaccine and trust in medical authority.' *Vaccine.* In press – corrected proof). I am the first author of this paper, with co-authors T Cresswell, D Wilson and C Panter-Brick. I was solely responsible for the data collection, analysis and drafting of the manuscript.

The length of this thesis is 71,426 words.

STATEMENT OF COPYRIGHT

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CHAPTER 1
THE MMR CONTROVERSY

1.1 Public fears about the MMR vaccine in Britain

This thesis investigates the process by which parents evaluate contradictory information about risk in order to make the decision whether to have their children immunised with the measles, mumps and rubella, or MMR, vaccine. The MMR vaccine has been the subject of tremendous controversy about risk in the UK in the last seven years, following widely publicised reports that the vaccine may be linked to autism and Crohn's disease (inflammation of the bowel).

The Wakefield publication

In 1998, gastroenterologist Andrew Wakefield published a paper in the *Lancet*, which described a small group of children who had been referred to his paediatric gastroenterology unit with concurrent developmental regression and gastrointestinal problems (Wakefield et al. 1998). 9 of the 12 children had become autistic. The paper suggested a possible trigger: the parents of 8 of the 12 children associated the onset of these problems with MMR vaccination. This was reported in the popular media as a scientific claim of a possible link between the MMR vaccine and autism, initiating an impassioned debate about the vaccine's safety. A mechanism for the supposed link between MMR vaccine and autism evolved in popular and media discussions, whereby the mumps component of the vaccine is purported to somehow allow measles virus from the vaccine into the intestine of susceptible individuals; the measles virus then renders the intestine permeable to certain peptides (becoming a 'leaky gut'), which then enter the bloodstream and interfere with the central-nervous-system opiods, subsequently disrupting normal neuroregulation and brain development, and causing the autistic behaviour (Mills 2002, p. 27, Wakefield et al. 1998).

Frightening risks

Although a large number of subsequent studies have failed to confirm such risk from the MMR vaccine (e.g., Chen et al. 2004, Farrington, Miller, and Taylor 2001, Honda, Shimizu, and Rutter 2005, Kaye, del Mar Melero-Montes, and Jick 2001, Klein and Diehl 2004, Madsen et al. 2002a, Peltolta et al. 1998, Smeeth et al. 2004, Taylor et al. 1999a), the prospect of a child developing autism is so frightening that an uproar of anxiety emerged among UK parents and in the media. At the same time, MMR confers immunity to diseases that also represent frightening risks. Potential complications of measles range from otitis media and respiratory ailments, which occur frequently with the disease and present a significant burden on health services, to more serious and rarer complications such as blindness, encephalitis and even death (Noah 1988a). Mumps, though generally less severe than measles, is a major cause of viral meningitis, and may sometimes result in testicular atrophy and nerve deafness (Noah 1988b). Rubella, though rarely serious in adults and children, has devastating effects when exposure occurs during pregnancy: spontaneous abortion, stillbirth, and structural and developmental birth defects (De Wals and Lechat 1988). For all three of these diseases, maintaining sufficiently high levels of immunity in the population to prevent the spread of the disease among susceptible individuals ('herd immunity') is a major public health priority. Thus the Department of Health continues to maintain that the vaccine is not only safe, but also a vital component of its preventive strategy, and in 2001 launched a £3 million campaign to promote the vaccine as 'the safest way for parents to protect their children' (Boseley 2001a, NHS Health Promotion England 2001).

Separate immunisations?

A series of three separate vaccinations for measles, mumps and rubella, temporally spaced so as to give children time to respond to each immunisation before exposing them to the others, has been widely perceived as a safer alternative to the MMR. Private clinics have been set up across the country to offer these 'single vaccines,' typically at prices around £80 per injection, in addition to any consultation fees. However, there is to date no published work about the relative safety of the triple versus serial single vaccine, and health officials have expressed concern about the safety, efficacy and practicability of this regimen (Duckworth 2001, Miller 2001).

Parents caught in the middle

Caught in the middle of this debate are the parents who must evaluate reports of the potential dangers of MMR, on the one hand, and on the other the risk of exposing their children to measles, mumps and rubella by not vaccinating them, or delaying children's immunity to dangerous diseases by opting for the series of single injections. The reports, coming from both sides of the debate, are often very dramatic and worrying. Pressure groups representing parents who think their children have been damaged by vaccines (e.g., 'JABS') tell of healthy, happy children who suddenly became unresponsive, miserable, and difficult within days of MMR vaccination. Newspaper and television reports featured these unfortunate families, but also described the looming threat of measles outbreaks across the UK if MMR vaccination rates did not increase. Leaflets distributed to parents through NHS GP surgeries starkly described the serious and even fatal complications that can result from measles, mumps and congenital rubella (NHS Health Promotion England 2001). Michael Fitzpatrick, a London GP who is also the father of an autistic child, wrote a book detailing the research on MMR and autism in an effort to 'reassure parents faced with decisions about vaccinations that they have nothing to fear in MMR and every reason to welcome the protection it affords their children' (Fitzpatrick 2004, p. x). The controversy featured prominently in public venues ranging from special television programmes (Hear the Silence, 2003b) and features in parenting magazines (Godridge 2003), to a dedicated exhibit at the Science Museum in London. For many parents, this situation presented a bewildering and distressing dilemma.

In addition to the conflicting information about the MMR vaccine, a variety of materials offering advice about immunisation in general also feed into parents' decisions. Popular parenting books and magazines are full of advice on vaccination. Most general-purpose parenting books recommend following standard immunisation schedules (Eisenberg, Murkoff, and Hathaway 1996, Green 2004, Johnson and Johnson Ltd. 2002, Murkoff, Eisenberg, and Hathaway 2003, Stoppard 2003). They remind parents of the devastating effects of vaccine-preventable diseases, and offer remedies for coping with the short-term discomfort and side effects (e.g., fevers) of vaccination. A few writers take a less conventional approach, offering alternative, delayed immunisation schedules for parents concerned about the potential effects of immunising very small children (Cave and Mitchell 2001, Romm 2001). There is also a vocal anti-vaccine camp, producing books specifically warning parents of the many dangers that have been ascribed to vaccinations (McTaggart 2000). Thus, parents evaluate and interpret a wide range of advice in making their decisions about vaccination in general, and about MMR in particular.

1.2 Significance of the controversy

Falling immunisation rates

What is the public health and social significance of this controversy? A marked reduction in MMR uptake rates, shown in Figure 1.1, has been documented by the Department of Health since the 1998 publication (Wakefield et al. 1998). Nationwide in 2002-3, only 81.8% of children had been given the MMR by their 2nd birthday (Lancucki 2003), which was down by over 5% since 2000-01. Regional statistics present an even more dramatic picture, with far lower uptake rates in certain districts. The Kensington and Chelsea (London) primary care organisation, for instance, reported an uptake rate of just 58% in 2002-3. In Cambridge and Durham, the two principal locations where this study was performed, MMR uptake rates were 83% and 88%, respectively, for that year. In January 2004, the Department of Health bouyantly reported the first quarterly increase in MMR uptake since the start of the controversy, as the national rate rose by 0.9% (Frith 2004). That this small increase was cause for special comment and pride demonstrates how far below targets MMR uptake had fallen.

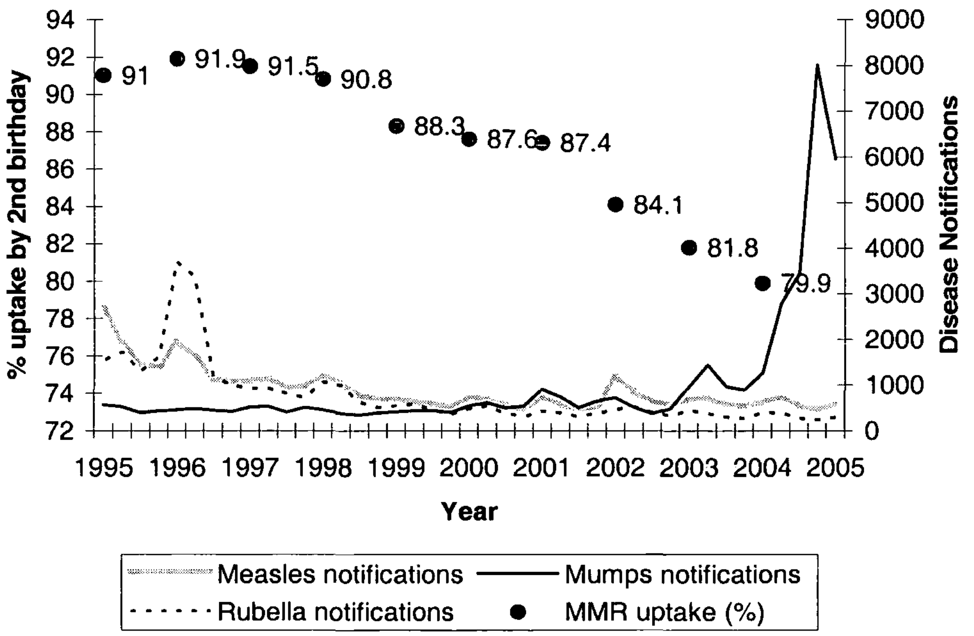

Figure 1.1 MMR uptake and notifications for measles, mumps and rubella, 1992-2004 (Department of Health 2004, Health Protection Agency 2005a, Health Protection Agency 2005b, Health Protection Agency 2005c).

This drop in MMR uptake is, of course, significant because the levels reported in the wake of the controversy were well below the 95% target rate needed to ensure herd immunity of the population. Thus, health officials warned that outbreaks of measles, mumps and rubella were likely, putting the population at risk of permanent damage from disease complications and death. It is difficult to say how much these fears have been borne out. The notification statistics for measles, mumps and rubella do show some increases while MMR immunisation rates were falling (Figure 1.1), but it is difficult to identify any consistent trend. As of 2002, measles notifications had risen significantly over the preceding three years, although the number of reported cases was still lower than the 1998 figure. The incidence of rubella fell sharply between 1998-9, but shows no apparent trend of increase during the years of the MMR controversy (2003a). Notifications of mumps rose in 2001, but declined to near-baseline levels the following year. Mumps notifications increased dramatically in 2004; however, these cases occurred primarily among young adults (who were too old to have received MMR as children), rather than among small children not receiving the MMR currently. But, of course, individuals of all ages are vulnerable when immunisation levels are too low to ensure herd immunity and pathogen circulation is increased during outbreaks such as this.

It should be noted that the reported MMR uptake rates may in fact underestimate population immunity to the three diseases for several reasons. First, centralised computer records of immunisation may be incomplete. Even more importantly, perhaps, MMR is not the only means of conferring immunity to measles, mumps and rubella. Natural exposure to the diseases is one way; immunising against the three diseases separately is another. Because the NHS does not provide separate immunisations for measles, mumps and rubella, the Department of Health has no registry of their administration. We do not know how many of the parents who have refused MMR vaccination for their children have paid for the separate immunisations to be administered privately, versus the number who have not immunised their children against these diseases at all, although one recent survey (conducted by health visitors contacting families with no record of MMR uptake) reported a 21% uptake of single vaccines among children not immunised with MMR in three Lancashire Primary Care Trusts (PCTs) (Wragg and Gornall 2004). Furthermore, the efficacy of the separate vaccines, relative to that of the MMR, is poorly understood, so even if the true vaccination rate were known, it would still be difficult to estimate the percentage of children who were immune to each of the diseases.

Loss of trust

The other key consequence of the MMR controversy in the UK has been a loss of trust between many parents and the health service sector. In this light, the MMR controversy follows in the path of such crises in public trust as the bovine spongiform encephalopathy (BSE) epidemic, in which government scientific advisors lost credibility by reversing their assurances to the public that BSE posed no health threat to humans (Bellaby 2003, Caplan 2000, Murphy-Lawless 2003, Rowell 2003). To handle risk, government and medical authorities create policies and distribute 'expert' knowledge to the public. In the case of MMR, this top-down communication approach was at odds with many parents' experiences and concerns. In such cases, trust is eroded: many parents no longer trust the health service to provide reliable information. But health professionals' trust in parents, to comply with risk-management measures, is also critical, and is also damaged when communication breaks down (cf. Rogers 2002). In turn, members of the public express resentment that they are not trusted to make sound decisions for themselves. The breakdown in trust occurring as a result of controversies like those surrounding the safety of MMR and BSE may spill over to other aspects of health care provision, fundamentally damaging the trust that is necessary for the implementation of effective public health measures and the provision of medical care.

1.3 Media coverage of the controversy: Chronology

Media reports have been particularly important in galvanising public opinion about the MMR, and many commentators have attributed parental concerns about the MMR vaccine to worrying reports in the media (Anderson 1999, Bedford and Elliman 2003, Begg et al. 1998, Elliman and Bedford 2001). A study combining media content analysis and a public opinion survey explicitly linked the media reporting about MMR with public beliefs about the safety of the vaccine (Hargreaves, Lewis, and Speers 2003, Lewis and Speers 2003). Examining 561 media reports on MMR between January and September 2002, the authors found a marked anti-MMR bias: over two thirds of the reports mentioned the suggested link between MMR and autism, but only half of the television reports and one third of the newspaper articles said that the bulk of scientific evidence supported the safety of the vaccine. Rather than explaining the substance of the claims for or against the suggested link between MMR and autism, most of the media's 'attempts to balance claims about the risks of the MMR jab tended merely to indicate that there were two competing bodies of evidence' (Hargreaves, Lewis, and Speers 2003, p. 23) and did not reflect the true balance of scientific opinion on the matter. Corresponding to this trend in the media coverage, over half of those polled during this period of extensive coverage of the controversy believed that medical opinion was evenly divided over the safety of the MMR vaccine.

In order to understand and contextualise the parental views explored throughout this thesis, it is instructive to examine the events that came to public attention via the mass media and how these events were reported. This section provides a chronology of the MMR controversy derived from reports in national UK newspapers (*The Guardian, The Independent, The Times, The Telegraph,* and *The Daily Mail*). A number of scientific studies related to the controversy are mentioned, but discussion of these studies is limited here to coverage that was available to parents through the news media. Although it was beyond the scope of this thesis to assess quantitatively the content of media reports about the MMR vaccine, this chronology demonstrates how the controversy was reported over time.

Background

In 1968, a single vaccine for measles was introduced in the UK; prior to that the UK saw 160,000-800,000 cases of measles per year, possibly killing over one hundred children annually (Boseley 2002). This vaccine was replaced by the combined measles, mumps and rubella (MMR) vaccine in 1988 in the UK, though the MMR had already been in use in the United States since 1975. 1988 also marked the last epidemic of measles observed in the UK (prior to the controversy over MMR's safety described here), with 80,000 cases and 15-20 deaths. Interestingly, MMR was also introduced and made compulsory in Japan around this time (1989), although it was replaced in 1993 with separate immunisations for measles and rubella (given simultaneously, with mumps vaccine being given only to children whose parents specifically requested it) because the form of MMR vaccine used there appeared to be associated with an unacceptably high level of side effects (NHS Immunisation Information 2005). Whereas Japan had previously had near-universal immunisation coverage for measles, only 70 percent were vaccinated against the disease in the early

1990s (2002a) and Japan subsequently experienced 79 deaths from measles between 1992 and 1997 (Wise 2001). A threefold increase in the number of measles cases in Japan was seen in 2002 (to 12,000 in the first six months), which Japanese officials attributed to the low vaccination rates of the 1990s (2002a). However, it is unclear to what extent the separate immunisation policy contributed to this low uptake.

Questioning the safety of MMR

Following its introduction in the UK, the MMR vaccine received little special attention until August 1997, when newspapers briefly reported an as yet unpublished study conducted by researchers at the Royal Free Hospital in London suggesting a link between MMR, autism and bowel disorder (1997a). The following month, parents from the group JABS (which provides support for and advocates on behalf of parents who believe their children have been damaged by vaccines) met health minister Tessa Jowell to demand withdrawal of the MMR vaccine after gathering details of 1000 cases of alleged adverse reactions (1997b).

In February 1998 the Royal Free researchers, led by Dr. Andrew Wakefield, published the results of their study in *The Lancet* (Wakefield et al. 1998). The research team also held a press conference in which Andrew Wakefield unexpectedly stated that he felt enough doubt had been cast on the MMR to avoid giving it to his own children, and suggested that administering the three vaccines separately might be safer (Laurance 1998b). Notably, the other authors of the study did not comment on the safety of the MMR vaccine or recommend against its use. In March a group of 37 scientific experts were assembled to evaluate the evidence on MMR and concluded that the vaccine was safe (Laurance 1998a). However, the director of JABS, Mrs. Jackie Fletcher, publicly expressed concern that the issue was not given sufficient time for debate. The Chief Medical Officer Sir Kenneth Calman called on parents to take their children for MMR vaccination (Boseley 1998b), and the Assistant Director-General of the World Health Organization Ralph Henderson attacked the Wakefield study (Boseley 1998a). A large-scale Finnish study reported in May that there was no evidence of any link between MMR vaccination and autism (1998b, Peltola et al. 1998).

Escalating controversy

In spite of these reassurances, the Public Health Laboratory Service reported in June that MMR vaccine uptake was on the decline in Wales (Boseley 1998c, Thomas, Salmon, and King 1998), and Pasteur Merieux MSD withdrew sale of their single measles vaccine from Britain, because they could not keep up with rising demand (Buncombe 1998). Now parents were forced to go to the continent if they wanted to obtain the single measles vaccine for their children. In November 1998 eight families, represented by solicitor Richard Barr, lodged writs in the High Court against the manufacturers of the MMR vaccine, and a further 350 families were granted legal aid for similar cases (1998a).

In June 1999 further evidence against the claim that MMR was associated with autism emerged, when *The Lancet* published a study of 500 autistic children from north London, finding no increase in risk of autism following MMR vaccination (Taylor et al. 1999b). However, parents of allegedly vaccine-damaged children said they would continue to fight for compensation despite government reassurances over MMR safety (Laurance 1999). In August, *BMJ* published a report saying that the single mumps vaccine previously imported into the UK did not offer any protection, and the Government banned the import of single vaccine substitutes for MMR (Rumbelow 1999, Schlegel et al. 1999). In September, the *Journal of the Royal Society of Medicine* accused doctors of dropping patients, including children who had not received MMR vaccination, from their registers in order to increase profits (Norton 1999).

Outbreak worries and a mass advertising campaign

The first half of 2000 saw an outbreak of measles in Dublin, in which 844 suspected cases were reported (as compared to152 notifications between 1995-1999), 101 children were hospitalised, and 2 children died (Laurance 2000). In April 2000, another committee, this time brought together by the Medical Research Council, reviewed the evidence and again concluded that there was no link between vaccination and autism (Connor 2000). However, five days later, reports of measles virus found in the gut of 24 out of 25 autistic children were presented as new evidence suggesting a link between the MMR vaccine and chronic illness in children, including autism (Laing 2000).

By the start of 2001, Department of Health officials were concerned that MMR uptake rates were still falling, and launched a £3 million advertising campaign to promote the MMR (Hall 2001a). This campaign budget included £1 million for television advertising (featuring children surrounded by prowling lions as a symbol of risk from measles, mumps and rubella), and the popular children's health author Dr. Miriam Stoppard was consulted for advice about how to present the pro-MMR message to parents. The National Autistic Society criticised this move, saying that the money should have been spent on research rather than advertising (Boseley 2001a).

Further challenges to the MMR programme

In December 2000, another widely publicised paper by Andrew Wakefield appeared in the journal *Adverse Drug Reactions & Toxicology Review*, in which he questioned the adequacy of the safety testing that MMR had been subjected to prior to its release (Wakefield 2001). The following month, newspapers reported that 500 parents were now planning to sue the Department of Health, claiming the vaccine had damaged their children, and 850 families had been given legal aid (Hall 2001b). Later that year, in August, a doctor was reported to the General Medical Council for opening a clinic offering separate vaccines (Fraser 2001), although in November he was cleared and allowed to continue, on the condition that he provide parents with up-to-date information on the evidence about the safety of MMR (Boseley 2001b). In September doctors David Elliman and Helen Bedford reviewed the evidence on separate MMR vaccines. They warned parents that it is risky to vaccinate with unlicensed products, which may be ineffective and carry a slightly higher risk of meningitis (Duckworth 2001). In December 2001, Andrew Wakefield resigned under pressure from the Royal Free Hospital in London (Meikle 2001).

The Prime Minister drawn into the fray

Also in December of 2001, a seemingly trivial event occurred which generated an enormous amount of media coverage and came to symbolise for many parents the Government's mishandling of the MMR dispute. A *Daily Mail* reporter asked Prime Minister Tony Blair if his son Leo would have the MMR. When Blair refused to answer, insisting that members of his family are entitled to privacy regarding medical matters, many began to speculate that Blair was publicly – and hypocritically – supporting a dangerous vaccine that he would not give to his own child (Riddell 2001). In particular, the fact that Cherie Blair's half sister was a known opponent of MMR immunisation was taken as indicative of the family's private attitude to the vaccine. This situation was resolved somewhat in early February 2002, when *The Independent* ran a full-page cover story saying that Leo Blair had had the MMR (Dillon 2002a), but the Prime Minister refused to confirm this report, again citing the importance of privacy in personal medical matters. There was some speculation in the newspapers that this statement may have been deliberately leaked by Downing Street, and many members of the public remained unconvinced that the child had in fact been immunised with MMR. As late as 2004, the Sunday Times ran a story suggesting that Leo Blair had received the immunisation, but only when he was much older than the recommended 12 to 15 months, and only after intense public and political pressure to reveal the decision (Rogers and O'Reilly 2004).

A flurry of activity around the controversy

The early part of 2002 saw the largest amount of media coverage to date about the MMR controversy, with several stories breaking nearly every month. The fieldwork for this thesis began at the end of 2002, so it is particularly relevant to trace the developments that the research participants may have followed in the year before their participation in the study.

In January, a *Pediatrics* review article exonerated the practice of combining vaccines, saying that babies' immune systems are capable of handling up to 10,000 different infections at a time (Offit et al. 2002). In February, the BBC programme *Panorama* ran a special feature entitled 'MMR - Every Parent's Choice,' presenting both sides of the debate on MMR and the difficulty many parents had in making a decision about the vaccine. In addition, no fewer than six major news stories related to the MMR appeared that month: (1) a measles outbreak occurred, with 36 cases in south London confirmed by 24 February, 5 in County Durham, and several more suspected (Carrell 2002); (2) the private medical company Direct Health 2000 opened a two-day 'outreach clinic' offering single vaccines in Darlington (Fraser 2002a); (3) a new advertising campaign was launched, featuring an open letter to GP surgeries and televised appeals on the BBC from Chief Medical Officer Liam Donaldson (the first time since the recognition of AIDS in the 1980s that the BBC had been used to broadcast a government health warning in this manner) (Brown 2002); (4) the Government pledged an extra £2.5 million for research into the causes of autism (Hall 2002a); (5) the Patients' Association expressed concern that GPs were removing children without MMR vaccination from their patient lists (Duckworth 2002a); and (6) Researchers at Dublin University reported that they had found traces of measles virus in children with bowel disease, lending some tentative support to the theory that measles vaccination could be responsible for a new type of autism-inducing bowel disease (Duckworth 2002b, Uhlmann et al. 2002).

The politics around the MMR issue continued to be quite important; in April Conservative MP Julie Kirkbride announced plans to introduce a bill in Parliament allowing parents to choose single vaccines for free under the NHS (Dillon 2002b). The following month, Lord May called on the Government to quantify the risk posed by MMR because parents were not persuaded by blanket assurances that there is no risk of autism (Highfield 2002).

MMR, family conflict, and the court

An interesting court case emerged in July 2002, when two MMR-refusing mothers were brought to court by the children's divorced fathers (Payne 2002). In both cases, the fathers did not have custody of the children, but wanted the children to receive the MMR. A year later, the mothers were ordered to have the children immunised with the MMR, and their appeals of this decision were unsuccessful (Waterhouse 2003). This was a dramatic, and rather extreme, example of how such a politically contentious issue can also become divisive within families.

Separate vaccines and target payments

Also in July 2002, obtaining single-antigen vaccines privately became more difficult, when the Government ordered the wholesale supplier of the single rubella vaccine to decrease the amount supplied to private clinics (Vallely 2002). Rubella is the only one of the three single vaccines that is currently licensed for use in the UK, because it is given to women planning pregnancy who do not already have rubella antibodies.

Also that month, British GPs voted to abandon the system of vaccination target payments (Hall 2002b). Under that system, GPs earned £2865 if their practice achieved ninety percent vaccination uptake, and £955 for a seventy percent vaccination uptake. Many doctors had previously admitted to using 'scare tactics' (Morrison 2001) to persuade parents to vaccinate their children, because of financial pressures under the vaccination target scheme. Furthermore, parents who knew about the vaccination targets had begun to question the objectivity of their doctors' advice about the MMR. This issue resurfaced a year later, when GPs called for chief medical officers to resign over the 'cash for jabs' system (Derbyshire 2003a).

'MMR: The facts'

In September 2002 the Department of Health launched a new website, 'MMR: The facts' (http://www.mmrthefacts.nhs.uk/). The website features information about the vaccine and the scientific studies supporting its safety, news about the MMR controversy, frequently asked questions, and a forum for parents to submit their own questions about the vaccine to Department of Health members. A pamphlet with the same title and highlighting key points from the website was also produced to be distributed through GP surgeries (NHS Health Promotion England 2001).

Despite such public health measures to promote the vaccine's safety, the *Times* produced a three-page colour feature entitled 'Autism and MMR: Open Up the Debate' (Cavendish 2002). This 'reopening' of the debate was in response to two studies from America that seemed to cast further doubt on the vaccine. In the first study, Dr. Vijendra Singh (Utah University) found an unusual MMR antibody in 75% of autistic children but not in children without autism (Singh et al. 2002). In the second, Robert Byrd (University of California) claimed that increases in autism prevalence were not due to different diagnosis or increased awareness, but must be explained in terms of environmental factors (such as vaccination) (Byrd 2002).

More about separate vaccines

In November 2002 the private-sector company Direct Health 2000 was invited by an NHS GP, Dr. Peter Smith of Kingston, Surrey, to hold a clinic in his NHS surgery, providing single vaccines to patients who had refused the MMR vaccine (Fraser 2002b). Dr. Smith maintained that he supported MMR vaccination, but wanted to facilitate immunisation for parents who were not convinced of its safety. By helping them to find an alternative, he reasoned, their children would not go unvaccinated. Also that month, representatives of Direct Health 2000 accused the Medicines Control Agency of conspiring to force parents to allow their children to have the MMR, after the MCA banned imports of the single mumps vaccine Pavivac from the Czech Republic (Hawkes 2002). A final story, which received a good deal of press that month, was the publication of a Danish study in the *New England Journal of Medicine* examining the records of over 500,000 children and finding no link between MMR and autism (Madsen et al. 2002b).

The beginning of 2003 was marked by warnings about disease outbreaks caused by falling MMR uptake. The London Assembly warned that MMR vaccination rates were much lower in London than nationwide (73% vs. 85%) and urged the Government to help boost immunisation levels by introducing a childhood call and recall system, and to issue a review of the reporting of possible side-effects (Wright 2003). In addition the Health Protection Authority announced that mumps cases in

Wales had doubled over the past year (143 in 2002, up from 65 in 2001) (de Bruxelles 2003). At the same time, requests for the importation of separate measles and mumps vaccines had increased dramatically: demand for single measles vaccine rose from 11,818 requests in 2001 to 71, 859 in 2002, and demand for mumps vaccine rose from 17,800 to 39,089 (Laurance 2003). In March 2003, Desumo Information and Health Care (Worcester) was ordered to stop offering single vaccines until the company was registered with the National Care Standards Commission, leaving 5,000 families uncertain about how their children's vaccination courses would be completed (Fraser 2003).

Private clinics shut down

The acceptability of private clinics offering single vaccines - and of the NHS's refusal to administer separate vaccines to those who wanted them - became an even more salient issue in the summer of 2003, when two clinics offering separate measles, mumps and rubella vaccines were shut down for improperly administering the vaccines (Hawkes 2003). In July 2003 the Department of Health sent urgent messages to family doctors saying that up to 40,000 children vaccinated at the Elstree Aerodrome in Hertfordshire and Hillsborough Arena in Sheffield were at risk of the diseases and should be re-immunised with MMR. In August, Dr. David Pugh, from the Elstee Aeromedical centre, was charged in court with forgery of blood test results relating to single measles, mumps and rubella vaccines (Laurance 2004b, Payne 2004) and was eventually arrested in December 2004 (Sapsted 2004).

Measles and mumps spread

Further concern about the spread of measles and mumps arose in the second half of 2003. In August, Vincent Jansen (Royal Holloway, London) reported in *Science* that British measles cases had risen as MMR vaccination rates fell, with the measles 'reproductive number' (an indicator of the potential for epidemics occurring) increasing from 0.47 (1995-1998) to 0.82 (1999-2002) (Jansen et al. 2003). In the same month, reports that single mumps vaccines were in short supply meant that many children whose parents had refused the MMR were left unimmunised for mumps (Ebron 2003). In September, annual immunisation uptake figures were released, showing MMR uptake to be at a record low (79%) since the vaccine was introduced (Boseley 2003). By November American health experts were warning that Britain could spread measles to the US if it did not increase its level of MMR uptake (Lister 2003), and in December outbreaks of mumps at UK universities sparked a campaign to give the MMR vaccine to students (Longrigg 2003).

Legal aid revoked, and more publicity

In October 2003, the parents (by now, more than 1500) who were suing the vaccine manufacturers over alleged damage to their children lost their legal aid funding for the case (Martin 2003). Although the parents appealed, the appeal was quickly turned down. This decision is still being contested in an ongoing campaign by the parents' support group JABS; by the end of 2004 it seemed likely that 100 families involved in this litigation would have their legal aid restored (Doward 2004).

Also in October 2003, Simon Murch, a co-author of the original *Lancet* paper (Wakefield et al. 1998), warned in a letter to *The Lancet* that measles epidemics were likely to occur in the coming winter if MMR uptake did not increase (Derbyshire 2003b, Murch 2003). Although Murch claimed that he had not changed his views about MMR (i.e., that he had never believed there was firm evidence linking the vaccine with the behavioural and bowel disorders described in the paper), Andrew Wakefield claimed on Radio 4's Today programme that Murch had been pressured into publicly changing his view on MMR.

On 15 December, Channel Five aired a teledrama entitled 'Hear the Silence,' portraying a mother's struggle, aided by Dr. Wakefield, to find recognition and treatment for her autistic son, whom she believed had been damaged by the MMR vaccine (2003b). The programme was aired despite protests from doctors and the Department of Health that it misrepresented the controversy and could further undermine the Department of Health's immunisation programme (Wells and Boseley 2003).

Controversy fading away?

By 2004, however, there was some optimism among health officials that the controversy over MMR was waning. The Health Protection Agency optimistically reported the first rise in MMR uptake since April 2002, increasing by 0.9 percent over the previous quarter, to 79.8 percent of all two-year-olds (Frith 2004). Also, another study lending support to the safety of the MMR was published, in which Hershel Jick and James Kaye (Boston University) claimed that the rise in childhood autism could be explained by changing diagnoses of behavioural disorders (Jick and Kaye 2003).

In February 2004 a High Court judge rejected an application for judicial review of withdrawal of legal aid funding on behalf of the lead cases in a group action involving some 1,000 families (Hawkes 2004, Taylor 2004). MMR litigation costs had so far run to £15 million. The High Court also requested Irish courts to order Prof. John O'Leary to hand over all the raw data from his study (finding traces of measles in the bodies of 80% of the 91 autistic children he tested), which was a pivotal part of the case against the vaccine manufacturers, to be re-examined by independent experts (Deer 2004a).

In May several of the families who were filing legal action for damage following MMR immunisation accused Merck & Co of trying to intimidate them into dropping legal action. Lawyers from the pharmaceutical firm had written to the parents, saying that the children and their parents would be 'at risk of facing a liability for any further costs Merck continues to incur in defending their claim' following the families' legal aid being revoked (Meikle 2004a).

A new set of allegations

In February 2004, a few months before the survey questionnaire for this thesis was mailed out, the Sunday Times reporter Brian Deer revealed that Wakefield had been paid £55,000 for his research by the legal team preparing a case against the vaccine manufacturers (Deer 2004c, Horton 2004). Wakefield had disclosed a link with the Legal Aid Board in a letter to *The Lancet* in May 1998 (Booth 2004), three months after the publication of his study, but did not mention the money that had already been paid for the published study. Richard Horton, the editor of *The Lancet,* proclaimed that he would not have published the 1998 paper had he known about this conflict of interest (Meikle 2004b, Wright, Hawkes, and Lister 2004). Wakefield, reportedly 'badly shaken by the latest round of publicity, rarely venturing out of his home... increasingly anxious, believing that his phone is bugged and that there is an orchestrated campaign against him' (Laurance 2004c), responded by hiring a libel lawyer to demand an apology for casting doubt on his honesty (Henry 2004) and said he would welcome an inquiry into his conduct (Hall 2004a).

Wakefield was also accused in the House of Commons of unethical conduct during his study when Dr. Evan Harris, MP, former health spokesman and member of the BMA's medical ethics committee, accused him of failing to receive correct ethical approval for performing invasive spinal taps on the autistic children in his care. According to Harris, Wakefield had altered the study design after it was authorised by the Royal Free Hospital's ethics panel (Henderson 2004). Wakefield was ultimately cleared of this charge (Horton 2004), but his professional reputation was seriously compromised by the allegations.

By March most of Wakefield's former collaborators retracted their support for the hypothesis linking MMR with autism. John O'Leary said his findings 'did not support the MMR/autism hypothesis' and that he was 'shocked' by the findings of Wakefield's misconduct (Deer 2004b). 10 of the 12 co-authors of the original paper retracted their 'interpretation' of the data that MMR might lead to autism, in a statement published by the Lancet (Meikle 2004c, Rogers and Deer 2004). However, MP Ian Gibson (chairman of the Science and Technology Select Committee) expressed outrage that the paper was not retracted completely (Coates 2004).

More disease concerns

In April 2004 'the first known victims of the MMR scare in Britain', two boys left mentally and physically impaired after contracting measles, were identified (Goswami and Ungoed-Thomas 2004). Both boys had been unable to receive the vaccine for medical reasons unrelated to the controversy, but were believed to have contracted the disease because immunisation rates had fallen in their area. Wakefield continued to defend his concern, saying that he had always advised for children to be vaccinated, and blamed the Government for failing to offer separate vaccinations as an alternative to the MMR. At the same time, an Irish consultant, who had treated three babies who died during the Dublin measles epidemic in 2000, called for junior schools not to admit unimmunised children (McDonald 2004).

A few months later, in July, the 'most serious outbreak of mumps for more than a decade' was announced: 578 confirmed cases were reported in England and Wales in first quarter of 2004, the highest number since records began in 1995 and double the previous quarter (Derbyshire 2004). A rise in mumps had been observed since 1999 and attributed to the MMR scare, though others questioned the link with MMR since most cases were among 14-22 year olds who hadn't received MMR as infants (Bateson 2004). In the autumn of 2004 a campaign was launched to provide MMR vaccine for unimmunised university students (Hall 2004c). In April 2005 the campaign had to be suspended because of a shortage in the supply of MMR vaccine (Laurance 2005b), and in May health officials warned that 'Britain is in the grip of a mumps epidemic', with an 18-fold increase in mumps notifications over the previous year.

New vaccine formula introduced

In September 2004 a minor change in the British immunisation programme came into effect, providing an interesting example of how concern about one vaccine can spill over to others. Previously, infant vaccinations against diphtheria, tetanus, pertussis and *Haemophilus Influenzae* type B (Hib) were given in one injection, together with a separate injection of meningitis C vaccine and oral polio vaccine (at 2, 3 and 4 months of age). Because of theoretical concerns about the use of live polio virus in the oral vaccine (which was excreted in stools and could be harmful to immuno-compromised individuals exposed to it), the Department of Health opted to replace the oral polio vaccine and DTP/Hib formulation with a combined injection providing immunisation for all five together. Initial reports of this change included statements from JABS spokespeople, concerned that the new formulation had not been tested sufficiently (Hall 2004b). This concern was explicitly linked to the MMR fears; indeed, the language used to describe the formulation (as a new 'five-in-one jab') echoed the 'three-in-one' terminology that had already come to define the MMR in popular discussions. However, after the initial reports these concerns seem to have died down quickly.

More studies refuting the MMR-autism link

Also in September 2004, a 'comprehensive' study, funded by the Medical Research Council to investigate the hypothetical link between MMR vaccine and autism, reported that no such association had been found (Laurance 2004a, Smeeth et al. 2004). The researchers had examined the vaccination records of 1294 autistic children, finding that they were actually less likely to have received the MMR vaccine than children in the control group (although the difference was not significant).

Another interesting study was reported in March 2005, drawing on the experience of Japan, which had discontinued the MMR vaccine in 1993 (2005, Honda, Shimizu, and Rutter 2005, Laurance 2005a). This study found that the incidence of autism continued to rise in Japan even after 1993, suggesting that MMR vaccine was not implicated in Britain's rise in autism.

1.4 Other vaccination controversies

Early opposition to vaccination

The current UK controversy over MMR should also be situated in the context of other controversies about the principles behind, and implementation of, vaccination programmes. From its inception, the practice of vaccinating individuals to protect them from later, more severe, infections generated controversy. Vaccination became an important tool for public health promoters in 1798, when Edward Jenner developed a vaccine to prevent smallpox. To make a significant public health impact, the use of vaccination had to be widespread, so governments often became involved in introducing measures to ensure that large segments of the population complied with the vaccination regime. Greenough (1995) described the street riots and other struggles that occurred in 19th century America and Europe over compulsory vaccination laws. Greenough also pointed out that such resistance is by no means unique to the early vaccination campaigns:

> Yet the potential for resistance is always present, because encounters with government vaccinators are never about immunisation alone. Public health measures derive their authority from the police power of the state, and people do not lightly offer themselves (or their immune systems) to government, even when its authority is legitimate (Greenough 1995, p. 633).

The smallpox eradication campagin

In 1966 the World Health Organization launched an ambitious (and, in the end, successful) programme aimed at eradicating smallpox from the world. The eradication of smallpox is often touted as one of the greatest achievements of modern public health, but vaccinating enough people to eradicate the disease required overcoming significant resistance in different parts of the world. One reason for resistance, particularly in areas of South Asia, was that an indigenous practice of variolation, or inoculating people by scratching material from infected sores into the skin, already existed; thus, people did not perceive any need for Western smallpox vaccines (Streefland, Chowdhury, and Ramos-Jimenez 1999). This resistance to immunisation was often overcome with heavy-handed coercive techniques. Greenough (1995) described the intimidation and coercion used by physician-epidemiologists in the WHO smallpox eradication campaign in South Asia. Their techniques included physically containing individuals who had not yet been vaccinated until they consented to vaccination, and intimidating host-country medical staff. Although in the short term, these techniques were hailed as hugely successful because they resulted in the elimination of smallpox, in the long term, these events probably contributed to serious problems of trust in international and local health workers.

Such trust is a vital component of campaigns that aim to control, rather than eradicate, diseases (including measles, mumps and rubella), because such campaigns require widespread public acceptance sustained over a long period of time. In such cases, the diseases are still present in the population, but are prevented from spreading because most people in the population have been immunised. However, when trust in the public health officials promoting vaccination fails (or is undermined by coercive techniques considered unacceptable to the public), and uptake of vaccination is affected, then disease outbreaks and epidemics may be seen. Das and Das (2003) found that vaccination demand in India is related to trust developed in the course of accessing other medical services. The continued circulation of measles, mumps and rubella in the UK, of course, is a principal reason that the controversy over MMR has generated so much concern.

Global vaccination initiatives

Following on the eradication of smallpox, a number of global child vaccination initiatives were launched to prevent deaths from childhood diseases. For example, in the early 1980s UNICEF developed the 'GOBI' programme which focused on four identified areas for 'special attention' in child health – **g**rowth monitoring, **o**ral rehydration, **b**reast-feeding promotion and **i**mmunisation (later expanded to GOBI-FFF, encompassing family planning, feeding and female development as well) (Claeson and Waldman 2000, p. 1235). Immunisation received particular emphasis under the Universal Programme on Immunisation (UPI) and the WHO's Expanded Programme on Immunisation (EPI), which sought to eliminate or dramatically reduce the prevalence of six immunisable diseases – tetanus, pertussis, diphtheria, tuberculosis, poliomyelitis and measles – around the globe (Cutts 1998). The initiatives are a key facet of the Selective Primary Health Care (SPHC) strategy that emerged in the 1980s as a modification of the Primary Health Care (PHC) ideal expounded at the WHO's conference at Alma Ata in 1978. Whereas PHC was based upon a broad approach to public health, in which small-scale projects, developed in participation with local communities, would predominate, proponents of SPHC argued that a more cost-effective approach, which would save more lives, was to target scarce resources to select diseases which were associated with the highest mortality and morbidity and had low-cost technologies available for prevention and treatment (1988). Thus, the priorities for childhood immunisation were set by top-level international policy makers, rather than by local communities. Such global SPHC measures have therefore been criticised for their failure to respond to local health needs and values (Banerji 1999, Banerji 2004, Wright 1995).

Community demand for vaccinations in South Asia

One practice frequently used in the EPI campaign to encourage widespread uptake of immunisations is to introduce intensive vaccination campaigns, using widespread media messages and vaccination camps to reach a large number of children in a short amount of time. The reasoning behind the use of such campaigns, which are financially impossible to sustain over a long period of time, is that once the public have been introduced to the benefits of vaccination (in the form of lower rates of illness and suffering) they will seek out such technology on their own. Mark Nichter (1995) questioned this assumption by distinguishing between ‘active demand’ (in which people would seek out vaccinations, as hoped by the EPI planners) and ‘passive acceptance’ (in which people would accept vaccinations during the campaign, but the demand would not be sustained beyond the end of the campaign).

Nichter’s argument was based on case studies showing how people in South Asia interpreted public health messages and understood vaccines to work in relation to locally recognised illness categories, as a principal factor determining community demand for vaccinations. A major problem with public demand for vaccines in South

Asia that Nichter encountered was the widespread belief that vaccines were equivalent and had a cumulative effect. Parents might want their child to receive one or a few vaccines, but not perceive a need for additional vaccinations if the child seemed to be basically healthy; they often did not understand the idea that different vaccines protected against different – and specific – diseases. This view seemed to be a consequence of health care workers giving parents very vague messages about vaccination (e.g., 'Vaccinations are good for a child's health.') because of time constraints or because they did not believe that illiterate parents would be able to understand more complex messages about vaccination. Another consequence of giving vague messages was that parents often expected vaccines to protect against illnesses that they were not designed to prevent. When a child who has received some vaccinations falls ill from any disease, this may be attributed to the vaccination's failure, thus undermining confidence in the immunisation programme as a whole.

Developing the model of vaccine acceptance

Streefland *et al.* (1999) expanded Nichter's model based on the distinction of active demand from passive acceptance, to identify a range of possible responses to vaccination programmes: acceptance, social demand, and non-acceptance. Acceptance of vaccines exists along a continuum from active to passive acceptance, and may or may not be rooted in a well-informed understanding of vaccination. Social demand, however, is more active and is based upon a perception of some general or specific benefit from vaccination; it is grounded in trust in the biomedical system, and exhibited when parents request vaccinations. Non-acceptance may be either individual (exhibited by a refusal to vaccinate) or collective (exhibited by organised resistance to vaccination). However, Streefland *et al.* noted that these categories are not mutually exclusive. Gradations of acceptance exist, and parents may change from acceptance to non-acceptance. For instance, a parent may vaccinate one child but later refuse to vaccinate a younger child, may stop vaccinating during the course of a child's immunisation course, or may refuse a specific vaccine but accept others. Certainly all three of these patterns can be observed in UK parents' responses to the MMR controversy. At the aggregate level, these different patterns of vaccine acceptance and non-acceptance lead to 'dynamic configurations of fully immunised, partially immunised, and non-immunised children' (Streefland, Chowdhury, and Ramos-Jimenez 1999, p. 1710).

Principled opposition to vaccination in industrialised countries

A number of authors have documented general resistance to vaccination in industrialised countries, particularly on the part of proponents and practitioners of certain complementary and alternative medical traditions. One of the most influential opponents of vaccination in the UK is the Australian writer and speaker Dr. Viera Scheibner (Leask and McIntyre 2003, Scheibner 2003). Dr. Scheibner conducts frequent speaking tours through Europe, North America and Australasia, sponsored by local anti-vaccine lobby groups, promoting her message that vaccines are ineffective and dangerous, and linking vaccines with such frightening dangers as cot death, asthma, cancers, and 'Shaken Baby Syndrome'. She bolsters these claims with extensive references to published medical sources and appeals to her own scientific credentials, although pro-vaccination critics have pointed out that Scheibner's scientific background is in micropalaeontology rather than health, and that the medical literature she draws upon is highly filtered and often misrepresented. In her writings and lectures, Scheibner proposes homeopathic alternatives to vaccination, and tends to downplay the seriousness of vaccine-preventable diseases. Measles, for instance, she described as 'an important development milestone in the life and maturing processes in children' (Scheibner 2001, Leask and McIntyre 2003, p. 4702). For parents concerned about the possible risks of vaccination and disillusioned by 'medical arrogance' over parents' concerns or claims that their children have suffered bad reactions to a vaccine, the anti-vaccine message put forth by such public figures can be extremely compelling.

Other groups demonstrate similar trends in opposing vaccination on ideological or alternative medical grounds. For instance, Streefland (Streefland 2001, Streefland, Chowdhury, and Ramos-Jimenez 1999) described 'New Age' anthroposophic communities in the Netherlands who hold 'contesting explanatory models of immunity' (Streefland 2001, p. 168) that view biomedical interventions such as vaccination as compromising the balance and natural immune boosting strategies that their philosophy emphasises. Schmidt and Ernst (2003) documented anti-MMR advice given by homeopaths and chiropractors over the internet. Garrett (2001) described widespread opposition to vaccination in Russia, leading to a vaccination rate of just 34% in Moscow in 1992, which was fuelled by outspoken physicians as well as alternative child care gurus. During the Soviet era, vaccination was compulsory but was not supported by access to up-to-date international research, so ineffective vaccines were sometimes used and physicians were trained to believe that many Russian children were 'weak' and could not tolerate vaccinations. In the post-Soviet era, highly decorated Russian physicians declared that vaccines contained dangerous poisons, and that vaccination programmes were killing children 'with AIDS, tumours or blood cancer' and were responsible for the disintegration of the human gene pool (Garrett 2001, p. 160). Boris Nikitin, a self-styled and widely followed child rearing expert, summarised his case against vaccination in very similar terms to Viera Scheibner's view on infectious diseases in childhood:

> Nature has designed a certain stage in child development when natural immunity is formed. This natural mechanism is called children's infections... So this immunisation of society is a great medical mistake. (quoted in Garrett 2001, p. 159)

Such resistance, or collective action against vaccination, may be directed against vaccinations generally, or against particular vaccinations with alleged adverse effects, such as pertussis vaccination, MMR vaccination in the UK, and Hepatitis B vaccination in France (Streefland 2001). In any case, resistance to vaccination is fuelled by increasing doubt over the legitimacy of the state as the protector of public health and facilitated by new communication technologies such as the Internet, which allow reports about vaccine risks to circulate quickly. Indeed, Streefland noted that health professionals in modern society tend increasingly to shift responsibility for, and decisions about, children's health to the parents, and this shift may contribute to parents' uncertainty about vaccinations and loss of trust in expert medical systems.

The pertussis vaccine scare (1970s-1980s)

A vaccine controversy bearing a striking amount of similarity to the present controversy over MMR vaccination was the dispute that emerged over the safety of the whole-cell pertussis (whooping cough) vaccine in Great Britain in the 1970s and 1980s. The pertussis vaccine controversy has been called 'the most significant setback for the cause of immunisation since the smallpox vaccine debates of the previous century' (Baker 2003, p. 4003). Although the debate originally emerged in Britain, it ultimately spread to Japan, the United States, Soviet Union and Australia, leading to sharp declines in pertussis vaccination followed by a series of whooping cough epidemics (Gangarosa et al. 1998).

The controversy, like the current MMR controversy, emerged with the publication of an article describing a small number of children believed to have been damaged by the vaccine (Kulenkampff, Schwartzman, and Wilson 1974). In this case, the article was concerned with 36 children being treated at the Hospital for Sick

Children at Great Ormond Street, who had suffered severe neurological complications in the aftermath of DTP immunisation. Like MMR, DTP is a combined vaccine for three diseases (diphtheria, tetanus and pertussis). Because the pertussis component of the triple vaccine used at the time contained bacterial cells and was more reactogenic than the diphtherial and tetanus toxoids also present in the DTP vaccine, this component was assumed to be the culprit in reactions following immunisation with DTP (Department of Health and Social Security, 1977, p. 20-21). Pertussis was recognised to be particularly harmful to infants under six months of age, below the age at which DTP immunisation was administered at that time. Thus, the primary benefit of pertussis immunisation was in providing 'herd immunity', not to the children being immunised, but rather to the younger infants they might come in contact with. The very serious complications thought to be associated with pertussis vaccine therefore seemed especially salient to many parents, who felt that their children were being put at risk for the sake of protecting somebody else (Ashley 1977).

The medical community initially appeared to be sharply divided over the safety of the pertussis vaccine. The Joint Committee on Vaccination and Immunisation (JCVI) met immediately following the article's publication and expressed support for the vaccine, but the government did not take any further action to restore public confidence in the vaccine. Several prominent physicians, including one of the authors of the Great Ormond Street article and even a member of the JCVI, publicly criticised the JCVI's decision to continue to endorse the vaccine. At the same time, general practitioners and health visitors were following much more liberal interpretations of the contraindications to vaccination than the government, so that the vaccine was withheld from many children on such grounds as being 'jittery' following a breach delivery or family history of allergies (Baker 2003, Hull 1981).

A parents' advocacy group, the Association of Parents of Vaccine-Damaged Children, was formed to provide support for parents and to focus public attention on the issue. This group played a comparable role in the pertussis vaccine controversy to that played by the JABS ('Justice, Awareness and Basic Support') parents' group in the MMR controversy. In addition to ensuring a prominent media profile and campaigning to place pertussis vaccine high on the nation's political agenda, the Association of Parents of Vaccine-Damaged Children also submitted cases of children with neurological damage allegedly caused by the pertussis vaccine to government medical panels for investigation. As a result, the Government in 1979 passed the Vaccine Damage Payments Act, resulting in the lump-sum payment of £10,000 to each of 638 people allegedly harmed by whooping cough vaccination (Healy 1978, Healy 1980).

In 1977, the government launched a series of investigations into the vaccine's safety (Baker 2003, Department of Health and Social Security 1977). Two advisory panels reviewed individual cases, including those submitted by the Association of Parents of Vaccine-Damaged Children, and a very large case-control study, the National Childhood Encephalopathy Study (NCES), examined the possibility of immunisation as a risk factor for acute neurological illness. While the advisory panels reviewing individual cases concluded that they could not prove or disprove whether the vaccine caused encephalopathy, the NCES authors reported in 1981 that pertussis vaccine was associated with an increased risk of acute neurological illness, but that the risk appeared to be very low, and that risk of permanent neurological damage was even lower (Baker 2003, Department of Health and Social Security 1981). At this point, the government launched a major education and media campaign to increase vaccination uptake. Most physicians seemed to feel the debate had been resolved by this study, but the controversy continued in the legal battle of the parents who believed their children had been damaged by the vaccine. The final legal case, in which the Wellcome Foundation undertook to clear the vaccine's reputation through a detailed critical analysis of the few cases that had led the NCES to the conclusion that pertussis vaccine could cause neurological damage, was ended in 1988, with a ruling against the aggrieved parents.

Because there are so many striking parallels between the pertussis and MMR controversies, many people – parents and public health professionals alike – have looked to the earlier controversy for guidance about how to handle the MMR scare. One point of comparison between the pertussis and the MMR vaccine controversies bears special mention. The pertussis vaccine controversy had a far greater impact on immunisation uptake and disease outbreaks than the MMR case. By 1977, pertussis immunisation uptake was down from 77% to 33%, and some districts even recorded an uptake rate of just 9% (Swansea research unit of the Royal College of General Practitioners 1981). In terms of disease burden, at least four significant outbreaks of whooping cough occurred during the course of the vaccine scare. The first of these, in 1979, had 102,500 reported cases throughout the United Kingdom and an estimated 36 fatalities. The dramatic outbreaks of whooping cough that occurred in the 1970s and 1980s may be taken as an alarming warning about the need for aggressive pro-vaccine publicity campaigns. On the other hand, the relatively lower impact of the MMR controversy is reassuring. Since no epidemics of measles, mumps or rubella have occurred on the scale of the pertussis outbreaks, comparing these two controversies may be misleading and needlessly alarmist. An in-depth understanding of parental views and decision-making, such as that undertaken in this thesis, will be required to understand why the two vaccine scares have had such different outcomes in terms of vaccine uptake.

Thimerosal preservative

Although the debate over MMR vaccination has not received the same amount of attention in other countries as it has in the UK, a different debate about a suspected link between vaccination and autism is currently going on in the United States. The preservative thimerosal, or ethyl mercury, is widely used as a preservative in vaccines, eyedrops and contact lens solutions to prevent bacterial contamination (Freed et al. 2002). Because this preservative contains mercury and, like all mercury-containing compounds, is neurotoxic at high doses, its use in vaccines administered in childhood (for instance, the hepatitis B vaccine which is now routinely administered to infants in the United States) has been proposed as a possible cause of autism and other developmental disorders.

It is difficult to determine what would constitute acceptable levels of thimerosal exposure, because there are only very limited data on the incremental and cumulative effects of the compound. Most estimates are based on published guidelines about safe exposure levels of methyl mercury, a structurally similar compound, but it is not known to what extent the body absorbs and processes thimerosal relative to methyl mercury. Even the guidelines on methyl mercury are confusing because different organisations – from the World Health Organization to the US Food and Drug Administration (FDA) and the Environmental Protection Agency (EPA) – have published different recommendations for different purposes. Whereas American committees have determined that the total amount of thimerosal that infants were exposed to from vaccines exceeded the amount of mercury exposure allowed by the EPA recommendations, and thus instituted a major change in the infant immunisation schedule (so that hepatitis B vaccine is no longer administered at birth), European panels have generally followed the less conservative WHO guidelines and recommended no change to immunisation schedules based on thimerosal concerns. Furthermore, few European countries use thimerosal-containing vaccines for very young infants (Freed et al. 2002).

The epidemiological studies on thimerosal's safety appear to be split between those suggesting an association between thimerosal-containing DTaP vaccine and neurodevelopmental disorders (Geier and Geier 2003) and those refuting the proposed link with autism (Hviid et al. 2003, Stehr-Green et al. 2003). However, as with the concerns over MMR, groups of parents who believe that their children have been adversely affected play a key role in bringing the issue to public attention (Ayres 2003).

Reporting and compensation of adverse events following vaccination

These controversies highlight the need for an effective system for reporting adverse events following immunisation, assessing the risk of such events occurring, and compensating the victims of serious reactions to immunisation. In the UK, a 'Yellow Card' scheme is in place for centralised reporting of suspected adverse reactions to medical treatments. Under this scheme, doctors report serious suspected reactions (i.e., one which is fatal, life-threatening, disabling, incapacitating or resulting in hospitalisation) to a currently marketed vaccine, and all suspected reactions to a new vaccine, to the Post Licensing Division of the Medicines Control Agency (MCA). The MCA then compiles a national computer database and reviews the number, pattern and severity of the reported reactions to identify possible problems (Salisbury and Begg 1996).

Because practitioners are often reluctant to report as suspected adverse reactions any complications that are not already recognised as side effects from the vaccine, parents may feel frustrated that certain concerns following immunisation are not registered with the MCA. This represents an important flaw in the reporting system: when parents fail to convince their physicians to report a suspected reaction, some new, and possibly real, reactions and side effects could go unrecognised because the parents' concerns never reach the central registry system. Because epidemiological studies tend to rely on centralised medical records, the studies would fail to find associations because cases of adverse reactions do not show up in the registries that they are investigating. Parents then feel compelled to report the suspected reactions through the media and the legal system. However, since these institutions are not generally recognised to have scientific validity, concerned parents and epidemiologists end up arguing past one another.

Related to the issue of how suspected vaccine reactions should be reported is what sort of compensation should be given to the families of children suffering serious medical complications that they attribute to vaccine damage. In the UK, the Vaccine Damage Payment Scheme 'provides a single, tax free payment for people who have suffered severe mental and/or physical disablement of 80% or more' as a result of vaccination against diphtheria, pertussis, measles, tuberculosis, mumps, tetanus, poliomyelitis, rubella, smallpox or *Haemophilus influenzae* type b (Salisbury and Begg 1996, p. 35). The payment – currently valued at £100,000 – is not intended as compensation for the damage, but rather to help those suffering and their families to cope with the burdens of the damage. Decisions of eligibility are made on behalf of the Secretary of State for Social Security, based on a medical officer's assessment of the extent of disability and whether it was caused by the immunisation. The 80%

disability requirement is modelled on the Industrial Injuries Disablement Benefit Scheme and means, for instance, that an individual would have to be amputated below the hip or the shoulder, or have a corrected vision of 6/60 in both eyes, to qualify. The advocacy group JABS has criticised this requirement, citing the example of a child whose left leg was paralysed and slightly withered following polio immunisation, but was considered only 50% disabled by the Vaccine Damage Payment Unit and therefore ineligible for the payment (Fletcher 1995). The requirement was lowered to 60% disability in 2002 (Department for Work and Pensions 2004).

By contrast, the United States operates a 'no-fault' compensation programme for patients suffering serious adverse reactions following required childhood immunisations (Evans 1999, Mitchell, Philipose, and Sanford 1993, Ridgway 1999). This scheme was instituted in 1988 to give parents an alternative to suing vaccine manufacturers, and thus relieve the manufacturers' liability burden. The system does not involve vaccine manufacturers or health care providers; rather, claimants petition directly to the US Claims Court. A special, randomly selected lawyer then determines the amount of compensation to be given. Petitioners cannot file a civil suit until they have filed a claim, received a decision, and rejected it; they can also request a review of the decision. The process is speeded because claimants are not required to prove causation for conditions that are included in the programme's 'Vaccine Injury Table', which lists recognised complications of the required vaccinations. In the UK, some commentators have called for the institution of a similar scheme to help prevent suspected damage from vaccines leading to costly legal actions and public controversies undermining the immunisation programme (Horton 2004).

Compulsion and enforcement

A final, crucial policy issue emerging from the many controversies over public vaccination programmes is the implementation of measures to encourage high uptake of vaccines. As a preventative public health measure, vaccination programmes depend on high levels of compliance in order to be effective and to ensure 'herd immunity' for the population. The principle behind 'herd immunity' is that when a sufficient proportion of the population is immunised, then the diseases are unlikely to emerge within the population, so that even the few individuals who have not been immunised will be protected. When vaccination rates fall below a certain threshold, the diseases can begin to resurface. Then individuals who have not been fully immunised – whether because of age, opposition to the vaccine, illnesses that contraindicate vaccination, or because immunity was not conferred at the time of vaccination – will be left vulnerable to the diseases. Thus, ensuring high levels of immunisation against particular diseases is a major component of contemporary public health programmes (King 1999).

There are two basic strategies for ensuring uptake of immunisation: (1) encouragement, accompanied by education about the vaccines, their side effects and the diseases that they protect against, and (2) compulsion. In general, compulsory immunisation policies are less effective than voluntary policies based on education. The process of legislating changes to the immunisation schedule tends to be costly and time-consuming, effectively rendering compulsive immunisation programmes inflexible with respect to new developments in vaccine technology or disease burden (Greco 1997). Countries facing this problem may resort to a two-tiered system, in which some vaccinations are legally mandatory and others are recommended but not specifically mandatory. New vaccines, or vaccines targeting recent disease concerns, typically fall under the latter classification. But these are also the vaccines for which a high uptake rate is most important, because high levels of immunity will not already be present in the population. Unfortunately, though, the two-tiered system makes the non-compulsory vaccines seem, to many members of the public, to be unnecessary or extraneous; thus, uptake of the 'recommended' vaccines is likely to be disappointingly low. In fact, Greco (1997) documented this effect in comparing the uptake of immunisations in several European countries with and without mandatory vaccination policies. Education, he argued, is a far more efficient and effective strategy for promoting immunisation.

Industrialised countries in the West have adopted varying strategies of vaccine compulsion and education. For instance, Italy has laws making some, but not all, of its childhood vaccines compulsory, but these are rarely enforced and vaccination coverage is generally less than hoped for (Greco 1997, Salisbury 2004). France operates a policy of financial reimbursement for certain 'recommended' vaccines, in addition to offering others without the financial reimbursement. In the United States only children with documented evidence of certain vaccinations can attend school, although religious and philosophical exemptions may be granted. Such enforcement of vaccination is currently being challenged in the US legal courts (Foundation for Health Choice n.d.). In Britain, the Netherlands and Scandinavia, immunisation is not compulsory, although uptake is generally quite high (Lancucki 2003, Salisbury 2004). The strategy used in Britain to encourage immunisation consists of information being given to parents (e.g., leaflets on immunisation given to parents shortly after birth and at routine health checks in the early years of life), encouragement from GPs and other healthcare professionals, particularly health visitors, and specially targeted publicity campaigns (Bradley 2000).

1.5 Research on parental attitudes to MMR

The important political and public health implications of the MMR controversy have aroused a great deal of academic interest, and a number of quantitative and qualitative studies of parents' attitudes to, and decisions about, the vaccine have been published in recent years. These studies have been useful for many public health purposes, such as monitoring the parental acceptance and uptake of MMR, but have been limited in the insight they offer about how parents conceptualise the risk of the vaccine and make their decisions. Such a gap is significant because it perpetuates the problem of parents not feeling that their views and concerns have been understood and taken seriously. The study undertaken for this thesis used an anthropological approach to obtain an in-depth understanding of UK parents' risk concepts and decision-making processes about MMR. This section reviews the previous research on parental attitudes to the vaccine. The final section of this chapter describes the anthropological approach of the present study, and explains how this approach can generate novel insights into the controversy.

Quantitative studies

Many of the researchers investigating parental attitudes to MMR have used quantitative methods to track vaccine acceptance rates and determine which factors are associated with MMR refusal. Despite a high level of public-health concern about falling immunisation rates, at least one study, using routine surveillance data, concluded that adverse media coverage had relatively little impact on mothers' attitudes to MMR (Ramsay et al. 2002). Middleton and Baker (2003) looked at the social distribution of MMR immunisation. Examining the relationship between affluence and MMR uptake in 60 English health authorities over the period from 1991 to 2001, the authors found different trends for the period 1991-1997 (before the

Wakefield paper) and the period 1998-2001 (after the publication of the Wakefield paper). In the first period, overall MMR immunisation coverage increased, particularly in the more deprived health authorities, so that inequality in coverage decreased over time. However, after 1997, MMR immunisation coverage fell in all authorities, but the decline was somewhat higher in more affluent health authorities. Thus, inequality in coverage also decreased in the latter period, although immunisation rates were now declining. Middleton and Baker concluded that 'affluent populations are, in general, the first to take up practices that are perceived as protective of child health; in the latter part of the decade, this meant declining immunisation.'

In a quantitative survey of factors affecting uptake of MMR, Pareek and Pattison (2000) noted that failure to take up the second dose was related not just to fear of the vaccine, but also to the belief that the second dose was a 'booster,' and so less important to children's health than the first dose. Mothers were not convinced by arguments about herd immunity in making decisions for their own children. Parents said that their most trusted information source about vaccination was the GP, although in fact they received more information from their health visitors. The actual source for most parents' information on the MMR vaccine was television.

In another survey, Petrovic *et al.* (2001) assessed health professionals' views about the second dose of MMR that is currently reccomended before children start school. Although this study did not look at parents' views *per se*, it is nonetheless very important, because health professionals are an important source of information about vaccination for many parents. The results showed a stunning lack of consensus and support for the immunisation reccomendations on the part of the health visitors and practice nurses. Nearly half said they had reservations about the two-dose policy, and only 20% said that they would unequivically recommend the second dose to a parent who was wavering about the decision. A third of the practice nurses said that the MMR vaccine was 'very likely or possibly associated with Crohn's disease,' and 27% thought it was associated with autism. One fifth of GPs had not read the section on MMR in the guide *Immunisation Against Infectious Diseases* (known as the 'green book') and nearly a third had not received the Health Education Authority's fact sheet on MMR. However, a more recent survey of health professionals commissioned by the Department of Health (BMRB Social Research 2003a) suggests that this situation may be changing. In that study, 93% of health visitors, 94% of practice nurses, and 90% of GPs agreed with the statement 'I feel confident explaining to parents the reasons for giving the second dose of the MMR vaccine.' Likewise, nearly 90% of respondents in each of the three groups agreed with the statement 'The policy of giving a second dose of MMR vaccine is entirely appropriate.'

The Department of Health also commissions twice-yearly tracking surveys of mothers' attitudes (and now, more generally, those of 'primary caregivers') to immunisations, which it uses to evaluate its immunisation programmes (BMRB Social Research 2003b, Yarwood 2004). The interview schedule for these surveys is based on a core set of questions developed by the Health Education Authority in the early 1990s, as well as questions specifically tailored to address issues of current concern, including attitudes to the MMR vaccine. These surveys showed that although spontaneous recall of the MMR vaccine was lower in October 2003 than in previous years (so that MMR appeared to be less 'top of mind' than at the height of the media coverage in 2002), the perceived safety of MMR amongst primary caregivers showed negligible change from February 2002. Only 63% of primary caregivers in October 2003 rated the MMR vaccine as 'completely safe' or carrying 'only a slight risk'. Furthermore, the perceived severity of the diseases measles, mumps and rubella was low (with 32%, 24%, and 40% of parents rating each of the three diseases, respectively, as 'very serious') and relatively stable, with the exception of a peak in perceived severity of measles in February 2002. Older caregivers, and those from higher social grades, 'despite their tendency to be more cynical towards immunisations' (BMRB Social Research 2003b, p. 37), were more likely to rate the various immunisations as being safe. Only 6% of the primary caregivers polled in October 2003 had refused MMR immunisation outright, but 20% had delayed the immunisation, mostly because of concerns about its safety, and 11% claimed that they would not give the MMR to a future child.

Few studies have explicitly addressed parents' decisions about single-antigen vaccines obtained through private clinics. Routinely collected statistics do not provide information about uptake of single-antigen vaccines for measles, mumps and rubella, although one recent survey estimated uptake of single vaccines among children not immunised with MMR at 21% in Lancashire (Wragg and Gornall 2004).

Qualitative studies

In addition to its tracking surveys, the Department of Health also commissioned qualitative work, in the form of focus groups, on MMR acceptance (Petts and Niemeyer 2004). These demonstrated that parents are not passive recipients of risk messages from the media, but actively seek information, particularly in face-to-face contact with health professionals, and interpret it in light of their own understanding, reinforced by social networks. Unfortunately, the in-depth analysis provided by this study was limited by its exclusion of any parents who had refused the MMR vaccine.

A few other qualitative studies about parents' views of the vaccine have been published. Sporton and Francis (2001) conducted 13 interviews with parents living in a deprived inner-city area of the UK, who had chosen not to immunise their children. Although the paper did not specifically discuss MMR, the parents described their perceptions of childhood diseases and immunisation, their fears of the risk of side effects, and the risk-benefit analyses behind their decisions not to immunise. Evans *et al.* (2001) conducted six focus groups in Avon and Gloucestershire, with a total of 48 parents, in order to understand what influences parents' decisions on whether or not to accept MMR vaccination. They found that even parents who had accepted the MMR found the decision to be difficult and stressful, and were unhappy with pressure that they had experienced from health professionals. Four key influences on parents' decisions emerged from the focus groups: (1) beliefs about the comparative risks of MMR and of contracting the diseases, (2) media and other information about the safety of MMR, (3) trust in health professionals and attitudes towards complying with medical advice, and (4) views on the importance of individual choice. A research team in Brighton (Poltorak et al. 2005) interviewed 23 mothers and participated in 'MMR talk' at carer and toddler groups. They concluded that the decision-making process incorporated and was shaped by personal and family histories, birth experiences and related feelings of control, personal assessments of their children's health and vulnerabilities, engagement with the health services and social networks and conversations. Such factors have often been overlooked in the drive to meet parents' information needs, and the authors argued that official engagement with these issues is 'essential in developing an effective discourse around vaccination that parents and professionals could share, and that might help to rebuild trust relations around this controversial issue' (Poltorak et al. 2005, p. 718).

Further writings about parents, risk and MMR

A number of other articles published in medical journals have described reasons why parents may be fearful of giving their children the MMR, and suggested ways that health professionals might improve their risk communication strategies. For instance, Elliman and Bedford (2001) blamed parental confusion and anxiety about the MMR on the 'latest media onslaught' and complained that 'incorrect media reports of vaccine uptake "plummeting" could become a self-fulfilling prophecy' (Elliman and Bedford 2001, p. 184). Bellaby (2003) argued that parents want to be assured that risk to their children is eliminated and will act in what they perceive to be their children's best interest. Noting that some parents were 'predisposed' to distrust the chief medical officer's decision not to offer single disease vaccinations after the government's earlier handling of the BSE crisis, Bellaby said that after 1998 'many UK parents would probably interpret the chief medical officer's argument as insulting, both to their conviction that they were acting in their children's interests and to their competence as responsible parents to ensure that individual vaccination courses were completed' (Bellaby 2003, p. 727).

Hobson-West (2003) offered another view of public resistance to MMR vaccination, based on her analysis of health promotion materials designed to persuade parents to choose the MMR vaccine. She found that these materials chiefly adopted a language of risk. People are assumed to make decisions by comparing individual risks, and public concern about vaccination to stem from a misjudgement of risk; thus, the usual response is to provide more risk statistics in an effort to help parents to correct their risk assessments. Hobson-West argued that these assumptions may be inconsistent with parents' basic conceptions of health and disease. In particular, she suggested that uncertainty and necessity may be more salient categories than the risk/benefit framework of the health promotion materials. If this is the case, then a substantial revision of the communication strategy for addressing the MMR controversy would be necessary. However, it must be emphasised that this thought-provoking hypothesis was not derived or tested through any research with parents themselves.

Richard Horton, who as editor of *The Lancet* was ultimately responsible for the publication of the Wakefield paper (Wakefield et al. 1998), wrote a book about the MMR controversy and the wider concerns about science and society that it highlighted (Horton 2004). In the book, Horton expressed deep reservations about the extent to which medical research is underpinned, and probably influenced, by corporate sponsorship and other financial conflicts of interest. At the same time, our society lacks the institutional arrangements and scientific literacy that would be necessary to foster 'the democratic control of science in society' (Horton 2004, p. 170). Such conditions provide little outlet for public involvement in setting the agenda for scientific and medical research (e.g., demanding more investment into autism care and understanding why the prevalence of this distressing problem has increased so much in recent decades). Public values and uncertainties then find expression in media reporting which may or may not accurately reflect the balance of 'expert' scientific opinion, and in making public health matters personal: the public may not be able to shape national scientific agendas or immunisation policies, but parents can (and do) take it upon themselves to decide to what extent they will comply with those policies in vaccinating their children.

1.6 Scope for anthropological contributions and overview of thesis

The anthropological approach

The study presented in this thesis provides an extensive, detailed, and empathetic evaluation of how parents themselves express their understanding of the issue and the process by which they make their decisions. Focus group discussions and in-depth ethnographic interviews were conducted with a relatively large number of parents (N=87) in order to develop a detailed picture of parents' experiences with making a decision about MMR vaccination. This approach allows for a comparison between the parents' viewpoints and those of medical and public health professionals, identifying key areas of communication failure (and success!). The results of this anthropological study of parents' views were then used to develop a survey documenting the distribution of those views in a large sample of the population. Findings were presented to groups of both parents and health professionals for feedback, thus contributing to real understanding between parents and health professionals about this important, and contentious, topic.

Another strength of the anthropological approach adopted in this study is its critical interpretation of, and contribution to, a growing body of literature on the social construction of risk and trust. This study contributes to the development of the social theory of risk because of several important features of the MMR controversy. First, the MMR debate represents a situation in which parents must evaluate contradictory information about risk and make some determination about the relative trustworthiness of a range of information sources. Second, all of the decisions that a parent might take are associated with some risk, and so the study describes how parents go about balancing risks against one another and choosing which risks they are most concerned about. Third, the importance of herd immunity to successful immunisation programmes allows for an investigation of how individual and collective risks and benefits are related to, and often viewed as opposed to, one another. Fourth, an additional level of social and legal complexity is introduced when people are making or contesting decisions about risk, not on their own behalf, but on behalf of children who are unable to make their own decisions. This thesis advances the discussion by critically evaluating how social theory and empirical data shed light on one another with respect to these issues, which are only recently beginning to be incorporated into the literature on risk and sociocultural theory.

Overview of thesis

How, then, do parents make important decisions in the face of such frightening and contradictory reports about risk? Three important themes are implicit in this question, and will be explored in my thesis: the social construction of risk, the building blocks of trust, and the complexity of the decision-making process. With reference to these themes, the aim of this thesis is to give expression to the parents involved in making decisions about the MMR vaccine, in order to improve policy and practice for this and other health-risk controversies.

Chapter 2 presents a review of the current literature on sociocultural theories of risk and trust in medical decision-making. In my study I explored many of the themes presented in Chapter 2 by talking to parents in focus groups and interviews, and tested the general agreement of my findings amongst a large group (N=996) of parents using a mail-based survey. The methods that I used are described in Chapter 3. Chapters 4-6 will examine in detail the way that private decision-making is informed by these ideas. In Chapter 4, the viewpoints that parents expressed in the focus groups and interviews are presented and discussed. Serving as a bridge between the qualitative methods of Chapter 4 and the quantitative methods of the postal survey is a technique known as cultural consensus analysis. This technique was used to evaluate the degree of agreement among informants in their responses to sets of questions, and to develop suitable questions for the postal survey, and the results are shown in Chapter 5. The findings of the mail-based survey are presented and discussed in Chapter 6. Finally, Chapter 7 summarises the implications of the study's findings and offers a discussion about possible ways forward.

CHAPTER 2
THE SOCIAL CONSTRUCTION OF RISK AND TRUST

> No lesson seems to be so deeply inculcated by the experience of life as that you should never trust experts. If you believe the doctors, nothing is wholesome. If you believe the theologians, nothing is innocent. If you believe the soldiers, nothing is safe. They all require to have their strong wine diluted by a very large admixture of insipid common sense.
>
> *Lord Salisbury (3rd Marquess of Salisbury), letter to Lord Lutton, 15 June 1877*

2.1 Overview of social science literature on risk

The MMR vaccine controversy hinges on contested notions of risk, trust (or lack thereof) between members of the public and the medical establishment, and the role of parents as decision makers. How do we make important medical decisions, like whether to immunise our children with a controversial vaccine, in the face of frightening and contradictory reports about risk? Although such decisions are ultimately undertaken by individuals, social context plays a key role in shaping public debates and policies, as well as in forming individuals' notions and decisions about risk. Hence, researchers in the social sciences have long been concerned with the ways in which risk is socially constructed and portrayed. Deborah Lupton (1999) highlighted three important streams in the social scientific theory of risk, which are only recently being brought together by researchers in an integrated approach: (1) anthropological work, following the cultural theory of Mary Douglas on the social and cultural construction of risk (Douglas 1985, Douglas 1992, Douglas and Wildavsky 1982); (2) the sociological 'risk society' theory of Ulrich Beck and Anthony Giddens (Beck 1992b, Beck 1994, Beck 1999, Giddens 1990, Giddens 1991, Giddens 1994b, Lash, Szerszynski, and Wynne 1996); and (3) Michel Foucault's notion of 'governmentality' which includes mechanisms of defining risk, surveillance and regulating populations (Castel 1991, Foucault 1991). A further stream of research on risk, which forms an important background to the perspective of this thesis, is the psychometric work on risk perception and the social amplification of risk (Fischhoff, Bostrom, and Quadrel 1993, Freudenberg 1988, Kasperson et al. 1998, Pidgeon 1999, Slovic 2000). Throughout this literature, *trust* is also conceived as playing a fundamental role in determining how risks are constructed and navigated.

This chapter provides a comprehensive review of the social scientific literature on risk and trust. Much of this literature, particularly that written more than ten years ago, is concerned primarily with ecological (environmental) risk. However, today's news headlines and popular attention are much more often focused on individual health risks. This thesis is primarily concerned with risk and trust as they relate to health in particular, although it is necessary to cover in some detail the literature dealing with ecological risk as background to the more recent interest in risk to health.

2.2 Cultural theory

Why do people disagree on which risks to worry about?

One of the most significant works about the social construction of risk is *Risk and Culture,* by anthropologist Mary Douglas and political scientist Aaron Wildavsky (1982). All risks, they argued, are socially constructed, because identifying a risk requires a particular configuration of ideas about what outcomes would be undesirable, and what conditions put us in danger of experiencing those outcomes. The risks that we choose to regard as salient have to do with what kind of society we want. Douglas and Wildavsky began their book by asking:

> Can we know the risks we face, now or in the future? No, we cannot; but yes, we must act as if we do. Some dangers are unknown; others are known, but not by us because no one person can know everything. Most people cannot be aware of most dangers at most times. Hence, no one can calculate precisely the total risk to be faced. How, then, do people decide which risks to take and which to ignore? On what basis are certain dangers guarded against and others relegated to secondary status? (Douglas and Wildavsky 1982, p. 1)

Different people worry about different risks, disagreement is deep and widespread, and programmes enacted to reduce risk consistently come up short. Why is this? Risk is a product of 'knowledge about the future and consent about the most desired prospects' (Douglas and Wildavsky 1982, p. 5). Total knowledge is impossible because even as expanding science produces knowledge, it also opens up new realms that we do not understand or know about. Yet total knowledge is what would be required if we were really to understand the risks that face us. And even if we had sufficient knowledge, Douglas and Wildavsky went on to argue, ranking risks as a society is impossible because there is no consensus on the criteria for evaluating risks.

Pollution, risk and blame

The criteria for evaluating risks, according to cultural theory, are determined by and reflect wider social objectives.

> How do we decide which risks to face? We choose the risks in the same package as we choose our social institutions. Since an individual cannot look in all directions at once, social life demands organization of bias. People order their universe through social bias. By bringing these biases out into the open, we will understand better which policy differences can be reconciled and which cannot (Douglas and Wildavsky 1982, p. 9).

Thus, the identification of risks has to do primarily with a cultural predisposition toward a particular kind of social outlook. This theory builds on Mary Douglas's earlier work on purity laws and danger (Douglas 1966), in which distinctions between clean and unclean were conceived as tools for establishing social order and maintaining social boundaries. In *Purity and Danger*, Douglas wrote of the function of taboos against 'pollution' (or religious defilement), in protecting 'primitive' society 'from behaviour that will wreck it' (Douglas 1992, p. 4). In modern Western society, fears about different kinds of 'pollution' (e.g., of the physical environment) perform the same role.

Cultural theory links these different concerns about pollution through the notion of 'risk', giving 'a way of thinking about culture that draws the social environment systematically into the picture of individual choices. It provides a method of analysing public debates as positions taken in a conflict between cultures' (Douglas 1992, p. xi). Risks pose a threat not only to individual well-being, but also to the prevailing social order. Thus, the type of risks that we fear will depend on the type of social order that we are committed to. Put in other words, the social construction of risk depends upon cultural predispositions.

Related to the question of what risks people fear is the question of how people explain misfortune. This has long been a preoccupation of social anthropologists. Evans-Pritchard (1937) noted that there are two levels of causal explanation for unfortunate events: one dealing with the physical mechanism by which the event occurs, and the other for explaining why it happened to this particular person at this particular time. For instance, if a hut collapsed and killed somebody sitting underneath, the Azande (the people about whom Evans-Pritchard wrote this classic ethnography) understood that the hut collapsed because the wood had been damaged by termites (Evans-Pritchard 1937, p. 69-70). However, witchcraft, or in other cases, the known transgression of social boundaries, was invoked in order to explain why it had happened at this particular time and to this particular person.

The need to explain the particular occurrence of misfortune to particular people is by no means unique to Azande social life, and all societies have developed mechanisms of blame and responsibility to address this question. According to Douglas, these explanations can entail moralistic victim-blaming (e.g., punishment for sin), individual malevolence, or an outside enemy. A society's system of justice reflects which of these blame mechanisms are invoked: it may respond to a member's death, for instance, by exhorting the community to obey the laws in order to avoid such a fate; it may search for and punish the responsible individual; or it may band together in order to inflict communal punishment on the external foe. Furthermore, pollution and communal prescriptions about assigning blame are a 'weapon of mutual coercion' (Douglas 1992, p. 6) that reinforce social structures and individual duties to the community (Douglas 1992, p. 6, Douglas and Calvez 1990).

Even (perhaps especially!) in modern, high-technology societies, risk and blame are cultural and political currency. Despite the intense efforts of a new host of professional 'risk analysts,' we are no closer than the Azande diviners to understanding definitively why bad things happen to particular individuals. 'Knowledge always lacks. Ambiguity always lurks. If you want to cast blame, there are always loopholes for reading the evidence right' (Douglas 1992, p. 9). So in all societies, risk and blame are shaped by cultural predispositions. Risk is invoked to hold individuals, corporations, and governments accountable for harm when they do not comply with accepted ways of behaving. For instance, failure to engage local residents in public discussions about the siting of hazardous waste dumps becomes a 'risk' issue when people suspect that their illnesses have been caused by their proximity to a toxic dump. At the same time, risk calculations are also used by the accused to deflect blame from themselves with claims that the alleged risks were exaggerated or manufactured from irrational hysteria.

Risk disputes express points of tension and value conflicts in society, and 'narratives of risk are pervaded by concepts of accountability, responsibility, liability, and blame' (Nelkin, 2003, p. viii). These points of conflict may reflect more specific issues than immediately suggested by Douglas's framework. For instance, Nelkin (2003) suggested that anxiety about risk from new medical procedures may stem from resentment about the growing power of corporate management of medical care. Indeed, the last ten years have seen a notable shift in emphasis from ecological risk to personalised health risks, both in popular discourse and in the social scientific risk literature. I would suggest that this change reflects larger changes in social concerns: the importance of national identity has arguably declined over this period, while consumerism increasingly defines our personal identities. In this social environment health is treated as both a commodity and a right, so it is a key focal point for talk about risk, blame and responsibility.

Cultural predispositions

Risk and Culture (Douglas and Wildavsky 1982) focuses on two cultural predispositions evident in 20th-century American culture and their adherents' consequent views on risks. Egalitarians, also refered to as 'the border' or 'sectarians', are concerned about the effects that our actions will have on the entire social community or ecosystem; they want to protect the most vulnerable members of society, and tend to be more concerned about the health risks posed by environmental pollution. Free-market individualists (or 'the centre'), on the other hand, view nature as being resilient, and worry more about the risks to their own success from excessive regulation.

Further work (Adams 1995, Adams 1997, Wildavsky and Dake 1990) has expanded this classification to include hierarchists (who trust in regulatory authorities to safeguard us from technological dangers but fear things that threaten the established authority), as well as sometimes fatalists (who understand themselves to be helpless in the face of risks) and hermits (who remain aloof from debates about risk, though perhaps analysing them without choosing sides). Adams (1995, 1997) usefully schematised this classification along two axes, representing on the one hand degrees of collectivization and on the other, egalitarianism in the aspired-to social order (Figure 2.1).

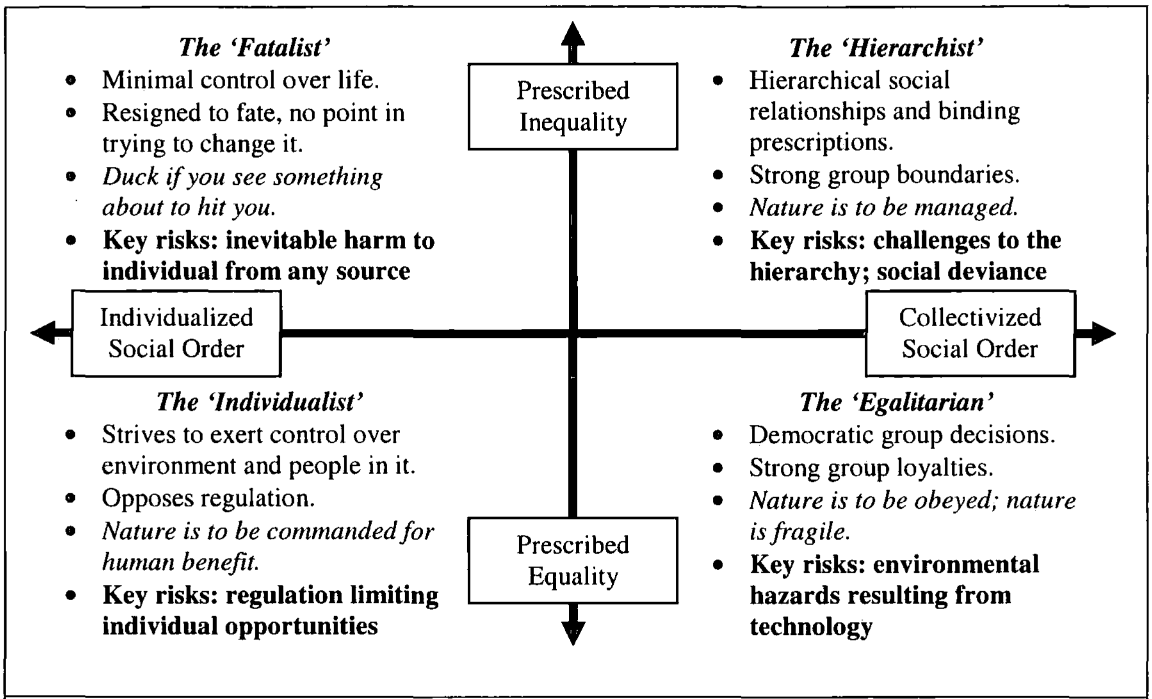

Figure 2.1 Schematic diagram showing four different 'rationalities' or cultural predispositions to different types of risks. A fifth category, the 'hermit', may be thought of as hovering above the plane shown in the diagram, observing but not engaging in, dialogue about risk. Adapted from (Adams 1997, p. 296).

Regardless of the specific number of 'cultural biases' included in the scheme, the essential point is this: cultural biases associated with social groupings result in predispositions that form the primary determinant for which type of risks – e.g., technological, economical, or socially deviant – people fear. These sorts of differences make it very hard to achieve societal consensus and acceptable policy decisions about what types of risks we should be concerned about and how we should use common resources to manage risk. In addition, danger and blame are used by social groups to reinforce group boundaries and expectations for members' behaviour.

Research issues

The cultural theory approach has been criticised for not been empirically demonstrated. Despite some apparent success in testing the hypothesis that societal concerns can be predicted by people's cultural biases (Dake 1991), such studies are fraught with an inherent methodological problem: how can the researcher categorise people into one of the cultural groups, apart from pointing to beliefs (which will be closely related to beliefs about risk)? Such an analysis quickly breaks down into tautology (Adams 1995, p. 64). Another difficulty with the theory is that it does not account for how the different cultural biases emerge within a single society. *Risk and Culture* (Douglas and Wildavsky 1982) likens the 'egalitarian' predisposition to primitive societies, but does not explain why some people in industrial societies would identify with one 'culture' and others with a different one.

Yet, if we do not look to the theory as a predictive model, but rather as emphasising the mutually reinforcing interrelations between social organisation and risk anxiety, then this objection becomes less important for the application of cultural theory to research on risk. Cultural theory provides a useful contextual framework in which to understand variance in notions about risk. Douglas (1992, p. 46-47) proposed four 'cultural questions' that can profitably be investigated to shed light on how these themes are linked in a particular cultural context:

1. What (and to what extent) is the bearing of a particular risk on the individual perceiver's purposes?
2. How much is the community part of the individual's purposes?
3. Is the risk thought to affect the individual or collective good?
4. To what extent do community members support authority, commitment, boundaries and structure?

These questions will be addressed with respect to the MMR vaccine in the remaining chapters of this thesis.

2.3 The risk society

Late modernity and reflexivity

The 'risk society' approach expounded by the German sociologist Ulrich Beck (1992ba) has also enjoyed widespread influence in the social science literature on risk (see, for instance, Bujra 2000, Bunton, Nettleton, and Burrows 1995, Caplan 2000a, Jackson and Scott 1999). This theoretical orientation takes as its point of departure the designation of our current historical period as 'late modernity'. New consequences of modernity – particularly risks brought about as a result of industrialisation – have now begun to emerge into the public consciousness, such that people '*choose* new and unexpected forms of the social and the political' (Beck 1999, p. 1, emphasis in original).

Social relations are not fixed, but are reflexively ordered and re-ordered 'in the light of continual inputs of knowledge affecting the actions of individuals and groups' (Giddens 1990, p. 17). Thus, the late modern period is characterised by 'reflexivity', in which modernity begins to reflect on itself and its structures (Beck 1992ab, Beck 1994, Beck 1999, Giddens 1991, Giddens 1994a, Lash 1994). This statement is rather problematic in English because we do not normally attribute agency or thought capacity to abstract concepts like 'modernity'. It may be better to think of people living in the late modern era interacting in new ways with the structures and institutions of modernity. In any case, such 'reflexivity' is a new feature of social life, and as such represents a qualitative shift in the institutions, structures and modes of action of modern life from the early modern period. However, it results not from a breakdown of modern values and processes, but rather from their very success in penetrating virtually every area of life. For this reason, Beck and his colleagues reject the post-modernist claim that modern institutions have broken down or been deconstructed; rather, these institutions have continued to develop rapidly along the same trajectory as in the early modern period, but with a dramatic change in their effects.

Risk in late modernity

As the process of industrial modernization has developed, its benefits have been accompanied by a multitude of harms. Such harms, in Beck's view, do not result simply from the poor conduct or regulation of particular actors, but are rather an inevitable consequence, inherent to the process of industrialisation. The benefits and the harms from modernization are inextricable. Thus, a central part of reflexivity is a growing awareness of risk. Industrialisation has created risks that are spinning out of control, so that we must be increasingly preoccupied with how to live with or change the dangers generated by industrialisation. Together with this collapse of controllability has come a loss of certainty about the safety and benefits of new technologies.

Beck explicitly takes issue with the cultural theorists' assertion that there is no substantive difference between the dangers of early history and those of developed civilisation (Beck 1999, p. 23). In Beck's view, the risks of late modernity are both qualitatively and quantitatively different from those faced by previous generations: they are in many ways invisible, 'localized in the sphere of *physical and chemical formulas*' (Beck 1992ba, p. 21, emphasis in original), yet carry a previously impossible potential for catastrophe and irreversible harm. Now it is possible to imagine, as a direct result of scientific exploitation of nature and industrialisation, that humanity could bring about its own total destruction, for example in a nuclear war or by such massive environmental pollution as to make the earth uninhabitable. These risks have become so central to late modern social life that the industrial society of the early modern period can be said to have been replaced by a new 'risk society' (Beck 1992ab).

'Risk' as a way of coping with modern threats

Beck's definition of risk places it exclusively in the domain of reflexive modernity: '*Risk* may be defined as a *systematic way of dealing with the hazards and insecurities induced and introduced by modernization itself*' (Beck 1992ba, p. 21, emphasis in original). Elsewhere, Beck is more explicit about how the risk concept is used to cope with the collapse of controllability and certainty in the reflexive, late modern period:

> Risk is the modern approach to foresee and control the future consequences of human action, the various unintended consequences of radicalized modernization. It is an (institutionalized) attempt, a cognitive map, to colonize the future. (Beck 1999, p. 3)

This is a difficult definition of risk, because it differs significantly from the common usage of the term, in which 'risk' refers to the threat itself, or to the likelihood of coming to some harm. For Beck, 'risk' is not the danger itself, but the means of coping with insecurity and uncertainty that we face in the modern era. The insecurity and uncertainty arise because of widespread *knowledge* about danger, or potential dangers. But this knowledge is also deeply linked to *unawareness* about dangers (Beck 1999). In many cases, we simply cannot know the extent of the threats around us; furthermore, even if we do know about the abstract probabilities, we do not know whether or when they will result in our own personal harm (returning us to the problem of explaining misfortune described by Evans-Pritchard).

Despite the confusion caused by Beck's use of the term 'risk', I present his treatment of the concept in detail in this section because it provides an important background to understanding how people in modern Western societies reflect on and manipulate their uncertainties and risk concepts. However, throughout the rest of this thesis, I will use the term 'risk' in its conventional sense, to refer to threats, feared dangers and likelihood of harm.

Creeping, unseen risk

The dangers arising from industrialisation were at first unnoticed: like cats, they crept in, not showing their claws until it is too late for us to be startled and run to safety. Now, modernity and its attendant threats are so fully entrenched that they have become largely unavoidable, even though we are increasingly aware of their presence and critical of the forces that generate them. As Beck notes,

> The transition from the industrial to the risk period of modernity occurs undesired, unseen and compulsively in the wake of the autonomized dynamism of modernization, following the pattern of latent side effects. One can virtually say that the constellations of risk society are produced because the certitudes of industrial society... dominate the thought and action of people and institutions in industrial society (Beck 1994, p. 5).

Risk, as 'a way of dealing with the hazards' (Beck 1992ba, p. 21), requires knowledge about their origins. Because the new risks are largely invisible, seemingly esoteric knowledge plays an increasingly important role in the risk society. People work to establish causal links between seemingly unrelated phenomena (e.g., use of the pesticide DDT and the health of babies who may be found to be receiving residues of the pesticide in their mothers' milk (Beck 1992b, p. 25, Smith 1999)). These people include not only scientists, but also other members of the public who are increasingly becoming concerned about the effects of chemicals, nuclear power, and the like, on their health and on the environment. As we shall see below, the public efforts to establish causal links, to produce knowledge about risk, have consequences that are at least as important as the technical, scientific demonstration of such links (or the lack thereof).

Belief and the social consequences of risk

Risks must be believed, because they can't be experienced as such. (How can we experience the danger posed by pesticides in the water supply, until we begin to get sick and die?) Therefore, important debates emerge about what risks we, as a society, are willing to accept, and what risks we are willing to believe in. This is not to suggest that the threats are not real. The hazards represented by these risks continue to affect us, whether we believe in them or not. Risks are both material (i.e., they have a physical reality) and immaterial (i.e., they are socially constructed); risk statements are both statements of knowledge and of value (Beck 1999, p. 26, 138).

Competing rationalities and risk definitions become entangled in a debate about how we wish to live. This point, of course, echoes the cultural theory of risk, but Beck places the argument in a rather different context. Whereas Douglas's concern was with why some things are defined as risks and others are not, by different groups of people and at different times, Beck is interested rather in how the definition of risk is a reflection on and critique of modernity itself, even as we are inextricably bound to it. As we expect from cultural theory, different sectors of the population will have different concerns and ways of talking about risk. But Beck takes a more monolithic view of 'the public,' placing it in opposition to science. In particular, scientific and lay public arguments end up talking past one another:

> Social movements raise questions that are not answered by the risk technicians at all, and the technicians answer questions which miss the point of what was really asked and what feeds public anxiety (Beck 1992b, p. 30)... The social effect of risk definitions is therefore not dependent on their scientific validity (Beck 1992b, p. 32).

In this light, risks have profound social and political consequences, independently from their physical reality. Indeed, as Frankenberg notes, when

> the epidemiological measurement of future risk coincides with present discontents at the same time renders more precisely popular perceptions of causation in the recent past, it may be more than acceptable – it may be explosive (Frankenberg 1993, p. 235).

What matters is public belief in, and anxiety about, risks, for which governments and industries are held accountable. Whatever the scientific evidence about the potential dangers posed by industry (and this is often incomplete), insecurity and uncertainty arise whenever people fear, or believe in, potential dangers. People will act on their insecurity and fears, whether or not the harms they expect ever come to pass. Furthermore, as we shall see in Section 2.5 (p. 89), perceptions of risk often lead people to change their risk-related behaviour, which then in fact does alter their physical level of danger.

Distribution of 'goods' and 'bads'

Because the social consequences of risks pivot on public experience and belief in them, defining risks has become a political act, or a 'power game' (Beck 1999, p. 4). Also, the distribution of harmful consequences emerging from technical progress is now highly politicized. Whereas industrial society was concerned with the distribution of 'goods', risk society is concerned with the distribution of 'bads'. The quest for safety has outstripped the quest for wealth. 'Risk-creation in the name of modernity and progress is constantly transformed into a private burden for citizens who must deal with it as informed consumers' (Murphy-Lawless 2003, p. 212-213).

According to Beck, risk (or the 'bads' of the risk society) can never be distributed fairly. Many studies have demonstrated social inequalities in the distribution and management of risk (Bullard 1993, Bullard 2000, Farmer 1999, Kroll-Smith, Brown, and Gunter 2000, Kroll-Smith and Floyd 1997, Szasz 1994). Technological and business decisions are made by balancing expected benefits and expected risks. However, the communities that have to live with the risks taken by others (e.g., engineers or business leaders) do not necessarily enjoy the benefits of those decisions. In particular, the economically disadvantaged or otherwise socially marginalised often lack the clout to resist pollution and dangers to their communities: 'Pollution follows the poor' (Beck 1999, p. 5). On a more positive note, Beck suggests that 'risk sharing,' in which members of diverse nations and communities recognise that our fates with respect to modern risks are intertwined, may be a way of building borderless, post-national communities (Beck 1999, p. 16).

Not only do disparities arise in the political discussions about *who* shall shoulder the risks from techno-industrial decisions, but defining *what* constitutes a salient risk, with respect to any given decision, is also a charged political issue. For instance, Bray (Bray 2003) examined the scientific debates about the safety of genetically modified crops (in terms of consumer health and environmental effects), highlighting the need to take into account other dimensions of risk, which cannot be evaluated in biological studies, like the effects of technology on the livelihoods of poor farmers. The poor farmers in question are rarely heard in the 'dubiously democratic political procedures through which GMOs are approved' (Bray 2003, p. 186).

Beck contends that it is the industrial generation, not the number of deaths or injuries, that makes risk a political issue. Thus, he contrasts risk debate in late modernity against anxieties of earlier times. Only in late modernity is risk debate about accountability and responsibility, because in the risk society threats come about as the result of people's economic decisions (Beck 1999, p. 50). This is, of course, in stark contrast to Mary Douglas's work demonstrating underlying similarities in attributions of blame for misfortune between tribal and modern societies.

Expertise and ambivalence

Risks deepen dependency on experts. Because of the high level of technical knowledge required to understand the science behind industrial risks, the very people producing a threat are the ones we turn to for interpretation; indeed, they have a 'monopoly of interpretation' (Beck 1999, p. 58). So engineers (or other technical experts) are allowed to answer – by their own internal standards – the social and political question, 'how safe is safe enough?' And yet, when risks are assessed by experts, they enter the public domain, and the public may or may not tolerate the same level of danger, or the same dangers, as the experts: 'Risks pointed out by experts at the same time disarm these experts, because they force everyone to decide for themselves: what is still tolerable and what no longer' (Beck 1999, p. 141-142).

Beck distinguished between two types of knowledge: one based upon experience, and the other based rather on data, procedures and manufacturing. The latter, apparently, is the basis for technological development and 'expert' risk assessments. The public discussion of threats, on the other hand, 'is related to everyday life, is drenched with experience and plays with cultural symbols' (Beck 1994, p. 30).

When experts do not acknowledge public ambivalence, and fail to connect their assessments to public experiences and concerns, their plans are likely to meet with opposition. They are often dismayed by such opposition, convinced as they are that their plans were formulated rationally, in the interest of the public good. They fail to recognise the 'onset of ambivalence' (Beck 1994, p. 29). Dialogue between opposing opinions does not resolve the conflicts but only hardens them, precisely because the authorities demand an unambivalent consensus among industry, politics, science and the public. Usually, this means that experts are called on to 'educate' the public, while the public are rarely invited to 'educate' the experts about their own experiences and how these may be relevant to the issues at hand.

Dorothy Nelkin has pointed out that the cumulative nature of risk warnings has fostered distrust in science, which is now seen as 'embedded in corporate agendas and imbued with conflicts of interest' (Nelkin 2003, p. xii). The evolution of risk disputes depends more on lobbies and social groups than on the nature of the risk. Ignoring the social, ethical, and political issues in risk disputes will preclude long-term resolution. Thus, the role of risk in modern society is related to the erosion of public trust in governments and science as society becomes increasingly complex in late modernity. The relationship between risk and trust will be discussed in detail in Section 2.6.

In order for compromises to be achieved, Beck urged that we must dispense with 'the old, instrumentally rational order, according to which the task is for specialists to 'enlighten' laypeople' (1994, p. 30). To this end, Beck made five demands:

1. De-monopolize expertise (no longer assume that experts and administrators know better what is good for everyone).
2. Include in decision-making those nonspecialists for whom the decisions will be socially relevant
3. Open the structure of decision-making (no longer proceed as though decisions have already been made and simply need to be sold to the public)
4. Hold negotiations in public dialogue 'between the broadest variety of agents, with the result of additional uncontrollability' (Beck 1994, p. 29), rather than behind closed doors.
5. Strive for agreement and widespread sanctioning of norms for these processes (e.g., how to conduct discussion, debates, voting, approving).

Adams (1995, p. 185) criticised such prescriptions, saying that those without technical, scientific competence will be unable to 'separate truly stupid or nonsensical ideas from those deserving of their protection.' But in situations where trust in scientific experts has already broken down, it may be necessary to take these sorts of steps before scientists will have the credibility to make publicly acceptable decisions. Beck acknowledged that there is no guarantee that such measures will succeed; nor can they abolish conflict or the dangers posed by industrial production. But he maintained that they can 'urge prevention and precaution and work towards a symmetry of unavoidable sacrifices. And they can practice and integrate ambivalences, as well as revealing winners and losers, making them public and thereby improving the preconditions for political action' (Beck 1994, p. 30).

2.4 Risk in relation to knowledge, power and surveillance

Foucault's contributions to the study of risk

The third social science stream of analysis of risk issues follows the methods and writings of Michel Foucault (Castel 1991, Foucault 1991, Turner 1997). Foucault himself did not write about 'risk' as such. Nonetheless, his central themes of knowledge, power and surveillance are readily applied to discourses about risk and public health.

Foucault is widely regarded as one of the intellectual giants of the twentieth century, and there is hardly a field of study that has not been influenced by his thought. But his work has also been criticised, sometimes fiercely, as we would expect for such an influential author (e.g., Anderson 1984, Habermas 1986, Said 1986, Walzer 1986). It is not my desire here to debate the merits or demerits of Foucault's thinking and influence, but rather to present an example of a 'Foucauldian' approach to the study of risk, in the sense that it draws on the work of scholars indebted to Foucault for their methodology and analysis. Four concepts in particular deserve special mention: knowledge (the way that elements in a discourse are related to one another); power, especially bio-power (the close alignment of knowledge and power relations to manage and regulate life projects); surveillance (of individuals and populations); and resistance (or power expressed in opposition to other power manifestations). Under each of these headings (knowledge, power, surveillance, resistance) I will first outline the methodological and theoretical considerations, and then offer a Foucauldian analysis of how these ideas are manifest in the practice and discourse of contemporary public health.

Risk knowledge

'Knowledge' in the Foucauldian sense represents the relations between things that are produced in discourse. To unpack this statement, let us think of discourse as a set of propositions with a regular and systematic organisation. For instance, medicine may be conceived as a discourse, whose propositions are governed by the rules of scientific enquiry and their application to ill or healthy bodies. Illness itself is a category that emerges from medical discourse, and *knowledge* relates illness to symptoms, to physiological processes, to behaviours or environmental conditions – all of which are also categories that are produced (as items that we can talk about) from medical discourse.

We could identify several different risk discourses: epidemiological, penal, litigious, and so on. A Foucauldian analysis of discourse entails identifying the rules of the production of statements, (particularly those rules which delimit what sort of proposition is permissible within a given discourse and how *new* propositions may be produced) and identifying the ways that material practice and thought are linked (Kendall and Wickham 1999, p. 42-47). In the following paragraph I undertake a Foucauldian exercise in examining the role of knowledge in the epidemiological discourse about risk.

The science of epidemiology is largely concerned with generating knowledge about behaviours, the environment and other 'risk factors' that are associated with conditions of ill-health. Legitimate knowledge in epidemiological research must be based on statistically significant correlations between observed phenomena. Risks, 'at-risk' groups, and 'risky' people and things can all be thought of as being produced by the epidemiological discourse. Prior to this discourse, we had sickness, fear, and contagions (all of which may be 'things' produced in other discourses) but we did not put them together to formulate ideas or knowledge about 'risk'. But this knowledge is not merely about abstract thought linking things that were not previously related in this way. The knowledge also has a practical (or, in Foucault's terminology, 'material') component. In the epidemiological risk discourse, individuals and populations must be monitored for signs of risk. Statistics about an enormous variety of behaviours (e.g., smoking, immunisation, work, sexual practice) and health markers are routinely collected. Once risky behaviours or conditions are identified through public health surveillance techniques, there is a moral imperative to eliminate or reduce the risk through disciplined intervention[1]. This brings us to our second theme: power.

'Bio-power'

Power is the process by which the practical and abstract components of knowledge are connected. It is a relation between forces, and is a necessary and intrinsic part of dialogue. However, Foucault's notion of power is very different from that employed, for instance, in Marxist theory. For Foucault, power

> is not essentially repressive; it is not possessed, but is practised. Power is not the prerogative of 'masters', but passes through every force. We should think of power not as an attribute (and ask 'What is it?'), but as an exercise (and ask 'How does it work?') (Kendall and Wickham 1999, p. 50).

Continuing the Foucauldian exercise in evaluating the public health discourse, we see that the objects[2] of power are represented as data points, or as 'at-risk' patients

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[1] This treatment glosses over the important difference between statistical correlations and causes.

[2] Somewhat confusingly, Foucault referred to the objects of power as 'subjects' (like people as subjects of a sovereign ruler or as subject to some force), and described at length the various techniques by which subjects are produced (for a useful overview, see Rabinow 1984).

in need of intervention to prevent future ill-health. Power even objectifies 'the sheer fact of being alive in natural history or biology' (Foucault 1982, quoted in Rabinow 1984, p. 8). This forms the basis for what Foucault terms 'bio-power', which describes how knowledge and power relations are closely aligned in managing and regulating life projects (Foucault 1990). Such a regime 'whose task is to take charge of life needs continuous regulatory and corrective mechanisms... [it] has to qualify, measure, appraise, and hierarchize' (Foucault 1984, p. 266). Thus, the public health apparatus becomes increasingly involved in people's day-to-day lives, exercising bio-power through its surveillance and intervention efforts. Knowledge about risk makes social institutions, together with individuals, accountable (Nichter 2003, p. 30 (n. 8)).

Later, Foucault coined the term 'governmentality' to refer to the mechanisms for regulating and controlling populations through an apparatus of security, requiring many specific 'expert' knowledges (Foucault 1991, Turner 1997). Governments may act on populations either directly through mass campaigns, or indirectly through various techniques – often operating without people's full awareness – to compel certain behaviours and activities.

Self-regulation and surveillance

The role of individuals in monitoring and managing their own risks is increasingly central to public health discourse about risk. Foucault's famous image of the 'panopticon' can help to explain how such self-surveillance comes about (Foucault 1979, p. 195-230, Rabinow 1984, p. 18-20). The panopticon is imagined as a tower from which an unseen observer can watch all that goes on around it. Knowing that they are being observed, those under the panopticon's gaze will modify their actions, only doing those things which they are prepared for the person in the tower to see. Because the observer is unseen, however, the people under observation never know if there is actually anybody in the tower at any given time. So they must continue to behave as though they were being observed, even when there is nobody in the tower. To accomplish this, they engage in practices of self-surveillance and self-discipline.

Extending the panopticon-metaphor to the public health discourse on risk, the public health surveillance apparatus is the observer in the tower. But instead of direct, face-to-face observation and contact between expert observers and subjects, this surveillance is based on abstract risk calculations (Castel 1991, Petersen 1997). Statistics have become a 'major technical factor' (Foucault 1991, p. 99) in the management of populations: risk (as a combination of abstract factors indicating a greater or lesser probability of some undesirable event or behaviour) has become dissociated from concrete individuals or groups (e.g., criminals and the mentally ill) who formerly represented 'dangers' (Castel 1991). In the field of public health, the shift in focus from individuals to populations and risk factors has been especially marked. The so-called 'new public health' emphasises lifestyle and environmental risk factors (including physical, psychological and social apsects) in the production of illness (Petersen and Lupton 1996). An expanding system of expert knowledge, expressed in statistics, reports and so on, forms a central part of the public health enterprise, facilitating the 'rendering of social life into a calculable form' to make subjects 'governable' (Petersen and Lupton 1996, p. 15). Epidemiological and population data are routinely collected to monitor trends, and to enable investigation of the interrelationship between specific variables and health or illness outcomes.

Knowledge in the epidemological discourse of risk flows in many different directions. The public health apparatus not only collects data about risk factors and individuals, but it also communicates information about risk to the population through 'health education'. Indeed, health education is instrumental in the exercise of bio-power, because it defines norms of health and healthy behaviour, and promotes self-discipline for the achievement of good health (for an example of this process, see Gastaldo 1997). The 'new public health' emphasises the rights and obligations of individual citizens to 'take up and conform to the imperatives of "expert" public health knowledges' (Petersen and Lupton 1996, p. 61). Individuals are charged with a moral imperative to act on the basis of their risk knowledge (e.g., to immunise their children, or to stop smoking), undertaking for themselves the regulatory role of the all-seeing medical gaze.

Furthermore, citizens are also expected to be concerned for the health of others, particularly children. 'Ideal "healthy" citizens follow public health directives and recommendations, immunising their children on schedule and participating in various screening programmes' (Petersen and Lupton 1996, p. 69). Indeed, children's health has a special prominence in public health efforts and has been enshrined as a right by the United Nations Convention on the Rights of the Child (Child Rights Information Network (CRIN) 2002). Risks to children are often viewed as 'inherently more grave than risks to adults' (Jackson and Scott 1999, p. 90). Such emphasis on children's health risks may be explained by a number of factors. Children are particularly vulnerable to many health risks; child morbidity and mortality result in a heavy loss of human capital; there is often much greater scope for effective interventions to protect children's health than adults' health (Panter-Brick 2003). Mothers in particular are held responsible for promoting children's health, and are the targets of many child-health information campaigns (e.g., about the importance of immunisation or the dangers of smoking during pregnancy). Some feminist scholars have criticised the child-health education efforts directed at women, arguing that such campaigns make mothers responsible for their children's health, while ignoring the broader social factors over which they have no control, as well as men's behaviours, affecting children's health (Daykin and Naidoo 1995).

Control and resistance

There is a fundamental tension between Foucault's vision of modernity and the 'risk society' theory of Beck and Giddens, as noted by Turner (1997). Whereas the risk society theory posits that social actions in late modernity are increasingly flexible, reflexive and contingent in response to uncertainty and risks, Foucault emphasised the importance of regulation, administration and control as key features of modern society. Turner suggested that this tension can be resolved by examining the ways that contingency, uncertainty and flexibility might prompt surveillance and social control measures. For instance, the expansion of generalised risk anxiety may lead to increased demand for preventative medicine, which operates largely through surveillance of risk factors, identification of early warning signs and efforts to change or regulate health-related behaviours.

Although people may want preventative medicine as a way of coping with uncertainty and risk, they may also fiercely resist its surveillance and controlling actions (see, e.g., Gastaldo 1997). Recall that the Foucauldian notion of power is not unidirectional, but describes a reciprocal relationship between 'forces'. What, then, of the other directions of the power flow? Resistance is an integral part of power: each force has the power to affect and be affected by other forces. In a Foucauldian analysis, whenever we identify a manifestation of the exercise of power, we should also look for a counter-power: how is resistance exercised?

Turning once more to the epidemiological discourse, let us consider the ways that statements about risk are set forward in different contexts. Epidemiological research findings are subject to a host of methodological quandaries, such as ambiguity in defining risk factors and difficulty in classifying people for epidemiological analysis. Although the limitations posed by such problems are usually acknowledged in specialist reporting of research results, they are often overlooked when findings are translated into media presentations for the lay public and policy debates (Petersen and Lupton 1996, p. 43). Tables, graphs and other ways of illustrating quantitative knowledge are powerful rhetorical devices for presenting epidemiological 'truth'. But the facts contained in such devices, however rigorous the methodology behind them, support various interests, including commercial interests. When these interests come to the public attention, the epidemiological facts supporting them are often contested in the public arena. The debate over the MMR vaccine is a case in point: many parents and other commentators have treated with suspicion the studies demonstrating that the vaccine is safe, because that finding supports the financial interests of the vaccine manufacturers. Resistance is expressed in a variety of ways, from non-compliance to expressing contrary views in the mass media, or even abandoning the conventional medical sector altogether.

2.5 Public perceptions of risk

Psychometric studies

A number of authors, noting large disparities between lay public perceptions of risk and 'expert' calculations of risk probabilities, have sought explanation for such disparities in certain qualities of the risks themselves, in the ways that risk information is communicated (or miscommunicated) to the public, and in the ways that risk events are 'amplified' through media coverage and public response. The psychometric approach to risk perception aims to produce *quantitative* measures of people's perceptions of risks and benefits. This theoretical framework 'assumes risk is subjectively defined by individuals who may be influenced by a wide array of psychological, social, institutional and cultural factors' that can be quantified and modeled (Slovic 2000, p. xxii).

Under the psychometric model, a number of 'errors' can be identified in the cognitive processes that members of the public use to evaluate risks. Such errors include misjudging sample implications; errors of prediction (misunderstanding regression); availability bias (judging the probability of an event by the ease with which relevant instances can be remembered or imagined; anchoring bias (insufficiently adjusting an approximation to accommodate new information); and hindsight bias. Because lay people seldom have ready access to statistical evidence when they are asked to evaluate risks, they 'must rely on inferences based on what they remember hearing or observing about the risk in question' (Slovic 2000, p. 105). The cognitive 'errors' listed above result from heuristic devices that people use to make such inferences. Thus, the more easily people can recall or imagine an instance of the risk in question, the higher they will rate its likelihood of occurring again. Experts and laypeople alike tend to be overconfident in their risk estimates (as compared to statistically computed probabilities), and the psychometric researchers attribute this tendency to a desire for certainty. The desire for certainty also leads people either to deny risks or to want them to be outlawed, rather than to acknowledge ambiguity or relativity about risks. This tendency is enshrined in the so-called 'precautionary principle' (Resnik 2004), which stipulates erring on the side of caution by avoiding a potentially risky technology or practice when there is uncertainty about the extent of the risk that it poses.

The psychometric researchers (Slovic 2000) also asked members of the League of Women Voters and their spouses about their perceptions of the risks posed by a wide array of technologies and activities, and performed factor analyses on the responses to determine what factors led people to perceive some risks as being greater than others. Two principal factors were identified. The first factor was related to the controllability of a technology. Technologies that were new, had delayed or unknown effects, were perceived as being uncontrollable and for which exposure was involuntary were seen as being more risky than familiar technologies with known, immediate effects that were taken on a voluntary basis. Examples of risks rated highly in this factor include pesticides and food preservatives, while alcoholic beverages and mountain climbing were at the other end of the scale. The second factor could be classified as 'dread': risks that were certain to be fatal or catastrophic, such as aviation and handguns, had a high dread factor, while common technologies whose risks were usually chronic and non-fatal, such as antibiotics and home appliances, received low ratings on this scale. Nuclear power was rated highly on both scales, and was generally perceived as the riskiest technology. Vaccination was low on the dread scale, and fell in the middle on the controllability scale (Fischhoff, Slovic, and Lichtenstein 2000, p. 98).

Beyond the emphasis in the psychometric paradigm of risk perception on reasons for 'inaccurate' estimation of risks by the public, the approach also acknowledges that lay concepts reflect different and important issues that are not taken into account by probabilistic assessments. Slovic notes that

> there is wisdom as well as error in public attitudes and perceptions. Lay people sometimes lack certain information about hazards. However, their basic conceptualization of risk is much richer than that of the experts and reflects legitimate concerns that are typically omitted from expert risk assessments. As a result, risk communication and management efforts are destined to fail unless they are structured as a two-way process. Each side [expert and lay] must respect the insights and intelligence of the other (Slovic 2000, p. 231).

Despite the lack of technical information often displayed by the public, Freudenberg (1988) has argued that public reactions to controversial technologies – so often castigated as 'irrational' – may in fact be both rational and prudent. Comparing the public to a corporate board of trustees evaluating the recommendations of its technical experts, he suggested several 'warning signs' that should lead a prudent public to question the evaluations of risk experts:

- Specialists have direct interest in outcomes
- Specialists' past recommendations were wrong
- Specialists' activities and recommendations have broader implications
- Other experts indicate there may be reason for worry
- The situation contains a large element of the unknown
- The potential consequences of mistakes could be especially severe
- Errors have the potential to be irreversible (Freudenberg 1988, p. 48).

Earle and Cvetkovitch (1995) showed how the contemporary field of risk assessment is necessarily limited in its efforts to anticipate risks on the basis of knowledge about past occurrences and the present physical and social environment. The analytical techniques used in risk assessment assume a predictable social environment and the availability of adequate knowledge. Since most real problems, by contrast, are characterised by 'unstable or unpredictable social environments, disagreement on goals, and lack of adequate knowledge' (Earle and Cvetkovitch 1995, p. 64), what we need instead are strategies based on resilience. Social interaction here is held up as the strategy of resilience, whereas cogitation (i.e., risk assessment) is the error-prone, overconfident strategy of anticipation, reliant on past experience in its attempts to anticipate the future. Furthermore, because the expert risk assessor is set apart from other members of society by 'his belief in his mastery of the facts' (Earle and Cvetkovitch 1995, p. 64), the pronouncements of risk assessors are likely to be viewed with scepticism by other members of society:

> Unfortunately, the justification he offers for his privileged powers is convincing only to persons very similar to himself. Outside that small group, his facts are

> interpreted as opinions, his pronouncements as just another voice in a raucous public debate. And convinced of his correctness, the risk assessor's only interest in debate is in winning. Failing that, he withdraws, giving up on social interaction, a risk too great to take. (Earle and Cvetkovitch 1995, p. 64-65)

An example of this phenomenon, as we shall see in Chapter 4, is the large number of people who expressed the feeling that NHS information about the MMR vaccine was 'biased' or 'only presenting the government's view'. The Department of Health response, repeatedly, was to argue in its own scientific terms that there is no evidence associating MMR with autism. But these arguments, true as they were, failed to engage with the opposing views.

The work of Slovic and others using psychometric laboratory tests to evaluate risk perception has been extensively praised by risk analysts seeking to understand why public opinion is often at odds with their claims (Royal Society Study Group 1992). However, Mary Douglas forcefully criticised the psychometric approach to risk perception as being trite, tautological, methodologically flawed and apolitical (Douglas 1997). She complained that despite an enormous investment of resources, the psychometric experiments have not shed any light on 'big decisions' or *why* people take risks like living on earthquake faults or near nuclear power stations. Furthermore, the research does not explain how factors like 'availability' and 'dread' emerge in the public consciousness. Indeed, to say that 'certain events are feared because the dread factor is associated with them' (Douglas 1997, p. 125) is tautological; it certainly does not move us any closer to understanding why, for instance, chemical disinfectants are more dreaded than microwave ovens, and oral contraceptives more than vaccination (Slovic 2000, p. 142). Douglas's greatest critique of the psychometric paradigm is its failure to take into account interactions among people, culture and politics:

> The respondents are chosen and the questions designed as if nothing in their previous lives or personal experience would make a difference to their response to

> risks and probabilities; this is a rejection of the reciprocal influence between culture and beliefs (Douglas 1997, p. 125).

In effect, she argued, such research ignores the ways that subjects develop their 'perceptual lenses' and thus 'disables it from relevance to risk perception' (Douglas 1997, p. 131).

The social amplification of risk

How do lay perceptions of risk come to be so different from the experts' views? Cultural theory and reflexive modernisation theory both point to broader social issues at play. Another approach describes the 'social structures and processes of risk experience, the resulting repercussions on individual and group perceptions, and the effects of these responses on community, society and economy' (Kasperson et al. 1998, p. 150) in an attempt to unify the psychological, social and cultural approaches to risk perception (Royal Society Study Group 1992, p. 114-116). According to this framework, known as 'the social amplification of risk,' information ('signals', symbols and images) about risk events generates new interpretations and responses as it flows among different people and social groups. This results in a 'ripple effect', so that the impact of a single event extends far beyond the immediate environment in which the event occurred. For example, a chemical spill may have only a small, contained physical effect on a limited number of victims. But as news of the spill spreads, and public concern about the causes and possible consequences of this spill grows, people will become concerned about other, similar spills (past or future). This concern may also lead to more general concerns about environmental damage and industrial responsibility, and these new concerns will shape the further reporting and discussion of the event (and others like it). People may begin to change their consumption habits, enter into litigation and community protests, or move house.

These behaviours are likely to impact not only the company responsible for the spill, but other companies in the industry, and even completely different technologies.

Of course, the media play a significant role in the social amplification process. Wildavsky (1994) compared scientific results about health and environmental risks with their public presentation in the media. He criticized the 'bad reporting practices' of the media who misinform and upset the public through unawareness, wilful omissions, mistakes, exaggerations and dogmatisms. Boyne (2003) noted that there is no rigorous language within the broadcast media for talking about risk, no distinction between measured and estimated risk, and rarely any detailed discussion of statistical information or historical antecedents. Reporting cutting-edge stories, not being 'kept out of the loop', and generating spectacle and entertainment are top priorities for today's commercial media industry. In consequence, media presentation of risk tends to be dramatic, generating widespread perceptions of great risk, distrust and the development of public action groups.

Like cultural theory and the risk society theory, the social amplification of risk model gives centrality to socio-cultural factors in risk perception and behaviour, though unlike the other theories it does not explicitly take politics into account. However, as Douglas pointed out, the very name of this model belies an embedded political agenda. The social amplification of risk is 'directed to explaining how things seem to be more dangerous than they really are' (Douglas 1997, p. 126). The implication is that the public worry too much about technological risks, and that this undue worry results in significant economic damage to industry and society. We must not overlook the potential for indeterminacy and error in expert interpretations of evidence. In some cases, local, non-scientific knowledge has been shown to generate more accurate estimates of risk. A widely reported example is Brian Wynne's (1996) account of how Cumbrian sheep farmers' knowledge of the effects of nuclear radiation from the Chernobyl accident was more extensive and accurate than the scientists' knowledge. Despite the bias toward legitimating technical risk estimates, it is, however, very useful to have a model highlighting how the perceptions and consequences of risk change and build on one another as they are communicated.

Risk compensation

The impact of public risk perceptions is not experienced only in social, economic and political terms. Risk perceptions can actually change the physical risks, through behavioural responses to the risks. In Adams's (1995) model of 'risk compensation,' each individual is seen to have his or her own 'risk thermostat': a level of risk-taking that represents a comfortable (for that individual) balance between risk and expected benefit. For instance, some drivers go faster than others because their threshold for risk is higher or because they seek a higher level of benefit from fast driving (arriving more quickly at their destination, thrill or impressing onlookers (Adams 1995, p. 135-157). When people perceive a change in the level of risk, they will modify their behaviour so as to revert to their accepted level of risk and benefit. If a section of road appears particularly dangerous to the driver, then she will reduce her speed to compensate. This behaviour modification will then have a real impact on the physical danger level. Some risk-behaviour modifications may impel people, seeking to avoid one risk, to take another risk instead (as, for instance, when parents avoid vaccinating their children).

Acceptable risk: How safe is safe enough?

Although we may not like it, most of us are aware that it is impossible to live in a world without risk, so the question becomes, 'how safe is safe enough?' Beck claimed that this question is answered (though not without dispute) by engineers and other technical experts (see p. 73). Psychometric studies have sought to learn what risks we, as a society, are willing to accept in order to avoid other risks. Two psychometric approaches have been used to address this question. The first approach, pioneered by Chauncy Starr (Starr 1969), looked at 'revealed preferences' for public risk-taking. The assumption behind this approach was that people take risks that they find acceptable: by trial and error, society has arrived at an 'optimum' balance between risks and benefits. Preferences were thus revealed by risk-taking behaviour. Looking at historic and current risk-benefit trade-offs, Starr concluded that the publicly acceptable risk from an activity was roughly proportional to the third power of benefit for that activity, but that the public will accept risks from voluntary activities (e.g., skiing) roughly 1000 times greater than from involuntary hazards, with the same benefit level (Slovic 1987). This approach was used in an attempt to persuade people to accept other risks, especially those arising from nuclear technology, by showing that they were statistically less likely than risks that people voluntarily exposed themselves to, such as dying from smoking-induced diseases.

The next generation of acceptable risk researchers, however, recognised that risk-taking behaviour does not necessarily represent voluntary acceptance of the risk. The 'expressed preferences' approach developed by Fischhoff *et al.* (2000) also uses the psychometric paradigm (Starr 1969). In contrast to the assumptions behind the 'revealed preferences' framework, Fischhoff found that people tend to view their current risk levels for most activities as unacceptably high. Like Starr, Fischhoff found people willing to tolerate higher risks for activities that they saw as highly beneficial, but other factors than voluntariness also seemed to be salient. Such factors included familiarity, control, catastrophic potential, equality and level of knowledge.

But even this idea of acceptable risk, recognising as it does that risks are not always incurred voluntarily, is problematic. The approach still takes 'the public' as its unit of analysis, but it fails to take account of the inequitable distribution of risks among the public, even within a single population. Paul Farmer (1999) described at length the many ways that poor people are at greater risk of contracting and of dying from infectious diseases, yet noted that rigorous analyses of poverty, powerlessness and despair were conspicuously absent from most of the literature on AIDS risk. Individuals may accept certain levels of risk for themselves when they anticipate benefits from doing so. But extending this analysis beyond the level of the individual means that the more powerful members of society will determine what level of risk is acceptable for others: the ultimate implication of this reasoning is that some lives are expendable.

Both the risk society approach and the psychometric approach tend to assess risk debates in terms of 'the [lay] public' versus 'the experts'. But it is vital to look for competing risk notions and interests among members of the public themselves. And in cases like the MMR debate, where the very existence of particular risks are called into question, we must consider the heterogeneity that exists not only in terms of what risks people are willing to accept, but also in terms of how risks are defined and what sort of evidence about risk people accept.

2.6 Ethnographic case studies of socially constructed health risks

Most of the social theories of risk described above have been criticised for disintegrating into tautology or lacking true explanatory power. For empirical grounding, I turn now to several published case studies to see what people in a variety of contexts and facing a variety of risky situations say about the construction of risk.

Expanding anthropological interest in risk is reflected in recent books (Caplan 2000b, Harthorn and Oaks 2003, Lupton 1999) and conference panels[3]. This section presents in detail a few case studies from the ethnographic record that refer to health risks in particular and shed light on the theoretical debates presented above.

Expert and lay experience of risk

A number of anthropologists building on the notion that social groupings inform notions of risk (though not always explicitly) have noted fundamental discordances between 'expert' and 'lay' notions of risk. These studies have focused on the meaning and experience of risk in people's lives. To the 'at-risk' individual, uncertainty, ambiguity and threatened ill-health or death mean it is not satisfactory to think about risk simply in terms of numbers of affected individuals in the population. Risk is instead an extremely personal issue, and as such, will be conceived and dealt with in very different ways from those employed by the statistician-epidemiologist or risk technician. The ethnographic treatments of risk also highlight the intense political implications for discourse about risk.

One of the formative studies highlighting different expert and lay concepts of risk is Sandra Gifford's (1986) description of the ambiguity of risk conveyed by a diagnosis of benign breast disease (an identified risk factor for breast cancer). 'Epidemiological risk' is framed in terms of 'relationships which are objective, depersonalized, quantitative, and scientifically measured' (Gifford 1986, p. 217) at the level of the population. On the other hand, 'clinical' and 'lay risk' are lived and experienced at the level of the individual. Gifford described the difficult process of

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[3] Examples include the 'Risk Revisited' series at Goldsmiths College, autumn 1997; the Biosocial Society conference 'Health Risks in Social Context,' May 2002; the panel 'The anthropology of vulnerability: perception and communication of risk' at the American Anthropological Association annual meeting, November 2003; 'Science, risk and discovery' at the Association of Social Anthropologists decennial conference, July 2003; 'Intersections of Risk and Culture in Health and Environment' at the Society for Applied Anthropology annual conference, March 2004.

translating epidemiological risk first into clinical risk (concerned with how to manage individual patients' conditions) and lay risk (concerned with how to live with uncertainty on a day-to-day basis). For a patient with benign breast disease, risk is an uncertainty about how much danger she is in, anxiety about whether her 'high-risk' status will lead to disease, and often the need to make some decision about how to manage the risk.

The language of risk

Building on Gifford's schema of the three types of risk (epidemiological, clinical and lay), Kaufert and O'Neil (1993) showed how these three 'risk languages' were evident in public meetings about childbirth practices in the Keewatin district of northern Canada. Because they lived in very remote, climatically harsh environments, Inuit women were required to travel great distances to give birth in southern hospitals far away from their families. According to epidemiologists, the risk of a mother or infant dying in childbirth was too great if the mother stayed at home or gave birth in a nursing station, and doctors personalised this risk by highlighting the number of maternal deaths they had actually witnessed. Although the Inuit women generally complied with the policy of 'evacuation' to southern hospitals (because they had little other choice), they complained that having to leave their community to give birth placed a great burden on them. Furthermore, the statistical notion of risk used to justify the policy was at odds with their own experience that women could safely deliver babies in Keewatin. Women talked about 'being high pressured' and 'things not being quite as risky as you think' (Kaufert and O'Neil 1993, p. 45). But this discourse about childbirth was about far more than practical concerns or different conceptions of risk: it was also very emotional, and very political. Dispute about risk was a forum for expressing underlying power struggles: medical authority extending its control (in the Foucauldian sense) over the previously normal event of childbirth; patriarchal medical practitioners displacing the traditional role of the nurse-midwife; and colonial-type power struggles between the southern policy makers and those living in the far North.

Day's (2000) study of the politics of sexual risk among London prostitutes also found competing notions of risk between medical experts and the sex workers. Like the Inuit childbirth research (Kaufert and O'Neil 1993), this chapter made very explicit the politics of risk definition. The different language of risk used by the sex workers was not just a response to the need to interpret risk for the individual, but it was also an active critique of the stigmatisation associated with an 'at risk' label. Although the sex workers were, in the medical view, 'laypeople' in terms of their training in medicine and epidemiology, and at extremely high risk for contracting sexually transmitted infections, they considered themselves to understand the epidemiology better than the experts 'because they could filter out some of the prejudices that blinded most people to the real risks of the job' (Day 2000, p. 48). They distrusted the epidemiological figures, viewing them as reflecting prejudice rather than fact. The sex workers employed a 'second medical language of risk relating to public health' (p. 49) in opposition to the mainstream practice of labelling prostitutes as 'at risk' of disease or as posing a risk to the rest of society. Rather than focusing on whether they were 'at risk' or 'risky', the prostitutes' language of risk was instead couched in terms of risk reduction or avoidance. It represented active, often positive measures to assess their personal risks and to protect themselves. Such measures included attending frequent medical check-ups, insisting on and even educating clients about condom use, and performing non-penetrative sex acts. Their language of risk also 'involved claims to safety, professional status and full citizenship in civil society' (p. 49).

Risky behaviour

Other studies have described lay people's reasons for persisting in risky behaviour, despite full knowledge and awareness of the possible outcomes. For instance, Mexican farm workers working with dangerous pesticides knew a great deal about the toxicity of the chemicals they were spraying; however, other cultural, practical and perceptual factors kept them from using protective equipment to minimise their exposure. Most of the farmers had experienced symptoms (such as headaches and dizziness) from their pesticide exposure, but considered them to be minor, short-term complaints that did not warrant the high levels of expense and discomfort that using safety equipment would entail (Hunt et al. 1999).

Janet Bujra (2000) described changing practices and attitudes toward 'safer sex' in Tanzania, in the face of the AIDS epidemic. In this context, men were increasingly discussing and using condoms, as a means of reducing risk of HIV infection. However, the use of condoms was itself seen as risky, because it came to symbolise distrust (and suspected infidelity) between partners. Risk and trust are intimately linked. In this case study, trusting one's partner amplified the risk of contracting HIV, but the serious disruption in trust brought about by the AIDS epidemic has also had deleterious impacts on many facets of social interaction. In the final section of this chapter, I will consider the relationship between risk and trust, and possible ways of preserving or rebuilding trust in the face of risk debates that undermine social trust.

2.7 Risk and Trust

Trust as a bet

Bujra's (2000) study of AIDS prevention in Tanzania described how risk was closely related to intimate personal trust. In this case, trusting in the fidelity of one's partner (and therefore not using a condom) was a gamble: if the partner was not in fact trustworthy, then investing trust increased the risk of contracting HIV; however, this gesture of trust was symbolically important and may have helped to reinforce trustworthiness and fidelity among the partners. So the gamble is taken because there is some benefit, or expected benefit, of doing so. This view of trust is endorsed by Sztompka (1999), who described trust as a calculated bet, assigned on the basis of past experience or some other form of knowledge (e.g., a person's reputation).

The same notion of trust – as a calculated bet, with some expected benefit – applies not just to trust between individuals, but also to trust between groups of people, or between people and institutions. What sort of benefits can we expect from trusting in groups or institutions? The principal benefit is, as Niklas Luhmann (1979) outlined in his classic treatise on the matter, the reduction of complexity. We do not have the time or resources to take upon ourselves all of the work that is necessary to participate in complicated social arrangements and tasks (e.g., setting a national budget or testing the safety of a vaccine). However, by allocating most of this work to specialists, and trusting in their performance, we are able greatly to reduce the complexity that we must assume for ourselves, and to engage in tasks that would be otherwise impossible:

> trust, by the reduction of complexity, discloses possibilities for action which would have remained improbable and unattractive without trust – which would not, in other words, have been pursued. (Luhmann 1979, p. 25)

Late modernity and the importance of trust in institutions

Anthony Giddens (1990) emphasised the importance of trust for dealing with the 'disembedded' nature of social relations in late modernity. Modernity has brought about new 'modes of life,' removed from traditional types of social order. One consequence of this is reflexivity, as described in Section 2.3 (p. 66): reflecting on new social structures and a constant influx of knowledge, people in today's societies of the West engage in a continual re-evaluation and re-ordering of their lives and social relations. Another consequence is what Giddens calls the 'disembedding of social systems', in which social relations are removed 'from the immediacy of context' (Giddens 1990, p. 28). Social interactions have become increasingly reliant on abstract systems ('symbolic tokens' such as money, and 'expert systems') rather than personal relationships and interactions. We are so reliant on expert systems that even the simplest actions would be impossible without them. Consider all of the expert systems implicated in dwelling in a modern house: architectural and building codes, electrical safety standards, accounting, legal and computational systems involved in issuing and managing a mortgage, and so on.

We cannot possibly understand all of the systems underpinning our day-to-day lives (unless we opt out of modern life altogether!), and so we must trust in them. The new, disembedded form of social interaction depends on trust, not in individuals, but in abstract capacities. Trust in symbolic tokens and expert systems implies that we have faith in the principles by which they operate, although we are generally ignorant of those principles. In fact, it is precisely because we are ignorant of their inner workings that we are reliant on trust (otherwise it would not be trust but calculated confidence).

Most of our day-to-day reliance on expert systems occurs through what Giddens termed 'faceless commitments' – we trust that people whom we do not know and have never even seen have done and continue to do their jobs in such a way as to protect us from danger. But sometimes we need contact with the expert system for reassurance: the calm demeanour of a flight attendant or the professionalism of a doctor reminds us that the abstract system in which we place our trust is operated by real 'flesh-and blood' people. Such points of connection, which Giddens referred to as 'facework commitments', help to maintain or build trust, but also represent 'places of vulnerability for abstract systems' (Giddens 1990, p. 88). Trust in the experts themselves (the people representing expert systems) is important alongside trust in institutions, but this inter-personal trust is restricted to our faith in the experts to follow the principles properly, rather than in the principles *per se* (which are instead the objects of trust in systems).

For Giddens, the opposite of trust is not mistrust but paralysis and panic: 'If basic trust is not developed or its inherent ambivalence not contained, the outcome is persistent existential anxiety... *angst* or *dread*' (Giddens 1990, p. 100). Contrary to the view of trust as a calculated bet, freely invested in some actor because we expect some benefit in return, there is no real alternative to Giddens's trust in abstract systems. Choosing not to trust would mean removing ourselves from modernity altogether. However, this trust does coexist with and is usually counterbalanced by a pragmatic, sceptical attitude toward those systems. Within this framework, there are many possible configurations of trust and scepticism.

As we find dramatically in many public risk debates, one such configuration involves widespread distrust of particular experts and their expertise. When trust between experts and the public is lost, many players work hard to restore it, in recognition of the vital role played by institutional trust in modern society. However, this is widely regarded as a very difficult process, and the collapse of trust has been said to be governed by an 'asymmetry principle' (Slovic 1993). This view is summarised cleverly by an aphorism attributed to the Dutch statesman Johan Rudolf Thorbecke (1798-1872): 'Trust comes on foot but leaves on horseback' (Calman 2002). In particular, media reporting of negative (trust-undermining) events is said to have a much greater impact than reporting of positive (trust-building) events. Luhmann (2002) attributed this to the symbolic significance of individual events. Since the chief function of trust is to reduce complexity, within the parameters of trust we develop a simplified image of situations. When a falsehood or mistake comes to our attention, we take it to be indicative of the general pattern of performance, and lose trust in the people or agencies responsible.

Recent researchers have questioned the asymmetry principle, on the basis of psychometric studies indicating that negative information in fact has little impact on people's attitudes of trust (Cvetkovich et al. 2002). In fact, the converse may be more accurate: people's predispositions to trust or distrust a given technology were found to significantly impact the way that they rated positive or negative information about that technology. Media reporting and public responses to it are both shaped in large measure by previously existing social attitudes (Negrine 1994).

Trust in health care

Health care is one of the principal expert systems in contemporary Britain. The National Health Service embodies values that 'are the closest we come to shared values of civil society'(Neuberger 2003, p. vi). Trust is important in this context, as in others, because it allows us to go about our business without excessive interference in terms of management, policing and so forth. A breakdown in trust is detrimental to the effectiveness of medical intervention and invites micromanagement of health care (Mechanic 1998). There is limited evidence suggesting that trust is associated with patients' adherence to advice and satisfaction with physicians, though not independently associated with improved health status (Safran et al. 1998). Indeed, it has even been argued that there is a moral imperative for doctors to trust their patients (Rogers 2002).

Yet public trust in the system of health care appears to be in a state of crisis, prompting much discussion about the reasons for loss of trust in health care and how trust can be rebuilt (Alaszewski 2003, Calman 2002, Calnan and Sanford 2004, Checkland, Marshall, and Harrison 2004, Garrett 2001, Harrison, Innes, and van Zwanenberg 2003, Harrison and Smith 2004). Although 'trust' is a concept frequently invoked in discussions about relationships between the public and health care systems, or between patients and medical practitioners, there is little consensus about what precisely the term means, how it can be operationalised, what its determinants are, or how trust can be improved. Remarkably, Pearson et al., in their systematic review of the literature, found not a single published study documenting a successful intervention that measurably improved patient-physician trust (Pearson and Raeke 2000, p. 511)!

As with other fields of expertise, it is important to distinguish between impersonal trust in the system itself and interpersonal trust in individual practitioners, and to examine the relationship between these forms of trust. Gilbert (2005) claimed that for healthcare workers, interpersonal trust is both necessary and sufficient for the development of impersonal trust in health care, but that the reverse is not the case. This is because interpersonal trust is based on skilled fulfilment of professional expectations and adherence to professional standards; however, impersonal trust is not based on any contact with individuals but rather is established through the system in which professionals are embedded. Impersonal trust is also related to professional authority, is political and is dynamic. It can be claimed, contested, and lost through social and political processes.

Can we say, with Gilbert, that interpersonal trust is sufficient for establishing impersonal trust in health care? MORI survey reports have shown that trust in doctors is still high relative to other professions, even as trust in health care and the NHS seems to be on the decline in Britain (MORI Social Research Institute 2003). Likewise, Hall and colleagues (2002) found a somewhat higher level of interpersonal trust than generalised, impersonal trust in physicians. Calnan and Sanford (2004), in their cross-sectional national (UK) survey (N=1187) found that low levels of trust were generally related to concerns about health care organisation and finance (e.g., cutting costs and waiting lists). However, they also found that the most significant dimensions for measuring patient trust specifically concerned individual practitioners: the extent to which a doctor is patient centred, and the perceived level of professional expertise. The authors concluded:

> This appears to suggest that general assessments of public trust in health care might be replaced by questions about specific dimensions of micro level health care such as professional expertise and the doctor-patient relationship. The analysis seems to suggest that public views about trust tend to match the views of "users" about the quality of health care rather than the broader concerns of "citizens" with how the services are run and paid for (Calnan and Sanford 2004, p. 96).

Professional recognition of patient participation and efforts to promote partnerships between patients and professionals can form the basis of renewed trust. One qualitative study among breast cancer patients found that patients valued doctors' forming individual relationships with them and respecting them, over provision of information and choice (Wright, Holcombe, and Salmon 2004).

However, there may well be instances in which blind trust in health care services would not be appropriate. A number of scandals involving doctors or the health care system, such as Dr. Harold Shipman's murdering many of his patients and the unauthorised removal and retention of deceased children's organs at Alder Hey, have received a great deal of media attention. David Mechanic has pointed out that appropriate sceptism is not the same as distrust (Mechanic 1998, p. 663). Today's patients are critical, informed, and demand control over their own options. Such a critical stance can, under the right circumstances, exist within a broad framework of trust and active engagement with the health service.

In the face of highly publicised scandals, controversies and diminished confidence in the health care system, the British Government has instituted a series of regulations on the health service, performance targets and measures to ensure accountability of its members. A challenge for public policy is to strike the right balance between trust and regulation. While a certain degree of regulation may be necessary to provide the conditions that foster trust (cf. Mechanic 1998, p. 663, Poortinga and Pidgeon 2003), excessive regulation detracts from the atmosphere of trust (Harrison, Innes, and van Zwanenberg 2003).

Several authors have also distinguished between 'confidence' and 'trust' in the health care system (Checkland, Marshall, and Harrison 2004, Harrison and Smith 2004, Smith 2001). In this distinction, confidence is based on the assumption of security provided by abstract, expert systems and regulations, while trust is necessary in the face of vulnerability or uncertainty, and tends to exist between individuals rather than between individuals and systems. Checkland et al. (2004) argued that currently in the UK, the government is responding to an apparent failure of trust in health care with a model of regulation that is based not on trust but on confidence in institutions. This model emphasises accountability, meeting targets and rules. The practical problems with this approach are that it entails large costs (in monitoring agencies and practitioners), obscures the uncertainty that is still present in much medical care (which leads to unrealistic expectations and, ultimately, diminished confidence), and reduces practitioners' moral incentive to be trustworthy (Harrison and Smith 2004). At the same time, health services are being reorganised to make them more cost efficient and more transparent in their running (e.g., grouping GPs into large practices). In consequence, patients have less and less opportunity to develop strong relationships with particular practitioners. The mechanisms that are meant to check the reliability of practitioners may, to some extent, increase trust in the system's checks and balances, but this comes at the cost of relationships between humans (Etchells 2003, O'Neill 2002). If interpersonal trust in practitioners is necessary for fostering trust in the system, as Gilbert (2005) claims, then a culture of regulation will ultimately diminish trust. There will always be uncertainties, problems, and instances of poor conduct in health care. Acknowledging the uncertainty that makes trust necessary and fostering openness between patients and physicians (at the micro-level) (Checkland, Marshall, and Harrison 2004, p. 134) as well as between the public and health care systems (at the macro-level) (Dibben and Davies 2004) might be a more productive strategy for addressing the breakdown in trust in medical care.

Social trust and cosmopolitanism

The ability to acknowledge this sort of uncertainty but preserve an overarching trust in the system may well be very difficult to bring about, as the asymmetry principle tells us. The image of trust arriving on foot but fleeing on horseback (Calman 2002) is very appealing on the surface. It seems to explain why we often do not trust our politicians and why we encounter so many reports of diminished faith in medicine and the NHS, and is a favoured truism of many politicians and social observers. However, there is an important ethical and social problem with this infatuation with the asymmetry principle. Too often, it becomes an excuse not to be more trustworthy: a maligned public figure can lament trust galloping away on its horse, but claim that it is all too easy for that to happen, as the media misreported the situation, or else the public misunderstood, and now it is too late to regain trust, and so on. But is it possible to imagine an atmosphere of trust that is more stable than this, that is able to withstand problematic instances without falling apart? Clearly we expect such an atmosphere in our closest personal relationships. The challenge, then, is to extend this interpersonal trust to a civic society built upon a strong foundation of social trust. Creating such a society would of course require a great deal of investment – but for precisely that reason the members of the society would presumably have a greater interest in maintaining it. What would it take to achieve such a level of trust?

One problem currently is that trust between the public and those working in the public service is rarely conceived as a two-way process. The public may or may not trust politicians or doctors, for example, but whether the politicians and doctors trust the public is a largely unexamined question. This is surprising, because public outcries about scandals and controversies in the public service sector highlight the public's desire to have its perspective heard, respected and – crucially – trusted. Instead of investing trust in the public, however, all too often we see public officials trying to escape blame (or deflect it onto others) without addressing the social roots of the problems. A greater willingness to take risks, listen to and, indeed, *trust* the public would likely result in a public willing to forgive more mistakes and become more trusting itself.

Not only is trust essential for navigating everyday life in late modernity, but it also promotes an important sense of social cohesion. It is vital to creating social capital and economic prosperity. Social trust is based on shared cultural values, a common 'language of good and evil' (Fukuyama 1995, p. 270). Individuals must recognise one another's common values in order to trust, and this recognition depends on communication. Communication of shared values within social groups is generally widespread and fairly well understood. However, Earle and Cvetkovitch (1995) took this analysis a step further in advocating a particular form of social trust they termed 'cosmopolitan social trust'. This form of trust relies on flexibility, communication across social boundaries, and imagination to find common values *across* different social groups and to develop solutions to problems that were previously beset by inter-group divisions.

To illustrate the need for common values across diverse social groups, Earle and Cvetkovitch cited several examples of community contexts in which they were engaged in evaluating risk management and social trust. In these situations, they found that a lack of shared values between stakeholders undermined the implementation of solutions. They called on civic leaders to foster 'emergent commonalities designed to cope with the specific problem at hand... to encourage the creation of emergent sets of values that would move stakeholders beyond their traditional, entrenched positions' (Earle and Cvetkovitch 1995, p. 115).

Communication is necessary for cosmopolitan social trust, as it is only through communication that common ground between parties can be identified (or forged). Here, the argument starts to become circular, as the authors explain that social trust is needed for communication across groups:

> A necessary condition for communication is a relation of relevance between the participants. Relevance, like social trust, is based on shared cultural values; the

> former is a special case of the latter. In this sense, then, communication is dependent on social trust. (Earle and Cvetkovitch 1995, p. 120)

If cosmopolitan social trust depends on communication to establish and nurture shared values, and communication depends on social trust, then breaking into this cycle demands a widespread leap of faith and goodwill. Happily, Earle and Cvetkovitch have offered a tool for building enduring social trust. That tool is narrative.

The importance of narrative for building trust

Narrative, according to the *Oxford English Reference Dictionary* (2002), is 'a spoken or written account of connected events in order of happening; the practice or art of narration'. The practice of narrative is the process through which discrete events become connected and thus acquire meaning. Such meaning gives narrative an immense capacity for expressing emotions and for persuasion, which are both crucial for enabling communication across society. Whereas science can demonstrate the validity of isolated facts, narrative links these facts with interpretations (Earle and Cvetkovitch 1995, p. 134, Fish 1980).

As we shall see in Chapter 4, narrative had a very important role in the MMR controversy. Those claiming that MMR causes autism made heavy use of narrative, focusing on the stories of children allegedly damaged by the vaccine. By contrast, those seeking to refute these claims tended to eschew narrative, preferring to discuss 'the facts'. The narrative-based accounts arguably had a much more powerful effect on public views than did the facts-based approach.

However, not all narratives will generate meaning that is conducive to building cosmopolitan social trust. For instance, Earle and Cvetkovitch described the traditional American narrative of public participation as an unsuccessful narrative in this respect. Its principal downfalls are that it does not recognise division of labour as an inescapable social condition of modern, stratified societies (instead, all citizens are expected to act as policy analysts), and that it does not recognise the cognitive, temporal and monetary limitations of human capabilities. 'Public participation can work only if the narrative that guides it is fully social and fully human'(Earle and Cvetkovitch 1995, p. 150). Because it is actually oriented toward individualism (each individual is expected to assume full responsibility for policy analysis in order to participate), this vision in fact discourages public (community) participation.

Effective public participation, the authors argued, would acknowledge human limitations as well as the need for leadership, and be

> based on cosmopolitanism – diversely related individuals – risk taking, favoring wide, loose, overlapping communities, multiple selves, and fluidity within universal human limits. Cosmopolitan social trust is such a narrative, comprising the values of the cosmopolitan leader – acknowledgment of personal and community limits, the social self, and a willingness to create communities. (Earle and Cvetkovitch 1995, p. 150)

To persuade people to abandon the old narrative in favour of the cosmopolitan narrative requires leaders who are willing to acknowledge their own limitations and the contributions of communities; a community that is open to new, emerging narratives and values; and the imaginative use of narrative to conduct public dialogue and develop emerging meanings from events and facts. The final chapter of this thesis will explore ways that these elements might be brought together to address public health concerns like the controversy over the MMR vaccine.

2.8 Conclusion

This chapter has covered a broad swathe of social theory about risk and trust from divergent disciplines and perspectives. These perspectives are rarely integrated, but each offers an important facet to our understanding of the context in which health decisions are made. We can summarise and draw together these perspectives as follows:

Risk talk is always political, and it reflects wider concerns about the type of society we want to live in. Assigning blame is a way of coping with uncertainty. Recent years have seen a growing awareness of the risks arising from modern industrialisation, and this awareness has shaken the way we think about modernity and about society itself. Discourse about risk can be seen as an expression of power relations, and provides a platform for surveillance of populations. Lay members of the public and expert risk assessors often come to different conclusions about the magnitude and importance of technological risks, because they use different evaluative categories. However, trust in expert systems is a necessary undertaking in late modernity, as a way of reducing complexity and handling risk. Some forms of trust are easily undermined. Fostering enduring trust requires community mobilisation, narratives that bind diverse groups of people together, and effective, imaginative, risk-taking leadership. The remainder of this thesis examines how risk and trust were configured in parental decisions and responses to the MMR vaccine controversy.

CHAPTER 3
QUALITATIVE AND QUANTITATIVE METHODS

3.1 Overview of study components

My investigation of parents' risk constructs and MMR decision making was conducted in two phases: a qualitative, ethnographic phase (Phase I) and a large-scale quantitative survey (Phase II). As shown in Figure 3.1, the first phase used focus groups, face-to-face interviews and email correspondence to develop a fine-grained ethnographic description of parents' perceptions and roles in the MMR debate. The survey was used to evaluate the general level of agreement with my ethnographic findings, using a large sample of parents, and to evaluate the public health implications of these findings.

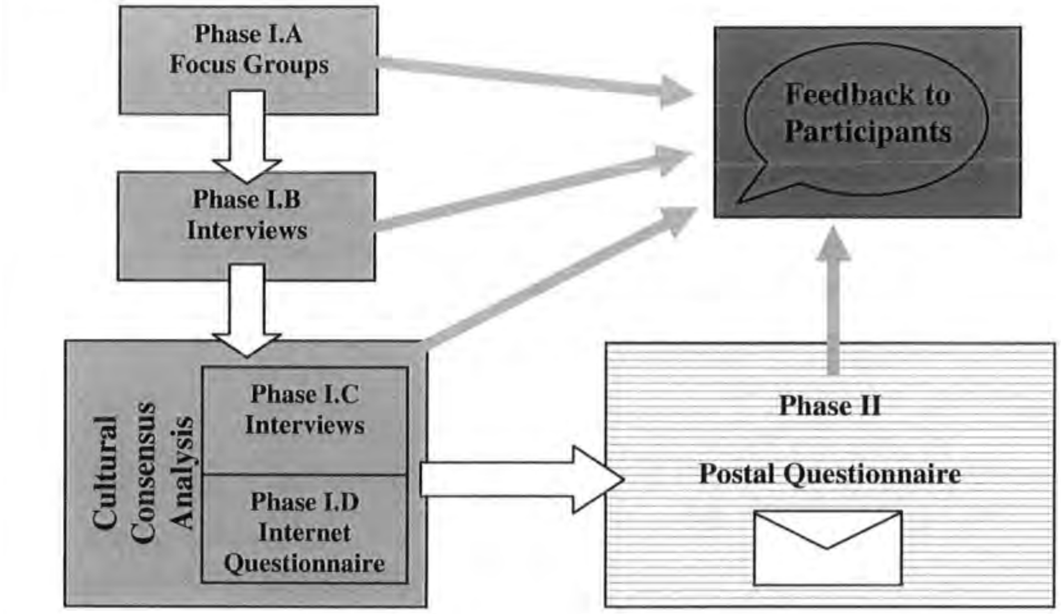

Figure 3.1 Relationship of study components.

Ethnographic phase (Phase I)

Focus groups (Phase I.A) were used to begin the fieldwork phase of the project, in order to generate ideas about salient topics and issues for parents discussing the MMR. Beginning the study with focus groups had several advantages. First, I was able to hear from a number of parents at once, providing a quick entry into the topic. In addition, the largely self-directing nature of focus group discussions meant that I was able to listen to the issues that parents themselves freely brought up or queried one another about, so that I was able to direct later lines of questioning to topics that I knew at least some parents were interested to talk about.

Having thus started discussing the MMR vaccine in terms described to me by parents themselves, I developed a protocol for conducting semi-structured face-to-face interviews (Phase I.B). The format for the first interviews included several free-listing questions, as well as open-ended prompts to encourage participants to talk about their views and experiences. The protocol was also modified to be emailed to parents whom I encountered on the internet message board for JABS (www.jabs.org.uk), an organisation that tracks and provides support for parents who think their children have been damaged by a vaccine.

Data from the first 20 (Phase I.B) interviews were used to construct an instrument for performing cultural consensus analysis (Romney, Weller, and Batchelder 1986, Weller 1987), a formal technique that quantitatively assesses the degree of consensus among a group of informants' responses to a set of questions about a cultural domain (in this case, cultural domains were construed as themes related to making a decision about the MMR vaccine). The cultural consensus analysis data were collected in the context of further semi-structured ethnographic interviews (Phase I.C), and also through a dedicated project web site that was advertised on the JABS message board and other Internet-based parenting discussion groups (Phase I.D).

Throughout the study, I also visited many parent-toddler groups to recruit parents for interviews. Attendance at these groups also provided rich opportunities for many informal discussions about the MMR vaccine with parents, which were important in shaping the interpretations presented in this thesis. Thus, a number of 'ethnographic' techniques were used to develop a picture of how parents make their decisions about the MMR vaccine and evaluate public policy on this issue.

Postal survey (Phase II)

The techniques described above do not tell us how widely applicable this picture is to a larger population. The sample used for interviewing and for consensus analysis is relatively small and is purposive rather than random. The public-health consequences of the MMR controversy are significant primarily because of the large numbers of people involved. Thus, knowing about the pervasiveness and distribution of parents' ideas about the risk posed by MMR vaccine in the wider UK population is an important objective of the study. For this a large-scale survey (Phase II) was undertaken among the parents of all children in two birth-year cohorts in the Durham and Chester-le-Street Primary Care Trust (PCT). Results from Phase I were used to develop a questionnaire for the postal survey. This survey was used to determine the level of agreement among MMR-accepting and MMR-refusing parents with statements related to the MMR controversy, their use of information sources, and levels of single-antigen vaccination among children not receiving the MMR vaccine.

3.2 Ethics

Phase I (Focus groups and interviews)

Permission to conduct Phase I of the study was granted by the Durham University Ethics Advisory Committee in July 2002 (Application Number 01 EAC 87). Further permission to modify the study to include interviews conducted by email, and approval of the interview questionnaire, were also granted by the Durham University Ethics Advisory Committee in February 2003.

Safeguarding the well-being of research participants is, of course, one of the foremost ethical responsibilities for any research with human subjects. The American Anthropological Association's professional code of ethics states as the first ethical obligation to the people being studied: 'To avoid harm or wrong, understanding that the development of knowledge can lead to change which may be positive or negative' (American Anthropological Association 1998, p. 2). But what about the development of uncertainty? The incomplete knowledge that is implicit in discussions of risk can provoke anxiety and prompt people to change their actions. Thus, researchers investigating risk have an ethical dilemma before them: how to avoid introducing doubt, with its potential for provoking anxiety on the part of research participants, while maintaining openness and honesty with participants. Despite the rapidly growing interest in researching the social contexts of health risks, this is an issue that is not explicitly treated by published ethical guidelines for anthropology and human biology. How can one query parents about the reported risk of autism, without introducing anxiety for those who must decide whether to immunise their children against three childhood diseases which are themselves also 'risky', while maintaining a neutral position on the claims about the vaccine's safety? Careful and sensitive interviewing was required to avoid introducing doubt about the vaccine where it did not exist before. However, inducing doubt and anxiety in parents' minds during the focus groups (Phase I.A) remained a concern, because the research design necessitated allowing parents to have an open discussion with one another about their thoughts and decisions. In order to minimise this possibility, parents were organised into focus groups with others who had made similar decisions to their own. Thus, parents who had serious concerns about the vaccine's safety were more likely to bring these up with others who already shared their worries. In addition, at the end of each focus group discussion, parents were offered information from the Department of Health and a health professional contact, along with a disclaimer that the researcher does not endorse any particular position. This was chosen as the appropriate source for referral, as it is peer-reviewed and under a professional ethical code, unlike other sources.

Another ethical concern about Phase I of the study brought up by a member of the Durham University Ethics Advisory Committee was whether my experience making a decision about the MMR vaccine for my own children would make it difficult for me to be impartial, and what I would do if a parent asked me for advice. Although I do have young children of my own, I was sympathetic with the difficulty of the decision and the different decisions that parents made. I emphasised to participants that I was not engaged in studying the relative safety and benefit of the vaccine, but rather parents' perceptions, and so could not offer any advice about the vaccine itself. If they asked, I did tell parents what I did with my own children, again stressing that I was sympathetic with people who chose otherwise. I also answered questions that parents asked about specific points, such as how long the vaccine had been used or what types of research had been conducted on the link with autism.

Phase II (Postal survey)

Approval for the quantitative survey was given by the County Durham and Darlington NHS Local Research Ethics Committee in February 2004 (Application Number 144/Feb04).

Two major ethical issues were addressed in the study design for Phase II: the handling of sensitive data, including parents' addresses, and the possibility of worrying or upsetting some parents with the questionnaire. In order to protect the privacy of parents in the study population, the Child Health Information Service identified qualifying parents and mailed them a letter inviting them to participate in the study; those agreeing to participate then mailed me their addresses themselves. The questionnaires were all returned anonymously in order to protect the identity of parents providing potentially sensitive information about their children's medical histories.

My experience conducting interviews with parents had suggested that most parents who might have found this to be a particularly sensitive topic (parents of autistic children, for instance) were, in fact, glad for the chance to express their own views. Nonetheless, the questionnaire was mailed to a large number of parents, and it is impossible to anticipate the reaction of every parent. In anticipation of any concerns raised as a result of the study, local GP's and health visitors were informed about the research. Participants were encouraged to contact these health professionals if they had any concerns. They were also given contact information for the researcher, and the URL for the project's website, in case they wanted to learn more about the study. A further concern expressed by one member of the ethics committee was that parents of deceased children might be contacted to participate in the study, which would be discourteous and potentially distressing. This concern was allayed because the Child Health Information Service, which handled the initial mail-out, is routinely notified of child deaths, and removes those names from its lists.[1]

Benefit of the Study

The anticipated benefit of this research to individuals and to society is another key ethical issue. This project represents a step to fostering better understanding between the public and those setting and implementing policy about a vital public health issue. For parents to assume responsibility for their children's destinies, they require both solid information on topics such as risk, as well as ways to make use of the knowledge that take it beyond pseudo-empowerment based on faulty information or logic of application. Policy-makers and clinicians can better serve the public if they understand the parents' perceptions about the risks involved and their decision-making processes. Furthermore, the experience of participating in the study was helpful for many parents, providing an opportunity to clarify their own thinking about the topic.

3.3 Data collection: Ethnographic phase

Recruitment of participants

This was a multi-site study, consisting of interviews conducted primarily in Cambridge and Durham, with one interview conducted in London, and on-line communication with participants from all around the UK. Participants were recruited in a number of ways. Sampling was opportunistic in the first instance, to gather a

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[1] Unfortunately, this situation did in fact arise. One response slip was returned stating that the child had died. The Director of Public Health and the Child Health Information Services were immediately notified. The family had been using an out-of-district GP service, so the local Child Health Information Services had not been notified of the death. A letter of apology from the Director of Public Health was sent to the family, and the records were corrected.

range of perspectives about the vaccine.[2] However, the opportunistic sample initially provided few members of a key group: parents dissenting from the NHS advice about MMR. Therefore, snowball sampling and purposive recruiting from Internet sites likely to attract dissenting parents were also used. NHS clinics, however, were not used as recruiting sites, because I was concerned that parents recruited from clinics promoting MMR might be inhibited in discussing dissenting views. Throughout the recruiting process, I asked for *parents* without specifying a gender, although most of the parents whom I encountered, and who volunteered to participate in the study, were mothers. Initially I advertised for parents who either (a) had a child between 8 and 15 months and were thus due to have the MMR soon, (b) had a child who had been given the MMR in the last year, or (c) had opted not to have their child given the MMR. However, I found that a number of parents whose children were older than two years nonetheless had quite strong views about the controversy and were interested in participating in the study. I thus modified my approach, asking for 'parents of young children who would be willing to discuss their views and experiences about the MMR vaccine.'

Community centres, which host meetings and activities of various organisations and also serve as focal points for information of local interest, were one of the most important resources for recruiting participants. I posted flyers advertising the study on notice boards at the community centres and in public libraries in Durham and Cambridge, and a number of parents contacted me after seeing these. In addition, I contacted all of the local nurseries in Cambridge and asked them to post flyers about

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[2] Recall that the qualitative data gathered in Phase I were used to generate a questionnaire for use with a large sample in Phase II. Thus, the objective at this stage was to recruit parents with a variety of perspectives and to generate a well-developed picture of these perspectives; thus, random sampling was not required at this stage.

the study. A few nursery managers asked me questions about the study's aims and funding, but all agreed to post flyers once these had been answered.

More importantly, I visited sessions organised for parents with young children (held in community centres, or in churches and other halls), waiting areas for parents picking their children up from playgroups, and café or lounge areas and parks where families gathered. At these venues I personally distributed flyers to parents, told parents about the study, and chatted informally about the MMR and about raising children. When parents expressed interest in participating in the study, I usually arranged an interview time or took their telephone numbers; other parents preferred to take the flyer and contact me after thinking more about the study. This strategy was generally more effective than posting flyers, because parents had a chance to talk to me about the study and arrange for a convenient time without having to make an effort to contact me. Once I had already conducted over fifty interviews, I began interviewing some parents, and distributing questionnaires for cultural consensus analysis, during the playgroup sessions themselves.

Because the recruiting strategy involved informally meeting parents to describe the study rather than inviting a pre-set number of parents from a specified population, it was not possible to quantify refusals to participate. Parents who declined to participate generally cited lack of time as the reason for refusal. Two parents declined to participate because they were in strong disagreement with their partners about whether to immunise their children and feared raising the issue at home by participating in a formal interview. However, both of these parents were happy to informally discuss their views with me at the playgroups where I met them.

I also used the Internet to recruit participants. JABS ('Justice, Awareness and Basic Service') is an organisation providing support for parents who believe their children have been harmed by vaccines, and has in recent years provided anti-vaccine information to parents as well as information on sources offering separate immunisations for measles, mumps, and rubella. A message board on this organisation's website (www.jabs.org.uk) frequently features vociferous debates about the MMR and requests for advice from worried parents. On two occasions I posted messages to this board describing the study and inviting parents to email me if they would be interested in discussing their views about the MMR. Later, I launched a project website (www.dur.ac.uk/anthropology/Projects/MMR) and used the JABS message board, as well as other on-line parents' groups, to invite parents to complete an on-line questionnaire (Phase I.D).

Focus groups (Phase I.A)

Three focus groups were held at the beginning of the study to provide an initial sense for what aspects of MMR decision making parents would talk about. These groups were segregated according to the children's vaccination status, in order to foster supportive discussion of experiences rather than debates. Thus, one group was comprised of parents who had refused the MMR for their youngest child, one group of parents whose youngest child had had the MMR, and one group of parents whose youngest child would soon be due to have the MMR. Some of the parents in the third group had already made up their minds about whether their child would have the vaccine, and others had not.

At the time of recruiting for the focus groups, I asked parents whether or not their children had had the MMR in order to determine which group would be most appropriate for them. I also asked what times they would be available and took their phone numbers. I then determined a meeting time for each group, based on when most of the parents had said they would be available, and contacted each recruited parent to inform them of the time and location of the focus group discussion. The three focus groups were held in two different community centres in Cambridge over a one-week period (29 November to 4 December 2002). I arranged for two childcare workers to attend each group and brought children's toys. Large rooms were booked, so that the parents and I could sit at tables on one side of the room, and children could play on the other side of the room. This allowed more parents to attend without having to worry about finding childcare or leaving their children in an unfamiliar crèche, while minimising disruption to the discussions. In addition food (lunch or breakfast, depending on the time) and drinks were provided for participants. Each participant also received a £5 voucher from Mothercare and reimbursement for travel expenses. Each group lasted for approximately one hour, with several parents remaining for a further half hour of informal discussion.

As parents arrived, I gave them an information sheet about the study and asked them to complete a consent form and a one-page questionnaire (Appendix A). The questionnaire contained simple questions about the participants' children and their feelings about the MMR, in order to encourage participants to start thinking about the discussion topic, and also asked for basic demographic information.

I began each group by reading a prepared statement thanking parents for participating and explaining the purpose of the discussion (Appendix B). I emphasised that parents should treat the group as simply a discussion between parents about the MMR vaccine, that there were no right or wrong answers but that I wanted to hear about the experiences of everyone in the group. I provided some instructions for how participants could jump-start the discussion if it should taper off or get off track, and for how to draw quiet members into the discussion. With this responsibility delegated to the participants, the discussions were able to proceed fairly smoothly with minimal input from me. Parents were reminded of the importance of mutual respect and confidentiality. To start the discussion, I asked the participants to talk about what they had written about the MMR on their questionnaires.

When participants started to seem like they were running out of things to say (generally around halfway through the discussion) I used a focusing exercise strategy advocated by David Morgan (Morgan 1997) to stimulate further discussion. I presented the group with a set of cards listing various potential sources of information about the MMR (internet, newspapers, GP, health visitor, television, family members, scientific articles, friends, NHS pamphlets, and several blank cards for participants to add their own sources). I then asked participants to talk about how these might or might not be used, and to rank them (negotiating the ranking with other members of the group) in terms of how 'useful and trustworthy' they would find the sources for getting information about the MMR. This activity generated a good deal of discussion about whom parents trusted or relied on and why.

At the end of the discussion, I read another prepared statement (Appendix B) thanking parents for participating and reminding them that the nature of the study was to study parents' attitudes and decisions, not to endorse any particular opinion. Parents were, however, offered an NHS leaflet about the MMR (NHS Health Promotion England 2001) and contact information for a local health visitor, in case they had concerns arising from the discussion or wanted more official information.

One participant in the last focus group conducted asked whether I could send them a report at the end of my study so that they could 'learn more about what [they] had taken part in'. This seemed to me to be a very good suggestion, as it would provide a way of giving something back to the parents who had helped provide information for me, as well as to solicit feedback about the conclusions drawn from the study. The participants at that group gave me their addresses to receive this report.

The focus group discussions were tape recorded and transcribed, although the tape recorder malfunctioned for one of the groups; additionally, I took extensive notes during the discussions. Each participant was identified by a pseudonym in the transcripts. The coding and analysis strategies used for handling the focus group and interview transcripts are described in Section 3.4.

Interviews (Phase I.B and I.C)

After the three focus groups I conducted 52 in-depth interviews about the MMR vaccine with individual parents, and briefly interviewed a further 23 parents. Most of these were conducted in participants' homes during the day, but in other cases were conducted in the evening or in other locations, including participants' workplace, my home, my university office, and cafés. The 52 in-depth interviews ranged in length from 35 to 90 minutes, with the median interview length being 55 minutes. Interview participants were also offered £5 Mothercare vouchers and reimbursement for any travel expenses they may have incurred to attend the interview. Like the focus groups, interviews were tape recorded and transcribed (except for interviews conducted during playgroups or on short notice when a tape recorder was not available). In addition, extensive notes were taken during the interviews on a prepared data recording sheet. The transcripts and notes were later coded and analysed for thematic content (see Section 3.4).

Information on the age, occupation, and highest level of education for interview participants and their partners was collected, in order to determine the demographic characteristics of the interview sample. Participants were given the chance to invent a pseudonym for themselves. Some of the parents obviously enjoyed making up names for themselves, although most wanted to leave this up to me, and a few indicated that they preferred to be identified by their real names. When parents expressly asked to have their real names used, I have honoured that wish, but have not made any efforts in my reporting to distinguish between real and false names. Interviewees were also asked whether they would like to be sent a short report summarising the results of my interviews, and mailing addresses were collected for sending this report.

Two sets of interviews were conducted. The first set (Phase I.B), consisting of 17 face-to-face interviews and 3 email ‘interviews’, was used to explore in detail the views and experiences of a small but diverse group of participants, and as a basis for the cultural consensus questionnaire. A series of open-ended questions (Appendix C) was loosely used to structure these interviews, encouraging participants to discuss their views and experiences of making a decision about the MMR vaccine. In addition, participants were asked to generate free lists (Weller and Romney 1988) in response to the questions listed in Table 3.1. The protocol was used more heavily when participants seemed to be inhibited or to prefer answering questions to directing the conversation themselves. In general, though, my strategy was to let participants talk freely, only prompting them with prepared questions when they stopped talking.

1. What are the things that you, as a parent, need to do in order to have a healthy child?
2. What are the things that we, as a society, need to do in order to protect the health of our children?
3. What risks to health should we be concerned about?
4. What do you think are the most important things to consider when taking a decision about vaccination?
5. Where might you or another parent go if you wanted to get information about the MMR vaccine?

Table 3.1 Prompts for free-listing exercises used in the first set of 20 interviews.

Data from this first set of interviews were used to construct a series of systematic data-collection activities to be used in conjunction with open-ended discussions in subsequent interviews (Phase I.C). The responses to the free-listing exercises were tabulated, with very similar responses grouped together (Appendix D). The most common responses to the two free-listing questions directly related to making a decision about vaccination ('What do you think are the most important things to consider when taking a decision about vaccination?' and 'Where might you or another parent go if you wanted to get information about the MMR vaccine?') were used in two card-sorting tasks. These tasks were a modification of the constrained pile sort described by Weller and Romney (Weller and Romney 1988). The cards were shuffled before each task in order to eliminate order bias in parents' responses. In the first task, participants were given sixteen laminated cards on which were printed the names of potential sources of information about the MMR (Table 3.2). Parents were asked to sort them into two piles – those that they would find more useful, and those that they would find less useful, for getting information about the MMR – and then to rank the information sources according to how 'useful and trustworthy' they would find them. I also asked parents why they had ordered the cards in the way they did and which, if any, of the information sources they had actually used in making a decision for their own children.

1. Internet
2. GP
3. Health visitor
4. Library
5. Family members with a health background
6. People at baby/ toddler groups
7. NHS Direct
8. Television
9. Leaflets
10. Group of parents who feel MMR has affected their children
11. Newspaper
12. Alternative health practitioner
13. Medical journal
14. Radio
15. Perspectives from other countries
16. Books on children's health

Table 3.2 Information sources used in first card-sorting activity.

In the second card-sorting task, parents were given twelve laminated cards on which were printed considerations that parents might take into account when making a decision about a vaccine (Table 3.3). Parents were asked to indicate for each card whether the consideration, if taken in isolation, would make them more or less likely to have the MMR for their children or would not affect their decision. Many parents found this task to be confusing at first, but readily talked about their assessments of each of the printed considerations and were then able to tell me what role these had played in their own decisions. A few parents who had very strong views found the task to be too difficult to complete, because they felt that their decisions had already been formed before thinking along the systematic lines required by this exercise. The two card-sorting exercises were used for the Cambridge interviews, but were not continued for the interviews in Durham, because they was very time consuming and some parents found them confusing.

1. Vaccine risks and side effects
2. Seriousness and effects of disease
3. Health of child on the day of vaccination
4. Likelihood of exposure to the disease
5. Public health impact (herd immunity, benefit to population as a whole)
6. Distress and discomfort to child
7. What you did with the first child (family history)
8. How effective the vaccine is
9. How long the vaccine has been used
10. What the medical experts say about it
11. Number of vaccines given at once
12. Cost

Table 3.3 Vaccination considerations used in second card-sorting activity.

Finally, I constructed a set of 62 statements (Appendix E) extracted from the first set of interviews, presented in random order (to eliminate order bias in the results), along with a 6-point Likert scale (an interval scale for which each number indicates a level of agreement or disagreement with the statement) (Bernard 2002, Weller 1998). Participants were asked to read the list of statements, circling one number for each statement to indicate how strongly they agreed or disagreed with it (1=strongly agree, 6=strongly disagree). An even number of options on the scale was chosen to force a decision as to overall agreement or disagreement with each statement, so that the data analysis could either be based on the full scale (giving some indication of how strongly people feel about the statements), or a dichotomous breakdown of agreement vs. disagreement. This strategy is based on that used by Kempton *et al.* (Kempton, Boster, and Hartley 1995) to study environmental values in American culture. Initially the list comprised 84 statements, but in pilot interviews I found that this was too long to hold some participants' attention. The list was shortened to 62 items, covering perceived safety of the MMR, the scientific studies on the MMR-autism link, the seriousness of the diseases and importance of herd immunity, government and media handling of the controversy, general issues relating to health, risk and trust, and locus of control. A table for self-reporting of demographic data (age, occupation, and education of self and partner) was added to the bottom of this questionnaire. I also added the questions, 'How would you characterise your political views?' and 'How strongly do you hold those views?' because some interviewees indicated that their views on MMR were related to broader political dispositions. Most participants were quite happy to answer all, or most, of the demographic questions, although many did not answer the question on political views.

To conduct the second set of interviews (Phase I.C) I began by explaining to parents that I wanted to start off talking about their families and their experiences with the MMR, and then would proceed to some activities, based on things that other parents had said in earlier interviews, so that I could compare different people's responses. I asked parents how many children they had, what their children's health was like, how many had had the MMR, and to tell me about making the decision whether to have their children given the MMR. No standard set of follow-up questions was used, but I did ask probing and clarifying questions to get as full a picture as possible about how parents had made their decisions about the MMR, how they evaluated the risk reports they had encountered, whose advice they trusted and why, and whether they had any ideas for how parents might be helped to make better choices or feel more confident about their choices. When parents indicated that they had little more to say, I proceeded to the formal activities described above. The tape recorder was left on while participants completed these activities, and I encouraged parents to make comments as they went along.

A 'saturation' point (Strauss and Corbin 1998, p. 136) was reached after approximately 50 interviews were completed: few new themes were emerging, and it seemed counterproductive to continue conducting extensive interviews with all the parents I recruited. From this point, I continued meeting parents to administer the 62-item questionnaire and chatted with them about their decisions, recording what they said. Parents were allowed to talk as long as they wanted and in a few cases I did arrange to meet these parents for a longer, formal interview. However, in most cases the interviews in this later set were brief and were centred on the questionnaire.

Web-based questionnaire (Phase I.D)

In order to gather data for the 62-item questionnaire from a larger sample than could feasibly be obtained in personal interviews alone, I developed a web-based version of it. In addition to the 62 statements about the MMR and the demographic data collected in the interviews, this questionnaire also asked participants which vaccine(s) their children had received, which region of the UK they lived in, and how much time per week they spent using the Internet. They were also given an open section in which they were asked to describe how they had made their decisions about MMR vaccination. The questionnaire was included on a web site dedicated to the MMR study (www.dur.ac.uk/anthropology/Projects/MMR), which also included general information about the project, statistics about MMR uptake, lists of presentations based on this study, and project reports.

As I was particularly interested to increase the sample of MMR refusers, the web-based questionnaire was initially advertised on the message boards of two groups that have been outspoken against the current government policy on MMR: JABS (www.jabs.org.uk) and, at the emailed invitation of one of its founders who had found the project website, Choice (www.choice.freeservers.com). Invitations to complete the on-line questionnaire were also spread by word-of-mouth and by email sent to the Medical Anthropology Research Group and Infant-Child Research Network at Durham University. Furthermore, a number of responses came from people who found the project website while conducting internet searches for websites giving information about the MMR vaccine. The internet questionnaire generated a total of 99 responses between its launch in December 2003 and July 2004.

Reporting findings to participants

Upon completion of Phase I of the project, a brief report (Appendix G) was prepared and mailed to the 65 interview and focus group participants who had requested one. Accompanying this report was a form on which participants could provide their responses to the conclusions presented, and a stamped, addressed return envelope. A separate report of the internet questionnaire results was prepared and emailed to participants who requested one.

3.4 Analysis: Ethnographic phase

Transcripts from all the focus groups and interviews were carefully read several times to build an interpretive framework for qualitative analysis. The analysis approach used here involved both answering questions of *a priori* research interest and searching for emergent themes from the participants' own words.

The *a priori* research questions were as follows:

1. How did parents conceptualise risk from the vaccine and from the diseases it was meant to protect against?
2. What was the process by which parents went about making their decisions?
3. What was the relationship between individual and population-level risk in parents' thinking and decision making?
4. How did parents evaluate information from different sources about the MMR vaccine?
5. Was risk perception related to trust, and what factors contributed to trust or lack of trust?

A list of keywords related to each of these questions was developed (e.g., risk of autism, risk of disease, decision-making process) and keywords were then assigned to blocks of text. Focus group and interview transcripts were coded using AnSWR, a qualitative data analysis package available for free from the United States Centers for Disease Control and Prevention (http://www.cdc.gov/hiv/software/answr.htm). Text blocks were also coded according to which participant was speaking, and what decision that participant had made about MMR immunisation.

In addition, emergent themes were identified using techniques discussed by Ryan and Bernard (2003): searching the transcripts for frequently recurring topics, and looking for similarities and differences between lines of text and whole interviews. A number of surprising themes, such as parents' efforts to identify vulnerable children, were identified in this way and were given their own keywords for the coding process.

AnSWR was then used to generate a list of all passages related to each keyword. These passages were read in relation to one another to develop an outline of salient issues for discussion in Chapter 4. Within this outline, I developed arguments about what parents said. These arguments were primarily based on careful reading of the coded passages and their context in the interviews, and informed by the social science theory of risk and trust reviewed in Chapter 2. Segments of text from the transcripts were selected to illustrate key points, following Mason (2002, p. 173-204). Where these quotations were meant to represent ideas that many parents expressed, I indicated numbers of parents expressing similar views. These numbers do not, of course, carry any statistical meaning but are offered to give some sense for how frequently certain ideas came up in the context of the interviews. In other cases, quotations were selected because they were unique but expressed important nuances for the overall argument.

Cultural consensus analysis (Phase I.C and I.D): Background

Analysis of the systematic data collection exercises (i.e., the two card-sorting exercises and the 62-item Likert scale questionnaire) was undertaken using cultural consensus analysis, an anthropological technique used to determine whether a group of respondents exhibit consensus in their answers to a group of questions about a particular cultural domain (Bernard 2002, p. 193-200, Romney, Weller, and Batchelder 1986, Weller 1987). This technique is a useful bridge between qualitative and quantitative methodologies, because it can assess the degree of consensus for a relatively small group of participants from a purposive (non-random) sample, and provide guidance for the development of larger-scale survey questionnaires. Essentially, the technique works using the statistical technique of factor analysis; however, unlike a conventional factor analysis, the informants, rather than questions, are used as variables, and groups of informants constitute the factors, or 'cultural groups'. Then, idealised sets of responses (like 'answer keys' to a given set of questions) can be constructed from similarities among the participants' responses.

The assumptions underlying this method are (1) that individual beliefs and behaviour are based on belief models and norms shared within cultural and social groups, as well as on individual factors such as life experiences, (2) that variation in individuals' knowledge or sharing of an underlying group norm or belief system ('cultural model') can be described probabilistically, and (3) that the greater the extent to which respondents agree with one another in their answers to a set of questions about a given cultural domain, the more those answers approximate the shared model. Cultural consensus analysis was originally developed as a tool for cultural anthropologists to identify informants with high levels of knowledge of a given cultural domain that the anthropologist wished to learn more about. The technique measures consensus among informants' responses to a set of questions. Informants who agree more with the consensual answers are judged to be more knowledgeable about the cultural domain. Thus, the method seeks to determine, first, whether one (or more) shared models are informing a set of respondents' answers; second, how completely each informant shares in the consensual model; and finally, a description of the model (an 'answer key' to the set of questions).

The cultural consensus method has been used in a large number of studies ranging in topic from narrowly-specified areas of traditional ethnographic enquiry (e.g., Boster's (1985) test of informants' knowledge of the names of manioc types) to very complex social issues (e.g., Kempton, Boster et al. (1995) on environmental values in America and Caulkins (2001) on Celtic identity) and health-related topics (Chavez et al. 2001, Dressler 2002, Dressler 2003, e.g., Dressler and Bindon 2000). Because this is a widely used technique (though not especially common in the UK), it provides a recognised theoretical framework for linking the individual, cultural, and social levels of behaviour, and allows for the replicable analysis of systematically collected data.

Rationale for using cultural consensus analysis in this study

To make good use of the qualitative data collected in the focus groups and interviews, particularly in generating the large-scale postal survey that formed Phase II of this project, required a rigorous, systematic analysis addressing the following important questions:

1. Once a (more or less exhaustive) list of issues and themes from the interviews was developed, how do we know which ones are the most salient and important? Bloor *et al* (2001) warned against assuming that topics that receive a great deal of discussion time are those which informants think are the most important – they might simply be those that the informants find the most interesting to discuss!

2. In terms of how parents think about MMR and risk, can we identify one or more group 'norms' of which some parents will be more representative than others?
3. What factors or beliefs underlie a given parent's decision whether or not to vaccinate?

Cultural consensus analysis can help to answer each of these questions, because it tests for the degree of consensus among informants (question 2) and identifies a representative 'answer key' to a set of questions (questions 1 and 3). Although Robert Aunger, in his critique of the cultural consensus technique (Aunger 1999, Aunger 2003) warned against constructions of culture based on shared knowledge, and against over-reliance on the 'answer keys' thus generated, the identification of group norms can provide useful hypotheses for testing in larger, representative surveys.

Method description

The method is performed in five steps: (1) an appropriate questionnaire about the domain under investigation is constructed; (2) the questionnaire is administered to a group of informants; (3) a factor analysis is performed among the informants, using questionnaire items as units of observation; (4) the eigenvalues for the first two factors are examined, to test for consensus among informants; and (5) an ethnographic 'answer key' to the questionnaire is generated (if consensus is found to exist among these informants with respect to the cultural domain under question).

In the first step, the questionnaire is typically based on previously collected ethnographic data, such as the preliminary phase of ethnographic interviewing used in this study. The technique allows for a number of questionnaire formats, including dichotomous or multiple-choice questions, open-ended (short answer) questions, pile sorting tasks, ranking tasks, Likert scale (agree-disagree) questions, and scenarios

(Bernard 2002). However, all of the questions should relate to a single cultural domain[3], and should be equally difficult to answer. The first card-sorting task used in this study (ranking the trustworthiness of information sources) was treated as a ranking task and the second (in which participants were asked to tell whether particular considerations would make them more, equally, or less likely to accept MMR vaccination) was treated as a multiple-choice questionnaire. The 62-item questionnaire was analysed using the Likert scale responses as interval data, following the procedure employed by Kempton *et al.* (1995).

The sample used for cultural consensus analysis can be quite small. According to the method's originators, a sample of just 17 is needed to achieve results at the 95% confidence level, with 95% of the items answered 'correctly', and assuming 0.5 average level of 'cultural competence'[4] (Romney, Batchelder, and Weller 1987). Larger samples are needed when the 'competence' level is lower, i.e., when informants agree less, on average, with the consensual set of answers to the questionnaire. The technique does not require a random sample, because it is designed to identify particularly knowledgeable informants about shared cultural data, not to make inferences about how widely the knowledge is held in a population. However, the sample should cover the range of potential cultural knowledge (e.g., sampling from different age groups, genders, SES) (Dressler 2002, Handwerker 1998, Handwerker and Wozniak 1997).

To perform the analysis, an unrotated factor analysis is run on the informants, using questionnaire items as units of observation. Thus, the total number of

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[3] A domain is an 'organized set of words, concepts, or sentences, all on the same level of contrast, that jointly refer to a single conceptual sphere' (Weller and Romney 1988, p. 9). Thus, for instance, informants might be asked to identify a carrot, a cauliflower and a leek as members of the cultural domain 'vegetables'; statements about the safety of MMR vaccine represent another cultural domain.

[4] A 0.5 level of cultural competence means that participants agree with the consensus answer, on average, 50% of the time.

informants is reduced to a small number of groups (factors), based on the similarity of their questionnaire responses to one another's. This is the inverse of a conventional factor analysis, which identifies factors among questionnaire items based on related answers given by a group of people. Although a specialist software package (ANTHROPAC) exists to perform this analysis automatically (Borgatti 1996), it does not display the correlation matrices and communalities tables. Several analyses did not work initially because a few cases had insufficient variation to calculate correlations, and it was not possible in ANTHROPAC to identify these. Therefore, the factor analyses were performed in SPSS version 11.0, after removing the cases with insufficient variation. This procedure allowed for the successful evaluation of a much higher proportion of data subsets than was possible using ANTHROPAC. Minimal differences in results were obtained using SPSS and ANTHROPAC for the subsets that could be analysed in both packages.

Initially, I tried performing the factor analyses using the unweighted least squares method of factor extraction. However, there were some subsets of the data for which eigenvalues could not be extracted using the least squares method because there were communalities (i.e., the proportions of variance that is common, or explained by the underlying factors) less than 0 or greater than 1. Principal components analysis is a related procedure that is not affected by this problem, because the test inserts 1 in the diagonal of the communality matrix (Field 2000, p. 433-434, Kline 1994, p. 28-43). Theoretically, principal components analysis is less desirable because it does not separate error from specific variance. It was nonetheless performed for all domains in this analysis, in order to compare the results obtained by principal components analysis with those obtained by unweighted least squares extraction, and to estimate the degree of consensus for domains that could not be evaluated using the least squares factor analysis method. In all cases that could be analysed with both techniques, there were minimal difference in the results obtained.

By convention, a three-factor solution is obtained. The eigenvalues for each of these factors, which provide a measure of the substantive importance of each extracted factor (Field 2000, p. 436-7), are then compared. If the ratio of the first to the second eigenvalue is greater than 3.0, by convention, then a single-factor solution is assumed, and we say that the informants exhibit consensus in their responses to the questionnaire items. That is, the largest group explains three times as much (or more) of the variance in the data as the next largest group, so we assume that the answers given by that group represent a single, shared cultural model. If two groups (or more) both explain a large proportion of the total variation, then we need to consider the existence of competing cultural models. If the sample is large enough, these subgroups can then be analyzed separately.

To provide a visual depiction of how similar or dissimilar parents are to one another in their responses to the questions, multi-dimensional scaling (MDS) was used, again performed using informants, rather than questions, as variables. This procedure plotted each informant on a graph along two axes determined by calculating Euclidean proximities from parents' responses. The distance between any two data points (i.e., parents) represents the similarity of their responses to given statements in thematic groupings. It should be noted that the axes produced by MDS do not themselves have any inherent meaning.

The next step that is normally undertaken in cultural consensus analysis is to determine the 'cultural competence' of each informant, if the assumption of consensus (i.e., a single-factor solution, as evidenced by a 3:1 or greater ratio of the first to second eigenvalues) is met. This value is the factor loading, or the amount of agreement between the informant's responses and the idealized responses given by the first factor. Finally, all of the responses are weighted, giving more weight to the answers of informants with high factor loadings, and a weighted average is computed for each question. This weighted average is used to generate an 'answer key' to the questionnaire, which represents the 'culturally correct', or consensual, answers to each of the questions.

For this study, the 62-item questionnaire was broken into six thematic subgroups of statements, each representing a key theme or 'cultural domain' (labelled A-F in Appendix E). The five themes were:

A. the safety of MMR and the 2-dose schedule
B. the appropriateness of the scientific studies on MMR
C. the seriousness of measles, mumps and rubella, and the importance of herd immunity
D. information and the handling of the issue by government and media
E. children's health, risk, and trust
F. locus of control

For each of these domains, MDS plots were generated, and then cultural consensus analysis was performed for the sample as a whole, and then separately for MMR refusers and MMR acceptors. MMR acceptors were defined as parents who had given, or planned to give, MMR vaccine to their youngest child. MMR refusers included parents who had given, or planned to give, either separate vaccines or no vaccines for measles, mumps and rubella to their youngest child. When the youngest child was so young that the parents had not yet considered whether to give the MMR, then the distinction was based on the decision taken for the next youngest child in the family.

For each domain in which a single-factor solution was obtained, an 'answer key' to the questions in that domain can be determined. First, the factor loadings (for the first factor) are computed for each informant. These values reflect each informant's overall level of agreement with the consensus response. Then, a weighted average is computed by multiplying each informant's response with the factor loading for that informant.

3.5 Data collection: Survey

Questionnaire design

A questionnaire (Appendix F) was developed on the basis of the qualitative interviews previously conducted in Phase I, and piloted among parents in public areas of Durham City. The questionnaire contained 4 sections:

1. The target child's year of birth and whether the child had received MMR or single measles, mumps and rubella vaccines.
2. 20 statements related to MMR vaccination, accompanied by a 4-point Likert scale (Bernard 2002) to indicate the extent of agreement or disagreement (strongly agree, agree, disagree, strongly disagree). These statements represented a simplified, condensed version of the questionnaire used for cultural consensus analysis in the interview phase, and were selected to test the distribution of attitudes about key issues with important implications for policy and communication. An even number of choices were given on the Likert-scale questions to force respondents to 'take a stand' facilitating comparison of proportions of parents agreeing and disagreeing with each statement. A balance of 'pro-MMR' and 'anti-MMR' statements was used, reflecting the balance emerging among parents in the qualitative work.

3. The respondent's use of and satisfaction with a variety of information sources ('MMR the facts' leaflet, NHS/Department of Health website, health visitor, practice nurse, GP, anti-MMR organisation, other).
4. The respondent's gender, age, occupation, level of education and number and age of children.

Power calculation

Sample size was calculated to detect differences in responses between MMR-accepting and MMR-refusing parents, on the basis of pilot data indicating 35% and 50% agreement, respectively, with statements regarding vaccination, at the 0.90 power level and 0.05 significance level, assuming a 1 in 6 MMR refusal rate (Department of Health 2004). This required a sample size of 816 returned questionnaires (Machin et al. 1997). A typical postal survey response rate of 30% (Bernard 2002) would require inviting 2720 parents to participate in the study. As each birth-year cohort in the local Primary Care Trust (PCT) had approximately 1400 children, it was decided to mail the questionnaire to parents from two birth-year cohorts.

Mail-out protocol

A letter (Appendix F) from the Director of Public Health for the Durham and Chester-le-Street PCT was mailed to all parents in the PCT with a child born between 1 October 2000 and 30 September 2002 (N=2742), explaining the study and inviting parents to participate. Parents who chose to participate returned a consent slip with their addresses. This strategy was adopted for several reasons. Requesting parents' consent to participate before mailing the questionnaire satisfied ethical concerns about my access to data including parental addresses and children's immunisation records. Furthermore, contacting all parents rather than selecting participants on the basis of immunisation records ensured that parents who are accessing vaccination outside the NHS were included. A drawback of this two-step process is that it may have resulted in a lower response rate than if parents had received the questionnaire in the first mailing.

Questionnaires were mailed to all parents returning consent forms, together with a further participant information letter (Appendix F), a £5 voucher from Mothercare, and a stamped, addressed return envelope. Parents were assured that their responses would remain anonymous and confidential and they were provided with contact information for the principal investigator and the URL for the project's website.

3.6 Analysis: Survey

Data Handling

Quantitative data were transferred into an SPSS spreadsheet for statistical analysis and double-checked for accuracy. Analytic codes for occupational class were obtained using the National Statistics Socio-economic Classification (NS-SEC) Reduced Method (Office for National Statistics 2004). The survey respondent's stated occupation was coded according to the Standard Occupational Classification 2000 coding index (Office for National Statistics 2000) and employment status (employer, self-employed, manager employee, supervisor employee, or other employee) was determined from the respondent's job title and response to the question 'Are/were you an employee or self-employed?'. These two variables were collated to obtain the NS-SEC analytic code using the derivation table for the Reduced Method - NS-SEC Analytic Classes (Office for National Statistics 2004). Many respondents were mothers who were not working outside the home, but full-time mothers come from a wide variety of socio-economic backgrounds. Thus, when a respondent's occupation was given as 'unemployed,' housewife,' 'mother,' or was otherwise uncodeable, the partner's occupation was used as a proxy for the respondent's occupational class.

Qualitative data on information sources were tabulated, grouping similar responses into appropriate categories. Additional qualitative comments of interest were flagged for use in interpreting quantitative results. Questionnaires were held in a locked office until all data were entered and verified, and then destroyed.

Statistical analyses

Quantitative analyses were undertaken using SPSS for Windows, version 10.0. Chi-square tests were used to evaluate differences in proportions of:

- MMR-accepting and refusing parents agreeing (i.e., answering either 'agree' or 'strongly agree' on the Likert scale) with each of the 20 statements related to MMR vaccination (Section 2 of the questionnaire, see Appendix F).
- MMR-accepting and refusing parents strongly agreeing, strongly disagreeing or expressing an intermediate opinion (i.e., answering either 'agree' or 'disagree') with each of the 20 statements related to MMR vaccination (Section 2 of the questionnaire, see Appendix F). Because the even number of choices on the agree-disagree scale did not allow parents to express ambivalence about the statements, this test provided a more detailed assessment of which statements respondents felt strongly about.
- MMR-accepting and refusing parents using and satisfied with the information sources (Section 3 of the questionnaire, see Appendix F).
- Parents in each annual birth cohort opting for MMR or single vaccines.

- Parents of different occupational classes and educational levels opting for MMR or single vaccines.

Multivariate logistic regression was used to evaluate the relationship between parental age, education (university degree vs. no degree), occupational class (1-2 vs. 3-8), number of children and MMR acceptance.

The descriptive findings from the Phase I interviews and focus groups are presented in the following chapter. Chapter 5 presents the cultural consensus analyses that were performed, and Chapter 6 presents the results of the Phase II postal survey.

CHAPTER 4
WHAT PARENTS SAY: RISK, TRUST AND DECISION-MAKING

4.1 Overview

British parents who had a small child during the years of the MMR controversy all had to make the very important decision about whether to follow medical advice and give their children the MMR vaccine, or to avoid it because of fears about its safety. To make the risk judgements necessary for making this decision, they had to weigh ideas about risk with ideas about their own children's vulnerability, responsibility for individual children's health with responsibility to the community, contradictory information with trust and distrust. The opinions and narratives that parents shared with me formed a complex picture of how risk, trust and decision-making processes are related. This chapter presents the qualitative findings from Phase I (focus groups and interviews) of the study. It hinges on parents' discussions of the importance of medical decision-making on behalf of their children, and their understanding of risk, trust and responsibility. The chapter ends with a detailed presentation of one mother's experience, which captures the concerns of many parents in making a decision about the MMR.

Description of focus group and interview participants

87 parents participated in Phase I of this study. Attendance at the focus groups was disappointing: although I had aimed to have 6-8 parents at each group and had over-recruited, only 12 parents attended the three groups. Three parents attended the refusers' group, only two attended the vaccinating group (perhaps because the weather was bad that day), and seven attended the group of babies nearly due for the MMR. A total of 75 parents participated in the interviews: 48 in Cambridge between January and July 2003, 1 in London in March 2003, 23 in Durham between October

2003 and February 2004, and 3 via email.

Of the 87 parents who participated in this phase of the study, 56 had vaccinated their children with the MMR at the time of interview, 16 had (or were planning to have) separate vaccines, 10 did not vaccinate at all for measles, mumps and rubella, and 5 were still undecided (Figure 4.1). Parents were recruited from a broad range of educational and socioeconomic backgrounds, but on the whole the study group in this phase was well-educated and affluent, as shown in Table 4.1 summarising the sample characteristics.

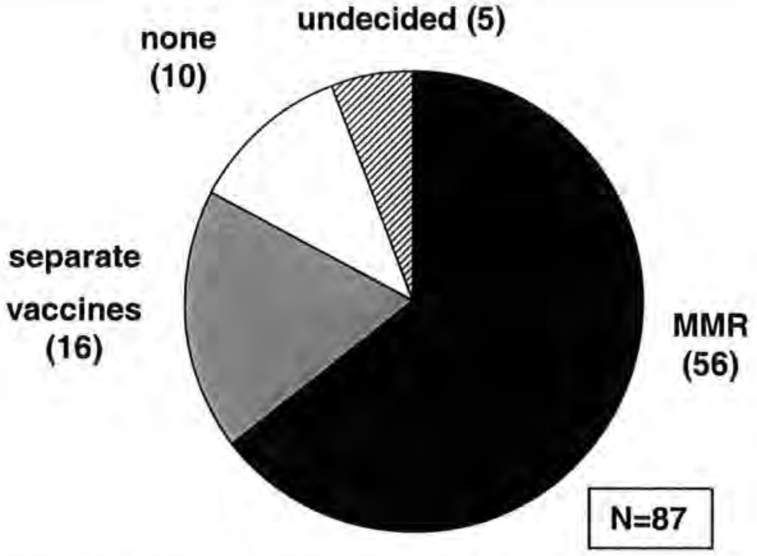

Figure 4.1 Phase I participants' decisions about MMR immunisation.

Sample characteristic	N (%)	Mean (SD)	Range
Female gender	77 (89%)	N/A	N/A
Had a university degree	51 (58%)	N/A	N/A
NS-SEC: 1.1/1.2 (higher managerial)	19 (21.6)	N/A	N/A
2 (professional/	36 (40.9)		
supervisory)	12 (13.6)		
3 (intermediate	4 (4.5)		
occupations)	2 (2.3)		
4 (self-employed)	8 (9.1)		
5 (technical occupations)	1 (1.1)		
6 (semi routine)	6 (6.8)		
7 (routine occupations)			
8 (unemployed) or missing			
Age	N/A	34.7 (6.3)	21-57
Number of children	N/A	1.86 (0.86)	1-6

Table 4.1 Characteristics of the Phase I sample.

4.2 A very important decision to make

> It is probably the hardest sole decision that I've had to take so far as a parent and I've put it on a par with the issue we are also facing now as to which school to use. It is at that sort of level. *(Jane, immunised her children with MMR)*

> I'm really glad that that's over and that I don't have to worry about that now that I've made that decision. Because I think the longer this goes on the harder and harder it is for parents to know what's best. But I'm really glad that I have just done it and she doesn't seem to have suffered from it. *(Caroline, immunised her daughter with MMR)*

What is it about the MMR vaccine that made this such a difficult – and important – decision for many parents? Certainly, the controversy about the vaccine received a high level of public awareness, and so parents were keenly aware of the important health consequences of their decision:

> The other option of not having anything, I viewed as quite irresponsible given how awful... because measles is such a serious disease and can be lethal, can cause deafness and whatever and is a very nasty disease. So, obviously, I'm not keen for Chris to get measles. *(Schwartz, immunised his son with MMR)*

> Back in 1996 it was before all the controversy and it did not seem to be an important decision. However, in retrospect it turned out to be a very important decision as my son had a bad reaction to it 8 days later and developed autism as a direct result. *(Sheila, immunised her son with MMR and now suing the vaccine manufacturers)*

So the dramatic consequences, or feared consequences, of this decision made it a very important one for parents. Uncertainty about the likelihood of those consequences – about risk – also made it a difficult decision for many. Forty of the parents I spoke to explicitly mentioned that they had found the decision about MMR to be a difficult one to make. But this decision was also important for another, perhaps even more fundamental, reason. Parents were being required to make a choice that would have important consequences, not for their own health, but for the health of their children who are completely unable to decide for themselves. So getting this decision 'right' came to symbolise what it means to be a good parent, to make choices on behalf of one's children that will have the best outcomes, given the constraints and information available to the parents at the time (*cf.* Alderson 1990).

> Kids can't make their own decisions. You have to do it for them, and that's really hard. *(Alison, had not yet immunised her daughter)*

> What's hard is knowing that I have the control of the decision for my baby. He can't decide for himself, and what if I make the wrong one? I'm not a gambling man. I can't gamble with something like that. It's all about protecting little Tim over there. *(Clive, planning to immunise his son with separate vaccines, not MMR)*

Fundamentally, Clive, Alison and others like them needed to get the decision right in order to view themselves as good parents. Not 'gambling' with his son's health was for Clive a way of expressing responsibility for something too precious to be treated casually. This does not mean that all, or even most, parents agonized about the MMR decision. Many told me that they had taken their children for the MMR with hardly a second thought. But they went on to explain why they believed it was important to immunise children against diseases, and their reasoning for not being especially concerned by the media reports of risk from the vaccine. In other words, even when it was not a difficult decision for parents to make, they felt that it was an important decision to make, for the well-being of their children.

Since the desire to protect children from risk formed the ultimate basis for parents' decisions about the MMR, the next section of this chapter describes in depth how parents talked about risk, determining how much and what sort of risks they were prepared to accept, and balancing the risks of immunising against those of not doing so. Assessing those risks required evaluating the evidence about risk, which is discussed in Section 4.4. To assess the evidence, parents relied on the judgements and information provided by others: experts, other parents, the media, medical professionals. So trust in those others – and sometimes the absence or loss of such trust – was a critical factor. Therefore, Section 4.5 addresses the ways that parents allocated trust, and the responsibilities that they felt must be shouldered by those experts and information sources and, ultimately, by themselves as parents. Section 4.6 describes two strategies – delaying immunisation and separate immunisations – that some parents adopted as a way of coping with uncertainty and trying to avoid both the risks of MMR immunisation and of not immunising. The final section of this chapter details the experience of one mother, illustrating how the themes of risk, trust and decision making came together in her case.

4.3 Thinking about risk

Zero risk?

Unlike the large-scale technologies that comprise the subject of most studies on 'acceptable risk', where 'risk' can be measured in terms of annual fatalities or morbidity and decisions made at the community level (Fischhoff et al. 1981, Löfstedt and Frewer 1998), the risks and decisions entailed in medical procedures like vaccination are largely incurred at the individual level.[1] In such cases, the individuals making decisions about the procedure do not think of risk in terms of numbers of people who may be harmed or of distribution of benefits within the community. Rather, risk is construed as the likelihood – or uncertainty about the likelihood – that *this particular individual* will come to harm as a result of undergoing the procedure in question. That likelihood must be balanced against the anticipated benefits of the procedure in order to decide whether the risk is acceptable. When it comes to making decisions on behalf of one's children, parents are particularly anxious to avoid causing any harm, particularly long-term damage. In consequence, many observers (e.g., Bellaby 2003) have claimed that parents demand 'zero risk' for

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[1] There are, in addition to the individual risks of vaccinating or not, health implications for the population as well. These are considered below on p. 158. However, most parents, even when taking into account the population-level considerations, explicitly prioritized their own children's health and safety above that of the population.

their children. This observation may be followed by an explanation, often perceived by parents as condescending, that although we all seek to minimise risks, the notion of 'zero risk' is illusory and leads to unrealistic demands on the part of parents and misapprehensions about vaccines. The parents I interviewed sometimes described other parents this way:

> People nowadays, they expect a no-risk life. That's where the problem comes from. Life's a risky business... People expect, I see this all the time, people expect to have things done, and to be 100% perfect, you know we're all smiling. Life's not like that... If you have an injection there's a risk there. And you either sit at home wrapped in cotton wool, or go on and live. Then the population nowadays is really in this no-risk psychology. And they must think 'Our lives had bloody well be perfect.' And when it doesn't go perfect, they start moaning. It's weird. *(Peter, immunised his children with MMR)*

How accurate is Peter's characterisation of other parents as demanding 'zero risk' for their children? On the whole, the parents I interviewed recognised that to completely eliminate risk is not possible. Children's health was consistently described as one of the most important responsibilities of parenthood, and parents used a wide variety of strategies to promote their children's health. This mother's response when I asked how she protects her daughter from risk was typical of what many parents said:

> I try and encourage her to learn things herself really, and maybe I try and protect her from risk. But not – you know, I don't endanger her but, you know, I kind of just let her fall over and learn that is what happens if you are going to teeter on the brink and not hold onto anything... I prefer for her to learn for herself rather than me protecting her all the time because I might not always be there to do it. *(Nicola, immunised her daughter with separate vaccines, not MMR)*

Managing children's risk entailed reducing their exposure to serious risks as much as possible, while teaching the children responsible behaviour that would ultimately allow them to protect themselves. Parents adopted this strategy precisely because they recognised that it was not possible to keep their children away from risk altogether.

Despite the parents' recognition that there are unavoidable risks in life, many also expressed an unwillingness to take any chance of exposing their children to certain *particular* risks. For instance, this mother was particularly concerned to avoid 'unnecessary' risks for her children:

> Yes, but I think the issue here is, you know, is this an unnecessary risk? I think everybody appreciates that in life there are risks, but it's whether you [have to take the risk], and also it is very hard as a parent because you are not making that decision about yourself, you are making that decision for your child. Who do you love more than your children? You want to know, am I putting him at unnecessary risk? *(Katie, immunised her children with MMR)*

Thus, Fischhoff's and Slovic's observation that the magnitude of a risk is not always the most important factor for its acceptability appears to be borne out in this case (Fischhoff et al. 1981, Slovic 2000). Katie's emphasis on the necessity of exposure echoes Hobson-West's suggestion that uncertainty/necessity may be a more useful dichotomy than risk/benefit for understanding parental decisions about vaccination (Hobson-West 2003).

Parents who chose not to expose their children to the MMR vaccine explained that even if the risk of autism were very small, 'if there is a risk then it should be too great however small it is' (*Sam, did not immunise her son against measles, mumps or rubella*). Even if the autism concerns turned out to be unfounded, these parents preferred to err on the side of caution with respect to this particular risk, because the idea of a bright, healthy child succumbing to the problems that had been described in the newspapers' MMR 'horror stories' was completely unimaginable:

> Yeah, the autism and the MMR and that was all that mattered to me. I wanted to rule that out... The whole research thing became irrelevant. It was a case of 'this is my daughter'. I don't want to risk anything that anybody has said... I do not want to sit there as a parent and be concerned that that was going to happen to my child... I didn't want to have to ever think that I gave my daughter something that has ever been highlighted that maybe it could cause autism... As far as I was concerned that was the end. *(Dianne, immunised her daughter with separate vaccines and with MMR)*

For these mothers, it seems that the risk of autism attributed to MMR scored high on the 'dread factor' identified by Slovic (2000). That consideration, far more than the likelihood of the risk, or even the research demonstrating whether it was a real risk, made up these mothers' minds about not giving their children the MMR vaccine.

Balancing risks

In the case of MMR, where any decision taken is known to be accompanied by some risk, parents engaged in a process of evaluating and balancing alternative risks, 'weighing the risks of vaccinating against the risks of not vaccinating' (*Preetha, immunised her daughter with MMR).* Parents were explicit about weighing the risks of vaccination, on the one hand, and the risks of disease, on the other, in a highly rational sort of risk evaluation. However, they performed this calculation in the face of a large degree of uncertainty about the relative risks and benefits, which made their assessments at times ambiguous and difficult. Furthermore, the calculation took into account far more than simply the relative likelihoods of harm from vaccinating or from not vaccinating – the risks on either side of this decision represented different types of risk and were thus evaluated differently. Previous experiences or dispositions and strong emotions also played a significant role in parents' evaluation and assessment of the risks involved in vaccinating their children, or not, with the MMR:

> So it was the emotion rather than the hard logical fact. You cope with the hard logical fact, the risks of having the innoculation and then there being an epidemic or whatever and my child suffering with all the possible complications... It was always, you know, a certainty that they would be innoculated. But it was more coming to terms with the emotion of it. *(Jane, immunised her children with MMR)*

Jane was adamant that she was completely convinced of the importance and safety of immunising her children with the MMR, on the basis of 'the hard, logical fact.' But despite her rational conviction, she found the process of deciding and then taking her children for the MMR to be very difficult, because of the emotionally charged discussion surrounding the vaccine.

Although emotion is often viewed as clouding rational decision-making, Priscilla Alderson (1990) argued that emotions form a crucial part of the rational process by which parents make medical decisions for their children. When emotion is absent, this suggests that parents have not fully grasped the implications of their child's condition or of the procedure under consideration. Likewise, for most of the parents considering MMR vaccination, it was the emotional action of imagining their child suffering from measles infection or from autism that made them take seriously the task of risk calculation necessary for making this decision.

Risks from MMR vaccination

The risks that parents feared from MMR vaccination include, of course, the purported links with autism and bowel disease, as well as other side effects (ranging from the mild, e.g., rashes, to the serious, e.g., convulsions) and more nebulous concerns like immune system overload, allergies and depriving children of the opportunity to develop 'natural immunity'. It is instructive to consider each of these risks in turn, concentrating on what parents were actually afraid could happen to their children, and on how they evaluated information, anecdotes and experiences to assess the likelihood and seriousness of the risks.

Concern about autism and digestive disorders as a risk of MMR vaccination came from reports (generally in the media or from advocacy groups) about the Wakefield research (Wakefield et al. 1998), and from anecdotes or firsthand experience of children whose behaviour changed suddenly following MMR vaccination. The following description from a mother who contacted me via the JABS message board, is characteristic of the reports that parents had heard of children whose personalities apparently changed dramatically following MMR vaccination:

> I am convinced my son's autism was a direct result of the MMR because prior to having it he had never been ill, there was nothing on his medical records or in his child development book that had given any concern to me or the health professionals. At his 3-month, 6-month and 9-month checks there was nothing recorded as unusual by the health visitors. James was a very calm, placid baby, ate well and slept for 12 hours every night even when teething. He was saying a few words and was very alert. He used to eat 2 Weetabix for breakfast every day and they had no effect on him. After [having the injection], he was so ill with the fever and vomiting, he stayed restless and irritable from that moment on. He wouldn't sleep, became a fussy eater and constantly grizzled. He stopped learning new words and started throwing toys

> around. Over the next three months he started to self-injure, banging his head on the floor, etc. At his 18-month check there were concerns highlighted over his behaviour. I have since discovered that he now has a leaky gut and that his stomach lining was damaged by something (the MMR). If he eats Weetabix now for instance, within 20 minutes he is rolling on the floor screaming. *(Sheila, immunised her son with MMR and now suing the vaccine manufacturers)*

The parents I interviewed were familiar with such stories but typically had little first-hand experience of autism themselves. Most were aware that the term 'autism' covers a broad spectrum of behavioural characteristics, and felt confused about whether MMR was allegedly linked to autistic behaviours across this spectrum, or only to the most severe types depicted in the media. But autism was nonetheless a very frightening prospect:

> But then all the stories you hear were very scary and a friend of mine, a speech therapist and she deals with two children whose parents are convinced that, you know, their child's had problems since having the MMR. Even though you can't prove it, to know someone that actually knows children who have sort of changed quite dramatically was quite scary. *(Marsha, planning to immunise her child with MMR)*

The crucial aspect of Sheila's poignant testimony, which echoes many similar cases highlighted by the media, is the contrast between her son's normal, even advanced, development prior to his MMR vaccination and the disturbing symptoms and behaviors that followed. As his mother, she had observed and interacted with James extensively both before and after his autism was manifested. This gave her a special knowledge about her son that nobody else could claim. Marsha's fears were based on having heard similar accounts, both on the news and from a personal friend. It was the sudden change, rather than the ill-defined symptoms, that was particularly worrying.

A common critique of the vaccine's safety trials was that they only followed immunised children for a few weeks, and so would necessarily have missed any long-term effects of the vaccine. Often mothers wondered how quickly after immunisation the children might begin to 'change', and a few explicitly mentioned they would like to see that issue addressed in informational leaflets about the vaccine. Seven parents whose children had received the MMR expressed feeling relief when, after a week or two, the children were not displaying any signs of autism, but they worried that they did not know how long they should continue to watch for these. A few mothers even asked me how long it would take for autistic symptoms to become apparent after the vaccine was given.[2]

Although the alleged link with autism was the most widely publicised concern about the MMR vaccine, parents frequently cited other health problems as potential risks from the vaccine. For instance, children's mild digestive problems and allergies were sometimes attributed to the MMR or other vaccines. Immune system overload was another frequently mentioned risk of MMR vaccination:

> I think what worries me is that the shots is *[sic]* just overwhelming with three things in one. And can be really hard for them to have to fight off. *(Caroline, immunised her daughter with MMR)*
>
> Since giving her the single [measles vaccine] we've spoken to a geneticist who says that there is quite a strong link between overloading the system with vaccines and, not autism, but actually overloading your system leading on to other problems. *(Brenda, immunised her daughter with separate vaccines, not MMR)*

At several points in her interview, Brenda insisted upon the importance of a holistic approach to health and medical intervention. The immune system is not localized to any particular part or function of the body: it pervades Brenda's holistic notion of the body. As Emily Martin (2000) found among her American informants, the immune system is viewed as central to the body's overall health, but is itself intricate and delicately balanced; it must be maintained so that it can flexibly and effectively cope with a multitude of challenges from the environment. Disrupting the immune system, in this view, can cause a wide range of problems, which may or may not be recognized as related by scientists looking only at infection or immediate side

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[2] Similarly, Sophie Day also reported instances of informants asking her questions about areas of uncertainty with respect to risk (e.g., a prostitute asking her how much sperm was required to transmit HIV) (Day 2000).

effects from vaccination. Note also that Brenda's claim about the danger of overloading the immune system was based on advice that she had received from a scientific expert, albeit one from a field not normally expected to comment on vaccination or the immune system. Her holistic view of medicine allowed her to incorporate information from a wide range of specialists into an overall picture of 'the system' that would probably surprise most immunology and vaccination experts.

Thirty-one parents said that they felt it was too taxing for a child's immune system to receive three vaccines - any three vaccines - at the same time. They often queried the immunisations given at two, three and four months (when six vaccines are given at once) as well, but were more inclined to accept those vaccines because there was less media attention challenging their safety and because the diseases being immunised against, especially polio and meningitis, were particularly frightening:

> I think at the time I felt safer with those injections. Because there hadn't been hype about it. There hadn't been any side effects of the fear of autism that has been mentioned. And I think because they are tried and tested you feel, and certainly Meningitis C I feel is far more severe and worrying a disease to catch than measles, rubella and mumps. So I was happier perhaps with that one. *(Sabrena, immunised her children with separate vaccines, not MMR)*

Another concern, expressed particularly by some users of homeopathy and other alternative medical traditions, was that artificially preventing children from contracting diseases could harm them. 'Natural immunity,' i.e., the immunity that a child would gain from an actual case of the disease, was said to be superior to vaccine immunity. Another version of this belief holds that diseases like measles can be a good and necessary milestone for a child's immunological development, and that preventing it can lead to problems:

> Yeah, well it suppresses, if it stops the disease, and you need to get the disease. If you need to do measles in order to move on immunologically, and in your whole health, not just immune system, then it's stopping you from doing that, if you have the vaccine to stop you getting ill. But of course it might not do that, you might just get it in a different way. *(Sorcha, did not immunise her children at all)*

Sorcha, a practicing homeopath, viewed the fevers and rashes accompanying measles as a way for the body to express and cope with underlying disruptions. A vaccine that prevents measles would thus thwart this mechanism, and the same disruption would then have to be expressed in some other, possibly more dangerous, way.

Parents also mentioned medically recognised side effects, ranging from rash to convulsions, although these were not typically seen as being so frightening as the more nebulous risks of autism, allergies, and immune overload. The reason for this is unclear, although one explanation suggested by the way that parents talked about these side effects is that since they are medically recognised, medics would presumably be prepared to deal with them.

Risks of not immunising

In considering the risks of measles, mumps and rubella that children would be exposed to if they were not immunised, parents evaluated the seriousness and the likelihood of exposure of the three diseases. A number of nuanced factors entered into these evaluations, such as the quality of the child's living conditions and diet (which, if good, was thought to mitigate against possible complications of the diseases) and the overall level of vaccination in the community. In general, parents recognised that falling vaccination rates meant that their children, if unimmunised, were more likely to catch measles, mumps or rubella. In fact, three parents I interviewed reported that their children had recently had cases of measles or rubella (though none with serious complications), and other children did die in outbreaks of measles resulting from diminished MMR uptake during this controversy (McDonald and Ungoed Thomas 2004).

Measles was seen as the most serious of the three diseases by far. However, parents were divided as to how serious they thought it would be for a child to contract measles. For most parents, knowing that measles can be fatal was enough to want to protect their children from it. They may have known, or even just heard stories about, people who suffered blindness or other complications of measles, and therefore chose not to risk exposing their children to the disease. On the other hand, some parents also remembered when measles was a common childhood illness, and did not think of it as a particularly frightening prospect. They described memories of having measles themselves as being unpleasant, but no more serious than other accepted illnesses like chicken pox.

> 'Things like mumps and measles I had them when I was little, and so I was fine. And my daughter's had the measles. And that was, you know, she wasn't very well, but she got over it.' *(Susan, did not immunise her children for measles, mumps or rubella)*

Parents who had traveled to other countries or generally expressed awareness about international issues often cited the serious impact of measles in developing countries as a reason to be particularly concerned about not allowing the disease to make a resurgence in the UK. Alternatively, other parents felt that the generally higher standards of living, nutrition and sanitation enjoyed here meant that measles was not such a concern in the UK as in developing countries.

Despite this large range of views on the seriousness of measles, most parents did express concerns about not wanting their children to be exposed to the disease. Here is a typical statement:

> That would be the one I'd be particularly worried about, because I think the measles, because there is *[sic]* a lot of side effects associated with that... I've heard like that measles are very, very dangerous. There's like a 1 in 15 chance that there would be some long-term effects. *(Fiona, immunised her son with MMR)*

Even parents who had no plans at all to immunise their children against measles frequently said that they would worry, and perhaps reconsider their decision, if they heard about cases of measles arising in the local area. Although many pro-MMR parents suggested that highlighting the potential dangers of measles might help other parents to make better decisions about the MMR, this evidence suggests that in fact most parents were well aware of the potential risks from a disease like measles. Thus, further campaigns highlighting the dangers of the disease (which some parents described as 'scare tactics') may not necessarily be helpful, although it is unclear to what extent parents' current views about the diseases are shaped by such campaigns.

Parents were again divided over the degree to which they perceived mumps to be a serious childhood illness. The most common reason that parents gave for wanting to avoid their children catching mumps was the discomfort and suffering that they associated with an episode of the disease.

> I remember having mumps and it was awful... It really hurt. I thought, I really don't want either of them to have to go through that because it was so sore. *(Rebecca, immunised her children with MMR)*

Most parents had heard that males might be rendered sterile from the disease, but viewed this as a somewhat remote possibility. Notably, no parents mentioned viral meningitis as a complication of mumps, although this is the major concern cited in medical literature and warnings about the disease. Meningitis was frequently mentioned in other contexts as a very scary disease, so it is particularly striking that the message that mumps may be a cause of meningitis does not appear to have been communicated effectively to parents.

Rubella was generally not seen as a serious condition for children, in accordance with the medical advice about rubella. Most parents understood that rubella was included in the childhood vaccination programme in order to prevent infection from circulating to pregnant women, whose foetuses would then be at risk of congenital rubella syndrome. Parents were typically vague about what this would actually entail, but recognised that some sort of measures should be taken to protect pregnant women from exposure to rubella. However, they often stated that they did not understand why universal childhood vaccination for rubella was needed, when they remembered teenage girls being vaccinated so that the vulnerable population – potentially pregnant women – would be immune.

A different, but very important, type of risk that parents perceived from not allowing their children to be vaccinated with MMR was the social risk of being seen as a bad or irresponsible parent. Being struck from GP patient lists was an extreme consequence of this social risk that many parents feared.

> When [the GP] found out that I wasn't going to have Sara immunised until at least after she was six months old so that her own immune system could have a chance to develop, the first things she said was, 'I see children in my surgery every autumn with very, very serious, you know, whooping cough. What would you do if she got whooping cough and blah, blah, blah,' and really put this huge guilt trip on me… So, I felt quite dejected when I came out and felt I was a bad parent. *(Kathryn, did not immunise her children for measles, mumps or rubella)*

Although she was acting out of concern for her daughter's health, Kathryn was very sensitive to her doctor's accusation that she was putting Sara at risk by not immunising her on schedule. However, she was not so sensitive to the doctor's opinion that she changed her decision; rather, she felt guilty at first and then came to view the doctor's advice and opinions with suspicion. For others, though, feeling that they would be viewed as bad parents did make them more likely to comply with medical advice. This was particularly the case when parents were unsure about their decision, or placed a high value on being respected by their doctors or health visitors.

Individual vs. population risks and protection

Public health concern over the currently low rates of MMR uptake stems from the need to achieve high levels of immunity in the population in order to prevent outbreaks of measles, mumps and rubella. This consideration has been widely highlighted in media reporting of drops in MMR vaccination rates. Most parents were aware of the concept, if not the name, of 'herd immunity.' Aware of the falling immunisation rates in their community, some parents were particularly keen to immunise their children because they knew that their children were more likely to contract the diseases when fewer in the population were immunised. Contributing to the herd immunity of the population by vaccinating one's own children was seen by many as a parent's responsibility to the community. This idea was spontaneously expressed by well over a third (37) of the parents I spoke to.

On the other hand, parents also expressed the view that their own children's health and safety was a more important concern than the small contribution to the health of the population that they could offer by vaccinating their children. This did not necessarily constitute a reason to avoid the MMR, but parents who expressed the responsibility to maintain herd immunity as a reason to vaccinate had typically already decided to do so for the benefit of their own children's health, anyway.

An alternative view of herd immunity was that it could be used to protect one's children without having to vaccinate them. Public health professionals have expressed particular concern about this view as legitimating the decision not to vaccinate, and have called parents who rely on herd immunity rather than vaccination to protect their children 'selfish' (2001, Berger 1999). Although some parents who had not immunised their children did say that they were not particularly concerned about their children catching diseases because overall levels of the diseases were 'so low in this country,' most parents were very critical of this idea. Immunising parents sometimes referred to non-immunising parents as 'irresponsible', and the parents who opted against immunisation did so with the understanding that they must be prepared to nurse their children through any disease episodes that they might encounter.

> I find that irresponsible and irritating. Because I'm putting chemicals into my children's bodies, putting my children at risk to protect their children... There have been outbreaks, pockets of illness because it is very, very trendy to actually be doing that [not immunising] and what the neighbour does... So you actually end up with big pockets of people who aren't vaccinating. Therefore, they are at greater risk than ever. *(Valerie, immunised her children with separate vaccines, not MMR)*

Valerie was indignant with parents who refused immunisation altogether, because she viewed their decision as having a detrimental effect on the community. Although she had opted for separate vaccines for her children, she still felt that these 'chemicals' put her children at some risk, albeit a necessary risk for the sake of protecting her own and other children from illness. She resented her own children having to assume a risk that would protect others not willing to take the same risk.

Risk and vulnerability

As set forward at the start of Section 4.3 (p. 147), parents deciding about MMR vaccination construed risk as the likelihood of a particular child coming to harm as a result of being immunised or not. Parents consciously weighed possible outcomes against one another, but were left with a large amount of uncertainty about the likelihood of such outcomes happening to their child. Focusing on vulnerability, i.e., seeking explanations for why some children seem to be more likely to suffer particular adverse outcomes than others, was a means of coping with this uncertainty. These explanations were then used to guide parents' decisions about the vaccine. They might serve as a precaution that a child was especially likely to be harmed by the vaccine (or by not having it), or as a reassurance that the child was unlikely to suffer damage as a result of the parent's decision.

Several characteristics of children or their families were repeatedly identified as giving rise to an increased sense of vulnerability. In particular, parents whose children had allergies or digestive disorders, had been born prematurely, or seemed to be generally unwell, as well as those with a family history of these problems or of autism, were more likely to express special concerns about the MMR. Additionally, boys were sometimes seen to be at greater risk, because the prevalence of autism is greater among boys (Bender 2003).

A related perception, mentioned by 16 parents, was that MMR is safe for most children but that a tiny minority, such as the children featured in the Wakefield *et al.* (1998) paper, are somehow (perhaps genetically) predisposed to be adversely affected by it. According to this perspective, the difficulty lies in determining whether one's child would be a part of that minority, rather than the majority of children who would benefit from the vaccine. A few parents desired a blood test to identify children who would be damaged by the vaccine.

Parents also believed that some children were more vulnerable to the diseases measles, mumps and rubella than others. Children who did not attend nursery or school were understood to be less at risk of catching an infectious disease, because they had less contact with other children. And some parents expected that if their children did contract one of those diseases, they would fare better than others, because they were generally strong and healthy, living in good environments, and fed a nutritious, 'immune-boosting' diet. Other parents, by contrast, were particularly adamant that their children must have the MMR, because they had medical conditions that would make a case of measles or mumps especially dangerous for them.

4.4 Evaluating the evidence about risk

Contradictory information and uncertainty

> Now, you get tiny little snippets of information here, there and everywhere. You try to put together the whole of the story for yourself, and whether you get the whole story or whether you get half of it and make up the rest, and whether it's right or wrong, you just don't know in the end, do you, what to do? *(Eileen, did not immunise her child with MMR)*

An additional layer of uncertainty complicated the situation. Parents were exposed to contradictory information and claims about the safety of the vaccine from many different sources. So not only were parents uncertain about whether their own children would be adversely affected, but they were also uncertain about whether the risks from the vaccine were in fact real and, if so, what the nature and magnitude of these risks would be.

Therefore, seeking and evaluating information about the vaccine was a crucial part of the decision-making process. There was, however, a wide range in the extent to which parents actively sought out information about the vaccine. Many parents were content to base their decisions on brief information, such as they found in the media or in leaflets from their doctor's surgeries. At the other end of the range, a few mothers showed me folders they had assembled, bulging with newspaper clippings, leaflets, printouts from Internet sites, and articles about the vaccine. Most parents fell somewhere in between:

> We did look at the Department of Health website, which was good. My husband works for the NHS so he kind of had some sources that I can't remember, but I can remember him sort of pulling off information... I spoke to my GP about it, but I mean I just got sort of party line from him. So that was pretty standard. [I spoke to] my cousin who's a doctor. I have bookmarked on the web sort of parental websites, likes Mums Net. But I didn't look at those and I don't know why. I think it's because I felt the information wouldn't be particularly in-depth. *(Preetha, immunised her daughter with MMR)*

As I show with the survey results in Chapter 6, Preetha's experience of consulting some sources for information about the vaccines, but without going to great lengths to find corroborating sources, was quite common among parents.

Risk communication and information sources

The main information sources that parents used to obtain information about the risk of MMR included NHS leaflets, medical professionals, the Internet, friends and family members, the media and anti-vaccine organisations. Interview participants discussed the pros and cons of using each of these sources, as presented below.

The principal NHS leaflet dealing with the safety of the MMR vaccine that was available to parents was a six-panel leaflet entitled 'MMR the Facts'. This leaflet had sections explaining what measles, mumps and rubella are, what side effects from the vaccine have been recognised, why the Department of Health believes the vaccine is safe and not linked with autism, why separate immunisations are not offered, and a letter from the Chief Medical Officer urging parents to 'make the best decision - protect your child with MMR' (NHS Health Promotion England 2001a). Most parents said that they had seen this leaflet but did not remember it in great detail. However, when I showed them a copy and asked them to read it, many said they thought the information was easy to understand and helpful. A few asked to keep the copy that I provided. However, a majority of the parents who had opted against the MMR, as well as several who had chosen the MMR for their children, expressed concern that the leaflet appeared to trivialise the concerns about autism and failed to recognise the good intentions of parents who were concerned or chose separate immunisations for their children. For instance:

> They are just trying to cover their back by saying that autism, there was an increase in autism before the jab was introduced. But nobody heard about the increase before the jab. I just think there needs to be a report saying how many autism cases there were before the MMR jab. But they are not going to issue something like that because then parents aren't going to go in and say, 'Oh yes, we'll have the jab now that we've read that report...' Emotional blackmail really. It says 'measles can kill. It is highly infectious.' Kind of in between the lines, 'if you don't have the jab it could kill your child.' That's not how it is going to happen. *(Jenny, immunised her son with MMR)*

This reading between the lines detected a strong message that was at odds with many parents' experience. Most parents in Britain today grew up when measles was a common childhood illness that could be treated. Although they were aware that it could have serious complications, they seemed to be exaggerated in leaflets like this. In addition, they often felt that their children were unlikely to contract measles even if they were not vaccinated. By contrast, they had not heard about the worrying increase in autism until the MMR controversy emerged. Jenny's scepticism at this apparent contradiction was compounded by the heavy-handed tone of the leaflet, which she likened to 'emotional blackmail'.

GPs and health visitors were the main medical professionals that parents mentioned having talked to about the MMR. Occasionally, parents had based their decisions on the opinions – both pro- and anti-MMR – of specialist consultants (e.g., if a child was being treated for a particular health problem that was seen to make them more vulnerable to infection or to autism and digestive problems). Parents' evaluations of the information and advice they got from health professionals varied according to their overall experience and level of trust in particular individuals, but tended to fall into two groups. In the first group, parents valued the advice because it came from a trusted, knowledgeable source. In the second, parents felt they were being given 'biased,' 'party-line' information on MMR, rather than the individual professional's true opinion. In both cases, many parents reported feeling reassured upon hearing that the health professional had given his or her own children the MMR vaccine.

> I do value my doctor and I've been with her for a while, so I think I would go with what she would say. Because she actually has a young baby as well. I think if she told me, 'I'm not going to give my baby the MMR vaccine,' that would probably change my view because she's my doctor and I would respect what she says. So at the moment I would be inclined to give her the vaccine. But if my doctor said 'I'm not doing it for the following reasons' then I would stop. I don't know whether I would stop for any other person. *(Catherine, immunised her baby with MMR)*

> I spoke to my health visitor about it. And I said, 'Can you tell me honestly what your feelings on the MMR is?' And she said to me that she would recommend that Karyn should have it. But even so I still felt that it was as though she had given me a kind of brain-washed answer. That she'd been told, you know, 'If parents want information then we need to get across to them the importance of having the jab and tell them that's what they ought to be thinking and doing rather than saying "OK, if it was my children".' I didn't feel that she was being honest with me. *(Katie, immunised her children with MMR)*

Both of these quotes point to the importance of trusting relationships with health professionals for parents trying to evaluate information about the MMR vaccine. Whereas Catherine trusted her doctor and said that she would follow any advice her doctor gave, Katie was unconvinced by her health visitor's presentation and felt that she was not being honest. As we shall see below (p. 174), parents' perceptions of practitioners' interests were often dependent on previous experiences and personal relationships with them.

The Internet was a popular source of information about the MMR vaccine: many parents had used search engines to find information for and against the vaccine, and parents who did not have access to the Internet said that they would have used it to get information if they had had access. However, all the parents who used the Internet expressed caution about the information and opinions available there, because 'anybody could put anything on the Internet' *(Rebecca, immunised her child with MMR)*. Parents tended to find this source useful for obtaining a range of views, rather than for obtaining solid, trustworthy information.

Friends and family members were among the most frequently cited sources of information, although, like the Internet, they were used primarily for obtaining a variety of perspectives about the vaccine. Most parents said that they had found it very helpful to hear about the experiences of others whose children had already had the vaccine. Parents who had a friend or family member with a medical background of some sort found them to be a particularly useful, and trusted, source of information. Parents were reassured to talk to somebody whose children had been fine after the MMR, and to know what sort of mild reactions to expect. In a few cases, friends or acquaintances had attributed serious complications (including autism) in their children to the vaccine, prompting concern on the part of the interview participants. In a few other cases, parents used information about obtaining separate immunisations at private clinics that had already been gathered by a friend.

The media, particularly television and newspapers, were often the first place that parents had heard about the allegations of a link between MMR and autism. Some parents reported that they hesitated before giving the vaccine only because of the media coverage. Parents also frequently said that the media were 'biased' and had over-sensationalised the issue. Interestingly, however, they did not agree on the direction of this perceived bias. Even readers of the same newspaper made opposing claims. Typically, these parents felt that the media were biased in the opposite direction from their own position about the MMR vaccine.

A minority (16 out of 87) of parents used organisations that advocated against the MMR, or against vaccines in general, in making their decisions: many of the parents who were familiar with organisations such as JABS described them as 'extreme' or 'less likely to be useful because [they are] very difficult to control' *(Angela, immunised her child with MMR).* However, for a few parents, these organisations were an extremely important source, even the primary source, of information about the MMR vaccine. Citing distrust in the Government's medical authority, previous experiences when doctors had failed to help with medical problems, and a preference for alternative or 'natural' medical traditions, these parents had read extensively about the dangers of vaccines. Dr. Viera Scheibner (see Chapter 1) was particularly influential, and all the parents who had read her writings pointed out that her claims were based on published medical literature. When the claims were refuted by other scientists, this was viewed as 'bias' or a 'cover up' on the part of the medical establishment:

> This is just, this is all medical research. This is not her pontificating or making something up. This is all what she has pulled out of the medical journals. The information is there, the damage that vaccines do is there. But I don't understand really why it is just squashed. But why the medical establishment, they have it but it is just like, 'no.' *(Sorcha, did not immunise her children at all)*

That the evidence against vaccines came from 'medical research' gave it authority. To Sorcha, the 'damage that vaccines do' should be self-evident from the results of this research. Although most doctors advocating vaccines would claim that other studies had offered more persuasive evidence that vaccines were generally safe and had saved many lives from disease, Sorcha interpreted their dismissal of

Scheibner's claims differently: 'it is just squashed'. Ultimately, she did not trust the expertise or the authority of the pro-vaccine scientists. The following section elaborates on this question of trust, and of what constitutes trustworthy expertise, which emerged frequently in parents' discussions about the MMR vaccine.

Epidemiology vs. case studies

How did parents evaluate the reports - which they were universally aware of - about the claim that the MMR might be associated with autism and digestive disorder? Most were aware that the research by Andrew Wakefield had been largely discredited by the scientific community, although, as expected, parents varied widely in the degree to which they understood why. The small sample size upon which the 1998 article was based was the most frequently cited reason for viewing the research as 'flawed'. Several parents also expressed the idea that autism may occur for other, unknown, reasons, or that autism appears to be increasing only because diagnostic standards have changed, and that its onset following MMR vaccination was simply coincidental. However, even when parents recognised that there were significant problems with the research behind the MMR controversy, many still felt that the research had raised important questions that deserved further investigation.

> Dr. Wakefield, he has, unfortunately for him, he has been discredited, hasn't he, now, more or less. But it was good for him to generate some thought and some open public discussion about it. I think that's always good. *(Joy, immunised her son with MMR)*

Most of the evidence for the safety of the MMR that parents were familiar with consisted of large-scale epidemiological studies finding no association between the vaccine and autism. However, they were concerned that epidemiological evidence would overlook some children who might have really been harmed by the vaccine. If the reaction was real but extremely rare, then these children would not 'show up' in the statistical analyses. Parents who felt sympathetic to the concerns raised by

Wakefield and his colleagues (Wakefield et al. 1998) but gave their children the MMR anyway had concluded that the likelihood of any particular child being affected was not large enough to justify witholding vaccination, even if the vaccine had caused autism in some children.

In order to come to terms with the claims of parents who believed their children had been harmed by the MMR vaccine, twelve parents said they wanted more research concentrating on detailed case studies of those children. Most did not specify what sort of study should be performed to find the underlying causes of those children's autism, although some were familiar with the investigations revealing the presence of measles virus (apparently of vaccine, rather than wild, origin) in the intestines of some of the autistic children (Uhlmann et al. 2002), and the efforts of the parents involved in the lawsuit over MMR vaccine to have spinal taps or other tests performed on their children (Deer 2004). These parents felt that such tests were a more precise way to understand the risk posed by MMR to a small minority of children than epidemiological surveys:

> There are work *[sic]* that are picking up on the vaccine strain virus in the gut of some of these kids. More research into the actual biology probably [is needed]. Yeah, hands on, you know... But to actually get the statistics on, you know, real biology there. Rather than the sort of broad things. *(Jo, did not immunise her son against measles, mumps or rubella)*

A further source of concern about the large-scale studies and official statistics demonstrating the safety of the MMR vaccine was that vaccine adverse reactions might not always be reported to the central registries. Several parents cited instances in which they, or others they knew, presented concerns following vaccination but were not taken seriously, and thus questioned the claims that no adverse effects had been found – how many effects had simply not been reported because doctors were not listening to the parents who brought their children forward?

In contrast to the parents who immunised their children despite uncertainty about the possibilty of it causing autism, for other parents even an extremely slight risk of autism was too great. These parents took a fundamentally different epistemological approach to the problem than the epidemiological one used by the health authorities to support the position that MMR was safe (Elliman and Bedford 2001, NHS Health Promotion England 2001b, Taylor et al. 1999). They demanded a different type of evidence about the safety of the vaccine, which would focus on the individuals who had reportedly been adversely affected. Anecdotal accounts of the dramatic behavioural changes that other parents had observed in their own children were extremely salient, because of the special nature of the relationship between parents and children.

> And to me I tell you the clinching thing on why I wanted the single vaccines was the parents on the television that were showing their children... That was the clinching thing, that these parents were so convinced that it was the MMR. Be it that or not be it that, that's what they truly believed. And then showing videos of their children before and after. Okay, again, they say that it's just the signs of autism come out at about the same time that MMR is given. But still, to them it was the MMR. They truly believed that, do you know what I mean? *(Dianne, immunised her daughter separately and with MMR)*
>
> When, you know, you tell the GP and you tell the Health Visitor and they kind of almost [say] 'Don't be silly.' You know, or 'What do you know?' And yet, and I think an informed parent can certainly have a lot more information, you know, available in that afternoon about your child but also about what they found out on the web and that they can actually, yes, possibly have more information sometimes than a GP. That obviously if you're considering huge numbers of ideas. Some parents are probably an absolute pain but, erm, not to be dismissed. *(Jo, did not immunise her second child for measles, mumps and rubella, after her first child had a bad reaction to MMR)*

Dianne's reasoning for placing so much importance on the other parents' claims was that parents know their own children better than anybody else, and so are in a unique position to notice changes in their behaviour and personalities. Likewise, Jo, a PhD-level scientist who described herself as 'pro-vaccination', drew on her experience as a mother and her own research on the internet, more than her scientific training, to make her case to the doctors and health visitor. As a mother, she had access to first-hand information about her son that her GP would otherwise have missed, and she was adamant that such experiences were 'not to be dismissed'. The challenge for doctors and scientists is to find ways of taking seriously these experiences while interpreting other types of evidence.

Such talk highlights the importance of narrative for linking and interpreting observations (Earle and Cvetkovitch 1995, Fish 1980). Epidemiological findings can suggest whether or not there is a statistical association between events like MMR immunisation and the occurrence of autism. But these findings in and of themselves lack the rich meaning offered by the narrative accounts found in parents' descriptions of their children changing and in the media. Some proponents of the MMR vaccine have begun to incorporate powerful narratives into their arguments. For instance, Michael Fitzpatrick described his experience overcoming feelings of guilt as the father of an autistic boy (Fitzpatrick 2004) and newspapers have presented several narrative accounts of children who caught measles (Goswami and Ungoed-Thomas 2004, McDonald and Ungoed Thomas 2004). Many parents were indeed persuaded by these narratives. It is important to recognise the importance and the value of narrative, because simply dismissing parents' anecdotal accounts of changes they observed in their children has resulted in many parents feeling that important facts had been overlooked or, even worse, covered up by the medical establishment.

4.5 Trust and responsibility

The role of trust

The discussion of reviewing information sources and evidence makes it clear that parents making decisions about the MMR vaccine for their children were dependent on many other people. People working for government bodies such as the Department of Health formulated policies and advice on the basis of medical and epidemiological evidence. Medical researchers conducted investigations into the safety of MMR and the epidemiology of the diseases it protects against. Other experts evaluated these studies and interpreted them for the public. Many other agents (e.g., reporters, other parents) communicated and reinterpreted this information. In most cases, the arguments about the vaccine took place beyond the realm of the parents' experience and knowledge. Therefore, the information and advice had to be taken – or not – on the basis of *trust*.

Because the claims and advice offered by medical experts, other parents and government agencies were often contradictory, parents had to decide whom to believe based on trusting certain people and distrusting others. Trust could not be universal, because trusting one party meant rejecting the advice of another. When parents were unable to trust any of the sources of information and advice about the MMR, they did not know whom to believe. This situation was bewildering, frustrating and overwhelming:

> I think you can just take what everybody says, whatever you read, take it all on board, and [you] just have to weigh up how you feel at the end of it. I don't know whether this expert from this university or study, or whatever, I don't know whether that person knows any better than the next 'expert'. I think that we just have to take it all on board. That's the trouble really, I don't know which expert to believe. Tony Blair stands up and says 'this is right,' we don't want to believe him either. *(Valerie, immunised her children with separate vaccines, not MMR)*

Parents frequently talked about what made them trust certain agents and distrust others when it came to making decisions about their children's health, as presented in the sections that follow.

Trust in the Government and politics

Many parents perceived the MMR debate to be a political issue. There were a number of reasons for this. Much of the media reporting had highlighted clashes between advocacy groups and government health authorities about providing children with alternatives to the MMR. A few Ministers of Parliament had made the MMR vaccine a point of debate in Westminster. Tony Blair's refusal to reveal whether his son had received the vaccine was mentioned in twenty interviews.

> Also I think, like Tony Blair didn't make it [any easier to decide], when he wouldn't say whether his child had had it or not. You kind of think, well, why won't you, if your child had had it and hadn't had the three separate jabs, surely you would just say. So, but, it makes you sort of, I know it's a private matter obviously, but as he is in the public eye and he's saying, 'yes, have this jab, it is safe.' He should say whether his son had the jab or not. *(Alice, immunised her child with MMR)*

The politicisation of the MMR debate was a great problem, because parents tended to report categorically that they did not trust politicians. Government ministers' mishandling of other issues related to risk (such as the BSE crisis, in which the Government at first insisted that there was no risk to humans and later warned that the virus could infect and kill people (Caplan 2000, Murphy-Lawless 2003, Rowell 2003) seriously undermined parents' confidence in governmental pronouncements that the MMR vaccine was safe. And perceptions that politicians had lied about other issues (such as the justification for going to war in Iraq) undermined belief in the Government's integrity.

> But because of their history of government mis-management of public health issues in this country I think a lot of people are very, very suspicious when the government says 'oh there's nothing to worry about, don't you worry'. That actually brings out a very negative reaction. Even then you think there must be something in it. Simply because there are a history of things like salmonella and eggs. There were some others of course, BSE was the big one which I think has destroyed people's trust. I think in general actually things like food safety. People are very suspicious of the way the government handles it here. Because there is a perception that it is protection of business and trust fund. Which I go along with a bit. So yes I think they could've handled it better. *(Angela, immunised her son with MMR)*

So the Government's emphatic support for the MMR vaccine may have actually diminished, rather than restored, public confidence when the issue became political. Some parents reported that they trusted the Government's decisions only after evaluating the relevant evidence themselves.

> I don't think the politicians have made a very useful contribution to the controversy, to be honest with you. Because intrinsically we don't trust them. Whoever they are, whatever party, there's always a suspicion. *(Peter, immunised his children with MMR)*

> Yeah, trust. I think a lot of this has been on trust. But trust in an informed,

> knowledgeable way, not just trust for trust's sake. I don't think I'd trust any government unless there was facts and figures to back up what they were saying. I certainly wouldn't trust somebody saying 'do this because it's good for you.' I'd need to know why it is. *(Sabrena, immunised her child with separate vaccines, not MMR)*

It seems, then, that one of the crucial functions of trust in modern society – eliminating the need for citizens to become experts in everything by allowing them to delegate responsibility for decisions to others (Earle and Cvetkovitch 1995, Fukuyama 1995, Giddens 1990) - had broken down in the case of MMR in the UK.

On the other hand, a number of parents did trust government health agencies in their capacity to regulate medical products like vaccines and monitor epidemics to formulate recommendations about vaccines. Those who did not trust government agencies to act appropriately in this role cited financial interests as a reason for distrust. Immunising children with the MMR vaccine was understood to represent a lower cost to the NHS than either providing separate immunisations for the three diseases or treating children who contracted measles, mumps or rubella. For parents worried that MMR was unsafe, the apparent prioritising of cost over children's health and well-being was alarming.

> Well I just think if the government had more money, they would do it, they could do it legally, single vaccines. But they don't because it costs them money. But we are talking about children's healthcare, not money. And money to come over health is a bad issue really. *(Jenny, immunised her son with MMR)*

Some parents also suspected that government policy-makers were colluding with pharmaceutical companies, pushing immunisations for the manufacturers' financial gain rather than for the health of the nation's children.

Across the spectrum of parents' own beliefs or decisions about the MMR vaccine, many parents found the Government's approach to be 'defensive' and therefore off-putting. The Government, they said, was too heavy-handed in its approach. Parents wanted the Government to do more to acknowledge uncertainty, as well as the good intentions of parents who questioned its policy on MMR or opted not to allow their children to have it. Many parents felt that government health officials should be more trusting of parents and their capacity to act in the best interest of their own children's health. The Department of Health's refusal to offer separate vaccines, to many parents, was emblematic of this defensiveness and contributed to the problem of distrust. If parents were given more options, then they might be less inclined to believe the Government was 'pushing' a dubious or hidden agenda; furthermore, some parents who were not immunising their children might be motivated to do so. This viewpoint was not universal, but it is interesting to note that it was put forward by twenty-four parents, including both those who fully supported the MMR and parents who did not.

Trust in medical advice

Dissociated from government political agendas, medical advice in general was trusted by the parents I talked to.[3] They valued the experience and training of medical professionals. Also, knowing that doctors, nurses and epidemiologists follow a well-established professional code of practice inspired confidence in the recommendations they made.

> Yeah. Because I feel, well, they've been trained to do their job and they're a lot more qualified than I am. And yes, I'm using them. You know, well, I'm putting my children in their trust. *(Amy, immunised her son with MMR)*

Personal relationships with particular medical professionals were extremely important for parents' trust. The importance of relationships with doctors, nurses and health visitors to parents' use of information from those medics was discussed on p. 164, above. In particular, taking time to listen to parents and attention to 'little things' that demonstrated competence and interest in patients' concerns were important bases for trusting relationships between parents and individual health professionals.

> Yes, I've had some excellent doctors in the past and others who I feel, you know, as soon as you go in, they are standing up for you to go. I guess I'm quite sensitive to that actually... Yes, I would say that more of doctors although I have had some excellent ones too and I have quite a good one at the moment. I wouldn't necessarily say that of health visitors. I sometimes find that they don't always know what you are asking or don't have the answers to questions that you thought they would know about. I've, there was some research on breast-feeding that I was asking the health visitor about and they didn't have a clue what I was on about. Just little things like that, which make me feel sort of, well, lacking in confidence. *(Helen, immunised her daughter with MMR)*

One practice that undermined parents' trust in their GPs was the vaccination target payment scheme, in which doctors were paid according to the percentage of their patients who were fully immunised. The following excerpt was from a focus group of parents who had refused the MMR:

> Eileen: Um, basically when I spoke to the GP and told her that we were debating, I didn't say whether we were or were not going to have it, then she gave me the, just the standard spiel, you know, 'you must have it, you must have over 80% of the population vaccinated' and this, that and the other.
>
> [voiceover] Yeah, they need 80% to get paid.
>
> [another voiceover] They just vaccinate to get their money.
>
> Cecily: That's right, they get paid.

Knowing that doctors were paid for successfully promoting vaccines made these mothers feel cynical about the doctors' motives in dealing with parents who resisted. Although these women had already been made wary of the vaccine, the policy of vaccination target payments resulted in a situation in which it would be very difficult for doctors to offer advice or alternative perspectives that the mothers would trust.

Another very important critique that many parents made, of both medical and government strategies to convince parents to allow their children to be given the MMR, was that they relied on emotional manipulation and exaggerated the potential consequences of not immunising. For instance, several mothers described how their GPs had 'pressured' them into having the vaccine by talking about children who had

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[3] The exception to this observation is parents who disagreed with conventional medical practices and instead followed one or more alternative medical traditions. But these parents also were generally trusting of the medical advice given by practitioners of their preferred tradition.

died of measles. Department of Health warnings about the threat of a potential outbreak of measles were also sometimes dismissed as 'scaremongering' or 'misrepresentation':

> So I hate that it's all that misrepresentation and it uses fear and parents are terrified not to vaccinate because they couldn't live with the consequences. But what they don't realise is that they might have to live with consequences of a child being damaged. *(Sorcha, did not immunise her children at all)*

Such appeals to fear and emotion were salient because of parents' tremendous emotional investment in their children's well-being: 'Who do you love more than your children?' *(Katie, immunised her children with MMR).* Interestingly, this same quote might support either immunising or not immunising. But parents sometimes felt that their strong emotions were being exploited to prompt them into a particular action in a way that clouded rational discussion and decision-making. This feeling of emotional exploitation was very damaging to trust between parents and medical authorities. It should be pointed out, though, that some parents also described similar feelings of exploitation about many of the reports of the problems with autism allegedly caused by the MMR.

Responsibility

The theme of trust was also closely linked to that of responsibility. Building and maintaining the trust that is vital for preserving and promoting children's health was seen as a key responsibility of all the parties involved in the MMR debate. In particular, parents discussed the responsibilities of three classes of actors: the Government, the media and parents.

Parents held the Government broadly responsible for protecting the population from risks to health, informing people about risks, and enabling people to make good decisions about risks and their health. This meant taking the alleged link between MMR and autism seriously, and sponsoring extensive, high-quality research that would investigate the vaccine's safety and explain the currently high incidence of childhood autism. It also meant being free from conflicts of interest (e.g., vaccine committee members having stock interests in vaccine-manufacturing companies) and maintaining open communication with citizens. To some parents, it meant offering choices about vaccine formulation (MMR vs. separate components); to others, it meant evaluating the available evidence and making a well-reasoned decision about the single best option to offer. Despite the generally low level of trust in politicians and ambivalence about how well the Government regulates and protects us from health risks, most parents did respect the immense difficulty of the Government's situation.

> Well, as I say I have a tendency to trust the government line on it. Whilst also understanding that actually it is very difficult for them to admit to any negative effects, whereas I do assume there have to be possibly [adverse reactions] in some children. It must be difficult for the government agency trying to promote it... I think it's very difficult. *(Angela, immunised her child with MMR)*

Many parents said that they were glad that the media had highlighted the initial concerns about the MMR vaccine, prompting public discussion and investigation of the possibility of its link with autism. However, many (24 out of 87) said that the media had irresponsibly carried the story too far. They felt angry that the stories of autistic children had been sensationalised, and that the scientific evidence about the vaccine had been distorted or had not been given enough coverage to counter-balance the negative reporting about the vaccine.

> What makes me really mad is that the media are being really irresponsible about this. It's not in their interest for the general population to be well informed, but to sell newspapers. Children's health is not something to sell newspapers on. *(Brian, immunised his children with MMR)*

Of course, the most important responsibilities discussed in these interviews were those borne by the parents themselves. The parents' chief responsibility was to protect their children's health. This meant actively learning about children's health and safety, providing a healthy environment, instilling good habits (e.g., providing a healthy diet, teaching traffic safety), and making well-informed judgements about medical procedures such as vaccination. Many parents also perceived a responsibility to protect their children and others' by immunising, as discussed in the section on individual and population risks (p. 158). Parents wanted their responsibilities, and their good intentions to fulfil these responsibilities, to be recognised by other parents, by health professionals, and by government officials.

> I just feel they didn't play particularly fairly with people because it is all emotional stuff. It is all about parents wanting to do the right thing for their children. That's the bottom-line. And you want healthy children. You want to do the right thing. You want to be responsible and you want help to get there with the right information. And people shouldn't mess around with you. *(Linda, immunised with MMR)*

When these responsibilities were mutually recognised and respected, parents entered into trusting relationships that fostered dialogue and cooperative decision-making.

4.6 Compromise strategies

Many parents, as I have noted above, did not find the decision about MMR vaccination to be a difficult one. Others, however, wrestled with uncertainty and contradictory information. They often adopted a compromise solution, which sought to eliminate or minimise the risk from MMR, while also conferring protection against the diseases measles, mumps and rubella. Two such strategies were delaying vaccination and immunising separately through private clinics. Parents who adopted these strategies recognised the problems that they entailed, but felt that they offered the best solution to the conundrum.

Delaying vaccination

Parents who felt ambivalent about the MMR often delayed immunising their children in order to give themselves more time to make the decision. Many parents had slightly postponed the immunisation because the child was unwell on the scheduled date, or the time was inconvenient for some other reason. However, twelve parents told me that they had put off, or were putting off, the MMR immunisation by several months or even indefinitely. When appointments (which were automatically generated by a central office and sent to parents) came in the mail, they would ignore them or phone the surgery to make an excuse. The parents who did this were dissatisfied with the lack of resolution that such a strategy offered, but were reluctant to make an irrevocable decision. They were torn between fear of the vaccine and fear of not immunising. Most of these parents told me they were fairly sure that they would eventually take their children for the MMR, but had so far stopped themselves every time an appointment came through because 'you think, what about if there is a link, what if in a few years' time they say there is a link, what if your child is that small minority that gets it [autism]?' *(Alison, had not yet immunised her daughter).* As long as there was no apparent urgency to vaccinate, their reluctance to take a decisive action that they might later regret prevailed. However, these parents also said that if they heard of local outbreaks of measles, mumps or rubella, then they would feel more motivated to have their children vaccinated quickly.

Other parents made a more deliberate decision to postpone MMR immunisation until their children were older than the recommended 12-15 months. There were two reasons for this delay. The first was that older, bigger children were presumed to be more capable of handling the challenge to the immune system posed by the vaccine. Allowing children's immune systems to 'develop' meant that they would be less susceptible to side effects or 'immune overload'.

The second reason relates to one of the arguments that had been used to refute the alleged link between MMR and autism. According to this argument, the onset of autistic symptoms appears to follow MMR immunisation in some children because the age when autistic symptoms begin to appear anyway happens to coincide with the age at which children are given the MMR. Some parents chose to wait until their children had passed this age, making sure that they did not display any signs of autistic behaviour, before allowing them to receive the MMR. This way, they were more confident that their children were not in the 'small minority' they thought might be susceptible to problems caused by the vaccine.

Separate vaccines

> On reflection, I really didn't want my daughter to go unvaccinated (especially as I was hearing horror stories of the diseases themselves from colleagues at work) and as I was so anti-MMR, the single route was my only option. *(Dawn, immunised her daughter with separate vaccines, not MMR)*

Parents who opted to immunise their children with each component of the MMR separately felt that this option was safer than the combined MMR vaccine because giving children only one virus at a time 'doesn't place such stress on the immune system' *(Sarah, did not immunise her son because she could not obtain separate vaccines through the NHS).* One mother gave a more detailed account of why she felt that giving a series of single vaccines was safer than giving them all at once:

> My understanding of the single vaccines is that studies have shown that it is when the mumps vaccine is given with the measles one that the mumps vaccine damages the gut wall and enables the measles virus to take up residence there. Therefore, the single measles vaccine should be much safer than the MMR. Of course, if the child already has a damaged gut and allergies and digestive problems then they should avoid the single measles vaccine as well. *(Sheila, immunised her son with MMR and now suing the vaccine manufacturers)*

These two explanations for preferring separate immunisations to the combined MMR reflect rather different concepts of the body and relationships between parents and 'expert' information sources. Sarah's explanation, which was more common among the parents I interviewed, is based on the holistic view of the body with the immune system as a sensitive, unifying feature (as described by Brenda on p. 153 and by Emily Martin (2000)). When expertise was invoked to explain or defend this view, the experts in question tended to be alternative medical practitioners or scientists not specializing in immunology or infectious diseases; their expertise was invoked across the compartmental boundaries set up by conventional medical science. Sheila's explanation, on the other hand, is heavily indebted to Dr. Wakefield's research and hypotheses (Wakefield 2001, Wakefield et al. 1998), and offers a molecular-anatomical mechanism for the supposed action of the triple vaccine. Although Dr. Wakefield was a gastroenterologist and not an immune specialist (a fact readily pointed out by his critics), the hypothetical mechanism he offered is based on specific actions of the viruses on specific organs: the explanation conforms to a medical view of the body as being made up of discreet but interrelated parts, even while it challenges widely accepted medical ideas about the action of combined vaccines. It is worth noting here also that Sheila was particularly reliant on Dr. Wakefield's research because she was a claimant in the legal action against the MMR vaccine manufacturers, and Dr. Wakefield's work constituted the principal medical evidence in this case.

Parents who had opted for the separate immunisations generally perceived these as offering the same benefits as MMR in terms of disease protection. A major Department of Health argument against separate injections is that the in-between period leaves children vulnerable to the diseases, but parents who had followed this course generally didn't see the gap – generally ranging from a few weeks to three months – as being long enough to pose a threat.

> I don't want him to go on being unimmunised. But I just think this is a very short space of time. *(Valerie, immunised her children with separate vaccines, not MMR)*

Rubella vaccine was often given first, because it is the only one of the three single vaccines that is currently licensed in the UK. This allowed providers to take advantage of a legal loophole allowing single vaccines to be given to children who had already started on this course. However, measles immunisation was thought to be the most urgent of the three vaccines because measles was understood to be the most serious of the three diseases. Thus, this mother was very happy that her daughter had been given measles vaccine first, and was not concerned about the extra weeks that she would be waiting to be immunised against mumps and rubella:

> As far as I know measles is the worst. It was going to protect and she had that first. That means she's automatically protected against the worst of the three. Erm, I presume the rubella is only for the herd... [to keep them from infecting] pregnant women... The government aren't worried about my child, they're actually worried about protecting pregnant women. *(Brenda, immunised her child with separate vaccines, not MMR)*

Another official argument against using three separate vaccines rather than the MMR was that fewer children would actually receive the full course of immunisation if they had to come on three different occasions rather than just once (NHS Health Promotion England 2001b). Citing the experience from a different vaccine controversy in the 1970s and 1980s, when the pertussis component of the DPT vaccine was allegedly responsible for neurological damage, NHS doctors have argued that when separate vaccines were offered before, immunisation rates fell dramatically, and many children suffered or died as a result. However, this comparison does not seem entirely persuasive because in the first case, parents were afraid of one component of the DTP vaccine in particular, so it is not surprising that they might accept the others but refuse to immunise their children against pertussis. On the other hand, the MMR controversy centres on the combination of the components; none of the three immunisations are posited by the Wakefield hypothesis to be unsafe in themselves. So we might reasonably expect more parents to follow through with a complete course of the three vaccines (measles, mumps and rubella) than was seen in the pertussis case. Most parents I interviewed rejected the claim that separating the vaccines would result in lower immunisation rates among parents who opted for three separate vaccines rather than the MMR:

> I was very tempted initially to get the single vaccines. The argument about parents not remembering seemed ridiculous. Of course you would remember to come back for the others. *(Audrey, immunised her son with MMR)*

> As far as turning up for the one or the other if you're going to pay for the injections then I don't see the point of paying and not turning up… If the NHS offers that as a free service which you weren't paying for then I think probably more people would do it, if they didn't have to pay for it and if it's free and if it's in the best interest of a child, a responsible parent surely would follow that. *(Sabrena, immunised her child with separate vaccines, not MMR)*

As these mothers noted, the parents who had chosen single-component vaccines had all made a considerable investment of time, research, and money to find a provider and pay for the vaccines. Therefore, the suggestion that parents who wanted single vaccines for their children would not take their responsibilities seriously enough to ensure that their children received the full course was considered offensive.

A far more serious problem with the course of separate immunisations was the lack of government control over the quality of unlicensed, imported vaccines or in those administering them. In other words, opting for the separate vaccines may be a risky precaution – in trying to protect their children from the perceived risks of MMR, parents are instead putting their trust behind a vaccine regimen whose safety and efficacy have not been determined, and in largely unregulated clinics. This concern was cited by many parents as a reason *not* to follow the single-vaccine course, but instead to have the MMR. Others felt that this constituted a reason that the Government should take a more active role in regulating, and possibly also providing, single-antigen vaccines for measles, mumps and rubella:

> I would just try and ensure that there is as much vaccination as possible. Whether it came from MMR or whether it came from individual vaccines. I would just try and make sure the quality of the vaccines was good rather than trying to clamp down on them. I would try maybe to get a really good source of them and have it controlled and give people a choice. I'm sure a lot of parents when they say, you know, 'We've got a choice. Well I'm quite happy to go for MMR.' But if you don't have a choice you think, 'Well, why were they pushed to this?'. You don't have any control. If the only control I have is to say 'No, I refuse it,' you kind of *[sic]*. It's not a good choice

really, is it? *(Nicola, immunised her daughter with separate vaccines, not MMR)*

Nicola's argument for offering parents the choice of single-antigen vaccines was based more on concern that more children should be immunised, rather than on her own concern that the MMR vaccine was unsafe. She told me that she was not especially opposed to the MMR personally, but opted to go to a private clinic offering separate vaccines because the opportunity had arisen to do so and she had a mild preference for that method. But she knew that many parents did not have access or could not afford the fees of the private clinics, and were therefore not vaccinating their children at all against measles, mumps, and rubella. The government, she felt, had a responsibility to make the vaccines available to their children, even if this meant administering them in a non-preferred form. The policy of 'trying to clamp down on them' constrained parental control and trust in the Government's authority over children's health.

4.7 One mother's story: an illustration of risk, trust and the decision-making process

During the period when I was conducting these interviews, the lack of quality regulation in some private clinics administering separate measles, mumps and rubella vaccines was highlighted by the dramatic closure of two such clinics for failure to follow proper protocols for vaccine storage. One mother I interviewed, Dianne, had immunised her daughter at one of the clinics that had been closed. Although her experience was unusual among UK parents, it underscores the difficulties that many parents faced with balancing risks and deciding who to trust. Her story is presented here in some detail, by way of summarising the key points about risk, trust and decision-making presented in this chapter.

Frightened by the media reports and parent testimonies about autism following MMR vaccination, Dianne, a nurse, determined not to expose her daughter to the vaccine. Because she was also worried about exposing her to risks from measles and the other diseases, Dianne began searching for a provider of single-antigen vaccines. Together with a friend in the same situation, she found an internet listing of private practices offering the vaccines. Here, Dianne describes the process by which they chose a provider from this list:

> I wanted her to be vaccinated as quickly as possible and so [my friend] got a whole list of names and picked the one a) that was nearest and b) who was also British. I know that might sound awful but he was obviously like an English doctor. There's an awful lot of other doctors that weren't... It was ironic really that the clinic got closed down in the end because we were looking for someone that obviously wasn't just making money and actually that is probably what he was doing, but that's what we were looking for. I know that sounds – I don't know, maybe I'm not politically correct to say that [of] someone else that's not British, do you know what I mean? But it was that.

Lacking knowledge of any of the providers on the list, the two mothers had used British-ness as a basis for trust. They phoned the clinic in question, took their children on three separate occasions for the vaccines, and felt relieved. Later, however, Dianne came to regret the trust she had placed in the clinic and in the organisation providing the list of names:

> Really I've made massive [assumptions], you know, I haven't really looked into it, I haven't. It was all done on an emotional level not on scientific base and really you know I was quite happy to go off and do, you know, what I want. Do you know what I mean? It was just enough to have the single vaccines, not know where they're from, not really know who's administering them. Hand my money over. That in itself is a mugs game, isn't it? Do you know what I mean? It could have been anybody. This is another thing that I realised at the time, was that these places on the Internet were recommended by this thing called JABS. Well again in retrospect when all this thing came up about this clinic I realised I didn't even know what JABS stood for. That could have said recommended by anything. Really if you look at, as I say it was all done on a completely emotional basis. I didn't look into [it]. It was quite, it was stupid really, again in retrospect.

Several months after the vaccinations, Dianne's mother phoned: she had read in the newspaper, and seen on television, that the clinic where Dianne's daughter had been immunised had been shut down because children had not been immunised properly. At first, Dianne assumed that the reports were sensationalised, and that everything was fine. However, when she tried unsuccessfully to phone the clinic, she became concerned and phoned NHS Direct and a health visitor within the Trust that had shut the clinic down. They advised her to give her daughter the MMR, and sent a large information pack.

Still frightened of the MMR vaccine, but also concerned whether her daughter was protected from measles, mumps and rubella, Dianne eventually convinced her GP to do a blood test for antibodies to the three diseases. She was shocked to learn that her daughter was not immune to any of them. By this time, she had another baby and felt unable to go through the process again of finding a single-vaccine provider and take her daughter for the three injections. Feeling that she 'would never forgive myself if something had happened - if she'd caught measles and or something happened to my son,' she finally took her daughter to the local GP surgery to receive the MMR vaccine.

At the time I interviewed her, Dianne was relieved that her daughter was vaccinated and had not apparently suffered any complications. However, she was very upset about the ordeal, and had not yet decided whether she would seek out separate vaccines for the baby or give him the MMR. She still wished that she could take her children to her own NHS surgery, which she trusted, for the course of separate vaccines, which she saw as a less risky means of protecting from measles, mumps and rubella than the combined MMR.

> And I was mortified at having to give it to her. I was really, really upset. And apart from the fact that I put her through three separate injections for no immunity, then to have her blood taken, and then the MMR, and now she's got a phobia about the doctors. So it's been hideous really. It has been hideous, but so yes she has had it but not through me initially wanting her to have it.

Dianne's story is in many ways atypical of parents' experiences with the MMR controversy. Few parents – indeed, none of the other parents that I interviewed – had used both single-antigen vaccines and the MMR for the same child. However, her story clearly illustrates many feelings and themes that were a part of many other parents' experiences. As for many parents, the importance that Dianne attached to the decision she made about immunising her daughter hinged on her sense of responsibility to protect her child, whom she loved and who was not yet capable of making this decision for herself but would have to live with the long-term consequences. 'I would feel awful if anything happened' was a very common sentiment behind the decisions that parents made for their children. Dianne's story also illustrates the way that parents balanced the risks of immunising and of not immunising, conscious that risk could not be completely eliminated but anxious to minimise certain risks that were particularly frightening. Finally, like other parents making this decision for their children, she evaluated evidence from a variety of sources, and made determinations based on her trust in those sources (which ultimately had to be re-evaluated).

This chapter has shown a range of ways that parents balanced risks, made trust judgements, and made immunisation decisions on behalf of their children. Because the MMR vaccine was a very contentious issue, it is important to determine systematically whether there were points of agreement and common experience, and where precisely were the points of divergence among parents. This issue is handled in the next chapter.

CHAPTER 5
CONSENSUS AND DIVERGENCE AMONG PARENTS

5.1 Overview

This chapter investigates the areas of consensus and divergence of opinion among MMR-accepting and MMR-refusing parents. It explores how the cultural consensus approach (Romney, Weller, and Batchelder 1986, Weller 1987) might be used to investigate a contentious issue. The first section provides an overview of the method, the cultural domains selected for investigation, and the areas of consensus that were found. In the following sections of the chapter, the findings for selected domains are discussed in detail.

Recap of method

Systematic data collection activities, including a 62-item Likert-scale questionnaire and two card-sorting exercises, were conducted in the course of Phase I interviews. These data were then analysed using cultural consensus analysis, to bridge the qualitative and quantitative phases of the project. The methodology behind cultural consensus analysis is described in detail in Chapter 3. Briefly, a set of questions about a single cultural domain is administered to a group of informants. A factor or principal components analysis is performed, using informants rather than questions as variables; a ratio of first to second eigenvalues larger than 3.0 demonstrates, by convention, a single-factor solution and consensus among informants. In cases of consensus, the extent to which each informant agrees with the consensual responses in that domain (i.e., the factor loadings) is computed. Weighted average responses across informants are computed to generate an 'answer key' representing consensual responses for each question.

In the following sections, I first report whether the consensus, or single factor, assumption is upheld (as shown by a ratio greater than or equal to 3.0 of the first to second eigenvalue), for the sample as a whole, and for the MMR-accepting and MMR-refusing subsamples. Where the single factor assumption is upheld, I report the weighted average answers to each question in the domain.

The 62-item questionnaire was divided into six different domains concerning (A) the safety of MMR and the 2-dose schedule; (B) the appropriateness of the scientific studies on MMR; (C) the seriousness of measles, mumps and rubella, and the importance of herd immunity; (D) information and the handling of the issue by government and media; (E) children's health, risk, and trust; and (F) locus of control. The questions included under each of these domains are shown in Appendix E. Two additional domains were derived from pile-sorting exercises: (G) one on sources of information about the vaccine (which parents ranked in terms of usefulness) and (H) one on issues relevant to vaccine decision-making (which parents sorted into considerations making them more, less or equally likely to accept MMR).

Methods of factor extraction

Although the principal components analysis method is theoretically less desirable than the least squares extraction method of factor analysis because it does not distinguish between the specific variance and error terms of communality, the results obtained with the two methods were very similar. The least squares method, in general, yielded slightly higher ratios between the two eigenvalues, but in no instances did this result in a different estimate of whether or not consensus occurred. Because more of the analyses could be performed using principal components analysis (due to some cases having communalities outside the acceptable range for least squares factor analysis), the remaining results reported in this chapter are derived from principal components analysis.

Overview of results

Given the heavily contested nature of the topics under consideration, we would expect parents to disagree in many of their responses. Indeed, in all domains except for one (H), consensus was not demonstrated among the sample as a whole (Table 5.1). However, when MMR-accepting (N=79) and MMR-refusing (N=72) parents were considered separately, most domains did show consensus among at least one of these groups.

	All sample N=151		MMR Acceptors N=79		MMR Refusers N=72	
Domain	**Eigenvalue Ratio (All)**	**Consensus? (All)**	**Eigenvalue Ratio (Acceptors)**	**Consensus? (Acceptors)**	**Eigenvalue Ratio (Refusers)**	**Consensus? (Refusers)**
A. Safety of MMR	2.92	N	5.06	Y	6.86	Y
B. Appropriateness of studies on safety of MMR	1.70	N	2.31	N	4.00	Y
C. Seriousness of diseases, herd immunity	1.91	N	3.56	Y	1.53	N
D. Information, government and media handling of the issue	2.71	N	1.88	N	5.69	Y
E. Health, risk and trust	1.34	N	1.29	N	8.95	Y
F. Locus of control	1.42	N	1.90	N	2.82	N
G. Ranking of information sources (N=31)	1.89	N	1.94	N	1.56	N
H. Sorting of vaccination considerations (N=31)	3.55	Y	2.63	N	3.42	Y

Table 5.1 Cultural consensus analysis results for 62-item questionnaire, eigenvalues obtained by principal components analysis, for overall sample and subsamples.

On the safety of MMR (Domain A), parental responses diverged into two groups, corresponding closely to the decision the parents had made about vaccinating their children with MMR. Within each of the subsamples, consensus was strongly indicated for this domain. This result is hardly surprising, as divergent opinions about the vaccine's safety were the chief driving force behind the controversy, and it thus lends support to the validity of the method. On the seriousness of the diseases (measles, mumps and rubella) and the importance of herd immunity (Domain C), only the MMR acceptors exhibited consensus in their responses. Conversely, three domains (B, D and E) exhibited consensus only among the MMR-refusing parents. It was somewhat surprising that consensus was not found among either of the groups in the locus of control domain (F), since much of the debate centred on parental 'choice' for single vaccines. Among MMR refusers, the eigenvalue ratio (2.8) was just shy of the conventional value needed for consensus.

The pile-sorting exercises (Domains G-H) were performed with a much smaller group of parents (N=31) than the questionnaire domains (N=151), and consequently the consensus estimations are less robust. No consensus was found in parents' ranking of information sources (Domain G). Parents did show consensus in their sorting of vaccination considerations into those that would make them more or less likely to choose MMR for the MMR-refusing subsample and also the overall sample. It appears that parents agreed on what course of action was suggested by most of these considerations (e.g., risks of immunisation discouraged parents from choosing the MMR, while what medical experts say encouraged them to choose the MMR), but perhaps disagreed about the relative importance of these considerations. Although I did try asking parents to rank the considerations in importance, many parents found this a difficult task, and so I was not able to evaluate consensus on ranking of the information sources.

Selection of domains for further discussion

To further illustrate the potential of the cultural consensus method, the findings from four of these domains are presented in greater detail. Domain A, on the safety of MMR, illustrates how the method produces an expected result of no consensus among the whole group but consensus within the two subgroups. Domains B and C, on the studies demonstrating the safety of MMR and the seriousness of the diseases, respectively, illustrate two domains with consensus among one subgroup only, corresponding to the position that made strong use of this domain in its arguments for or against the MMR vaccine. Domain E, on health, risk and trust, is evaluated in detail because of the interesting and surprising finding of strong consensus among the refusing group only.

5.2 An unsurprising finding validating the method

The first domain under consideration consisted of statements about the safety of MMR vaccine, the central issue in the British MMR controversy. The results of cultural consensus analysis of this domain are unsurprising: parents diverged in their responses but agreed within the MMR-refusing and MMR-accepting subgroups. Thus, the validity of the method in identifying areas of consensus and divergence is supported in this case at least (Table 5.2).

Sample	N	Eigenvalues	Ratio of 1st to 2nd eigenvalue	Mean (SD) factor loading	Range of factor loadings
All parents	151	91.024 31.157 17.740	2.92 (No consensus)	N/A	N/A
MMR acceptors	79	41.933 8.282 6.778	5.06 **(Consensus)**	0.53 (0.50)	-0.87 to 0.90
MMR refusers	72	50.286 7.329 7.046	6.86 **(Consensus)**	0.77 (0.33)	-0.80 to 0.99

Table 5.2 Cultural consensus analysis results: Questions on the safety of MMR vaccine (Domain A).

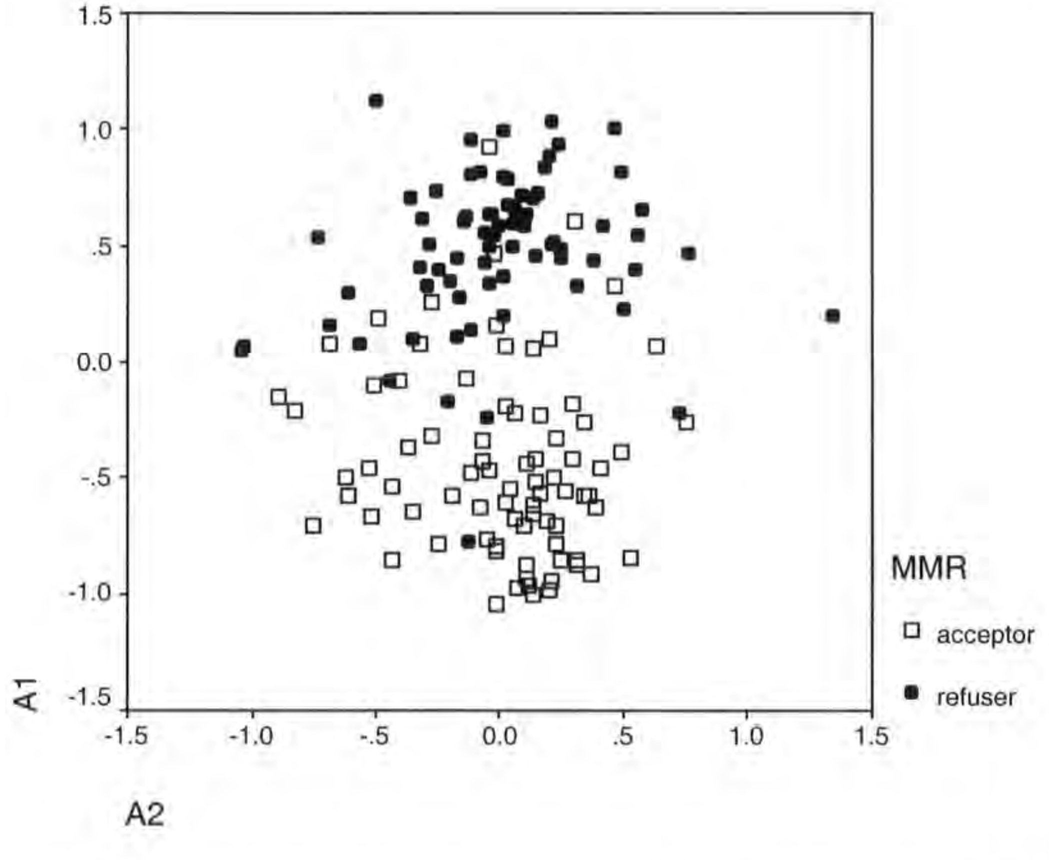

Figure 5.1 MDS plot of proximities among respondents' answers to questions on the safety of the MMR vaccine (Domain A).

For the sample as a whole, the ratio of the first to second eigenvalues on questions about the safety of the MMR vaccine was 2.92 (Table 5.2), not quite large enough to satisfy the one-factor (consensus) assumption. The MDS plot (Figure 5.1), derived from proximities among informants' responses to the questions in this domain, shows MMR-refusing and MMR-accepting parents clustering in different areas of the plot. That is, the responses within each of these groups were more similar than the responses between the two groups. This is not surprising, since parents' beliefs about the safety of the vaccine are one of the chief grounds for making their decisions about MMR immunisation. The finding is further corroborated by inspecting the factor loadings (i.e., the correlation coefficients between each informant and the factor) for the first factor (Figure 5.2): MMR refusers correlated strongly with the factor, while MMR acceptors had mostly negative coefficients. Loadings on the second factor were similar for both groups (0.24±0.35 for refusers and 0.26±0.41 for acceptors).

In contrast to the divergence found in the whole sample, the consensus assumption was upheld within each of the subgroups, with eigenvalue ratios of 5.06 for MMR acceptors and 6.86 for refusers (Table 5.2). The implication is that although it is not possible to compute an answer key for the sample as a whole, it is possible to compute separate answer keys for MMR acceptors and MMR refusers, as shown in Table 5.3. Parental answers are reported in two ways: as a numerical value on the 6-point Likert scale (computed as a weighted average of responses), and as a percentage of parents agreeing (i.e., answering 1, 2 or 3) with the statement. Both of these indicators show strong and expected differences between the responses of MMR-refusing and MMR-accepting parents.

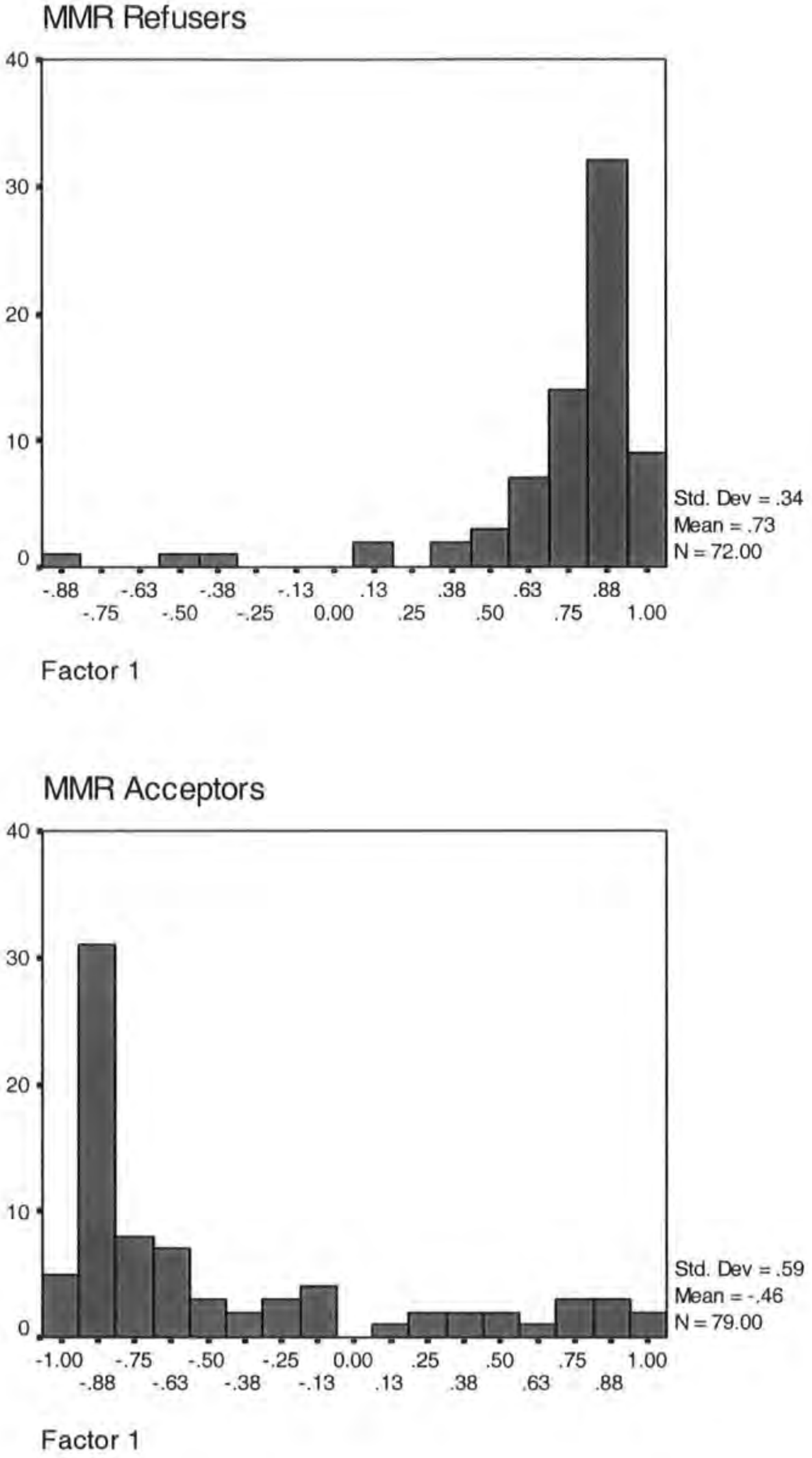

Figure 5.2 Distribution of MMR refusers' and acceptors' factor loadings on first factor in cultural consensus analysis for Domain A (safety of MMR).

Table 5.3 Answer keys to questions on the safety of MMR vaccine (Domain A). Agreement on 6-point scale with 1=strongly agree and 6=strongly disagree. % agreeing = % of parents answering 1-3 out of 6.

*13 informants removed with negative factor loadings. †4 informants removed with negative factor loadings.

Statement	**Percent Agreeing (MMR Acceptors)**	**Weighted Average Answer* (MMR Acceptors)**	**Percent Agreeing (MMR Refusers)**	**Weighted Average Answer† (MMR Refusers)**
The risk of autism from MMR may be very small, but I would feel so awful if something were to happen to my child that I'm not willing to expose him/her to it.	26.6	4.9951	93.0	1.3558
I would let my child have a second dose of MMR (booster jab), but only if a blood test said they weren't immune	36.7	4.2826	26.4	4.8556
All children should have 2 doses of MMR before starting school to be sure that they are protected.	74.7	2.1629	12.5	5.3584
There is no reliable information available to me about how safe the MMR jab is.	35.4	4.6554	87.5	1.8159
The benefits of having the MMR jab outweigh the risks.	91.1	1.2387	15.3	4.9741
I don't really believe the reports about risk from MMR, but I still worry about my child having it.	43	3.9329	23.9	4.687
A number of children in this country now have autism as a direct result of MMR vaccination.	20.3	5.2485	84.3	2.1296
I'm not sure that the single vaccines for measles, mumps, and rubella are really safe.	55.7	2.9398	43.7	3.7646
I would have better peace of mind about my child's health if he/she got single jabs for measles, mumps, and rubella	30.4	5.0283	93.1	1.4632
MMR is safe for most children, but certain children with sensitive immune systems could be damaged by it.	67.1	3.4296	71.8	2.7912
MMR vaccination seems to be a significant factor in childhood allergies.	22.8	4.9514	59.4	3.0255
The majority of the evidence indicates that there is no link between MMR and autism.	82.3	1.5911	20.8	4.7147

5.3 Domains with consensus among one group only

Now let us consider two contrasting domains in which consensus was found only in one of the subsamples. Domain B, on the appropriateness of the scientific studies about the safety of MMR, showed consensus among the MMR refusers (Table 5.4), while Domain C, on herd immunity and the seriousness of measles, mumps and rubella, showed consensus among the MMR acceptors (Table 5.5). The MDS plots (Figures 5.3 and 5.4) clearly show differences between the MMR-accepting and MMR-refusing groups in each of these domains.

Sample	N	Eigenvalues	Ratio of 1st to 2nd eigenvalue	Average factor loading	Range of factor loadings
All parents	140	70.641 41.609 27.751	1.70 (No consensus)	N/A	N/A
MMR acceptors	72	41.456 17.938 13.606	2.31 (No Consensus)	N/A	N/A
MMR refusers	68	34.221 8.551 7.948	4.10 **(Consensus)**	0.61 (0.38)	-0.53 to 0.98

Table 5.4 Cultural consensus analysis results: Questions on information and the government and media handling of the issue (Domain B).

Sample	N	Eigenvalues	Ratio of 1st to 2nd eigenvalue	Average factor loading	Range of factor loadings
All parents	140	91.911 48.089 0.000	1.91 (No consensus)	N/A	N/A
MMR acceptors	75	43.552 12.218 10.231	3.56 (Consensus)	0.55 (0.53)	-0.85 to 0.99
MMR refusers	65	24.555 16.038 9.710	1.53 (No consensus)	N/A	N/A

Table 5.5 Cultural consensus analysis results: Questions on herd immunity and the seriousness of measles, mumps and rubella (Domain C).

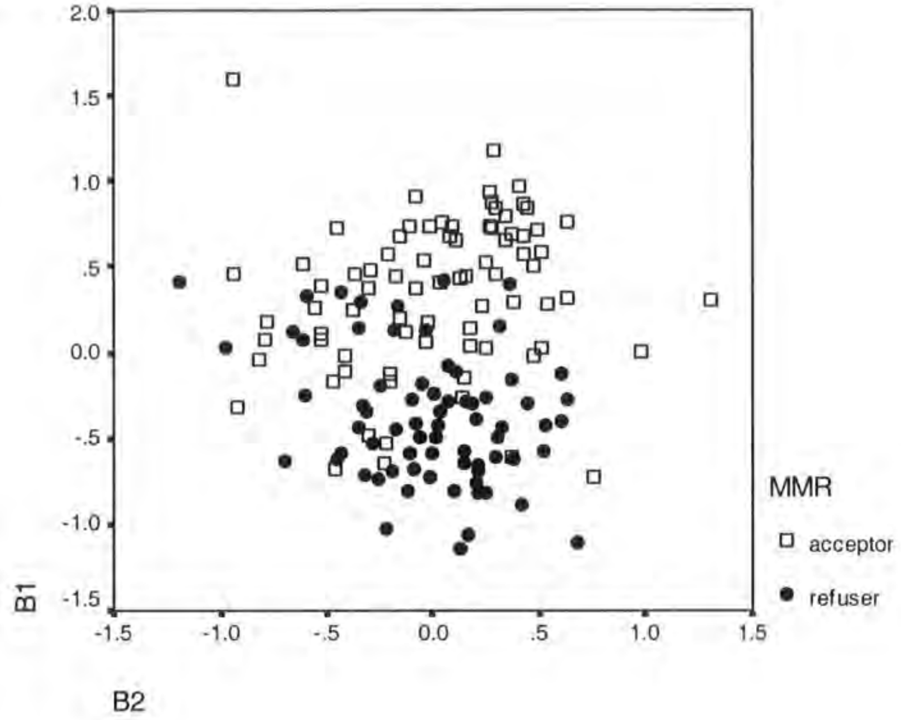

Figure 5.3 MDS plot of proximities among respondents' answers to questions on herd immunity and the seriousness of measles, mumps and rubella (Domain B).

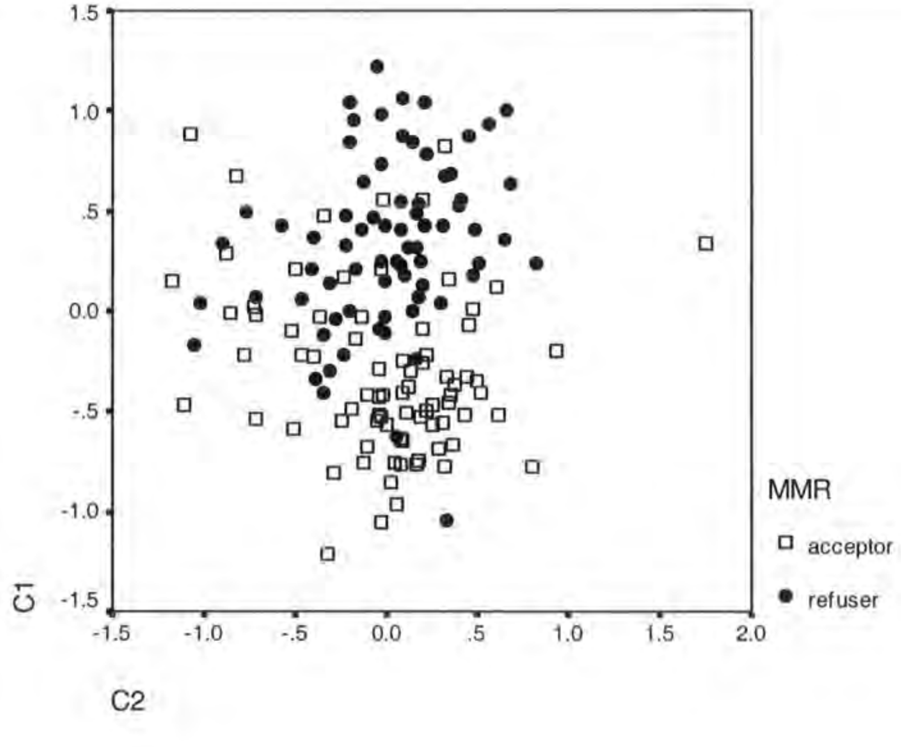

Figure 5.4 MDS plot of proximities among respondents' answers to questions on herd immunity and the seriousness of measles, mumps and rubella (Domain C).

The answers to questions in these domains show that MMR-refusing parents were critical of the studies demonstrating that the MMR vaccine is safe (Domain B, Table 5.6), and MMR-accepting parents were convinced that measles, mumps and rubella are serious diseases (Domain C, Table 5.7). It was not possible to compute an answer key for the MMR acceptors on Domain B, or the refusers on Domain C, because there was no consensus in these groups.

Statement	**Weighted Average Answer (MMR Refusers)**	**Percent Agreeing (MMR Refusers)**
It will never be possible to prove with 100% certainty whether MMR is safe.	2.41	72.2
The study that suggested a link between MMR and autism was performed on such a small sample that it's not really valid.	4.91	22.2
Big, epidemiological studies using statistics are the best way to determine whether or not MMR causes autism.	3.87	48.6
If a study were done that clinically examined those children whose parents thought they had been damaged by the MMR, then we could have a better idea about how safe it is than we do now.	1.53	79.2
The research demonstrating the safety of MMR is not trustworthy, because it was funded by the government or pharmaceutical companies.	1.53	86.1
I don't know what kind of studies were done on the link between MMR and autism.	4.59	31.9
It's really important to have scientists going against the conventional wisdom in medicine, because you never know what important discoveries will be made that way.	1.90	94.4
We haven't had the length of time, since the MMR vaccine was introduced, needed to investigate its effects fully.	2.31	73.6
Nobody really knows how vaccines work, or how they are broken down by the body.	2.80	66.7

Table 5.6 Answer keys to questions the appropriateness of the studies conducted on the safety of MMR (Domain B). Agreement on 6-point scale with 1=strongly agree and 6=strongly disagree. % agreeing = % of parents answering 1-3 out of 6. (MMR refusers only; MMR acceptors did not exhibit consensus in this domain.)

Statement	**Weighted Average Answer (MMR Acceptors)**	**Percent Agreeing (MMR Acceptors)**
I get angry with people who don't vaccinate their kids, because I am putting my kids at risk (by having them vaccinated) to protect those other children.	3.41	48.1
My child is not very likely to get measles even if he/she isn't vaccinated, because levels of the disease are so low.	4.50	38.0
We need to see more kids getting vaccinated with the MMR so that measles outbreaks don't occur.	1.57	75.9
There is no real point in having boys vaccinated against rubella.	5.10	31.6
I would be very afraid of my child contracting measles if he/she were not immunised.	1.88	89.9
We should do whatever we can to prevent children contracting measles, because the potential complications can be very serious.	1.39	93.7
Delaying my child's getting immunity by having the single vaccines instead of MMR would put them at risk.	1.89	82.3
I have a responsibility to have my children vaccinated, so that children who can't be vaccinated for serious reasons will be protected.	1.90	88.6
My own children's health and safety is a more important consideration to me than the impact of my decisions on the population.	2.83	74.7
We shouldn't assume that a vaccine is right for everyone just because it is for the majority.	2.94	75.9
Measles, mumps, and rubella used to be described in medical textbooks as common childhood illnesses with only rare complications, but now it is described as very serious and life-threatening. There is no justifiable reason for this change.	4.44	29.1
I don't know much about measles, mumps, or rubella, so I don't really know how serious these diseases are.	5.18	22.8

Table 5.7 Answer keys to questions on herd immunity and the seriousness of measles, mumps and rubella (Domain C). Agreement on 6-point scale with 1=strongly agree and 6=strongly disagree. % agreeing = % of parents answering 1-3 out of 6. (MMR acceptors only; MMR refusers did not exhibit consensus in this domain.)

One interpretation explaining these findings relates to the different arguments offered by the opposing camps in the debate about the MMR vaccine. Proponents of the vaccine have argued stridently that the risks posed by measles, mumps and rubella are far greater and more serious than the hypothetical risk posed by the MMR vaccine. On the other hand, opponents of the vaccine have argued with equal fervour that the tests demonstrating its safety were inadequate, flawed (e.g., not following children for a long enough time), or inappropriate (e.g., concentrating on epidemiology rather than in-depth evaluation of particular cases).

Criticism of the studies demonstrating the safety of the MMR vaccine (Domain B) was one of the central components of the anti-MMR campaign, and this is reflected in the consensual responses offered by the MMR-refusing parents. By contrast, MMR-accepting parents were split. For instance, many gave their children the vaccine despite uncertainty about whether the studies demonstrating its safety were adequate; others emphatically maintained that the vaccine had an excellent, well-researched safety record.

To interpret the finding for Domain C, we should note that parents who accepted the vaccine for their children very often cited concern about the diseases as the chief reason for their decision. They tended overwhelmingly to agree with the importance of protecting children from these diseases, and thus exhibited consensus in their views on the seriousness of these diseases and the importance of maintaining population-level immunity to them. Parents who had refused the MMR, on the other hand, were divided in how seriously they took the threat of these diseases. While some parents turning down MMR vaccination were not concerned about their children catching measles, mumps or rubella and did not consider it particularly important to contribute to overall levels of immunity in the population, other MMR-refusing parents did nonetheless want to protect their children from the diseases and therefore opted for single-antigen vaccines as an alternative to MMR. It would be interesting to evaluate the degree of consensus in this domain among parents who had obtained separate vaccines and parents who had not vaccinated at all, but that is beyond the scope of this exercise.

5.4 Health, risk and trust

The result for the questions on health, risk and trust (Domain E) is more surprising. These questions made no mention of the MMR controversy, but were much more general in scope. It is remarkable that the sample as a whole did not achieve consensus in this domain, whereas MMR refusers displayed a very strong consensus (with a first to second eigenvalue ratio of 8.95, three times the conventional requirement, Table 5.7). The MDS plot (Figure 5.5) shows a good deal of overlap between the MMR acceptors and refusers, but with less scattering among the refusers. It seems plausible that these parents had a particular configuration of ideas about health and risk broadly speaking that played into their vaccination decision-making, and these ideas merit careful investigation. Overwhelmingly, they agreed that children's health is very important and that they should do as much as possible to protect their children's health, and they disagreed with the statement that there is no point in worrying about risk (Table 5.9).

Sample	N	Eigenvalues	Ratio of 1st to 2nd eigenvalue	Average factor loading	Range of factor loadings
All parents	112	64.144 47.856 0.000	1.34 (No consensus)	N/A	N/A
MMR acceptors	67	26.592 20.601 19.807	1.29 (No consensus)	N/A	N/A
MMR refusers	72	57.628 6.442 4.143	8.95 (Consensus)	0.89 (0.11)	0.48 to 0.99

Table 5.8 Cultural consensus analysis results: Questions on health, risk and trust (Domain E).

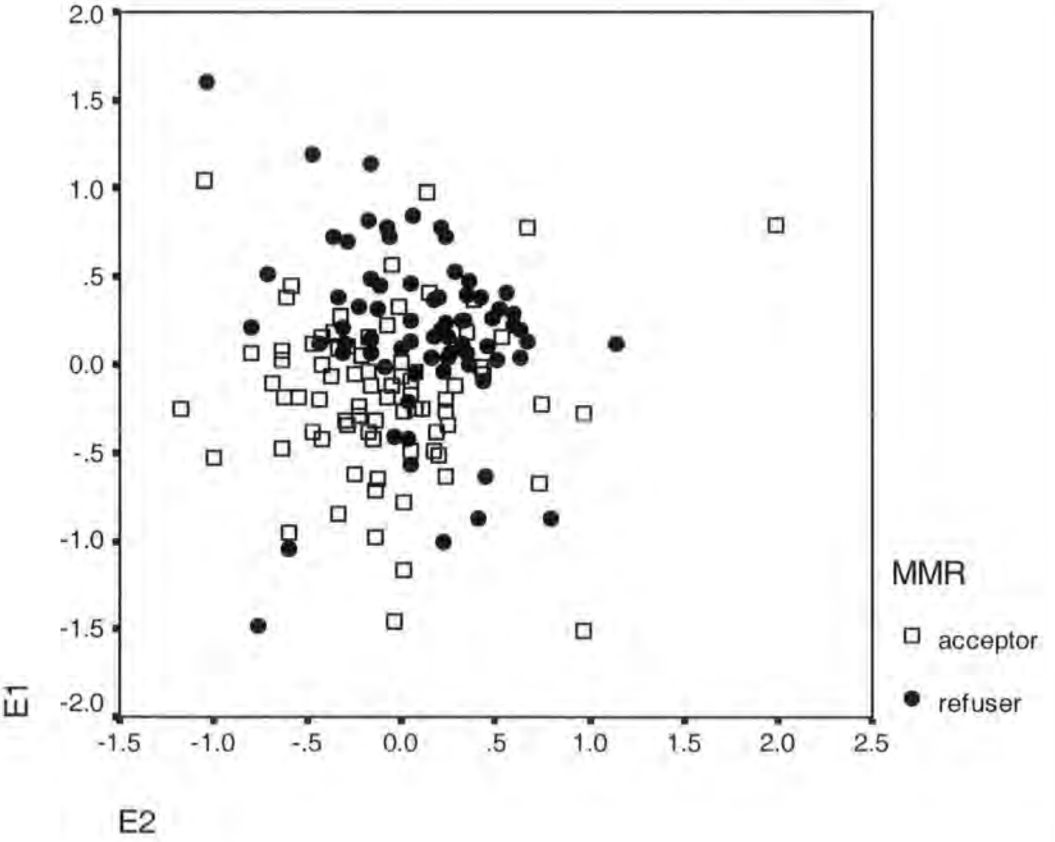

Figure 5.5 MDS plot of proximities among respondents' answers to questions on health, risk and trust (Domain E).

Statement	**Weighted Average Answer (MMR Refusers)**	**Percent Agreeing (MMR Refusers)**
Nothing could be more important than children's health.	1.66	94.4
Everything we do has a risk, but you have to let your kids live. It's no good sitting at home wrapped in cotton wool all day!	2.82	79.2
It is important to keep informed about risks to our children's health, and to protect them as much as possible.	1.37	100.0
Growing up in today's world is a dangerous business.	2.66	72.2
There's no point worrying about risk, because it all really depends on fate. 'What will be will be.'	5.41	6.9
I think that, in general, the government does a good job of protecting us from risk.	4.25	33.3
There is a lot that parents can do to help their children stay healthy.	1.44	100.0
People should take more responsibility for their own health.	2.05	91.7
It's really important to get it right when we make decisions about our children's health, because they can't decide for themselves but will have to live with the consequences of what we decide.	1.58	90.3

Table 5.9 Answer keys to questions on health, risk and trust (Domain E). Agreement on 6-point scale with 1=strongly agree and 6=strongly disagree. % agreeing = % of parents answering 1-3 out of 6. (MMR refusers only; MMR acceptors did not exhibit consensus in this domain.)

5.5 Discussion

Implications of results

Returning to the questions posed in Chapter 3 (p. 132-133), we can now say that there are different group 'norms' in terms of how parents think about the MMR vaccine and risk; there were very few areas of consensus among all sample parents in the questions chosen as relevant to the MMR debate. For domains and subgroups of informants in which the single factor (consensus) assumption was upheld, I generated answer keys that can be used to assess the relative importance of different themes and the factors underlying parents' decision to vaccinate or not. Assuming that the most important areas are those that elicited the most extreme responses, we can look at the answer keys generated across groups for responses near 1 and 6 of the Likert scale. For MMR acceptors, these include conviction in the safety of the MMR vaccine and the importance of vaccinating children to protect them from measles, mumps and rubella. For MMR refusers, these include uncertainty about the safety of the vaccine, the inadequacy of studies demonstrating the vaccine's safety, and the overriding importance of protecting children from health risks.

The different areas of consensus and divergence may be helpful in developing a refined risk communication strategy that can be adapted to parents with different outlooks and concerns. For instance, although MMR-accepting parents were generally in agreement about the importance of protecting children from measles, mumps and rubella (Domain C), the MMR-refusing parents were divided on this point. A risk-communication strategy emphasising the dangers of these diseases, as embodied in the leaflet 'MMR the Facts' (NHS Health Promotion England 2001), may be too limited to be convincing for all parents. Some are already convinced of the seriousness of the diseases, and instead need more information about the relative safety and benefits of MMR vs. single-antigen vaccines. Others view the diseases as normal occurrences, and are unwilling to expose their children to the vaccine for the sake of herd immunity to protect other children from diseases that they perceive as posing a minimal threat. For these parents, information about the dangers of the diseases might be useful, but it would likely be more influential if provided in such a way as to acknowledge parents' own experiences (which often include uneventful cases of measles, mumps and rubella) and views. The strong degree of consensus among MMR-refusing parents in the domains related to the appropriateness of the studies on the safety of the MMR (Domain B) and on the MMR-related information and policy offered by the government and the media (Domain D) suggests that a fundamental problem is lack of trust in the medical establishment. Furthermore, these parents agreed strongly in their responses to questions on health and risk that were unrelated to the MMR controversy. They viewed themselves as protectors of their children's health, and felt that this responsibility was of the utmost importance. In fact, it was on this domain that the MMR-refusing parents exhibited the strongest consensus. Health professionals' failure to recognise parents' good intentions, then, is likely to result in alienation of parents rather than increased uptake of the MMR vaccine.

Suitability of the technique for the project

The objective of characterising group 'norms' and identifying which individuals are more or less representative of those norms, is rather controversial. Robert Aunger (1999, 2003) criticised cultural consensus analysis on the grounds that the model, in treating culture as 'shared knowledge,' generates idealised group characterisations that, he argues, do not necessarily correspond to the models held by any of the individuals in the group. The 'culture as shared knowledge' view, he claims, is therefore 'idealistic', rather than 'realistic'. Romney (1999) argued, in response to Aunger, that the cultural consensus theory is a statistical model and, as such, is neither idealistic nor realistic, but only describes how well the data fit a given mathematical model. One way out of this debate might be simply to avoid some of the loaded terminology about culture used by the proponents of the model: for instance, I have tended to use the term 'factor loadings' to describe the extent to which individual informants agree with the shared answers, rather than 'cultural competences' as the proponents do.

Aunger's comments provide an important caution in interpreting results obtained by consensus analysis, but the technique is nonetheless well suited for this project on MMR risk evaluations. My purpose here is not to enter the debate about what constitutes 'culture,' but rather to understand whether the views of a particular group of people (whether or not they are a 'culture') can be characterised by one or more models. The issue of whether the consensus model uses an 'idealistic' or 'realistic' idea of 'culture,' is thus tangential to my own project.

Aunger's point about the dangers of reifying a group identity or mental construct, at the expense of giving adequate attention to individual ideas, is again an important caution. However, in the present case, characterising group 'norms' (if they are found by consensus analysis to exist) is actually both acceptable and important, because of the public health implications (which are defined at the 'group' level) of the project. Any actions taken at a public level (e.g., public health messages or vaccination policy decisions) will have to be targeted to large groups of people, and basing policy recommendations on very idiosyncratic views would clearly be ineffective. On the other hand, it is very important to get as clear and in-depth an idea as possible of what the views of parents actually are: one of the biggest problems undermining the Department of Health's defence of MMR seems to be that many parents do not agree with the way that their views and decision-making processes have been characterised. Recall the three aims of cultural consensus analysis: to determine (1) if consensus exists (can we identify a group 'norm?'), and then, if it does, (2) which individuals respond to a set of questions in a manner most characteristic of that consensus and (3) what the consensual set of answers should be. The latter point, while perhaps objectionable from the point of view of those studying the relationship between individuals and their 'culture,' could be useful in forming public health policy measures. Public health communication must effectively target parents' concerns and particular information needs. Thus, it is critical to understand accurately how parents view this issue, and if this is not uniform across the population (say, if more than one consensual view are found), then more than one communication approach may be needed. It might be argued that the practice of weighting responses to determine the 'answer key' is inappropriate, since all parents are making decisions about vaccination whether or not they agree with one another. To offset this difficulty, the answer keys obtained by cultural consensus analysis were compared to straightforward percentages of parents agreeing and disagreeing with each statement, checking for any instances where the two methods gave inconsistent results.

One further advantage of the present study is that the cultural consensus data were collected during an extensive interviewing project, so the conclusions drawn from the cultural consensus analysis could be compared with, and placed within the context of, the participants' own explanations for their views and motivations.

Methodological problems and application for development of survey tool

The results presented here should be interpreted with caution, as there are several problems with the application of the cultural consensus method in this study.

The chief problem was that in some domains a number of data points had to be removed before the analyses could be performed, and I was unable to find a way of testing the impact that these exclusions had on the results obtained. Furthermore, the requirement that all questions in a given domain must be of equal difficulty was sometimes violated, as some questions had far more variance in their responses than others. Nonetheless, this exercise did provide an interesting example of what can be done with the cultural consensus method to evaluate areas of agreement and divergence on a controversial issue like the MMR vaccine, and it would be worthwhile to pursue these analyses further.

Despite these problems, the administration and analysis of this questionnaire was very important in developing an instrument to use in the large-scale postal survey of Phase II. Identifying points of agreement, disagreement and significance provided categories to be investigated for a much larger sample. In consequence, I included on the Phase II questionnaire statements about the safety of MMR and separate vaccines, the importance of vaccination for protecting children from diseases, and trust in the medical establishment. Also, the use of the 62-item questionnaire in the course of in-depth interviews served as a preliminary piloting of questions to be included on the survey. Most of the Phase II survey questions were adapted from the Phase I cultural consensus questionnaire, with modifications suggested by the way that participants understood and answered them in the interviews. Survey findings are presented in the following chapter.

CHAPTER 6
MMR ATTITUDES SURVEY

6.1 Aims and response

Study aims

This chapter presents the results of a survey among parents in the Durham and Chester-le-Street Primary Care Trust (PCT), investigating how widely the views described in Chapter 4 and 5 are held in a much larger sample. The survey had the following aims:

1. To determine the level of agreement among MMR-accepting and MMR-refusing parents with statements about (a) the safety of MMR vaccine, (b) single-antigen vaccines, (c) the importance of immunisation, and (d) trust in medical authority.
2. To determine what sources of information parents had accessed, and which were considered to be most useful.
3. To examine differences between MMR-accepting and MMR-refusing parents in attitudes to MMR, use of information, socioeconomic status and education.
4. To estimate the uptake of single-antigen vaccines among children not immunised with MMR, and thus to provide an estimate of overall immunisation coverage for measles, mumps and rubella.

Response rate and demographic characteristics of respondents

1107 parents of 2742 mailed (40.4%) returned forms consenting to participate and were sent a postal questionnaire (Appendix F). Of these, 996 returned questionnaires, representing 36.3% of all parents invited to participate. The rate of dropout was very low, with 90% of parents who agreed to participate completing a questionnaire.

Demographic and socio-economic characteristics of the survey respondents and for the PCT area during the 2001 census (Office for National Statistics) are summarised in Table 6.1. A greater proportion of respondents belonged to higher socio-economic classes and had higher levels of educational qualification, relative to the PCT population.

	Mean (SD)	**Range**		
Age	33.10 (5.36)	18-56	N=994 (2 missing)	
Number of children	1.91 (0.88)	1-7	N=994 (2 missing)	
	Category		**Sample %**	**PCT %**
Sex of parent	mother		93.6	N/A
	father		6.1	N/A
	other carer / missing		0.3	N/A
Occupational class[‡]	1.1 (higher managerial)		4.2	2.8
	1.2 (higher professional)		8.7	4.5
	2 (lower professional/ higher supervisory)		29.1	17.2
	3 (intermediate occupations)		27.2	9.3
	4 (employers in small organisations/ self-employed)		4.2	4.3
	5 (lower supervisory/ technical occupations)		2.2	7.1
	6 (semi routine)		10.1	10.3
	7 (routine occupations)		7.7	9.8
	8 (unemployed) or missing		6.4	34.8
Highest educational qualification	No qualifications		4.4	28.8
	Non-degree qualification:		62.0	44.8
	1 or more O-levels/ GCSEs		*29.7*	
	1 or more A/ AS levels		*17.8*	
	NVQ		*14.5*	
	Degree or higher		32.9	19.8
	First degree		*17.6*	
	Higher degree		*15.3*	
	missing		0.8	6.6

[‡]National Statistics Socio-economic Classification Reduced Method

Table 6.1 Demographic and socio-economic characteristics of survey respondents with comparison to Primary Care Trust population.

6.2 Immunisation decisions

Among the children of survey respondents, 889 (89.3%) had received the MMR vaccine, as shown in Figure 6.1. 72 (7.2%) children had embarked on a course of single-antigen vaccines, although only 19 (26.4% of those who had embarked on the course) had received all three immunisations. Of those who had not completed a course of single vaccines, 50 (94.3%) planned to obtain all three vaccines and 3 did not. 31 children (3.1%) had received neither MMR nor single vaccines. Only 4 respondents (0.4%) did not provide data on immunisation uptake. Immunisation against mumps had the lowest uptake of the three antigens, with 91.4% coverage among all target children (Table 6.2) and only 20.4% coverage among children not immunised with MMR vaccine.

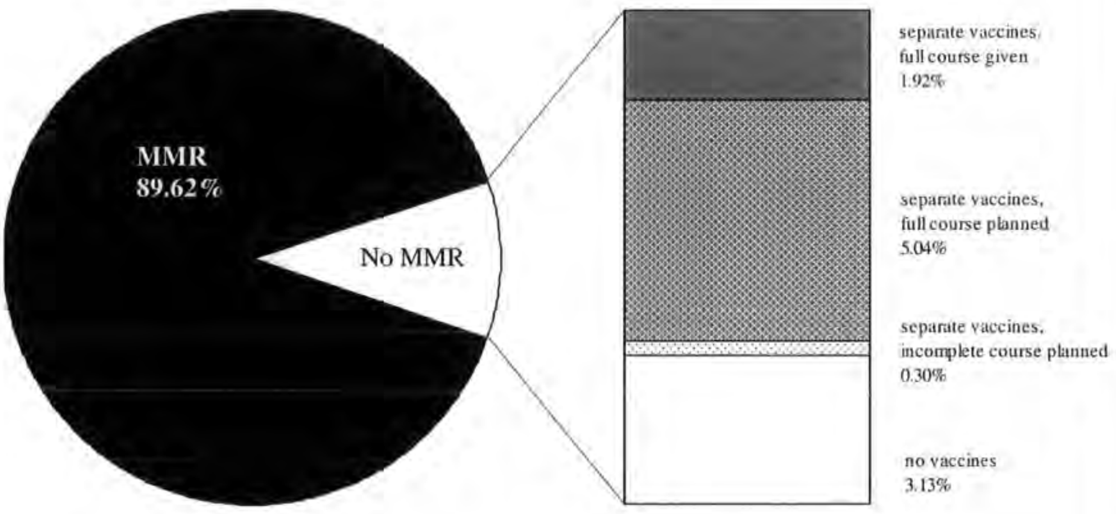

Figure 6.1 Immunisation status of survey respondents' children.

	N MMR	N Single Vaccines	Total N (%) Immunised	Total N (%) Not Immunised	Data missing	Total
Measles	889	69	958 (96.2)	34 (3.4)	4 (0.4)	996
Mumps	889	21	910 (91.4)	82 (8.2)	4 (0.4)	996
Rubella	889	66	955 (95.9)	37 (3.7)	4 (0.4)	996

Table 6.2 Immunisation coverage among survey respondents' children, by antigen.

The older cohort (born between 1 October 2000 and 30 September 2001) had a slightly higher uptake of MMR than the 2001-2 cohort (91.5% vs. 87.7%, $\chi^2=3.833$, $p=0.05$). Among children who had not received the MMR, the older cohort was also more likely to have embarked on a course of separate vaccines (82.1% vs. 62.9%, $\chi^2=4.622$, $p=0.032$).

In a multivariate logistic regression, only number of children predicted MMR acceptance (OR=0.713, $p=0.021$). In single analyses, there was no association between MMR acceptance and parental educational attainment ($\chi^2=0.8901$, $p=0.970$), occupational class ($\chi^2=9.761$, $p=0.282$), or age ($t=-0.485$, $p=0.628$). Furthermore, among parents who had refused the MMR, there was no significant association between educational attainment or occupational class and uptake of single-antigen vaccines ($\chi^2=4.826$, $p=0.438$ and $\chi^2=6.086$, $p=0.638$, respectively). MMR-accepting parents did have larger families than refusing parents (mean (SD) 1.94 (0.880) children vs. 1.73 (0.834), $t=2.33$, $p=0.020$).

6.3 Agreement with statements related to vaccination

There were statistically significant differences between the proportions of MMR-accepting and MMR-refusing parents agreeing with all of the statements about MMR vaccine and immunisation (Tables 6.3-6.6). As expected, MMR-refusing parents were far less likely to agree that scientific evidence has shown the vaccine to be safe (no link with autism) than parents who had given it to their children (Table 3.a.i; 19.6% vs. 70.5%, $\chi^2=109.6$, $p<0.00001$). However, even the MMR acceptors showed a high degree of ambivalence about the safety of MMR. For instance, 76.2% of the MMR-accepting parents felt that more time was needed to investigate the vaccine's effects (Table 6.3.c), while 66.4% said that potential complications of the vaccine could be serious for children (Table 6.3.d).

Parents were also ambivalent about the appropriateness of separate vaccines as an alternative to the MMR. 49.6% of the MMR-accepting parents felt that separate vaccines were safe, compared with 80.4% of MMR-refusing parents (Table 6.4.a; $\chi^2=36.9$, $p<0.00001$). Only one parent whose child had had separate vaccines disagreed with this statement, whereas 14 (45.2%) of the parents whose children had received no vaccines for measles, mumps and rubella agreed. A high proportion (28.6% overall) of parents did not agree that children were at risk from the time lag between separate vaccinations (Table 6.4.b) and, to an even greater extent (44.1% overall), that a lot of people would not show up for all three vaccines if they were offered separately by the NHS (Table 6.4.c).

In contrast with their concern about the safety of MMR vaccine, parents in both groups indicated support for vaccination in principle, although this was higher among MMR acceptors than among MMR refusers (Table 6.5). Notably, 95.1% of parents agreed that measles is a very serious disease (Table 6.5.e), although they were less convinced that their children were actually likely to contract the disease if unimmunised (Table 6.5.f; 80.0% overall agreement; 83.9% MMR acceptors; 47.7% MMR refusers).

Table 6.3 Parental agreement with statements about the safety of MMR.

Statement	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**	χ^2 **(p)** (Strongly Agree or Agree vs Disagree or Strongly Disagree)
	N (%) Agreeing: MMR Acceptors **N (%) Agreeing: MMR Refusers** *N (%) Agreeing: Overall*				N=889 **N=107** *N=996*
d. Possible complications of MMR vaccination can be very serious for children.	120 (13.9) **54 (51.4)** *174 (17.9)*	470 (54.3) **48 (45.7)** *518 (53.3)*	262 (30.3) **3 (2.9)** *265 (27.3)*	14 (1.6) **0 (0)** *14 (1.4)*	38.496 (0.0000000005)
c. More time is needed to be able to fully investigate the effects of the MMR vaccine.	186 (21.0) **59 (55.1)** *245 (24.7)*	491 (55.5) **44 (41.1)** *535 (54.0)*	186 (21.0) **4 (3.7)** *190 (19.2)*	21 (2.4) **0 (0)** *21 (2.1)*	22.054 (0.000002)
b. It cannot be proved with 100% certainty that the MMR vaccine is safe.	111 (12.6) **46 (43.4)** *157 (15.9)*	606 (68.7) **55 (51.9)** *661 (66.9)*	150 (17.0) **4 (3.8)** *154 (15.6)*	15 (1.7) **1 (0.9)** *16 (1.6)*	13.002 (0.0003)
a. Scientific evidence shows that there is no link between MMR and autism.	93 (10.7) **1 (1.0)** *94 (9.6)*	534 (61.2) **20 (19.4)** *554 (56.8)*	230 (26.4) **59 (57.3)** *289 (29.6)*	15 (1.7) **23 (22.3)** *38 (3.8)*	109.675 (<0.0000000001)

Table 6.4 Parental agreement with statements about separate vaccines.

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree	χ^2 (p) (Strongly Agree or Agree vs Disagree or Strongly Disagree)
c. If separate vaccines were offered by the NHS, a lot of people wouldn't show up for all three jabs.	138 (15.5) **8 (7.5)** *146 (14.7)*	389 (43.8) **24 (22.4)** *413 (41.5)*	316 (35.6) **47 (43.9)** *363 (36.5)*	45 (5.1) **28 (26.2)** *73 (7.3)*	33.621 (0.000000006)
b. Children receiving separate vaccines instead of MMR are at risk from the time lag between the vaccinations.	155 (17.7) **4 (3.8)** *159 (16.3)*	493 (56.4) **41 (39.4)** *534 (54.6)*	216 (24.7) **50 (48.1)** *266 (27.2)*	10 (1.1) **9 (8.7)** *19 (1.9)*	42.900 (0.0000000005)
a Separate vaccines for measles, mumps, and rubella are safe for children.	30 (3.5) **26 (25.0)** *56 (5.8)*	411 (47.7) **60 (57.7)** *471 (48.8)*	369 (42.8) **15 (14.4)** *384 (39.8)*	52 (6.0) **3 (2.9)** *55 (5.7)*	37.218 (0.000000001)

N (%) Agreeing: MMR Acceptors	N=889
N (%) Agreeing: MMR Refusers	**N=107**
N (%) Agreeing: Overall	*N=996*

Table 6.5 Parental agreement with statements about vaccination (in general).

Statement	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**	**χ^2 (p)** (Strongly Agree or Agree vs Disagree or Strongly Disagree)
f. My child is likely to get measles if he/she isn't vaccinated.	201 (22.7) **3 (2.8)** *204 (20.5)*	545 (61.5) **48 (44.9)** *593 (59.7)*	136 (15.3) **53 (49.5)** *189 (19.0)*	4 (0.5) **3 (2.8)** *7 (0.7)*	80.440 (<0.0000000001)
e. Measles is a very serious disease.	550 (62.1) **33 (31.1)** *583 (58.8)*	306 (34.6) **58 (54.7)** *364 (36.7)*	28 (3.2) **15 (14.2)** *43 (4.3)*	1 (0.1) **0 (0)** *1 (0.1)*	1 cell has expected count<5
d. People who don't vaccinate their kids put others at risk.	505 (57.0) **26 (24.8)** *531 (53.6)*	312 (47.7) **51 (48.6)** *363 (36.6)*	67 (7.6) **18 (17.1)** *85 (8.6)*	2 (0.2) **10 (9.5)** *12 (1.2)*	37.891 (0.0000000007)
c. I have a responsibility to have my child vaccinated for the protection of all children.	462 (52.0) **30 (28.3)** *492 (49.5)*	352 (39.6) **47 (44.3)** *399 (40.1)*	69 (7.8) **21 (19.8)** *90 (9.1)*	5 (0.6) **8 (7.5)** *13 (1.3)*	36.902 (0.000000001)
b. More kids should be vaccinated against measles, mumps and rubella so that outbreaks don't occur.	470 (52.9) **26 (24.5)** *496 (49.9)*	401 (45.2) **61 (57.5)** *462 (46.5)*	17 (1.9) **16 (15.1)** *33 (3.3)*	0 (0) **3 (2.8)** *3 (0.3)*	1 cell has expected count<5
a. Vaccination is one way that parents can make a positive contribution to their children's health..	500 (56.2) **33 (30.8)** *533 (53.5)*	373 (42.0) **65 (60.7)** *438 (44.0)*	14 (1.6) **8 (7.5)** *22 (2.2)*	2 (0.2) **1 (0.9)** *3 (0.3)*	1 cell has expected count<5
	N (%) Agreeing: MMR Acceptors **N (%) Agreeing: MMR Refusers** *N (%) Agreeing: Overall*				N=889 **N=107** *N=996*

Parents made a distinction between 'doctors' and 'my doctor,' trusting their own doctors far more than the medical establishment to take their concerns seriously (Table 6.6.a-b). Whereas 51.8% of the respondents overall felt that doctors are too dismissive of parents' claims about vaccine side effects, 78.8% of parents felt that their concerns about MMR were taken seriously by their own doctors. Among MMR-refusing parents, 87.9% felt that doctors (in general) were too dismissive of parents' claims about side effects (Table 6.6.a), whereas nearly half felt that their concerns were taken seriously by their own doctor (Table 6.6.b). However, responses to these two questions were highly correlated with one another (Pearson's $\rho=-0.401$, $p<0.00001$). The responses indicate a considerable level of distrust in the government's role in regulating risk, particularly among the MMR-refusing parents with only 38.3% agreeing that the government would stop MMR if there was a serious risk (Table 6.6.f) and only 39.3% agreeing that the government does a good job in protecting us from risks to health (Table 6.6.g). Responses to the two questions about the government were also highly correlated (Pearson's $\rho=0.526$, $p<0.00001$).

Table 6.6 Parental agreement with statements about trust in doctors and government.

Statement	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**	χ^2 **(p)** (Strongly Agree or Agree vs Disagree or Strongly Disagree)
g. The government does a good job of protecting us from risks to health.	97 (11.1) **1 (1.0)** *98 (10.0)*	609 (69.6) **41 (40.6)** *650 (66.6)*	149 (17.0) **44 (43.6)** *193 (19.8)*	20 (2.3) **15 (14.9)** *35 (3.6)*	77.327 (<0.0000000001)
f. The government would stop the MMR if there was evidence of a serious risk.	221 (25.3) **11 (10.6)** *232 (23.7)*	509 (58.2) **30 (28.8)** *539 (55.1)*	131 (15.0) **52 (50.0)** *183 (18.7)*	13 (1.5) **11 (10.6)** *24 (2.5)*	108.332 (<0.0000000001)
e. The NHS does not recognise the good intentions of parents who opt for single vaccines for their children.	91 (10.3) **54 (50.5)** *145 (14.7)*	392 (44.5) **46 (43.0)** *438 (44.3)*	381 (43.2) **7 (6.5)** *388 (39.3)*	17 (1.9) **0 (0)** *17 (1.7)*	58.875 (<0.0000000001)
d. The government is too defensive about MMR.	136 (15.5) **70 (65.4)** *206 (21.0)*	381 (43.5) **31 (29.0)** *412 (41.9)*	344 (39.3) **6 (5.6)** *350 (35.6)*	15 (1.7) **0 (0)** *15 (1.5)*	51.113 (<0.0000000001)
c. Parents should make health decisions for their own children rather than leaving it up to professionals.	152 (17.4) **44 (42.7)** *196 (20.1)*	412 (47.2) **47 (45.6)** *459 (47.0)*	297 (34.0) **11 (10.7)** *308 (31.6)*	12 (1.4) **1 (1.0)** *13 (1.3)*	25.534 (0.000001)
b. If I have any concerns about MMR they are taken seriously by my doctor.	127 (14.8) **9 (8.7)** *136 (14.1)*	606 (70.5) **43 (41.7)** *649 (67.5)*	118 (13.7) **40 (38.8)** *158 (16.4)*	8 (0.9) **11 (10.7)** *19 (2.0)*	74.384 (<0.0000000001)
a. Doctors are too dismissive of what parents claim about vaccine side effects.	78 (8.9) **43 (40.6)** *121 (12.3)*	344 (39.3) **51 (48.1)** *395 (40.2)*	437 (49.9) **12 (11.3)** *449 (45.7)*	17 (1.9) **0 (0)** *17 (1.7)*	62.218 (<0.0000000001)
	N (%) Agreeing: MMR Acceptors **N (%) Agreeing: MMR Refusers** *N (%) Agreeing: Overall*				N=889 **N=107** *N=996*

6.4 Use of information sources

934 parents (93.8%) had consulted one or more sources of information about the MMR vaccine. As shown in Figure 6.2, health visitors and the 'MMR the Facts' leaflet were the most frequently consulted sources (consulted by 64.1% and 60.7% of parents, respectively). MMR-refusers were more likely than MMR-acceptors to have used health visitors, general practitioners, anti-MMR organisations and other sources of advice. The sources listed most commonly under 'other' included friends and other parents, the Internet, television and other media, and family members, as shown in Table 6.7.

Parental satisfaction with the information sources was generally high (Table 6.8). MMR-accepting parents were more likely to find NHS sources to be useful. MMR-refusing parents were less likely to find the information and approach provided by NHS sources, particularly the GP and practice nurse, to be useful and appropriate, but were more likely to have consulted these sources than MMR-accepting parents.

Write-in comments about the information sources suggested that a primary reason for dissatisfaction was the perception that NHS sources were one-sided and towed the government line on MMR (Appendix H, Tables 1-5). Many parents also noted that they found the information provided by organisations advising against the MMR to be biased and wished that an independent, 'balanced' source were available (Appendix H, Table 6). However, there were also many positive comments about the NHS professionals. Parents often praised their understanding of parental concerns, and said that they gave good, reassuring information to help them make their decisions (Tables 6.11-6.13). The comments also point to many connections between the various NHS information sources: health visitors, GPs and practice nurses referred parents to one another, and distributed leaflets and videos about the vaccine.

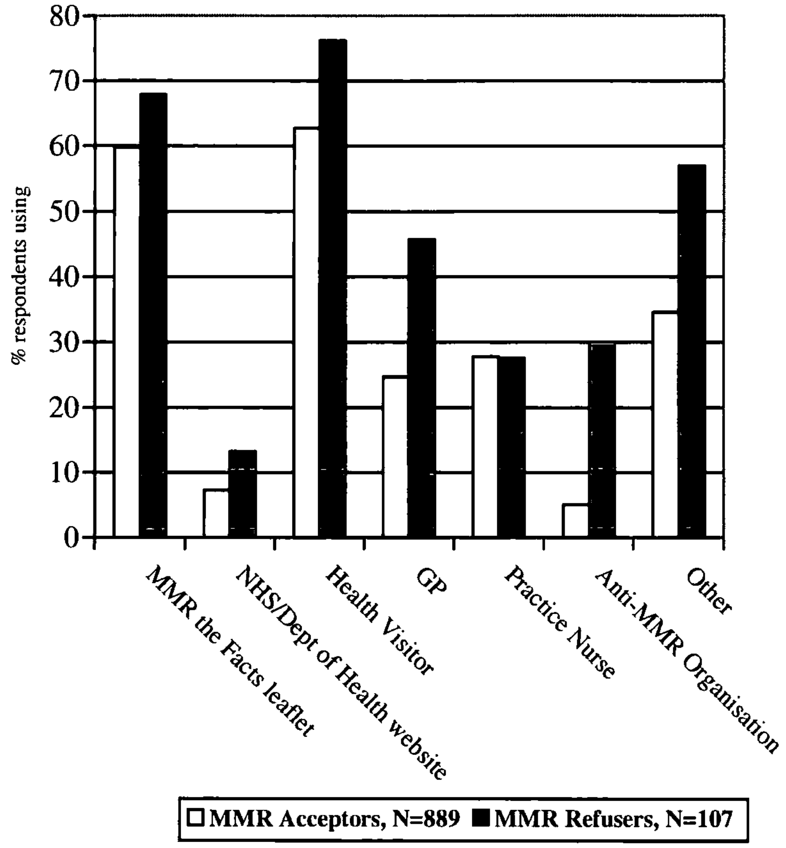

Figure 6.2 Parental use of information sources.

Information source	**Number of parents naming source**
Friends/ Other parents	94
Internet	78
Television	76
Newspaper	70
Family or friends in healthcare professions	41
Unspecified media/ press/ news	40
Family member	30
Medical journals/ Medline search/ research reports	29
NHS Video	24
Parents of autistic children/ work with autistic children	22
Magazines	21
Other healthcare professionals (specialist doctors, midwife)	19
Leaflets	17
Books (child health, library, Birth to Five)	15
Radio	11
Experience with vaccinating older children	9
Overseas medical opinion	8
Own professional knowledge	5
Information from a course (e.g., Open University)	5
NHS Direct	3
Private Eye	3
Personal experience with measles or mumps	2
National Childbirth Trust	1
Information on looked after children from Social Services	1
Vaccine package insert from nurse	1
MP	1
Homeopath	1
CD-ROM from GP	1
Prayer	1
Anthroposophic writings	1
Posters in GP surgery	1

Table 6.7 'Other' information sources used by parents.

	N (%) of parents using information source			Difference between MMR acceptors and refusers
Information source	**MMR acceptors**	**MMR refusers**	**Overall**	χ^2 **(p)**
'MMR the Facts' leaflet	**N=527**	**N=72**	**N=599**	
found information useful	490 (95.1)	42 (63.6)	532 (91.6)	75.214 (<0.00001)
found presentation appropriate	494 (96.9)	61 (93.8)	555 (96.5)	*
NHS/Dept. of Health website	**N=64**	**N=14**	**N=78**	
found information useful	57 (95.0)	11 (78.6)	68 (91.9)	*
found presentation appropriate	58 (95.1)	11 (84.6) †	69 (93.2)	*
Health visitor	**N=555**	**N=80**	**N=635**	
found information useful	496 (91.0)	49 (62.8)	545 (87.5)	49.504 (<0.00001)
found approach appropriate	501 (92.6)	50 (64.1)	551 (89.0)	56.640 (<0.00001)
GP	**N=217**	**N=48**	**N=265**	
found information useful	189 (87.9)	19 (41.3)	208 (79.7)	50.853 (<0.00001)
found approach appropriate	189 (87.5)	25 (56.8)	214 (82.3)	23.630 (<0.00001)
Practice nurse	**N=246**	**N=29**	**N=275**	
found information useful	226 (93.8)	13 (48.1)	239 (89.2)	*
found approach appropriate	229 (94.6)	15 (55.6)	244 (90.7)	*
Anti-MMR organisation	**N=45**	**N=31**	**N=76**	
found information useful	32 (76.2)	29 (100.0) †	61 (85.9)	*
found approach appropriate	22 (56.4)	29 (100.0) †	51 (75.0)	16.9 (0.00004)

* one or more crosstabs cells have expected counts less than 5
† percentages different due to missing data

Table 6.8 Parental evaluations of information sources.

6.5 Discussion of survey findings

Both MMR acceptors and MMR refusers showed a high degree of ambivalence about the safety of MMR. The percentage of parents agreeing that there is no scientifically demonstrated link between MMR vaccine and autism (65%) is remarkably similar to the percentage reporting that the vaccine 'was safe or carried only a slight risk' (67%) in the Health Promotion England survey (Ramsay et al. 2002), but the high level of agreement with related statements in this questionnaire suggesting uncertainty about the safety of the vaccine suggest a less optimistic view than that expressed by Ramsay *et al.* Although the uptake of MMR vaccine has not dropped as much as many feared in response to the controversy, it is still below target levels needed for herd immunity. Furthermore, the high level of concern about the safety of the vaccine expressed even by parents who had immunised their children is worrying in its implications for public confidence and trust in health care.

Many commentators have attributed parental concerns about the MMR vaccine to worrying reports in the media (Anderson 1999, Bedford and Elliman 2003, Begg et al. 1998, Elliman and Bedford 2001). Although this association was not explicitly tested in this survey, the anti-MMR media reporting had significantly died down by the time the questionnaire was mailed to parents.

Parents were similarly ambivalent about the appropriateness of separate vaccines as an alternative to the MMR. Although a high percentage of parents disagreed that people would not show up for all three single vaccines (44% overall and 70% of MMR refusers), only 26% of those who embarked on a course of single vaccines had in fact completed it. However, the reason for this may have more to do with supply than with motivation, as restrictions on the import of single mumps vaccine (because of safety concerns about the vaccine (Joint Committee on

Vaccination and Immunisation (JCVI) 2003)) made it very difficult for many private immunisation providers to obtain. 11 parents, unprompted, wrote on the questionnaire that they had been waiting for a long time (up to 2 years) to obtain single mumps vaccine for their children. Furthermore, all but 3 of the parents who had embarked upon but not completed a course of separate vaccines (94%) planned to complete the course.

More optimistically, high percentages of parents in both groups agreed with statements indicating support for immunisation in principle. For example, parents agreed that measles is a very serious disease, although they were less convinced that their children were actually likely to contract the disease if unimmunised. Although other studies have also suggested that parents are aware of the importance of immunisation (Gellin, Maibach, and Marcuse 2000, Ramsay et al. 2002), it is still common to find in the literature claims that the controversy around MMR vaccination was possible only because successful immunisation campaigns have made parents forget how serious diseases like measles can be (Begg et al. 1998, Whyte and Liversidge 2001).

Parents displayed a considerable level of distrust in the government's role in regulating risk, especially MMR-refusing parents, and felt that their good intentions were not recognised by the NHS. More than 1 in 5 of all parents did not agree that the government would stop MMR if there was evidence of risk, with more than 3 in 5 of MMR-refusing parents expressing this view. However, parents were generally happy with information about the MMR from individual practitioners, thus distinguishing between 'doctors' (in general) and 'my doctor' in terms of whom they would trust. The tendency to trust individual doctors while challenging the medical profession as a whole was highlighted in a recent King's Fund report (Rosen and Dewar 2004), which called on medical professionals to respond to these challenges by ensuring that professional behaviour reflects patients' expectations.

Parents were generally happy with all of the information sources available to them. When parents did not find these sources useful, qualitative comments on the questionnaires suggested the reason was that they felt a health professional 'represents the Government so is unable to give impartial advice.' The findings suggest that government efforts to promote the MMR vaccine are little trusted and may undermine the efforts of practitioners, known to parents, to provide professional advice. Practitioners should continue to provide parents with accurate information, while communicating respect for parents' intentions to protect their children's health.

Acceptance of MMR vaccine was not associated with parental education, occupational class or parental age, but with larger family size, in this sample. This finding may represent increased confidence in the vaccine among parents who had already immunised an older child. However, the lack of association between these factors and MMR uptake may reflect a sample bias and should be interpreted with caution.

MMR uptake in this sample was higher than the uptake as recorded by the CHIS in July 2004 for children in the PCT born between 1st Oct 2000 to 30 Sept 2002 (89% vs 84%), and this may reflect a tendency for children from higher social classes to have higher vaccination rates. Over two thirds of parents who did not accept the MMR vaccine had embarked on a course of separate vaccines, but very few had completed it. This reflects a much higher uptake rate than the 21% found in the Lancashire study (Wragg and Gornall 2004), although the lower response rate of a postal survey as compared to direct contact by health visitors may have resulted in considerable self-selection bias. Uptake of mumps vaccine was lowest for those children receiving single vaccines. Notably, mumps infection is the only one of the 3 diseases with recent confirmed cases in the PCT (Cresswell 2004), although mainly among young adults. Mumps outbreaks around the UK have prompted concern about potential outbreaks among under-immunised children (Gupta, Best, and MacMahon 2005).

The questionnaire response rate of 36% compares favourably to other postal questionnaire surveys (Bernard 2002). Respondents were from higher socio-economic classes and had higher levels of educational qualification than the general PCT population (as is often the case with postal survey research). Therefore caution must be used when interpreting the findings in relation to all parents.

Because the survey was generated on the basis of extensive interview data, it addresses areas of concern identified by parents themselves and provides information about parental evaluation of relative risks of MMR vaccination and non-vaccination. Using self-reported data about children's immunisation is a potential weakness, which is offset, however, by the previously unavailable information obtained about immunisation accessed outside the NHS.

CHAPTER 7
LOOKING FORWARD

7.1 Fears about MMR and the social construction of risk

This thesis has presented parents' views and roles in the British MMR controversy from a variety of perspectives and using diverse methodologies. The worrying reports that sparked this debate seven years ago and the public health response clearly framed this debate as a 'risk' issue. Therefore, this final chapter starts by highlighting the views that parents expressed about risk, contextualising them within the theoretical perspectives from the social sciences. The next sections similarly situate trust and parental decision-making roles, which are both closely related to ideas about risk. Following is a discussion about the methodological contributions offered by this study. The last two sections discuss the implications of my findings for other public health controversies and suggest a forward-looking stance for protecting children's health, rebuilding trust and coping with crises like this in the future.

Differing risk concerns

As one would expect from reading the social science literature on risk reviewed in Chapter 2, parents often differed from one another and from public health experts in terms of which risks to their children's health they worried about. They recognised that life presents unavoidable risks, but for certain particular risks this was considered unacceptable. The specific risks that parents were unwilling to countenance included (for different parents) early mortality (e.g., from measles), the dramatic onset of autism in a previously bright and happy child, and being viewed as a bad parent. Other concerns, whether biological concerns related to a particular child's vulnerabilities or social concerns related to good parenting, child protection and autonomy, were crucial in determining which risks the parents considered most salient. Cultural consensus analysis showed that for all of the domains related to particular risks, only members of particular subgroups (MMR acceptors or refusers) were in agreement with one another.

This much is consistent with Douglas's cultural theory of risk (Douglas 1985, Douglas 1992, Douglas and Wildavsky 1982), which posited that our societies have deep, possibly irreconcilable, disagreements about risk because members of different social groups have competing notions about what sort of outcomes would be undesirable. Risk is invoked to hold individuals, corporations, and governments accountable for harm when they do not comply with accepted ways of behaving. This line of analysis also supports the claim made by the psychometricians (Fischhoff, Bostrom, and Quadrel 1993, Freudenberg 1988, Kasperson et al. 1998, Pidgeon 1999, Slovic 2000) that technical risk experts and lay members of the public may well be focused on different considerations when making their evaluations and comparisons of risks.

Ambivalence about risks

However, a finding of this study that is not well covered by the notion that risk concerns differ among social groups is the degree to which ambivalence was expressed even at the level of individuals. Disagreement was found not only between entrenched positions, but parents also often second-guessed their own decisions and concerns. This ambivalence is expressed to some extent by the idea of the 'risk society' (Beck 1992, Beck 1994, Beck 1999, Giddens 1990, Giddens 1991, Giddens 1994, Lash, Szerszynski, and Wynne 1996) in its emphasis on the continual reformulation of social orders and risk evaluations. But the degree to which survey respondents in my study simultaneously expressed concerns about the MMR vaccine, the single-antigen alternative, and measles disease is striking.

Individual and communal risks

Although secondary to protecting their own children from risk, protecting the health of the population was also an important concern for many parents. The high levels of immunisation needed to maintain 'herd immunity' and prevent the circulation of wild virus in the population constituted the chief reason for public health concern about this controversy. Weighing their responsibilities to their own children and to the community was an important part of parents' risk evaluations. It also provided an important focal point for indignation and accusations among different groups of parents. While many immunising parents were outraged by parents who did not help to maintain overall levels of immunity by vaccinating their children, non-immunising parents felt it was unfair for their children to be exposed to a vaccine for the sake of protecting other people's children from diseases.

Douglas's research questions

This recap of my findings on risk and the MMR vaccine controversy prepares us to return to the four research questions posed by Mary Douglas (1992, p. 46-47) for investigating risk in a particular cultural context (See Chapter 2, p. 65). To simplify matters, let us consider here just the two most discussed of the many risks that parents mentioned in this context: the risk of autism and the risk of measles.

1. *What (and to what extent) is the bearing of a particular risk on the individual perceiver's purposes?*

For the first two risks – of autism and of measles – the chief purpose of parents perceiving the risks was obviously and overwhelmingly that of protecting her or his children from harm. However, other purposes also played an important part in shaping what parents thought would harm their children. Parental resistance to pharmaceutical corporations' monetary interests or to government control over medical choice disposed some to give a favourable reading to the suggested link with autism. For others, it was a travesty that technological solutions offering alleviation from childhood pain and illness would not be used; measles then seemed to be the more important risk.

2. *How much is the community part of the individual's purposes?*

For all parents, the overriding concern was their own child's health. However, for some, protecting the community was also a very important consideration.

3. *Is the risk thought to affect the individual or collective good?*

Autism was thought to affect the individual good primarily, although parents did often discuss the impact of rising prevalence of autism on parents, carers and society at large. The risk of measles was thought to affect both the individual (through illness episodes and complications) and collective (through virus circulation) good.

4. *To what extent do community members support authority, commitment, boundaries and structure?*

Just as parents differed in their purposes related to risk perception and their emphases on individual and communal welfare, so too did they vary in their support for authority and structured social boundaries. First and foremost, they demanded support for parents to act in the interest of their children's health. For some, the unique relationship between parents and children meant that other social authorities should have little scope for intervention. According to this view, parents must be believed when they report changes in their children's behaviour, and other parents must be free to choose whether, when and how (i.e., MMR or separate vaccines) to immunise their children, because they understand their own children's needs and vulnerabilities best. At the other end of the spectrum were parents who saw their role as part of a social order with place for many others to contribute to their children's upbringing and health. Such parents welcomed authority to fund and interpret medical research, administer a complex national health service, and support families coping with difficult conditions like autism or complications arising from measles.

7.2 The building blocks of trust

The need for trust

The risks invoked in the controversy about MMR vaccine were at once intensely personal and intensely political. Parents' chief concern was to protect their own children from harm, but uncertainty about the nature and likelihood of different harms meant that parents had to turn to other sources for information and interpretations. Therefore, trust – in information sources, in government and in medical authority – was a key component of parental decisions. The fundamental role of parents in protecting their children from risk made trust especially important. This trust was determined by and contributed to the wider social and political concerns of the parents. Events like the MMR controversy that resulted in the erosion of trust between parents and health care professionals have detrimental effects on the effectiveness of medical intervention (Safran et al. 1998), invite micromanagement of health care (Mechanic 1998), and 'could lead to disharmony and discord' (Calman 2002, p. 168) that undermine public participation in the democratic political process.

In modern societies, trust is necessary to reduce complexity to manageable proportions, allowing us to abdicate responsibility for day-to-day operations to expert systems (Giddens 1990, Giddens 1994, Luhmann 1979). In matters of public health, decisions must be made at the level of public policy, because they affect the population collectively. Furthermore, they typically involve technical evaluations that are beyond the everyday knowledge of most individuals who will be affected by the policy makers' decisions. Members of the public could certainly learn the relevant concepts to take part in this decision-making, but it is not feasible for every person to learn all the details of all the situations necessitating public policy decisions in our society. Furthermore, as Calman (2002) pointed out, even if every member of the public were sufficiently informed and invited to consultation, it is very unlikely that a unanimous decision would be reached. Dissenters would be unhappy with the outcome, having advocated a choice that was not used. The solution used in democratic political regimes is for decisions affecting the collective good to be made by elected representatives or advisory bodies responsible to elected assemblies. This solution is imperfect, because it cannot always cope with dissent from the representatives' decisions, but it is generally upheld as a system that has operated well (Calman 2002, p. 168). Trust is then crucial, both to legitimise the decisions taken by representative bodies and to avoid the sense of paralysis arising from lack of trust in institutions (Giddens 1990, p. 100).

The erosion of trust

In the MMR controversy, trust appears to have broken down in many respects. Many parents felt that they could not accept professional and government interpretations of the evidence on the basis of trust. They described previous instances in which they felt trust had been betrayed by political and medical policy makers. Perhaps even more importantly, they felt that trust was not reciprocated when policy makers and health practitioners did not communicate respect for parents' good intentions to protect their children's health and rationale for challenging official reassurances about the vaccine's safety.

Impersonal and interpersonal trust

Much has been made of the distinction between impersonal and interpersonal trust in health care (Calnan and Sanford 2004, Gilbert 2005, Hall et al. 2002, Harrison, Innes, and van Zwanenberg 2003, Rosen and Dewar 2004). My findings suggested that in the MMR debate, both forms of trust suffered in some quarters, but trust in known practitioners fared better than impersonal trust in the health care system. In the postal survey, parents expressed very low trust in the government's risk-regulating role, with more than 1 in 5 of all parents disagreeing that the government would stop MMR if there was evidence of risk, and more than 3 in 5 of MMR-refusing parents expressing this view. Furthermore, half of MMR acceptors and 89% of MMR refusers felt that doctors were too dismissive of parental concerns. However, only 14% of acceptors and half of refusers felt that their own doctor did not take their concerns seriously, and parents were generally happy with information about the MMR from individual practitioners. The greatest obstacles to interpersonal trust between parents and health practitioners emerging from the interviews and comments on the survey questionnaire were failure to communicate respect for parents and the appearance of professional integrity being compromised by financial incentives or government mandates to avoid discussion of certain topics. When parental and professional responsibilities for promoting children's health were mutually recognised and respected, parents entered into trusting relationships that fostered dialogue and cooperative decision-making.

Cosmopolitan trust

This point evokes the need for 'cosmopolitan social trust' argued by Earle and Cvetkovich (1995). This form of trust relies on flexibility, communication across social boundaries, and imagination to find common values *across* different social groups and to develop solutions to problems that were previously beset by inter-group divisions. In the case of public health disputes, cosmopolitan social trust could provide a platform for agreed norms of dialogue and decision making, as advocated by Beck (1994, p. 29-30). This scenario would not eliminate dissent, but dissent would be more tolerable if all parties recognised the fairness of the process by which decisions were made. It would also provide a mechanism for incorporating diverse concerns into decision making and communication strategies. For example, many parents would have been much more comfortable giving their children the MMR vaccine if they felt that the claims of parents reporting changes in their children's behaviours had been taken more seriously and investigated clinically, rather than relying on broad epidemiological studies alone to demonstrate that the MMR vaccine was not associated with autism.

This form of robust social trust is, naturally, very difficult to bring about and maintain. Earle and Cvetkovich (1995) suggested that a key tool for fostering this form of trust is narrative. Indeed, narrative was used to far greater effect by those claiming damage from the MMR vaccine than by those asserting that the vaccine was safe. Recognising the value of parents' anecdotal accounts will go a long way toward making them feel listened to and empowered by the medical establishment, and in turn more likely to trust the considered judgements of experts who take their concerns into account alongside the accumulated evidence from epidemiology and clinical studies.

7.3 The complexity of the decision making process

Parental roles and voices

Trying to understand how this crisis of confidence and trust came about, several writers have outlined a progression of events leading from the *Lancet* publication (Wakefield et al. 1998) to the public outcry and diminished public confidence in the MMR vaccine (Begg, Ramsay et al. 1998; Anderson 1999; Elliman and Bedford 2001; Jewell 2001; Mills 2002; Bedford and Elliman 2003; Bellaby 2003). These events are recounted in detail in Section 1.3, but it is worth recounting here the narrative developed by these authors to account for the controversy:

At a press conference held shortly after the article's publication in 1998, Dr. Wakefield unexpectedly stated that he had serious concerns about the safety of the combined MMR vaccine, and recommended a series of single-antigen vaccines for measles, mumps, and rubella, administered with several months' time between each, as a potentially safer alternative. The news media began to report this as a scientific claim of a possible link between the MMR vaccine and autism, fuelling popular fears of the vaccine. In 2001, the British government initiated a £3 million advertising campaign to promote the vaccine (Boseley 2001). Doctors working independently from the National Health Service (NHS) began setting up private clinics offering single-antigen vaccines to parents (an option the NHS refused to adopt), charging around £80 ($150 US) per injection. Prime Minister Tony Blair came under intense pressure to reveal whether his own son had received the vaccine, but deflected the issue. In February 2004 serious allegations against Dr. Wakefield emerged, that he had failed to disclose a conflict of interest (receiving Legal Aid payments to help build a case against the vaccine manufacturers) when his research was published (Deer 2004).

The account presented in the preceding paragraph focuses on the roles of the media and of medical 'experts' (Dr. Wakefield and the Royal Free team, government and public health authorities) in shaping the controversy. Parents are portrayed as recipients of media images (conveying misinformation about the balance of scientific opinion on the matter) and expert information. Parental challenges to the MMR vaccination program (such as demands for single-antigen vaccines) are presumed to be the result of insufficient information or of risk calculations that are clouded by an unwarranted emotional response to the media images of suffering autistic children (Elliman and Bedford 2001; Jewell 2001; Sporton and Francis 2001; Whyte and Liversidge 2001; Salisbury and Yarwood 2004). However, these accounts have largely overlooked the roles that parents have actually played in shaping the debate about MMR, as well as parents' own expertise in navigating an array of contradictory information to make vaccination decisions for their children. In many ways, parents were caught in the middle of this debate, weighing a raft of contradictory information to make decisions for their children. The aim of this thesis has been to give voice to the parents' concerns and to understand the basis for their decision making.

Who is responsible for children's health?

One of the chief concerns that figured into parents' decisions about the MMR vaccine was their keen sense of responsibility for their children's health. Parents discussed their decisions about MMR in the context of many other ways of promoting and protecting their children's health, such as actively learning as much as possible about children's health and safety, providing a healthy environment, and instilling 'good habits' in the children. Similarly, Poltorak and his colleagues in Brighton found that 'MMR talk' did not take place in isolation, but rather was situated among personal and family histories, feelings of control, personal assessments of children's health and vulnerabilities, engagement with the health services and social networks and conversations (Poltorak et al. 2005).

The MMR decision took on a great importance and for many came to symbolise what it means to be a good parent (*cf.* Alderson 1990). Even when it was not a difficult decision for parents to make, they felt that it was an extremely important decision, for the well-being of their children. Parents viewed their decisions about MMR – whether they decided to protect their children and others from diseases by immunising or to withold MMR immunisation until they were more convinced of its safety – as an important way of exercising parental responsibility. Most parents who refused the MMR vaccine made a significant investment of time and money to obtain single-antigen vaccines for their children. (In my postal survey findings, 70% of those not giving MMR had embarked on a course of separate vaccines, and of these only 3 (6%) did not plan to complete the course.) They therefore wanted their responsibilities, and their good intentions to fulfil these responsibilities, to be recognised by other parents, by health professionals, and by government officials.

Parents also saw other figures as having important responsibilities for protecting children's health. The Government, though little trusted, was expected to protect the population from risks to health, inform people about risks, and facilitate members of the public making good decisions about their own health. The media, ideally, were upheld as a whistle-blower and a source of information to parents, though many felt that the media had acted irresponsibly in continuing the MMR story for as long as it did. And, finally, health professionals were recognised to play an important role in advising parents and providing services. However, parents were very sensitive to advice that they perceived as being motivated by financial gain (e.g., target payments for GPs with certain percentages of parents immunising their children) or disrespect for parental concerns, rather than genuine personal and professional conviction. Many parents were reassured to learn that their health practitioners had gone through the same decision as parents themselves, and had given the MMR vaccine to their own children.

7.4 MMR in the context of other vaccination controversies

Fortunately, the controversy over MMR never reached the levels of unrest that were seen in the 19th Century, when with the introduction of compulsory immunisation laws prompted street riots (Greenough 1995). Nonetheless, this controversy is set to take its place in a long history of resistance to vaccination, and it will certainly not be the last instance of such resistance. What parallels can we draw between this and the other vaccination controversies, and what lessons can we learn from them?

Vaccine resistance, acceptance and demand

The models of vaccine acceptance described in Section 1.4 (p. 34-36) (Nichter 1995, Streefland, Chowdhury, and Ramos-Jimenez 1999) can help make sense of the wide range of parental views of the MMR vaccine. Resistance to vaccination in general and the MMR vaccine in particular emerged for many different reasons, including loss of trust in the biomedical system or its government and industrial ties, anxiety about the reported link with autism, and wider ideas about risk and protecting children's health. Although the British Department of Health does not employ heavy-handed coercive techniques like those used in the smallpox eradication campaign (Greenough 1995), many parents did feel that the 'top-down' approach of experts deciding which vaccines would be offered did not adequately heed their concerns.

Just as other authors have criticised the 'top-down' approach of Selective Primary Health Care as being unresponsive to local needs and values (Banerji 1999, Banerji 2004, Wright 1995), so did these parents lose confidence in the government's medical authority, and turn away from its policies on vaccination.

There were also very many parents who passively accepted the recommended immunisation schedule, including MMR, for their children. Such parents varied in their understanding of how vaccines work and how the recommendations are determined, but generally trusted that 'the injections are there for a purpose' *(Laura, immunised her children with MMR).* Although these parents' acceptance was not limited to an intensive vaccination campaign period as in Nichter's South Asian research (Nichter 1995), Nichter's warning about the dangers of giving vague messages about the benefits of vaccination is still apposite. There were parents for whom a child's tendency toward non-specific illness indicated that the vaccines had not worked, or had even compromised the child's immune system, and such ideas certainly contributed to the resistance to MMR and other vaccines. But clearly, there were also many parents who exhibited what Streefland *et al.* (1999) referred to as 'social demand': they actively sought vaccination because they perceived it offered benefits to their children. Interestingly, these parents were found not only among those who immunised their children with the MMR vaccine, but also among those who refused the MMR but nonetheless wanted their children to be immunised against measles, mumps and rubella. In fact, nearly all of the parents who had obtained single-antigen vaccines for their children demonstrated a high level of motivation and demand for the vaccines. Feeling let down by the health service that offered them no alternative to the MMR vaccine, and often having access only to vague messages about the Department of Health's reasons for viewing the single-antigen vaccines as a riskier option, they invested their trust instead in private clinics.

Comparing the MMR and pertussis vaccine scares

The current controversy over the MMR vaccine has often been likened to the pertussis vaccine scare of the 1970s and 1980s, which is described in Section 1.4 (p. 38-42). Indeed, there are many points of similarity. Both emerged in Britain with the publication of a paper describing a small number of children believed to have suffered neurological damage following immunisation. Both controversies were propelled by parent advocacy groups and legal actions on behalf of the affected children. And both resulted in diminished confidence in the vaccine in question and the public health system. However, the impact on immunisation uptake was far less for the MMR than for the pertussis controversy. (Nationwide, pertussis vaccine uptake fell to just 33% in 1977, compared to an MMR uptake rate of 82% at the height of the controversy in 2002 (Department of Health 2004, Swansea research unit of the Royal College of General Practitioners 1981).)

It is difficult to account for this dramatic difference, but I think that one key probably lies in parental views of the benefit and importance of vaccination. In the 1970s the chief benefit of the pertussis vaccine was to infants who were themselves too young to be vaccinated, by immunising enough children to prevent the disease from circulating (Ashley 1977). Thus, many parents did not view the vaccine as being particularly beneficial to their own children. By contrast, measles and mumps (though generally not rubella) are widely understood to be a danger to all children: 95% of the parents responding to my survey agreed that measles is a serious disease. So there was a strong belief in the importance of immunising, even if parents were concerned about the vaccine's safety. The parents I interviewed were adamant that their own children's health and safety was a much more important consideration than the marginal effect that their individual decisions would have on the health of the community, even when they also believed the latter point to be important. Thus, it makes sense that parents who perceived a benefit to their own children, rather than to other children in the community only, would be much more inclined to accept an immunisation about which they had some lingering doubts.

Department of Health doctors have also cited the experience of the pertussis vaccine scare as justification for the current policy of not providing separate vaccines for measles, mumps and rubella (NHS Health Promotion England 2001). During the pertussis vaccine crisis, the DTP vaccine was made available in separate components to try to offset parental anxiety and avoid compromising the immunisation programme as a whole. When separate vaccines were offered before, the reasoning goes, immunisation rates fell dramatically, and many children suffered or died as a result. However, this comparison does not seem entirely persuasive because in the first case, parents were afraid of one component of the DTP vaccine in particular, so it is not surprising that they might accept the others but refuse to immunise their children against pertussis. On the other hand, the MMR controversy centres on the *combination* of the components; none of the three immunisations are posited by the Wakefield hypothesis to be unsafe by themselves. So we might reasonably expect more parents to follow through with a complete course of the three separate vaccines (measles, mumps and rubella) than was seen in the pertussis case. In fact, only 25% of the survey respondents who had embarked on a course of separate vaccines had completed the course, although nearly all indicated an intention to do so.

7.5 Methodological contributions

Integrating qualitative and quantitative methodologies

One of the major strengths of this study was its integration of qualitative and quantitative methods to address different facets of the British MMR controversy. Previously published research has been either qualitative or quantitative in nature, yielding important findings but lacking the integrated picture offered by a combined approach.

The qualitative studies have provided important insight into the context of parental decision-making, although one of the most in-depth of them (Petts and Niemeyer 2004) was limited by its exclusion of MMR-refusing parents. They have highlighted the significance of competing notions of risk from the vaccine and from infectious diseases, trust (or lack thereof) in medical practitioners and Government, and personalised interaction with health professionals.

Because immunisation uptake is crucial at the level of the population, as well as the individual, it is important to assess the extent to which such findings can be extrapolated to larger samples. Previous quantitative studies have suggested that general practitioners (GPs) are the most trusted source of information about the vaccine (Pareek and Pattison 2000), that adverse media coverage has had relatively little impact on mothers' attitudes to MMR (Ramsay et al. 2002), and that the decline in MMR uptake after 1997 was somewhat higher in more affluent health authorities (Middleton and Baker 2003). However, none of these studies have addressed the issues raised by parents themselves in the qualitative work. This is what I did explicitly, in constructing the survey questionnaire from statements that parents made in the ethnographic phase of my research. Thus, I was able both to generate a fine-grained picture of parents' own views and explanations, and also to test the extent to which this picture was applicable to a large sample of survey respondents.

Cultural consensus analysis

The MMR vaccine was a very difficult topic to write about, because it was so contentious. For nearly every statement I could make about parental views, there were several among my informants who strongly rejected the view. To fairly present such a range of competing views, I have endeavoured to indicate how often particular themes emerged and whether contrary views were also expressed. In the presentation of results from the survey, I have given the percentages of parental responses on each point of the Likert scale, also as an indicator of the extent to which particular views were contested.

In addition, I decided to probe this aspect of the topic further by formally testing for areas of consensus and divergence among parental views, using the technique of cultural consensus analysis (Romney, Weller, and Batchelder 1986, Weller 1987). Use of this technique is relatively novel in the UK, although it has been widely used by US anthropologists. In general, I found it to be a very useful technique for evaluating a contentious issue like the MMR vaccine. I did encounter some problems with the data and the analyses, which are documented in Section 5.5. I hope to consult with American users of the method and to re-visit these analyses upon completion of the PhD.

The consensus analyses revealed, as expected, divergence between MMR-accepting and MMR-refusing parents on nearly all of the domains investigated. More interesting were the areas where consensus was found. Among MMR acceptors, in addition to consensus on the safety of the MMR vaccine, consensus was found for questions covering the seriousness of measles, mumps and rubella – the chief reason given by health professionals and parents to immunise with MMR. Among MMR-refusers, who also agreed among themselves on the (un)safety of the MMR vaccine, consensus was found for questions dealing with the appropriateness of studies demonstrating the vaccine's safety and government handling of the issue – the two major platforms of the anti-MMR advocates. That consensus was not found among both groups on these domains suggests that parents made their decisions by weighing the relevant importance of core values and arguments, acting upon a particular set of beliefs even if they still accepted some of the arguments of the opposing side.

Informants and sample composition: Talking to the 'chattering classes'?

Many commentators have suggested that concern about the MMR vaccine was localised to middle-class parents (Albert 2004, Goldacre 2005, Laurance 2001, Smith 2004). Middle-class parents have been very vocal in the media debate (e.g., writing letters in the newspapers) and constituted a large market for private clinics providing single-antigen vaccines. A chief aim of this thesis was to provide a voice for parents involved in making decisions about the MMR vaccine, requiring recruitment of informants beyond the groups who had already found a voice for their concerns. In addition, a smaller aim of the postal survey was to investigate the extent to which refusal of the MMR vaccine corresponded to socioeconomic position. Both aims required sampling from a broad range of socioeconomic and educational backgrounds.

The extent to which I was able to recruit from these different groups of parents was limited to some degree by the opportunistic sampling strategy used in the ethnographic phase and by the self-selection of participants in the postal survey. In both phases of the study, the samples were not representative of the population in that they disproportionately included parents from higher occupational class and education levels: 66% and 42% of the participants in Phase I and Phase II, respectively, were from NS-SEC classes 1 and 2. This makes it difficult to extrapolate the findings of this study to *all* British parents' views on the MMR vaccine controversy. However, both phases of the study did include participants from all occupational classes and from a wide range of educational backgrounds (see Tables 4.1, p. 144 and 6.1, p. 211), and so we can make some tentative observations about the importance of socioeconomic position for parents' part in this controversy.

In the survey, no association was found between MMR uptake and occupational class or educational qualifications. In the interviews, lower-SES parents frequently expressed ambivalence about the MMR vaccine's safety, as did many higher-SES parents. Their decision to take their children for the MMR vaccine despite reservations about its safety was often related to their inability to pay for the single-antigen vaccines that the middle-class parents could access. Parents from all backgrounds wanted recognition of their parental responsibilities, their knowledge of their children, and their good intentions for their children's health. I am advocating a communication approach that emphasises trusting, personal relationships between parents and healthcare practitioners. Communication emerging from such relationships will naturally be tailored to parents' concerns and understanding. But it would be a mistake to base communication strategies on the blanket assumption that concern about the MMR vaccine exists solely among well-educated, affluent parents.

A personal reflection

A final methodological consideration that needs to be discussed is my own role in the MMR controversy. I am a parent of young children and, although I have worked hard to maintain a 'neutral' stance in my fieldwork and analysis, it is inevitable that my own views will have shaped the account presented here. Informants often asked me whether I had given the MMR vaccine to my own children and whether I was 'for' or 'against' the vaccine. When (and only when) asked, I answered honestly: I chose to give all of my children the MMR vaccine, on time, and I have no reservations about my decision. But I also believe that there were a number of problems with the way that the issue was handled and issues that need to be further addressed, so that I am sympathetic to other parents' concerns. Furthermore, I stressed that by eliciting a detailed account of these concerns, I hoped to contribute to measures that would meet parents' and children's needs and better multi-directional communication between parents, health professionals and policy makers.

7.6 A way forward?

It is clear that although much of the media attention about the MMR vaccine has died down, many parents still have lingering doubts about the vaccine. Furthermore, this will certainly not be the last vaccination controversy. Any analysis of this episode must look forward as well as back, implementing lessons from this controversy for the future. Such a forward stance should have three objectives: to continue protecting children from diseases and harmful vaccine side effects, to rebuild trust, and to cope successfully with similar controversies in the future. To these ends, I have identified three practical strategies for improving dialogue between parents, health practitioners and medical policy makers. First, we must find ways to involve the public more fully in framing the research agenda about health risks. Second, the procedures for reporting suspected adverse reactions to vaccines and other drugs or procedures should be streamlined, publicised and made widely available to the public. Finally, sound personal relationships between patients and health care practitioners should be fostered as one of the chief strengths of the National Health Service. Before discussing these recommendations, however, I must spend some time discussing the suggestion that was most often mentioned by parents themselves, namely, providing single-antigen vaccines as an alternative to the MMR vaccine.

Single vaccines?

Many parents who participated in this study wished that they could obtain separate, single-antigen vaccines for measles, mumps and rubella in their normal NHS clinics. The rationale for this demand was an extension of the 'precautionary principle' (Resnik 2004): parents wanted to avoid the MMR vaccine because they were uncertain about its safety, but they also wanted to protect their children from the risks of contracting measles, mumps or rubella.

However, as Calman (2002) and Adams (1995) both pointed out, measures designed to prevent one sort of risk often end up shifting the risk somewhere else. The Department of Health, in fact, was also invoking the precautionary principle in its refusal to offer these vaccines. The safety and efficacy of this regimen is far less clear than that of the combined MMR vaccine, and there are particular concerns about the safety of the single mumps vaccine offered by some clinics (Joint Committee on Vaccination and Immunisation (JCVI) 2003). On scientific, biomedical grounds, there appears to be little case for offering separate vaccines to parents.

Yet many parents are unfamiliar with or unpersuaded by this argument. If the problem with separate vaccines is lack of data, they reason, then shouldn't we be investing in research on these vaccines and developing good-quality alternatives to the MMR? Several parents I interviewed told me that their children had not been immunised because they were afraid to let them have the MMR but could not afford to obtain separate vaccines for them. It does seem that some way of accommodating these parents is necessary to ensure that their children are fully protected. There would be serious problems with introducing NHS-provided separate vaccines, particularly the current unavailability of a demonstrably safe and effective source of such vaccines. A more feasible, though less immediate, solution would be to improve communication with parents about what we know of the currently existing single-antigen vaccines (e.g., where and how they are manufactured, what specific risks are known or suspected, how well we understand their efficacy), and at the same time to take seriously parents' desire for more research on the course of single vaccines. A full discussion of that possibility might result in a decision not to expend limited resources on such research, but such a discussion must take place, publicly, before we can hope for such a decision to be widely accepted. On the other hand, if it were determined from public discussion that such research would significantly help to increase parental confidence and trust, then we would need to find ways for scientists and members of the public to work together in developing research questions and protocols that would be both symbolically and scientifically meaningful.

Involve the public in framing the research agenda

Let us return now to Beck's proposals for opening the decision-making process about public risks (Beck 1994, see p. 74 of this thesis). Of course, it would be neither possible nor desirable to spend large amounts of money researching every hypothesis about risk that comes about. Our current system of research funding tends to support only those investigations of hypotheses with the most scientific plausibility. However, even ideas that fail to convince most scientists can have important consequences if they seem plausible enough to other people. Parental refusal to immunise with the MMR is an excellent case in point. In such cases, it could be a very prudent allocation of resources to conduct research that will specifically address nuanced concerns of non-specialist members of the public. For instance, epidemiologists and physicians have pointed to the large number of large-scale studies finding no association between MMR and autism, and are thus satisfied that the vaccine does not carry this risk. But to many parents, such studies are almost irrelevant, because they neither eliminate the suspicion that the vaccine does cause a very small number of autism cases nor explain what causes the pathology attributed to the vaccine. If further investigations of the cases highlighted in the media would reassure parents that their concerns were understood and taken seriously, then it would probably be worth undertaking them.

Thus, I agree with Beck that we need greater public participation in framing agendas for research. Of course, to generate scientifically meaningful results, such participation should be done in cooperation with professional scientists. The process and grounds for research funding allocation should be made as transparent as possible and communicated to as many members of the public as are interested. Furthermore, in an effective partnership, all parties should listen to what sort of evidence would persuade members of the other parties. This would involve not so much listening to non-experts' interpretations of expert-generated data (which is likely to please nobody), as non-expert input into what data are sought in the first place. This might require creative work incorporating both statistical analyses and narrative.

Richard Horton, in his book on the MMR controversy (Horton 2004, p. 154-157), praised several innovations around the UK that aim to make science more publicly accessible. These include the Science Media Centre, an organisation for promoting scientific voices to the news media; Café Scientifique, a forum for scientists to hold informal talks with members of the public; and the very successful Cheltenham Festival of Science. Another platform, not mentioned by Horton, is the Science Museum in London. From October 2002, the Science Museum hosted an exhibit on the MMR controversy (Science Museum 2002), including a series of drop-in events for members of the public to meet experts, an evening discussion and debate about controversial vaccines, and a website on which people could post questions and opinions about the MMR vaccine (http://www.sciencemuseum.org.uk/antenna/mmr). Clearly, these endeavours represent a positive step toward developing the interface between science and society. But for the most part, the focus of all of these initiatives is on presenting science *to* the public. What we still lack, and urgently need, are similar platforms for presenting public concerns to scientific funding bodies and policy-makers.

Streamline and publicise procedures for reporting adverse reactions

Another concrete way to improve parental confidence and increase public participation in vaccine-safety research would be to streamline, publicise and make widely available the procedures for reporting suspected adverse reactions. Few parents were aware of the Yellow Card scheme or how it worked (described on p. 43-44). Those with any experience of filing a report under this scheme felt that it had serious limitations. The main limitations that parents perceived were difficulties convincing a doctor to register a suspicion and lack of awareness of the scheme. These factors combined to make many parents wary of the quality of the data upon which statistics asserting no relationship between vaccination and adverse events were based. Opening up the process would mean allowing parents or patients to file suspected reactions themselves, without first having to convince a doctor that there may be a link between the events. This might generate a much more cumbersome database, but it could be useful for generating new hypotheses for investigation if recurrent suspected reactions were tracked in a centralised system. To be successful, this system would also have to be widely known, and patients would need ready access to advice about how to file a report.

Focus on sound relationships between parents and health practitioners

We have seen from previous vaccination controversies and from other countries' immunisation programmes that measures involving compulsion foster distrust and are less effective, in the long run, than those involving encouragement and education (Greco 1997, Greenough 1995). A further finding from this research has been that 'top-down' vaccine promotion can be detrimental to parental confidence if it comes from a little-trusted source. For the most part, though, parents did express satisfaction and trust in individual health care practitioners, with whom they had developed interpersonal relationships. These relationships should be fostered and should be the primary basis for further communication about health risks.

Recognising the role of health professionals

The health professionals involved in this controversy have been presented with the very daunting task of addressing parental and scientific concerns while continuing to provide information and immunisation coverage to the nation's children. I have the luxury of being able to observe and comment without having to make and put into effect such far-reaching and often controversial decisions. This position offers a vantage point from which possibilities for coping with crises of public confidence and rebuilding trust become visible. I hope that my comments will therefore be taken not as condemnations of current policies and practices, but rather as suggestions emerging from engagement with parents. These suggestions are offered in recognition and deep admiration of the dedication with which the health professionals pursue their important work. The next step required is to implement interventions based on the principles of fully involving the public in framing scientific research agendas, streamlining the reporting procedures for suspected adverse reactions, and fostering trusting personal relationships between patients and health care practitioners.

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APPENDIX A
FORMS PRESENTED TO FOCUS GROUP PARTICIPANTS

Thank you for volunteering to participate in this study on parents' perceptions and decisions about the measles, mumps, and rubella (MMR) vaccine. As you know, this vaccine has been highlighted in both media and Department of Health reports, and has been a source of concern for many parents. This project aims to describe how parents evaluate reported risks and make decisions, in order to improve understanding between parents and health professionals.

Please note that this project is NOT investigating the relative safety or benefits of the MMR vaccine. It is only studying parents' views and how parents make decisions on behalf of their children.

Please read the description below of the procedure that will be used in this study, and your specific rights as a participant.

- This research is being conducted by a postgraduate research student, Rachel Casiday, under the supervision of Dr. Catherine Panter-Brick in the University of Durham Department of Anthropology and Dr. Tricia Cresswell, of the Northern & Yorkshire Public Health Observatory.
- You have the right to withdraw from this study at any time, and for any reason. You do not have to give a reason for withdrawing if you do not wish to.
- This focus group discussion will be tape-recorded, and the tape-recording will later be transcribed (copied word-for-word into writing), so that important themes can be analysed. Only the primary researcher, Rachel Casiday, the supervisors (named above), and the transcriptionist, Abril Symonds, will be given access to the tapes and written transciptions from this study.
- All information that you provide will remain confidential, and you will be identified by a number, whose identity will be known only to the interviewer, Rachel Casiday.
- If you provide permission to use quotations from your transcript in the final research report, this will be done without revealing your identity (generally by using a false name), and you are free to refuse permission to use quotations from your transcript.
- At the close of the project, all tapes and written transcriptions will be destroyed.
- The researcher is not associated with any health service or other party with a vested interest in this research.

Should you have any further questions about any aspect of this study, you can contact:
Catherine Panter-Brick
Department of Anthropology
University of Durham
43 Old Elvet
Durham DH1 3HN
Phone: **0191 374 2854**; email: **catherine.panter-brick@durham.ac.uk**
Alternatively, you can contact **Rachel Casiday** by telephone, on **01223 327 370**.
Please keep this information sheet for your reference.

CONSENT FORM (Approved by University of Durham Ethics Advisory Committee)

TITLE OF PROJECT: Risk Conceptualisation and Decision-Making in the Face of Contradictory Information: the Case of MMR

(The participant should complete the whole of this sheet himself/herself)

	Please cross out as necessary
Have you read the Participant Information Sheet?	YES / NO
Have you had an opportunity to ask questions and discuss the study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information about the study?	YES / NO
Do you agree to have this interview/ focus group tape recorded and transcribed?	YES / NO
Do you consent to have quotations from the written transcript used in the reporting of this research, **without revealing your identity**?	YES / NO

Who have you spoken to? Dr/Mr/Mrs/Ms/Prof. ....

Do you understand that you are free to withdraw from the study: * at any time and * without having to give a reason for withdrawing?	YES / NO

Signed .... **Date** ....

(NAME IN BLOCK LETTERS) ....

Pre-Focus Group Questionnaire Group_____

1. First Name (to be used only to identify your comments) ____________________

2. You were selected for this group because you have recently had a child immunised with the MMR vaccine. Briefly, how did you go about making the decision to have your child given the MMR?

OR You were selected for this group because you have recently decided not to have your child immunised with the MMR vaccine. Briefly, how did you go about making this decision?

OR Briefly, how would you characterise your feelings right now about your child having the MMR vaccine?

3. What do YOU think are the most important things to consider when taking a decision about vaccination?

4. How many children do you have? _________

5. What are their ages?

   ____

6. How many of your children have had the MMR vaccine? _________

The following voluntary information will help compare your views with other people's from similar backgrounds:

7. Are you a mother or a father? ☐ MOTHER ☐ FATHER

8. How old are you?

   ☐ less than 25
   ☐ 25-29
   ☐ 30-34
   ☐ 35-39
   ☐ 40-44
   ☐ over 44

9. What is your occupation? (before maternity leave, if applicable)

   ____

10. Do you have a partner? ☐ YES ☐ NO

11. What is your **partner's** occupation? (before maternity leave, if applicable)

    ____

12. What is the highest level of education you have attained?

    ____

APPENDIX B
FOCUS GROUP OPENING AND CLOSING STATEMENTS

Instructions to read at start of focus group:

Thank you all for participating in this focus group about the MMR vaccine. What I am interested in is how you, as parents, make decisions about the MMR on behalf of your children, and what you think are the important points to discuss about this topic. To help you start this discussion, I will ask you to talk about your answers to the bold-faced question that you answered on the questionnaire. After that, you should be able to carry on your own discussing your experiences with one another. You were all chosen for this group because you have a child whom you have decided not to have vaccinated with the MMR (or to have vaccinated, or near the age when MMR vaccine is normally given), so you should think of this as an opportunity to comfortably discuss your views and experiences.

If the discussion tends to get off track, someone will usually pull the group back around to the MMR vaccine. I will jump in if necessary, but usually one of you takes care of that. If the group runs out of things to say, just remember that what we're interested in is MMR and how you make decisions about it, and that we want to bring up as many different things about this as possible. So what usually happens is that someone will think of something that hasn't come up yet and then that will restart the discussion.

If your experience is a little different from what others are saying, then that is exactly when I really want to hear from you. Often someone says, 'I guess my experience is different from everyone else's...' and then they find out that the same things have happened to other people too, but no one else would have mentioned it if someone hadn't brought it up first. If someone hasn't really joined in, or you seem to be hearing from the same people all the time, try asking a question of someone who hasn't spoken as much. Maybe you can remember something they said at the start to ask them a question that will draw them back into the discussion.

I want to hear as many stories as possible. Even if you think your experience is just like everyone else's, don't just say 'I agree.' We want to hear your story, because there is always something unique in each person's own experiences. We need to hear as many different things from as many of you as time allows. There really aren't any right or wrong answers for this discussion—we're here to learn about your experiences. Please do remember that this topic may be sensitive or emotional for some people, and all of the views expressed today should be treated both respectfully and confidentially.

Would somebody like to start by telling us about what you wrote on the questionnaire?

after c. 40 minutes:

Now I'm going to interrupt you for just a moment and ask you to do an activity as a group. I have here several cards with the names of different sources of information on them. How would you rank these, in terms of how much you would rely on them as accessible and trustworthy sources of information about MMR? I have left a few cards blank, in case there are other information sources that you might think of. You may or may not agree on how the cards should be arranged, so in trying to rank these information sources you will need to explain how you would or would not use them or find them trustworthy.

Disclaimer to be given after the end of focus group discussions

(Revised 15.11.02)

Thank you for your participation in today's focus group discussion. I hope that it has been a good experience for all of you and has given you an opportunity to express your thoughts about the MMR vaccine.

Occasionally, discussions of this type may cause people to think about things in ways that they had not previously thought of them, and this may sometimes cause concern for focus group participants. Please remember that the nature of this project is to study parents' attitudes and decisions. Thus, I cannot offer any advice on the MMR vaccine or endorse any particular opinion.

However, if you do have concerns and would like more official information, I have available a publication from the Department of Health about MMR, as well as contact details for a Health Visitor who has agreed to discuss any concerns about the vaccine with partipants from this study. These information sources have a known policy and are under their own professional codes of practice. I am not endorsing or promoting their opinions, but only making this public information available to you if you want it.

Health Visitor Anne Considine has kindly agreed to be contacted by participants in this study regarding their concerns about MMR. She is quite sympathetic with parents' need to make their own decisions and will be happy to discuss any concerns about MMR that you may have as a result of participating in this study, or to provide additional information. She can be contacted on **01480 356 275.**

APPENDIX C
INTERVIEW PROTOCOL

0 Introduction and Permission

Thank you for volunteering to participate in this study. I am a postgraduate student from Durham University, and this is a study on how parents in the UK feel and make decisions about the MMR vaccine. Your answers will be held in confidence. It is faster if I tape, because I don't have to write everything as I go. Do you mind if I use the tape recorder? You can ask me to turn it off at any time if you like.

I Family and MMR Experience

I would like to start off talking about your children and your own experiences with the MMR vaccine.

I.A How many children do you have, and what are their ages?

I.B Are your children generally healthy?

I.C How many of your children have had the MMR?

I.D Do you think that the controversy about MMR is an important issue? How do you feel, generally speaking, about the MMR vaccine?

I.E Did you ever feel like you had to make a conscious decision about whether you wanted your child(ren) to have the MMR? Could you please describe your experience of making that decision?

II Free Listing (try to finish within half hour of interview start)

Now, I would like to do an activity called 'free listing', where you name as many things as you can think of that are relevant to each of the questions that I am about to ask you. For example, if I asked you to name activities that children do in school, you might list reading books, playing, learning to add and subtract, and so on. There are no right or wrong answers, but please try to list as many things as you can. We will talk about them in more detail in a few minutes.

II.A What are the things that you, as a parent, need to do in order to have a healthy child?

II.B What are the things that we, as a society, need to do in order to protect the health of our children?

II.C What risks to health should we be concerned about?

II.D What do you think are the most important things to consider when taking a decision about vaccination?

II.E What things do you think have been **good** about the way that the MMR issue has been handled

a: by the government
b: by the media
c: by the general public?

II.F What things do you think have been **bad** about the way that the MMR issue has been handled

a: by the government
b: by the media
c: by the general public?

II.G Where might you or another parent go if you wanted to get information about the MMR vaccine?

III Elaboration on Free List Responses

(ask for elaboration where appropriate, then ask if participant wants to add anything to the responses)

IV Further Questions

IV.A (if not already discussed) Do you talk with other people about the MMR? Who have you talked to? Has this affected your attitudes at all?

IV.B How influential do you think that the media are with respect to public attitudes about the MMR? Have they affected your own attitudes at all? (if not already discussed:) Do you think that the media have acted appropriately in their reporting on MMR? What about the NHS and Department of Health?

IV.C Do you think there has been enough communication between the people on the 2 sides of this debate, and parents? (if not:) What could be done to improve communication?

IV.D Do you yourself know anybody who has been affected by measles? Had a bad reaction to a vaccine? Have you known anybody who has had autism or a digestive disorder?

IV.E (if not already discussed) Do you feel that single vaccines should be considered as an alternative to MMR? Why or why not? Do you think that parents should be given the option of having single vaccines? Should they have to pay for them if they take this option?

IV.F Are you familiar with the concept of 'herd immunity' (i.e., the idea that individuals who are not vaccinated will be protected from the diseases if enough people in the population are vaccinated to keep infection levels down)? Do you think that this is an important consideration? If so, how? If not, why not?

IV.G How trusting would you say you are generally of the government, the NHS, and doctors' views? Are your views on MMR typical of your views on health-care issues? How so?

IV.H How concerned are you about 'risks' generally? How do you respond to reports of things being 'risky'? Ask for elaboration with respect to examples generated in the free-listing question.

IV.I How much of a role do you think financial concerns have played in this issue? How do you feel about that?

IV.J Is there anything else that you would like to talk about?

V Background Information

Finally, I'd like to ask some background questions, so that I can accurately sample a range of people. If there are any questions you'd rather not answer, just say so.

V.A Which age range do you belong to? (less than 25, 25-29, 30-34, 35-39, 40-44, over 44)

V.B Do you work, or did you work before having children? What is your occupation?

V.C Do you have a partner? What does (or did) your partner do?

V.D What is the highest level of formal education that you have attained? (If A-level or higher, what did you study?)

V.E What about your partner?

V.F If any quotations from this interview are used in my research report, you will be identified with a false name. Would you like to make up a name for yourself?

(Record:)
M/F
how recruited
date, time, length of interview
where interview conducted
other observations

APPENDIX D
RESULTS OF FREE-LISTING EXERCISES

What do you as a parent need to do to have a healthy child? • 20 respondents, giving 86 different answers • median number of answers per list=7 (range 2-17) • very similar items were grouped together, yielding 52 different answers (grouped categories in italics) • 22 answers were given by ≥3 respondents (15% of sample), as shown below:	number of respondents listing item
1. give a healthy diet	19
2. play and interact with them- give them attention	8
3. good hygiene	7
4. exercise	7
5. love them	6
6. dress them appropriately and keep them warm	5
7. attend regular health and growth checks	5
8. encourage good sleep pattern	5
9. fresh air	5
10. protect them from dangers and harm	5
11. education	4
12. ensure they are happy- emotional, mental health	4
13. boost their immune system as a preventative measure	3
14. protect them from disease	3
15. take them to the doctor when they are ill	3
16. expose to some germs	3
17. keep them safe from accidents	3
18. keep informed about children's health issues	3
19. keep them secure	3
20. help them develop socially	3
21. support them	3
22. vaccinate	3

What do we as a society need to do to have healthy children? - 20 respondents, giving 89 different answers - median number of answers per list=5 (range 2-11) - very similar items were grouped together, yielding 48 different answers (grouped categories in italics) - 12 answers were given by ≥3 respondents (15% of sample), as shown below:	number of respondents listing item
1. promote healthy lifestyles and diets	10
2. clean up the environment from pollution	5
3. ensure we have access to good medical care	5
4. regulate food additives and food production	4
5. don't limit children's freedom too much	4
6. limit road traffic danger	3
7. educate children about health and safety	3
8. educate parents about children's health	3
9. provide play and leisure facilities for children	3
10. protect children from dangerous people and things	3
11. conduct and publicise research on children's health	3
12. immunization	3

What risks to health should we be concerned about? - 18 respondents, giving 65 different answers - median number of answers per list=5 (range 1-15) - very similar items were grouped together, yielding 39 different answers (grouped categories in italics) - 10 answers were given by ≥3 respondents (15% of sample), as shown below:	number of respondents listing item
1. diseases	7
2. people that would hurt your children	7
3. driving and cars	5
4. additives and pesticides in food	5
5. accidents (e.g., falling)	4
6. poor diet	4
7. smoking	4
8. drugs and alcohol	3
9. risks in everyday life, activities	3
10. pollution	3

What things are important to take into consideration when making a decision about vaccination? • 20 respondents, giving 47 different answers • median number of answers per list=4 (range 3-9) • very similar items were grouped together, yielding 34 different answers (grouped categories in italics) • 9 answers were given by ≥3 respondents (15% of sample), as shown below:	number of respondents listing item
1. vaccine risks and side effects	13
2. seriousness and effects of disease	8
3. weighing risks of vaccinating against not vaccinating	7
4. risk of not vaccinating (exposure to disease)	6
5. health of child on day of vaccination	4
6. is it really necessary?	3
7. likelihood of getting the disease	3
8. public health impact (herd immunity, benefit to population as a whole)	3
9. read up on it and talk about it	3

Where might you or another parent go for information on the MMR vaccine? • 20 respondents, giving 59 different answers • median number of answers per list=5 (range 1-11) • very similar items were grouped together, yielding 32 different answers (grouped categories in italics) • 16 answers were given by ≥3 respondents (15% of sample), as shown below:	number of respondents listing item
1. internet	18
2. GP/ doctor	11
3. health visitor	11
4. library	9
5. family members with health background	7
6. people at baby/toddler groups	5
7. NHS (including NHS Direct and NHS website)	4
8. other health workers at the doctor's surgery	4
9. television	4
10. other countries' perspectives on the web (e.g., Dutch, American policies)	3
11. group of parents who feel MMR has affected their kids (JABS)	3
12. leaflets (e.g., MMR the facts)	3
13. word of mouth/ other people	3
14. medical journals	3
15. newspaper	3
16. parents whose kids have had the MMR	3

APPENDIX E
STATEMENTS ON CULTURAL CONSENSUS ANALYSIS QUESTIONNAIRE

strongly agree **strongly disagree**

1 2 3 4 5 6

Domain A. Safety of MMR and the 2-dose schedule

A1	The majority of the evidence indicates that there is no link between MMR and autism.	mild pro
A2	MMR vaccination seems to be a significant factor in childhood allergies.	mild anti
A3	MMR is safe for most children, but certain children with sensitive immune systems could be damaged by it.	mild anti
A4	I would have better peace of mind about my child's health if he/she got single jabs for measles, mumps, and rubella instead of the MMR.	mild anti
A5	I'm not sure that the single vaccines for measles, mumps, and rubella are really safe.	mild ambig
A6	A number of children in this country now have autism as a direct result of MMR vaccination.	very strong anti
A7	I don't really believe the reports about risk from MMR, but I still worry about my child having it.	mild ambig
A8	The benefits of having the MMR jab outweigh the risks.	strong pro
A9	There is no reliable information available to me about how safe the MMR jab is.	ambig
A1	All children should have 2 doses of MMR before starting school to be sure that they are protected.	strong pro
A1	I would let my child have a second dose of MMR (booster jab), but only if a blood test said they weren't immune already.	ambig
A1	The risk of autism from MMR may be very small, but I would feel so awful if something were to happen to my child that I'm not willing to expose him/her to it.	mild anti
	7 pro (4 strong, 3 mild), 7 anti (3 strong, 4 mild), 6 ambiguous	

Domain B. Nature of Scientific Studies of MMR

B1	It will never be possible to prove with 100% certainty whether MMR is safe.	ambig
B2	The study that suggested a link between MMR and autism was performed on such a small sample that it's not really valid.	strong pro
B3	Big, epidemiological studies using statistics are the best way to determine whether or not MMR causes autism.	mild pro
B4	If a study were done that clinically examined those children whose parents thought they had been damaged by the MMR, then we could have a better idea about how safe it is than we do now.	mild anti
B5	The research demonstrating the safety of MMR is not trustworthy, because it was funded by the government or pharmaceutical companies.	strong anti
B6	I don't know what kind of studies were done on the link between MMR and autism.	ambig
B7	It is really important to have scientists going against the conventional wisdom in medicine, because you never know what important discoveries will be made that way.	mild anti
B8	We haven't had the length of time, since the MMR vaccine was introduced, needed to investigate its effects fully.	mild anti
B9	Nobody really knows how vaccines work, or how they are broken down by the body.	mild anti
	4 pro (2 strong, 2 mild), 5 anti (1 strong, 4 mild), 2 ambig	

Domain C. Seriousness of Diseases and Herd Immunity

C1.	I get angry with people who don't vaccinate their kids, because I am putting my kids at risk (by having them vaccinated) to protect those other children.	ambig
C2.	My child is not very likely to get measles even if he/she isn't vaccinated, because levels of the disease are so low.	mild anti
C3.	We need to see more kids getting vaccinated with the MMR so that measles outbreaks don't occur.	strong pro
C4.	There is no real point in having boys vaccinated against rubella.	strong anti
C5.	I would be very afraid of my child contracting measles if he/she were not immunised.	strong pro
C6.	We should do whatever we can to prevent children contracting measles, because the potential complications can be very serious.	strong pro
C7.	Delaying my child's getting immunity by having the single vaccines instead of MMR would put them at risk.	mild pro
C8.	I have a responsibility to have my children vaccinated, so that children who can't be vaccinated for serious reasons will be protected.	strong pro
C9.	My own children's health and safety is a more important consideration to me than the impact of my decisions on the population.	ambig
C10	We shouldn't assume that a vaccine is right for everyone just because it is for the majority.	mild anti
C1	Measles, mumps, and rubella used to be described in medical textbooks as common childhood illnesses with only rare complications, but now it is described as very serious and life-threatening. There is no justifiable reason for this change.	strong anti
C1	I don't know much about measles, mumps, or rubella, so I don't really know how serious these diseases are.	ambig
	6 pro (4 strong, 2 mild), 6 anti (3 strong, 3 mild), 4 ambig	

Domain D. Information, Handling of the Issue by Govt and Media

D1	The media have hyped up the MMR controversy all out of proportion.	strong pro
D2	The NHS does not do an adequate job of reporting adverse vaccine reactions, because doctors are too dismissive of what parents claim.	mild anti
D3	The Department of Health is in a very difficult position trying to restore confidence in the MMR, and I am sympathetic with how they are trying to handle it.	mild pro
D4	The government seems to be very defensive about MMR, and I find that off-putting.	ambig
D5	Most of the information about MMR available from the NHS is really just emotional blackmail.	strong anti
D6	Parents who opt for single vaccines are trying to do what is best for their children, but they have been treated as some kind of monsters by the NHS.	strong anti
D7	I wish that the information available to me about the jab were more balanced.	ambig
D8	The leaflets from the doctor's surgery would be more helpful if they included statistics about the diseases and side effects for my city, not just the country as a whole.	ambig
D9	I have done a lot of research on my own about the MMR.	ambig
D1	Parents who want single vaccines should pay for them, since the NHS is already so strapped.	mild pro
D1	My own views on MMR haven't been affected much by the media.	ambig.
D1	If there was a serious health risk from MMR, I am sure that the government would take it off the market straight away.	strong pro
D1	Parents get tiny bits of information about the MMR from different places, but it is really difficult to put it together and know what to make of it all.	
	7 pro (2 strong, 5 mild), 4 anti (2 strong, 2 mild), 11 ambig	

Domain E. Health, Risk, and Trust

E1.	Nothing could be more important than children's health.	
E2.	Everything we do has a risk, but you have to let your kids live. It's no good sitting at home wrapped in cotton wool all day!	
E3.	It is important to keep informed about risks to our children's health, and to protect them as much as possible.	
E4.	Growing up in today's world is a dangerous business.	
E5.	There's no point worrying about risk, because it all really depends on fate. 'What will be will be.'	
E6.	I think that, in general, the government does a good job of protecting us from risk.	
E7.	There is a lot that parents can do to help their children stay healthy.	
E8.	People should take more responsibility for their own health.	
E9.	It's really important to get it right when we make decisions about our children's health, because they can't decide for themselves but will have to live with the consequences of what we decide.	

Domain F. Locus of Control

F1.	I pretty much just go along with what I am told to do about my children's health.	
F2.	I am upset about parents not being given enough choice about the MMR.	
F3.	Vaccination is one way that parents can make a positive contribution to their children's health.	
F4.	I would feel better about having my child get the MMR if I felt like I my concerns were taken seriously by my doctor and others in the NHS.	
F5.	Not allowing my child to have the MMR is a way that I, as a parent, can have some control over the risks that he/she is exposed to.	
F6.	The whole controversy about MMR is based more on anxiety and fear than on information and knowledge.	
F7.	One problem with offering single vaccines is that a lot of people wouldn't show up for all three.	

APPENDIX F
LETTERS AND QUESTIONNAIRE USED IN MAIL SURVEY

tricia.cresswell@durhamclspct.nhs.uk

Tel: (0191) 301 1479
Fax : (0191) 301 1472

Our Ref hdodds/tcltrs/mmrstudy2604.04

21 April 2004

Dear Parent/Guardian

MMR Study

The PCT is working with Durham University on a research study funded by the Wellcome Trust about parents' views on the Measles, Mumps and Rubella (MMR) vaccine. The purpose of this letter is to ask if you would be prepared, as a parent, to take part in this study which will simply involve the completion of a questionnaire.

The aim of the study is to describe how parents make decisions about MMR vaccine in order to improve understanding between parents and health professionals. The study is not investigating the safety or benefits of the MMR vaccine but is studying parents' views and how parents make decisions on behalf of their children. Your answers to the questionnaire will be both anonymous and confidential.

If you are willing to complete the questionnaire, please return the attached reply slip to Ms Rachel Casiday, the Study Investigator, in the enclosed envelope.

A £3.00 Mothercare voucher will be sent to all parents agreeing to complete the questionnaire as a thank you for the time taken.

Thank you for your help.

Yours sincerely

Dr Tricia Cresswell
Director of Public Health

I am willing to participate in the study of parents' views on the MMR vaccine. Please send me a questionnaire.

Name : ....

Address : ....
....

Please return to Rachel Casiday, MMR Study Investigator, Department of Anthropology, University of Durham, 43 Old Elvet, Durham. DH1 3HN

University
of Durham

Department of Anthropology

MMR Study

University of Durham
43 Old Elvet
Durham DH1 3HN
England
Main Switchboard: **0191 334 2000**
Direct Line: **0191 334 6100**
Fax: **0191 334 6101**

17 May 2004

Dear parents,

I am writing to you because you recently responded to a request from Dr. Tricia Cresswell, of the Durham and Chester-le-Street Primary Care Trust, to participate in a study about parents' views on the MMR vaccine. This study is being conducted at Durham University and is funded by the Wellcome Trust (an independent research-funding charity that aims to improve health). As you know, the MMR has been highlighted in both media and Department of Health reports, and has been a source of concern for many parents. This project aims to describe how parents evaluate reported risks and make decisions, in order to improve understanding between parents and health professionals. Please note that this project is NOT investigating the relative safety or benefits of the MMR vaccine. It is studying parents' views and how parents make decisions on behalf of their children.

Enclosed you will find a questionnaire that should be completed by the person in your household who normally makes medical decisions on behalf of your child(ren). This questionnaire typically takes less than 10 minutes to complete. I am also enclosing £3 in Mothercare vouchers, to thank you for your participation in this research. When you have completed the questionnaire, please return it in the envelope provided.

Your answers to this survey will be anonymous and confidential. Your GP and Health Visitor have been notified that this study is taking place and are prepared to discuss any concerns that you might have as a result of participating in this study. If you have any questions about the study or how the information you provide will be used, or to request a report at the end of the study, you can contact me at the address given above or by email (R.E.Casiday@durham.ac.uk). Alternatively, you can visit the project's web site: http://www.dur.ac.uk/anthropology/Projects/MMR.

Thank you very much for your help. You are contributing to important research that will be used to help improve public health communication and services.

Sincerely,

Rachel Casiday

Rachel Casiday

MMR Attitudes Survey

MMR Study University of Durham The Wellcome Trust

This survey contains 4 sections. Your answers will help to improve communication between parents and public health professionals. Please complete all 4 sections.
It would be very helpful if you could return this questionnaire within 2 weeks.

Section 1. This section asks about your decision whether or not to immunise your child with the MMR (measles, mumps and rubella) vaccine. It refers to your child who is currently between 1-3 years old.

1. **In which year was your child born?**
   ☐ 1 Oct 2000 – 30 Sept 2001
   ☐ 1 Oct 2001 – 30 Sept 2002
   ☐ I have more than one child born in this time period. (Please tick the above box for the eldest child born in this time period and answer the following for that child.)

2. **Which of the following has this child been given? (please tick one box)**

   ☐ MMR (combined) vaccine

   ☐ Separate jabs for measles, mumps and rubella (Child has had all 3.)

   ☐ Only some of the separate jabs, but plan to get all 3

   (Please state which ones your child <u>has</u> had: ____________________

   ☐ Only some of the separate jabs, and do not plan to get all 3

   (Please state which ones your child <u>has</u> had: ____________________

   ☐ No vaccines for measles, mumps or rubella

Section 2. This section contains 20 statements made by other parents about the MMR. Please indicate how strongly you agree or disagree with each one. Please try to answer every question, even if you do not have a strong opinion.

1. **Scientific evidence shows that there is no link between MMR and autism.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

2. **It cannot proved with 100% certainty that the MMR vaccine is safe.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

3. **More time is needed to be able to fully investigate the effects of the MMR vaccine.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

4. **Separate vaccines for measles, mumps, and rubella are safe for children.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

5. **If separate vaccines were offered by the NHS, a lot of people wouldn't show up for all three jabs.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

6. **People who don't vaccinate their kids put others at risk.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Please continue to the next page.

7. **My child is likely to get measles if he/she isn't vaccinated.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

8. **More kids should be vaccinated against measles, mumps and rubella so that outbreaks don't occur.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

9. **Measles is a very serious disease.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

10. **Possible complications of MMR vaccination can be very serious for children.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

11. **Children receiving separate vaccines instead of MMR are at risk from the time lag between the vaccinations.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

12. **I have a responsibility to have my child vaccinated for the protection of all children.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

13. **Doctors are too dismissive of what parents claim about vaccine side effects.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

14. **The government is too defensive about MMR.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

15. **The NHS does not recognise the good intentions of parents who opt for separate vaccines for their children.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

16. **The government would stop the MMR if there was evidence of a serious risk.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

17. **The government does a good job of protecting us from risks to health.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

18. **Vaccination is one way that parents can make a positive contribution to their children's health.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

19. **If I have any concerns about MMR they are taken seriously by my doctor.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

20. **Parents should make health decisions for their own children rather than leaving it up to professionals.**
☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

Please continue to the next page.

Section 3. This section asks about several sources of information about the MMR that are currently available to parents.

1. 'MMR The facts' leaflet

Have you seen this leaflet? *(if no, skip to next item)* ☐ Yes ☐ No

Did you find the information in this leaflet to be useful? ☐ Yes ☐ No

Did you find the presentation of this leaflet (for example, layout, writing style) to be appropriate? ☐ Yes ☐ No

Do you have any particular comments about this leaflet?

2. NHS/Dept of Health website about MMR

Have you seen this website? *(if no, skip to next item)* ☐ Yes ☐ No

Did you find the information in this website to be useful? ☐ Yes ☐ No

Did you find the presentation of this website (for example, layout, writing style) to be appropriate? ☐ Yes ☐ No

Do you have any particular comments about this website?

3. Your health visitor

Have you talked to your health visitor about the MMR? *(if no, skip to next item)* ☐ Yes ☐ No

Did you find that the health visitor gave you useful information? ☐ Yes ☐ No

Did you find the health visitor's approach to be appropriate? ☐ Yes ☐ No

Do you have any particular comments about talking to your health visitor about the MMR?

4. Your GP

Have you talked to your GP about the MMR? *(if no, skip to next item)* ☐ Yes ☐ No

Did you find that the GP gave you useful information? ☐ Yes ☐ No

Did you find the GP's approach to be appropriate? ☐ Yes ☐ No

Do you have any particular comments about talking to your GP about the MMR?

5. Practice Nurse at GP Surgery

Have you talked to your practice nurse about the MMR? *(if no, skip to next item)* ☐ Yes ☐ No

Did you find that the practice nurse gave you useful information? ☐ Yes ☐ No

Did you find the nurse's approach to be appropriate? ☐ Yes ☐ No

Do you have any particular comments about talking to your practice nurse about the MMR?

Please continue to the next page.

5. Organisations advocating against the MMR

Have you obtained information about the MMR from an organisation that advises <u>against</u> children having the MMR? *(if no, skip to next item)* ☐ Yes ☐ No

If you can, please state which organisation(s) you got information from:

____

Did you find that the organisation(s) gave you useful information? ☐ Yes ☐ No

Did you find the organisation's approach to be appropriate? ☐ Yes ☐ No

Do you have any comments about the information from organisation(s) advising against the MMR?

____

____

6. Other sources of information

Are there any other sources that you used to obtain information about the MMR? *(if no, skip to next item)* ☐ Yes ☐ No

Please list the sources, and any comments you have about them:

____

____

____

Section 4. This section asks for some information about you. It will be used to compare responses from different groups of people.

1. Are you a (tick one)
- ☐ **mother**
- ☐ **father**
- ☐ **other carer**

2. How many children do you have? _______

3. How old are your children? _____________
____

	You	**Your partner** (if applicable)
4. age		
5. occupation (before maternity leave, if applicable)	**job title/description:** ______________________ ______________________ Are (were) you an ☐ **employee** or ☐ **self employed**?	**job title/description:** ______________________ ______________________ Is (was) your partner an ☐ **employee** or ☐ **self employed**?
6. Educational qualification(s) (please tick)	☐ No qualifications ☐ 1 or more O-levels/ GCSEs ☐ 1 or more A levels/ AS levels ☐ First degree (e.g., BA, BSc) ☐ Higher Degree (e.g., MA, PhD, PGCE) ☐ NVQ (Level _______)	☐ No qualifications ☐ 1 or more O-levels/ GCSEs ☐ 1 or more A levels/ AS levels ☐ First degree (e.g., BA, BSc) ☐ Higher Degree (e.g., MA, PhD, PGCE) ☐ NVQ (Level _______)

Thank you very much for completing this questionnaire. Please return it in the stamped, addressed envelope provided.

(Return to: R Casiday, MMR Study Investigator, University of Durham, Department of Anthropology, 43 Old Elvet, Durham DH1 3HN)

APPENDIX G
REPORT SENT TO INTERVIEW PARTICIPANTS

MMR Study

19 July 2004

Dear parents,

Some time ago you participated in a study that I am conducting about parents' attitudes to the MMR vaccine. I have prepared the enclosed brief report summarising the results of the interviews and focus groups. I hope that you will find this report interesting. I would be very interested to hear about your reactions to the findings presented here. If you have any comments or feedback about this report, please send them to me in the enclosed envelope.

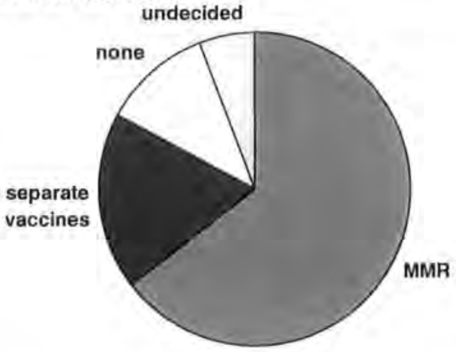
Thank you very much for participating in the study. Your time and comments have been very helpful to me!

Best wishes,

Rachel Casiday

Report for MMR Interview and Focus Group Participants

☐ 87 parents participated in this phase of the study.
  - 56 had vaccinated their children with the MMR
  - 16 had (or were planning to have) separate vaccines
  - 10 did not vaccinate for measles, mumps and rubella
  - 5 were still undecided.



- The most important factors in making decisions about vaccination were:
  1. the seriousness and effects of the disease
  2. vaccine risks and side effects
  3. what the experts say
- The sources of information about the MMR that parents found the most helpful were:
  1. GP
  2. family members with a health background
  3. the Internet
- Almost all of the parents were aware of the main arguments for and against the MMR.
- Whether single vaccines should be provided by the NHS was a divisive issue.
  - Problems with obtaining separate vaccines privately include (1) uncertainty about the safety, efficacy and administration of the vaccines, and (2) personal cost to parents who choose this route.
  - In some cases, parents chose not to vaccinate their children at all because the cost of obtaining single vaccines was prohibitive.
  - On the other hand, many parents felt that offering this choice on the NHS would not be a justifiable use of resources, since the medical establishment is firmly convinced of the safety of MMR.
- One of the main problems in the MMR controversy is that parents, government officials and medical professionals often do not recognise one another's common concern for the health and welfare of the nation's children.
- The following actions could be useful in addressing this problem:
  - Medical professionals and government officials should do more to recognise that parents - whether or not they opt for the MMR - are working hard to make the best decision for their children's health.
  - Parents often find asking health professionals with children of their own how they have handled this issue for their own children to be a useful strategy in building trust.
  - Govt health officials should be careful not to sound defensive or accusatory toward parents.
  - Medical professionals should be made familiar with anti-vaccine arguments and be comfortable discussing them with concerned parents.
  - Parents should be informed about the potential consequences of measles, mumps and rubella, and the likelihood of their children contracting these diseases. However, this should be done without resort to 'scare tactics' and exaggerated forecasts of impending epidemics.

Feedback sheet: MMR Interview and Focus Group Participants' Report

Please complete and return this form in the enclosed stamped envelope to:

Rachel Casiday
Department of Anthropology
University of Durham
43 Old Elvet
Durham DH1 2RY

Name (optional): ____

Overall, do you think that the findings reported here are consistent with your own perceptions of the MMR controversy?

Overall, did you find the information presented in this report interesting and relevant?

Do you feel that the suggested actions listed at the end of the report would be helpful?

Do you feel that the suggested actions listed at the end of the report would be feasible?

Please give any other comments that you have:

APPENDIX H
COMMENTS MADE BY SURVEY RESPONDENTS ABOUT MMR INFORMATION SOURCES

Comment	**Number of parents making comment**
Biased/ one-sided in information presented	26
Informative/ gave relevant information to help make decision	21
Not enough information/ did not give guidance to make an informed decision/ should have more documented references	15
Don't remember the contents	9
Didn't change my views/ didn't make me more confident about the MMR jab	8
No evidence, just government line	6
Doesn't deal with debate as it appears to parents	6
Simple and easy to read	4
No information about risks and side effects of MMR	3
Everyone should read it/ not enough people read it properly	3
Increased concern about the MMR	3
Reassuring	2
Balanced/ more balanced than I expected	2
Confusing	2
Handy	1
Could have been more argumentative	1
Told me what I knew already to back up my case to my husband who was anti-MMR	1
Available to anyone interested	1
Made me think harder but in the end you just don't know for sure	1
Doesn't support parents who decide not to vaccinate	1
Not given by health professionals, obtained myself from NHS Direct	1
Saw but didn't read it	1
Patronising to intelligence of parents	1

Table 1 Parental comments about 'MMR the Facts' leaflet

Comment	**Number of parents making comment**
Biased	6
Needs to be advertised more/ didn't know it existed/ will visit now that I know there's a website	3
Too much heavy information	1
Didn't fully respond to our questions and concerns	1
Can't remember details	1
Should have detailed <u>why</u> research suggested link to autism and then showed why flawed	1

Table 2 Parental comments about NHS/Dept of Health website about MMR

Comment	**Number of parents making comment**
Informative/ gave information needed to make up my mind	32
Can only recommend MMR because following government guidelines/ towed the party line/ pressured by her profession	22
Excellent/ very helpful	21
Reinforced decision to vaccinate/ allayed concern/ reassuring	21
Gave book/ video/ leaflet	17
Showed concern/ understanding	16
Only gave information on one side/ no balanced view	16
No information on single jabs	14
Made me feel empowered as a parent/ it was my decision	13
Dismissed concerns as nonsense/ patronising	11
Useful talking face-to-face/ easy to talk to/ good 2-way discussion	11
Not enough information given/ only very general information	9
Not biased/ was balanced/ very fair	7
No need to discuss because I already knew I would vaccinate	6
If not for health visitor's reassurance I wouldn't have had the MMR/ really changed my opinion	5
Gave advice about separate jabs/ said to get separate jabs ASAP	5
I have come to know her and value her opinion and experience/ already had a trusting relationship with her	5
Wouldn't be drawn into discussion/ not prepared to listen	5
She had no opinion either way	5
Like she was talking from a text book/ programmed	4
Gave her own experience as a parent, which reassured me	4
Said to talk to doctor if concerned	3
Didn't return phone call/ follow up with information as promised	3
Hasn't seen my child in years	3
Advised to wait until child was older	2
Felt I was being bullied	2
Told me 'off the record' she didn't think MMR was safe/ said she wouldn't give her own kids the MMR	2
Knows my views against MMR so doesn't bring it up any more	2
Very unhelpful	1
Sent student around unannounced because I needed to be 'put straight'	1
Had knowledge from scientific evidence but not individual cases	1
Not up to date with research	1
Confusing	1
Did not appreciate input from student health visitor as this was a family decision	1
Like her but wouldn't change my mind just for her	1
Strongly advised to vaccinate	1

Table 3 Parental comments about health visitor

Comment	**Number of parents making comment**
Reassuring/ especially helpful	19
Not independent/ following government policy	17
See mothers as overanxious/ patronising/ uninterested in concerns	10
Spoke as a parent	9
Understanding about concerns/ acknowledged my fears	9
Good advice	8
No advice on single jabs	7
Biased/ alternatives were not offered, discussed or explained/ no information on risks of jab	7
Advised that all children should be vaccinated	6
I trust him, he's always been straight with me/ she's a rock	6
Feel if he could have given separate jabs he would have/ fine about my decision to have separate jabs/ helped give separate jabs	6
Provided useful information to make an informed decision	5
Didn't come across as biased	5
Not enough information	3
2 GPs gave conflicting opinions	3
Took time to answer my questions	3
Told me to vaccinate ASAP because of disease outbreaks	3
Not prepared to listen/ more interested in handing out leaflet	3
Don't trust because government pays doctors to vaccinate	2
No comment on individual children	2
Confirmed what I already knew	2
Said he <u>hasn't</u> had his kids done	2
No pressure felt either way/ sat on the fence	2
Like a robot reading from a text book	1
Should tell parents high risk to others if they don't vaccinate	1
Said boys were at no more risk than girls, which I believe to be untrue	1
Very abrasive and stern	1
Said talk to the health visitor	1
Referred to paediatrician, which was helpful	1
Helpful but I'd already made up my mind	1
Comments were interesting	1
Defensive about MMR	1

Table 4 Parental comments about GP

Comment	**Number of parents making comment**
Gave good and useful information/ very helpful and answered my questions	17
Just following government practice/ towed party line/ just want records to show good uptake	16
Approachable/ ready to listen/ understanding/ non-judgemental	11
Reinforced decision to vaccinate/ made me feel more confident/ reassuring	8
No information on separate vaccinations	4
Brief – a bit of information just before the jab was given	4
Another mother's point of view	4
Dismissive and unhelpful	3
Went to the trouble of printing all the information she could	3
Told us to talk to the doctor or health visitor	3
Objective	2
Respected my decision to get single vaccines	2
Said single vaccines were from abroad and may be unsafe	2
Not well informed, knew less than me as a parent/ Gave wrong information	2
Did not even discuss side effects of MMR	1
Supported my decision to wait until 15 months to immunise	1
My kids and I like the practice nurse	1
Made me feel stupid and irresponsible although I have considered all vaccinations intelligently and thoroughly	1
Recommended MMR when I couldn't talk during a blood pressure test	1
Should tell of high risk if parents don't take the vaccine	1
Gave video	1
Offered single rubella vaccine but offer withdrawn when queried by GP	1
Told me there was more debate about MMR in the 'affluent' South	1
I wasn't told my daughter was given a different form of MMR because the usual one was unavailable, then had to go again a year later because she didn't have enough protection	1
Seemed surprised I was asking for information	1
Said my daughter wouldn't have a second reaction to the vaccine but she did	1

Table 5 Parental comments about practice nurse

Source of information	Number of parents naming source
Private clinic offering separate vaccines (esp. Direct Health 2000)	18
JABS	12
Internet	12
What Doctors Don't Tell You	3
Autistic Society	3
Magazine	1
Sunderland University	1

Comment	Number of parents making comment
Biased/ very difficult to find a balanced position	8
Objective/ more balanced	5
Scary!/ alarmist	4
Tries to make links that aren't proven	3
Told things GP and health visitor hadn't/ have relevant concerns	3
Mostly interested in money for single vaccines/ did not refund the money I had paid them when I decided to have the MMR	2
Probably don't appreciate the public health risks of non-vaccination	2
Tries to make you feel guilty	1
Propaganda patronising	1
No factual information	1
Appreciate that parents have the right to choose	1

Table 6 Named sources of anti-MMR information and parental comments about organisations advising against MMR