

Behavioural determinants of parents' vaccination decisions

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2. Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, Fraser G, Sevdalis N. **Omission bias and vaccine rejection by parents of healthy children: Implications for the influenza A/H1N1 vaccination programme.** Vaccine 2010 Jun 7;28(25):4181-5
3. Brown KF, Long SJ, Athanasiou T, Vincent CA, Kroll JS, Sevdalis N. **Systematic reviews of methodologically disparate data: A practical guide.** In press with Journal of Evaluation in Clinical Practice

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2. Brown KF, Shanley R, Cowley NAL, van Wijgerden J, Toff P, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, Fraser G, Sevdalis N. **Attitudinal and demographic predictors of measles, mumps and rubella (MMR) vaccine acceptance: Development and validation of an evidence-based measurement instrument.** Under review with Vaccine, July 2010.
3. Brown KF, Murphy A, Sevdalis N. **Preparing for the next pandemic: Predicting inexperienced decision-makers' responses to a new vaccine for an unfamiliar infection.** Under review with Health Expectations, July 2010

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5. Brown KF, Sevdalis N, van Wijgerden J, Green J, Hudson MJ, Ramsay M, Vincent CA, Fraser G, Kroll JS. **UK parents' decisions about the measles, mumps and rubella (MMR) vaccine: A qualitative grounded theory study.** Under internal review for submission to Social Science and Medicine.

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3. Brown, KF. **Parental decision-making about childhood immunisations: An example of a 'reluctantly shared decision'.** *Assisting Decision Makers: A workshop meeting.* Psychology Department, University College London. 16 April 2010.
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Departmental seminars and symposia

1. Brown KF, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent C, Fraser G, Sevdalis N. **How do parents prioritise information in vaccine decisions? A multifactorial experimental model** (poster). *Imperial College Graduate School of Life Sciences and Medicine Summer Symposium*, Imperial College London, 9 July 2010. ****WINNER OF NATURE REVIEWS POSTER COMPETITION****
2. Brown KF. **Factors underlying parental decisions about combination childhood vaccinations: A systematic review**. *Clinical Safety Research Unit monthly seminar*, Imperial College London, 22 May 2009.
3. Brown KF. **Helping parents protect their children: Behavioural determinants of parental vaccination decisions**. *Department of Biosurgery and Surgical Technology Research Afternoon*, Imperial College London, 18 December 2008.
4. Brown KF. **Helping parents protect their children: Behavioural determinants of parental vaccination decisions**. *Department of Biosurgery and Surgical Technology weekly seminar*, Imperial College London, 11 February 2008.
5. Brown KF. **Helping parents protect their children: Behavioural determinants of parental vaccination decisions**. *Clinical Safety Research Unit monthly seminar*, Imperial College London, 29 January 2008.

International conference presentations

1. Brown KF, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent CA, Fraser G, Sevdalis N. **Multidimensional omission bias in parents' vaccine decision-making** (oral). *Society for Medical Decision Making conference*, Innsbruck, 30 May-2 June 2010. ****TOP-RANKED ABSTRACT PRESENTED IN PLENARY SESSION****

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3. Brown KF, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent C, Fraser G, Sevdalis N. **How do parents prioritise information in vaccine decisions? A multifactorial experimental model** (poster). *Society for Medical Decision Making conference*, Innsbruck, 30 May-2 June 2010.
4. Brown KF, Sevdalis N, Green J, Hudson MJ, Ramsay M, van Wijgerden J, Fraser G, Kroll JS. **UK parents' decisions about the measles, mumps and rubella (MMR) vaccine: A qualitative grounded theory study** (poster). *European Society of Paediatric Infectious Diseases conference*, Brussels, 9-13 June 2009.
5. Brown KF, Murphy A, Green J, Hudson MJ, Kroll JS, Ramsay M, Fraser G, Sevdalis N. **Experimentally modelling immunisation decisions: The effects of disease, vaccine reaction and health professional factors** (poster). *European Society of Paediatric Infectious Diseases conference*, Brussels, 9-13 June 2009.
6. Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green, Long SJ, Vincent CA, Fraser G, Sevdalis N. **Factors underlying parental decisions about childhood vaccination: A systematic review** (poster). *European Society of Paediatric Infectious Diseases conference*, Brussels, 9-13 June 2009.
7. Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green, Long SJ, Vincent CA, Fraser G, Sevdalis N. **Factors underlying parental decisions about childhood vaccination: A systematic review** (poster). *European Health Psychology Society/British Psychological Society Division of Health Psychology conference*, Bath, 9-12 September 2008.

UK conference presentations

1. Brown KE, Shanley R, Cowley NAL, van Wijgerden J, Toff P, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent CA, Fraser G, Sevdalis N. **The UK MMR catch-up campaign 2008-9: Evaluation in two London Primary Care Trusts** (accepted for poster). *Health Protection Agency conference*, Coventry, 14-15 September 2010.
2. Brown KE, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent C, Fraser G, Sevdalis N. **How do parents prioritise information in vaccine decisions? A multifactorial experimental model** (accepted for oral). *Health Protection Agency conference*, Coventry, 14-15 September 2010.
3. Brown KE, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent CA, Fraser G, Sevdalis N. **Multidimensional omission bias in parents' vaccine decision-making** (accepted for poster). *British Psychological Society Division of Health Psychology conference*, Belfast, 15-17 September 2010.
4. Brown KE, Shanley R, Cowley NAL, van Wijgerden J, Toff P, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent CA, Fraser G, Sevdalis N. **The UK MMR catch-up campaign 2008-9: Evaluation in two London Primary Care Trusts** (accepted for oral). *British Psychological Society Division of Health Psychology conference*, Belfast, 15-17 September 2010.
5. Brown KE, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent C, Fraser G, Sevdalis N. **How do parents prioritise information in vaccine decisions? A multifactorial experimental model** (accepted for oral). *British Psychological Society Division of Health Psychology conference*, Belfast, 15-17 September 2010.
6. Brown KE, Murphy A, Green J, Hudson MJ, Kroll JS, Ramsay M, Fraser G, Sevdalis N. **Experimentally modelling immunisation decisions: The effects of disease, vaccine reaction and health professional factors** (poster). *Health Protection Agency conference*, Coventry, 14-16 September 2009.

7. Brown KF, Sevdalis N, Green J, Hudson MJ, Ramsay M, van Wijgerden J, Fraser G, Kroll JS. **UK parents' decisions about the measles, mumps and rubella (MMR) vaccine: A qualitative grounded theory study** (oral). *Health Protection Agency conference*, Coventry, 14-16 September 2009.
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11. Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green, Long SJ, Vincent CA, Fraser G, Sevdalis N. **Factors underlying parental decisions about childhood vaccination: A systematic review** (poster). *Health Protection Agency conference*, Coventry, 15-16 September 2008.

Grants

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2. Brown KE, Fraser G, Sevdalis N. **Attitudes towards MMR among parents of 3 to 18 year-olds targeted in the MMR catch-up campaign 2008-2009.** *Health Protection Agency Pump-Priming Small Initiatives Fund*. £8153.40, awarded 2 March 2009.

Reports

1. Brown KE, Shanley R, Cowley NAL, van Wijgerden J, Toff P, Kroll JS, Ramsay M, Hudson MJ, Green J, Vincent CA, Fraser G, Sevdalis N. **NHS London MMR catch-up campaign 2008-9: Attitudinal evaluation report.** Submitted 3 March 2010.

Abstract

Childhood immunisation effectively protects personal and public health, but a sizeable minority of parents actively reject vaccines for their children. This Thesis explores how parents decide whether to have their children immunised, in order to inform efforts to improve immunisation uptake.

A consistent profile of beliefs relating to vaccine rejection emerged across a systematic review of existing evidence, a semi-structured interview study (n=24), and two evidence-based questionnaire studies (n=900), which all focused on the measles, mumps and rubella (MMR) vaccine. Vaccine-rejecting parents doubted vaccine safety and efficacy, mistrusted health professionals and immunisation policy, perceived 'pro-vaccine' bias in most available information, believed most vaccine-preventable diseases are mild and uncommon, and were not motivated by the potential social benefits of MMR uptake. The review also indicated several pervasive methodological flaws in the evidence – including retrospective designs, parent-reported outcomes, and lack of multifactorial models – which were remedied in the new empirical work. Three behavioural experiments (n=703) were then used to explore the influence of this belief profile on immunisation decision-making under controlled conditions. These experiments indicated that the belief profile was less influential when decision-makers mistrusted vaccine providers and policy, were generally anxious, or sought to assimilate multiple belief profile factors on the basis of limited information. They also showed that information processing limitations and biases may influence decisions independently of information content, and accordingly written risk communication method was found in the final study (n=42) to impact on outcomes even after adjusting for information content.

These findings indicate that parents' immunisation decisions are typically not borne of simple vaccine versus disease risk-benefit analyses. Interventions to increase trust in the immunisation system and to communicate the social desirability (and normality) of vaccine acceptance may improve immunisation uptake and support informed, satisfying decision-making.

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1 General introduction

1.1 Childhood immunisation in the UK: An overview of the context in which parents make their decisions

Children in the UK are recommended to receive a comprehensive programme of immunisations in their first five years of life (Department of Health, 2010). This programme comprises six different vaccines given across twelve separate injections (as most vaccines require multiple doses to ensure immunity). These injections are typically given across six appointments, with between one and three separate injections at each visit. The programme protects against ten diseases in total. The UK preschool immunisation schedule is shown in Table 1.1.

Table 1.1: UK preschool immunisation schedule 2006-present

Age	Vaccines given	Diseases protected against
2 months	DTaP/IPV/Hib (dose 1) PCV (dose 1)	Diphtheria + Tetanus + Pertussis (whooping cough) + Polio + Haemophilus influenzae type b Pneumococcal infection
3 months	DTaP/IPV/Hib (dose 2) MenC (dose 1)	Diphtheria + Tetanus + Pertussis + Polio + Haemophilus influenzae type b Meningococcal disease type C
4 months	DTaP/IPV/Hib (dose 3) PCV (dose 2) MenC (dose 2)	Diphtheria + Tetanus+ Pertussis + Polio + Haemophilus influenzae type b Pneumococcal infection Meningococcal disease type C
12 months	Hib/MenC (dose 1 in this combination, doses 4 and 3 for each disease respectively)	Haemophilus influenzae type b + Meningococcal disease type C
13 months	MMR (dose 1) PCV (dose 3)	Measles + Mumps + Rubella Pneumococcal infection
3 years and 4 months	MMR (dose 2) DTaP/IPV (dose 1 in this combination, dose 4 for these diseases)	Measles + Mumps + Rubella Diphtheria + Tetanus + Pertussis + Polio

In addition to these vaccines which are recommended for all children (except those with relevant contraindications), a programme of selective immunisations is also in place for children at particular risk of specific diseases, due for example to their own health status, presence of disease (or problems fighting disease) in their immediate family, or high disease incidence in their place of birth. This selective programme includes immunisations for hepatitis B, tuberculosis and seasonal influenza. Further, during the course of this programme of research, a vaccine for 2009 A/H1N1 influenza (swine flu) was recommended to all children between 6 months and 5 years old (Department of Health, 2009). This decision was made in response to the increased risk of hospitalisation due to swine flu infection for this age group. Outside of the NHS, a number of vaccines for preschool children are available, at a price, through private providers. These include individual components of the combination vaccines available on the NHS (i.e. separate diphtheria, tetanus, polio, measles and rubella vaccines), vaccines available only to children defined as at-risk within the NHS selective immunisation programmes (e.g. hepatitis B and tuberculosis vaccines), and vaccines not currently given to children within the NHS (e.g. chicken pox vaccine).

The UK routine childhood immunisation schedule began in 1940, when the diphtheria vaccine became the first to be centrally funded by UK Government (Mortimer, 2010). A timeline of the introduction of vaccines by disease is shown in Figure 1.1 (based on information from the Green Book; Department of Health, 2010). Other changes to the schedule have included shifts in the age at which vaccines are administered, moves from live to inactivated vaccines, introduction of more effective conjugated and adjuvanted vaccines, and use of multivalent and combination vaccines which protect against several strains of the same disease, or against more than one disease, in a single injection. Currently, the UK schedule is set by the Department of Health, on the basis of independent scientific advice from the Joint Committee on Vaccination and Immunisation (JCVI). The JCVI is a board of experts and laypersons concerned with evaluating evidence on the prevalence and

severity of infectious diseases, and the efficacy, safety and cost of vaccines, in order to make recommendations on whether and how the schedule should respond to infectious disease threats (Department of Health, 2010). It was formed in 1963 to advise on polio immunisation (Hall, 2010), and has been pivotal in every major change to the UK immunisation schedule since.

Figure 1.1: Timeline of introduction of vaccines to UK routine childhood immunisation schedule

Year	Vaccine introduced to protect against...
1940	Diphtheria
1956	Polio
1957	Pertussis
1961	Tetanus
1968	Measles
1988	Mumps, rubella
1992	Haemophilus influenzae Type b
1999	Meningococcal disease type C
2006	Pneumococcal infection

Whilst practice nurses and GPs administer vaccines, and GP practices or Primary Care Trusts write to parents to advise them when their child is due to attend for an immunisation, these sources tend not to provide information to parents unless it is specifically requested (Redsell and Bedford, 2010). Most parents receive information about immunisation from their health visitor or from Department of Health (DH) leaflets (Bedford & Lansley, 2006). A number of DH information leaflets about preschool immunisation are available, though perhaps the most comprehensive is 'A guide to immunisations up to 13 months of age' (Department of Health, 2007). This leaflet summarises the immunisation schedule and provides general information about immunisation including how vaccines work, basis for the schedule (including evidence on vaccine timing, safety and efficacy), contraindications, and common side effects and how to treat them. The leaflet also provides

information about the symptoms, prevalence and transmission methods of each of the diseases protected against with the routine schedule, and any specific contraindications and side effects for each vaccine. Information on vaccines in the selective schedule, plus some basic advice on travel vaccines, is also provided.

Parents may also seek advice and information from 'non-official' sources, including the media, websites, and friends or family. The accuracy of information from these sources is questionable, and online and media information may be more concerned with rhetoric than with education (Keelan, Pavri-Garcia *et al*, 2007; Leask, Chapman *et al*, 2002; Wolfe, Sharp *et al*, 2002; Hargreaves, Lewis *et al*, 2003; Guillaume & Bath, 2008). Practitioners of alternative or complementary medicine, or in clinics providing immunisations on a private basis, may also provide information which conflicts with the official DH view. Immunisation rates are lower among parents who take information from these 'non-official' sources than among parents who use information from DH leaflets and NHS practitioners (Cassell, Leach *et al*, 2005; MacDonald, Henderson *et al*, 2004; Bedford & Lansley, 2006). However, the cross-sectional design of most studies exploring this precludes assessment of the causality of this relationship.

1.2 Childhood immunisation uptake and vaccine-preventable disease incidence in the UK: How big is the problem?

Immunisation against contagious diseases has been credited with making a greater contribution to public health than any other intervention except the provision of clean water (Plotkin & Plotkin, 2008). Immunisation prevents disease via two routes: personal immunity, whereby immunised people exposed to infection mount an immune response destroying that infection before it makes

them seriously ill or is transmitted to others around them; and herd immunity, whereby non-immune people (e.g. those who choose not to immunise, who cannot be immunised, or for whom immunisation fails) are less likely to be exposed to infection because of this reduced transmission in their population (Fine, 1993). Accordingly, when either of these routes to disease prevention is compromised, so is the efficacy of immunisation in protecting the health of the population.

The proportion of the population which must be immunised in order to confer herd immunity varies by a combination of disease and environmental factors, including the contagiousness of the disease, the number of susceptible people, and the frequency and duration of contact between them (Fine, 1993). For example, 75-86% vaccine coverage may confer herd immunity for a less contagious infection like mumps, but for a more infectious disease like pertussis 92-94% coverage is required (Fine, 1993), and these thresholds may be higher in densely populated areas. On this basis, the World Health Organization (WHO) has set a global objective of $\geq 90\%$ national coverage with their recommended immunisation schedule by 2010 (World Health Organization, 2005). In line with Europe-specific WHO guidance (WHO Regional Office for Europe, 1996), the Department of Health (DH) has set a UK target of $\geq 95\%$ uptake for three doses of DTaP/IPV/Hib vaccine (preventing diphtheria, tetanus, pertussis, polio and Haemophilus Influenzae type B) in the first year of life and for one dose of MMR vaccine (preventing measles, mumps and rubella) in the second year of life (Department of Health, 2009).

These DH targets are currently unmet, as UK coverage in 2008-9 was below 95% for every childhood immunisation in the schedule (NHS Information Centre, 2009). Ninety-three per cent of UK children had received 3 DTaP/IPV/Hib doses by 12 months, and 86% of UK children had received 1 MMR dose by 24 months. Vaccine uptake is lower in England than in the other UK countries, as Scotland, Wales

and Northern Ireland attain 96-97% for 3xDTaP/IPV/Hib by 12 months and 88-92% for 1xMMR by 24 months, whilst England attains 92% and 85% respectively). Within England, particularly low coverage is observed in London (83% for 3xDTaP/IPV/Hib by 12 months and 76% for 1xMMR by 24 months), which skews the countrywide mean, though no English region exceeds 88% uptake for 1 MMR dose by 24 months. Receipt of 1 MMR dose by 24 months in England has remained at or below the current level of 85% for almost a decade having slumped from a high of 92% in 1995-1997 (Health Protection Agency, 2005) to an historic low of 80% in 2003-2004 (NHS Information Centre, 2009). In England only 78% of children receive the recommended two MMR doses by age 5 (NHS Information Centre, 2009). That rates of receipt of the full two-dose MMR programme are over ten percentage points lower than rates of receipt of the full three-dose DTaP/IPV/Hib programme indicates that MMR vaccine may be perceived differently to other vaccines by parents. Reasons why MMR may be a 'special case' are outlined in sections 1.3 and 1.4.

Low vaccine coverage leaves the UK population at risk of disease outbreaks and epidemics. Measles is a particular problem, as low MMR uptake has persisted for many years and measles is a highly infectious disease (Jansen, Stollenwerk *et al*, 2003; Jick & Wilcox Hagberg, 2010). In 2009, 1144 cases of measles were confirmed in England and Wales, in comparison with 92 cases a decade earlier. 2006 and 2008 saw the first deaths from acute measles infection since 1992 (Health Protection Agency, 2010), both in unimmunised teenagers with underlying health problems. Because the outcomes of vaccine-preventable diseases can be so severe, improving uptake remains high on the child health agenda (Department of Health and Department for Children, Schools and Families, 2009; The Conservative Party, 2010).

1.3 Understanding and improving suboptimal immunisation uptake

Qualitative and quantitative research seeking to identify factors underpinning suboptimal immunisation uptake, and to quantify their prevalence and influence (Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002; Gardner, McAteer *et al*, 2008) has identified two broad mechanisms through which children do not receive vaccines: ‘passive default’ borne generally of practical barriers; and ‘active resistance’ borne generally of anti-vaccine beliefs (Fitzpatrick, 2004). Although this evidence base provides little concrete guidance on the relative influence of the many factors identified to impact on immunisation receipt (as discussed in Chapter 2), it has informed a substantial number of interventions aimed at improving uptake (National Institute for Health and Clinical Excellence, 2009; Briss, Rodewald *et al*, 2000).

The practical barriers which underpin passively defaulted immunisation include forgetting to make or attend appointments, not being registered with an immunisation provider, struggling to obtain an appointment, being unable to travel to an immunisation provider, or being unable to take time off work to attend the appointment (Mills, Jadad *et al*, 2005; Tickner, Leman *et al*, 2006). Interventions to overcome these barriers, both at parent and service provider level, have generally been successful in increasing uptake (Briss, Rodewald *et al*, 2000). For example, reminding parents to make or attend appointments, typically via post or phone, has been shown to increase uptake of routine childhood immunisations by 2-34% (Szilagyi, Bordley *et al*, 2000; Jacobson-Vann & Szilagyi, 2005); and reducing the financial burden of immunisations or improving access to healthcare boosted uptake of immunisation in general by up to 29% and 7% respectively (Shefer, Briss *et al*, 1999). Reminders for clinicians, often through automated alerts on their computer systems, also work well, improving uptake by up to 67% (Shefer, Briss *et al*, 1999).

The applicability of this evidence base to the UK is, however, questionable. Firstly, most studies evaluating passive default interventions have been conducted in the US. The few UK interventions designed to reduce passive default on MMR have shown no effect on uptake (Gardner, McAteer *et al*, 2008). Secondly, and perhaps most importantly, suboptimal uptake of preschool vaccines in the UK is a product of parents' active resistance, as opposed to passive defaulting, in around one-half of cases not immunised with the primary schedule vaccines and three-quarters of cases not immunised with MMR dose 1 (Samad, Butler *et al*, 2006; Pearce, Law *et al*, 2008), therefore interventions to address practical barriers are perhaps unlikely to substantially improve UK vaccine uptake, particularly in the case of MMR.

Interventions addressing parents' active resistance to immunisation have typically focused on education and information (Briss, Rodewald *et al*, 2000; Shefer, Briss *et al*, 1999): for example, informing parents of the prevalence and severity of a disease, or the safety and efficacy of a vaccine. Most of these educational interventions have been implemented alongside practical barrier-reducing schemes, and such dual-approach interventions have increased uptake by up to 29%; however, the multi-component nature of these programmes make it difficult to partial out the independent effects of education on immunisation uptake (Briss, Rodewald *et al*, 2000; Shefer, Briss *et al*, 1999). Where education has been provided without other intervention, positive effects on immunisation intentions have been small and largely non-significant; this alongside the sizeable effects attributable to practical barriers interventions suggests that educational interventions add little value. However, it is not clear to what extent the intensity of contact involved in multi-component interventions boosts their efficacy, beyond the effect attributable to program content. Again, most of this material is from the US, and UK interventions to reduce active resistance to immunisation (most in the context of MMR) are sparse. Most studies have evaluated only intervention acceptability rather than impact on uptake, though one study which provided

information and facilitated parent discussion groups observed an increase in uptake (Gardner, McAteer *et al*, 2008).

Furthermore, the evidence base underpinning interventions both for passive default and for active resistance has a number of methodological limitations and is unable to assess empirically the key independent predictors of uptake on which interventions should focus (see Chapter 2), and the evaluation of interventions based on that evidence base is also inadequate to inform policy.

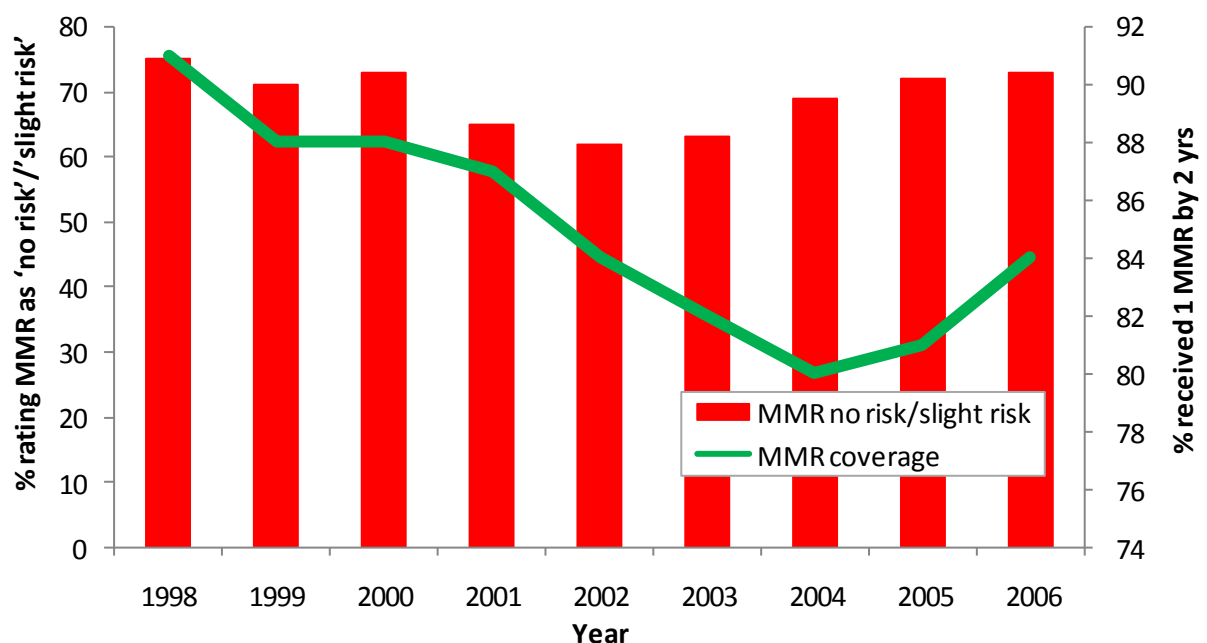
Research to clarify the relative importance of predictive factors, and the development of tools with which to robustly evaluate interventions is required.

1.4 The role of immunisation controversies

Rates of MMR non-immunisation in particular reflect the prevalence of parental concerns about the safety of this vaccine; as shown in Figure 1.2 and Figure 1.3, which plot data from regular Department of Health surveys of parents' attitudes toward aspects of the immunisation process (Smith, Yarwood *et al*, 2007) against Health Protection Agency COVER programme MMR uptake data (NHS Information Centre, 2009). These concerns peaked following extensive media coverage (Hargreaves, Lewis *et al*, 2003; Guillaume & Bath, 2008) of a purported link between MMR and autism/bowel symptoms. The first (and only) peer-reviewed publication which implied this link reported that, in a case study sample of 12 children, developmental/behavioural abnormalities and bowel symptoms followed receipt of MMR vaccine, but concluded that further research was required to ascertain any causal link (Wakefield, Murch *et al*, 1998). In a press release for the paper, lead author Dr Wakefield expanded on this conclusion by recommending (despite his published data offering no grounds for his assertion) that parents should reject MMR vaccine in favour of separate

measles, mumps and rubella vaccines (Elliman & Bedford, 2007). The MMR-autism link has since been consistently disproven (Elliman & Bedford, 2007, DiStefano, 2007) and the paper originally suggesting the link has been retracted (The Editors of the Lancet, 2010). Further, Dr Wakefield has been struck from the General Medical Council (GMC) register following a GMC ruling that he acted unethically (Triggle, 2010; General Medical Council, 2010). However, the post-MMR controversy recovery is proving a slow process, as described in Section 1.2. The focus on a specific, greatly feared potential side effect (autism), the extensive media coverage of this purported link, and the availability of alternatives, are factors specific to MMR vaccine among other vaccines in the UK schedule, and for this reason, parents' decisions about MMR may be quite different from their decisions about other vaccines (Tickner, Leman et al, 2007).

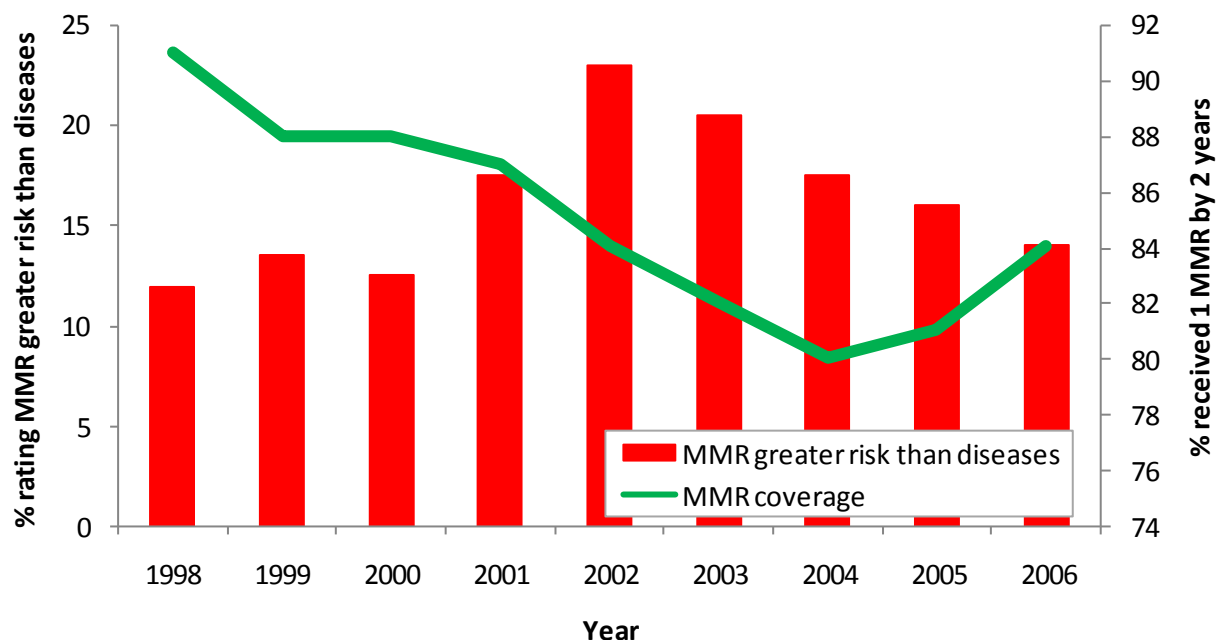
Figure 1.2: MMR coverage and parents' beliefs about MMR safety (HPA and DH data)



Controversy around an immunisation, sparked by a scientific publication and propagated by a slew of media coverage, is not a phenomenon unique to MMR. In 1974, a study of 36 cases was published by a group of clinicians at Great Ormond Street Hospital linking the DTP (diphtheria-tetanus-pertussis) vaccine with severe neurological complications (Kulenkampff, Schwartzman *et al*, 1974).

Newspaper and television reports of “vaccine-damaged” children followed, and DTP uptake fell from 77% to 33%, resulting in disease epidemics and deaths (Griffith, 1989; Baker, 2003). Uptake recovered in the late 1980s following a number of failed legal challenges, a shift in the media’s focus from vaccine damage to disease damage (Baker, 2003), and the Government’s decision to release an evidence-based risk estimate for permanent neurological injury (1 in 310,000).

Figure 1.3: MMR coverage and parents’ beliefs about MMR risk vs disease risk (HPA and DH data)



Further, immunisation controversy is not a modern phenomenon in the UK. Arguably the most intense public uproar around an immunisation programme came in response to compulsory smallpox vaccination of children in the mid 1800s (Wolfe, 2002), with financial or custodial penalties for non-immunising parents. This controversy stemmed in part from safety fears and scepticism around the efficacy of the vaccine, but mainly from the public’s displeasure at the state’s intrusion into what had hitherto been a personal decision. Such was the strength of public opposition that by the end of the 19th century the Government relaxed the penalties for non-immunisation and

introduced a conscience clause allowing parents to opt out of immunisation on the grounds of safety or efficacy concerns.

Even in the absence of high-profile controversies like those outlined above, the interaction between immunisation uptake, disease incidence and vaccine adverse events results in natural fluctuations in uptake over time (Chen & Orenstein, 1996). When an immunisation is first introduced, uptake is low and disease incidence is high; and in the absence of safety concerns (i.e. vaccine adverse events) uptake will increase steadily. However, as the number of individuals receiving the vaccine increases, so does the number reacting unfavourably to it, increasing concerns over safety. These concerns, coupled with a perceived lack of susceptibility to the disease (due to the vaccine having significantly decreased incidence rates), result in a fall in vaccine uptake. This fall causes disease incidence to increase once more, and vaccine adverse events become less common as fewer people receive the vaccine; therefore the vaccine is once again perceived as safe and necessary and uptake climbs accordingly. This cycle can continue indefinitely, ending only when the disease is eradicated and the immunisation program is ended.

High-profile controversies and the natural ebb and flow of demand for vaccine undoubtedly influence which factors are most salient to immunisation decision-making populations. The salience and processing of information around these factors, however, may vary independently of this, at individual level. Experimental psychology offers insights into the contribution of information processing to immunisation decisions.

1.5 Cognitive biases and immunisation decision-making

In addition to qualitative and quantitative research identifying and assessing the influence of specific factors on parents' behaviour around childhood immunisation, a number of experimental studies have homed in on the way in which biases in the processing of information relevant to these factors can further impact upon vaccine decisions. Many of the factors which have been shown to influence parents' vaccine decisions are inherently uncertain. For example, a child may or may not have an adverse reaction to a vaccine, and they may or may not catch the disease against which the vaccine protects. When decision-makers are faced with probabilistic risks like these, rather than with definite risks (e.g. certainty that without a particular treatment a patient will die), they may apply a number of unconscious biases to their 'reading' of the information, which can impact upon their decisions (Kahneman, Slovic *et al*, 1982; Kahneman & Tversky, 1979, Serpell & Green, 2006).

Relevant biases include:

- **Omission bias** (Ritov & Baron, 1990; Connolly & Reb, 2003, Wroe, Bhan *et al*, 2005): Decision-makers consider ill effects from their own action (e.g. accepting a vaccine and having an adverse reaction to it) to be worse than ill effects from their inaction or from "fate" (e.g. not taking the vaccine and catching the disease), perhaps because they anticipate greater regret will arise from the former than from the latter
- **Ambiguity aversion** (Meszaros, Asch *et al*, 1996; Ritov & Baron, 1990): Decision-makers prefer to withhold action when they believe or are told that a vital piece of information is missing, even when that information is presently impossible to obtain

- **Loss aversion** (Abhyankar, O’Conner *et al*, 2008; Baron & Ritov, 1994; Kahneman & Tversky, 1979): Decision-makers prefer to avoid a loss rather than to make a gain of the same size, therefore they avoid risks to retain good outcomes and take risks to avoid poor outcomes
- **Availability heuristic** (Tversky & Kahneman, 1982): Decision-makers estimate uncertain probabilities based upon the ease with which they can bring perceived trustworthy examples of each outcome to mind

Psychological research in the past 30 years has shown that these factors can affect human decision-making in a range of situations (Kahneman, Slovic *et al* 1982; Baron, 2008). To date, however, little ecologically valid, methodologically sound research has addressed the presence and impact of these cognitive biases in the thinking processes of parents deciding whether to have their children immunised.

1.6 Introduction summary

This Introduction chapter has briefly summarised the context in which UK parents make their immunisation decisions, in terms of the immunisation schedule and available information about immunisation, the controversy around MMR and the natural fluctuations in vaccine demand as a function of reduced disease prevalence, and the interventions which have been implemented to facilitate and encourage immunisation uptake. It has also shown the extent and consequences of suboptimal immunisation coverage in the UK, which perhaps demonstrates that current efforts to understand and change parents’ decisions to reject (or inability to access) immunisation, particularly in the case of MMR vaccine, have been only partially successful. Finally, it has indicated a possible role for parents’ flawed or biased processing of information during immunisation decision-making.

These factors in combination indicate a number of directions for this programme of PhD research. Conceptual and methodological gaps in the evidence around influences on parents' immunisation decision-making need to be identified and rectified, in order to improve our understanding of (and ability to intervene upon) parental rejection of immunisation. If as suspected MMR decisions are shown to be strongly influenced by factors not relevant to many other vaccine decisions, given the currently unique set of circumstances surrounding MMR, immunisation decisions made on the basis of closely controlled information may provide generalisable insight into decision influences and the role of information processing biases and limitations. Finally, methods to intervene at the level of information processing should be explored. In line with these research directions, the specific aims of my PhD research programme are shown below.

1.7 Thesis Aims

1. To describe the factors found by qualitative and quantitative research to inform parental decisions about combination vaccinations (Chapters 2 and 3)
2. To identify gaps and weaknesses in this knowledge base and to devise remedies for them (Chapters 2, 3 and 4)
3. To determine predictors of behavioural, cognitive and affective immunisation decision outcomes (Chapters 4,5,7 and 8)
4. To assess the presence and impact of information processing biases and limitations in immunisation decisions (Chapters 5, 6 and 7)
5. To explore interventions to improve immunisation uptake in light of identified factors and biases (Chapter 8)

2 Factors underlying parental decisions about combination childhood vaccinations including MMR: A systematic review

2.1 Introduction

Decisions to reject childhood immunisations are rooted in complex belief structures, and by understanding and modifying these beliefs it may be possible to influence decisions, thereby improving uptake. To this end, many studies have examined parental beliefs about childhood vaccinations (Tickner, Leman *et al*, 2006; Serpell & Green, 2006; Nagaraj, 2006; Sturm, Mays *et al*, 2005). Studies have been conducted in numerous countries, with various vaccines, and differing vaccination policies and vaccine-preventable disease prevalence. Further, these studies span several decades, taking in multiple vaccine scares and disease outbreaks.

To impact significantly on the conduct of policymakers, parents, practitioners and researchers, this existing large body of evidence must be rendered accessible using objective methods. There are no up-to-date, systematic reviews of parental beliefs about and attitudes toward childhood vaccination suitable to inform local or national interventions to improve vaccine uptake. Narrative reviews identify a number of factors which may influence vaccine uptake, including practical barriers to and facilitators of uptake, media and lay representations of disease and vaccination, and trust in healthcare providers (Tickner, Leman *et al*, 2006; Serpell & Green, 2006; Douglas, 2000; Hinman, 1991). Three systematic reviews identify commonalities in the evidence base which generally support the conclusions of narrative syntheses, however their methodologies and scopes limit their suitability to inform current policy and practice (Nagaraj, 2006; Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002). The most recent of these (Nagaraj, 2006) reports research on parental beliefs only as a small component, and comprises both empirical and anecdotal evidence about the views of parents and health professionals. A slightly older review (Mills, Jadad *et al*, 2005) considers only qualitative studies reporting barriers to uptake of the entire vaccine schedule. These studies

may not be generalisable to a specific vaccine, because uptake varies by vaccine (UNICEF and World Health Organisation, 2009), which suggests that parents may not make decisions about the entire vaccine schedule, but rather about individual vaccines. The oldest review (Roberts, Dixon-Woods *et al*, 2002) used Bayesian meta-analysis to calculate the influence of various factors on vaccine uptake, but incorporated only studies published to July 1999 – predating the MMR controversy which took hold in the UK around the turn of the century (Anderberg, Chevalier *et al*, 2008).

This review aims to identify and synthesise evidence on which factors underpin decisions about combination vaccines (which protect against more than one disease in a single shot). Combination vaccines have been selected because it is “inevitable” (Bar-Zeev & Buttery, 2006) that more vaccines will be offered in combination rather than separately in the future (Rabinovich, McInnes *et al*, 1994; Falk & Ball, 2001), and because combination-specific concerns may play a key role in parents’ decisions and behaviour (as indicated by some parents’ willingness to pay for separate measles, mumps and rubella vaccines) but the extent to which these concerns are addressed in the literature is unclear.

2.2 Method

2.2.1 Search strategy and selection criteria

MedLine (including In-Process & Other Non-Indexed Citations), PsycINFO, EMBASE, Maternity and Infant Care, and International Bibliography of the Social Sciences were searched through Ovid. Reference lists of seminal articles and contents lists of appropriate journals were scrutinised, and unpublished literature and non-journal publications from relevant agencies were sought.

Keywords and MeSH terms were generated around four facets dictated by the review question: parent, decision, child and vaccine. Terms were first harvested from relevant papers (including previous reviews), and then supplemented through thesaurus checking and discussion within the research team. The search was limited to abstracts and titles of papers published in English between 1987 and January 2008, using human samples, with abstracts available. A sensitivity checking procedure was implemented whereby a set of known relevant papers was sought within the retrieved records, with the search modified to retrieve any articles conspicuously absent (and others similarly catalogued). In this way, hand searching informed, and was incorporated into, the search strategy. The final search strategy was run on 24th January 2008. The full listing of search terms and strategies is shown in Figure 11.1 in Chapter 11 (Appendices).

All articles retrieved by the search were assessed according to a number of inclusion criteria. Included studies were required to present empirical data, to focus on routine childhood vaccinations (e.g. not catch-up programmes, adolescent vaccinations, specific population groups), to present vaccine uptake data and link this directly to factors underlying uptake (i.e. within individual participants or groups of participants), to present parent-reported barriers to uptake or parents' cognitive/emotional appraisal of vaccination (not demographics or knowledge only, and not barriers derived from medical records or other health professional opinion), to present data collected in a developed country (countries ranked "high" or "medium" in UN Human Development Index 2007/2008 (United Nations Development Programme, 2008)), and to focus on one or more explicitly identified combination vaccinations (not the vaccine schedule as a whole). One reviewer applied the criteria to all abstracts, with a subset of 100 checked by a blinded second reviewer. There was an acceptable level of agreement between reviewers, with a Kappa score of 0.71 ($p < 0.001$).

Discrepancies were resolved through discussion, resulting in the progression to the next stage of all

abstracts with discordant decisions. At this stage, full papers for all possibly relevant abstracts were retrieved and all inclusion criteria re-applied to these papers.

Of the 440 articles identified, 136 abstracts appeared potentially relevant; full papers were retrieved for further screening. Of these, 105 papers were further excluded according to the criteria detailed above, leaving 31 – three of which (Hilton, Petticrew *et al*, 2007; Hilton, Petticrew *et al*, 2006; Hilton, Hunt *et al*, 2007) reported different elements of data from the same sample – eligible for inclusion in the review (Table 2.1). A flowchart of progress through the study inclusion process is shown in Figure 2.1.

Table 2.1: Methodological and participant characteristics of studies

Reference	Location	Year data collected	Sample size†	Methodology	Mothers or fathers	Comparison or cohort*	Demographics	Vaccine	Retrospective or prospective	Uptake measure	Quality score‡
Alfredsson (2004)	Gothenburg, Sweden	1999	118 (68 / 50)	Quantitative: postal q'aire	Parents (% mothers not specified)	Comparison	City	MMR	Retrospective	Objective	10 / 22
Bardenheier (2004)	US (nationwide)	2001	2315 (1299 / 1016)	Quantitative: telephone q'aire	Mothers (unclear)	Comparison	Not reported	MMR (or MCV) and DTaP (or DTP)	Retrospective	Objective	10 / 22
Binkin (1994)	Seven regions in Italy	1992-3 (unclear)	895	Quantitative: Face-to-face structured interview	Mothers	Cohort: Unvaccinated	Not reported	Measles and DT	Mixed (parents of children 12-23 months)	Not clear, probably subjective	2 / 10
Bond (1999)	Melbourne, Australia	1997	1779 (1494 / 285)	Quantitative: postal q'aire	Parents (% mothers not specified)	Comparison	Metropolitan districts	MMR	Retrospective	Mainly subjective (87% cases)	12 / 22
Casiday (2006a)	Durham, UK	2002-2004	87 (56 / 31)	Qualitative: 3 focus groups, 71 individual interviews	77 mothers, 10 fathers	Comparison	Mixed	MMR	Mixed (82/87 had acted or had intention, 5 undecided)	Subjective	11 / 22, 13 / 22
Casiday (2006b)	Durham, UK	2004	996 (889 / 103) 4 missing	Quantitative: postal q'aire	93.6% mothers	Comparison	Mixed (higher than average in PCT)	MMR	Retrospective	Subjective	8 / 22
Casiday (2007)	Cambridge & Durham, UK	2002-2004	87 (56 / 31)	Qualitative: 3 focus groups, 71 individual interviews	77 mothers, 10 fathers	Comparison	Mixed	MMR	Mixed (82/87 had acted or had intention, 5 undecided)	Subjective	11 / 22, 13 / 22
Cassell (2006)	Brighton and Hove PCT, UK	2004	452 (258 / 193) 1 missing	Quantitative: postal q'aire	Mothers	Comparison	MMR uptake lower than in UK as whole (69 vs 86%)	MMR	Retrospective	Objective	8 / 22
Dannetun (2005)	Ostergotland Sweden	2003	173	Quantitative: telephone q'aire	Parents (% mothers not specified)	Cohort: Unvaccinated	Not reported	MMR	Retrospective	Objective	2 / 10
Evans (2001)	Avon and Gloucs, UK	1998-2001 (unclear)	48 (Unclear / Unclear)	Qualitative: focus groups	43 mothers, 5 fathers	Comparison	Not reported	MMR	Retrospective	Unclear (probably objective)	15 / 22
Flynn (2004)	Brighton & Hove, UK	1999-2001 (unclear)	511 (397 / 114)	Quantitative: postal q'aire	94.2% mothers	Comparison	Not reported	MMR	Prospective	Objective	14 / 22

Reference	Location	Year data collected	Sample size†	Methodology	Mothers or fathers	Comparison or cohort*	Demographics	Vaccine	Retrospective or prospective	Uptake measure	Quality score‡
Gellatly (2005)	Edinburgh, UK	2003-2004	110 (80 / 30)	Quantitative: self-administered q'aire (postal?)	Parents (% mothers not specified)	Comparison	Mixed	MMR	Retrospective	Subjective	6 / 22
Hilton (2007a)	Scotland, UK	2002-2003	72 (51 / 21)	Qualitative: focus groups	64 mothers, 8 fathers	Comparison	Mixed	MMR and DTaP/IPV /Hib	Retrospective	Unclear (probably objective)	14 / 22
Hilton (2006)	Scotland, UK	2002-2003	72 (51 / 21)	Qualitative: focus groups	64 mothers, 8 fathers	Comparison	Mixed	MMR and DTaP/IPV /Hib	Retrospective	Unclear (probably objective)	12 / 22
Hilton (2007b)	Scotland, UK	2002-2003	72 (51 / 21)	Qualitative: focus groups	64 mothers, 8 fathers	Comparison	Mixed	MMR and DTaP/IPV /Hib	Retrospective	Unclear (probably objective)	12 / 22
Impicciatore (2000)	6 districts in Italy	1997	1035 (441 / 594)	Quantitative: face-to-face q'aire	Mothers	Comparison	Mixed	MMR	Retrospective	Subjective	8 / 22
Jones (1992)	Australia	1989	171	Quantitative: face-to face and telephone interviews	Parents (% mothers not specified)	Cohort: Unvaccinated	Inner-city	DTP+OPV and MMR	Retrospective	Subjective (objective checks "where possible")	0 / 10
Lawrence (2003)	Australia (nationwide)	2001	506	Quantitative: telephone q'aire	Parents (% mothers not specified)	Cohort: Unvaccinated	Mixed	MMR	Retrospective	Objective	4 / 10
Lewis (1988)	Utah, US	1986	2029 (1410 / 619)	Quantitative: postal q'aire	Parents (% mothers not specified)	Comparison	Not reported	DTP	Retrospective	Subjective	6 / 22
Lieu (1994)	California, US	1992-1993	167	Quantitative: postal q'aire	Approx. 95% mothers	Cohort: Vaccinated	80% white practice	DTP	Retrospective	Objective	2/10
MacDonald (2004)	Scotland, UK	2001	278 (157 / 121)	Quantitative: postal q'aire	Parents (% mothers not specified)	Comparison	Not reported	MMR and DTP	Retrospective	Objective	6 / 22
McMurray (2004)	Leeds, UK	2002-2003	69 (52 / 17)	Qualitative: individual interviews	64 mothers, 5 fathers	Comparison	Mixed	MMR	Retrospective	Subjective	14 / 22
Murphy (1994)	Dublin, Rep. Ireland	1991	102	Quantitative: face-to-face, interviewer administered q'aire	Parents (% mothers not specified)	Cohort: Unvaccinated	Mixed	MMR	Retrospective	Objective on 75/102, rest subjective	0/10

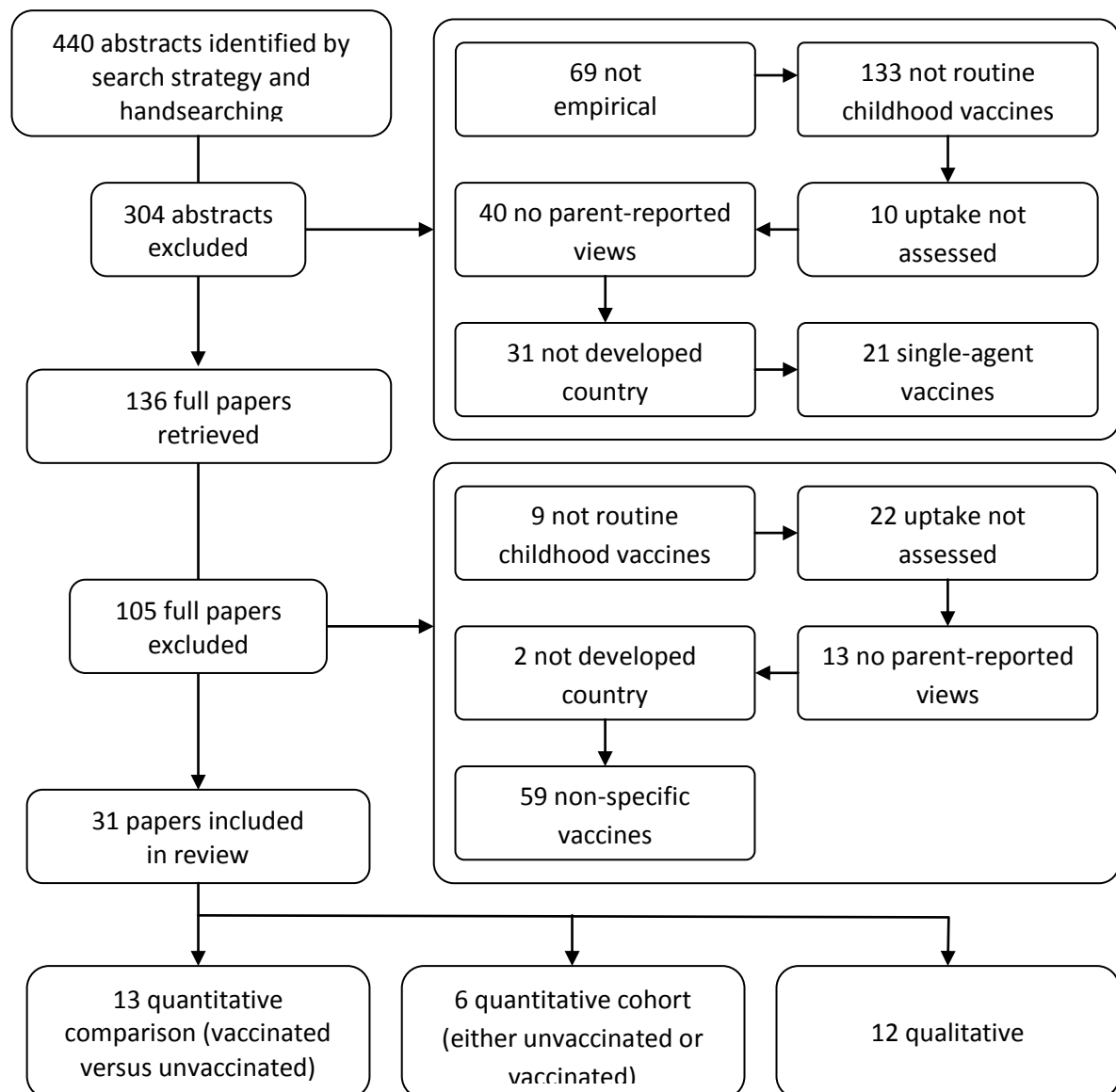
Reference	Location	Year data collected	Sample size†	Methodology	Mothers or fathers	Comparison or cohort*	Demographics	Vaccine	Retrospective or prospective	Uptake measure	Quality score‡
New (1991)	Salford and Lancaster, UK	1988	242 (123 / 119)	Qualitative: structured individual interviews	Mothers (though fathers also present at “some” interviews)	Comparison	Lancaster – mixed urban and rural, higher than average uptake; Salford, inner-city, lower than average uptake	DTP/ Polio	Retrospective	Objective	6 / 22
Petrovic (2003)	North Wales, UK	1998	230 (155 / 75)	Quantitative: postal q’aire	Parents (% mothers not specified)	Comparison	Not reported	MMR-2	Retrospective	Objective	8 / 22
Petts (2004)	West Midlands, UK	2002	64 (Unclear / Unclear)	Qualitative: focus groups	Mainly mothers (one group fathers)	Comparison (“intenders” and “have-dones” vs “Not yet decideds”)	“Take up rates consistent with the national average”	MMR	Mixed (“have-dones” = retrospective; “intenders”, “not yet decideds” = prospective)	Subjective	7 / 22
Poltorak (2005)	Brighton, UK	2003	23 (12 / 11)	Qualitative: focus groups and individual interviews	Mothers	Comparison: (Vaccinated includes “intenders”)	Low MMR uptake city. Mixed SES (sampled from deprived and affluent areas)	MMR	Mixed (“have-dones” = retrospective; “intenders”, “not yet decideds” = prospective)	Subjective	7 / 22, 9 / 22
Smailbegovic (2003)	Hackney, UK	2000-2003 (unclear)	10	Qualitative: individual interviews	Mothers	Cohort: Vaccinated	Not reported	MMR	Retrospective	Objective	4 / 22
Tickner (2007)	Southern England	2005-2006	22 (19 / 3)	Qualitative: semi-structured, individual, face to face	21 mothers, 1 father	Comparison	All white British, 50% with degree	DTaP/IPV /Hib	Mixed	Subjective	17 / 22
Trauth (2002)	Pittsburgh, US	1996-1997	483 (Unclear / Unclear)	Quantitative: telephone interview	Parents (% mothers not specified)	Comparison (Unvaccinated includes “late vaccinated”)	Low-income families, urban setting	DTP	Retrospective	Objective	14 / 22
Wroe (2005)	Bromley PCT, UK	2002-2004 (unclear)	114 (70 / 43) 1 missing	Quantitative: postal q’aire	Parents (% mothers not specified)	Comparison	Not reported	MMR	Prospective	Subjective	12 / 22

†: Total (vaccinators / non-vaccinators)

*: Comparison = vaccinated VS unvaccinated; cohort = vaccinated OR unvaccinated

‡: two scores = focus groups score, individual interviews score

Figure 2.1: Progress of articles through the selection process



2.2.2 Analysis of study quality, data extraction and data synthesis

The methodological quality of included studies was assessed using revised versions of previously validated checklists for quantitative (Wells, Shea *et al*, 2008) and qualitative (Critical Appraisal Skills Programme, 2006) studies, as recommended by the Cochrane Collaboration (Reeves, Deeks *et al*, 2008) and used in previous relevant systematic reviews (Mills, Jadad *et al*, 2005; Jefferson, 2003). Revisions included addition and clarification of items, modification of generic items, and expansion of scoring systems, to allow for differentiation between conduct quality and reporting quality. Revised and original validated checklist scores were strongly and significantly correlated (Pearson $r = 0.91$, $p < 0.001$). Qualitative and quantitative comparison studies could receive a maximum of 22 points, and quantitative cohort studies a maximum of 10 points, with higher scores indicating better quality.

A Grounded Theory (Glaser & Strauss, 1967) approach (in which data are extracted to codes derived from the data, rather than to a set of predefined codes) was used for data extraction from both qualitative and quantitative papers. This approach is recommended for use with qualitative data (Booth, 2001) because it facilitates systematic extraction without compromising the richness of the data. Applying this technique to quantitative data is less orthodox; however as there was little consistency across these data in the areas assessed or the methodologies used, the traditional approach of using a data extraction form to draw out comparable information across all papers was considered inappropriate. Because this approach is iterative and interpretative, statistical assessment of agreement in coding between reviewers is not appropriate; any disparities in reviewers' coding were resolved through discussion. Factors from a previous systematic review (Mills, Jadad *et al*, 2005) were used as an initial framework. Additional factors were generated in the light of emerging findings from the analysis. Material could be coded to more than one factor. Data were attributed to a vaccination decision where this information was provided. 62 initial factors

were identified and collapsed into eleven broad factors – seven of which were covered by over 50% of studies (vaccine, healthcare system/Government, information needs, disease, parenting/social context, practicalities, demographics) and four by under 50% (non-official sources of information, decision making, individual differences, lifestyle factors).

Data content was synthesised and patterns and differences summarised across and within the three study types (quantitative comparison, quantitative cohort, qualitative). Table 2.2 and Table 2.3 provide summary data, whilst Table 11.1, Table 11.2 and Figure 11.2 in Chapter 11 (Appendices) provide more detailed data. It was not possible to calculate effect sizes from the data as reported.

2.3 Results

2.3.1 Characteristics of studies

Two-thirds of included studies (including all the qualitative studies) were conducted in the UK and Eire. A higher proportion of UK/Eire studies than studies from elsewhere reported on healthcare system/Government factors, non-official sources of information, decision-making, and individual differences. There is little evidence of any systematic differences in findings between UK/Eire studies and studies from elsewhere, except on some demographic factors – parental education, income, family size and parental age. Nineteen of the 31 included studies focused on MMR decisions only, 5 focused on both MMR and diphtheria, tetanus, pertussis, polio and Haemophilus Influenzae type B (DT, DTP, DTP+OPV, DTaP/IPV/Hib) decisions, and 6 focused on non-MMR decisions only (DT, DTaP, DTP, IPV, Hib).

Table 2.2: Summary results for main factors: Quantitative comparison studies

Ref	Vaccine factors	Healthcare system / Government	Information needs	Disease factors	Parenting / social context	Practicalities	Demographics	Non-official sources of information	Decision-making	Individual differences	Lifestyle factors
Alfredsson (2004)	↓ General safety concerns ↑ Perceived effective ↓ Advance planning	↑ Satisfied with HP discussion*	Not assessed	↓ Disease serious ↓ Natural immunity preferable	Not assessed	↑ Have vaccinated previously ***	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Bardenheier (2004)	↓ General safety concerns * – Perceived effective ↓ Perceived autism link* ↓ Experience of VAE * ↓ Too many shots *	Not assessed	Not assessed	↓ Disease serious* ↓ Disease likely	↓ Legal issues influence decision	↑ Have vaccinated previously* ↑ Plan to vaccinate in future* – Plan to postpone vaccine – Financial cost is barrier to uptake	↑ Higher parental education ↑ Higher parental income* ↑ Higher parental age* ↑ 2-parent family ↑ Non-white ethnicity ↑ Decision for firstborn ↑ Social welfare recipient	Not assessed	Not assessed	Not assessed	Not assessed
Bond (1999)	↑ General safety concerns – Perceived effective*	– Satisfied with HP discussion ***	Not assessed	↓ Disease serious ↓ Disease likely*	Not assessed	Not assessed	↑ Higher parental education ↑ Higher parental income	Not assessed	Not assessed	Not assessed	Not assessed

Ref	Vaccine factors	Healthcare system / Government	Information needs	Disease factors	Parenting / social context	Practicalities	Demographics	Non-official sources of information	Decision-making	Individual differences	Lifestyle factors
Casiday (2006b)	↓ General safety concerns*** – Perceived effective ↓ Perceived autism link* ↓ Would prefer singles***	↑ Trusts Govt/health system*** ↑ Research adequate***	Not assessed	↓ Disease serious ↓ Disease likely*** ↓ Outbreaks influence decision	↑ Vaccination is social responsibility*** ↓ Values parents' right to choose***	Not assessed	– Higher parental education – Higher parental income ↑ Larger family* – Higher parental age	Not assessed	Not assessed	Not assessed	Not assessed
Cassell (2006)	↓ General safety concerns*** ↓ Perceived autism link ↓ Experience of VAE *** ↓ Would prefer singles*** ↓ Immune overload concerns*** ↓ Advance planning***	↑ Trusts Govt/health system*** ↑ Research adequate*** ↑ HP supports decision***	↑ Own knowledge perceived adequate***	↓ Disease serious*** ↓ Natural immunity preferable***	↑ Vaccination is social responsibility*** ↓ Values parents' right to choose*** ↑ Peers support/concur with decision*** – Parents share responsibility for decision ↓ Engagement in personal research***	Not assessed	↓ Higher parental education ↓ Higher parental age ↑ Decision for firstborn	↓ Media reports trusted and influential***	↑ Anticipates regret as consequence of disease***	↓ Immune systems differ by child***	↓ Favours non-medical approach to healthcare***
Flynn (2004)	↓ General safety concerns** ↓ Experience of VAE	↑ Trusts Govt/health system*	Not assessed	↑ Disease likely	↑ Peers support/concur with decision	↑ Have vaccinated previously***	↑ Higher parental income ↑ Larger family ↓ Higher parental age – 2-parent family	– Media reports trusted and influential *	– Anticipates regret as consequence of disease	Not assessed	Not assessed

Ref	Vaccine factors	Healthcare system / Government	Information needs	Disease factors	Parenting / social context	Practicalities	Demographics	Non-official sources of information	Decision-making	Individual differences	Lifestyle factors
Gellatly (2005)	↓ General safety concerns* ↓ Would prefer singles ↓ Immune overload concerns*	– Trusts Govt/ health system – Satisfied with HP discussion – HP supports decision	– Own knowledge perceived adequate*	Not assessed	↑ Vaccination is social responsibility *	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Impicciatore (2000)39	– Perceived effective**	Not assessed	– Own knowledge perceived adequate*	Not assessed	Not assessed	Not assessed	↑ Higher parental education* ↑ Higher parental income* ↓ Larger family ↑ Higher parental age	Not assessed	Not assessed	Not assessed	Not assessed
Lewis (1988)	↑ General safety concerns*** – Perceived effective	– HP supports decision	Not assessed	Not assessed	↓ Legal issues influence decision	– Plan to vaccinate in future***	Not assessed	↓ Media reports trusted and influential	Not assessed	Not assessed	Not assessed
MacDonald (2004)	↓ General safety concerns** ↓ Perceived autism link	– Trusts Govt/ health system – Satisfied with HP discussion	– Own knowledge perceived adequate	Not assessed	Not assessed	Not assessed	↓ Higher parental income ↓ Larger family – 2-parent family ↓ Social welfare recipient*	↓ Media reports trusted and influential * ↓ Organised groups and internet influence decision*	Not assessed	Not assessed	Not assessed
Petrovic (2003)	↓ General safety concerns* ↓ Immune overload concerns	Not assessed	Not assessed	↓ Disease serious	Not assessed	↑ Plan to vaccinate in future	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed

Ref	Vaccine factors	Healthcare system / Government	Information needs	Disease factors	Parenting / social context	Practicalities	Demographics	Non-official sources of information	Decision-making	Individual differences	Lifestyle factors
Trauth (2002)	↓ General safety concerns	Not assessed	↑ Own knowledge perceived adequate*	↓ Disease likely	Not assessed	Not assessed	↑ Higher parental education ↑ Higher parental income ↓ Larger family* ↓ Non-white ethnicity – Higher parental education	Not assessed	Not assessed	Not assessed	Not assessed
Wroe (2005)	– Perceived effective*	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	– Larger family – 2-parent family – Non-white ethnicity	Not assessed	↑ Anticipates regret as consequence of disease*	Not assessed	Not Assessed
*=significant at 0.05		**=significant at 0.01		***=significant at 0.001		↑= vaccine uptake increases with variable		↓= vaccine uptake decreases with variable		– = vaccine uptake unchanged with variable	

Table 2.3: Summary results for main factors - Quantitative cohort studies

Ref	Vaccine factors	Healthcare system / Government	Information needs	Disease factors	Parenting / social context	Practicalities	Demographics	Non-official sources of information	Decision-making	Individual differences	Lifestyle factors
Binkin (1994) (D)	– General safety concerns 8.1%	– HP supports decision 6.1%	Not assessed	– Natural immunity preferable 8.9% – Disease likely 81.0%	Not assessed	– Perceived contra-indications 16.0%	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Dannetun (2005) (D)	– General safety concerns 64.0% – Given too young 55%	– Satisfied with HP discussion 66.0%	– Own knowledge perceived adequate 76.0%	– Natural immunity preferable 50% – Outbreaks influence decision 51.5%	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Jones (1992) (D)	– Perceived effective 85.7%	Not assessed	– Own knowledge perceived adequate 55.0%	Not assessed	Not assessed	– Perceived contra-indications 27.0%	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Lawrence (2003)(D)	– General safety concerns 5.6% – Perceived effective 91.9%	Not assessed	– Own knowledge perceived adequate 71.2%	Not assessed	Not assessed	– Perceived contra-indications 18.0%	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Lieu (1994)(A)	– General safety concerns 59.0%	– Satisfied with HP discussion 66.0%	– Own knowledge perceived adequate 92.0%	Not assessed	– Values parents' right to choose 13%	– Have vaccinated previously 86.0%	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
Murphy (1994)(D)	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed	– Perceived contra-indications 42.0%	Not assessed	Not assessed	Not assessed	Not assessed	Not Assessed
A=acceptors						D=decliners					

Most studies reported data collected during and soon after the emergence of the MMR controversy in the UK. Participants were mainly mothers. Most studies used a retrospective design – in which parents were recruited, and their attitudes and other predictors assessed, after they had made and/or acted upon their vaccination decision; and these uptake decisions/behaviours were typically assessed subjectively using parent-reported intention (in some prospective designs) or behaviour (in retrospective and some prospective designs), rather than objectively, e.g. using medical records. Evidence from all included articles is summarised below. The seven factors for which there is most evidence are summarised individually, with the remaining four factors summarised in combination.

2.3.2 Vaccine factors

In comparison studies, lower vaccine uptake was typically linked with general side effects/safety concerns (relationship observed in 9 of 11 relevant studies, $p < 0.05$ in 7 of these), lower perceived vaccine effectiveness and importance (6 of 7 studies, 3 $p < 0.05$), belief that vaccine causes autism (4 of 4, 2 $p < 0.05$), own and others' experiences of vaccines and vaccine adverse events (3 of 3, 2 $p < 0.05$), belief in safety of single vaccines (3 of 3, 2 $p < 0.05$), belief in a danger of immune overload (3 of 3, 2 $p < 0.05$), thinking about vaccine in advance of it being due (2 of 2, 2 $p < 0.05$), and belief that children receive too many shots (1 of 1, 1 $p < 0.05$).

Cohort studies of vaccine-declining parents found substantial variation in the prevalence of general safety concerns, small proportions of parents citing “disagreeing with” or “not believing in” vaccines as a reason for non-vaccination, and majority agreement that vaccines are provided at too young an age.

Qualitative studies reported a number of specific vaccine safety concerns including risks of asthma, allergies and autism. General safety fears were linked to experience of side effects or reactions (typically second- or third-hand negative experience) and concern about immune overload particularly for immature immune systems (hence single vaccines were considered safer than, and therefore preferable to, combined vaccines – though parents were dissatisfied with information about and access to them). Autism-specific dialogues again incorporated experience of an MMR-autism link, belief that this link is small but significant, and weighing autism against disease (suggesting that autism is perceived as a reality of immunisation, as disease is perceived as a reality of non-immunisation). Perceptions of vaccine efficacy/importance were underpinned by previous experience of vaccine failure and the limited duration of protection afforded by vaccines. Parents demonstrated poor understanding of contraindications to, need for, and purpose of MMR. Parents discussed the peculiarity of MMR concerns in comparison with other vaccines, and of the MMR issue in the UK compared with other countries.

2.3.3 Healthcare system / Government

In comparison studies, lower vaccine uptake was typically linked with lower trust in healthcare system and/or Government (relationship observed in 5 of 5 studies, $p < 0.05$ in 3 of these), perception that discussion with health professionals about immunisation concerns was inadequate in length and depth, dismissive and difficult (4 of 4 studies, 3 $p < 0.05$), perception that vaccine research is vital but currently inadequate (2 of 2, 2 $p < 0.05$), and perception that health professionals do not agree with one's decision (3 of 3, 1 $p < 0.05$).

In unrelated cohorts, identical proportions of vaccine-acceptors and vaccine-decliners felt dissatisfied with their health professional consultations. One cohort study found a small proportion of vaccine decliners believed their health professional supported their decision.

Qualitative studies found time pressure in primary care, feeling condescended to, being depersonalised by “the system”, and unequal power relations prohibiting free discussion underpinned dissatisfaction with health professional consultations, regardless of uptake decision. Trust in individual health professionals and vaccine policymakers was compromised by perceived conflicted interests (linked with “toeing the party line”, meeting targets and, in UK studies only, obtaining financial reward), and previous personal experience or national issues (e.g. Prime Minister Tony Blair refusing to reveal his son Leo’s MMR status, and perceived unfounded Ministerial reassurances during the BSE controversy); but was buoyed by trust in professional expertise and health professionals sharing personal experience (e.g. confirming that they had vaccinated their own children). Vaccine-acceptors and decliners raised concerns around the amount and scope of research (particularly in relation to the “developing immune system”), and anomalous cases for which research cannot account or prepare. Some parents feared that vaccine refusal could negatively affect their relationship with their health professional, and viewed vaccine refusal as rebellion – there was some evidence of parents seeking out health professionals who support the decision they have already made.

2.3.4 Information needs

In comparison studies, lower vaccine uptake was typically linked with dissatisfaction with or perceived inadequacy of information / knowledge (relationship observed in 5 of 5 relevant studies, $p < 0.05$ in 4 of these).

Unrelated cohort studies found a smaller proportion of vaccine-decliners than vaccine-acceptors were satisfied with the information they were given.

In qualitative studies, parents reported dissatisfaction with the content and timing of information provided to them, with both NHS/Government information and non-official information perceived to be biased.

2.3.5 Disease factors

In comparison studies, lower vaccine uptake was typically linked with lower perceived disease severity (relationship observed in 4 of 6 relevant studies, $p < 0.05$ in 2 of these), lower perceived likelihood of catching vaccine-preventable disease (4 of 5 studies, 2 $p < 0.05$), and preference for natural immunity obtained by having the disease rather than the immunisation (2 of 2, 1 $p < 0.05$).

Two unrelated cohort studies assessed outbreak prevention views, with one noting that the majority of vaccine decliners cited this as a reason that “more kids should be vaccinated”, whilst the other found almost half of their vaccine-declining sample would not reconsider their own decision in light of an outbreak.

Qualitative studies found disease severity beliefs were informed by first- and second-hand experiences (typically vaccine-decliners cited mild disease cases, and vaccine-acceptors cited serious cases – though there was some crossover) and media coverage, and that parents were aware of a spectrum of severity ranging from routine cases to rare but serious complications (though many acknowledged gaps in their knowledge about diseases). Natural immunity was seen to be of a better

quality, more long-lasting, and generally preferable to that resulting from the “unnatural” intervention of immunisation. Parents who planned not to vaccinate had reconsidered, or believed they might reconsider that decision if a local outbreak occurred.

2.3.6 Parenting / Social context

In comparison studies, lower vaccine uptake was typically linked with disinclination to vaccinate for the benefit of wider society (relationship observed in 3 of 3 relevant studies, $p < 0.05$ in 3 of these), valuing parents’ right to choose whether to vaccinate (2 of 2 studies, 2 $p < 0.05$), lack of peer support for decision (2 of 2, 1 $p < 0.05$), and engagement in personal research (1 of 1, $p < 0.05$).

Qualitative studies showed that for vaccine-acceptors, protecting the community by vaccinating their child was a bonus (rather than a driver of uptake), whilst for vaccine-decliners viewed it was an unwelcome obligation in conflict with their primary aim to protect their own child. Parents felt they could control the presence of disease in their child’s life through nutrition, limited contact with other (infectious) children, protection from non-infection harms and taking appropriate action in the event of illness. Some vaccine-acceptors felt that vaccines are simply the normal thing to do, that vaccinating has never been questioned within the family, and that refusing vaccines makes you a bad parent. A number of parents highlighted the importance of parental choice to opt for single versus combined shots. Parents felt that personal research was expected of them but that relying only on rational evidence is inadequate because they should (but often don’t) instinctively know what to do. New mothers reported limited opportunities to discuss vaccination options with peers, and limited time to engage in personal research.

2.3.7 Practicalities

In comparison studies, lower vaccine uptake was typically linked with having missed or declined vaccinations previously (relationship observed in 3 of 3 relevant studies, $p < 0.05$ in 3 of these), and planning to give vaccinations in future (3 of 3 studies, 2 $p < 0.05$). Plans to postpone vaccination (1 relevant study) and financial costs (1 relevant study) were not linked with uptake.

Across five cohort studies ($n=2293$), perceived contraindications on the appointment day were cited as a reason for not vaccinating by 34% of vaccine-decliners.

Qualitative studies described a dual mechanism underpinning the influence of perceived contraindications on uptake – that illness at the time of vaccination compromises a child's ability to cope with vaccine, and that the vaccine compromises a child's ability to cope with the current illness. Several parents wished to postpone vaccination until the risk of autism was believed to have passed – apparently a regret minimising rationale. Other practical barriers to uptake included difficulty finding time (and childcare for other, older children) for the immunisation appointment and for pre-decisional research, parents' own phobias and anticipated guilt, problems with getting to the clinic or poor facilities within the clinic, and uncertainty about who was to arrange the appointment.

2.3.8 Demographics

In comparison studies, lower vaccine uptake was typically linked with lower parental income (relationship observed in 5 of 7 relevant studies, $p < 0.05$ in 2 of these), lower parental education (4 of 6 studies, 1 $p < 0.05$), and the child in question not being firstborn (2 of 2, 1 $p < 0.05$). Mixed

relationships with uptake were observed for family size (7 studies), parental age (5 studies), ethnicity (3 studies), and family being in receipt of social welfare (2 studies).

2.3.9 Factors with a smaller evidence base

Four factors (non-official sources of information, decision-making, individual differences, and lifestyle factors) are more sparsely evidenced (covered in less than 50% of studies). These factors are summarised below.

In comparison studies, lower vaccine uptake was typically linked with favourable opinion and use of media reports (relationship observed in 3 of 4 relevant studies, $p < 0.05$ in 2 of these), anticipated regret as a consequence of vaccinating (2 of 3 studies, both $p < 0.05$; vaccine-acceptors anticipated regret from vaccinating and from not vaccinating with roughly equal frequency, whilst far more vaccine-decliners anticipated regret from vaccinating than from not vaccinating), influence from organised groups and the internet (1 study, $p < 0.05$), post-decision satisfaction (1 study, $p < 0.05$), belief in variation in immune systems among children (1 study, $p < 0.05$), and alternative healthcare preferences and behaviour change in response to perceived danger from BSE and GM crops (1 study, $p < 0.05$).

Qualitative studies showed media coverage prompted concern and further personal research, though parents' opinions varied as to whether this was useful or detrimental for decision making. The absence of reports about DTaP/IPV/Hib (in comparison with MMR coverage) was discussed in two studies as an indicator of its safety. Testimony from other parents (in organised groups and online and in media reports) was trusted more than official statistics, because parents were

perceived to have no agenda, and to be accessible and experienced. Parents were aware that they anticipated regret, typically describing an explicit comparison of perceived risk and severity of vaccine adverse events (feared more by vaccine-decliners) with perceived risk and severity of diseases (feared more by vaccine-acceptors). At individual level, the presence of illness and lifestyle factors promoting health were related to both the risk of vaccine damage, and the risk of (or ability to cope with) disease. A small number of vaccine-undecided parents discussed homeopathy and diet as alternatives to vaccination, and three themes underpinning non-vaccination emerged: opposition to the use of animals in vaccine development, belief that fate or God's will rather than medical intervention should dictate the health of the child, and valuing personal choice (and resentment of perceived removal of choice).

2.3.10 Methodological aspects of reviewed studies

Quality assessment for qualitative studies is shown in Table 2.4. For individual interview studies, the mean quality score was 10.7 out of 22, with a range of 4 to 17. For focus group studies, the mean score was 10.9, with a range of 7 to 15. Of 150 "lost points" (where a score less than the maximum 2 points was given) in total, the majority were lost due to inadequate reporting, e.g. failure to report the information required to score the quality assessment item (68%) rather than clear failure to meet criteria. Studies typically failed to report having reached thematic saturation (the point at which all salient themes appear to have emerged) and having used more than one data analyst, and failed to assess vaccination status objectively.

Quality assessment for quantitative studies is shown in Table 2.5. For cohort-type studies (including either vaccine-acceptors or vaccine-decliners, not both), the mean quality score was 1.7 out of 10, with a range of 0 to 4. For comparison type studies (including both vaccine-acceptors and vaccine-

decliners), the mean score was 9.4 out of 22, with a range of 6 to 14. Of 214 “lost points”, the majority were lost due to clear failure to meet criteria (79%) rather than inadequate reporting. Studies typically failed to use validated instruments to assess parents’ views and to collect parents’ views prospectively in relation to their vaccination decision/behaviour, failed to report power calculations and obtained unequal response rates for vaccine-accepting parent versus vaccine rejectors.

Table 2.4: Quality checklist and scores, qualitative studies

Item	Individual interviews							Focus groups								TOTAL STUDIES MEETING CRITERION (%)
	Casiday (2006)	Casiday (2007)	McMurray (2004)	New (1991)	Poltorak (2005)	Smailbegovic (2003)	Tickner (2007)	Casiday (2006)	Casiday (2007)	Evans (2001)	Hilton (2007)	Hilton (2006)	Hilton (2007)	Petts (2004)	Poltorak (2005)	
Were participants representative of parents of vaccination-age children in the immediate population?*	2	2	2	ns	1	0	1	2	2	1	2	2	2	0	1	12/15 (80)
Were the data transcribed verbatim (i.e. were audiotapes, videotapes or field notes used)?	2	1	2	ns	2	ns	2	2	1	2	2	2	2	2	2	13/15 (87)
If interviews were conducted, were the questions predefined?	2	2	2	2	1	ns	2	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	6/7 (86)
If focus groups were used, was the facilitator trained?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	ns	ns	ns	ns	ns	ns	ns	ns	0/8 (0)
Was saturation achieved?	ns	ns	ns	ns	ns	ns	2	ns	ns	2	ns	ns	ns	ns	ns	2/15 (13)
Was there a description of how the research factors were identified?	2	2	2	0	1	0	2	2	2	2	2	2	2	1	0	12/15 (80)
Were the research findings analysed by more than one assessor?	ns	ns	2	ns	2	ns	2	ns	ns	2	2	ns	ns	ns	ns	5/15 (33)
Were participants answers reviewed for clarification (i.e. member check)?	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	0/15 (0)
Were sequences from the original data presented (i.e. quotes)?	2	2	2	2	1	0	2	2	2	2	2	2	2	2	2	14/15 (93)
Did the study report ethical review?	2	2	2	0	0	2	2	2	2	2	2	2	2	0	0	11/15 (73)
Was vaccination status assessed objectively?*	0	ns	0	2	0	2	0	0	ns	1	1	1	1	0	0	6/15 (40)
Were data collected prospectively?*	1	1	0	0	1	0	2	1	1	0	0	0	0	1	1	8/15 (53)
Score, out of 22	13	12	14	6	9	4	17	11	9	15	14	12	12	7	7	
*: item added to original scale 0: criterion not met 1: criterion partially met 2: criterion fully met ns: unclear whether criterion met n/a: criterion not applicable																

Table 2.5: Quality checklist and scores, quantitative studies

Item	Cohort						Comparison														TOTAL STUDIES MEETING CRITERION (%)
	Binkin (1994)	Dannetun (2007)	Jones (1992)	Lawrence (2003)	Lieu (1994)*	Murphy (1994)	Alfredsson (2004)	Bardenheier (2004)	Bond (1999)	Casiday (2006)	Cassell (2006)	Flynn (2004)	Gellatly (2005)	Impicciatore (2000)	Lewis (1988)	MacDonald (2004)	Petrovic (2003)	Trauth (2002)	Wroe (2005)		
Was vaccination status assessed objectively (i.e. through official records) for all participants?	0	2	0	2	2	0	2	2	0	0	2	2	0	2	2	2	2	2	0	12/19 (63)	
Were participants representative of parents of vaccination-age children in the population (vaccine uptake)?	n/a	n/a	n/a	n/a	n/a	n/a	0	2	0	0	0	ns	ns	ns	0	ns	ns	2	2	3/13 (23)	
Were participants representative of parents of vaccination-age children in the population (demographics)?	2	ns	ns	ns	0	ns	ns	ns	2	0	0	2	ns	0	0	ns	ns	2	2	5/19 (26)	
Were vaccinators and non-vaccinators drawn from the same population?	n/a	n/a	n/a	n/a	n/a	n/a	2	2	2	2	2	2	2	2	2	2	2	2	2	13/13 (100)	
Were demographic differences between vaccinators and non-vaccinators matched or controlled for in sampling or analysis?	n/a	n/a	n/a	n/a	n/a	n/a	0	2	2	0	0	2	0	2	0	0	0	2	2	6/13 (46)	
Were vaccinators and non-vaccinators assessed using identical instruments and methodologies?	n/a	n/a	n/a	n/a	n/a	n/a	2	2	2	2	2	2	2	2	2	2	2	2	2	13/13 (100)	
Was the response rate the same for vaccinators and non-vaccinators?	n/a	n/a	n/a	n/a	n/a	n/a	2	ns	2	ns	0	ns	ns	ns	0	0	ns	ns	ns	2/13 (15)	
Were validated instruments used to assess beliefs etc.?	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0/19 (0)	
Was a power calculation reported?	n/a	n/a	n/a	n/a	n/a	n/a	0	0	0	2	0	0	0	0	0	0	2	0	0	2/13 (15)	
Did the study report ethical review?	0	0	0	2	0	0	2	0	2	2	2	2	2	0	0	0	0	2	0	8/19 (42)	
Were data collected prospectively?	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	2	2/19 (11)	
Score, out of 22 (or 10, for cohort studies)	2	2	0	4	2	0	10	10	12	8	8	14	6	8	6	6	8	14	12		
0: criterion clearly not met 1: criterion partially met 2: criterion fully met ns: unclear whether criterion met n/a: criterion not applicable																					

2.4 Discussion

2.4.1 Summary of review findings

This review identifies and synthesises quantitative and qualitative evidence on the factors underlying parental decisions about combination childhood vaccines. Quantitative data demonstrate that generally parents making vaccination decisions act in accordance with their attitudes and beliefs about vaccine-related factors (Figure 2.2). However, on some factors vaccine-acceptors and decliners did not differ. Accordingly, the qualitative data reveal that, whilst vaccine-acceptors generally hold attitudes and beliefs more conducive to vaccinating than do vaccine-decliners, they are not without their doubts. These findings may suggest that (particularly in the absence of restrictive questionnaire response options) many parents are not entirely polarised in their opinions of vaccination – feeling strongly about some factors but with more mixed views on others. That parents may hold a mixed profile of attitudes to vaccination highlights the complex and multifactorial nature of the decision.

Whilst this review included only studies exploring factors underlying decisions about combination vaccines, coverage of factors specifically relevant to combination vaccines was sparse. Where assessed, there were consistent and significant relationships between negative perceptions of combination vaccines (e.g. belief in safety/preferability of separate vaccines and fear of immune overload) and lower vaccine uptake, and qualitative evidence that these issues were more influential in MMR decisions than in decisions about other combination vaccines. The predictive influence of these factors warrants further exploration.

Figure 2.2: Characteristics of vaccine-declining parents

In comparison with vaccine-accepting parents, those who decline combination vaccines for their children are*:

- Less likely to perceive vaccines to be safe and effective
- Less likely to believe diseases are serious and that their child is likely to catch them
- Less trusting in the healthcare system and in Government
- Less satisfied with their vaccine-related knowledge information they have received
- More likely to believe MMR causes autism
- Less satisfied with their immunisation-related interactions with HCPs
- More likely to view media reports about vaccination favourably
- More likely to have experienced vaccine adverse events
- More convinced of the benefits of single vaccines
- More concerned about immune overload
- Less likely to view vaccinating as a positive social “responsibility”
- Less likely to have vaccinated previously and to plan to do so again in future
- Less likely to anticipate regret as a consequence of not vaccinating (versus vaccinating)
- Less likely to perceive that their HCP supports their decision
- Likely to have started thinking about the vaccination decision earlier
- Less likely to perceive that current vaccine research is adequate
- More likely to express preference for natural immunity
- Less happy to defer to medical advice about vaccination
- Less likely to perceive their peers as supportive of their decision

In most of the studies which assessed them, demographic characteristics were not significantly related to vaccine uptake. Where consistent differences were observed, they showed that, in comparison with vaccine-accepting parents, vaccine-decliners:

- Have lower incomes
- Have lower levels of educational attainment
- Are less likely to be making the decision for their firstborn child

* Based on factors assessed by at least two quantitative comparison studies, in order of coverage (most to least)

2.4.2 Quality of reviewed studies

Persistent methodological shortcomings and inadequate reporting meant that most studies were awarded less than half of the points available in quality scoring, calling into question the reliability of the reviewed data. Many studies used subjective measures of vaccine uptake (e.g. self-reported, unverified intention or behaviour), thus potentially overestimating actual uptake (Suarez, Simpson *et al*, 1997; Willis, Brittingham *et al*, 1999). Variance in uptake may have been incorrectly attributed to beliefs and attitudes, due to failure to control for demographics (a known predictor of uptake) (Pearce, Law *et al*, 2008; Wright & Polack, 2006; Mixer, Jamrozik *et al*, 2007). Retrospective designs may have been subject to consistency bias, whereby past behaviours and attitudes are remembered as more aligned with current attitudes and behaviours than they actually were at the time (Pieters, Baumgartner *et al*, 2006; Roberts, 1985). Samples were often more affluent and more highly educated than the population norm, with higher response rates among vaccine-acceptors than vaccine-decliners, meaning that data cannot be reliably extrapolated. Many studies reported statistical tests inadequately by omitting p values, limiting their interpretation.

Coverage of relevant factors across studies was non-systematic. Several factors predictive of behaviour in quantitative studies have not been explored qualitatively. Other factors emerged as salient in qualitative work but their contribution to uptake has not been quantified. Some factors have received substantial research interest, others very little. Lack of systematic coverage may provide only a partial representation of parental decision-making.

2.4.3 Strengths and limitations of review methodology

This systematic review fills a conspicuous gap in the literature by synthesising knowledge to date (and in light of the MMR controversy) about the factors underlying parental decisions about

combination vaccines. Whilst combination vaccines currently dominate immunisation schedules in the developed world and this dominance is expected to increase, single-antigen vaccines are still used and the findings of this review should be generalised to parental decisions about those vaccines with caution. Only data from developed countries is reported here, as the inclusion of data from nations where practical access limitations are the primary barrier was felt likely to reduce the review's capacity to explore conscious decision-making. A separate review of parents' immunisation decisions in developing countries may be necessary. Some large and respected UK surveys of parents' MMR attitudes, e.g. Smith, Yarwood *et al*, 2007, were excluded from the review because they do not link parents' views with their vaccine uptake intention or behaviour, however review results are analogous with such survey findings, indicating that pertinent themes were not missed through their exclusion. The coding of data to broad factors was intended to bring structure to the disparate evidence base, however some factors may not be mutually exclusive (for example, perceived contraindications to vaccination are coded here as a practical factor but could also be considered a vaccine factor) and should be used as a 'map' to the literature rather than a rigid schema for decision-making. All of the vaccines on which the reviewed studies focused are given in two or more doses, and parents' decisions were assessed most frequently in relation to the first dose or the full dose schedule, therefore generalisation to 'booster' doses should be cautious; separate reviews specific to individual doses may be worthwhile when the evidence base grows. The high proportion of MMR studies in the review means not all the findings can be generalised to all combination vaccines: most themes emerged across vaccines but some are specific to MMR (e.g. fear of vaccine-related autism) and the review makes clear where this is the case.

The review employs a standard methodology (NHS Centre for Reviews and Dissemination, 2001; Higgins & Green, 2008), however its findings should be interpreted in light of possible recognised limitations in the identification, selection and interpretation of relevant work (McAuley, Pham *et al*,

2000; Conn, Valentine *et al*, 2003). Whilst unpublished studies were sought for inclusion in the review, no relevant material was identified, however this may be attributable to difficulties in searching the dispersed and poorly-catalogued grey literature. Studies with non-significant results, smaller effect sizes and those conducted without formal funding and with small samples (e.g. within local service improvement programmes) are over-represented in the grey literature (Conn, Valentine, Cooper *et al*, 2003; Hopewell, McDonald, Clarke *et al*, 2008), and if this review has overlooked studies of this type then the significance and magnitude of some results patterns may have been overestimated and issues of particular local importance underestimated. Publication bias in the review area cannot be assessed using standard methods (e.g. trim-and-fill) as outcomes are heterogeneous but review findings must be interpreted with this potential bias in mind.

Triangulating the results of this and other reviews with findings from large, representative and methodologically rigorous empirical studies could provide the most robust data on factors underlying parental immunisation decisions (Ioannidis, Cappelleri *et al*, 1998; LeLorier, Gregoire *et al*, 1997; Furukawa, 2004). The exclusion of articles published in a language other than English (only 2.3% of all articles identified by the search strategy) is not unusual and is unlikely to have influenced the findings of the review (Moher, Pham *et al*, 2000; Pham, Klassen *et al*, 2005).

Many systematic reviews of non-RCT studies fail to assess study quality (Deeks, Dinnes *et al*, 2003), therefore the application of recommended quality checklists is a strength of the present review. My amended scoring systems permitted distinction between poor reporting versus poor study conduct. Integrating quality assessment with data synthesis was challenging due to data diversity, therefore the quality assessment serves mainly to highlight directions for future research. Exclusion of poor quality studies was deemed inappropriate given the substantial proportion of low-scoring studies and lack of validated cut-offs for low versus high quality. The inclusion of studies with poor quality scores may have influenced the overall findings of the review (Juni, Altman *et al*, 2001), and study

findings should be interpreted with these scores in mind. However, there is no evidence here that the findings of the lowest scoring studies differed systematically from those of the highest scoring studies.

Content/thematic analysis, comprehensively describing study content unbounded by a priori notions of which factors would or should emerge, was arguably the only viable approach to data extraction given the diversity of the data. Data extraction tables were cross-checked by a second reviewer to minimise subjectivity. Selective reporting in included studies (particularly among qualitative studies (Mills, Jadad *et al*, 2005; Dixon-Woods & Fitzpatrick, 2001), though quantitative studies are not immune (Chan, Hrobjartsson *et al*, 2004)) may have compromised systematicity.

It is possible that parents who plan to vaccinate differ from those who have vaccinated; that late vaccine-acceptors differ from on-time vaccine-acceptors, and that partial vaccine-acceptors differ from complete vaccine-acceptors and vaccine-decliners. Definitions of vaccine-acceptors and vaccine-decliners varied on these characteristics in reviewed studies, and though every effort was made to standardise definitions for the review, reporting limitations mean that the groups of vaccine-acceptors and vaccine-decliners compared may have been heterogeneous. Factors underlying these various permutations of behaviour should be reviewed when sufficient data are available.

2.4.4 Implications for policy and practice

Many factors identified in this review are already addressed in information provided routinely to parents (Department of Health, 2007), however as advice from personal health professionals may be

more powerful than generic materials it is vital that individual practitioners reinforce these points in consultation. Other factors, including discussions on natural versus artificial immunity and anticipated regret as a consequence of not vaccinating, could also be usefully incorporated. As vaccine-decliners may hold strong views on some factors but be less polarised on others, multifactorial interventions could aim to identify the factors on which parents are not polarised and improve attitudes towards these, and to increase the perceived importance of these factors within the decision – persistent challenges to decliners’ strongly-held views may encourage a more defensive (and vocal) anti-vaccine position. Immunisation training/guidance for health professionals could focus more on improving parents’ satisfaction with vaccination consultations; and fostering trusting relationships with parents in the context of immunisation (NHS Evidence, 2008). It is important to note, however, that under current policy around three-quarters of children in developed countries are fully immunised (World Health Organisation, 2009a; World Health Organisation, 2009b), therefore any policy changes aiming to increase uptake by better meeting the needs of the consciously vaccine-declining minority must be carefully tested to ensure they have no detrimental effect on uptake in the vaccine-accepting majority. Further, attitude-change interventions should work in tandem with, and must certainly not replace, efforts to remove practical barriers to accessing vaccination, which are a notable cause of non-immunisation (Serpell & Green, 2006; National Institute for Health and Clinical Excellence, 2009).

2.4.5 Directions for future research

A number of the methodological limitations tarnishing the data reviewed here are relatively easily remedied. Self-reported vaccine uptake data should be supplemented with objective data from primary care records to produce a more reliable, though likely still imperfect, measure of uptake. Although the latter is considered the ‘gold standard’ (Rodewald, Maes *et al*, 1999) neither source is infallible: parents may forget how many doses have been received or report additional doses to

avoid expected reprimand, and official systems quickly become out-of-date and are prone to human error. Prospective longitudinal data collection is possible where an “entry point” is identified (e.g. scheduled child health reviews, vaccine reminder correspondence), and is useful as data reviewed here suggest some immunisation decisions are made well in advance of behavioural enaction. However, resource implications (Bowling, 2002) and the possibility of disproportional representation of some groups must be taken into account. Representative samples may be obtained if strategies proven to improve response rates among “hard to reach” participant groups (McColl, Jacoby *et al*, 2001; Dormandy, Brown *et al*, 2008; Edward, Roberts *et al*, 2002), (e.g. providing language support, using telephone questionnaires, and offering financial incentives) are used.

Though this review demonstrates that vaccine-acceptors and vaccine-decliners do think differently on a number of factors, evidence-based interventions to manipulate immunisation-related cognitions generally have only small effects on behaviour (Briss, Rodewald *et al*, 2000), perhaps due to incorrect focus or content informed by a quantitative evidence base. Future empirical investigations should explore the mechanisms underpinning decision-makers’ reasoning, seeking to elucidate potential cognitive biases (Brown, Kroll *et al*, 2010b) and emotional preferences (Sevdalis & Harvey, 2006; Sevdalis & Harvey, 2007), which the qualitative studies reviewed here suggest may impact on vaccination decisions.

The MMR controversy has been impacting on parents’ vaccine decisions for over a decade and, as this review demonstrates, has spawned a sizeable literature. Understanding whether and how parents’ attitudes and concerns have changed during this period, either with a review specific to the purpose, or through replication of studies conducted at the start of the controversy, may help us to

understand how the MMR controversy might evolve and how new vaccine controversies may play out.

As no standard tool for assessment of immunisation decision-making exists, studies conducted to date measure different factors in different ways, resulting in a disparate body of data. The development and application of a valid instrument is vital to our understanding of immunisation decision-making across populations and contexts.

2.5 Conclusions and next steps

My review found that factors which inform parents' decisions about specific combination childhood immunisations have been explored in a number of studies, and this body of work provides evidence that parents generally act in line with their attitudes, which are typically multifactorial and complex. This review also indicated a number of methodological flaws and conceptual gaps across the qualitative and quantitative literatures in this area, which may have impacted on the reliability and completeness of study results.

My qualitative study which is reported in the next chapter, and my quantitative tool development and application which is reported in Chapter 4, seek to overcome these limitations in order to strengthen the knowledge base. Both of these studies provide a timely update to the literature, as the most recent data on MMR decision-making were collected in 2004, before MMR uptake began to recover after the controversy. They also overcome the key methodological limitation of self-report MMR status, by obtaining objective MMR uptake data from GP and PCT records. In addition,

the qualitative study improves methodologically on previous comparable work by using a prospective design to minimise the impact of consistency bias, and validating the analysis using dual-analyst coding and member checking; and extends the evidence base conceptually by exploring parents' views about normative behaviour and probabilistic risks around MMR. The quantitative studies offer both methodological and conceptual extensions to the evidence base by multifactorially modelling attitudinal and demographic predictors of actual MMR uptake in both routine and catch-up settings, using a measure with demonstrated psychometric properties; these attributes have, to my knowledge, never been combined in a single study.

3 Parents' decision-making about MMR dose 1: A qualitative analysis

3.1 Preface

My systematic review reported in Chapter 2 identified a number of qualitative studies exploring parents' decision-making about immunisations, all of which were conducted in the UK, and all but two of which explored decisions about MMR. However, at the time of the review (2008) the most recent published UK qualitative data on MMR decision-making was four years old, and no data had been collected and published since uptake had begun to recover following the MMR controversy. Further, the qualitative studies identified in the review suffered from a range of methodological flaws. Finally, qualitative studies had not sufficiently explored parents' thinking around risk uncertainty and behavioural/outcome norms in relation to MMR decision-making. These factors in combination rendered the secondary analysis of these data (within the systematic review) inadequate to inform subsequent studies in the Thesis.

This chapter reports my qualitative study designed primarily to obtain an up-to-date, comprehensive and methodologically robust picture of general factors underlying parents' MMR decision-making, and secondly to examine more specifically parents' perceptions of norms and probabilistic risks around MMR.

3.2 Introduction

In vaccination as in many other healthcare contexts, patient-centred decision-making is increasingly favoured over traditional paternalism (Taylor, 2009), and clinicians are encouraged to reach a mutually agreeable and informed decision with the parent about whether their child will be

vaccinated (British Medical Association, 2003; Redsell, Bedford *et al*, 2010, Department of Health, 2010). As the role of parents in vaccine decision-making has grown, so has the need for vaccine decision-making research to identify and explore issues salient to parents. However quantitative methods (e.g. large scale surveys, psychological experiments), which dominate the vaccine decision-making literature (Brown, Kroll *et al*, 2010a; Roberts, Dixon-Woods *et al*, 2002; Falagas & Zarkadoulia, 2008), may miss salient issues because the research agenda is defined by how researchers and clinicians think parents make vaccine decisions, rather than by how parents describe their vaccine decisions themselves. Qualitative methods can overcome this limitation by allowing participants more freedom to define the agenda, but are sometimes not considered an appropriate source of evidence by clinicians and policymakers (Petticrew & Roberts, 2003; Hawker, Payne *et al*, 2002), perhaps because these methods seek to describe rather than to quantify, and are necessarily interpretative (Strauss & Corbin, 1998; Pope & Mays, 2006). However, as clear standards for qualitative study design, conduct and reporting have been developed (Elliott, Fischer *et al*, 1999; Murphy, Dingwall *et al*, 1998; Critical Appraisal Skills Program, 2006), so the inclusion of qualitative evidence to inform practice and policy has been increasingly legitimised and valued (Noyes, Popay *et al*, 2009; Dixon-Woods & Fitzpatrick, 2001; Tan, Stokes *et al*, 2009; National Institute for Health and Clinical Excellence, 2009).

The systematic review reported in Chapter 2, and other published reviews of parental vaccine decision-making (Roberts, Dixon-Woods *et al*, 2002, Mills, Jadad *et al*, 2005; Falagas, Zarkadoulia *et al*, 2008), identify differences between quantitative and qualitative findings which highlight the importance of a mixed-methods approach. Some factors emerging as salient to parents in qualitative studies have not yet been assessed quantitatively, for example parents in qualitative studies consistently suggest that financial incentives may bias vaccine providers' clinical judgment (e.g. Evans, Stoddart *et al*, 2001; Hilton, Petticrew *et al*, 2007; McMurray, Cheater *et al*, 2004), but the

prevalence of this concern in the wider population has not been established. Some factors selected by researchers for quantitative assessment do not appear to be salient to parents in qualitative studies, for example despite assessment in several quantitative studies (e.g. Bardenheier, Yusuf *et al*, 2004; Flynn & Ogden, 2004; Trauth, Zimmerman *et al* 2002) perceived disease susceptibility has not emerged as an important issue for parents in qualitative work (and has shown no consistent quantitative relationship with vaccine uptake). Finally, some factors have had their role in parents' vaccine decisions explored using both methodologies, for example both perceived vaccine effectiveness and preference for natural immunity have been linked with vaccine uptake quantitatively (e.g. Casiday, Cresswell *et al*, 2006; Wroe, Bhan *et al*, 2005, Alredsson, Svensson *et al*, 2004; Cassell, Leach *et al*, 2006), and qualitative studies (Evans, Stoddart *et al*, 2001; Hilton, Hunt *et al*, 2007) have unearthed a shared mechanism underpinning both – perceived longevity of protection.

Whilst the current qualitative literature provides some insight into vaccine decision-making, the methodological quality of that literature and the period of time in which it was created calls into question the completeness of the findings in relation to current MMR decisions. First, interviews typically take place after a decision has been made and enacted (e.g. Smailbegovic, Laing *et al*, 2003; New & Senior, 1991), and the consistency bias (Schachter, 1999) means that these retrospective accounts of decision-making may 'edit out' thoughts which were part of the process but which do not fit with the eventual decision outcome. This can give an impression of unrealistically simplistic decision process, and means those thoughts which could have 'derailed' the final decision – and the reasons why they failed to do so – cannot be explored. Second, vaccine uptake has typically been assessed using parental report rather than through official records (e.g. Casiday, 2006; Petts & Niemeyer, 2004), thereby introducing a margin of error around parents' memory of, awareness of, and willingness to be open about whether and when their child was vaccinated (Hawe, Wilson *et al*,

1991; Suarez, Simpson *et al*, 1997; Bolton, Holt *et al*, 1998). Third, most studies report analyses carried out by only one researcher (e.g. Casiday, 2006; Smailbegovic, Laing *et al*, 2003; New & Senior, 1991), and no studies report a “member check” in which research participants review the analysis to check that they agree with the analyst’s interpretation of their interview (Critical Appraisal Skills Program, 2006), despite the utility of these techniques to identify and address conscious or unconscious analytic biases (Mays & Pope, 1995). These design, conduct and analysis flaws, coupled with possible selective reporting (Mills, Jadad *et al*, 2005), and failure to assess MMR decision-making since uptake of the vaccine in England started to improve after its lowest point in 2004 (Health and Social Care Information Centre, 2009), render the existing qualitative evidence base suboptimal to inform policy, practice and further research.

A gap in the qualitative literature which is particularly relevant to this Thesis, is the failure to explore in any detail those factors expected to influence decisions when outcomes are uncertain (Kahneman, Slovic *et al*, 1982). These include comprehension, attribution, and perceived accuracy of probabilistic information about risk and normative behaviours (e.g. the chance of catching measles, and the proportion of the population which accepts MMR). Research indicates that these probabilities are processed in complex and often flawed ways by decision makers, and these complexities and flaws may usefully be elucidated by qualitative enquiry. Two phenomena established by behavioural decision research, the omission bias (Ritov & Baron, 1990; Baron & Ritov, 1994) and the availability bias (Tversky & Kahneman, 1982), are particularly relevant to the MMR context and illustrate these complexities. According to the omission bias, probabilities are weighted differently depending upon the action to which they are attributed, with negative outcomes of actions (e.g. reaction following vaccination) weighted more heavily than negative outcomes of inactions (e.g. disease following non-vaccination); however this weighting is dependent on what the decision-maker frames as the ‘action’, and that is in turn dependent on what the decision-maker

perceives to be the behavioural norm. The availability bias suggests that we estimate outcome likelihoods based on the frequency with which we can bring those outcomes to mind, therefore the likelihood of outcomes which receive heavy media coverage, or which are discussed most frequently in online forums are overestimated; however this may be dependent on the extent to which that media coverage is perceived trustworthy and the extent to which the cases discussed on forums are perceived relevant to the decision-maker's own circumstances. The perception of norms and probabilities around MMR behaviour and outcomes clearly warrants further qualitative exploration.

The present study has two aims: to obtain an up-to-date, comprehensive and methodologically robust picture of general factors underlying parents' MMR decision-making, and to examine more specifically parents' perceptions of norms and probabilistic risks around MMR.

3.3 Method

3.3.1 Participants and recruitment

Participants were parents with a child aged between 11 months and 3.5 years (MMR dose 1 age), who was registered with a GP in Ealing PCT, and who was eligible to receive MMR (i.e. had no confirmed contraindications) but had not yet received it, nor had received any single measles, mumps or rubella vaccine (hereafter referred to as 'singles').

A two-tiered purposive sampling frame was used to select parents primarily on their expected MMR decisions, and secondarily on their ethnicity. The primary aim of the sampling frame was to recruit parents into four 'decision groups': 1) accepting MMR on-time, 2) accepting MMR late, 3) taking one

or more singles, or 4) taking no MMR or singles. Sample size was not fixed in advance, as recruitment would continue until thematic saturation (the point at which no new themes emerge in new interviews; Pope & Mays, 2006) was reached within each decision group. The secondary aim was to recruit a sample broadly representative (though statistical representativeness is not necessary for qualitative work) of Ealing's ethnically diverse population (Office for National Statistics, 2004).

Parents were recruited initially through GP practices, childcare organisations, and community groups/online forums. As these recruitment routes alone failed to yield sufficient numbers of parents rejecting both MMR and singles, this decision group was additionally populated through chain referral (or 'snowball') sampling (Penrod, Preston *et al*, 2003) whereby the first parent recruited to this group facilitated contact with a friend, who then facilitated contact with another friend and so on. Recruitment via GP practices was led by practice nurses, whilst recruitment via the other routes was led by the researcher. Study information posters were also mounted in GP waiting rooms and communal areas in recruiting childcare organization buildings, and leaflets were enclosed with MMR reminder letters from some practices, to facilitate 'self-recruitment'. Participant materials (invitation letter, information sheet, translation sheet and consent form) are provided in Figures 11.3-11.6, Chapter 11 (Appendices).

3.3.2 Procedure and analysis

Ethical approval was obtained from Ealing and West London Mental Health Trust Research Ethics Committee (Reference 08/H0710/6). Parents eligible to participate were given an information pack by their recruiter, and telephoned/emailed/returned a postal contact slip to the researcher if they were willing to participate. Interview location (participant's home, workplace, or researcher's office),

time (day, evening or weekend) and method (face-to-face or telephone) were selected by participants. At the interview, written consent to participate (and for the researcher to obtain MMR uptake data from the child's GP) was obtained, and the participant received a £10 shopping voucher as a token of thanks. Language support was available and its use encouraged where the participant's English was limited.

Interviews were audio recorded and were guided by a semi-structured schedule (Figure 11.7, Chapter 11 Appendices) informed by the systematic review and comprising four topic areas to be discussed (personal details, planned MMR behaviour, general factors underpinning decision, identification of key 'decision drivers'), with specific 'top level' (e.g. vaccine, disease, parenting) and 'detail' (e.g. natural immunity, personal experience) prompts within each topic area. Interviews opened with a broad question '*What things have you thought about while making your decision about MMR?*' to identify topics salient to the participant, and the interviewer then asked the participant to go into more detail on each salient topic, using specific prompts where necessary. Top level prompt topics which were not immediately salient (and which did not emerge organically during the talk) were raised by the interviewer.

Interview recordings were professionally transcribed verbatim, and transcripts were checked against recordings for accuracy. GP practices were contacted 6 months after interview to obtain MMR-1 uptake data for the children of participants. Participants were assigned to decision group 1 (MMR on time) if their child received MMR by the day he/she turned 14 calendar months old (in line with the UK immunisation schedule which recommends MMR dose 1 at 13 months: Department of Health, 2010), to decision group 2 (MMR late) if MMR was received after 14 calendar months old, to decision group 3 (singles) if no MMR was given by time of data collection but the GP confirmed

singles had been given or the parent had intended to give singles, and to decision group 4 (no MMR or singles) if no MMR was given by time of data collection and the parent had intended to give no MMR or singles.

Transcripts were analysed according to the principles of Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) using NVivo 8 (QSR International Inc.). Data were first broken into small sections of homogeneous content ranging in size from a few words to a long paragraph, and grouped by that content into codes. Sections which covered the same content were grouped into the same code, and new codes were created as new content areas were found in the data. Each section could be grouped on more than one code, and sections with shared content but from different participants were grouped under the same code. During the coding process, links between codes were identified and memoed, and through this process codes were linked together and synthesised. Two measures were taken to counter analysis biases: eight transcripts distributed across the decision groups were analysed in duplicate by a second coder blinded to the first analyst's codes, and a further eight participants across the decision groups provided a member check by reviewing the coding of their interviews. The emergent methodology and blinding to codes between analysts meant that quantitative assessment of inter-coder reliability (e.g. using Cohen's Kappa) would have required 'coding of codes', therefore such quantitative assessment was considered inappropriate. Instead, a qualitative approach to reliability was taken, whereby the two coders discussed their codes, identified discrepancies and agreed how they should be rectified, and the discrepancies were traced and rectified beyond the original subset where necessary.

3.4 Results

Twenty-four parents (all mothers) participated in interviews between June 2008 and March 2009.

Their characteristics are shown in Table 3.1.

Twelve participants were recruited through GP practices, 3 through mother-and-baby groups, 6 through online parenting forums and 3 through chain referral recruitment. Parents giving MMR on-time or late were mainly recruited through GPs or mother-and-baby groups, whilst parents giving singles or no MMR were mainly recruited through online forums and chain referral. Thirteen interviews were conducted face-to-face (11 at participants' homes, 2 at participants' workplaces), and 11 by phone. One mother was interviewed with an interpreter.

In the following section I report first on the five key themes which emerged as the general factors underpinning parents' decisions (Aim 1), and then report parents' discussions around normative behaviours and probabilistic risks (Aim 2).

Table 3.1: Participant characteristics

ID	Age ^a	Education ^b	Job	Ethnicity	Child sex/age ^c	Birth order ^d	Decision group
P1	30	Degree (Nursing)	At-home mum	Black African	M 11	Second	MMR on time*
P2	32	Postgraduate (Practice nursing)	Practice nurse	White British	F 11	Second	MMR on time
P3	43	GCSE	At-home mum	White British	M 13	Second	MMR on time
P4	36	PhD (Biomedicine)	Clinical scientist	Black British	M 12	First	MMR on time
P5	31	Degree (Hospitality)	Manager	Asian	F 13	First	MMR on time
P6	39	Further Education (Childcare)	Nanny	White British	M 13	First	MMR on time
P7	36	Further Education (Secretarial)	Personal Assistant	White Irish	F 14	First	MMR late (5 weeks)
P8	44	Postgraduate (Nursing)	Adult nurse	White Australian	M 21	Second	MMR late (7.5 months)
P9	39	A-levels	Nanny	Black British	M 13	Second	MMR late (3 weeks)
P10	27	None	At-home mum	Black African	F 16	Third	MMR late*
P11	27	Postgraduate (English literature)	At-home mum	Asian British	M 13	Second	MMR late (1 week)
P12	41	Postgraduate (English literature)	Teacher	White American	F 14	Fifth	MMR late (3 weeks)
P13	37	Postgraduate (Accountancy)	Accountant	Chinese	M 11	First	Singles (measles only)
P14	27	Degree (Communication)	At-home mum	Mixed Brit/Afr	F 12	First	Singles (measles only)
P15	36	Degree (Science)	At-home mum	White Canadian	F [†]	First	Singles*
P16	40	BTEC (Business Finance)	At-home mum	Asian	M 33	First	Singles
P17	34	Postgraduate (Medical sciences)	At-home mum	Asian British	F&M 21 (twins)	First	Singles (postponed)
P18	33	Degree (Music)	Composer	White British	F 16	First	No MMR or singles ^e
P19	41	Degree (HR management)	At-home mum	White British	F 34	Third	No vaccines ^f
P20	38	Degree (Humanities)	At-home mum	White British	M 20	Second	No vaccines ^f
P21	36	Degree x2 (Business, Psych.)	Business-woman	White N. Zealand	M 38	First	No vaccines ^f
P22	38	Postgraduate (Management)	At-home mum	White British	M 23	Second	No vaccines ^{f*}
P23	33	Postgraduate (Transport logistics)	At-home mum	White Polish	F 11	First	No MMR or singles ^e
P24	30	Degree (Computer science)	At-home mum	White British	F 18	First	No vaccines

a: Years
 b: PG: postgraduate; FE: further education
 c: Months, to nearest whole month
 d: All firstborns were only children except P21
 * Self-report – no consent for objective uptake
 † Details not provided by mother
 e: Accepted some scheduled vaccines
 f: Accepted no scheduled vaccines

3.4.1 General factors underpinning parents' decisions about MMR dose 1

Parents' descriptions of their MMR decision-making revolved around five themes, each of which is discussed in detail below. The themes are shown in order of the frequency with which they emerged in the data. Figure 3.1 shows the five themes and their subthemes.

Figure 3.1: Themes and subthemes emerging in qualitative data

Vaccines and the MMR-autism controversy

- MMR versus other vaccines
- Who caused and perpetuated the MMR controversy
- Single measles-mumps and rubella vaccines
- Personal experience of relevant issues
- Vaccine schedule
- Vaccine ingredients
- Vaccine efficacy

Social context of MMR

- Judging other parents' decision-making quality and motivation
- Being/feeling judged by others for your own decision
- Judging and blaming oneself

Vaccine providers, policy and research

- Clinical judgment versus financial incentives and 'brainwashing' medical training
- Research adequacy and wilful versus accidental misconduct
- Health professionals sharing personal testimony
- Using trust to simplify the decision, and reduce self-blame
- Being/feeling pressured by one's health professional

Disease factors

- Personal experience of relevant issues
- Severity
- Susceptibility
- Natural immunity

Information needs

- Partiality in most information sources
- Official information (e.g. from Department of Health)
- Non-official information (e.g. from media and websites)
- Lay information (e.g. from family and friends)

3.4.1.1 Vaccines and the MMR-autism controversy

MMR versus other vaccines

Most parents, even those who planned to reject all vaccines for their child, said that they had thought more about MMR than they had about other vaccines, and most attributed this primarily to the MMR controversy having introduced doubts about MMR safety.

You know, if [the controversy] had never sort of happened I would probably just merrily gone along as if it was just the jab for 2 month, 4 month, 6 months and not really given it no thought whatsoever. (P8, MMR late)

I think because of all that controversy with autism I think [MMR] does [feel different], you know (P21, no MMR)

Yeah, but I guess I've probably thought more about this one, maybe because there is more controversy about it. (P14, singles)

Policy, research and practice responses to the controversy were also seen to set MMR apart from other vaccines - with mixed evaluations from parents.

I see MMR as one of the more important ones...there wouldn't have been so much research into it if it was just - you know, if they felt these are diseases that... nothing much is going to happen with them. (P8, MMR late)

I think, there seems to be this dramatic focus on the MMR while they were dumping off DTP with thimerosal in it but nobody mentioned that. (P20, no MMR)

Other parents highlighted that controversy-based MMR worry is compounded by the fact parents have months after the primary schedule to think about MMR

Whereas with MMR it's a drawn out process as well because you can't do it until the baby is a certain age, you've got to have certain injections beforehand. It's not like a quick stab when they're born. (P8, MMR late)

Who caused and perpetuated the MMR controversy

Similarities and differences emerged in how different decision groups perceived key players in the controversy. Whilst parents across the decision spectrum agreed that Dr Andrew Wakefield's 1998 study was fatally flawed, his motives for running it and the way the GMC handled his case were evaluated quite differently across the groups.

The only worry is that bloody Wakefield, and his silly little party research (P3, MMR on-time)

I don't think that he would do it just to get a name for himself and then to be treated the way that he has done I think he must have really believed that there was some serious concerns (P12, MMR late)

What I found very frustrating about that was that Dr Wakefield was just shot down, a witch hunt was made of him because he dared to suggest there may be a casual (sic) link (P19, no MMR)

The controversy was seen to have been perpetuated by heavy, unbalanced and irresponsible media coverage, and by Tony and Cherie Blair refusing to confirm whether son Leo had received MMR – both of which were roundly criticised.

I saw how it was just sensationalism and it's just based on fear and it doesn't give the correct information to either children who want, parents who want to vaccinate them and those who don't. There's just a void of information that people need to get and, yeah I just, I think it's irresponsible in the press to do that. (P24, no MMR)

The media cases claim these stories over and over and bring Wakefield up again. And not really being very balanced in their argument and their approach. (P4, MMR on-time)

Why didn't Tony [Blair] say, yeah actually, I did have my child vaccinated against MMR, because by him saying that, it would have got everybody, I think, who was unsure (P17, singles)

Single measles, mumps and rubella vaccines

Parents across decision groups considered taking single vaccines, though many (even some of those who eventually took singles) felt that the single vaccines industry exploits parent fear for high profits. Single vaccines were the 'control' against which alternatives (MMR or no vaccination) were evaluated, with both MMR acceptors and MMR rejectors viewing single vaccines as a compromise eliminating both MMR reaction fear and disease fear.

I know the cost has gone up, it was something like £250 they were looking for or something like that. So there is like, for parents as well, there's a lot of exploitation and preying on people's fears really, I suppose. (P19, no MMR)

You just think well for the peace of mind, even though it's quite expensive to have it done separately. Just have it separately if it's going to be safer, even if it's 1% chance that it could go wrong. (P16, singles)

If I have decided to not go with MMR as one vaccine I would definitely go it (sic) as individual vaccines (P1, MMR on-time)

Parents who opted to take single vaccines were more concerned about clinic reputability and access than about cost, as most felt they were paying for peace of mind as much as for a safe vaccine. Accordingly, these parents did not consider MMR unsafe specifically because it was a combination vaccine, and immune overload was not a concern raised by this group.

You've got to pay for it and that makes it, like you say, underground, a bit seedy, a bit with parents thinking well are the vaccines licensed and, it opens up a whole other can of worms.

(P19, no MMR)

It's quite difficult to get the right information on [singles], and knowing whether it's the right site, or if it's just not some random person. (P14, singles)

No, I don't think it's combination vaccines in general, I just, sometimes there's something about certain things that just don't work and there might be some sort of chemical mishap.

(P15, singles)

Personal experience of relevant issues

Several parents across decision groups reported second or third-hand experience of an MMR-autism link, and first-hand experience of vaccine failure and mild vaccine adverse events, though MMR acceptors attributed these to fluke or erroneous ascertainment of cause and effect, whilst rejectors viewed them as evidence of systematic problems with vaccination. Several parents rejecting MMR, but no parents accepting MMR, had direct experience of caring for children with autism.

[My husband's] brother has an autistic child. And they've taken the decision, they felt that the autism may have been linked to the MMR vaccine and he subsequently decided not to vaccinate his 2 sons where their daughter was vaccinated (P4, MMR on-time)

My friend told me he find out his son had, his son actually has autism. He keep on telling me he got the feeling that, before the injection his boy been, had, before the injection he's OK, but after the injection that little boy changed really a lot. (P13, singles)

When I was pregnant, they found that I'd, for some reason I seem to have lost my immunity.

Which is a bit weird. Even though I did have rubella vaccine when I was younger. (P2, MMR on-time)

There was an outbreak and a number of children got something and they'd all been vaccinated against it. So it's, I don't think it's foolproof. (P22, no MMR)

Some parents questioned the safety of giving MMR to egg-allergic children, and a few postponed MMR on this basis. Some parents rejecting all vaccines had a different spin on the interaction between allergies and vaccines, suggesting a possible causal link.

Even though I know the doctors have said, even though it's so broken down people who are allergic to eggs can still have the MMR, I was still quite concerned that I haven't actually tried her on egg yet... I'd probably quite like to wait until I've tried her on eggs. (P18, no MMR)

I think all that happens is if we just keep vaccinating everything we, just our immune systems will just turn in, nut allergy, multiple sclerosis, Parkinson's you know? (P20, no MMR)

Vaccine schedule

Immune overload concerns were specific to parents opting to give no vaccines at all, but were related to the immunisation schedule as a whole rather than to combination vaccines. These parents felt the schedule is too full, starts too early (with timing motivated by population accessibility rather than clinical necessity), covers diseases too mild or uncommon to warrant vaccination.

I can't quote you the figures but you probably know but the number of jabs they have before their first birthday is loads, shocking you know? And their immune system's not even developed

properly and at that age... it just seems to be so much for a little person to take. (P19, no MMR)

And diphtheria, when was the last case of diphtheria in this country? It's those sort of questions you need answered, why are we vaccinating against diphtheria? There doesn't seem to me that there's actually medical reasons why you [vaccinate] at that stage except that's when they can catch [you] (P20, no MMR)

Maintaining the recommended four-week gap between vaccines was the most important aspect of the schedule for MMR acceptors, primarily to maximise vaccine effectiveness rather than to minimise immune overload risk. Where vaccine postponement was planned, turning two years old was a common milestone, due to language development, increased disease risk due to increased socialising, and perceived immune system maturity. Accordingly, being confident that their child was developing normally reassured some parents that MMR would be safe for them.

I am aware that you have to give at least 4 weeks from that booster ... I wouldn't go, I wouldn't have it a week, I wouldn't have it 3 weeks after. I'd rather wait 4 weeks, or even a bit longer. (P3, MMR on-time)

Yes but I made the decision I wanted to wait until two years... they have to learn how to talk... some of my friends they give this injection to their children and they don't talk (P10, MMR late)

I'll wait till they're two, that's my target... a lot of my friends waited till they were two ... it seems like a good point, so they start going nurseries and different things. (P17, singles)

If [my son] had been behind in his milestones and I felt concerned in terms of his development as a child... then I would have actually discussed it more with my health visitor, before I'd have just gone straight in with the MMR.... but you know he's a happy, well adjusted little boy... so, I don't have any concerns there. (P4, MMR on-time)

Vaccine ingredients

Parents rejecting all vaccines for their children were also concerned about the adjuvants and preservatives which some vaccines contain or have contained previously, with several linking mercury, thimerosal, and aluminium to side effects including developmental problems. Some of these parents drew a comparison between the expectation for parents to be aware of the ingredients of foods they give their children, but to accept vaccines with little information on their constituent parts. No parents accepting MMR or taking single vaccines mentioned ingredients.

So OK they've taken [mercury] out, that's great, but then what about all the other unpleasant things that might be in them. (P22, no MMR)

If you spilt the contents of one of the [vaccine] syringes it would be a biohazard, you'd have to severely clear up the room. (P24, no MMR)

If I was going to put a sun cream on my child I'd probably read the back of the label. If I was going to give them some paracetamol I'd probably see what the dose should be... but I once rang up the doctor and said, 'could you just send me the bit of paper inside the [vaccine package]' and they just thought I was mad (P20, no MMR)

Vaccine efficacy

Only parents rejecting all vaccines questioned vaccine efficacy, suggesting two routes to vaccine failure: immunity wearing off, and atypical disease strains increasing to take the place of the vaccinated strains. In contrast, some parents accepting MMR or single vaccines argued that the only reason vaccination may 'fail' is if not enough people take it up.

We don't know are we just going to end up with a load of teenagers who have these illnesses when they're teenagers or in their early adulthood when it's much worse? (P20)

[Vaccination is] 200 years old, but it's still not proven to be effective, it hasn't eradicated the diseases, they've [just] been renamed. What viruses will come down the line - bigger, more scary things? (P24, no MMR)

The reason why [diseases] don't go away is because not everybody's been vaccinated so we can't kill off viruses. (P7, MMR late)

3.4.1.2 Social context

Judging other parents' decision-making quality and motivation

Parents who rejected MMR questioned the extent to which most parents taking their course of action really understand the issues around their decision (and felt that they were unusual in having 'good' knowledge about or justification for rejection), whilst parents who accepted MMR doubted not the knowledge of MMR rejectors, but their motivation. However, MMR acceptors still defended all parents' right to choose whether to give vaccines.

I'd like to think that my decision [to reject MMR] was quite a considered decision but I think with some parents that's not necessarily the case. (P19, no MMR)

I have friends [who have] decided that you know measles mumps and rubella might not kill their child so they're not going to actually have them vaccinated, very healthy children, probably vaccination wouldn't hurt them in any way, maybe make them uncomfortable for a day like every other child... it's a very selfish decision (P12, MMR late)

Definitely every parent has the right to say no. It's their child and how they want to vaccinate their child is entirely up to them. (P4, MMR on-time)

Other parents were judged also on whether they had taken responsibility for their child's wellbeing, or absolved themselves of it. Parents across groups defined their own course of action as the most responsible one: MMR rejectors felt that acceptors had taken the easy option and

had rejected responsibility for maintaining their child's health; and MMR acceptors felt that rejectors had opted out of making a difficult decision and prioritised their fear over their child's health. Central to responsibility for both course of action was being prepared to spot and treat infection with disease or vaccine reaction.

I think the only people that make this decision lightly are the ones that just go and get it because they got the [invitation] in the post, those are the only people I think, not people who don't... the people who just go along with it, like sheep... oh, that person's doing it, everybody else says it's OK, so I'm just going to follow along. (P15, singles)

When you give your child vaccinations you're handing responsibility for its health over to a doctor. If you take back that responsibility I think you pay more attention to nutrition and general wellbeing of the child than they have otherwise. (P24, no MMR)

He's too young to make that decision. So when it comes to injections. When he's older then that's different. But when he's young and he's my responsibility. I have to make that decision. (P6, MMR on-time)

Being/feeling judged by others for your own decision

Being judged by others appeared to be a concern mainly for parents rejecting MMR or taking single vaccines. Rejectors in particular frequently referred to fellow parents, clinicians and partners evaluating their decision negatively, and some specifically resented accusations that their decision was ill-informed and based only on the MMR-autism link. Despite this expectation and fear of being judged, only one mother stated that she concealed her decision from others.

At the base root of it is [my doctors] think I'm negligent [for not giving my child vaccines] or because I have one child with autism they think I'm mad, they think I've gone that way. (P20, no MMR)

My husband thinks I'm a total lunatic for believing [in a possible link between MMR and autism]. As much as my GP and the Paediatrician believes it was influenced by the Professor [Wakefield] and his buddies, it was partially, not totally I have to say, but it's just a personal belief. (P17, singles)

There was a stigma, I have to admit, there was a bit of a stigma about it and actually I didn't, I'd never instigate the conversation and I'd prefer not to let on that she was unvaccinated. (P24, no MMR)

Some parents accepting MMR were motivated to vaccinate because they feared their parenting would be evaluated negatively, particularly by health professionals, if their child were to contract measles, mumps or rubella.

I'd feel really uncomfortable having to go into hospital and think that there are people looking at me thinking, my God, why didn't she get him vaccinated? Let her baby become ill and potentially die or whatever. (P8, MMR late)

Several mothers rejecting MMR or taking singles discussed having to justify their decision to their partner and to reassure him about the decision, however they did not expect their partners to have engaged in any personal research to justify their own position.

I can't say that my partner would be exactly the same if I wasn't around, he probably just would've gone with the flow. (P15, singles)

[My boyfriend] kept asking for evidence and where I was getting, he was questioning the information that I was quoting to him, so it made me do even more research and the more I found it made me more resolved. (P24)

Although, I have been trying to persuade my husband that [MMR is] a good idea. (P14, singles)

Judging and blaming oneself

Across decision groups, parents expected and feared guilt if their chosen course of action resulted in a negative outcome for their child. However for many parents, this was not a decision driver, as their anticipated regret following disease equalled their anticipated regret following vaccine reaction. In contrast, anticipated relief following reaction-free vaccine administration was a driver for some MMR or single vaccine acceptors, whilst the absence of such closure was a persistent weight for some rejectors.

I think I'd be more worried that she'd get one of the diseases and then I'd feel guilty for the rest of my life for not having given her the jab. But then again, if she got autism, I'd feel exactly the same. (P14, singles)

I feel, when he's had this jab, and everything is done and it is all okay. I will think phew, what a relief. I'm really glad I've done it. And I'm really glad he's all right. (P3, MMR on-time)

Ideally I'd like to forget about it and that's it I've made a decision, but it keeps popping into my life almost by coincidence... and that doubt could always creep in. (P24, no MMR)

Regret was ameliorated in different ways across the different decision groups. Acceptors expected their guilt would be tempered by the knowledge that they had followed expert advice, whilst those rejectors with an autistic child were comforted by the knowledge that they had not caused or worsened that autism through having vaccinated. One mother whose child had a reaction to the single measles vaccine felt that this vindicated her decision to opt for singles, on the assumption that an MMR reaction would have been much worse.

Whereas if you do vaccinate and then it turns out that there was a problem with the vaccine, well you were just doing the best with the knowledge that you had there. (P9, MMR late)

We think [son's autism] would have been more severe now if we hadn't made that decision [not to give any vaccines]. (P21, no MMR)

Some MMR accepting parents felt that strong anti-MMR views were desirable because they reflected being sure about the decision and being aware of all the risks around MMR. In contrast, some MMR rejectors felt that their own self-doubt and need for reassurance was underestimated.

I'd like to think I was really passionately against it, but I'm not. (P11, MMR late)

I'm not, I've known parents who are very gung-ho and they're very, no way and I'll go to prison before I vaccinate so but the rest, for a lot of us it's, God are we leaving our children unprotected? Maybe we're being mad and we're leaving our children unprotected. (P20, no MMR)

3.4.1.3 Vaccine providers, policy and research

Clinical judgment versus financial incentives and 'brainwashing' medical training

Perceived trustworthiness of health professionals, policymakers and researchers working in vaccination divided MMR acceptors and rejectors. The sense that vaccine providers' clinical judgment may be over-ridden by financial incentives and performance targets emerged strongly among MMR rejectors, though one parent who gave MMR late cited hospital doctors' perceived impartiality on these grounds as a reason why their MMR advice was particularly influential for her.

[Doctors] have targets, if they don't vaccinate everyone in their patient list then I think they lose money. So the, if they're using targets rather than looking at it on a child by child basis and whether or not the child should have it, then I think the motivations are money ultimately. (P24, no MMR)

It did make all the difference to me to know that someone totally separate from, not from NHS let's say but totally separate from whether or not he was going to get funding whether or not

my child would have the MMR or not... to hear it from those doctors was completely convincing (P12, singles)

MMR-rejecting parents also feared clinicians' medical training removes their ability to evaluate parent-reported vaccine adverse events objectively, and that this may compromise both the vaccination prescribing and their management of possible adverse events.

People have been trained while immunisation has been a big thing so I don't think you can get the debate from them unless for some reason their own research has taken them down a different path (P20, no MMR)

I've read about where people haven't had the right service when their child is suffering and if their child has a fit then, or dies, then we'll try and look for any other reason than vaccination.
(P24, no MMR)

Research adequacy and wilful versus accidental misconduct

Purposeful misconduct at vaccine policy level was considered highly unlikely by parents accepting MMR. Some MMR rejectors suggested that unintentional misconduct may have arisen from a lack of appropriate research (and cited previous bad policy based on flawed science, including birth defects caused by Thalidomide), but acknowledged that the research they considered appropriate (exploring predisposition to regressive MMR-related autism, not funded in any part by pharmaceutical companies) was almost impossible to do and that some problems with vaccines may only emerge with the passage of time. Some parents taking single vaccines agreed that current MMR-related evidence is incomplete (but did not describe how) and stated that they would not accept MMR until that presumed missing information was provided.

I don't think that the government would just kind of sit back and watch all these millions of kids having it done, on a daily basis, and not do anything, like put it on hold or anything like that.

(P11, MMR late)

They say that nothing's been proven but I just don't think that there's been enough research into it (P15, singles)

Health professionals sharing personal testimony

Trust was not influenced by whether health professionals were willing to share their experience of vaccination as a parent (e.g. whether they had vaccinated their own child) – though professional experience, particularly from a practitioner with a long career and a history of providing useful advice, moved some parents.

If I'd have been against it, [GP saying he'd vaccinated his own child] would not have swayed me at all. I'd say, thank you very much but that might be for you. I'm not sure it's for me. I'm not ready to make that decision yet. (P4, MMR on-time)

My health visitor said in all the years that she's been practising as a health visitor, she has never come across a baby that's had MMR and there been a problem. I trust her and she was a very good professional and yeah, so that did, you know I thought that's got a lot of weight to it. (P3, MMR on-time)

Using trust to simplify the decision, and reduce self-blame

MMR-accepting parents used trust in their health professionals both to minimise the complexity of influences on their decision by reducing the need to seek and evaluate alternative sources of

advice, and to minimise anticipated regret by 'sharing' the decision (therefore the blame for any negative outcomes) with an expert.

If something went wrong with the vaccine at least I listened to, I read all the information, listened to someone that knows a lot more than I do and if that was meant to be then I feel that that was meant to be but I wouldn't want to take all the responsibility on myself by choosing not to vaccinate my children (P12, MMR late)

I trust, maybe I'm ignorant, I don't know, but I just trust the medical field. If they say he has to have one every so often then I will just follow that. But I imagine they know what they're doing. (P9, MMR late)

Being/feeling pressured by one's health professional

Most parents rejecting MMR, and some opting for single vaccines, spoke of their health professional questioning their decision at most appointments, or their practice sending repeated MMR reminders. For some parents these interventions created trepidation around interaction with their clinician, whilst for others they were little more than an irritation; parents in the latter group linked their ability to deflect these approaches to their confidence in their decision.

I always get the speech no matter what I've gone in for so even if we've gone in for an ingrown toenail I get the speech... 'Have we talked about his immunisations yet?' (P19, no MMR)

Although I can access quite easily the GP, I don't look forward to it and I do sometimes dread it... they ask me every time what is she vaccinated, or why isn't she vaccinated? So they're not at peace with my decision. (P24, no MMR)

I know I can't be pressured [by GPs to give MMR] now, I know that I've made my decision and that's it, I'm not going to fall out with anyone over it but I would just say, I've made the decision that she's not having the MMR. (P20, no MMR)

Some parents identified a distinction between advice and reassurance from their health professional: reassurance was of no use to them during decision-making and in some cases damaged their relationship with their clinician.

I did go to the doctor and ask them [for advice about egg allergy] and they just said yeah, you should definitely give them the MMR... that was their information they gave me... it was more 'don't be so stupid' actually I would say (P18, no MMR)

3.4.1.4 Disease factors

Personal experience of relevant issues

Many parents across decision groups had experienced measles, mumps and rubella in themselves or their siblings as children. Most of these first-hand experiences were mild, with more serious episodes experienced only second-hand.

Four days I had measles for as a child then I was right as rain. People used to go to measles parties for God's sake so those kids weren't dropping like flies all over the place. (P19, no MMR)

My mum is quite deaf in one ear and that was because she had measles when she was a child. So you know I just think... if she'd had that option when she was younger then, to have the MMR, then that might have been a bit better than having a lifelong hearing problem. (P2, MMR on-time)

Severity

Generally MMR rejectors perceived vaccine-preventable diseases, particularly measles, to be mild, preventable through non-vaccine routes, and treatable, therefore not warranting vaccination. This perception was central to their mistrust of vaccine providers and policy, which were seen to force parents to take unnecessary risks with their children through a combination of fear appeals and inadequate education.

I'm not sure a lot of the immunisations that we have nowadays are actually necessary because I think a lot of those diseases were being eradicated through sanitation and better health and better diets. (P20, no MMR)

[Vaccines are marketed] on the basis of fear so you do it because you're frightened of getting ill. And I think that's, if the modern medical system can't manage a bout of measles then maybe they need to readdress things. There's no information on how would you treat measles, I had, I really struggled to find information on how to properly treat a child when they have measles. (P24, no MMR)

Some parents opting for single vaccines felt that particular components of MMR were more vital than others, and this was linked in some cases to the gender of their child. One mother distinguished between rubella and the other components, identifying that as purely about population protection, with no benefit for the immunised child.

She hasn't had rubella because I don't think it's necessary in a small child. At the end of the day, the main issue with rubella is protecting pregnant women and I don't think it's necessary in a child, no. Rubella doesn't kill children. (P15, singles)

Susceptibility

Two routes to increased disease susceptibility – therefore motives to vaccinate – were identified by parents accepting MMR or single vaccines: their child mixing with unimmunised people from overseas (both in their ethnically diverse local communities and during foreign holidays), and their child (or an older sibling) going to nursery or school. Disease outbreaks were also salient for these parents but were linked to different behavioural plans – expedited vaccination for MMR acceptors and avoidance of social situations for single vaccine takers. Vaccine rejectors were unmoved by the thought of outbreaks, with two participants disputing the terminology used.

The population of London is just mad isn't it? There's just so many people, so many - there's so many coming from abroad that you know whether they're having their children vaccinated is, seems very unlikely. So it's going to make it worse in the community. (P3, MMR on-time)

As a Sri Lankan I will be travelling to Sri Lanka because that's my home and with the baby also... mumps and er measles I'm not too very sure about rubella but mumps and measles I know that she's very, she could be at risk. (P1, MMR on-time)

As my older one will be starting nursery in September. I don't know what kind of children are going to be in his class. And I don't know whether they'll be vaccinated all of them or not. And my worry is also he'll be bringing things home for his younger brother. (P11, MMR late)

Even the language that's used around it, they call it a measles outbreak if there is an outbreak, sounds like the Ebola virus or something. (P24, no MMR)

Natural immunity

A distinction was also drawn between the groups on the possible benefits of natural immunity following disease. Parents across groups spoke of the benefits of boosting the immune system through good nutrition and exposure to low-level pathogens, but vaccine accepting parents drew

the line earlier than did vaccine rejectors on the severity of diseases for which natural immunity was safe. This was linked to controllability around timing and severity of wild infections.

Vaccination gives them that earlier build up of an immunity earlier rather than leaving it to chance maybe. Although it will happen, it will be at a slow rate. We can expedite that and make sure that he has his first exposure to measles in a controlled way. (P4, MMR on-time)

I'd be a bit worried that my son especially, if it was a difficult time of year, or he was in the middle of school, or exams, or we were on holiday, and he gets something and we don't know the country we've gone to. They don't have the right medical treatment or whatever... I'd rather kind of [control it]. (P11, MMR late)

I wouldn't consider completely natural because measles is something that can kill. (P15, singles)

3.4.1.5 Information needs

Partiality in most information sources

Three key sources of information were identified by parents across decision groups: official Department of Health leaflets, non-official internet sites/forums and media, and friends/family. Most parents felt that no source provided unbiased information.

Well I think the internet is crap anyway, for any kind of decision. But it was the only place where I could look. I mean I don't really speak to any of the health visitors, and if I did they'd probably tell me to do it anyway. So apart from the internet I don't know where else to look really. (P14, singles)

There's nobody you can talk to about your decision, there's either people being paid to give the vaccination or loonies on the web (P20, no MMR)

Official information (e.g. from the Department of Health)

Official information leaflets were considered ill-timed by MMR acceptors, and insufficiently detailed by MMR rejectors, though the latter group distinguished between their preferred level of detail and that which they assumed was preferred by the majority of parents. MMR acceptors clarified that they used these official leaflets primarily to educate themselves on disease and vaccine adverse event symptoms, not for evidence on outcome prevalence to support decision-making.

And also that leaflet that's the first thing for me, what are the adverse events. And could he experience potentially of these? Do I need to be aware of them? (P4, MMR on-time)

I didn't want to go in too much, I just wanted to see what are the symptoms of that [disease]. I want to be aware what should I look for. I want to know about diseases but not too much, just to the point that I have to know as a parent, trust the doctors. (P23, no MMR)

Non-official information (e.g. from media and websites)

Non-official information was considered more confusing because of the range of views offered, and because of this was linked to information paralysis and feeling overwhelmed by the decision. Media sources were felt to have 'hyped up' the MMR story for commercial benefit and were therefore trusted less than parent testimony. Parent testimony, however, was felt to be prone to erroneous attribution of cause and effect, and parents who contributed to online forums or kept blogs were perceived to have more extreme views than the general parent population.

The thing is, the more you read more scary things you'll find and you'll just suddenly say, oh, what shall I do? (P13, singles)

One minute some people were saying there's absolutely no reason and there's no scientific evidence, and then the next day there was someone was saying that yes there could be some risk. (P16, singles)

You don't know where [the media] get their information from and sometimes they just do it to sort of, oooh I don't know, like maybe sell papers or get extra viewing figures on their TV. (P3, MMR on-time)

Most of them, 99%, mums [who blog], they will like to go to the separate one if they can afford for it or if they can arrange for it, but in my friends, can I say 50/50 (P13, singles)

Lay information (e.g. from friends and family)

Lay information typically took the form of advice rather than evidence, and for most parents served as a prompt to gather further information; however some parents based their decision primarily on this 'second hand' evidence, whilst others found it of no use. Parents who opted for single vaccines were particularly reliant on unofficial information and advice from family and friends to identify a reputable clinic, as they found this information was unavailable elsewhere.

I didn't know much about [single vaccines] to be honest and then my sister in law... said she heard that there, some doctors think that there is a risk if they have it all together, and then that's why I did it really. (P16, singles)

As soon as I told Mum I was [going to accept MMR], when I was going to do it, she said, 'well I wouldn't if I was you, I would research it much better before you take such a decision'. I try not to be influenced by family members, so I haven't really spoken about it. Because I know they haven't researched it, so there's no point. (P14, singles)

3.4.2 Perceptions of MMR-related norms and probabilistic risks

3.4.2.1 Behavioural norms

Whilst parents across decision groups felt that MMR acceptance is the norm in the UK, they were less clear about (and typically underestimated) the frequency of deviation from the norm. Some parents rejecting MMR relished the relative rarity of their decision. Others sought (but were denied) reassurance from their vaccine provider that they were not alone in their choice.

I think we were also looking for reassurance that it does happen, people don't vaccinate, we certainly didn't get it from the GP. (P24, no MMR)

When I brought up statistics with the nurse of the practice and said, well, actually since the controversy, they have said immunisations in MMR are down on several years ago and that people are taking the time to think about it and she argued with me and said, no, you're wrong, 95% of people get the MMR, if not 98. And I said really? Well, OK, then I guess I'm in the 2%. (P15, singles)

For some, awareness of the rate of MMR non-immunisation legitimised their feeling of having been poorly treated by their clinician. For one mother who eventually took single vaccines after being undecided for some time, it raised new doubts about MMR safety. For another, it motivated expedited MMR immunisation by challenging her previous faith in herd immunity.

I think they need to take, certainly a better look at how they treat people who don't have it, when it's a pretty high percentage. (P15, singles)

After having read [a parenting forum thread about MMR], some lady said, 'oh I don't regret not giving my child the MMR'. Some [other members] said, 'I waited until they were 3 plus'. And I thought, 'oh God, why is everybody doing this!?' (P14, singles)

I didn't know that people wouldn't [accept MMR] but I, when I spoke to a friend of mine she was really against it and she knows, she has a whole group of friends who are against

vaccinating and don't vaccinate. And that really worries me. And I just thought, well I need to get these done to protect my own kids from when they go to school'. (P11, MMR late)

Many distinguished between normative behaviour among their parents generation versus among their own generation, suggesting that their parents accepted vaccines simply because compliance to authority was the norm – and some said they wished it were still the norm today. Most were vaccinated themselves as children, though several were not given the pertussis vaccine due to the 1970s-80s controversy.

I think in the 60s you just do what the doctor said. In some ways it was probably better. (P19, no MMR)

I had vaccinations as a child and as a teenager, although when I was very young, it was when there was some controversy around the whooping cough vaccination. So I know that I wasn't vaccinated against whooping cough. And I did contract whooping cough when I was about 7. My mum told me how she felt absolutely terrible after that, that we weren't vaccinated against it. (P2, MMR on-time)

3.4.2.2 Probabilistic risks

Across groups, parents struggled to ascertain the likelihood of vaccine reaction and of disease, perceiving probabilities from official sources to be inaccurate or biased, and estimates based on anecdotal or unofficial evidence to be unrepresentative. Official probabilities were felt to underestimate vaccine risks and failure rates and to overestimate disease risks, because vaccine adverse events are either ignored or concealed by health professionals, and because the purpose of these official estimates is to encourage vaccination, not to facilitate informed decision-making.

I'd quite like to know of those outbreaks what percentage of those children has actually had the vaccination and I suspect it's higher than they think. (P20, no MMR)

There's quite a lot of propaganda and they're telling you measles is life threatening, they'll reel out some new story of some poor child that was blinded, or lost their, that are very, very, very rare, much rarer than autism. (P19, no MMR)

NHS information it is only going to tell you what they want it to tell you ... it tells you facts and figures, I'm not saying disputing the facts and figures that they give you, but there's other facts and figures out there that they don't necessarily give you. (P22, no MMR)

Anecdotal evidence was not perceived to be purposefully biased, but prone to erroneous and subjective reporting, and often of limited relevance to one's own circumstances. Accordingly, anecdotal evidence alone was considered insufficient for decision-making – but sufficient to create worry.

You make a judgement about your surroundings rather than on you know what's been written [in the papers] and to be honest yeah, I don't really have time to sit and read and [assess] where things went wrong. (P11, MMR late)

There were a few mums [on a TV debate] that said they would give the vaccination. And a few mums calling that their kids got sick. One mum did call that her kid got autism, I think. And when you hear things like that it makes you think about it again, rethink what you had in your mind before, even if you decided, yes I'll give it. And when you hear one woman is calling and she says think twice because her son got, well it's not confirmed it's because of that, but... it is stuck in my head, yeah. (P23, no MMR)

No parent stated that they engaged in explicit weighting of vaccine reaction probability against disease probability, instead risk-benefit analysis centred on the severity of the outcomes.

However, several parents who rejected MMR or gave single vaccines were put off MMR by the absence of a risk statistic for the MMR-autism link.

I've never seen any data from parents that have said, well I gave my child this vaccine and then they started to regress... I haven't seen any number crunching or anything on that (P19, no MMR)

I've like tried to search online to see how many cases of autism [are linked with MMR]. But I can't find any statistics. Which would probably sway me even more if I saw statistical evidence. (P14, singles)

3.5 Discussion

3.5.1 Main findings and comparison with other studies

The 24 mothers who participated in this study shared five key areas of thought informing their MMR dose 1 decision-making process:

- Beliefs about MMR vaccine, the controversy surrounding it, and the alternatives to taking it;
- Trust in and satisfaction with the health professionals who provide MMR, the policy to which those professionals work, and the research on which that policy is based;
- Availability and satisfaction with information about MMR and alternative courses of action from official and unofficial sources;
- Perceptions of the severity and local prevalence of measles, mumps and rubella infections;

- The social and personal consequences of the MMR decision.

These broad themes are directly comparable with those which have emerged in previous qualitative studies of MMR decision-making (Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005), and in more recently published work along similar lines (Austin, Campion-Smith *et al*, 2008; Tarrant & Thomson, 2008; Skea, Entwistle *et al*, 2008; Gardner, Davies *et al*, 2010; Tickner, Leman *et al*, 2010). The specific issues discussed within each theme, and the different views among groups of parents making different MMR decisions, also largely replicate those identified previously

A number of new themes emerged in this study. Firstly, several parents spontaneously mentioned Dr Andrew Wakefield (the author of the Lancet article which ignited the MMR controversy in 1998: Wakefield, Murch *et al*, 1998), and though the quality of his original paper was criticised across decision groups, Wakefield himself was viewed sympathetically even by some MMR acceptors. This novel finding may suggest that the Professional Misconduct case brought against Wakefield by the General Medical Council which opened in July 2007 (General Medical Council, 2010), around six months before the interviews took place, served for some parents to highlight the personal consequences of the MMR controversy for Wakefield rather than the wider public consequences of the controversy for MMR uptake, perhaps tempering the positive impact of the ruling on those parents' MMR attitudes and uptake. Secondly, it emerged that among parents taking single vaccines, immune overload from the combination MMR was not a salient concern. Instead, there was a sense that MMR is simply an unsafe vaccine, but exactly why it is unsafe is not known. The desire to avoid MMR was compounded for some parents by the feeling that not all the diseases against which it protects actually warrant vaccination. This may indicate that some general anti-vaccination arguments (as voiced by most of the MMR rejecting group in this study), including worry about vaccine additives and doubts about the necessity of vaccination, are

taking the place of MMR-specific concerns which were previously seen to motivate rejection of combined MMR. Thirdly, the risk of infectious disease was linked with immigrants in the UK and with travel abroad. Parents have previously been shown to consider some childhood infectious diseases of little concern in the UK today (Evans, Stoddart *et al*, 2001), but this sense that immigrant populations challenge the relative infrequency of infectious disease in the UK is novel, and may reflect a wider general dissatisfaction with the volume of UK immigration (Department for Communities and Local Government, 2010). Fourthly, many parents in this study criticised other parents' MMR decisions and decision-making, and MMR-rejecting parents often discussed feeling and being judged by other parents. This explicit tension between parents across and within decision groups has been observed infrequently elsewhere (Skea, Entwistle *et al*, 2008) and may reflect a shift toward MMR non-vaccination becoming socially unacceptable.

3.5.2 Strengths and limitations

This study overcame a number of methodological limitations which have blighted much of the qualitative evidence base on MMR decision-making. Analytic biases were countered through member checking and coding by two analysts, MMR uptake was assessed objectively, and decision-making data were collected prospectively. Participants were recruited from a range of sources in order to obtain views broadly representative of the general parent population rather than of 'activist' groups, language support was used to facilitate participation from a mother who would have otherwise been excluded as she spoke no English, and collecting data from parents across the MMR decision spectrum facilitated comparison within and between groups. However, the study is not without limitations. The interpretation of coded data was completed by a single analyst and only informally discussed with the second analyst, therefore bias could have remained at this stage. Member checking prior to interpretation but following coding may add little to the final analysis, because participants' may fail to comprehend or be unwilling to

challenge coding, with bias in interpretation thus potentially unchecked (Morse, Barrett *et al*, 2002). Chain referral proved vital to recruit parents refusing MMR, but as a result this decision group mainly comprised parents who had rejected all vaccines and who knew one another through an autism support network (three were parents of an autistic child), thus this group may have held views specific to their shared personal situation. Recruitment through GP practices may have been biased not only by which parents visited the practice, as parents rejecting standard vaccination were by definition less likely to attend, but also by some practice nurses' reluctance to inform perceived 'difficult' parents about the study. Whilst the data were analysed in line with the Grounded Theory method, it is recommended that data collection and interpretation takes place before the directly relevant literature is reviewed lest that knowledge influences the process (Glaser & Strauss, 1967; Strauss & Corbin, 1998), therefore the analysis presented here may not be wholly grounded in these new data alone.

3.5.3 Implications for policy and practice

Findings from qualitative research are not designed to be generalised as the sample is small and selective, however the present study adds to the canon of qualitative evidence on MMR decision-making which as a whole provides useful insight to inform policy and practice. Further, by replicating many of the findings from this body of work, the present study supports the validity of those previous findings despite their lack of methodological rigour. This study indicates, as others have previously, that trust in health professionals and vaccine policy is central to acceptance of MMR, and that this trust is undermined by perceived financial motives for promoting vaccination within the NHS, but also that some parents acknowledge single vaccine clinics exploit parent fear for profit. Policymakers and practitioners may consider clarifying the amount which GP practices receive per child per MMR dose, and comparing that with the substantially higher payments made by parents to single vaccine clinics. Further, the study suggests that perceptions of disease

severity and vaccine efficacy inform MMR decisions both directly and via trust in clinicians and policy. A GP who promotes a vaccine which a parent feels a) provides inconsistent or short-lived protection, and b) prevents a disease which is mild and treatable, may be perceived by that parent to lack professional competence, and to have prioritised their own (perhaps financial) motives above the patient's best interests; and as competence, fidelity and honesty are necessary conditions for trust (Hall, Dugan *et al*, 2001), this GP is likely to be mistrusted by the patient. Because of this dual mechanism, effective communication of vaccine and disease risks and benefits may be particularly central to improving MMR uptake, and should be a focus of policy and practice.

3.5.4 Directions for future research

The present study demonstrates that MMR decision-making can be effectively explored using a methodologically robust qualitative approach. Whilst the methodological limitations of previous work may have not unduly affected their findings, more rigorous work like this adds methodological robustness to the literature and may be viewed more favourably by policymakers and practitioners (Petticrew & Roberts, 2003; Hawker, Payne *et al*, 2002). On the basis of this study, further qualitative work may seek to explore the impact of the recent GMC Professional Misconduct ruling against Dr Wakefield (GMC, 2010); perceptions, understanding and information sources around vaccine ingredients; and the evolution and impact of perceived behavioural norms. Concern and knowledge about financial motives underpinning NHS vaccination practice and policy may be a priority for quantitative study.

3.6 Conclusions and next steps

My qualitative study showed that parents making decisions about MMR dose 1 considered a broad range of factors: the vaccine and the controversy around it, trust in their health professional and the wider policy/research environment, adequacy of official and unofficial advice and information, disease risk, and the social consequences and contributions of their choice. These findings confirmed the salience of these five factors for parents, and cemented their inclusion in my MMR attitudes measure in the next chapter, and in my multifactorial models in Chapters 5 and 7. Further, these findings showed that parents were unclear about behavioural and outcome norms, indicating that traditional definitions of the 'normal behaviour' or 'omission' in vaccination decision-making may underestimate the complexity of the situation for parents. My omission bias study in Chapter 6 explores this further.

4 Attitudinal and demographic predictors of measles, mumps and rubella (MMR) vaccine acceptance:

**Development and application of a reliable and valid
measurement tool**

4.1 Preface

My systematic review (Chapter 2) indicated common methodological limitations and substantial conceptual disparity in quantitative studies seeking to understand parents' MMR decision-making. Many studies had assessed MMR uptake using parent report rather than through reference to objective records, most studies had failed to control for demographic factors in their analyses on attitudinal predictors of uptake, and in the absence of a standard validated measure of relevant attitudes and demographics in this area the focus, scope and methods of measurement varied widely. These factors in combination rendered the evidence base disjointed, incomplete, of questionable validity, and of limited utility because quantitative synthesis was precluded.

My review (Chapter 2) thus identified a clear need for studies to overcome these methodological limitations. I concluded that developing a comprehensive evidence-based measure and validating it against objectively assessed MMR status through univariate and multivariate analyses would a) contribute high-quality new data to the presently lacking evidence base, b) facilitate my own further research and c) provide a vital tool for research and practical applications elsewhere. In addition to this contribution to the wider MMR decision-making research arena, this study allowed me to confirm which central themes should be included in my multivariate hypothetical vaccine decision-making models reported in Chapters 5, 6 and 7.

This two-part chapter therefore reports the development and validation (Part 1) and further application (Part 2) of my evidence-based MMR attitudes and demographics measure.

4.2 Part 1: Development and validation of the instrument

4.2.1 Introduction

Whilst access issues preclude MMR uptake for a significant minority of UK parents (National Institute for Health and Clinical Excellence), a recent large epidemiological study indicates that for around 75%, MMR non-immunisation is a product of conscious choice based on doubts around vaccine safety, efficacy and necessity (Pearce, Law *et al*, 2008). This key role for attitudes in MMR uptake is further supported by evidence from numerous smaller cross-sectional quantitative and qualitative studies, which find opinions about MMR differ between MMR acceptors and MMR rejectors (Brown, Kroll *et al*, 2010a; Roberts, Dixon-Woods *et al*, 2002; Falagas & Zarkadoulia, 2008; Mills, Jadad *et al*, 2005); and by the longitudinal MMR attitudes 'tracker' studies (Smith, Yarwood *et al*, 2007) which find that the MMR-related attitudes of representative UK population samples move in line with MMR uptake in the population overall (i.e. as attitudes improve so does MMR uptake).

Whilst this body of evidence demonstrates a general link between MMR-related attitudes and MMR intention/behaviour, it provides a limited basis for interventions, as methodological limitations prevent analysis of the relative importance of specific attitudes in predicting MMR behaviour. First, the absence of a validated 'gold standard' measure renders measurement of MMR-related attitudes in quantitative studies inconsistent, and precludes meta-analysis and reliable extrapolation of existing data (Brown, Kroll *et al*, 2010a). Instrument length varies widely: from a single open-ended item identifying the main reason why no MMR has been received (Pearce, Law *et al*, 2008), through more structured theory- and evidence-based questionnaires with tens of items (Casiday, Cresswell *et al*, 2006, Tickner, Leman *et al*, 2010), to highly detailed

tracker study instruments containing around 100 items (Smith, Yarwood *et al*, 2007). Instrument content is similarly variable: most tools assess only a subset of factors identified in the literature as predictors of parents' MMR behaviour/intention (Brown, Kroll *et al*, 2010a), and none to my knowledge are psychometrically validated (i.e. their capacity to adequately, reliably and consistently measure constructs of interest has not been tested). Second, the dominance of self-reported MMR uptake or intention, rather than objective assessment of coverage using General Practice or Primary Care Trust records (Brown, Kroll *et al*, 2010a), may compromise the validity and generalisability of individual study results. Whilst UK evidence on the reliability of parental recall of their child's measles-containing vaccine (MCV) immunisation status is sparse, US data suggest parental self-report typically overestimates vaccine coverage in comparison with objective measures (Hawe, Wilson *et al*, 1991; Suarez, Simpson *et al*, 1997; Bolton, Holt *et al*, 1998).

The present study aimed to address these methodological issues. I sought to develop and validate a scientifically robust and practically feasible MMR attitudes measurement instrument, aiming to overcome methodological limitations currently weakening the evidence base through evidence-based item selection, psychometric validation, and objective outcome assessment. The instrument was designed to robustly capture and quantify univariate and multivariate predictors of MMR uptake in both clinical and research applications.

4.2.2 Methods

4.2.2.1 Participants

2,952 children aged 4-16 years were selected from Child Health Information Systems (CHIS) in three UK Primary Care Trusts (PCTs: two in London, one in north-west England) between May and

December 2009. Children unimmunised or partially immunised with MMR were oversampled in order to compensate for the expected poorer response rate among parents of this group (Brown, Kroll *et al*, 2010a), and the sample was stratified by child age. PCTs provided postal and telephone contact details for the parent/guardian(s) of each child, the child's date of birth and MMR dose history.

4.2.2.2 Measurement instrument development

The instrument (Figure 4.1) was designed to display and to be assessed on a number of psychometric properties, which in combination indicate a robust measure (Anastasi & Urbina, 1997). The properties sought and the design steps taken to attain and test them are described below.

Content validity is the comprehensive assessment of all domains of interest for the instrument; in this case, the spectrum of attitudinal and demographic factors known to be relevant to parents' MMR decision-making. This property was attained by including a question on each of the 20 attitudes and seven demographics on which MMR-accepting parents and MMR-rejecting parents have been shown to significantly and consistently differ. These attitudes and demographics were identified through recent systematic reviews of relevant quantitative and qualitative evidence (Brown, Kroll *et al*, 2010a; Roberts, Dixon-Woods *et al*, 2002; Falagas & Zarkadoulia, 2008; Mills, Jadad *et al*, 2005), and through a recent large UK epidemiological study of demographic predictors of MMR intention/uptake (Pearce, Law *et al*, 2008). The items span attitudes toward five key dimensions: MMR vaccine, measles infection, social influences, information sources, and practical barriers. Attainment of this property was qualitatively tested through feedback from expert members of the project team (not reported).

Figure 4.1: Measurement instrument





Any questions about this survey?
Call 020 7594 3062

Please tell us more about your MMR decision

Please answer all questions in relation to the child named on the letter which came with this survey.

Here are some beliefs which parents may have about MMR (the vaccine) and measles (the disease).
Please tick ONE box for EACH belief to show how much you agree with that belief. Give an answer for every belief.

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
<i>EXAMPLE: I care very much about my child's welfare</i>	☐	☐	☐	☐	☒
1. MMR has serious side effects	☐	☐	☐	☐	☐
2. Measles is a serious illness	☐	☐	☐	☐	☐
3. MMR will protect my child against measles	☐	☐	☐	☐	☐
4. I have seen or heard about bad reactions to MMR	☐	☐	☐	☐	☐
5. I have seen or heard about bad cases of measles	☐	☐	☐	☐	☐
6. MMR is too much for my child's body to cope with	☐	☐	☐	☐	☐
7. I'd prefer to give single measles, mumps and rubella shots	☐	☐	☐	☐	☐
8. Without MMR, it is likely that my child will catch measles	☐	☐	☐	☐	☐
9. It is better to get natural immunity by catching measles	☐	☐	☐	☐	☐
10. I trust my GP and nurse to advise me about MMR	☐	☐	☐	☐	☐
11. Not enough scientific research has been done on MMR	☐	☐	☐	☐	☐
12. I'd like to protect other children by giving my child MMR	☐	☐	☐	☐	☐
13. I have done my own research about MMR (e.g. online)	☐	☐	☐	☐	☐
14. I have not given my other children MMR	☐	☐	☐	☐	☐
15. I do not believe newspaper and TV stories about MMR	☐	☐	☐	☐	☐
16. I would feel very bad if my child caught measles	☐	☐	☐	☐	☐
17. I would feel very bad if my child had a reaction to MMR	☐	☐	☐	☐	☐
18. I started thinking about MMR before my child was born	☐	☐	☐	☐	☐
19. Time/transport/cost makes it hard to take my child for MMR	☐	☐	☐	☐	☐
20. People important to me think I should give my child MMR	☐	☐	☐	☐	☐

21. In the past year, have you received a letter from your GP or PCT inviting you to bring your child for MMR?

☐ Yes
☐ No
☐ Not sure / don't remember

22. How old are you?

☐ 14-19 years
☐ 30-34 years

☐ 20-24 years
☐ 35-39 years

☐ 25-29 years
☐ 40 years +

23. What is your gender?

☐ Female

☐ Male

24. What is your highest educational qualification?

☐ None
☐ Degree

☐ GCSE
☐ Postgraduate

☐ A/AS level
☐ Other (explain).....

☐ Diploma

25. What is your ethnic group?

☐ White British
☐ White Other

☐ Black British
☐ Black other

☐ Asian British
☐ Asian other

☐ Other British
☐ Other/mixed

26. How many children live with you?

☐ 1
☐ 2

☐ 3

☐ 4 or more

27. What is your marital status?

☐ Single
☐ Living with partner

☐ Married

☐ Other

28. What is your job?

Please write in

Thank you for your time. Please return this survey by post, in the freepost envelope supplied

Internal consistency is the capacity of the instrument to obtain internally correlated responses to individual items which are intended to measure a shared broader construct. It is psychometrically desirable to group items together in scales as this reduces the possibility of measurement artefacts or outlying responses on a single item skewing the data. Grouping items also increases statistical power and provides clearer direction for intervention design. This property was attained by grouping together items which are conceptually linked and which have been correlated elsewhere in the literature (Brown, Kroll *et al*, 2010a). Attainment of this property was statistically tested by obtaining Cronbach's alpha coefficients for each of the scales.

Test-retest reliability is the capacity of the instrument to obtain consistent responses at two timepoints between which the attitudes assessed would not be expected to differ. This was attained through a) item selection and phrasing designed to tap stable 'evidence-based' cognitions rather than more changeable emotional states, and b) simple low-literacy questionnaire design including an intuitive and familiar five-point response scale, coupled with some reverse-scored items to encourage careful consideration of each one rather than rote answering. Attainment of this property was statistically assessed by administering the instrument to a subset of respondents at two timepoints and correlating responses.

Concurrent validity is the capacity of the instrument to distinguish between groups which are expected to differ on the measured items/scales. This was attained by assessing attitudes in the instrument on which parents have been shown to differ by their child's MMR status. Attainment of this property was statistically tested by comparing responses to each individual attitude item and each attitude scale between three participant subgroups: those whose child received MMR on-time, those whose child received MMR late, and those whose child did not receive MMR.

Predictive validity is the capacity of the instrument to predict an outcome which is expected to be predictable from the domains measured. This was attained again by assessing attitudes in the instrument which have been previously shown to relate to MMR intention/uptake. Attainment of

this property was statistically tested by entering all items assessed in the measurement instrument (both individually and as scales) into hierarchical logistic regressions with child's MMR status as the outcome.

4.2.2.3 Procedure

The Health Protection Agency classified the study as a service evaluation not requiring ethical approval. Consent to participate was implied through study completion. A copy of the instrument was posted to the parent/guardian of every child in the sample, along with a cover letter (Figure 11.8, Chapter 11 Appendices) explaining the purpose and provenance of the study, a freepost return envelope, and a translation sheet advising (in seven languages most commonly used in the PCTs: Arabic, Farsi, Polish, Punjabi, Somali, Tamil and Urdu) that translations were available on request. At 3 and 6 weeks after the first copy was sent, non-respondents received a reminder letter with another copy of the instrument and enclosures, to a maximum of two postal reminders per household. At 4 and 7 weeks after the first copy was sent, a telephone reminder was administered to non-respondents with a working telephone number provided by the PCT: a total of four attempts per reminder (2 daytime, 2 evening) were made, to a maximum of two answered calls or answerphone messages per household. During telephone reminders an interpreter was available, and participants were invited to respond to the instrument during the call rather than return their copy by post. A subset of 225 participants who responded to the first copy of the instrument with no reminders were sent a test-retest duplicate with enclosures and a cover letter explaining the purpose of the duplicate, approximately 3-6 weeks after they returned their first copy; no reminders were sent in relation to the test-retest duplicates.

CHIS-recorded MMR dose history at 5th birthday, and postcode-level Indices of Multiple Deprivation 2007 data (IMD2007 (Department of Communities and Local Government, 2007)), were obtained for the entire sample when every child had turned 5 years old. Where MMR dose history obtained at the end of the study period differed from that provided at the start, the most up-to-date history was used. For analysis, MMR dose history was categorised in line with HPA COVER methodology (Health Protection Agency, 2010) and the UK Department of Health immunisation schedule (Department of Health, 2007) during the study period: for MMR dose 1 analyses, “on-time” was defined as dose received up to and including child’s 2nd birthday, “late” was defined as dose received after child’s 2nd birthday up to and including child’s 5th birthday, and “none” was defined as no dose received by day after child’s 5th birthday. For MMR dose 2 analyses, “on-time” was defined as dose received after 3 years 4 months (recommended age for MMR dose 2 in immunisation schedule) up to and including child’s 5th birthday, and “none” was defined as no dose received by day after child’s 5th birthday. Free-text responses to the job item were coded by two independent analysts (good agreement between analysts: Cohen’s Kappa=0.91) to the 8-class version of the National Statistics Socio-Economic Classification (NS-SEC (Office for National Statistics, 2005)), where code 1 is the highest socio-economic class (higher managerial/higher professional/large employer) and code 8 the lowest (never worked/long-term unemployed/student etc); respondents classifying themselves as ‘mother’, ‘housewife’ or similar were coded to category 8.

4.2.2.4 Analysis

Data were analysed using SPSS v 17.0 (SPSS Inc). Response rates and respondent characteristics were assessed using all available data on the entire sample. Test-retest reliability analyses (Pearson’s *r* correlation coefficients) and tests of internal consistency of predefined attitude scales (Cronbach’s alpha coefficients) were conducted using the raw data. Subsequently, missing

values were imputed using within-participant scale means for scales of 5 items or more where up to 2 items were missing. Scale scores were calculated by summing scores (including imputed values) for individual items comprising the scale then dividing by the number of items in the scale.

In univariate analyses with nominal outcomes (parent ethnicity, parent marital status, MMR status category), Chi-square tests (unadjusted) and ordinal regression (adjusted for child age and IMD2007 score) were used. Ordinal outcomes (child age, parent age, education, number of children, occupation) were compared using Mann-Whitney tests and Kruskal-Wallis tests (unadjusted) and ANCOVA (adjusted as before). Scale outcomes (all attitude items, child age, IMD2007 score) were compared using independent samples t-tests and ANOVA (unadjusted) and ANCOVA (adjusted as before). Post-hoc pairwise comparisons (on-time vs late, late vs none, on-time vs none) were conducted for all three-group analyses using Mann-Whitney tests, Z tests, and post-hoc main effects comparison with Bonferroni correction for multiple comparisons.

Hierarchical logistic regressions were used to identify and quantify independent predictors of receipt and non-receipt of each MMR dose (late recipients of MMR dose 1 were excluded from these analyses). Predictors were entered in three steps starting with those expected, based on the literature, to be most predictive: first were objective demographics, then subjective (self-report) demographics, and finally attitudes.

4.2.3 Results

4.2.3.1 Response rate and respondent characteristics

535 (18.1%) parents/guardians completed the questionnaire. Responders were more likely than non-responders to have given their children MMR on time (timeliness of dose 1 $p < 0.001$,

timeliness of dose 2 $p<0.05$), to have younger children ($p<0.01$), and to live in less deprived postcode areas ($p<0.001$). Detailed data on respondent characteristics are shown in Table 4.1.

Table 4.1: Response rates and representativeness

	n	n(%) / Mean(SD)		p
		Responders	Non-responders	
MMR1 status at end of data collection†				
None	1384	224 (16.2)	1160 (83.8)	<0.05
Late	384	66 (17.2)	318 (82.8)	
On-time	1184	245 (20.7)	939 (79.3)	
MMR2 status at end of data collection†				
None	2327	369 (15.9)	1958 (84.1)	<0.001
On-time	625	166 (26.6)	459 (73.4)	
Child age (days) when MMR uptake data collected ‡	-	3698 (1353)	3875 (1411)	<0.01
IMD2007 score‡	-	26.20 (14.68)	30.66 (16.70)	<0.001
Total	2952	535 (18.1)	2417 (81.9)	-
†: n(%), p values for Chi-square test; ‡: mean(SD), p values for independent-samples t-test				

4.2.3.2 Internal consistency and test-retest reliability

Reliability and consistency analyses are presented in Table 4.2. Internal consistency was acceptable for each of the four scales (Cronbach's alpha 0.55 – 0.75) (Cortina, 1993), particularly given their small number of items and their intended purpose to compare between groups rather than within individuals. Test-retest reliability was good for all attitude scales ($r>0.80$, $p<0.01$) (Salkind, 2006) and was acceptable ($r>0.60$, $p<0.001$) for over half of the individual attitude items. Overall, the MMR individual items and scale were the strongest elements of the questionnaire.

4.2.3.3 Concurrent validity (univariate predictors of MMR receipt)

Concurrent validity analyses for the attitudes element of the instrument are presented in Table 4.3. Concurrent validity was demonstrated for over half of the individual attitude items and three of the five attitude scales. Eleven individual items predicted both MMR dose 1 and MMR dose 2 receipt ($p < 0.05$), many of which were MMR attitudes and information source attitudes, and none of which were measles attitudes. Chief among them in terms of effect size were preference for single measles, mumps and rubella vaccines (partial Eta squared = 0.06-0.09, thus 6-9% of variance in MMR receipt explained), previous MMR acceptance/rejection (5-9% variance explained), and wishing to protect others through vaccinating one's own child (6-8% variance explained). The MMR attitudes, social attitudes and information attitudes scales all predicted both MMR dose 1 and MMR dose 2 receipt ($p < 0.001$) with small to medium effects (4-10% variance explained by each scale; Stevens, 2002). The measles scale predicted only dose 1 receipt ($p < 0.05$) but the effect size was very small (1% variance explained) and no pairwise comparisons were significant. Adjustment for child age and deprivation generally had minimal effects on differences between MMR status groups, and the items on which adjustment effects were observed were more strongly related to MMR status among parents of younger children, who were concentrated in the late MMR dose 1 and on-time MMR dose 2 groups. Generally parents who gave their child MMR dose 1 on time differed from parents who gave no MMR but not from parents who gave MMR late.

Concurrent validity analyses for the demographics element of the instrument are presented in Table 4.4. Only parent ethnicity predicted both MMR dose 1 and MMR dose 2 receipt, with white British parents less likely than parents in other groups to give their children either dose on time. This effect persisted when child age and deprivation were controlled for ($p < 0.001$ – $p < 0.05$). Children aged 5-6 were significantly more likely to have received MMR dose 1 late than on-time or not at all ($p < 0.001$), but MMR status did not vary by child age for older children or for MMR dose 2. On-time receipt of

MMR dose 2 was associated with smaller family size ($p < 0.05$) and married parents, though the latter relationship appeared to be a function of deprivation (adjusted $p > 0.05$), as married parents were less likely than other parents to be deprived ($p < 0.001$).

Table 4.2: Internal consistency and test-retest reliability

Scale (n)	Item (n)	Test-retest: Pearson's <i>r</i> (p-level) ^a		Scale internal consistency	
		Item	Scale	Cronbach's alpha	N missing data
MMR Attitudes (411)	MMR has serious side effects [†] (518)	0.76 (<0.001)			
	MMR will protect my child against measles (519)	0.30 (<0.05)			
	I have seen or heard about bad reactions to MMR [†] (521)	0.67 (<0.001)			56 missing 1
	MMR is too much for my child's body to cope with [†] (519)	0.80 (<0.001)	0.89 (<0.01)	0.75	17 missing 2
	I'd prefer to give single measles, mumps and rubella shots [†] (516)	0.90 (<0.001)			11 missing 3+
	I have not given my other children MMR [†] (452)	0.76 (<0.001)			
	I would feel very bad if my child had a reaction to MMR [†] (512)	0.64 (<0.001)			
Measles Attitudes (488)	Measles is a serious illness (518)	0.38 (<0.01)			
	I have seen or heard about bad cases of measles (515)	0.59 (<0.001)			49 missing 1
	Without MMR, it is likely that my child will catch measles (521)	0.65 (<0.001)	0.86 (<0.01)	0.63	10 missing 2
	It is better to get natural immunity by catching measles [†] (516)	0.75 (<0.001)			13 missing 3+
	I would feel very bad if my child caught measles (521)	0.45 (<0.001)			
Social attitudes (505)	I'd like to protect other children by giving my child MMR (516)	0.68 (<0.001)	0.80 (<0.01)	0.68	-
	People important to me think I should give my child MMR (514)	0.58 (<0.001)			
Information attitudes (486)	I trust my GP and nurse to advise me about MMR (523)	0.53 (<0.001)			
	Not enough scientific research has been done on MMR [†] (519)	0.66 (<0.001)			36 missing 1
	I have done my own research about MMR (e.g. online) [†] (508)	0.72 (<0.001)	0.80 (<0.01)	0.55	11 missing 2
	I do not believe newspaper and TV stories about MMR (518)	0.35 (<0.01)			15 missing 3+
	I started thinking about MMR before my child was born [†] (514)	0.55 (<0.001)			
Practicalities (518)	Time/transport/cost makes it hard to take my child for MMR [†] (518)	0.49 (<0.001)	-	-	-

†: Reverse scored. a: Test-retest n=79

Table 4.3: Concurrent validity (univariate analyses of attitudes items and scales)

	<i>n</i>	MMR dose 1						MMR dose 2				
		Mean (SD) / n (%)			Comparison			Mean (SD) / n (%)		Comparison		
		On-time	Late	None	Unadj	Adj ^a	Adj. Effect size ^d	On-time	None	Unadj	Adj ^a	Adj. Effect size ^d
		208-240	57-66	187-223				140-162	312-367			
Individual items												
MMR has serious side effects†		3.2 (1.1) ^b	2.9 (1.0) ^{bc}	2.7 (1.1) ^c	<0.001	<0.001	0.05	3.2 (1.1)	2.9 (1.1)	<0.001	<0.001	0.02
Measles is a serious illness		4.3 (0.8) ^b	4.3 (0.7) ^b	4.2 (0.9) ^b	0.18	0.13	0.01	4.3 (0.8)	4.2 (0.9)	0.12	0.16	0.004
MMR will protect my child against measles		4.1 (0.9) ^b	4.1 (0.7) ^b	4.0 (0.9) ^b	0.16	0.13	0.01	4.1 (0.9)	4.0 (0.9)	0.16	0.18	0.003
I have seen or heard about bad reactions to MMR†		2.7 (1.1) ^b	2.3 (1.1) ^{bc}	2.3 (1.2) ^c	<0.01	<0.01	0.02	2.7 (1.1)	2.3 (1.1)	<0.001	<0.001	0.03
I have seen or heard about bad cases of measles		3.6 (1.1) ^b	3.6 (1.1) ^b	3.7 (1.0) ^b	0.58	0.70	0.001	3.5 (1.1)	3.6 (1.1)	0.26	0.21	0.003
MMR is too much for my child's body to cope with†		3.6 (1.1)	3.1 (1.1) ^b	3.0 (1.2) ^b	<0.001	<0.001	0.01	3.6 (1.1)	3.2 (1.2)	<0.001	<0.001	0.03
I'd prefer to give single measles, mumps and rubella shots†		3.2 (1.1)	2.5 (1.2) ^b	2.4 (1.3) ^b	<0.001	<0.001	0.09	3.2 (1.1)	2.6 (1.3)	<0.001	<0.001	0.06
Without MMR, it is likely that my child will catch measles		3.6 (1.0) ^b	3.3 (1.0) ^b	3.3 (1.0) ^b	<0.05	0.06	0.01	3.6 (1.0)	3.4 (1.0)	0.06	0.05	0.01
It is better to get natural immunity by catching measles†		3.8 (0.9) ^b	3.5 (0.9) ^b	3.6 (1.0) ^b	0.07	<0.05	0.01	3.8 (1.0)	3.6 (0.9)	0.18	0.23	0.003
I trust my GP and nurse to advise me about MMR		4.0 (0.9) ^b	3.5 (1.0) ^{bc}	3.5 (1.1) ^c	<0.001	<0.001	0.04	4.0 (0.8)	3.6 (1.1)	<0.001	<0.001	0.03
Not enough scientific research has been done on MMR†		3.2 (1.0)	2.7 (1.0) ^b	2.6 (1.1) ^b	<0.001	<0.001	0.07	3.2 (1.0)	2.8 (1.1)	<0.001	<0.001	0.03
I'd like to protect other		4.0 (0.8) ^b	3.6 (0.9) ^b	3.3 (1.2)	<0.001	<0.001	0.08	4.0 (0.8)	3.5 (1.1)	<0.001	<0.001	0.06

	MMR dose 1						MMR dose 2				
	Mean (SD) / n (%)			Comparison			Mean (SD) / n (%)			Comparison	
	On-time	Late	None	Unadj	Adj ^a	Adj. Effect size ^d	On-time	None	Unadj	Adj ^a	Adj. Effect size ^d
children by giving my child MMR											
I have done my own research about MMR (e.g. online) [†]	3.0 (1.2) ^b	2.6 (1.2) ^{bc}	2.6 (1.1) ^c	<0.001	<0.001	0.03	3.1 (1.2)	2.7 (1.2)	<0.001	<0.001	0.03
I have not given my other children MMR [†]	4.2 (1.0)	3.5 (1.3) ^b	3.3 (1.4) ^b	<0.001	<0.001	0.09	4.2 (1.0)	3.6 (1.3)	<0.001	<0.001	0.05
I do not believe newspaper and TV stories about MMR	3.2 (0.9) ^b	3.1 (0.8) ^b	3.0 (0.9) ^b	0.06	0.06	0.01	3.1 (0.9)	3.1 (0.9)	0.60	0.58	0.001
I would feel very bad if my child caught measles	4.3 (1.0) ^b	4.1 (1.0) ^b	4.1 (1.0) ^b	0.12	0.14	0.01	4.4 (0.9)	4.1 (1.0)	<0.01	<0.01	0.01
I would feel very bad if my child had a reaction to MMR [†]	1.8 (0.9) ^b	1.7 (0.9) ^{bc}	1.5 (0.8) ^c	<0.05	<0.05	0.01	1.8 (1.0)	1.6 (0.8)	0.07	<0.05	0.01
I started thinking about MMR before my child was born [†]	3.3 (1.3) ^b	3.5 (1.3) ^b	2.9 (1.3)	<0.001	<0.001	0.04	3.3 (1.3)	3.1 (1.3)	0.26	0.23	0.03
Time/transport/cost makes it hard to take my child for MMR [†]	4.3 (0.8) ^b	4.2 (0.7) ^b	4.3 (0.8) ^b	0.80	0.47	0.003	4.3 (0.9)	4.3 (0.8)	0.86	0.72	0.000
People important to me think I should give my child MMR	3.5 (1.1) ^b	3.2 (1.2) ^{bc}	3.0 (1.2) ^c	<0.001	<0.001	0.05	3.6 (1.0)	3.1 (1.2)	<0.001	<0.001	0.04
Scales											
MMR beliefs	3.2 (0.6)	2.9 (0.7) ^b	2.7 (0.7) ^b	<0.001	<0.001	0.10	3.2 (0.6)	2.9 (0.7)	<0.001	<0.001	0.06
Measles beliefs	3.9 (0.6) ^b	3.8 (0.6) ^b	3.8 (0.7) ^b	0.08	<0.05	0.01	3.9 (0.6)	3.8 (0.6)	0.06	0.08	0.01
Social and parenting beliefs	3.8 (0.8) ^b	3.4 (0.9) ^b	3.1 (1.1)	<0.001	<0.001	0.09	3.8 (0.7)	3.3 (1.0)	<0.001	<0.001	0.07
Information source beliefs	3.3 (0.6) ^b	3.1 (0.6) ^b	2.9 (0.7)	<0.001	<0.001	0.09	3.3 (0.6)	3.0 (0.7)	<0.001	<0.001	0.04
Practicalities	4.3 (0.8) ^b	4.2 (0.7) ^b	4.3 (0.8) ^b	0.80	0.47	0.03	4.3 (0.9)	4.3 (0.8)	0.86	0.72	0.000
[†] : reverse scored items; for all items higher scores = more 'pro-MMR' attitude. a: Adjusted for child age and IMD2007 score. Values which do not differ from one another are marked with the same superscript letter. d: Adjusted effect size = partial Eta squared.											

Table 4.4: Concurrent validity (univariate analyses of demographics items)

		MMR dose 1				MMR dose 2				
		n (%)		Comparison		n (%)		Comparison		
		On-time	Late	None	Unadj	Adj ^a	On-time	None	Unadj	Adj ^a
	<i>n</i>	216-245 _b	60-66	200-224 _b			158-166	346-369		
Child age (years)†										
5-6		59 (24)	31 (47)	57 (25)			55 (33)	92 (25)		
7-8		37 (15)	12 (18)	42 (19)			28 (17)	63 (17)		
9-10		36 (15)	9 (14)	33 (15)			23 (14)	55 (15)		
11-12		49 (20)	10 (15)	44 (20)			20 (12)	83 (22)		
13-14		26 (11)	3 (5)	25 (11)			18 (11)	36 (10)		
15-16		25 (10)	0 (0)	9 (4)			21 (13)	13 (4)		
17-18		13 (5)	1 (2)	14 (6)	<0.001	<0.001	1 (0)	27 (7)	0.14	0.13
Parent age (years)										
20-24		7 (3)	1 (2)	6 (3)			4 (3)	10 (3)		
25-29		7 (3)	5 (8)	12 (6)			5 (3)	19 (5)		
30-34		31 (13)	14 (22)	26 (12)			26 (16)	45 (13)		
35-39		66 (28)	14 (22)	63 (29)			47 (29)	96 (27)		
40+		127 (53)	31 (48)	109 (51)	0.40	0.75	80 (49)	187 (52)	0.66	0.89
Parent highest qualification										
None		20 (9)	5 (8)	17 (8)			15 (10)	27 (8)		
GCSE/O-level		49 (21)	13 (21)	50 (24)			26 (17)	86 (25)		
A/AS-level		30 (13)	9 (15)	27 (13)			27 (17)	39 (11)		
Diploma		49 (21)	8 (13)	43 (20)			27 (17)	73 (21)		
Degree		48 (21)	18 (29)	47 (22)			35 (22)	78 (23)		
Postgraduate degree		27 (12)	7 (11)	26 (12)			22 (14)	38 (11)		
Other		6 (3)	2 (3) _b	3 (1) _b	0.83	0.81	6 (4)	5 (1)	0.24	0.30
Parent ethnicity										
White British		114 (49)	43 (71)	143 (67)			58 (37)	242 (69)		
Black British		22 (9)	3 (5)	12 (6)			19 (12)	18 (5)		
Asian British		44 (19)	6 (10)	15 (7)			41 (26)	24 (7)		
Other British		2 (1)	0 (0)	2 (1)			1 (1)	3 (1)		
White other		16 (7)	3 (5)	13 (6)			13 (8)	19 (5)		
Black other		12 (5)	2 (3)	3 (1)			9 (6)	8 (2)		
Asian other		16 (7)	2 (3)	23 (11)			12 (8)	29 (8)		
Other or mixed		7 (3)	2 (3)	3 (1)	<0.01	<0.05	6 (4)	6 (2)	<0.001	<0.001
Number of children										
1		27 (12)	10 (15)	35 (17)			16 (10)	56 (16)		

	MMR dose 1					MMR dose 2				
	n (%)			Comparison		n (%)			Comparison	
	On-time	Late	None	Unadj	Adj ^a	On-time	None	Unadj	Adj ^a	
2	111 (47)	34 (52)	100 (47)			73 (46)	172 (49)			
3	62 (27)	16 (24)	45 (21)			45 (28)	78 (22)			
4+	34 (15)	6 (9)	32 (15)	0.30	0.41	25 (16)	47 (13)	<0.05	<0.05	
Parent marital status										
Single	31 (13)	9 (14)	43 (19)			20 (12)	63 (18)			
Cohabiting	25 (11)	11 (17)	22 (10)			13 (8)	45 (13)			
Married	171 (73)	40 (61)	141 (64)			124 (77)	228 (63)			
Other	7 (3)	6 (9)	16 (7)	0.05	0.34	5 (3)	24 (7)	<0.05	0.19	
Parent occupation (NS-SEC)										
1	20 (9)	8 (13)	28 (14)			18 (12)	38 (12)			
2	19 (9)	7 (12)	17 (9)			12 (8)	31 (10)			
3	12 (6)	4 (7)	11 (6)			8 (5)	19 (6)			
4	6 (3)	3 (5)	8 (4)			7 (5)	10 (3)			
5	20 (9)	4 (7)	24 (12)			16 (11)	32 (10)			
6	31 (14)	8 (13)	35 (18)			17 (11)	57 (17)			
7	34 (16)	6 (10)	27 (14)			19 (13)	48 (15)			
8	74 (34)	20 (33)	50 (25)	0.08	0.17	52 (35)	92 (28)	0.45	0.57	

a: Adjusted for child age and IMD2007 score. †: Adjusted for child age only. Values which do not differ are marked with same superscript letter.

4.2.3.4 Predictive validity (multivariate predictors of MMR receipt)

Predictive validity analyses for individual items and for the attitudes scales are presented in Table 4.5 and Table 4.6. Predictive validity was demonstrated for a number of items and scales. In the complete regression model incorporating all the individual attitude items, the only predictors of both MMR dose 1 receipt and MMR dose 2 receipt were being in a black or minority ethnicity (BME) group (OR=2.21-3.92, $p<0.001$ – $p<0.05$), having less experience of bad measles cases (OR=0.68-0.72, $p<0.05$), and anticipating less regret as a result of an MMR reaction (OR=1.53-1.76, $p<0.01$ – $p<0.05$). Believing that measles is serious (OR=1.49, $p<0.05$), having more experience of bad MMR reactions (OR=0.66, $p<0.05$), and having less preference for single vaccines (OR=1.58, $p<0.01$) predicted receipt of MMR dose 1 only. Younger child age (OR=0.89, $p<0.01$) predicted receipt of MMR dose 2 only.

In the complete regression model incorporating the attitude scales, being in a BME group (OR=1.94-4.15, $p<0.001$ – $p<0.05$), having positive MMR attitudes (OR=1.63-1.97, $p<0.05$), and having positive social attitudes (OR=1.64-1.72, $p<0.01$) all predicted both MMR dose 1 receipt and MMR dose 2 receipt. Positive information source beliefs predicted dose 1 receipt only (OR=1.76, $p<0.05$), and younger child age predicted dose 2 receipt only (OR=0.91, $p<0.01$).

Table 4.5: Predictive validity (linear regressions of individual items onto MMR status - on time versus none)

Predictor	Odds ratios						
	MMR dose 1			MMR dose 2			
	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3	
	<i>n</i>	322			359		
	<i>Nagelkerke R²</i>	0.002	0.11	0.38	0.01	0.21	0.39
Child age		1.02	1.02	0.97	0.97	0.94	0.89*
IMD2007 score		1.00	1.01	1.01	0.99	1.00	0.99
Parent age			1.09	1.33 [‡]		0.93	1.06
Parent BME ethnicity			2.65***	2.21*		4.42***	3.92***
Parent marital status [†]							
Cohabiting			1.71	1.75		0.81	0.65
Married			1.55	1.57		1.53	1.54
Other			0.51	0.49		0.63	0.62
Parent education ^{††}							
GCSE/O-level			1.27	1.13		0.70	0.82
A-level			1.30	1.40		1.59	2.38
Diploma			1.40	1.24		0.80	0.92
Degree			1.58	1.67		1.09	1.50
Postgraduate			2.53	2.20		1.93	2.88
Other			1.23	0.90		0.87	0.71
Number of children			1.10	1.30		1.13	1.29
Parent occupation (NS-SEC coded)			1.05	1.01		1.02	0.98
MMR has serious side effects				1.17			1.16
Measles is a severe illness				1.49*			1.20
MMR protects against measles				0.92			1.06
Seen/heard of bad MMR reactions				0.66*			0.84
Seen/heard of bad measles cases				0.68*			0.72*
Fear immune overload				0.90			1.15
Prefer separate vaccines				1.58**			1.26

Predictor	Odds ratios					
	MMR dose 1			MMR dose 2		
	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3
Without MMR, measles is likely			1.04			1.09
Prefer natural immunity			0.79			0.84
Trust GP/nurse's MMR advice			0.86			0.83
Scientific MMR research is adequate			1.05			0.97
Like social benefit of immunising			1.45 [‡]			1.55 [‡]
Done personal research			1.08			1.18
Rejected MMR for other children			1.28 [‡]			1.32
Does not believe media MMR stories			1.23			0.99
Anticipate regretting measles			1.12			1.34
Anticipate regretting MMR reaction			1.76 ^{**}			1.53 [*]
Thought about MMR pre-birth			1.21			1.04
Perceive practical barriers to MMR			1.12			0.84
Perceive pro-MMR social norms			1.24			1.17
†: Reference category = Single. ††: Reference category = No qualification. ***: p<0.001. **: p<0.01. *: p<0.05. ‡: p<0.10						

Table 4.6: Predictive validity (linear regression of scales onto MMR status - on time versus none)

Predictor	Odds ratios					
	MMR dose 1			MMR dose 2		
	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3
	<i>n</i>	373			415	
	<i>Nagelkerke R²</i>	0.002	0.09	0.01	0.20	0.31
Child age	1.01	1.01	0.97	0.96	0.94	0.91**
IMD2007 score	1.00	1.01	1.01	1.00	1.00	0.99
Parent age		1.09	1.24 [‡]		0.95	1.01
Parent BME ethnicity		2.26**	1.94*		4.05***	4.15***
Parent marital status [†]						
Cohabiting		2.15 [‡]	2.13		0.88	0.78
Married		1.93*	1.78		1.58	1.53
Other		0.76	0.64		0.79	0.67
Parent education ^{††}						
GCSE/O-level		1.10	1.03		0.69	0.75
A-level		1.46	1.61		1.92	2.27
Diploma		1.17	1.46		0.77	0.92
Degree		1.30	1.46		1.02	1.11
Postgraduate		1.78	1.80		1.49	1.68
Other		1.76	1.51		1.41	1.29
Number of children		1.11	1.19		1.14	1.18
Parent occupation (NS-SEC coded)		1.05	1.04		0.99	0.96
MMR beliefs			1.63*			1.97*
Measles beliefs			0.82			0.87
Social and parenting beliefs			1.72**			1.64**
Information source beliefs			1.76*			1.16
Practicalities			1.26			1.09

†: Reference category = Single. ††: Reference category = No qualification. ***: p<0.001. **: p<0.01. *: p<0.05. ‡: p<0.10

4.2.4 Discussion

4.2.4.1 Instrument quality, main findings and comparison with findings from other studies

A comprehensive battery of reliability, consistency and validity tests demonstrated that the attitude measurement instrument presented here is psychometrically robust. The instrument is able to elicit consistent responses at different time periods and on items which are conceptually/empirically linked, is able to discriminate between participants with differing MMR behaviours, and is able to predict MMR behaviour in multivariate analyses.

In validating the instrument a novel, high-quality set of data on current parental MMR decision-making has been obtained. The study found that black and minority ethnicity, favourable MMR attitudes (particularly lower anticipated regret in relation to MMR reaction) and favourable social attitudes were the only significant independent predictors of both MMR dose 1 receipt and MMR dose 2 receipt. Parents who gave MMR late were more attitudinally aligned with parents who gave MMR on-time than with parents who gave no MMR. Most of the results demonstrate a 'logical' relationship between attitudes and behaviour, such that positive attitudes towards the clinical and social aspects of the vaccine and negative attitudes towards the disease relate to MMR acceptance. Importantly, these findings concur with univariate analyses reported in the literature (Smith, Yarwood *et al*, 2007; Brown, Kroll *et al*, 2010a; National Institute for Health and Clinical Excellence, 2009; Roberts, Dixon-Woods *et al*, 2002; Falagas & Zarkadoulia, 2008; Mills, Jadad *et al*, 2005). The multivariate models reported here cannot be directly compared with those elsewhere in the literature, as to my knowledge no other models incorporate an equivalent breadth of attitude items along with objective outcome measures; indeed multivariate models are relatively uncommon in this literature, and therefore the models reported here make an incremental contribution to the knowledge base.

However, some curious relationships emerged, specifically those between MMR acceptance and less experience of measles and more experience of MMR reactions. The instrument measures experience as having 'seen or heard about' these events, to reflect how participants in qualitative studies commonly invoke second- or third-hand 'experiences' as contributing to their own decision-making (Brown, Kroll *et al*, 2010a). Accordingly, these unexpected relationships may stem from differential media coverage of MMR reactions and measles cases (Hargreaves, Lewis *et al*, 2003; Guillaume & Bath, 2008). Further, that these parents did not use such experiences to drive their behaviour may indicate they did not consider their experience of these outcomes to be representative of the statistical probability of their occurrence, and therefore either consciously or unconsciously failed to incorporate them.

4.2.4.2 Strengths and limitations

The study has a number of key methodological strengths. To my knowledge, this is the first study to combine a validated, comprehensive, evidence-based attitude measure with an objective measure of MMR uptake in a UK sample. The work is therefore uniquely positioned for use in the development and testing of MMR-related attitude change interventions at local (e.g. PCT) and national level. It is also one of the few studies to have assessed MMR attitudes among parents of older children and controlled for child age in analysis, demonstrating that attitudinal and demographic differences tend to persist even among parents who decided about MMR for their child some time ago. Moreover, by reporting effect sizes this study indicates the clinical as well as statistical significance of attitudinal differences by MMR uptake, providing clear evidence for the attitudes and beliefs on which interventions have the greatest potential to influence behaviour. Furthermore, the study comprises a larger proportion of parents of unimmunised children than obtained in comparable work (Brown, Kroll *et al*, 2010a; Casiday, Cresswell *et al*, 2006; Tickner, Leman *et al*, 2010), facilitating more robust analyses of the differences between MMR acceptors and MMR rejectors. Finally, the categorisation of MMR uptake in line with routine monitoring data

(Health Protection Agency, 2010) and the immunisation schedule (Department of Health, 2007) facilitates comparison with and extrapolation to larger epidemiological datasets, and removes the potentially confounding effect of poorer PCT/general practice data quality for vaccines given after age 5 (Capital Catch-up Regional Technical Planning Group, 2007).

There are also some methodological limitations to this work. The study employed a retrospective design in which attitudes were measured after MMR doses were received, therefore the extent to which these attitudes incorporate retrospective justification (Pieters, Baumgartner *et al*, 2006; Roberts, 1985) and are able to predict future MMR behaviour is yet to be ascertained. The instrument predicted under half of the variance in MMR behaviour, indicating either that some highly influential predictors were omitted, that parents were not completely truthful in their responses, or that a substantial proportion of MMR decision-making is unpredictable or uninformed (e.g. not in line with attitudes (Marteau, Dormandy *et al*, 2001)). The 20 attitudinal items were largely cognitions or evaluative attitudes (e.g. 'MMR has serious side effects'), rather than emotions or affective attitudes (e.g. 'I would feel very bad if my child had a reaction to MMR'), and a stronger focus on emotions may have predicted additional behavioural variance (Conner & Armitage, 2006). However worry, a potentially relevant emotion in MMR decision-making, has either not been measured (Smith, Yarwood *et al*, 2007; Casiday, Cresswell *et al*, 2006) or not been significant (Tickner, Leman *et al*, 2010) in other relevant studies, and whether parents experience such emotions during decision-making and/or would be willing to reveal their emotions in questionnaires requires further exploration. The response rate to this study was lower than that obtained in one recent study of MMR attitudes (Casiday, Cresswell *et al*, 2006), however many other relevant studies (Smith, Yarwood *et al*, 2007; Brown, Kroll *et al*, 2010a; Tickner, Leman *et al*, 2010) fail to report (or are unable to report, due to their recruitment methodologies) response rates, so ascertaining how this study compares to the wider literature in this respect is problematic. The response rate obtained

here is in part attributable to an inflated denominator (The London Regional Immunisation Steering Group, 2009) (approximately 10% of the original PCT-provided cases were confirmed non-contactable due to outdated address and phone details; the total number non-contactable is likely to be larger), and to the intentionally larger proportion of unimmunised cases in my sampled population than in other study populations (Casiday, Cresswell *et al*, 2006; Tickner, Leman *et al*, 2010), as non-immunising parents are less likely to respond to questionnaires of this type (Brown, Kroll *et al*, 2010a); but probably also reflects a failure to adequately recruit parents of deprived, unimmunised, older children, despite extensive efforts to render the questionnaire accessible through low-literacy design, alternative administration methods, and language support provision (Dormandy, Brown *et al*, 2008; Dormandy, Tsui *et al*, 2007).

4.2.4.3 Implications for policy and practice

These findings support the existing body of research which suggests that parents' attitudes are a key driver of their MMR behaviour, and provide specific direction for the populations and attitudes to target in interventions for maximum impact on MMR uptake. They also provide support for the dual-route hypothesis for suboptimal vaccine uptake (National Institute for Health and Clinical Excellence, 2009) – namely, that some parents fail to immunise because they are consciously opposed to the vaccine, whilst others fail to immunise because of practical barriers. The relationship between black and minority ethnicity and MMR acceptance was shown here to be stronger than, and independent to, any individual attitudinal predictor, suggesting either that members of these communities do not factor in the issues around MMR which are central for many of their white British counterparts and instead accept MMR on the basis of specific, culturally bound views not assessed here (Condon, 2002), or that the white British participants in this study faced barriers to uptake not met by BME parents. MMR beliefs (chiefly lower anticipated regret for MMR reaction and less preference for separate vaccines), and social and parenting beliefs (chiefly appreciating the benefits to wider

society of immunising one's own child) were the key attitudinal predictors of MMR acceptance, indicating that public health communication materials and individual practitioner approaches may usefully target these areas. Of particular interest to interventionists may be the central role of anticipated regret for MMR reaction (Wroe, Bhan *et al*, 2005; Brown, Kroll *et al* 2010b; Sevdalis & Harvey, 2007). Evidence from behavioural science suggests that regret anticipation is often inaccurate, such that anticipated regret is higher than actual eventual regret (Sevdalis & Harvey, 2007; Sevdalis & Harvey, 2006), and therefore that anticipating regret can lead to our 'irrationally' withholding a decision/action (e.g. making an omission, see Chapter 6). These potentially action-stifling regret considerations may be effectively countered by asking the parent if their child would prefer a greater or lesser chance of becoming unwell, and if it would matter to the child whether the cause of becoming unwell was the vaccine or the disease (Baron, 1992). Assuming that the parent believes that the chance of MMR reaction is lower than the chance of disease, this intervention brings the risk-benefit balance to the fore and highlights anticipated regret as an issue purely of concern to the parent, not to the child whose best interests the parent seeks to protect.

Interventions can be effectively tailored to specific populations by administering the study instrument to identify areas of concern, and can then be evaluated by administering the instrument post-intervention; PCTs may wish to consider monitoring attitudes with the instrument on a regular basis, facilitating prompt response to pockets of concern, rather than waiting for routine surveillance data to identify increased disease incidence or decreased vaccine uptake. Finally, with further refinement the instrument may be useful for targeting micro-level intervention, identifying parents with a few worries about MMR who may respond positively to intervention, and differentiating them from parents who are firmly opposed to MMR on all fronts and who therefore may not benefit from intervention – indeed may actively resent it, with possible implications for their communications with other parents and their ongoing relationship with their health professional (Hobson-West, 2007).

4.2.4.4 Directions for future research

Two strands of future research are indicated by the findings of this study. The first is to further explore attitudes around MMR and measles using the instrument in different populations, eventually bringing together a number of studies for meta-analysis to definitively identify and quantify key predictors of uptake. The ultimate aim of this strand is to inform the content and evaluation of national and international MMR interventions. The second is to further refine and develop the instrument to improve its psychometric properties and acceptability to the populations in which it is to be used, eventually creating a battery of variations for different languages and vaccines. The ultimate aim of this strand is to develop an overarching 'gold standard' measure applicable for use in a range of settings.

4.3 Part 2: Use of the instrument to identify determinants of response to the UK MMR catch-up campaign 2008-09

4.3.1 Introduction

From 1st September 2008 Primary Care Trusts (PCTs) across the UK were instructed to implement a catch-up campaign to increase coverage of measles, mumps and rubella (MMR) vaccine among children aged 13 months to 18 years (Department of Health, 2008). The campaign was mounted in order to 'reduce the risk of a measles epidemic... following a decade of relatively low vaccination uptake' (Department of Health, 2008). Children were prioritised first by MMR doses received, then by age, such that younger children with no MMR doses on their general practice (GP) or PCT record were the primary targets for the campaign. GPs/PCTs invited by post parents/caregivers of eligible children to bring their child to the GP surgery for catch-up MMR vaccination. Department of Health (DH) trial sentinel data for the first year of the catch-up campaign indicate a 5.1% increase in full MMR coverage among 5-18 year olds and a 2% decrease in the number who have no MMR doses recorded (Department of Health, 2009).

Vaccine catch-up campaigns either provide a new vaccine to children who were not offered it as part of their routine schedule (for example, because the vaccine was introduced after they had passed the appropriate age), or provide an existing vaccine to those who have not had it although it was available to them at the appropriate scheduled age (for example, because their parents could not access it or chose to reject it). The 2008-09 MMR catch-up campaign is an example of the latter, and limited evidence suggests that uptake for this type of campaign is usually well under 50%. A London primary school-based MMR catch-up in 2004/05 immunised less than 25% of all eligible children (Capital Catch-up Campaign Regional Technical Planning Group, 2007). MMR catch-ups following a

1996 American Academy of Pediatrics recommendation brought only 20-30% of suboptimally MMR-immunised US adolescents up-to-date (McCauley, Stokley *et al*, 2008). A 1994 secondary school MMR catch up in South Glamorgan reached coverage of 43.4% (Roberts, Sandifer *et al*, 1995) and a secondary school-leavers catch-up in a single London borough in 2006 immunised 47% (Lashkari & El Bashir, 2010). Evidence from a smaller campaign on a travellers' site in Manchester is more positive with 55 of 56 eligible cases immunised (Reynolds, Petrovic *et al*, 2008) – however in this population parents' motivation to immunise may have been unusually high, as the UK's first acute measles death in 14 years occurred in their community and triggered the catch-up campaign. Regardless of efficacy, these campaigns require significant funding (for example, in the 2004/5 London campaign DH provided £5,000 per PCT for programme expenses as well as providing printed materials, translations and vaccines at no additional cost to the PCTs (Capital Catch-up Regional Technical Planning Group, 2007)). Maximising response to such campaigns is thus crucial, however evaluation to date has been poor as most programmes fail either to collect or report relevant data.

Parents' attitudes are a key predictor of acceptance or refusal of MMR in the routine schedule, and they are likely also to play a central part in response to catch-up programmes (Pearce, Law *et al*, 2008; Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002). Data collected from school-based campaigns in London (Hadjikoumi, Niekerk *et al*, 2006) and Wales (Roberts, Sandifer *et al*, 1995) support this hypothesis, indicating that 33-58% of eligible children do not receive catch-up immunisation because their parents do not return the consent form (thus implicitly withholding consent), 4-12% are not immunised because their parents explicitly withhold consent, and 7% are not immunised despite their parents having consented because they do not attend the immunisation session. Parents' reasons for explicitly withholding consent varied between the two campaigns: in the Wales 1994 secondary school campaign most parents considered MMR unnecessary due to previous measles infection or vaccination, whilst in the London 2004/5 primary

school campaign most parents felt MMR undesirable due to safety concerns (particularly autism), or wanted the vaccine given at their general practice rather than in school. This variability is almost certainly a function of the different time periods (pre- versus post- MMR controversy) (Elliman, Bedford, 2007; Smith, Yarwood *et al*, 2007) and different populations (primary versus secondary school pupils) examined. In addition, however, methodological inadequacies may have also affected these data, including unrepresentative samples (the London evaluation was in one of the most affluent London PCTs (Greater London Authority Data Management and Analysis Group, 2008) and the Wales evaluation did not assess demographics) and open-ended questions (which may fail to elicit all reasons for refusal). Further, both of these evaluations only assessed reasons for catch-up MMR refusal, with no control group of parents who consented.

Whilst evidence on the reasons for previous disappointing responses to MMR catch-up campaigns is scant and methodologically limited, when considered in association with the evidence on factors underpinning acceptance of MMR in the routine schedule it indicates that non-response to MMR catch-up campaigns is linked with negative attitudes toward MMR vaccination in general. The present study tests this hypothesis in the context of the 2008-09 MMR catch-up campaign using a validated, evidence-based measure of attitudes and demographics (Chapter 4 Part 1) in a multi-PCT sample. The measure identifies univariate and multivariate predictors of response to the campaign, which can be targeted in future campaigns to maximise MMR uptake.

4.3.2 Methods

4.3.2.1 Participants

Child Health Information Systems (CHIS) in three UK PCTs (two in London, one in north-west England) were used to identify all children aged 5-17 years and with suboptimal CHIS-recorded MMR status (<2 doses) at 1st September 2008 (the first day of the UK MMR catch-up campaign 2008-09).

From this population, 2,300 children were randomly selected with stratification by child age. This sample size was selected to provide at least 80% power for hierarchical multiple regression to detect small to medium effects at the 0.05 significance level with a 20% response rate. PCTs provided postal and telephone contact details for the parent/guardian(s) of each child, plus the child's date of birth and MMR dose history.

4.3.2.2 Materials and procedure

The Health Protection Agency classified the study as a service evaluation not requiring ethical approval. Consent to participate was implied through questionnaire completion. The validated questionnaire (Chapter 4 Part 1 Figure 4.1 comprised seven demographic items and 20 attitude items all derived from the literature on factors underpinning parents' MMR and general vaccination decisions (Pearce, Law *et al*, 2008; Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002), and a single item assessing self-reported receipt of a postal MMR catch-up invitation. Attitude items took the form of statements with which the respondent indicated their level of agreement on five-point scales (1=strongly disagree, 5=strongly agree). Eleven of the 20 attitude items were negatively worded or related to 'anti-MMR' beliefs, and so were reverse scored: for every attitude item a higher score indicated more 'pro-MMR' attitude. The 20 attitude items (except item 19 assessing practical barriers) collapsed into four scales with adequate reliability: MMR beliefs (items 1,3,4,6,7,14,17, Cronbach's alpha=0.76), measles beliefs (items 2,5,8,9,16, Cronbach's alpha=0.68), social and parenting beliefs (items 12 and 20, Cronbach's alpha=0.73), and information source beliefs (items 10,11,13,15,18, Cronbach's alpha=0.59). Demographic data collected were parent (respondent) age, sex, highest educational qualification, ethnic group, number of children, marital status and job; responses were provided using tick-box options for all but the job item, which was free-text.

A copy of the questionnaire was posted to the parent/guardian of every child in the sample, along with a cover letter explaining the purpose and provenance of the study (Figure 11.8, Chapter 11 Appendices), a freepost return envelope, and a translation sheet advising (in seven languages most commonly used in the PCTs: Arabic, Farsi, Polish, Punjabi, Somali, Tamil and Urdu) that translations were available on request. At approximately 3 and 6 weeks after the first copy was sent, non-respondents received a reminder letter with another questionnaire and enclosures, to a maximum of two postal reminders per household. At approximately 4 and 7 weeks after the first copy was sent, a telephone reminder was administered to non-respondents with a working telephone number provided by the PCT: a total of four attempts per reminder (2 daytime, 2 evening) were made, to a maximum of two answered calls or answerphone messages per household. During telephone reminders interpreting was available, and participants were invited to respond to the questionnaire during the call rather than return their copy by post.

CHIS-recorded receipt of MMR dose(s) during the first year of the catch-up campaign (1st September 2008 – 31st August 2009), and postcode-level Indices of Multiple Deprivation 2007 data (IMD2007 (Department of Communities and Local Government, 2007)), were obtained for the entire sample. Where MMR dose history obtained at the end of the study period differed from that which had been provided at the start of the period, the most up-to-date history was used. Free-text responses to the job item were coded by two independent analysts (very good agreement between analysts: Cohen's Kappa 0.91) to the 8-class version of the National Statistics Socio-Economic Classification (NS-SEC (Office for National Statistics, 2005)), where code 1 is the highest socio-economic class (higher managerial/higher professional/large employer) and code 8 the lowest (never worked/long-term unemployed/student etc); respondents classifying themselves as 'mother', 'housewife' or similar were coded to category 8.

4.3.2.3 Analysis

Data were analysed using SPSS v 17.0 (SPSS Inc. Chicago, IL). Participation rates and participant characteristics were assessed using all available data on the entire sample. Missing values were imputed using within-participant scale means for scales of 5 items or more where up to 2 items were missing. Scale scores were calculated by summing scores (including imputed values) for individual items comprising the scale then dividing by the number of items in the scale.

Participants were split into two groups for further analysis: those whose child had received no MMR doses at the start of the catch-up period (henceforth referred to as 'unimmunised', and those whose child had received one MMR dose at that time ('partially immunised'). Univariate and multivariate comparisons were made within each group between those who gave MMR dose(s) during the catch-up period ('responders') and those who didn't ('non-responders').

In univariate analyses, nominal variables (parent ethnicity, parent marital status, catch-up invitation receipt) were compared using Chi-square tests (unadjusted) and ordinal regression (adjusted for child age and IMD2007 score). Ordinal variables (child age, IMD2007 score, parent age, education, number of children, job) were compared using Mann-Whitney tests (unadjusted) and ANCOVA (adjusted as before). Scale outcomes (all attitude items and scales) were compared using independent samples t-tests (unadjusted) and ANCOVA (adjusted as before), and partial Eta squared values were obtained to indicate the amount of variance in catch-up response explained by the item. Hierarchical logistic regression was used to identify and quantify independent predictors of MMR dose receipt. Predictors were entered in three steps starting with those expected, based on the literature (Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002), to

be most predictive: first were objective demographics, then subjective (self-report) demographics, and finally attitude scales.

4.3.3 Results

4.3.3.1 Participation rate and participant characteristics

365 of 2,300 (15.9%) identified cases returned a completed questionnaire. There was no difference in participation rate by MMR status, but participants had younger children ($p < 0.01$) and lived in less deprived postcode areas ($p < 0.001$) than did non-participants (Table 4.7).

4.3.3.2 Univariate predictors of receipt of MMR dose(s) during catch-up campaign

Parents of unimmunised children who responded to the catch-up campaign had younger children ($p < 0.05$) and were younger themselves ($p < 0.01$) than were their non-responding peers, and these effects persisted after adjustment for deprivation. Parents of partially immunised children who responded to the catch-up had younger children ($p < 0.001$), lower educational attainment ($p < 0.05$) and higher deprivation ($p < 0.05$) than their non-responding peers, though the deprivation effect was a function of age ($p > 0.05$ after adjustment). Only younger child age significantly predicted catch-up response for both unimmunised and partially immunised cases ($p < 0.001$) (Table 4.8).

Table 4.7: Study participation rates and representativeness

	n	n(%) / Mean(SD)		p
		Study participants	Study non-participants	
MMR status at end of data collection†				
0 doses	1166	182 (15.6)	984 (84.4)	0.31
1 dose	882	135 (15.3)	747 (84.7)	
2 doses	252	48 (19.0)	204 (81.0)	
Child age (days) at end of data collection ‡	-	3564 (1312)	3779 (1388)	<0.01
IMD2007 score‡	-	26.28 (15.64)	31.43 (17.14)	<0.001
Total	2300	365 (15.9)	1935 (84.1)	-
†: n(%), p values for Chi-square test; ‡: mean(SD), p values for independent samples t-test				

Table 4.8: Demographic characteristics by response to the MMR catch-up campaign

	<i>n</i>	Unimmunised				Partially immunised				All cases	
		n (%)		Comparison		n (%)		Comparison		Comparison	
		No resp.	Resp.	Unadj	Adj ^a	No resp.	Resp.	Unadj	Adj ^a	Unadj	Adj ^a
		164-182	28-31			101-111	37-41				
Child age (years) [†]											
5-6		52 (29)	17 (55)			19 (17)	27 (66)				
7-8		31 (17)	5 (16)			16 (14)	5 (12)				
9-10		29 (16)	2 (6)			18 (16)	3 (7)				
11-12		37 (20)	3 (10)			35 (32)	3 (7)				
13-14		17 (9)	2 (6)			10 (10)	3 (7)				
15-16		4 (2)	2 (6)			6 (5)	0 (0)				
17-18		12 (7)	0 (0)	<0.01	<0.05	7 (6)	0 (0)	<0.001	<0.001	<0.001	<0.001
IMD 2007 score [‡]											
<sample mean (31.4)		123 (68)	22 (71)			75 (68)	20 (50)				
≥ sample mean		58 (32)	9 (29)	0.74	0.87	36 (32)	20 (50)	<0.05	0.06	0.17	0.12
Parent age (years)											
20-24		4 (2)	1 (3)			2 (2)	1 (3)				
25-29		10 (6)	3 (10)			6 (6)	2 (5)				
30-34		19 (11)	6 (20)			13 (12)	9 (23)				
35-39		53 (30)	12 (40)			23 (22)	11 (28)				
40+		92 (52)	8 (27)	<0.05	<0.05	63 (59)	16 (41)	0.07	0.98	<0.01	0.15
Parent highest qualification											
None		15 (9)	2 (7)			4 (4)	5 (14)				
GCSE/O-level		41 (23)	9 (30)			23 (23)	9 (24)				
A/AS-level		22 (13)	3 (10)			12 (12)	8 (22)				
Diploma		36 (21)	3 (10)			27 (27)	7 (19)				
Degree		38 (22)	7 (23)			24 (24)	5 (14)				
Postgraduate degree		22 (13)	6 (20)			9 (9)	3 (8)				
Other		2 (1)	0 (0)	0.76	0.92	2 (2)	0 (0)	<0.05	<0.01	0.23	0.08
Parent ethnicity											
White British		122 (70)	22 (71)			72 (71)	32 (84)				
Black British		9 (5)	1 (3)			5 (5)	1 (3)				

	Unimmunised				Partially immunised				All cases	
	n (%)		Comparison		n (%)		Comparison		Comparison	
	No resp.	Resp.	Unadj	Adj ^a	No resp.	Resp.	Unadj	Adj ^a	Unadj	Adj ^a
Asian British	14 (8)	0 (0)			8 (8)	2 (3)				
Other British	1 (1)	1 (3)			1 (1)	0 (0)				
White other	8 (5)	4 (13)			5 (5)	1 (3)				
Black other	2 (1)	1 (3)			1 (1)	1 (3)				
Asian other	16 (9)	2 (7)			7 (7)	1 (3)				
Other or mixed	2 (1)	0 (0)	0.25	0.52	3 (3)	1 (3)	0.74	0.14	0.33	0.60
Number of children										
1	28 (16)	4 (13)			14 (14)	10 (25)				
2	82 (47)	17 (57)			54 (51)	19 (48)				
3	38 (22)	4 (13)			27 (26)	6 (15)				
4+	25 (15)	5 (17)	0.86	0.90	11 (10)	5 (13)	0.19	0.09	0.26	0.30
Parent marital status										
Single	35 (19)	7 (23)			15 (14)	6 (15)				
Cohabiting	20 (11)	5 (17)			15 (14)	8 (21)				
Married	113 (62)	14 (47)			72 (67)	23 (59)				
Other	14 (8)	4 (13)	0.41	0.49	5 (5)	2 (5)	0.77	0.54	0.35	0.50
Parent job (NS-SEC)										
1	24 (15)	2 (7)			8 (8)	5 (13)				
2	13 (8)	4 (14)			10 (10)	4 (11)				
3	9 (6)	2 (7)			5 (5)	5 (13)				
4	9 (5)	1 (4)			2 (2)	0 (0)				
5	21 (13)	3 (11)			6 (6)	2 (5)				
6	28 (17)	2 (7)			19 (19)	5 (13)				
7	19 (12)	5 (18)			16 (16)	9 (24)				
8	42 (26)	9 (32)	0.45	0.35	32 (33)	8 (21)	0.21	0.16	0.89	0.79

a: Adjusted for child age and IMD2007 score. †: Adjusted for IMD2007 score only. ‡ Adjusted for child age only.

Parents of unimmunised children who responded to the catch-up campaign were significantly more likely than their non-responding peers to have accepted MMR for siblings of the currently unimmunised child ($p<0.05$, 3% variance in response explained), to have not seen or heard about bad cases of measles, to believe that scientific research into MMR is adequate (both $p<0.05$, 2% variance), and to have overall more pro-vaccine MMR beliefs ($p<0.05$, 3% variance), social and parenting beliefs, and information source beliefs (both $p<0.05$, 2% variance). Parents of partially immunised children who responded to the catch-up were significantly more likely than their non-responding peers to value protecting others by immunising their own child ($p<0.001$, 9% variance explained), to feel that people important to them wanted them to accept MMR ($p<0.01$, 7% variance), to not believe that MMR has serious side effects ($p<0.01$, 6% variance), to not have seen or heard about bad MMR reactions ($p<0.05$, 5% variance), to not fear MMR would overload their child's immune system ($p<0.05$, 4% variance), to trust their GP/nurse's MMR advice, to not perceive practical barriers to MMR uptake (both $p<0.05$, 3% variance), and to have overall more pro-vaccine social and parenting beliefs ($p<0.001$, 10% variance), MMR beliefs ($p<0.05$, 4% variance), and information source beliefs ($p<0.05$, 3% variance). Overall, the attitudinal items most important to catch-up response for both unimmunised and partially immunised cases were disbelieving serious MMR side effects, valuing community benefit of immunisation, and perceiving peers/family to be pro-MMR (all $p<0.001$, 5% variance); accordingly social and parenting beliefs was the most important attitudes scale ($p<0.001$, 7% variance). Receipt of an MMR catch-up invitation was associated with response to the campaign for both unimmunised and partially immunised cases ($p<0.05$) – however this effect was not significant when adjusted for child age and deprivation: invitation receipt and campaign response were both primarily functions of younger child age (Table 4.9).

Table 4.9: Attitudes and catch-up invitation receipt by response to the MMR catch-up campaign

	<i>n</i>	Unimmunised					Partially immunised					All cases		
		Mean(SD) / n(%)		Comparison			Mean(SD) / n(%)		Comparison			Comparison		
		No response	Response	Unadj	Adj ^a	Adj. Effect size ^d	No response	Response	Unadj	Adj ^a	Adj. Effect size ^d	Unadj	Adj ^a	Adj. Effect size ^d
		152-182	27-31				98-110	27-41						
Individual items														
MMR side effects		2.7 (1.1)	3.0 (0.9)	0.08	0.06	0.02	2.9 (1.1)	3.6 (1.0)	<0.01	<0.01	0.06	<0.001	<0.001	0.05
Measles severity		4.2 (0.9)	4.3 (0.6)	0.55	0.84	0.001	4.3 (0.8)	4.5 (0.8)	0.17	0.38	0.01	0.14	0.30	0.003
MMR effectiveness		4.0 (0.9)	4.2 (0.5)	0.19	0.24	0.01	4.1 (0.8)	4.2 (0.9)	0.44	0.43	0.004	0.12	0.15	0.01
MMR reaction experience		2.3 (1.2)	2.5 (1.2)	0.47	0.34	0.004	2.2 (1.0)	2.7 (1.1)	<0.05	<0.01	0.05	<0.05	<0.05	0.02
Measles experience		3.6 (1.1)	4.1 (1.0)	<0.05	<0.05	0.02	3.6 (1.0)	3.6 (1.2)	0.91	0.51	0.003	0.18	0.17	0.01
Immune overload		3.0 (1.3)	3.2 (1.1)	0.41	0.20	0.01	3.2 (1.0)	3.6 (1.2)	<0.05	<0.05	0.04	<0.05	<0.05	0.03
Preference for separate shots		2.4 (1.3)	2.5 (1.3)	0.55	0.22	0.01	2.8 (1.2)	3.1 (1.2)	0.13	0.16	0.01	0.05	<0.01	0.02
Measles susceptibility		3.3 (1.1)	3.6 (0.9)	0.25	0.12	0.01	3.4 (1.0)	3.7 (0.8)	0.07	0.06	0.02	<0.05	<0.01	0.02
Natural immunity		3.6 (1.0)	3.8 (0.9)	0.40	0.40	0.003	3.6 (0.9)	3.9 (0.8)	0.06	0.08	0.02	<0.05	0.06	0.01
Trust GP/nurse MMR advice		3.5 (1.2)	3.7 (0.9)	0.18	0.06	0.02	2.9 (1.0)	3.1 (1.0)	0.12	<0.05	0.03	<0.05	<0.01	0.03
MMR scientific research		2.6 (1.1)	2.9 (1.1)	0.08	<0.05	0.02	3.6 (1.0)	4.3 (0.6)	0.38	0.23	0.01	<0.05	<0.01	0.02
Protecting community		3.3 (1.2)	3.5 (1.0)	0.24	0.10	0.01	2.7 (1.1)	3.0 (1.3)	<0.001	<0.001	0.09	<0.001	<0.001	0.05
Personal research		2.5 (1.1)	2.3 (1.2)	0.46	0.94	0.001	3.8 (1.1)	4.0 (1.3)	0.17	<0.05	0.04	0.46	0.07	0.01
MMR uptake for siblings		3.3 (1.5)	3.9 (1.1)	<0.05	<0.05	0.03	3.2 (0.9)	3.2 (0.9)	0.27	0.31	0.01	<0.01	<0.01	0.03
Trust media coverage		3.0 (1.0)	3.1 (0.9)	0.60	0.59	0.001	4.1 (1.0)	4.3 (0.9)	0.93	0.69	0.001	0.56	0.43	0.002
Anticipated regret measles		4.1 (1.0)	3.9 (1.1)	0.22	0.36	0.004	1.7 (0.8)	1.6 (0.7)	0.30	0.51	0.003	0.99	0.74	0.001
Anticipated regret MMR reaction		1.5 (0.8)	1.7 (1.0)	0.10	0.11	0.01	3.4 (0.2)	3.2 (1.3)	0.41	0.67	0.001	0.42	0.35	0.002
Advance thinking/planning		2.8 (1.3)	3.3 (1.4)	0.09	0.07	0.02	4.2 (0.8)	4.6 (0.6)	0.43	0.99	0.001	0.26	0.14	0.01
Practical barriers		4.3 (0.8)	4.3 (0.8)	0.78	0.42	0.003	4.2 (0.8)	4.6 (0.6)	<0.05	<0.05	0.03	0.14	0.46	0.002
Pro-MMR social norms		2.9 (1.2)	3.2 (1.1)	0.30	0.06	0.02	3.2 (1.2)	3.8 (1.0)	<0.01	<0.01	0.07	<0.01	<0.001	0.05

	Unimmunised					Partially immunised					All cases		
	Mean(SD) / n(%)		Comparison			Mean(SD) / n(%)		Comparison			Comparison		
	No response	Response	Unadj	Adj ^a	Adj. Effect size ^d	No response	Response	Unadj	Adj ^a	Adj. Effect size ^d	Unadj	Adj ^a	Adj. Effect size ^d
Scales													
MMR beliefs	2.7 (0.7)	3.0 (0.6)	<0.05	<0.05	0.03	2.9 (0.7)	3.2 (0.7)	<0.05	<0.05	0.04	<0.01	<0.001	0.04
Measles beliefs	3.8 (0.7)	3.9 (0.6)	0.30	0.23	0.01	3.8 (0.6)	4.0 (0.6)	0.09	0.21	0.01	<0.05	<0.05	0.01
Social and parenting beliefs	3.1 (1.1)	3.4 (0.9)	0.15	<0.05	0.02	3.4 (0.9)	4.0 (0.6)	<0.001	<0.001	0.10	<0.001	<0.001	0.07
Information source beliefs	2.9 (0.7)	3.1 (0.8)	0.14	<0.05	0.02	3.2 (0.6)	3.3 (0.6)	0.33	<0.05	0.03	<0.05	<0.01	0.03
Practicalities	4.3 (0.8)	4.3 (0.8)	0.78	0.42	0.003	4.2 (0.8)	4.6 (0.6)	<0.05	<0.05	0.03	0.14	0.46	0.002
Catch-up invitation receipt													
MMR invite received in past year	54 (30)	15 (48)	0.06	0.20	-	23 (21)	15 (37)	0.06	0.89	-	<0.05	0.35	-
a: Adjusted for child age and IMD2007 score. d: Adjusted effect size = partial Eta squared.													

4.3.3.3 Multivariate predictors of receipt of MMR dose(s) during catch-up campaign

See Table 4.10. Among parents of unimmunised children, response to the catch-up campaign was predicted by receipt of catch-up invitation (OR=3.45, $p<0.05$), younger parent age (OR=0.58, $p<0.05$), and residence in a less deprived postcode (OR=0.96, $p<0.05$). Among parents of partially immunised children, catch-up response was predicted by positive social and parenting beliefs (OR=9.61, $p<0.01$), lower parent educational attainment (OR=0.08, $p<0.05$), and younger child age (OR=0.44, $p<0.001$). Overall, response to the catch-up among both unimmunised and partially immunised cases was predicted by positive social and parenting beliefs (OR=1.76, $p<0.05$) and younger child age (OR=0.78, $p<0.001$).

Table 4.10: Independent predictors of response to the MMR catch-up campaign

Predictor	<i>n</i> <i>Nagelkerke R²</i>	Odds ratios								
		0 doses by catch-up start			1 dose by catch-up start			All cases		
		Step 1	Step 2	Step 3	Step 1	Step 2	Step 3	Step 1	Step 2	Step 3
			174			110			284	
		0.07	0.23	0.28	0.30	0.45	0.61	0.13	0.18	0.27
Child age		0.86*	0.93	0.93	0.67***	0.59***	0.44***	0.78***	0.80***	0.78***
IMD2007 score		0.98	0.96*	0.96*	1.01	1.00	0.98	1.00	0.99	0.99
Parent age			0.57*	0.58*		1.01	1.41		0.72*	0.79
Parent BME ethnicity			1.58	1.12		0.89	1.31		1.02	0.87
Parent married			0.41 [‡]	0.41 [‡]		0.28 [‡]	0.20 [‡]		0.56 [‡]	0.51 [‡]
Parent education ≥ degree			2.84 [‡]	3.21 [‡]		0.19*	0.08*		0.89	0.96
Number of children			1.35	1.35		0.73	0.58		0.95	0.98
Parent occupation			1.15	1.14		0.78 [‡]	0.74 [‡]		0.96	0.97
Catch-up invitation received			2.76*	3.45*		0.95	2.00		1.51	1.72
MMR beliefs				1.61			0.35			1.22
Measles beliefs				1.71			0.24 [‡]			1.01
Social and parenting beliefs				0.82			9.61**			1.76*
Information source beliefs				1.34			5.12 [‡]			1.18
Practicalities				0.76			1.93			0.94

***: p<0.001. **: p<0.01. *: p<0.05. ‡: p<0.10

4.3.4 Discussion

4.3.4.1 Summary of current findings and relation to previous work

Valuing the opportunity to protect others by immunising one's own child, feeling that immunising one's child with MMR is socially desirable, and having a younger child were the only independent predictors of MMR uptake during the catch-up campaign. Predictors of uptake differed by whether the dose in question was the first the child was to receive or the second: acceptance of a first dose was primarily predicted by receipt of a catch-up invitation, whilst acceptance of a second dose was predicted most strongly by attitudes towards the social aspects of MMR immunisation and trust in/use of MMR-related information sources. Univariate analyses indicated that parents who accepted MMR dose(s) during the catch-up campaign held a significantly different profile of attitudes around the topic than did parents who did not respond to the campaign, but that demographically the two groups were very similar.

Whilst to our knowledge attitudinal and demographic predictors of MMR uptake during catch-up campaigns have not previously been modelled in multivariate analyses, the present findings may be usefully compared with the few relevant models predicting routine MMR uptake. Perceived social desirability/benefit of MMR uptake, a key predictor in this work, was unrelated to PCT-recorded routine MMR uptake in 1999-2000 (Flynn & Ogden 2004), however perceived importance of eradicating rubella (similar to value placed on social benefit of MMR uptake) was a significant predictor of parent-reported MMR uptake in 2003-2004 (Gellatly, McVitie *et al*, 2005). Other key predictors in these studies were previous immunisation behaviour, trust in information sources, and belief in MMR side effects, and whilst these factors were related to catch-up MMR uptake in our univariate analyses, their independent impacts on catch-up behaviour were not significant. These differences may reflect evolving views on MMR in society as the MMR controversy abates, or the different ages of children whose parents participated in the routine uptake studies versus our catch-up study. Our univariate findings generally correlate with results from relevant studies of routine

MMR uptake (Cassell, Leach *et al*, 2006; Casiday, Cresswell *et al*, 2006), with some interesting differences, again perhaps a function of study period or population. For example, in the present study most parents anticipated regret as a consequence both of MMR reaction and of measles infection, and the extent of this regret did not vary by catch-up MMR uptake, however in 2004 (Cassell, Leach *et al*, 2006) routine MMR rejectors were more likely than MMR acceptors to anticipate regret for MMR reaction, and vice-versa. Also in this 2004 study (Cassell, Leach *et al*, 2006), benefitting the community by immunising one's own child was one of the few factors on which routine MMR acceptors and rejectors did not differ, whilst in the present study this was one of the most polarising issues. In the only post-MMR controversy assessment of attitudinal factors underpinning catch-up MMR uptake (during the London 2004/5 primary school campaign; Hadjikoumi, Niekerk *et al*, 2006) MMR safety concerns (particularly autism) were the most frequently cited reasons for catch-up MMR rejection, however in our multivariate analysis this factor did not figure, again perhaps a function of time elapsing since the controversy, and parents of older children being questioned,

4.3.4.2 Implications for policy and practice

There are at least three possible explanations for the finding that attitudes, particularly those about the social aspects of MMR immunisation, were more predictive of uptake among parents who were to give a second dose of MMR than they were among parents who were to give a first dose: parents deciding about a second dose (a) had chosen not to give that second dose previously but the catch-up campaign changed their minds; (b) had always held 'pro-MMR' beliefs but had simply forgotten to obtain that second dose and the campaign reminded them; or (c) were more able to consider 'peripheral' factors like social benefits and norms since they were reassured about MMR risks following their child's earlier receipt of an MMR dose. These explanations require further investigation, perhaps most effectively with a qualitative methodology, but they offer some useful directions for future catch-up programmes or interventions within the routine schedule. This study

also indicates that the attitudinal and demographic profile of parents who immunise in response to a catch-up campaign is different to that of parents who immunise within the routine schedule: key predictors of routine MMR receipt in this population are being of black/minority ethnicity and having positive MMR beliefs (Chapter 4 Part 1), but those factors did not figure in the prediction of catch-up MMR receipt. Catch-up campaigns may therefore require different information materials, health professional approaches, and population targeting than do routine campaigns. Finally, the study demonstrates a clear relationship between younger child age and catch-up MMR receipt in the context of this PCT-based programme. School-based approaches may be more effective in reaching older children (Lashkari & El Bashir, 2010).

4.3.4.3 Strengths and limitations

This study is one of only a handful to explore factors underpinning response to MMR catch-up programmes (Roberts, Sandifer *et al*, 1995; Hadjikoumi, Niekerk *et al*, 2006): despite the high costs (Capital Catch-up Campaign Regional Technical Planning Group, 2007) and persistent disappointing performance (Capital Catch-up Campaign Regional Technical Planning Group, 2007; McAuley, Stokley *et al*, 2008; Roberts, Sandifer *et al*, 1995; Lashkari, El Bashir, 2010) of such campaigns, evaluation to date has been sparse and methodologically limited. The present study used a validated evidence-based instrument (Chapter 4 Part 1) to assess a broad spectrum of predictors of MMR uptake, with a demographically diverse sample of catch-up MMR acceptors and rejectors, and an objective outcome measure. These methodological strengths are uncommon even in the much larger literature on routine schedule MMR decision-making (Brown, Kroll *et al*, 2010a). Importantly, these methodological advances allowed univariate and multivariate analyses which are, to my knowledge, unique contributions to the catch-up response prediction knowledge base. Further, the study demonstrates the viability of evaluating future catch-up campaigns with the instrument used here. However, the study is not without limitations. Though the sample size provided adequate statistical power, the modest participation rate may have compromised the generalisability of the

findings and was lower than has been obtained previously in catch-up populations (Roberts, Sandifer *et al*, 1995; Hadjikhouri, Niekerk *et al*, 2006). Whilst this is likely to be in part a function of poor PCT data quality (The London Regional Immunisation Steering Group, 2009) inflating the denominator in my participation rate calculations (previous studies obtained more reliable denominators by sampling through schools or from subpopulations of parents who had already responded to an immunisation consent request), and efforts were made to facilitate participation among hard-to-reach groups (Dormandy, Brown *et al*, 2008; Edwards, Roberts *et al*, 2009), it may also reflect my failure to access those deprived, low literacy, non English-speaking populations who fail both to respond to questionnaires about immunisation and to attend for immunisation (Pearce, Law *et al*, 2008; Brown, Kroll *et al*, 2010a; Falagas & Zarkadoulia, 2008). In addition, the cross-sectional design of the study means it is not possible to ascertain causality with these data: I cannot infer whether positive attitudes and MMR invitation receipt caused catch-up MMR uptake, or whether catch-up uptake created more positive attitudes and heightened parents' awareness of/memory for having received an invitation.

As discussed above, the present study cannot identify causal relationships due to its cross-sectional design, and these findings should be generalised with caution due to the modest response rate. However, it seems viable and desirable on the basis of the present findings to roll out the measurement instrument with a modified administration method in advance of the next catch-up campaign. This would allow collection of baseline attitudinal data, which can then be compared to post-campaign attitudes aiming to ascertain campaign efficacy in improving attitudes and beliefs. This strategy may be implemented over a large number of PCTs in a nationwide catch-up programme, or over individual PCTs running local programmes; the data can then be combined using meta-analytic techniques to obtain a comprehensive and reliable picture of predictors of MMR receipt during catch-up initiatives, thus contributing directly to rendering such campaigns more amenable to formal evaluation.

4.4 Conclusions and next steps

This study fills a conspicuous gap in the MMR literature by linking comprehensively and robustly measured attitudes and demographics with reliably and objectively measured MMR uptake. Clinical and research applications for the tool are indicated. Parents appear generally to act in line with their MMR and measles-related attitudes, though measles attitudes were the weakest predictor of behaviour and experience of measles and MMR reactions did not predict behaviour in the expected direction. Parent ethnicity is the strongest predictor of MMR behaviour, probably indicating that the MMR concerns assessed here are specific to white British parents (and that parents of black and minority ethnicity use other cues to make their decisions, or adhere to health professionals' recommendations more willingly), but perhaps suggesting that white British parents face barriers to uptake not met by their BME counterparts (though inequalities in access to care usually favour white British rather than BME patients: Davey-Smith, Chaturvedi, Harding et al, 2000). Anticipated regret for MMR reactions is a key specific attitudinal predictor of MMR status, but the impact of this factor can be ameliorated using techniques from behavioural science.

Receipt of a first-ever MMR dose during the catch-up period was predicted most strongly by receipt of an invitation letter from the GP/PCT, whilst receipt of a second dose during the campaign was predicted most strongly by appreciation of the social benefits (for oneself and for the community) of accepting MMR. Future local and national catch-up programmes should be designed with these differential motivations in mind, and can be robustly evaluated using the validated attitude assessment tool employed here.

The multivariate analyses reported here provide some support for the inclusion of vaccine, disease, social and official factors in the experimental models reported in Chapter 5 and 7. However, they

also confirm that some factors central to MMR decisions are not relevant to decisions about other vaccines, for example preference for single vaccines and concern about immune overload from a multiple-antigen vaccine. Using MMR as a context for the experiments comprising the remainder of the program of research would risk the generalisability of the resulting models, as parents may apply their real-life 'baggage' around MMR to their experimentally modelled decisions. This study therefore confirms that as intended, in order to develop a generalisable picture of immunisation decision-making, the experiments must employ hypothetical scenarios in which factors of interest are completely amenable to close control.

**5 Preparing for the next pandemic: Predicting
inexperienced decision-makers' responses to a new
vaccine for an unfamiliar infection**

5.1 Preface

As my systematic review (Chapter 2), interviews (Chapter 3) and large surveys (Chapter 4) identified attitudinal and demographic determinants of parental acceptance of MMR vaccine, so they also demonstrated that many of the factors central to parents' MMR decision-making may not be relevant to their decisions about other vaccines. The systematic review indicated several factors implicated in MMR rejection which play little part in rejection of other vaccines (predominantly those for diphtheria, tetanus and pertussis), including immune overload and autism fears, negative media attention to the vaccine, and parental affluence. The interviews found that most parents – even those rejecting all vaccines for their children – considered MMR to be different to other vaccines, primarily because of the controversy which has surrounded it. The surveys showed that MMR rejectors and acceptors differed on their preference for single vaccines, which is an option currently unique to MMR among combination vaccines in the UK schedule. Together, the findings from these first three studies confirmed that 'baggage' specific to MMR has a strong influence on parents' decisions, and therefore that decision models based on MMR may not be generalisable to other vaccines. This cemented my plan to move away from MMR for this second part of the Thesis, and to use hypothetical vaccine scenarios to test some theories of decision-making under uncertainty.

In order to make a contribution to policy and practice as well as to the general knowledge base around vaccine decision-making, it was important to contextualise this hypothetical approach and to demonstrate its applicability in real-world contexts. Whilst data were being collected for the studies reported in Chapters 5 and 6, the 'swine flu' (2009 A/H1N1 influenza) pandemic emerged, and whilst the data were being analysed a vaccine against this infection was introduced. My hypothetical modelling fitted neatly into this topical context.

This chapter reports the initial ‘proof of principle’ stage of my hypothetical modelling approach, in which I sought to manipulate multiple aspects of the decision-making scenario, both qualitative and quantitative, with an accessible sample of young adults.

5.2 Introduction

The world’s response to 2009 A/H1N1 influenza demonstrated that effective vaccines can be made available within months under pandemic conditions (Valdespino-Gomez, Garcia-Garcia *et al*, 2009; Rambhia & Nuzzo, 2009; Collin & de Radigues, 2009). It also provided a salutary reminder that the populations to which the infection presents the keenest threat (therefore to whom vaccines are offered first) may differ from those familiar with seasonal influenza vaccine or other routine vaccines (for example, very young children and pregnant women) (European Centre for Disease Prevention and Control, 2009). However, uptake of the 2009 A/H1N1 vaccine was lower than expected (Steelfisher, Blendon *et al*, 2010; Bordon, 2010; Seale, Heywood *et al*, 2010; United States Centers for Disease Control and Prevention, 2010; Department of Health, 2010).

Evidence from observational and experimental studies of vaccine decision-making (Tickner, Leman *et al*, 2006; Brown, Kroll *et al*, 2010a; Nagaraj, 2006; Mills, Jadad *et al*, 2005; Roberts, Dixon-Woods *et al*, 2002; Liao, Zimet *et al*, 1998; Zimet, Blythe *et al*, 2000; Tan, Goh *et al*, 2005; Prosser, Bridges *et al*, 2005; Sansom, Barker *et al*, 2001; Meszaros, Asch *et al*, 1996), and surveys of attitudes and behaviour during the 2009 A/H1N1 influenza pandemic (Rubin, Potts *et al*, 2010) identify a number of factors predictive of vaccine acceptance or rejection by parents making such decisions for their children:

- Probabilistic and contextual risk information about the likelihood and severity of disease and of vaccine adverse events (VAEs): perceptions of increased disease risk and decreased VAE risk are associated with higher vaccine uptake
- Relationship with and trust in healthcare providers: healthcare professionals perceived to be knowledgeable, trustworthy, and willing to share personal vaccine experiences with parents achieve higher uptake
- Social and moral norms: vaccine acceptors feel people important to them advocate vaccination, and acknowledge the societal benefits (e.g. herd immunity) of having their own children vaccinated

To date, the relationships between these factors and vaccine uptake have only been demonstrated in the contexts of specific diseases and/or vaccines with which the decision-makers are already familiar and about which they have already formed beliefs. These beliefs may be complex and variable within the population. Some may be specific to a particular vaccine or disease, for example autism concerns may be highly influential in MMR decisions but may not be frequently considered in decisions about other vaccines (Tickner, Leman *et al* 2006; Brown, Kroll *et al*, 2010a). For these reasons, extrapolating from vaccine/disease-specific decision models to decisions about novel diseases/vaccines may be inappropriate. Furthermore, this evidence typically does not explore the thinking of people who are novice at the task of making decisions about vaccines – for example, because their child is too young to have been offered any routine schedule vaccines, or because they have ‘passively’ accepted vaccines previously, without engaging in conscious deliberation about them (Fitzpatrick, 2004). There is evidence that parent age and child birth order is associated with vaccine uptake and views about vaccination (Brown, Kroll *et al*, 2010; Falagas & Zarkadoulia, 2008; Wu, Wisler-Sher *et al*, 2008; Cassell, Leach *et al*, 2006). Therefore it remains to be empirically demonstrated whether models of vaccine decision-making developed with older, experienced parents are applicable to decisions made by younger, primiparous parents.

The research reported here contributes to the understanding of the factors driving novice decision-makers' decisions about new vaccines for unfamiliar diseases. I report three studies using an experimental design which removes the potential confounders described above. In these studies, young adults (potential novice parent decision-makers) made immunisation decisions on the basis of precisely controlled information about unfamiliar, hypothetical vaccines and diseases, and the way in which they combined and weighted the information factors was assessed.

5.3 Study 1: Disease and vaccine reaction likelihood

Study 1 assesses whether novice decision-makers, faced with probabilistic risk information (i.e. likelihood of outcome occurrence) about a disease and vaccine with which they are unfamiliar, engage in 'rational' risk-benefit analyses. The following hypotheses are tested:

H1: Higher disease likelihood predicts higher intention to accept vaccine

H2: Lower VAE likelihood predicts higher intention to accept vaccine

5.3.1 Method

A 3 (disease likelihood: low, medium or high) by 3 (VAE likelihood: low, medium or high) factorial completely within-subjects design was employed. Participants (current and prospective university undergraduates) were recruited by a female researcher over two non-consecutive days. Participants completed the questionnaire at their convenience between lectures and other sessions at a large central London university.

Each participant received a paper questionnaire, headed with a short paragraph of background information setting the scene, and describing the severity of Disease A and of reaction to Vaccine B. Participants were advised that the likelihood of each outcome (child catching Disease A and child reacting to Vaccine B) would be systematically varied in a series of vignettes, and that for each vignette they would be required to rate how likely they would be to accept the vaccine for their child. To minimise context effects for both disease and vaccine, participants were instructed to use all the information on the questionnaire, but nothing else, when making these ratings. Demographic information was also collected. The nine possible combinations of the three levels of Disease A likelihood and three levels of Vaccine B reaction likelihood were then presented in nine vignettes (summary provided in Figure 5.1, full questionnaires for all studies in this chapter provided in Figures 11.9-11.11, Chapter 11 Appendices). Each level of likelihood was represented by a numerical probability (e.g. 1 in 10). Order of vignette presentation was randomised. For each vignette, participants rated their percentage likelihood to give their child Vaccine B by circling a number on an eleven-point scale of likelihood percentages, running from 0% to 100% with 10% intervals, and anchored at 0% = definitely won't and 100% = definitely will. In addition, in six free-text manipulation check items participants wrote (in the format "1 in") what they considered to be low, medium and high likelihoods of catching a disease and low, medium and high likelihoods of a VAE.

Figure 5.1: Questionnaire content for all studies

	Study 1 <i>disease and vaccine reaction likelihood</i>	Study 2 <i>disease and vaccine reaction severity</i>	Study 3 <i>health professional input</i>	
General instructions	You are the parent of a one-year-old child. You are considering whether to give your child Vaccine B to protect them against Disease A. Vaccine B offers effective protection against Disease A. Other details about the disease and vaccine are as follows:			
Background information (baseline attitude priming)	Disease A is a moderately severe childhood illness. Symptoms last 3-5 days and include fever, vomiting and fits.	There is a 1 in [50,000 = "anti-vaccine"; 2,000 = "vaccine-neutral"; 400 = "pro-vaccine"] chance of your child catching Disease A.	There is a 1 in [50,000 = "anti-vaccine"; 2,000 = "vaccine-neutral"; 400 = "pro-vaccine"] chance of your child catching Disease A. Disease A causes [fever and rash = "anti-vaccine"; fever and rash = "vaccine-neutral"; paralysis and brain damage = "pro-vaccine"].	
	Vaccine B can have moderately severe side effects, lasting 3-5 days and including fever, vomiting and fits.	There is a 1 in [30 = "anti-vaccine"; 1,500 = "vaccine-neutral"; 7,000 = "pro-vaccine"] chance of your child having side effects from Vaccine B.	There is a 1 in [30 = "anti-vaccine"; 1,500 = "vaccine-neutral"; 7,000 = "pro-vaccine"] chance of your child having side effects from Vaccine B. These are [paralysis and brain damage = "anti-vaccine"; vomiting and diarrhoea = "vaccine-neutral"; fever and rash = "pro-vaccine"].	
Levels of manipulated factors	Low likelihood = 1 in 10,000 Medium likelihood = 1 in 50 High likelihood = 1 in 10	Mild = fever and rash Moderate = vomiting and diarrhoea Severe = paralysis and brain damage	Consultation style:	Directive = encouraging Non-directive = neutral
			Personalisation of advice:	Personalised = GP's personal testimony Generic = health authority leaflet
			Trust in GP:	Low = Average communicator, random choice High = good communicator, recommended
Example vignette	There is a 1 in 50 chance that your child will catch disease A. There is also a 1 in 50 chance that your child will experience side effects from Vaccine B.	Disease A causes a low fever and a rash. Side effects of Vaccine B are also a low fever and a rash.	Your GP encourages you to give your child Vaccine B. She gives you some NHS leaflets about vaccine B and disease A. You feel that she is an average communicator, and you did not specifically choose her over another doctor.	

SPSS v. 17.0 was used for statistical analyses in all three studies. As some participants gave apparently habitual responses (selecting the same likelihood percentage for every vignette), which potentially compromised the generalisability of the analysis, raw data were screened to exclude outliers (any vignette response $>1.5 \times$ interquartile range outside the first or third quartiles; Fidell & Tabachnik, 2003). Participant-generated likelihoods given in manipulation check items were compared with their corresponding values in the vignettes using one-sample *t*-tests. Participant-generated likelihoods for VAE were compared with participant-generated likelihoods for disease at each of the three levels (low, medium or high) using paired samples *t*-tests. The effect of potential covariates on intention to immunise was assessed using one-way ANOVAs for each condition, with Bonferroni correction for multiple analyses. Hierarchical multiple linear regression analysis was used to test the independent and combined predictive value of any covariates (entered in block 1) and the main variables (entered in block 2) on intention to immunise.

5.3.2 Results

Data from 42 participants were analysed. The sample was 73.2% female, with a mean age of 17.7 years; it provided 80% power to detect medium-to-large effects in hierarchical multiple linear regression with a maximum of 6 predictors. In the manipulation check, participant-generated likelihoods did not differ significantly from those given in the vignettes at any level ($p > 0.05$). No significant differences were observed between participant-generated likelihoods for vaccine reaction and for disease ($p > 0.05$).

Four potential covariates (order of vignettes, recruitment day, sex, age) were tested. Only recruitment day had a significant effect on intention to immunise ($p < 0.05$) and was retained in further analyses. The regression model (Table 5.1; recruitment day entered in block 1; disease likelihood and vaccine reaction likelihood both entered in block 2) explained 49% of variance in

intention to immunise (adjusted $R^2=0.49$). Higher disease likelihood ($\beta=0.52$, $p<0.001$) and lower vaccine reaction likelihood ($\beta=-0.46$, $p<0.001$) predicted higher intention. In addition, participants recruited on the second day of the data collection had significantly higher intention, although this relationship was much weaker ($\beta=0.08$, $p<0.05$).

5.3.3 Discussion

These findings support hypotheses H1 and H2: in a novel disease/vaccine context, higher likelihood of disease and lower likelihood of VAE predict higher intention to accept a vaccine. Disease likelihood and VAE likelihood had comparable beta values, suggesting that participants afforded them roughly equal weighing in their decisions.

In Study 1, the disease and the VAE were identically severe, but the likelihood of their occurrence varied. Study 2 was designed to extend Study 1, by varying the severity of disease consequences and VAE whilst holding their respective likelihoods constant.

Table 5.1: Regression analyses

	Block	β											
		Study 1 (likelihood)		Study 2 (severity)		Study 3 (HP input)							
		1	2	1	2	Full sample		Low intention		Medium intention		High intention	
		1	2	1	2	1	2	1	2	1	2	1	2
Day of session		0.08	0.08*	0.08*	0.08**								
Vignette order				0.03	0.03								
Sex				-0.04	-0.01	-0.11**	-0.08**	-0.21**	0.21***	-0.15*	-0.15*	-0.13*	-0.13*
Age						0.01	0.01	-0.26***	-0.26***	0.16**	0.16**	0.27***	0.26***
Real-life HP advice adherence						0.20***	0.21***	0.17**	0.17**	-0.03	-0.03	-0.47***	0.47***
Disease likelihood			0.52***										
VAE likelihood			-0.46***										
Baseline attitude (likelihood)					0.17***								
Disease severity					0.55***								
VAE severity					-0.62***								
Baseline attitude (likelihood & severity)							0.50***						
HP directiveness							0.10**		0.13*		0.10		0.11*
Personalisation of advice							0.02		-0.02		0.04		0.01
Trust in HP							0.21***		0.28***		0.27***		0.16**

Study 1: Block 1 $R^2=0.01$, Adj $R^2=0.003$, Block 2 $R^2=0.49$, Adj $R^2=0.49$; Study 2: Block 1 $R^2=0.01$, Adj $R^2=0.01$, Block 2 $R^2=0.52$, Adj $R^2=0.51$; Study 3 Block 1 $R^2=0.06$, Adj $R^2=0.05$, Block 2 $R^2=0.36$, Adj $R^2=0.36$; * $p<0.05$; ** $p<0.01$; *** $p<0.001$

5.4 Study 2: Disease and vaccine reaction severity

Study 2 assesses whether novice decision-makers, faced with both probabilistic and contextual (i.e. both likelihood of outcome occurrence and severity of outcome) risk information about a disease and vaccine with which they are unfamiliar, engage in 'rational' risk-benefit analyses. This builds on Study 1 by complicating the influences on decision-making: providing less detailed information on a larger number of factors. The following hypotheses are tested:

H1: More severe disease predicts higher intention to accept vaccine

H2: Less severe VAE predicts higher intention to accept vaccine

H3: Likelihood information predicts intention to accept vaccine (as demonstrated in Study 1)

5.4.1 Method

A 3 (disease severity: mild, moderate or severe) by 3 (vaccine reaction severity: mild, moderate or severe) full-factorial mixed-model design was employed. Participants (none of whom had participated in the previous study) were drawn from the same population and recruited using the same methods and in the same setting as in Study 1.

Questionnaire format and instructions were analogous to those in Study 1. Three versions of the questionnaire were produced, each with different background information on the likelihood of the child catching Disease A and reacting to Vaccine B, intended to prime "pro-vaccine", "anti-vaccine", and "vaccine-neutral" baseline attitude (based on Study 1 manipulation check findings). Baseline attitude was the between-participants variable. Participants were advised that the symptoms of Disease A and of Vaccine B reaction would be systematically varied in a series of vignettes, and

instructed again to rate their likelihood of accepting Vaccine B with reference only to the information on the questionnaire.

The nine possible combinations of the three levels of Disease A severity and three levels of Vaccine B reaction severity were then presented in nine vignettes (Figure 5.1). Each level of severity was represented by a pair of symptoms. These symptoms were discussed with a senior paediatrician within the research group to ensure realism. Order of vignette presentation was randomised. Response format was identical to Study 1. In six manipulation check items participants rated the severity of each of the six symptoms used in the vignettes, using tick-boxes to select one option from the following: mild, mild-moderate, moderate, moderate-severe, severe, don't know.

As in Study 1, outliers were excluded; manipulation check responses were compared with corresponding values in the vignettes; the role of potential covariates was tested; and the independent and combined predictive value of all relevant variables on vaccination intention was assessed. All permutations of pairs of participant ratings for each symptom in the manipulation check were compared using a series of paired-samples *t*-tests.

5.4.2 Results

Data from 75 participants were analysed. The sample was 81.1% female, with a mean age of 18.5 years; it provided 80% power to detect medium-to-large effects in hierarchical multiple linear regression with a maximum of 7 predictors.

In the manipulation check, participants' ratings did not differ in symptom pairs intended to represent the same level of severity ($p > 0.05$). Ratings for symptoms intended to represent different severity levels differed significantly ($p < 0.001$). Participants rated symptoms intended to portray mild disease/VAE (low fever and rash) as significantly more severe than intended (both $p < 0.001$), symptoms intended to portray moderate disease/VAE (vomiting and diarrhoea) as significantly less severe than intended (vomiting $p < 0.01$, diarrhoea $p < 0.05$), one symptom intended to portray severe disease/VAE (paralysis) as significantly less severe than intended ($p < 0.05$) and the other symptom intended to portray severe disease/VAE (brain damage) as severe as intended ($p > 0.05$).

Four potential covariates (order of vignettes, recruitment day, sex, age) were tested. All had a significant effect ($p < 0.05$), except age, and so were retained in further analyses. The regression model (Table 5.1; order of vignettes, recruitment day, and sex entered in block 1; baseline attitude, disease severity and vaccine reaction severity entered in block 2) explained 51% of variance in intention to immunise (adjusted $R^2 = 0.51$). "Pro-vaccine" baseline attitude predicted higher intention ($\beta = 0.17$, $p < 0.001$). Higher disease severity ($\beta = 0.55$, $p < 0.001$) and lower vaccine reaction severity ($\beta = -0.62$, $p < 0.001$) predicted higher intention. Participants recruited on the second day had significantly higher intention, but as in Study 1 this relationship was weak ($\beta = 0.08$, $p < 0.05$).

5.4.3 Discussion

These findings support hypotheses H1 and H2: higher disease severity and lower VAE severity were associated with higher intention to accept vaccine. They also support H3, thus replicating Study 1: likelihood information predicts vaccination intention. Participants were also able to integrate likelihood information with severity information to reach their decisions. Disease and VAE severity had similar beta values, suggesting they were weighted fairly equally in participants' decisions, though vaccine reaction severity had slightly more impact in the model.

In Studies 1 and 2 numerical and contextual risk information was manipulated, with results as expected: more common and severe disease, and less common and severe VAE predicted higher intention to accept vaccine. However, regression analyses demonstrated that these factors predicted only around 50% of the variance in intention. Further, in real life these factors are not amenable to intervention. Health professional factors, including perceived trustworthiness and information provision style, have been consistently linked with vaccine acceptance (Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005) and there is some evidence that interventions can modify these factors (Rao, Anderson *et al*, 2007; McKinstry, Ashcroft *et al*, 2006). Study 3, therefore, explores how health professionals' attributes, which may be amenable to intervention, contribute to decisions grounded in vaccine and disease risk and severity information.

5.5 Study 3: Health professional input

Study 3 assesses whether novice decision-makers, faced with probabilistic and contextual risk information about a disease and vaccine with which they are unfamiliar, and information about the vaccine provider, engage in 'rational' risk-benefit analyses. This builds on Studies 1 and 2 by further complicating the influences on decision-making with the addition of more 'affective' detail.

Vaccine acceptance often relates to attributes of the health professional's (HP's) behaviour and of the professional-parent relationship. These attributes may take various forms (Brown, Kroll *et al*, 2010a; Mills, Jadad *et al*, 2005):

- HP's consultation style: Whether the parent feels directed to a particular decision (directive style), or supported to make their own decision (non-directive style)
- The manner in which the HP provides advice: Whether they provide standard information materials (sometimes interpreted as "following orders" from the health organisation), or share personal experience of vaccine decisions (sometimes interpreted as exercising personal clinical judgment)
- How much the decision-maker trusts the HP

Experimental manipulation of the first two factors involves identifying advice types and formats from relevant real-life vaccine decision-making studies and incorporating them in vignettes. The third factor, trust, is harder to manipulate convincingly in a paper-and-pencil vignette study; instead manipulation of factors underpinning trust is required. Two known predictors of trust in HPs are the HP's communication skill and whether the HP was actively chosen by the patient (for example, based on recommendation) or was selected at random (Hall, Dugan *et al*, 2001).

Study 3 is designed to test the influence of HP factors on immunisation intention in a hypothetical vaccine and disease scenario directly comparable to those used in Studies 1 and 2. The study also assesses how this information interacts with disease and VAE likelihood and severity as investigated in Studies 1 and 2. The following hypotheses are tested:

H1: Directive HP consultation style predicts higher intention to accept vaccine

H2: Trust in HP predicts higher intention to accept vaccine

H3: Personalised information from HP predicts higher intention to accept vaccine

H4: Likelihood and severity information predicts intention to accept vaccine (as demonstrated in Studies 1 and 2)

5.5.1 Method

A 2 (HP consultation style: directive or non-directive) by 2 (trust in HP: low or high) by 2 (personalisation of information: personalised or generic) full-factorial mixed-model design was employed. Participants (none of whom had participated in the previous two studies) were drawn from the same population and recruited using methods and settings analogous to those used in Studies 1 and 2.

Questionnaire format and instructions were identical to those in Studies 1 and 2. Three versions of the questionnaire were produced, each with different background information on the likelihood and severity of the child catching Disease A and reacting to Vaccine B (based on the results of studies 1 and 2), priming “pro-vaccine”, “anti-vaccine”, and “vaccine-neutral” baseline attitude. Baseline attitude was the between-participants variable. Participants were advised that attributes of their GP

consultation about this vaccine would be systematically varied in a series of vignettes, and instructed again to rate their likelihood of accepting Vaccine B with reference only to the information on the questionnaire.

The eight possible combinations of the two levels of HP consultation style, two levels of trust in HP, and two levels of personalisation of information provided were then presented in eight vignettes (Figure 5.1). Order of vignette presentation was randomized. Response format was identical to Studies 1 and 2.

Two potential covariates were assessed using tick-box items:

- Real-life trust in HPs' advice on treatment: never trust; rarely trust; sometimes trust; often trust; always trust
- Real-life adherence to HPs' advice on treatment: never adhere; rarely adhere; sometimes adhere; often adhere; always adhere

In manipulation check items participants used tick-boxes to rate eight aspects of the manipulations on the dimensions which they were intended to represent: directiveness of an HP providing encouragement to vaccinate and of providing neutral vaccination advice (not at all directive, a little directive, completely directive, unacceptably directive, don't know); usefulness of an HP providing NHS/Government material and of providing personal testimony (not at all useful, slightly useful, quite useful, very useful, don't know); and trustworthiness of an HP who is a good communicator, average communicator, recommended by a friend and not specifically chosen (mistrust, slightly mistrust, neither mistrust nor trust, slightly trust, trust, don't know).

As in Studies 1 and 2, outliers were excluded, manipulation check responses compared with corresponding values in the vignettes, the role of potential covariates tested, and the independent and combined predictive value of all relevant variables on intention to immunise assessed. In the manipulation check, participants' ratings for pairs of levels within each factor were compared using paired samples *t*-tests. Separate hierarchical multiple linear regression analyses were conducted for the three baseline attitude subgroups, with the same covariates as the main regression but no between-participants factor.

5.5.2 Results

Data from 104 participants were analysed. The sample was 83.7% female, with a mean age of 19.5 years; it provided 80% power to detect medium-to-large effects in hierarchical multiple linear regression with a maximum of 10 predictors.

In the manipulation check, all pairs of levels within each factor differed significantly ($p < 0.001$), except personal testimony versus leaflets ($p > 0.05$).

Six potential covariates (order of vignettes, recruitment day, sex, age, real-life trust in GP, real-life GP advice adherence) were tested. Participants differed by sex, age, and real-life GP advice adherence ($p < .05$) so only these three covariates were retained in further analyses. The regression model (Table 5.1; sex, age and real-life GP advice adherence entered in block 1; baseline attitude, GP consultation style, personalisation of advice, and trust in GP entered in block 2) explained 36% of variance in intention (adjusted $R^2 = 0.36$). Male participants ($\beta = -0.08$, $p < .05$) and those who reported greater adherence to their GP's advice in real life ($\beta = 0.21$, $p < .001$) had significantly higher intention.

"Pro-vaccine" baseline attitude predicted higher intention ($\beta=0.50$, $p<.001$). Directive GP style ($\beta=0.10$, $p<.01$) and trust in GP ($\beta=0.21$, $p<.001$) also predicted higher intention.

Regression analyses for the sample split by baseline attitude (Table 5.1) show the model predicted most variance (30%, adjusted $R^2=0.30$) when baseline attitude was "anti-vaccine", followed by "pro-vaccine" (21%, adjusted $R^2=0.21$) and "vaccine-neutral" (12%, adjusted $R^2=0.12$). At "anti-vaccine" and "vaccine-neutral" baselines the strongest independent predictor of intention was trust in HP ("anti-vaccine" baseline: $\beta=0.27$, $p<.001$; "vaccine-neutral" baseline: $\beta=0.28$, $p<.001$; higher trust linked with higher intention). At "pro-vaccine" baseline, the strongest predictor was real life adherence to HP's advice ($\beta=0.47$, $p<.001$; higher adherence linked with higher intention). Personalisation of advice was not predictive at any level of baseline attitude ($p>.05$). HPs' directiveness was a weak but significant predictor of higher intention at "anti-vaccine" and "pro-vaccine" baselines only ($\beta=0.13$, $p<.05$ and $\beta=0.11$, $p<.05$, respectively).

5.5.3 Discussion

These data support hypotheses H1 and H2: directive HP style and trust in HP were associated with higher intention to accept vaccine. H4 was also supported, thus replicating the findings of Studies 1 and 2: more severe and common disease paired with less severe and common VAE predicted higher intention to accept vaccine. H3 was not supported: personalised information was not related to intention to accept vaccine. In the full sample analysis, participants weighted vaccine and disease characteristics more heavily than HP input. In subgroup analyses, trust was the only manipulated HP input factor demonstrating consistently strong and significant impact – it was the strongest predictor when vaccine rejection or indecision was primed, but where the vaccine was clearly desirable trust in HP became less important, and "trait" adherence to HP advice became the stronger predictor. Age

and real-life adherence to HP treatment advice often predicted as much or more variance than experimentally manipulated factors.

5.6 General Discussion

5.6.1 Results and implications for practice and policy

The studies reported here demonstrate that vaccine decision-making novices can integrate information on disease, vaccine and some healthcare professional factors to make logical decisions about accepting a vaccine. Decisions appeared to be more consistent and more grounded in the information provided when that information was on disease and vaccine characteristics alone (Studies 1 and 2). Interestingly, in the study that incorporated health professional factors and collapsed disease and VAE likelihood and severity information into a single factor (Study 3) decisions were less grounded in the provided information (as demonstrated by the lower variance accounted for by the manipulated factors). This suggests that that these changes had either (a) overloaded decision-makers (through the addition of health professional factors), prompting them to inconsistently discount some pieces of provided information; (b) alerted them to hitherto unacknowledged complexity in the decision, prompting them to incorporate other unmeasured factors; or (c) provided them with insufficient detail on the factors most important to them (vaccine and disease outcomes), prompting them to make more cautious decisions. The first of these explanations is consonant with prevailing theories of working memory capacity, which suggest that young adults can work with only four 'chunks' of information (Cowan, 2001). The second and third accord with evidence that when decision-makers perceive some information potentially salient to their decision is missing, they are more reluctant to take action, and thus the predictive power of the provided information is diminished (Ritov & Baron, 1990). These findings may have implications for public health communication about vaccines with inexperienced decision-makers in view of a

pandemic. Provision of information not directly relevant to risk-benefit analysis, or failure to provide sufficient information on central attributes of the disease and vaccine, may result in reference to other (potentially unreliable sources) of information, and decision deferral.

The relative equality with which vaccine and disease attributes were weighted does not correspond with the theories of loss aversion (Tversky & Kahneman, 1992) and omission bias (Connolly & Reb, 2003; Brown, Kroll *et al*, 2010b), which have been applied frequently in the context of vaccine decisions. Loss aversion suggests that a loss is weighted around twice as heavily as a gain. According to omission bias, a loss arising through a commission (e.g. reacting to a vaccine) is weighted more heavily than a loss arising through an omission (e.g. catching a disease). Anticipated regret has been posited as a mechanism or alternative explanation for decisions apparently affected by these biases (Connolly & Reb, 2003; Sevdalis & Harvey, 2006; Sevdalis & Harvey, 2007), with decision-makers biased against options (regardless of whether these are commissions or omissions) for which they anticipate most regret if they result in a negative outcome. A possible explanation for the lack of omission bias and loss aversion observed in these studies is that the novel decision-making situation (operationalised via hypothetical diseases/vaccines) did not elicit anticipated regret. This may be a realistic reflection of decisions made during the early stages of a future pandemic before infection and vaccine reaction consequences are clear, as decision-makers may be unable to anticipate regret whilst they have limited knowledge of what it is that they might be regretting. Moreover, this pattern may also reflect reduced salience of negative vaccine consequences among vaccine decision-making novices who have not yet experienced post-decisional emotion in relation to vaccination or preventable disease. This explanation is tentative at the moment as regret was not assessed in these studies, and therefore remains to be tested empirically in future research. Finally, whilst differences between vaccine and disease weights were small, participants weighted disease likelihood slightly more heavily than vaccine reaction likelihood, whilst vaccine reaction severity was weighted slightly more heavily than disease severity. These findings suggest that public health communication about

vaccines in the next pandemic could usefully be focused on the likelihood (more than the severity) of disease and the severity (more than the likelihood) of vaccine reaction in order to simplify risk-benefit analysis for decision-makers.

5.6.2 Strengths, limitations, and directions for further research

This research addresses some limitations of the existing evidence base on vaccine decision-making to assist our understanding for the next pandemic. It describes how novice vaccination decision-makers may choose whether to accept an unfamiliar vaccine for an unfamiliar disease, using basic outcome likelihood and severity information, and evaluation of their vaccine provider. Coupled with the existing evidence base on public reactions to vaccines and infection, the ‘decision drivers’ that have emerged from the current studies can now be used as a basis to inform public health communications and vaccine procurement planning, tailored to novice versus experienced decision-makers.

A key strength of the approach taken here is that the carefully controlled, hypothetical nature of the study design provides excellent internal validity for the observed relative influence of each of the manipulated factors. Now the external validity of the analyses may be further informed by field studies. Hypothetical models akin to ours have been used extensively to study various decision-making processes (Baron, 2008) and in the context of vaccine decision-making, phenomena identified in experimental studies with naive decision-makers (typically students) have been replicated in field studies with parents. For example, the omission bias was first observed with students making decisions for their hypothetical child (Ritov & Baron, 1990), and has since been replicated with parents making real-life decisions (Brown, Kroll *et al*, 2010b; Wroe, Bhan *et al*, 2005). Taking the research reported here as ‘proof of concept’ regarding the range of factors that are considered by novice decision-makers in unfamiliar disease/vaccine contexts, further research

should employ experienced vaccine decision-makers – for example, by replicating the studies with parent participants.

The study is not without limitations. Whilst intention was the only viable outcome measure given the hypothetical design, the models may not perfectly predict what the present sample would actually do in real-life decisions because intention is a significantly but imperfect predictor of actual behaviour (Sheeran, 2002). Our statistical power, whilst likely sufficient for the likelihood manipulations, may have failed to detect some smaller magnitude effects of outcome severity and health professional attributes (Brewer, Chapman *et al*, 2007). Our design may have encouraged participants to consider multiple factors in a way which is not representative of real-life decisions, because decision-makers may refer to only a small subset of available cues when decisions must be made quickly or when the amount of information is overwhelming (Gigerenzer & Goldstein, 1996). Relating to this, our analyses did not incorporate a number of factors which may be relevant to vaccine decisions including education, ethnicity, social norms and media position (Tickner, Leman *et al*, 2006; Brown, Kroll *et al*, 2010a; Jackson, Cheater *et al*, 2008; Skea, Entwistle *et al*, 2008). Whilst this may reflect the limited information on these factors available when planning pandemic vaccination campaigns, and possible limited use of cues as described above, these factors may usefully be incorporated in replications of this work.

5.7 Conclusions and next steps

The research reported here investigates immunisation decision-making in light of two unique characteristics of pandemic vaccines: (a) most decision-makers will be unfamiliar with the disease and the vaccine; and (b) some decision-makers will be inexperienced with vaccination decisions. The

research indicates that young adults with limited vaccine decision-making experience make decisions based on risk-benefit analyses when provided with detailed information on disease and vaccine reaction likelihood and severity, but that increasing the number of factors to be considered and reducing the detail on each of those factors makes decisions less stable. Taken together with field studies and other evidence on public perceptions of and reactions to vaccines and infection, these findings can contribute to public health communications and vaccine procurement in the early stages of the next pandemic, as well as to our understanding of cognitive processes underpinning vaccine decision-making.

Effective communication of probabilistic risk will be central to maximising the quality of decisions based upon disease and vaccine reaction likelihood and severity information. My pilot study in Chapter 8 provides some insight into this area. This series of studies also demonstrated that multiple factors, including qualitative ones such as trustworthiness of health professional, can be simultaneously manipulated effectively in hypothetical scenarios. These multi-component scenarios were replicated and extended in my modelling study with a parent sample, which is reported in Chapter 7.

6 Omission bias and vaccine rejection by parents of healthy children: Implications for the influenza A/H1N1 vaccination programme

6.1 Preface

My series of small experiments with young adults reported in Chapter 5 demonstrated that multi-component, completely hypothetical vaccine and disease scenarios were acceptable and comprehensible to research participants, and that manipulations of quantitative (vaccine reaction and disease likelihood) and qualitative (vaccine reaction and disease severity, and health professional input) attributes in these scenarios impacted on intention to accept the vaccine.

Having proved the viability of modelling hypothetical vaccine decisions, my next study was designed primarily to generate values to populate the vignettes used in the large experiment reported in Chapter 7 and the risk communication methods pilot study (Chapter 8). In addition, this study allowed me to explore whether completely hypothetical scenarios would be acceptable to parents, and whether parents would demonstrate omission bias in response to hypothetical stimuli, as has been observed in studies which have used real-life disease or vaccine stimuli. Again, these findings were contextualised in relation to the 'swine flu' pandemic, to demonstrate their validity for practical application.

6.2 Introduction

Vaccines to prevent 2009 H1N1 influenza A ("swine flu") are being delivered first to, and have been expected to be well-received by, groups for whom the infection can be serious – e.g. elderly people, people with underlying medical conditions, pregnant women and young children. However, recent UK surveys suggest that rates of vaccine rejection both in these high-risk groups and in lower risk groups may be sizeable: 46% of parents of healthy children under 5 years (Boseley, 2009a), 30% of nurses

(Bowcott, 2009), 29% of doctors (Boseley, 2009b) and 48% of pregnant women (Boseley, 2009a) do not expect to accept the vaccine. The effect of the novelty of H1N1 vaccine in comparison with seasonal influenza vaccine is difficult to assess as the two vaccines are offered to different population groups and no 2009/10 uptake data for either vaccine are yet available. *Intended* H1N1 vaccine uptake is lower than *actual* seasonal influenza vaccine uptake (47.1% among people aged under 65 in high-risk groups, 16.5% for healthcare workers). In the light of psychological evidence showing that intention to take health-protective action translates to behaviour in only 43-74% of cases (Sheeran, 2002), actual H1N1 vaccine uptake is likely to be similar to or lower than seasonal influenza vaccine uptake. Poor uptake of H1N1 vaccine will facilitate infection transmission, placing unimmunised high-risk individuals at greater risk. A number of factors may predispose the public to be alert to and over-perceive real or putative adverse events, therefore perhaps to decline H1N1 vaccines: perceived inadequate safety testing, perceived low severity of H1N1 infection, extrapolated concerns about other vaccines, and cognitive biases in decision-making.

Fast-tracked vaccine safety and efficacy testing may be suggested by the media (and perceived by the public and some health professionals) to be inadequate (Bowcott, 2009; Boseley, 2009b; Rose, 2009; Cox, 2009). Whilst H1N1 vaccine preparation is methodologically identical to seasonal influenza vaccine manufacture (although some H1N1 vaccines may be adjuvanted for dose-sparing and/or to improve immunogenicity), many countries worked with regulators to fast-track approval for use by autumn 2009 (The Lancet, 2009). In fact approval of 2009 H1N1 influenza vaccine was not markedly faster than that of seasonal influenza vaccine – which too is not routinely tested in children, despite regular administration to those considered at risk of influenza complications – but mass administration of a fast-track approved vaccine to generally healthy people is unusual for most countries. The absence of detailed safety data in advance of programme implementation could predispose the public, media and concerned vaccine providers to be particularly alert to vaccine adverse events. Further, adverse events occurring

coincidentally with vaccination (almost inevitable given the huge number of doses) may be erroneously attributed by the public to the vaccine, leading to overestimation of adverse event frequency.

Comparisons with other “controversial” vaccines, including the A/New Jersey/8/76 H1N1 (“swine flu”), measles, mumps and rubella (MMR), and human papillomavirus (HPV) vaccines are likely to be made in the media, particularly if adverse events occur. A/New Jersey/8/76 H1N1 vaccine was used in the US in 1976 following a fatal case of influenza caused by a novel H1N1 strain in a military training camp, and was withdrawn after two months due to concerns regarding a link with Guillain-Barré syndrome (Schonberger, Bregman *et al*, 1979). Concerns persist over a purported link between MMR vaccine and autistic enterocolitis, though the Lancet paper from which these concerns stemmed has now been withdrawn by the journal, and the lead author has been ruled by the UK General Medical Council to have been “dishonest” and “irresponsible” in the way he conducted and reported his research (General Medical Council, 2010). HPV vaccine was recently linked (though this link has been very swiftly disproven) with the death of a UK schoolgirl. Wider concerns about vaccine policy may be concentrated on H1N1 vaccine due to the high profile of the campaign.

There is some evidence that 2009 H1N1 influenza was not perceived by the public and health professionals to be particularly severe (Bowcott O, 2009; Boseley S, 2009; Rubin, Amlot *et al*, 2009; Seale, McLaws *et al*, 2009), and that this perception was borne out by clinical data in the majority of cases (Dawood, Jain *et al*, 2009; Hackett, Hill *et al*, 2009). There is also evidence that some parents mistrust official information on vaccines and diseases, believing that vaccine risks are underplayed and disease risks overplayed (Rubin, Amlot *et al*, 2009; Hilton, Hunt *et al*, 2007). Vaccine uptake is positively linked with perceived disease and vaccine reaction severity (Cassell, Leach *et al*, 2006; Bardenheier, Yusuf *et al*, 2004), so 2009 H1N1 influenza vaccine may suffer poor uptake. Poor uptake and therefore low effectiveness at population level may be confounded in the public psyche with low effectiveness at the individual level, particularly if valid uptake estimates are not provided.

Evidence on the psychology of risk suggests that cognitive biases in decision-making are likely to exacerbate any unfavourable public response to adverse events linked to 2009 H1N1 influenza vaccine. Individuals making vaccine decisions (particularly parents deciding for children) are likely to display 'omission bias': rating outcomes arising from action (e.g. vaccine reaction arising from deliberate acceptance of vaccine) more unfavourably than outcomes from inaction (e.g. disease occurring through "taking a chance with fate"), even when those outcomes are objectively identical (Baron & Ritov, 1994; Kahneman & Tversky, 1982). This bias may be exacerbated by parents mistrustful of official information assuming vaccine risks are underplayed and disease risks are overplayed, and compensating for this perceived inaccuracy in their own decisions. Weighting vaccine risks more heavily than disease risks could result in vaccine safety concerns, minimal as they may be in well-informed, "official" and "rational" minds, inflicting disproportionately heavy damage on uptake rates. Such damage may take months or years to repair, reducing the potential for an early impact on disease transmission, and may affect uptake of other routine vaccines through reduced public confidence. Rational decision models (which do not take cognitive biases into account) are likely to underestimate these potential impacts when informing policy for 2009 H1N1 influenza vaccine.

Omission bias has been demonstrated with parent samples in relation to pertussis (Asch, Baron *et al*, 1994; Meszaros, Asch *et al*, 1996) and measles, mumps and rubella (MMR) (Wroe, Bhan *et al*, 2005) vaccines, however these studies are not appropriate to model and inform policy around public response to the 2009 H1N1 influenza vaccine because the contexts are not comparable. To support such modelling, here I present evidence of omission bias in a hypothetical disease and vaccine context with a parent sample.

6.3 Method

Parents of children aged between five and seven years were recruited to complete an online questionnaire through several online discussion forums on UK parenting advice websites (see Figures 11.12 and 11.13, Chapter 11 Appendices for recruitment posting and participant information sheet). On these forums, members post messages and hold virtual discussions about a wide range of issues (i.e. not only vaccination), typically but not exclusively parenting-related. All the websites took a neutral stance on vaccination in their editorial content, and informal assessment of the forums identified the presence of pro- and anti-vaccine views among members.

The questionnaire (see Figure 11.14, Chapter 11 Appendices), completed between April and June 2009, asked parents to define three hypothetical diseases (one mild, one moderate and one severe) and three hypothetical vaccine reactions (one mild, one moderate and one severe) by assigning to each of them a number of characteristics: one likelihood, two symptoms/signs, one minimum duration and one maximum duration. Participants selected these characteristics from predefined lists of options: 6 likelihood options (range: 0.0001% to 10%), 13 symptoms/signs options (range: crying/irritability to death), and 10 duration options (range: less than five minutes to rest of child's life). Each of the six questions was phrased using the following structure: "Please select from this list one likelihood which you feel defines a mild disease", with the number of options to be selected (one or two), the severity of the outcome (mild, moderate or severe), and the outcome (disease or vaccine reaction) changed in each one. The options available to define the hypothetical diseases were identical to the options available to define the hypothetical vaccine reactions, and participants could re-use options across the six hypothetical outcomes (e.g. a symptom selected to define a mild disease could also be used to define a severe disease and a moderate vaccine reaction).

Selections for disease characteristics were compared with selections for vaccine reaction characteristics to determine whether omission bias was present. Presence of omission bias is documented if respondents are willing to accept significantly “worse” outcomes (i.e. more likely, more severe, or of longer duration) when associated with a disease rather than when associated with a vaccine reaction. Paired samples *t*-tests in SPSS v17 were used to analyse the data. Presence of omission bias was also calculated for each respondent and regressed onto demographic characteristics by multiple logistic regression analysis.

6.4 Results

142 parents responded to the questionnaire. Respondents were predominantly white (98.9%), and mainly female (93.7%), married (80.6%), educated to undergraduate level or above (75.6%), over 35 years old (67.8%), and with an annual household income of over £50,000 (€58,000, \$82,500) (58.2%). The mean number of children under eighteen years living at home was 2.4 (SD 1.1), with the mean age of the youngest child 3.3 years (range 1-13 years) and of the oldest child 7.2 years (range 1-18 years).

Participants’ responses are shown in Table 6.1. All likelihoods were rated significantly higher when relating to vaccine reaction than to disease (low likelihood $p<0.001$, medium $p<0.001$, high $p<0.01$). Nine of thirteen symptoms/signs were rated significantly worse when occurring as a consequence of vaccine reaction than as a consequence of disease (loss of appetite, fever below 38.5 degrees, fever above 38.5 degrees, blotchy red rash all over body, vomiting and diarrhoea all $p<0.001$; small pink localised rash $p<0.01$; irritability/crying, novel seizure, joint pain all $p<0.05$). Five of six durations were rated significantly shorter when relating to disease than to vaccine reaction (short-term minimum, short-term maximum, medium-term minimum, long-term minimum $p<0.001$, medium-term maximum $p<0.01$). No demographic predictors of omission bias were found (in the regression model, all $p>0.05$).

Table 6.1: Participant ratings of disease and vaccine reaction characteristics

Factor	Modal response (% of respondents choosing option)		Difference
	Disease	Vaccine reaction	
Likelihood (<i>n</i> =125)			
Small	0.1% (40.8)	0.0001% (37.3)	<i>t</i> (1,124)=5.44***
Medium	1% (55.2)	1% (33.1)	<i>t</i> (1,124)=4.65***
Large	10% (78.4)	10% (53.5)	<i>t</i> (1,124)=2.98**
Symptoms/signs (<i>n</i> =99)			
Loss of appetite	Mild (92.9)	Mild (70.1)	<i>t</i> (1,98)=5.16***
Irritability/crying	Mild (82.8)	Mild (72.4)	<i>t</i> (1,98)=2.28*
Fever <38.5°C	Mild (93.9)	Mild (69.4)	<i>t</i> (1,98)=3.91***
Small pink rash on arms	Mild (62.6)	Moderate (56.7)	<i>t</i> (1,98)=3.37**
Fever >38.5 °C	Moderate (81.8)	Moderate (74.6)	<i>t</i> (1,98)=4.06***
Vomiting and diarrhoea	Moderate (74.7)	Moderate (71.6)	<i>t</i> (1,98)=4.78***
Joint pain	Moderate (69.7)	Moderate (66.4)	<i>t</i> (1,98)=2.24*
Blotchy red rash all over body	Moderate (66.7)	Moderate (67.2)	<i>t</i> (1,98)=4.64***
Brain damage	Severe (100.0)	Severe (97.8)	<i>t</i> (1,98)=-1.68
Death	Severe (99.0)	Severe (99.3)	<i>t</i> (1,98)=1.00
Paralysis	Severe (97.0)	Severe (99.3)	<i>t</i> (1,98)=1.78
Tissue swelling inhibiting breathing	Severe (81.8)	Severe (83.6)	<i>t</i> (1,98)=1.30
Seizure/convulsion	Severe (65.7)	Severe (73.1)	<i>t</i> (1,98)=2.00*
Duration (<i>n</i> =97)			
Short-term minimum	24 hours (43.3)	< 5 minutes (42.6)	<i>t</i> (1,96)=-7.68***
Short-term maximum	48 hours (43.3)	24 hours (39.5)	<i>t</i> (1,96)=-6.27***
Medium-term minimum	48 hours (33.0)	24 hours (29.5)	<i>t</i> (1,96)=-5.90***
Medium-term maximum	1 month (44.3)	1 week (36.4)	<i>t</i> (1,96)=-3.13**
Long-term minimum	1 month (37.1)	1 year (22.5)	<i>t</i> (1,96)=-3.93***
Long-term maximum	Lifelong (83.5)	Lifelong (90.7)	<i>t</i> (1,96)=0.74
* <i>p</i> <0.05; ** <i>p</i> <0.01; *** <i>p</i> <0.001			

6.5 Discussion

My findings show a strong presence of omission bias in these respondents: participants would accept a higher risk of their child catching a disease than they would of their child reacting to a vaccine, would consider a number of symptoms/signs as less serious if they were caused by a disease than if they were caused by a vaccine reaction, and would regard as acceptable a longer duration of symptoms/signs as a consequence of disease than as a consequence of vaccine reaction. It follows that vaccine reactions which objectively appear less unpleasant than or equally unpleasant to disease outcomes may be perceived by parents to be sufficient to warrant vaccine refusal. In addition, the media may give greater coverage to any putative vaccine adverse events than to serious disease outcomes (as occurred during the MMR controversy (Lewis & Speers, 2003; Guillaume & Bath, 2008), and people tend to overestimate the likelihood of those outcomes which they can most readily bring to mind (e.g. the most heavily reported ones) (Tversky & Kahneman, 1974). This 'availability effect' may be exacerbated by the public's predisposition to look out for vaccine adverse events if they are concerned about the adequacy of fast-tracked approval, and to mistakenly attribute coincidental health events to vaccination. Some parents who mistrust official information may assume official statistics on vaccine and disease risk are systematically manipulated to portray the vaccine as better and the disease as worse than they are in reality, and may compensate for this perceived inaccuracy in their own decisions. These factors, perhaps compounded by growing belief that the infection is mild, could result in comparatively minor and/or rare true or perceived adverse events reported after 2009 H1N1 influenza vaccination causing disproportionately (in comparison with rational decision models) large reductions in uptake.

Participants in this study – highly educated, predominantly female, predominantly white, and with a high household income – are not demographically representative of the UK population. This is probably a function of the online forums through which they were recruited, and is typical of

questionnaire studies. However, these parents are directly comparable with those who reported elsewhere their plans to reject H1N1 vaccine (Boseley, 2009a), having been recruited from almost identical sources. Further, these parents tend to be vocal opinion leaders; their dialogues on online forums are publicly accessible and they are often interviewed by the media. Their views may inform and influence other parents' opinions around vaccines (Skea, Entwistle *et al*, 2008; Sturm, Mays *et al*, 2005) and therefore an understanding of this opinion-leading group's thinking may provide a useful "head start" for policymakers. Respondents to this study have a similar demographic profile to parents declining vaccines in routine UK/EU vaccine schedules (Pearce, Law *et al*, 2008; Endrich, Blank *et al*, 2009), so are perhaps more likely than other population groups to refuse 2009 H1N1 influenza vaccine. Although demographic characteristics were not related to omission bias in this study, further studies should explore their role with more diverse samples.

Policy strategies that counter cognitive biases may reduce the risk of poor uptake (and subsequent reduced impact) in the 2009 H1N1 influenza vaccination programme and minimise damage to confidence in immunization. Evidence from behavioural science shows that omission bias is motivated by anticipated regret (Ritov & Baron, 1995; Connolly & Reb, 2003); people expect to feel more regret about consequences of actions (e.g. accepting a vaccine and reacting to it) than about consequences of inactions or "fate" (e.g. remaining unvaccinated and catching a disease). A number of strategies may mitigate the impact of omission bias: a) emphasising anticipated regret as a consequence of disease, b) highlighting vaccine refusal as the unusual, conscious action (versus acceptance as the norm), and c) encouraging parents to consider whether, if their child were making the decision for him/herself, they would prefer a greater or lesser chance of harm and would mind from which source – omission or commission – any such harms came (Baron's Golden Rule: Baron, 1992). These approaches have been linked with MMR uptake intention and behaviour (Wroe, Bhan *et al*, 2005; Burgess, Burgess *et al*, 2006), where vaccine safety concerns are perceived by some groups to have justified vaccine refusal; applying them in the absence of comparable controversy in

the H1N1 context may be even more successful. Omission bias is also exacerbated when decision-makers perceive an increased risk of negative outcome for particular individuals, perhaps based again on availability effects – belief that one may be at higher risk of vaccine adverse events leads to avoidance of vaccination until that belief is proven or disproven (Ritov & Baron, 1990). To reduce ambiguity around “risk factors” for vaccine adverse events, information about adverse event types and expected frequencies for the H1N1 vaccine programme should be provided as early as possible in the programme, adhering to principles of good vaccine risk communication including manipulating numerators rather than denominators (as neglectful processing of denominators may lead to erroneous comparisons between risks (Reyna & Brainerd, 2008)) and comparing disease and vaccine adverse event probabilities to one another, not to other events (as people tend to overestimate the frequency of rare risks and underestimate the frequency of common risks, this may reinforce misperceptions of vaccine adverse event and disease likelihoods). This may also reduce rates of erroneous attribution of unrelated effects to the vaccine (O’Connor, Pennie *et al*, 1996).

Given that many parents who refuse or are unsure about 2009 H1N1 influenza vaccine may also mistrust official sources of vaccine information (Mills, Jadad *et al*, 2005; Brown, Kroll *et al*, 2010a), the media will undoubtedly play a key role in public perceptions of the vaccine, and should be engaged from the earliest stage as informed advocates of vaccination (rather than being left open to engagement by anti-vaccine groups); however decision makers and health professionals need to be aware of how imbalance in media coverage may have a disproportionate impact on vaccine uptake due to omission bias and availability effects, and health professionals must be prepared to clarify media reports. The MMR experience suggests that an equal number of vaccine adverse event stories and negative disease outcome stories can indicate that the two eventualities are equally likely, regardless of the impartiality of the reporting within each story (Lewis & Speers, 2003).

Maintaining an honest and accessible public dialogue about vaccine safety testing and methods for monitoring adverse events (acknowledging that citing ‘no evidence’ for any emergent concerns may not be sufficient to allay public anxieties), and a clear line on the risks and benefits of the vaccine and of fast-tracking it to licensure, may be key to a successful 2009 H1N1 influenza vaccine programme, and potentially to positive knock-on effects for the routine schedule. The cognitive biases discussed here are arguably interwoven with complex decision influences (Sturm, Mays *et al*, 2005); Mills, Jadad *et al*, 2005; Hobson-West, 2003; Brown, Kroll *et al*, 2010a) and are not the only reasons for parents’ refusal of vaccines, however they offer promising lines of investigation and intervention, and insights from modern behavioural science can and should assist in this process.

6.6 Conclusions and next steps

This study demonstrates that parents may be biased against vaccines even when the likelihood of vaccine reaction is lower than the likelihood of disease, if those parents perceive the vaccine reaction symptoms to be at least as severe and long-lasting as the disease symptoms. This may have implications for the way in which information about current and new vaccines should be presented in order to minimise the impact of omission bias on vaccine uptake.

This study also demonstrated that questions about a hypothetical vaccine and disease were acceptable to parents, and provided data to populate the manipulated vignettes in the large experimental study reported in the next chapter.

7 Can parents make evidence-based vaccination decisions?

**Effects of trust and anxiety on vaccine-related
information use**

7.1 Preface

This chapter brings together findings and methods from all the previous chapters to produce a generalisable model of parents' vaccine decision-making. The systematic review (Chapter 2), interviews (Chapter 3) and large surveys (Chapter 4) provided the attributes to be included in the model, and indicated central roles for trust and anxiety in vaccine decisions, but demonstrated that modelling decisions in the highly-charged MMR context may introduce confounding factors and therefore that hypothetical situations were more likely to produce a generalisable model. The experimental studies with young adults (Chapter 5) and parents (Chapter 6) demonstrated that this hypothetical modelling approach was viable, even for qualitative attributes including trustworthiness of sources, and that hypothetical scenarios elicited responses akin to those observed in studies using real-life stimuli therefore were not ecologically invalid. The experimental study with parents (Chapter 6) provided values to populate the vignettes in this study, improving the ecological validity of the model further.

This chapter reports my large experimental study modelling how parents weight five key factors when deciding about a hypothetical vaccine for a hypothetical disease, and how their trust in vaccine providers/policy, and their general anxiety, impact on their use of this information.

7.2 Introduction

Although rejection of multiple vaccines may in part reflect ongoing practical barriers to uptake even in developed countries (Schaad, 1999; Pearce, Elliman *et al*, 2009; McIntyre & Leask, 2008), it likely also indicates that some parents fail to make evidence-based risk-benefit analyses about individual vaccines. Accordingly, interventions to increase vaccine uptake typically focus on either removing access barriers, or providing evidence on the risks and benefits of specific diseases and vaccines – with the former approach generally more successful than the latter (Briss, Rodewald *et al*, 2000). The failure of these evidence provision interventions can, according to theories of information transfer (Windahl, Signitzer *et al*, 2009), be attributed to flaws in one or more of the four key components of communication: the sender (the clinician or public health body providing the evidence), message (the evidence being provided), channel (the form in which the evidence is presented), or receiver (the parent for whom the evidence is intended). The first three of these components are bound together and have been the subject of substantial research interest (Briss, Rodewald *et al*, 2000), identifying characteristics of effective evidence output in the context of vaccination. Parents' flawed receipt of such communications, however, is much less well understood. Parents may fail to receive or use evidence communications as intended because they mistrust vaccine providers or disagree with mass vaccination policies, considering evidence from these sources of little use (Briss, Rodewald *et al*, 2000; Hobson-West, 2007; Evans, Stoddart *et al*, 2001; McMurray, Cheater *et al*, 2004; Hilton, Petticrew *et al*, 2007), or because their mental processing power is diminished by anxiety leaving them reliant on 'rules of thumb' rather than case-by-case evidence appraisals (Hilbig, 2008). Since trust in healthcare providers and policymakers is a function of a number of assumed modifiable factors (including the provider's communication style and whether they were chosen by or randomly allocated to the patient) (Hall, Dugan *et al*, 2001), and anxiety can be reduced using psychological therapies (Hunot, Churchill *et al*, 2007), it follows

that understanding their impact on parental decision-making may indicate new interventions to boost vaccine uptake.

The present study investigates the interaction between trust in vaccine providers and official vaccine policy, general anxiety, and processing of vaccine-relevant evidence using a quantitative behavioural field experiment. Evidence on key attributes known to predict vaccine decisions (Tickner, Leman *et al*, 2006; Mills, Jadad *et al*, 2005; Robert, Dixon-Woods *et al*, 2002; Brown, Kroll *et al*, 2010a; Falagas & Zarkadoulia, 2008) is provided in the context of a hypothetical disease and vaccine in order to eliminate potential bias from the almost infinite and unmeasurable 'baggage' that real-life diseases and vaccines are likely to carry for parents. The research question is whether parents with low provider/policy trust, and with high anxiety levels, attend to and process evidence differently during vaccine decision-making than do parents with higher trust and lower anxiety. The specific hypotheses tested are as follows:

H1: Parents with low trust in vaccine providers/policies are less influenced by evidence than are parents with high trust when making vaccine decisions

H2: Parents with high general anxiety are less influenced by evidence than are parents with low anxiety when making vaccine decisions

H3: Parents with low trust in providers/policies weight evidence on individual factors differently than do parents with high trust when making vaccine decisions

H4: Parents with high general anxiety weight evidence on individual factors differently than do parents with low anxiety when making vaccine decisions

7.3 Method

Ethical approval was obtained from Imperial College Research Ethics Committee (ICREC 9_2_2). Parents of primary school-age children were recruited to participate in the study through forums on a number of UK parenting websites (mumsnet.com, netmums.com, ukparentslounge.com, askamum.com, raisingkids.com, mumszone.co.uk) and through two London primary schools (see Figures 11.15 and 11.16, Chapter 11 Appendices for participant invitation posting and information sheet). Vaccination is not the dominant subject on any of these websites, but where it is mentioned editorially both pro- and anti-vaccine arguments are discussed, and a range of views on vaccination are expressed by parents on the forums. Participants were able to enter a draw to win £100 (US\$150, €111) shopping vouchers. Data were collected between May and September 2009.

Participants completed an online or paper questionnaire (contents identical across formats, see Figure 11.17 Chapter 11 Appendices) assessing provider/policy trust, general anxiety, evidence-based decision-making, and demographics. Provider/policy trust was assessed using an eight-item scale (Cronbach's $\alpha = 0.91$), in which participants rated from 1-4 (where 1=not at all and 4=very much) their agreement with statements about trust in health professionals, Government and vaccine research, perceived vaccine safety and efficacy, perceived disease severity and susceptibility, and previous vaccination behaviour. All statements were positively worded so that higher scores denoted higher provider/policy trust, missing data were prorated, and participants were categorised as having low trust if their scale score was below the sample mean.

General anxiety was assessed using the validated short-form State Trait Anxiety Inventory (SF-STAI (Marteau & Bekker, 1992)) in which participants rated from 1-4 (where 1=not at all and 4=very much) the extent to which they felt calm, tense, upset, relaxed, content and worried on a normal day (Cronbach's $\alpha = 0.83$). Items relating to positive feelings (calm, relaxed and content) were

reverse scored so that higher scores denoted higher anxiety, missing data were prorated, and participants were categorised as having high anxiety if their scale score was above the sample mean.

Evidence-based decision-making was assessed by measuring participants' intention to accept a hypothetical vaccine in a range of scenarios. These scenarios contained evidence on five factors known to predict vaccine uptake (Mills, Jadad *et al*, 2005; Robert, Dixon-Woods *et al*, 2002; Brown, Kroll *et al*, 2010a; Falagas & Zarkadoulia, 2008): vaccine characteristics (efficacy, reaction likelihood, severity and duration), disease characteristics (likelihood of catching, symptom severity and duration), lay sources of information/advice (friends/family advice and decisions for their own children, media position on vaccine), personal practicalities (child's general health on the day of the vaccine appointment, ease of vaccine access, and child-specific disease severity), and official sources of information/advice (personal health professional and Government advice, sample size of and findings from independent vaccine research). Content of the provided evidence was systematically and independently varied for each factor (except for official sources of information/advice which were pro-vaccine in every scenario, to reflect real-life vaccine policy) to create a spectrum of 81 scenarios. Scenarios ranged from those where the evidence clearly favoured the vaccine, to those where it clearly did not favour the vaccine, with more ambiguous scenarios in between. Participants viewed five randomly selected scenarios including a duplicate to assess within-participant response consistency. Responses did not differ at all between duplicated scenarios (Tukey's test $p=1.00$) demonstrating that the vignettes elicited highly consistent responses. Order of factors was randomised within each scenario to minimise order effects and scenarios were interspersed with other questions to minimise unconscious transfer of information between scenarios. For each scenario, participants rated their likelihood to accept the vaccine described on seven-point scales (1-7) where higher scores denoted higher likelihood of acceptance. Finally, demographic characteristics known to predict vaccine uptake (Pearce, Law *et al*, 2008; Samad, Tate *et al*, 2006) were assessed,

including participants' age group, gender, ethnicity, highest educational qualification, annual household income, marital status, number of children, and age and gender of each child.

Data were analysed using four hierarchical multiple linear regressions to identify predictors of intention to accept the vaccine among four subgroups of parents: a) parents with low provider/policy trust, b) parents with high provider/policy trust, c) parents with high general anxiety, and d) parents with low general anxiety. The predictors tested were demographics (excluding gender and ethnicity as variability in these data was negligible) entered in block 1, provider/policy trust (regressions c and d) or general anxiety (regressions a and b) entered in block 2, and the four manipulated evidence factors (vaccine characteristics, disease characteristics, lay sources of information/advice, and personal practicalities) entered in block 3.

7.4 Results

7.4.1 Respondent characteristics

264 parents responded to the questionnaire. Respondent characteristics are shown in Table 7.1. Recruitment through schools yielded a 9.2% (33/360) response rate. Among parents recruited online, 80.2% (264/329) who accessed the online questionnaire completed at least one scenario item, however response rate for all parents who saw the online recruitment messages cannot be calculated as this denominator is unknown.

7.4.2 Effect of provider/policy trust on parents' use of evidence

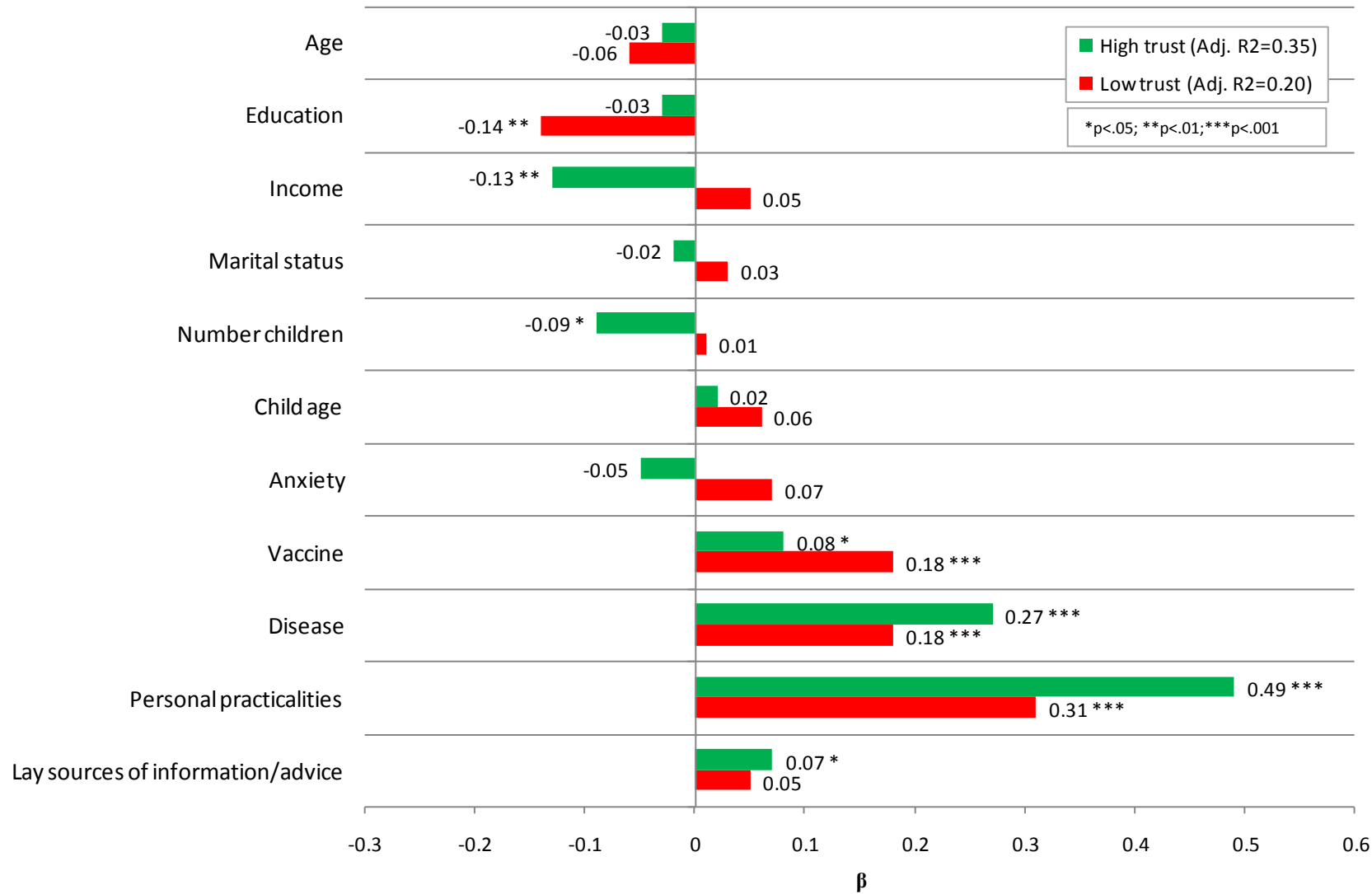
All predictors are shown in Figure 7.1. Participants with low provider/policy trust were less influenced by evidence in their decision-making about the hypothetical vaccines than were parents with high trust (hypothesis 1). Demographics, general anxiety and evidence content explained only 20% of the variability in decisions for low-trust parents (adjusted $R^2=0.20$), compared with 35% of variance for high-trust parents (adjusted $R^2=0.35$). In both regressions, evidence provided in the scenarios explained more variance in parents' intention to vaccinate than did any other single predictor (18-31%, $p<0.05$).

Participants with low provider/policy trust weighted evidence factors differently than did participants with high trust (hypothesis 2). Low-trust parents weighted vaccine-related evidence ($\beta=0.18$, $p<0.001$) and disease-related evidence ($\beta=0.18$, $p<0.001$) equally with one another and around half as heavily as personal practicalities ($\beta=0.31$, $p<0.001$). These parents also did not incorporate lay sources of information/advice in their decisions ($\beta=0.04$, $p>0.05$). In contrast, high-trust parents weighted disease-related evidence ($\beta=0.27$, $p<0.001$) over three times as heavily as vaccine-related evidence ($\beta=0.08$, $p<0.05$) and around half as heavily as personal practicalities ($\beta=0.49$, $p<0.001$), and they incorporated lay sources of information/advice in their decisions, albeit to a small extent ($\beta=0.07$, $p<0.05$).

Table 7.1: Respondent characteristics

Characteristic (n respondents)	n (%)	Mean (SD)
Age in years (244)		
14-19	0 (0)	-
20-24	6 (2.5)	-
25-29	38 (15.6)	-
30-34	70 (28.7)	-
35-39	85 (34.8)	-
40+	45 (18.4)	-
Sex (242)		
Female	232 (95.6)	-
Highest educational qualification (242)		
None	2 (0.8)	-
GCSE/O level	42 (17.4)	-
A/AS level	32 (13.2)	-
Diploma	48 (19.8)	-
Degree	66 (27.3)	-
Postgraduate	50 (20.7)	-
Other	2 (0.8)	-
Ethnicity (246)		
White	232 (94.3)	-
Black	3 (1.2)	-
Asian	7 (2.8)	-
Mixed or other	4 (1.6)	-
Annual household income (231)		
£0-10,000	19 (8.2)	-
£10,001-20,000	42 (18.2)	-
£20,001-30,000	42 (18.2)	-
£30,001-40,000	37 (16.0)	-
£40,001-50,000	34 (14.7)	-
£50,000+	57 (24.7)	-
Marital status (241)		
Married	177 (73.4)	-
Cohabiting	42 (17.4)	-
Single	22 (9.1)	-
Number of children under 18 (240)	-	2.26 (1.05)
Age of child(ren) under 18 (219)	-	5.22 (2.86)

Figure 7.1: Predictors of parents' evidence-based vaccine decision-making by level of trust in providers/policy

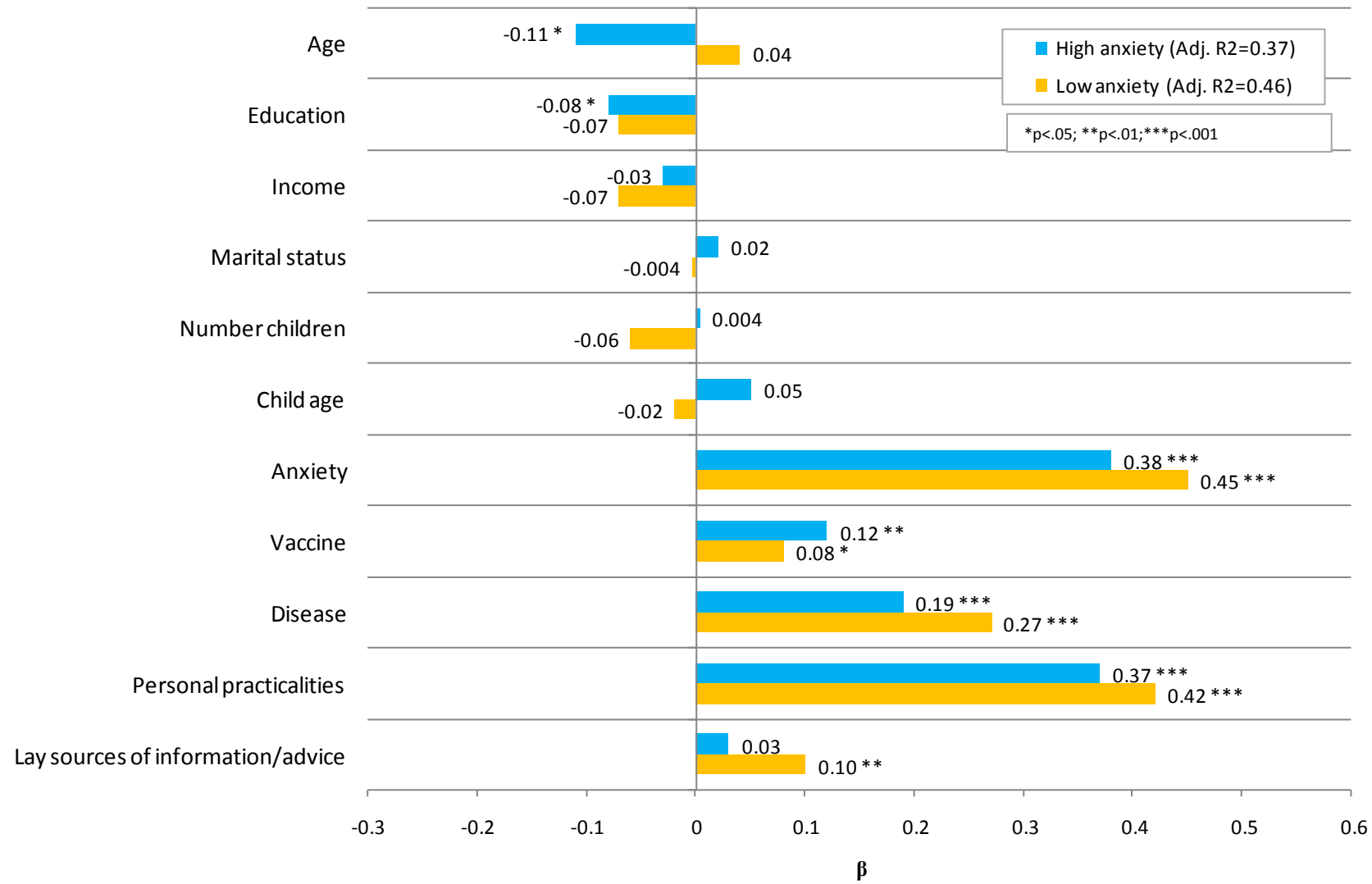


7.4.3 Effect of general anxiety on parents' use of evidence

All predictors are shown in Figure 7.2. Participants with high general anxiety were less influenced by evidence in their decision-making about the scenarios than were parents with lower general anxiety (hypothesis 3). The model incorporating demographics, provider/policy trust and evidence explained 37% of variance in decisions for highly anxious parents (adjusted $R^2=0.37$), compared with 46% of variance for parents with lower anxiety (adjusted $R^2=0.46$). In both regressions, evidence explained more variance in parents' intention to vaccinate than did any other single predictor (19-25%, $p<0.05$), with the second best predictor being provider/policy trust (16-17%, $p<0.05$).

Participants with high general anxiety weighted evidence factors differently than did participants with lower general anxiety (hypothesis 4). Highly anxious parents weighted disease-related evidence ($\beta=0.19$, $p<0.001$) about 50% more heavily than vaccine-related evidence ($\beta=0.12$, $p<0.01$) and around half as heavily as personal practicalities ($\beta=0.37$, $p<0.001$), and they did not incorporate lay sources of information/advice in their decisions ($\beta=0.03$, $p>0.05$). In contrast, less anxious parents weighted disease-related evidence ($\beta=0.27$, $p<0.001$) almost four times as heavily as vaccine-related evidence ($\beta=0.08$, $p<0.05$) and over half as heavily as personal practicalities ($\beta=0.42$, $p<0.001$), and they incorporated lay sources of information/advice in their decisions to a small extent ($\beta=0.10$, $p<0.01$).

Figure 7.2: Predictors of parents' evidence-based vaccine decision-making by general anxiety



7.5 Discussion

7.5.1 Summary of present findings and how they relate to existing evidence

All four of my research hypotheses were supported. Parents with lower trust in vaccine providers and policy, or with higher anxiety, incorporated evidence from hypothetical vaccine/disease scenarios into their decisions about whether to accept that vaccine for their child less than did their more trusting or less anxious peers (H1 and H2). However, low-trust, high-anxiety parents weighted vaccine-related and disease-related evidence more equally against one another to reach their vaccine uptake decisions than did high-trust, low-anxiety parents (H3 and H4). Regardless of parents' level of trust in vaccine providers/policies, or anxiety level, personal practicalities were the strongest predictor of vaccine uptake decisions. Anxiety had no impact on vaccine uptake decisions when the effect of trust in providers/policies was controlled for.

These findings indicate that, just as vaccine-accepting parents use trust in official sources of vaccination advice to minimise complexity during their vaccine decision-making (Casiday, 2006), so vaccine-refusing parents may use mistrust in those sources for a similar purpose. Trust in the advice source has been shown to predict the extent to which information is attended to and utilised in other contexts (Siegrist, Earle *et al*, 2003; Wilson & Sherrell, 1993), and has emerged as a salient issue for parents deciding about vaccines in several qualitative studies (McMurray, Cheater *et al*, 2004; Hilton, Petticrew *et al*, 2007; Mills, Jadad *et al*, 2005). The present study is the first to quantitatively delineate exactly how trust impacts on information use in vaccine decision-making and what the relative importance of trust is in comparison to other factors. Parents' differential weighting of vaccine-related evidence against disease-related evidence according to their trust in providers/policies may relate to the perceived utility of official sources of information-related evidence provided in the scenarios. Parents who trusted these sources may have felt the official

‘stamp of approval’ for the vaccine described in the scenarios removed the need for them to evaluate the vaccine-related evidence themselves, and focused instead on deciding whether the disease warranted vaccination at all. In contrast, parents who mistrusted those sources were not content to accept the official line on the vaccine so evaluated both vaccine-related and disease-related evidence equally.

The observed relationship between increased anxiety and reduced evidence use replicates findings from the psychological literature (Hilbig, 2008; Butler & Mathews, 1987). Importantly, this is the first time this relationship has been demonstrated in vaccine decision-making. That anxious parents here weighted vaccine-related and disease-related evidence more equally against one another than did non-anxious parents, is consistent with the psychological Processing-Efficiency Theory (Eysenck & Calvo, 1992), which suggests that though anxiety diminishes decision-makers’ mental capacity to process information, anxious people unconsciously compensate for this by expending more effort on making their decisions than do non-anxious people. Further, as anxious people pay more attention to threat information than to other information (Eysenck & Calvo, 1992), the relatively even distribution of parents’ attention across vaccine-related and disease-related evidence here would suggest that both the vaccine and the disease were perceived by anxious parents to be a threat.

Parental education, income, age and number of children were the only demographic predictors of intention to vaccinate in this study – with highly educated, wealthier, older parents with more children less likely to vaccinate. This demographic profile is consistent with US and UK data on parents of completely unvaccinated children (Smith, Chu *et al*, 2004; Samad, Tate *et al*, 2006) and UK data on parents of children unvaccinated with MMR (Pearce, Elliman *et al*, 2009; Flynn & Ogden, 2004), however it contrasts with the profile of parents of partially vaccinated children, who are typically poorer, younger, and with lower education (Brown, Kroll *et al*, 2010a). These demographic profiles may reflect two different routes to noncompliance with the vaccine schedule (National

Institute for Health and Clinical Excellence, 2009): conscious rejection (among affluent, educated, older parents) and accidental omission (among poorer, less educated, younger parents); it is this former group to which evidence-provision interventions (as opposed to reminders and recalls) are targeted – and thus to which the findings of this study are expected to be most pertinent.

7.5.2 Strengths and limitations of this study

This study used hypothetical vaccine/disease scenarios directly analogous to real-life vaccination decisions, in order to remove the potential confound of pre-existing perceptions about a real-life vaccine or disease. This design rendered real-life behavioural outcomes unavailable, therefore self-reported intention was employed as a proxy behavioural measure. Psychological research has shown that intentions to engage in a specific real-life behaviour translate to actual behaviour in at least 43-74% of cases (Sheeran, 2002) (and more frequently when the behaviour is within decision-makers' own control, as vaccine acceptance typically is in my population of interest), suggesting that my proxy measure provides a valid appropriation of actual behaviour. Importantly, the rate of 'translation' of intention to real-life behaviour is not expected to differ by trust in providers/policies or general anxiety, and therefore is not expected to affect the key findings of the study.

The study used a self-selected sample, which potentially compromises sample representativeness. However, respondent demographics indicate that parents across the spectrum of educational attainment and household income participated, which is relatively unusual for behavioural studies assessing parents' vaccination decisions or views (Brown, Kroll *et al*, 2010a), and which was arguably facilitated by the financial incentive (Edwards, Roberts *et al*, 2009). Because the sample is not skewed on key demographics, the findings from this study are expected to extrapolate reliably to the wider population.

7.5.3 Implications for policy and practice

These findings show a link between parents' high general anxiety and low trust in vaccine providers/policies, and their ineffective use of evidence during vaccine decision-making. This link indicates primarily that efforts to improve vaccine uptake should begin by improving trust in vaccine providers and policy before decision-relevant evidence is provided, as until the former is achieved the latter is unlikely to influence vaccine decisions. A second indication is that anxiety-reduction interventions may be effective in improving evidence use therefore potentially to improving vaccine uptake. A number of interventions to improve public trust around vaccination have been suggested (Cooper, Larson *et al*, 2008), including increasing lay membership of vaccination advisory and approval bodies (and improving public awareness of the number and diversity of these bodies), understanding (and harnessing, where viable) the power of opinion leaders within communities and parent groups, and conceding current gaps in knowledge about vaccination (at provider and policy level) rather than 'overselling' benefits.

Parents' differential weighting of vaccine-related evidence against disease-related evidence according to their trust in providers/policies and general anxiety may further suggest avenues for targeting information provision. As high-trust and low-anxious parents appear to be more heavily influenced in their vaccine decisions by disease-related evidence than vaccine-related evidence, communication may usefully focus more heavily – though not exclusively – on the former rather than the latter. Further, as personal practicalities, particularly perceived contraindications to vaccination, appeared to be more influential than any other factor, provision of information on this subject could be made a priority.

7.6 Conclusions and next steps

This study found that parents who are mistrustful of vaccine providers/policy or are highly anxious pay less attention to evidence when making vaccination decisions. For best results, interventions should improve parents' trust in these key official information sources, and reduce their anxiety, prior to the deployment of relevant evidence.

However, this study did not explore the impact of risk presentation methods on parents' use of information. The study reported in the final chapter of the Thesis investigates this issue.

8 How should probabilistic information be communicated to vaccine decision-makers? Effect of probability content and presentation on cognitive and emotional decision outcomes

8.1 Preface

My systematic review (Chapter 2) and qualitative interviews (Chapter 3) indicated that parents making decisions about childhood immunisation are often dissatisfied with information about vaccines and diseases, typically due to perceived partiality, poor timing, and lack of depth. Whilst neither the interviews nor the bulk of reviewed studies suggested the way in which information (specifically probabilistic information on risks of vaccine adverse reaction and of disease) was presented within official materials was a particularly salient problem, one study in the review found that younger parents and those with lower socioeconomic status struggled to comprehend probabilities presented as proportions (e.g. 1 in 100), and would prefer if percentages (e.g. 1%) were used (Petts & Niemeyer, 2004). Moreover, my experimental studies (Chapters 5 and 7) showed that decisions elicited wholly or primarily by probabilistic risk information presented as proportions were highly variable, and that the information itself explained less than half of that variability. Covariates measured in these studies (including demographics, anxiety, trust in vaccine providers/policy, and real-life adherence to medical advice) accounted for little of the remaining variance, implying a central role for some additional unmeasured factors, perhaps including comprehension of the data presented. These findings from the Thesis, along with the wider risk communication and perception literature reviewed below, indicate that methods of presenting probabilistic risks for vaccine decision-making warrant further exploration. This chapter reports a study in which I have started to address this.

8.2 Introduction

Effective risk communication is accepted as a central tenet of successful vaccination programmes (Stoto, Evans *et al*, 1998; Ball, Evans *et al*, 1998; Bostrom, 1997). Effectiveness in these discussion/opinion papers is typically conceptualised in terms of a number of ‘big issues’ – including fostering trust, demonstrating transparency, and ensuring accuracy, with the main objective being vaccine uptake improvement. What has traditionally received less attention both conceptually and empirically are the ‘nuts and bolts’ of getting this trusted, transparent, and accurate data across to parents. Practically, much of this data is probabilistic information about the likelihoods of diseases and of vaccine adverse events. Communication and comprehension of probabilistic risks is vital to health decisions where the action or illness involved has more than one possible outcome, and the likelihood of each of those possible outcomes can be estimated using relevant data. Health promotion interventions, and those which seek to maximise patient involvement in treatment decision-making, rely heavily upon effective communication of the likelihood that engaging in a behaviour (e.g. smoking a cigarette, or giving a vaccine) will result in a given outcome (e.g. developing lung cancer, or having anaphylaxis).

However, as efforts to involve patients in health decision-making are relatively new (Taylor, 2009), so is research into the cognitive, emotional, behavioural and health impacts of different methods of presenting probabilistic risk (Rothman & Kiviniemi, 1999; Berry, 2004; Ancker & Kaufman, 2007; Edwards, Elwyn *et al*, 2001, Edwards & Elwyn, 1999). Within this limited literature, which contains very few studies on vaccine/infectious disease risk communication, a number of attributes of probabilistic risk presentation have been shown to influence outcomes independently of the content of the risks presented. Some of these attributes are discussed below.

8.2.1 Framing

Behavioural outcomes are affected by whether the probabilities presented refer to a gain (e.g. likelihood of preventing disease through vaccination) or to a loss (e.g. likelihood of catching a disease having not vaccinated) arising from a particular choice, and these effects vary by whether the choice in question is about a detection behaviour (e.g. cancer screening) or a prevention behaviour (e.g. stopping smoking). Loss-framed probabilities result in higher intention/uptake for detection behaviours, whilst gain-framed probabilities result in higher intention/uptake for prevention behaviours (Edwards, Elwyn *et al*, 2001; Salovey, Schneider *et al*, 2002; Rothman, Bartels *et al*, 2006). This interaction between framing and behaviour type may relate to people's risk-avoidance when focused on gains (e.g. preventing cancer), and risk-seeking when focused on losses (e.g. identifying cancer). In general, people prefer not to jeopardise expected good outcomes (hence are risk-avoidant), but are willing to take chances to avoid poor outcomes (hence are risk-seeking; Kahneman & Tversky, 1979).

Though vaccination is ostensibly a prevention behaviour, because losses (vaccine adverse reaction) and gains (disease prevention) are likely to be approximately equally salient, particularly following a sustained period of high vaccine uptake and low disease incidence (Chen, 1999), and because decision-makers may doubt vaccine efficacy (Abhyankar, O'Connor *et al*, 2008; Bartels, Kelly *et al*, 2009), the focus of vaccination decisions may be on negative outcomes; therefore the impact of framing in this context may be more akin to that observed for detection behaviours. The current Department of Health immunisation information leaflet *A guide to immunisations up to 13 months of age* (Department of Health, 2007) uses loss framing throughout (e.g. 'Out of every ten babies immunised, one or two may get swelling, redness or tenderness at the injection site or get a mild fever', p22). Empirical evidence for a loss frame advantage in the context of vaccination decisions is scant, however: loss framing has been linked to higher intentions to receive MMR (Abhyankar,

O'Connor *et al*, 2008) and HPV (Gerend & Shepherd, 2007, Gerend, Shepherd *et al*, 2008) vaccines, but has been shown to have no effect on adult influenza (O'Connor, Pennie *et al*, 1996) and infant respiratory disease (Donovan & Jalleh, 2000) vaccine uptake. These studies are unable to assess whether the content of the probabilities presented (e.g. whether the vaccine was desirable or undesirable) interacted with any framing effects, and whether framing also impacted on cognitive and affective outcomes (e.g. comprehension and worry). Further, it is unclear whether decision-makers' existing beliefs about the diseases and vaccines addressed in these studies influenced their decisions independently of the content and framing of the information provided.

8.2.2 Format

Cognitive outcomes are affected by whether probabilities are presented numerically, verbally or graphically. Numerical presentations including proportions and percentages are problematic for many decision-makers, due to poor health numeracy and cognitive errors. For example, 16-20% of highly educated adults are unable to identify which of 1%, 5% or 10% is the largest risk (Lipkus, Samsa *et al*, 2001), and a substantial proportion of adults across the educational spectrum are unable to convert between proportions, percentages and frequencies (Ancker & Kaufman, 2007). Decision-makers may also ignore the denominator when interpreting proportions, resulting in errors when probabilities to be compared are presented with varying denominators rather than varying numerators (Reyna & Brainerd, 2008). For example, only 56% of patients could tell that a disease affecting 1 in 384 women was less common than one affecting 1 in 112 women (Grimes & Snively, 1999), and a cancer with a mortality rate of 1,286 out of 10,000 was rated more risky than one with a mortality rate of 24.14 out of 100 (Yamagishi, 1997).

Verbal presentations, for example 'high-risk' and 'low-risk', avoid these numerical processing problems, but are open to variable interpretation and are unpopular with decision-makers. For example, verbal descriptors are associated with poorer knowledge than are numeric presentations (Edwards, Elwyn *et al*, 2001), and an exploration of the quantification of verbal descriptors for likelihoods of generic treatment complications/side effects revealed standard deviations of 15-27 percentage points (Woloshin, Ruffin *et al*, 1994). Patients prefer numerical presentations over verbal descriptors (Shaw & Dear, 1990), perhaps because the former are perceived as more trustworthy (Gurmankin, Baron *et al*, 2004).

Graphical presentations including icon arrays (in which a population is represented by a group of icons, with those who experience different outcomes represented by differently shaped or coloured icons), histograms (in which different outcomes are represented by different bars), and risk ladders or line graphs (in which the likelihood of an outcome is plotted against or presented alongside various levels of a contributor to that outcome) overcome the imprecision of verbal descriptors and the misinterpretation of numerical descriptors, but are not without drawbacks (Ancker, Senathirajah *et al*, 2006). Graphics in which the entire population is shown support quantitative accuracy probably through visual processing – decision-makers compare the physical space taken up by each section of the population – which is in itself prone to error (Lipkus & Hollands, 1999). Further, visual processing works best when similar icons are grouped together, but this can diminish the sense that the risk is randomly dispersed across the population. Graphics which show only numerators can inflate perceived risk magnitude by effectively presenting absolute rather than relative risks, which is known to increase intention to act but is associated with poorer comprehension (Edwards, Elwyn *et al*, 2001), but where such graphics show small risks alongside large risks (often by changing the scale or by using a 'magnifying glass' to home in on a region of the graphic) the perceived size of all risks is reduced.

In the context of vaccination decision-making, evidence for the impact of presentation format is very sparse. Mothers have been found to prefer numeric rather than verbal information on vaccines, but the impact of these formats on outcomes was not assessed (Freeman & Bass, 1992). Graphics have been shown either to increase (Kaplan, Hammel *et al*, 1985) or to have no effect on (Weinstein, Sandman *et al*, 1994; Ancker, Weber *et al*, 2010) vaccination intentions compared with numerical presentations. The current Department of Health childhood immunisation information leaflet (Department of Health, 2007) uses proportions with constant numerators and varied denominators (e.g. 'The complications of measles affect one in every 15 children' p26, 'About one in every 1000 immunised children may have a fit caused by a fever' p28), which is contrary to evidence-based recommendations for health risk communication (Visschers, Meertens *et al*, 2009; Paling, 2003; Fagerlin, Ubel *et al*, 2007; Lipkus, 2007). However as this evidence is predominantly not related to vaccination, and assesses an incomplete profile of outcomes, whether this approach should be amended is currently unclear.

8.2.3 The present study

In light of the evidence around framing and formatting of likelihood information reviewed above, it follows that systematic research is needed to determine the optimal presentation method to facilitate informed and satisfying vaccination decision-making by parents. The study reported in this chapter aims to pilot-test the feasibility of and need for a multi-outcome, multi-predictor assessment of how probabilistic risks in the context of vaccination can be most effectively communicated.

8.3 Method

8.3.1 Participants

Ninety-seven parents of primary school-age children who participated in the evidence-based decision-making online experiment (Chapter 7), and consented to receive information about related research within the present program, were invited to participate (see Figures 11.18 and 11.19, Chapter 11 Appendices, for participant invitation email and information sheet).

8.3.2 Materials and procedure

The questionnaire (see Figure 11.20, Chapter 11 Appendices) was available online only. It comprised 18 brief vignettes which first described the symptoms and duration of an infectious disease and of a vaccine available to protect against that disease, then described the probability of catching the disease and of having a reaction to the vaccine. Symptoms and duration were held constant across the vignettes: disease caused ‘high fevers, on and off for 48 hours - 1 month’, and vaccine reaction caused ‘high fevers, on and off for 24 hours - 1 week’. Probability content, framing and format were systematically varied across the vignettes (which were presented in random order), using values generated in piloting with a similar parent sample (Chapter 6) to ensure relevance for the present population. Values were as follows:

- Content favoured either rejection of the vaccine (vaccine reaction probability higher than disease probability – 10% vs 0.1%), acceptance of the vaccine (vaccine reaction probability lower than disease probability – 0.0001% vs 10%), or was neutral (vaccine reaction probability and disease probability equal – 1% vs 1%)

- Framing related probabilities either to gains (probabilities of positive outcomes, i.e. not catching the disease and not having a reaction to the vaccine) or to losses (probabilities of negative outcomes, i.e. catching the disease and having a reaction to the vaccine). Within each vignette, vaccine reaction and disease probabilities were framed in the same way.
- Format showed probabilities either as percentages (0.0001%, 0.1%, 1%, 10%), proportions with denominators held constant (1 in 1 million, 1,000 in 1 million, 10,000 in 1 million, 100,000 in 1 million), or dot display graphics (see Figure 8.1). Within each vignette, vaccine reaction and disease probabilities were formatted in the same way.

For each vignette respondents completed four measures: (a) their intention to give their child the vaccine on the basis of the information provided, (b) how certain they were about the decision, (c) how worried they were about the decision, and (d) how easy they found it to comprehend the probabilistic information provided. Measures used 1-7 (intention, certainty, worry) or 1-10 (comprehension) scales with anchored endpoints (higher scores indicating higher intention, certainty, worry and comprehension). A number of demographic factors were also assessed: age, sex, ethnicity, education, household income, marital status, and number and age(s) of children. Finally, participants were invited to make free-text comments about their opinions and use of the information in the vignettes.

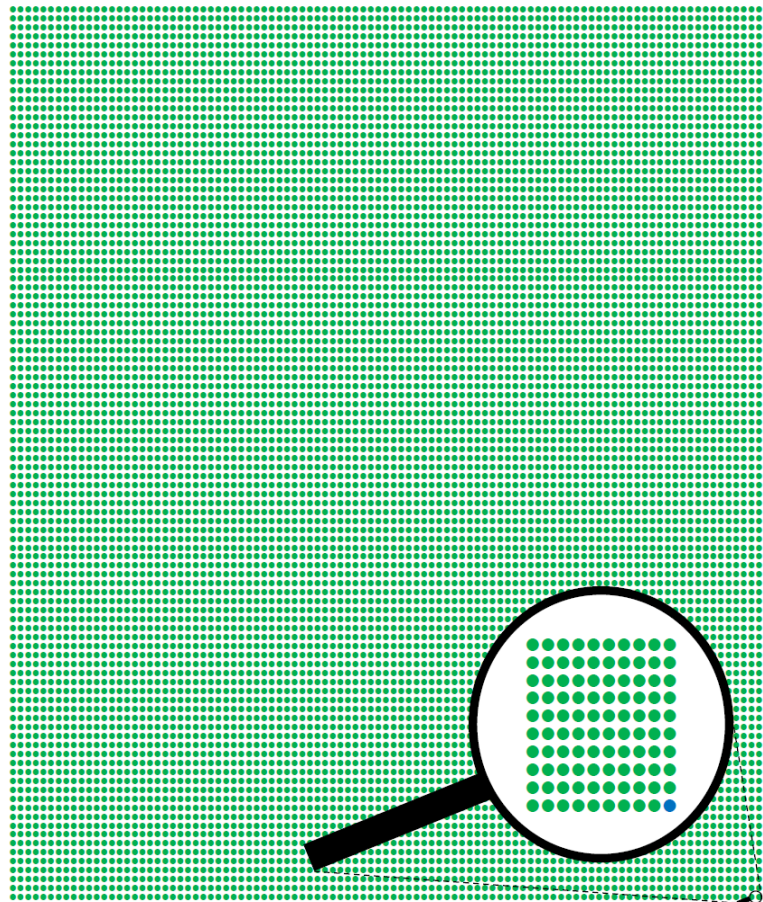
Ethical approval was obtained from Imperial College Research Ethics Committee (ICREC 9_2_2).

Participants were invited by email to participate in the study. The invitation email contained a link to the questionnaire administration website, which provided information about the study and the questionnaire itself in a single webpage. Two email reminders were sent, at one-month intervals following the initial invitation.

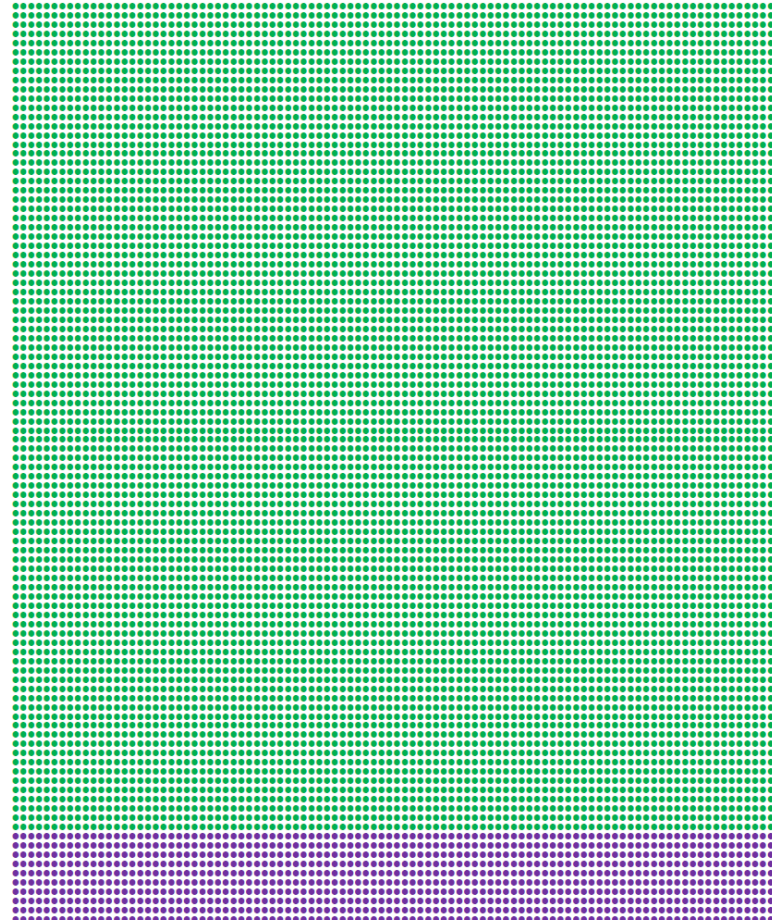
8.3.3 Analysis

Data were analysed using SPSS v 17.0 (SPSS Inc., Chicago, IL). Repeated measures ANOVAs were used to identify main and interaction effects of each of the three manipulated factors (probability content, format and framing). Participants with missing data or zero variability on vignette outcome measures were excluded from these analyses. Paired-samples t-tests with Bonferroni correction were used to interrogate significant effects.

Figure 8.1: Example of graphic presentation of probabilistic risks



This diagram represents 1 million children **who receive ImmunoVAX**.
Each dot represents 100 children.
The magnifying glass shows the contents of one dot (i.e. 100 individual children)
Green dots are children who do not have a reaction to ImmunoVAX.
Blue dots are children who have a reaction to ImmunoVAX.



This diagram represents 1 million children **not** vaccinated against ImmunoBUG.
Each dot represents 100 children.
Green dots are children who do not catch ImmunoBUG.
Purple dots are children who catch ImmunoBUG.

8.4 Results

8.4.1 Response rate and respondent characteristics

42 participants (43%) completed the questionnaire. Participants were mainly female, married, white, educated to degree level or above, aged 35 years or older, and with an annual household income of over £50,000. The mean number of children per participant was 2.5, the youngest child per participant was aged 3 years on average. Detailed participant characteristics are shown in Table 8.1.

8.4.2 Intention

Twelve participants with zero variability on the 'intention to accept vaccine' item (responded 'definitely would not give vaccine' for all vignettes) and 10 participants with missing data on vignettes were excluded, therefore 20 cases were included in the repeated measures analysis.

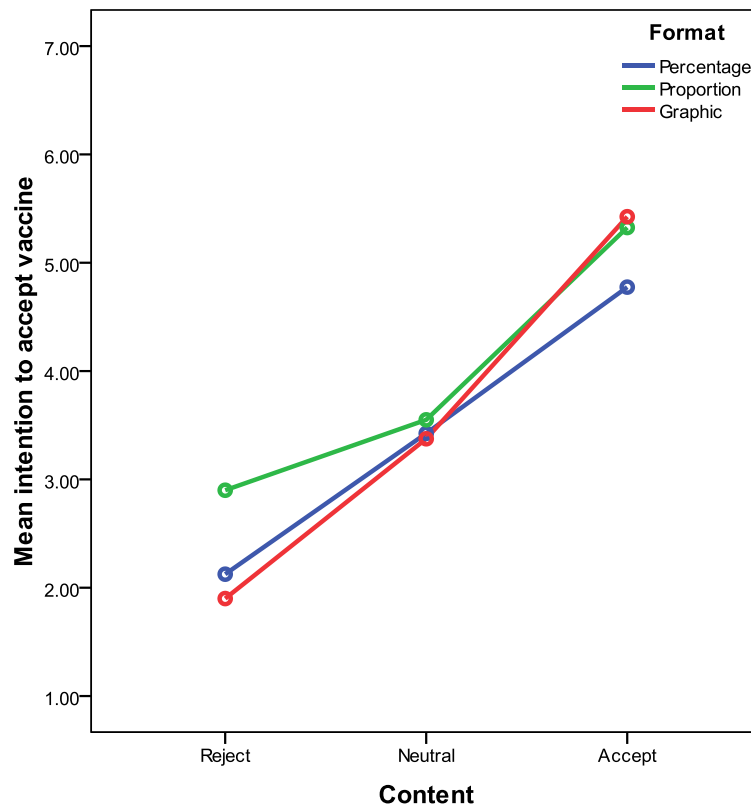
Analyses of main effects indicated that intention to accept vaccine was higher when data content favoured vaccine acceptance ($F(2,38)=55.94$, $p<0.001$) and when data format was proportions rather than percentages or graphics ($F(2,38)=5.68$, $p<0.01$; proportions vs percentages $p<0.05$, proportions vs graphics $p<0.05$). Framing had no effect on intention to accept vaccine ($p>0.05$).

There was also a significant interaction between content and format ($F(4,76)=3.81$, $p<0.01$; Figure 8.2). Format was only related to intention to accept vaccine when content favoured rejection or acceptance. When rejection was favoured, intention was significantly higher for proportions than for percentages ($t(2,20)=2.46$, $p<0.05$) or graphics ($t(2,28)=3.62$, $p<0.01$). When acceptance was favoured, intention was significantly higher for percentages than for graphics ($t(2,28)=4.12$, $p<0.001$), but did not differ between percentages and proportions, nor between proportions and graphics ($p>0.05$).

Table 8.1: Respondent characteristics

Characteristic	n (%)	Mean (SD)
Age in years		
20-24	3 (9.1)	-
25-29	3 (9.1)	-
30-34	6 (18.2)	-
35-39	12 (36.4)	-
40+	9 (27.3)	-
Sex		
Female	32 (97.0)	-
Highest educational qualification		
GCSE/O level	2 (6.1)	-
A/AS level	2 (6.1)	-
Diploma	5 (15.2)	-
Degree	14 (42.4)	-
Postgraduate	10 (30.3)	-
Ethnicity		
White	21 (72.4)	-
Black	4 (13.8)	-
Asian	3 (10.3)	-
Mixed or other	1 (3.4)	-
Annual household income		
£10,001-20,000	5 (17.2)	-
£20,001-30,000	5 (17.2)	-
£30,001-40,000	4 (13.8)	-
£40,001-50,000	3 (10.3)	-
£50,000+	12 (41.4)	-
Marital status		
Married	25 (75.8)	-
Cohabiting	5 (15.2)	-
Single	3 (9.1)	-
Number of children under 18	-	2.48 (1.64)
Age youngest child	-	3.12 (2.70)
n=29-33 for all demographics items – data missing for 9 participants.		

Figure 8.2: Interaction effects of content and format on intention to accept vaccine

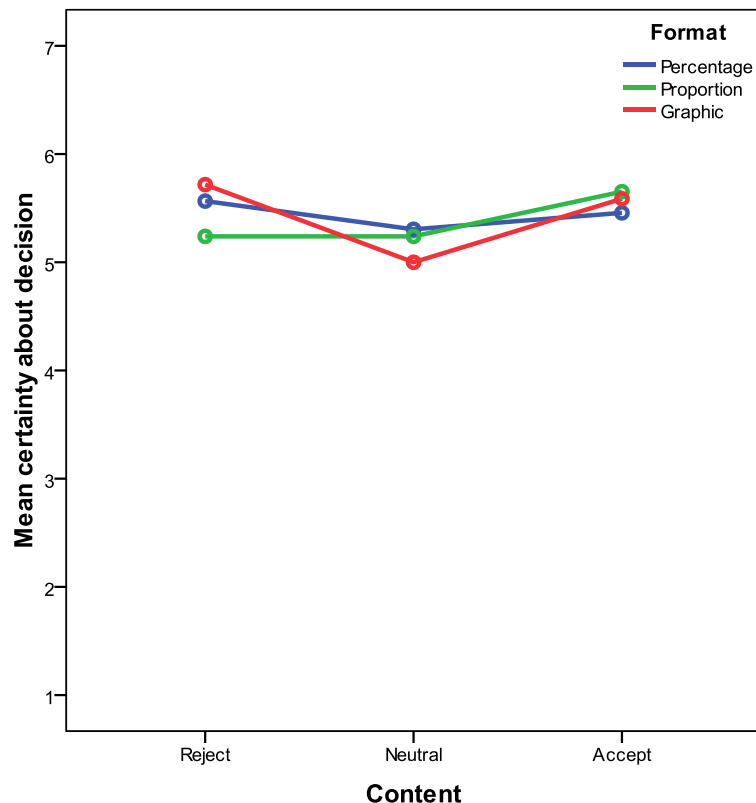


8.4.3 Certainty

Ten participants with zero variability on the 'sure about decision' item (responded 'extremely sure' for all vignettes) and 9 participants with missing data on vignettes were excluded, leaving 23 cases included in the repeated measures analysis.

There were no main effects of format, framing or content on decision certainty ($p > 0.05$). There was a significant interaction between format and content ($F(4,88) = 3.66$, $p < 0.05$; Figure 8.3): format was only related to certainty when content favoured rejection or neutrality. When rejection was favoured, certainty was significantly higher for graphics than for proportions ($t(2,29) = 2.43$, $p < 0.05$) but did not differ between graphics and percentages, nor between proportions and percentages ($p > 0.05$). When content was neutral, certainty was significantly higher for percentages than for graphics ($t(2,23) = 2.34$, $p < 0.05$) but did not differ between graphics and proportions, nor between proportions and percentages ($p > 0.05$).

Figure 8.3: Interaction effects of content and format on certainty about decision to accept vaccine



8.4.4 Worry

Ten participants with zero variability on the 'worried about decision' item (responded 'extremely relaxed' for all vignettes) and 10 participants with missing data on vignettes were excluded, leaving 22 cases included in the repeated measures analysis.

There were no main effects of format, framing or content on worry about decision ($p > 0.05$). There were two significant interactions, between format and framing ($F(2,42) = 3.39$, $p < 0.05$; Figure 8.4) and between format and content ($F(4,84) = 3.53$, $p < 0.05$; Figure 8.5). Format was only related to worry when data were gain-framed and content favoured neutrality; with this framing and content worry was significantly higher for graphics than for percentages ($t(2,22) = 3.14$, $p < 0.01$), but did not differ between graphics and proportions, nor between proportions and percentages ($p > 0.05$).

Figure 8.4: Interaction effects of framing and format on worry about decision to accept vaccine

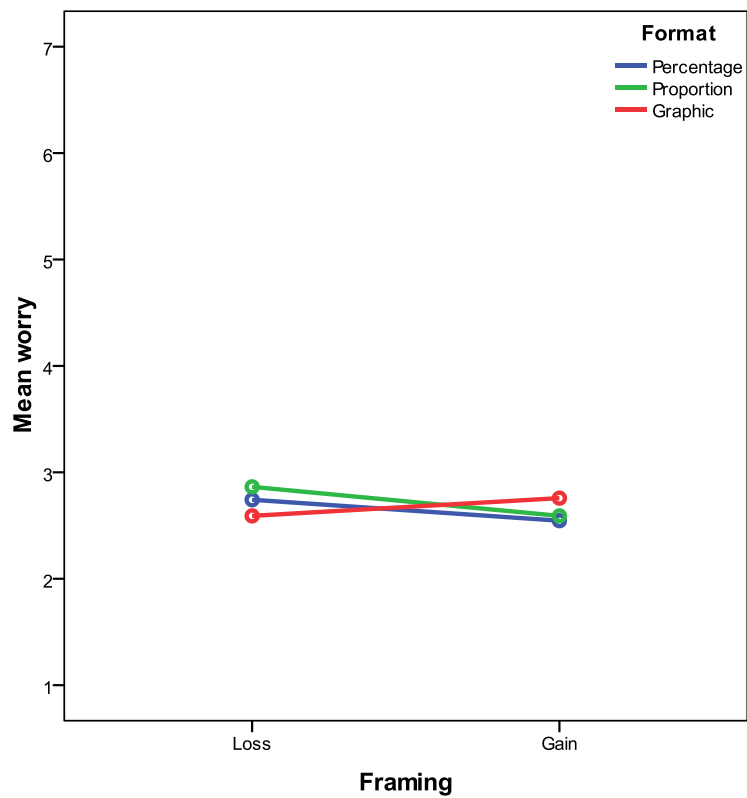
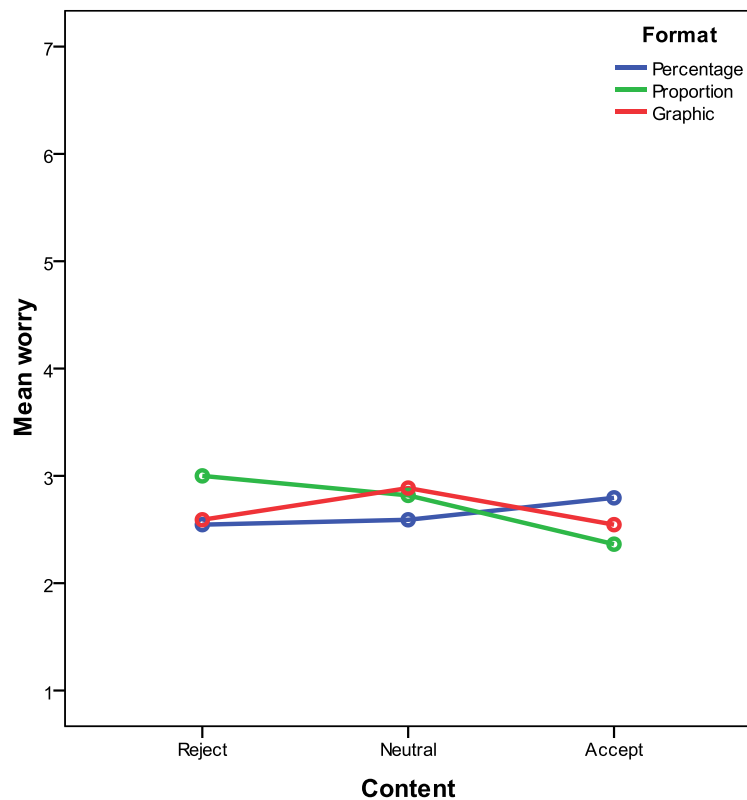


Figure 8.5: Interaction effects of content and format on worry about decision to accept vaccine



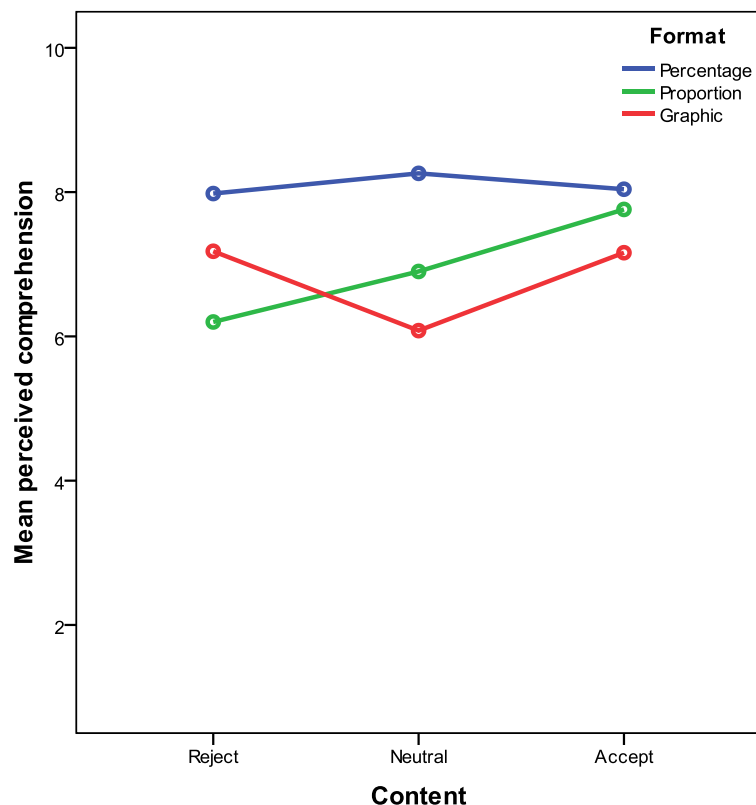
8.4.5 Perceived comprehension

Seven participants with zero variability on the 'understood information' item (responded 'completely understood' for all vignettes) and 10 participants with missing data on vignettes were excluded, leaving 25 cases included in the repeated measures analysis.

Analyses of main effects revealed that perceived comprehension was higher when data format was percentages rather than proportions or graphics ($F(1.5,36)=7.95$, $p<0.01$; percentages vs proportion $p<0.01$, percentages vs graphics $p<0.05$). Framing and content had no main effects on comprehension ($p>0.05$).

There was also a significant interaction between content and format ($F(4,64)=5.95$, $p<0.01$; Figure 8.6). When content favoured rejection or neutrality, comprehension was significantly higher for percentages than for proportions (rejection $t(2,25)=3.46$, $p<0.01$; neutrality $t(2,26)=3.40$, $p<0.01$) or graphics (rejection $t(2,25)=2.19$, $p<0.05$; neutrality $t(2,26)=4.35$, $p<0.001$), but did not differ between proportions and graphics ($p>0.05$). When content favoured acceptance, comprehension was significantly higher for percentages than for proportions ($t(2,24)=2.36$, $p<0.05$) but did not differ between percentages and graphics, nor between proportions and graphics ($p>0.05$).

Figure 8.6: Interaction effects of content and format on perceived comprehension of information



8.5 Discussion

8.5.1 Summary of findings and relation to existing evidence

These data indicate that, where vaccine rejection is not clearly favoured by likelihoods of vaccine reaction and disease, these probabilities are best presented as percentages rather than as proportions or graphics. Where these outcome probabilities favour acceptance of the vaccine or do not clearly prime either acceptance or rejection, presenting the data as percentages is related to higher intention, greater decision certainty, lower decision-related worry, and better perceived data comprehension. Where probabilities favour vaccine rejection, the optimal format is not clear, as no single format performs well on all outcomes assessed here. The present data also indicate that

whether probabilities are gain- or loss-framed has no impact on behavioural, cognitive or affective outcomes in this context.

Existing evidence for the effects of message framing and format on behavioural, cognitive and affective outcomes in vaccination decision-making is sparse and conflicting, and accordingly the present findings are concordant with some studies and discordant with others. No framing effect was observed here, which conflicts with studies of parents' decisions about MMR and HPV vaccines which have found a loss-frame advantage (Abhyankar, O'Connor *et al*, 2008; Gerend & Shepherd, 2007; Gerend, Shepherd *et al*, 2008), but concurs with studies of adult flu vaccine decisions and hypothetical vaccine infant respiratory disease decisions (O'Connor, Pennie *et al*, 1996; Donovan & Jalleh, 2000) which have found no impact of framing. This may be attributable to the higher salience of potential negative vaccination outcomes (which is linked to loss-frame advantage: Kahneman & Tversky, 1979) in the former two studies as compared with the latter two and the present study: MMR and HPV are real-life, controversial vaccines about which study participants may have had existing fears; whilst hypothetical or adult vaccines are unlikely to elicit such a depth of feeling. The observed affective benefits of using percentages over proportions or graphics have been demonstrated elsewhere (Timmermans, Ockhuysen-Vermey *et al*, 2008) though research in this area is sparse, however the apparent behavioural and cognitive advantages of using percentages were somewhat unexpected given that format is typically either not linked with these outcomes (Visschers, Meertens *et al*, 2009; Weinstein, Sandman *et al*, 1994; Ancker, Weber *et al*, 2010, Timmermans, Ockhuysen-Vermey *et al* 2008) or percentages are found to be the least motivational and comprehensible format (Kaplan, Hammel *et al*, 1985; Fagerlin, Ubel *et al*, 2007). However, some parent groups have indicated in qualitative studies that they would prefer percentages to proportions in vaccination risk communications (Petts & Niemeyer, 2004), and this study provides the first quantitative evidence for this preference.

8.5.2 Strengths and limitations

This study has a number of methodological strengths. To my knowledge, this small-scale pilot study is one of very few studies to have experimentally assessed the impact of risk presentation methods on vaccine decision-makers' choices, emotions and cognitions. Moreover, it is one of relatively few studies within the wider health risk communication literature to systematically compare the impact of framing and format on multiple outcomes (Edwards & Elwyn, 2000; Lipkus, 2007). The hypothetical vaccine and disease around which the vignettes were based facilitated disentanglement of the effects of the experimental manipulations from the 'baggage' which is attendant with any real-life vaccine and disease, and which is very difficult to reliably measure and control for. Finally, the parent sample provides ecological validity which is lacking from many risk communication studies, which typically recruit students (Pinon & Gambará, 2005).

Limitations are also present. The modestly-sized sample was powered to detect only medium-to-large effects, therefore some smaller effects may have been missed. The sample size, response rate, and online-only administration method present a risk of self-selection bias. Around 25% of participants displayed no variability on any of the outcomes assessed. From free-text comments that some participants made, lack of variability was to some degree attributable to their view that the disease described in the scenario was too mild to warrant vaccination under any circumstances. This suggests either that the scenarios were not sufficiently realistic for some parents, or that the sample comprised a high proportion of 'vaccine questioning' parents, both of which may have negative implications for the generalisability of the present findings. However, this study proves in principle that presentation style can influence key outcomes for vaccine decision-makers, and therefore that further experiments are warranted, with larger samples and more realistic and detailed vignette contents.

8.5.3 Implications for policy and practice, and directions for further research

The present findings indicate the current Department of Health immunisation information materials for parents (Department of Health, 2007) may not present probabilistic risks in the most appropriate format to maximise informed, emotionally positive vaccine acceptance. However, these findings are based on a small, self-selected sample, and as such must be replicated with a larger and more representative group of parents before any robust policy recommendations can be made.

In addition to eventually informing modifications to existing risk communication materials for parent vaccine decision-makers, 'best practice' for communicating probabilities to this group should be incorporated into new interventions. A possible evidence-based intervention emerges from the qualitative work reported in Chapter 3 and the experimental study reported in Chapter 6. The experiment indicated that parents were biased against vaccines versus diseases on multiple dimensions, and it was posited that this bias is attributable to preference for omissions (taking no action, i.e. not vaccinating) over commissions (taking action, i.e. vaccinating), perhaps because greater regret is anticipated for a negative outcome arising from action than for a negative outcome arising from inaction (Ritov & Baron, 1990; Connolly & Reb, 2003). The impact of this omission bias on behaviour depends on which course of action (vaccination or non-vaccination) is considered the omission, and that depends on which course of action is perceived to be normative; accordingly encouraging parents to view non-vaccination as the commission has been identified as a potential remedy for omission bias (Brown, Kroll *et al*, 2010b; Wroe, Bhan *et al*, 2005). However, the qualitative study (Chapter 3) revealed that some parents are not clear what normative vaccination behaviour in their community is. Current vaccination information materials (Department of Health, 2007) provide no information on vaccine uptake rates (probably because these rates are variable across the UK and over time, therefore including them in official materials would limit the location and lifespan of those materials), and though this information appears in media reports the extent to which parents use the media for this information is unknown, and their trust in the media as an information source is not high (Chapters 2 and 3). Therefore presenting vaccine coverage data at

local level, from a reputable source, using appropriate risk communication methods, may be an effective method of ameliorating omission bias. However, this is dependent on whether local uptake is high enough for vaccination to be considered normative. The potential impact of communicating high coverage to parents who may be considering 'free-riding' on local herd immunity (Skea, Entwistle *et al*, 2008) must also be considered.

8.6 Conclusions and next steps

Optimal methods for communicating probabilistic risks to parents making vaccination decisions are currently not well understood, and there is sparse but conflicting evidence on the impacts of framing (focusing on gains or losses) and formatting (numeric, verbal or graphic presentation). The present study found no effect of framing but clear behavioural, cognitive and affective advantages for presenting data as percentages rather than as proportions with constant denominators or dot-display graphics, with a moderating role in some cases for the objective desirability of the vaccine. These findings should be replicated in order to robustly ascertain the most effective methods of vaccination risk communication, with lessons learned incorporated into education materials for health professionals and information materials for parents.

9 General discussion

9.1 Summary of findings

This Thesis reports a programme of research exploring how parents decide whether to have their children immunised. The programme comprised a systematic review of the relevant quantitative and qualitative literature (Chapter 2), a semi-structured interview study (Chapter 3), and two large evidence-based questionnaire studies (Chapter 4) exploring decisions about specific real-life vaccines (predominantly MMR); and a series of four behavioural experiments (Chapters 5, 6, 7 and 8) exploring the mechanics of immunisation decision-making under controlled conditions using hypothetical vaccine and disease scenarios. The programme had five aims (Section 1.5), and the findings in relation to each of these aims are outlined below.

9.1.1 Aim 1: Describe factors found by qualitative and quantitative research to inform parental decisions about combination vaccinations

My systematic review (Chapter 2) and interview study (Chapter 3) identified a consistent profile of attitudes among parents rejecting MMR and other vaccines. These parents felt the vaccine they rejected was unsafe and did not provide consistent or long-lasting protection; they mistrusted health professionals and immunisation policy due often to perceived conflicted interests, and doubted officially-sanctioned research was sufficient or impartial; accordingly they perceived pro-vaccine bias in most available information from these sources (though many parents in the interview study also considered information from ‘unofficial’ media and online sources to be skewed); they believed most vaccine-preventable diseases are mild, uncommon and treatable, and that their impact can be lessened by maintaining health through good nutrition; and they did not agree that the societal benefit of high immunisation coverage warranted the risk vaccination posed to their individual child, nor were they motivated to gain social approval (or avoid social disapproval) through vaccinating. The review did not identify a consistent picture of demographic factors associated with vaccine

uptake. The limited data available suggested parents who omitted MMR in the UK differed demographically from parents who omitted MMR (or other vaccines) in other countries: the latter were typically less educated, less wealthy and younger than their MMR-accepting peers, whilst the former were found in some studies to be more educated, more wealthy and older than MMR acceptors in their population.

9.1.2 Aim 2: Identify gaps and weaknesses in this knowledge base, and devise remedies for them

My systematic review (Chapter 2) highlighted a number of gaps and methodological weaknesses in the literature reporting factors influencing parents' immunisation decisions. First, the absence of a validated, widely used measure of immunisation attitudes and beliefs emerged as a particular problem during the review process, as the disparity of the data (each study assessing a different set of factors using different questions and response formats) precluded quantitative analysis. This need was met with the design and testing of my comprehensive, evidence-based attitudes and demographics measure (Chapter 4). Second, multivariate analyses were rare in this literature (perhaps because measures were not sufficiently comprehensive) therefore the relative predictive value of, and interplay between, factors was not clear. My application of the validated tool to produce regression models of routine and catch-up MMR uptake (Chapter 4) went some way to remedying this. Third, the role of information processing biases and limitations had been explored very infrequently with parents, despite experimental psychology having recognised immunisation as a perfect example of decision-making under uncertainty for many years (Ritov & Baron, 1990; Baron & Ritov, 1994). My qualitative study (Chapter 3) began to fill this lacuna. In addition to these conceptual gaps, a number of apparently avoidable methodological weaknesses pervaded the design, conduct and analysis of relevant studies. Around half of the reviewed studies relied on parent-reported vaccine uptake, which can be unreliable. I obtained objective uptake data from GP

and PCT records for all of my studies assessing real-life decision-making (Chapters 3 and 4), however PCT records too were unreliable, with outdated contact details and staff error in harvesting data (see page 251 for more detailed discussion of this). In this respect, my best intentions to improve methodological quality in fact created an additional methodological limitation. Qualitative studies often failed to report thematic saturation, did not validate their analyses by double-coding with a second analyst or by reviewing analyses with participants, and collected data retrospectively in relation to the decision being made and acted upon. My interview study overcame all three of these limitations to produce more robust results. Quantitative studies often failed to control for demographic attributes when assessing the relationship between attitudes and behaviour. My questionnaire studies rectified this flaw by using multivariate analyses.

9.1.3 Aim 3: Determine predictors of behavioural, cognitive and affective immunisation decision outcomes

My questionnaire study exploring MMR decision-making (Chapter 4) and my behavioural experiments with young adults (Chapter 5) and parents (Chapters 7 and 8) all employed multivariate analyses to determine the independent predictive value of the 'belief profile' devised in Chapters 2 and 3, in relation to real-life objective MMR uptake and intention to accept a hypothetical vaccine for a hypothetical disease. The way in which parents prioritised factors differed between real-life MMR decisions and hypothetical decisions. The MMR studies found that perceived social benefit and social desirability of immunisation were the only factors independently predicting both routine and catch-up MMR uptake, but these factors were not among the strongest predictors of immunisation intention in the hypothetical model. However, these factors may not have been adequately salient in the hypothetical scenarios: the young adults study indicated that manipulations of qualitative factors like trust and perceived acceptability (as opposed to manipulations of quantitative factors like outcome likelihood and severity) did not impact on intention as expected. In the hypothetical model, personal practicalities (including clinic access and perceived contraindications such as fever on

vaccine appointment day) were the strongest predictor of intention, but in the MMR studies access issues had no relationship with uptake; this fits with indications from free-text responses in the hypothetical decisions study that contraindications (rather than clinic access) were the most important aspect of the personal practicalities factor. In the MMR decision models, vaccine factors were a stronger predictor than disease factors, whilst in the hypothetical decision models this pattern was reversed, perhaps because vaccine safety is such a central issue in MMR decisions following the purported MMR-autism link controversy (Elliman & Bedford, 2007; Smith, Yarwood *et al*, 2007). The differences between factors prioritised in real-life MMR decisions and factors prioritised in hypothetical immunisation decisions may reflect a) the uniqueness of debates and decisions about MMR in comparison with other vaccines, b) lack of true, immersive participant engagement in my experiments, or c) differences between samples in the studies. Ascertaining which of these explanations are correct will indicate whether real-life or hypothetical models best describe the relative influence of factors in immunisation decision-making, particularly for new (and non-controversial) vaccines; and therefore whether hypothetical models can provide an appropriate basis for policy recommendations under these circumstances. Further research is required to address these issues.

Whilst the multivariate models in the Thesis only assessed behavioural outcomes (i.e. actual or intended vaccine uptake), the final study comparing risk communication methods (Chapter 8) also assessed cognitive (understanding of information) and affective (satisfaction and worry) outcomes. This study indicated that communication of quantitative probabilistic risks using percentages rather than graphics or proportions was related to more positive outcomes on all three dimensions, independently of the actual content of those risks (e.g. whether the vaccine was desirable or undesirable).

9.1.4 Aim 4: Assess the presence and impact of information processing biases in immunisation decisions

My experimental studies with parents and young adults (Chapters 5, 7 and 8) all assessed how decision-makers processed provided information in order to choose whether to give their child the vaccine described. My study in which parents selected characteristics to describe a vaccine reaction and a disease episode (Chapter 6) did not obtain a behavioural outcome in this way, but was able to identify biased use of information. The study with young adults (Chapter 5) observed neither omission bias (overweighting of negative outcomes arising from action in comparison to negative outcomes arising from inaction; Ritov & Baron, 1990; Wroe, Bhan *et al*, 2005) nor loss aversion (preference for avoiding negative outcomes over obtaining positive outcomes; Abhyankar, O'Conner *et al*, 2008; Baron & Ritov, 1994), perhaps because participants were not sufficiently immersed in the hypothetical scenarios to anticipate regret (believed to be the mechanism by which omission bias and loss aversion occur; Connolly & Reb, 2003). However the results of this study did suggest an information processing limitation, such that decisions which required the integration of several pieces of information (e.g. vaccine attributes, disease attributes, and health professional attributes) were less grounded in that information than were decisions which involved fewer cues (e.g. only vaccine attributes and disease attributes). The characteristic selection study (Chapter 6) observed a clear multidimensional omission bias, such that parents selected more negative attributes to describe a vaccine than they did to describe a disease despite the vaccine and the disease being assigned identical qualitative labels (e.g. 'good', 'moderate', 'bad'); effectively parents required the vaccine reaction to be less likely, less severe and of shorter duration than the disease episode in order for the vaccine to be preferable to the disease. The model-building study with parents (Chapter 7) identified a possible 'halo effect' of general trust in vaccine providers and policymakers. Parents who trusted these sources underweighted the vaccine factors in the model in comparison with the disease factors, perhaps because their trust in the provider/policymaker who offered the vaccine was extrapolated to the vaccine itself. These parents may have felt less need to evaluate a

vaccine with a 'stamp of approval' from a trusted source. This study also identified that general anxiety and source mistrust limited information processing capacity, such that more anxious or mistrustful parents' decisions were less grounded in the provided information, but that in line with Processing Efficiency Theory (Eysenck & Calvo, 1992), anxiety and mistrust actually improved the efficiency with which the information was used (e.g. central factors were weighted more equally against one another). The risk communication study (Chapter 8) failed to observe any effect of framing (i.e. whether the probability of a good outcome or a bad outcome was presented), perhaps indicating that this sample was not loss-averse, as framing is believed to impact on decisions through focusing attention on the outcome which the decision-maker is motivated to obtain or avoid (Kahneman & Tversky, 1979; Edwards, Elwyn *et al*, 2001). However, this again may have been a function of the scenarios failing to elicit anticipated regret, believed to be the mechanism by which loss aversion occurs (Baron & Ritov, 1994). Overall, evidence of information processing biases in the Thesis is mixed, whilst evidence of information processing limitations is clearer.

9.1.5 Aim 5: Explore interventions to improve immunisation uptake in light of key factors and biases

My risk communication pilot study (Chapter 8) explored the impact of different methods of presenting numerical data for immunisation decision-making. Presenting numbers in an appropriate format was identified as a central area for intervention, as dissatisfaction with or absence of information about outcome probabilities and behavioural norms was identified as a central influencing factor in the systematic review (Chapter 2) and the interview study (Chapter 3); and decisions about hypothetical scenarios (Chapters 5 and 7) were explained only partially by the provided numerical data (and other measured predictors), perhaps indicating misinterpretation of those numerical data. This study indicated overall that presenting numbers as percentages rather than as graphics or proportions resulted in better understanding of the information, less worry and more certainty about the decision made, and higher intention to accept the vaccine. These findings

may inform a wide range of immunisation decision-making interventions which need to communicate numerical information about various factors; however the study was small and the scenarios simplistic, therefore replication and extension is necessary before the findings in relation to this aim can be considered reliable.

9.2 Strengths and limitations of the research programme

Through my PhD research programme I sought to make a novel and robust contribution to the knowledge base on parents' immunisation decision-making. In this section I describe the strengths and limitations of my research programme.

9.2.1 Design and analysis

My research could quantify and test the statistical significance of causal relationships between predictor factors (attitudes, demographics and risk communication formats) and vaccine uptake intention only in the experimental studies reported in Chapters 5, 7 and 8. The MMR questionnaire studies (Chapter 4) employed a cross-sectional design meaning they could not ascertain whether attitudes caused behaviour or behaviour shaped attitudes, and whilst the interview study collected attitudinal data prospectively, these data were not suitable for quantitative interrogation. These different research designs may have contributed to the different prioritisation of predictors in the MMR studies versus the hypothetical studies. A prospective design for the MMR studies in which parents completed the questionnaire before their child received MMR or single vaccines would have been preferable, and would be an important amendment in any replication of these studies.

Despite this limitation, the MMR questionnaire studies (Chapter 4) make a substantial contribution to the present and future knowledge base, through their testing and application of a comprehensive evidence-based tool to measure factors predicting MMR uptake. These studies, and the experimental work in Chapters 5 and 7, also provide multivariate models of decision-making which are rare in the relevant literature (Chapter 2), and which are necessary to provide targeted and focused interventions acting on the most influential factors in specific population groups. However, all of these models explained less than half of the variance in vaccine uptake behaviour or intention, which may indicate that they failed to incorporate some relevant factors, that they assessed relevant factors inappropriately, or that participants' decisions were not in line with their attitudes. The first and second explanations may mean interventions based on the models omit some important factors, whilst the third explanation indicates parents are making uninformed decisions (not in line with their values; Marteau, Dormandy *et al*, 2001). These studies may have been improved through more detailed piloting in which participants were invited to suggest other factors influencing their decisions (in addition to those already included in the questionnaire/scenarios) and these suggestions were coded and translated into additional items, however time and resource limitations precluded this in the present programme of research.

Whether decisions about hypothetical scenarios accurately replicate decisions about real-life immunisations is not currently known, and whilst the relationship between hypothetical and real-life decisions could have been elucidated here by involving participants from the MMR questionnaire studies in the experiments, the timing of studies within this programme did not allow for this. The systematic review, MMR questionnaire studies and semi-structured interviews indicated that real-life MMR decisions are multifactorial, emotive, and often made after many months of deliberation – and they end in real-life consequences for a real-life child. However in the experimental studies participants were effectively required to immerse themselves in completely hypothetical scenarios comprising multiple factors (of which they may have considered only a subset were this a real-life

decision), to imagine their complex emotional response to the situation, and to make a decision whether to accept the vaccine – a decision which would have no real-life consequences – all within minutes. The potential artificiality of this task may explain the differences in decision-making between the experiments and the real-life decision studies. However, alternative methods of modelling decisions may also have been flawed. For example, had the scenarios mixed real-life stimuli with hypothetical stimuli (e.g. a hypothetical vaccine for a real disease) the scenarios may have been more realistic therefore perhaps less demanding on the participant. However, preconceptions about the real life disease (which may have been diverse therefore difficult to reliably measure) may have influenced decisions, rendering the model biased and difficult to generalise. A longitudinal, highly immersive design may have more accurately replicated real-life decisions. In such a design, detailed stimuli could be provided at a number of timepoints (rather than in one single vignette) using realistic presentation methods (e.g. mocked-up newspaper articles and Department of Health leaflets), and participants could be given a longer period of time to make their decision. However, this design would have demanded more research resource and participant engagement than was feasible in the present programme of work. Further, it may have presented ethical concerns if the scenarios and materials were deemed sufficiently realistic to confuse some participants about whether the vaccine and disease actually existed. Before these alternative designs are explored, further research must assess how well the present design replicates real-life decisions.

9.2.2 Participants

I implemented several strategies to maximise participation and sample representativeness in my studies, including providing financial incentives, offering translated materials, providing the option to respond to questionnaires by telephone, recruiting from demographically and behaviourally diverse populations, and oversampling parents of unimmunised and underimmunised children (Dormandy, Brown *et al*, 2008; Edwards, Roberts *et al*, 2009; McColl, Jacoby *et al*, 2001). Despite this, my response rates were rather low and my participants were not representative of the wider

population. Recruitment in schools and PCTs yielded approximately 9-18% response, whilst response to online recruitment cannot be assessed as the denominator is unknown. Given the practical measures taken to facilitate involvement, the poor response may in part be attributable to poor quality PCT data inflating population denominators (The London Regional Immunisation Steering Group, 2009), or to potential participants' lack of interest in the research topic, which has been shown to be a central driver of participation (Edwards, Roberts *et al*, 2009). Though response was low, the number of participants in each study provided adequate statistical power for the tests conducted, therefore whilst generalisability may be compromised, the internal validity of the work remains intact. Where data on non-respondents were available (in the MMR questionnaire studies), they indicated that more deprived parents whose children were not adequately immunised were less likely to participate; this reflects findings from the systematic review (Chapter 2) and may therefore also be applicable to other studies in the Thesis. Accordingly, most parent participants in the studies reported here were white British, married, and aged over 35 years; and a sizeable proportion were educated to degree level or above and with a household annual income of over £50,000. However, these response biases were more pronounced in the studies which recruited parents online with no financial incentive (Chapters 6 and 8), as studies which recruited through schools, GPs and PCTs, with rewards or prize draws attached (Chapters 3, 4 and 7), obtained samples more diverse in education and income.

My use of a readily accessible undergraduate student sample may compromise the ecological validity of the findings from my first experiment (Chapter 5). This study sought to demonstrate that participants would accept and appropriately use completely hypothetical scenarios containing qualitative manipulations. However, it is debatable whether students' intentions to give a hypothetical vaccine to a hypothetical child accurately replicate parents' actual uptake of a real vaccine for their real child. Whilst this potential limitation may preclude the extrapolation of the model to experienced parents' decisions about established vaccines, the study arguably has a valid

application to modelling naive decision-makers behaviour, and may bear some relevance to understanding the decision-making of future parents who have not experienced a major vaccine controversy in their adult lifetime. Crucially, the sample is still appropriate to provide proof-of-principle for the larger study with parents reported in Chapter 7.

9.2.3 Outcome measures

The first part of the research programme (Chapters 3 and 4), which explored real-life MMR decision-making, was designed to improve upon existing evidence by assessing MMR uptake objectively through GP and PCT records rather than through parent-reported intention or behaviour. US evidence suggests parent report can be unreliable (Hawe, Wilson *et al*, 1991; Suarez, Simpson *et al*, 1997; Bolton, Holt *et al*, 1998) – perhaps because parents forget whether or when their child received MMR, or falsely state that their child had received MMR in order to avoid expected reprimand from their GP or PCT – therefore objective MMR uptake was intended to render the work more robust and acceptable to clinicians and policymakers. However, the official records I used were not as robust as anticipated, due to errors in data entry (e.g. doses not being recorded or not being transferred promptly from GP records to PCT records) and retrieval (e.g. PCT staff mistakenly applying filters which screened out some relevant doses). These studies would therefore have been stronger had the objective uptake data been cross-referenced with parent-report and any discrepancies explored and rectified, and the absence of such triangulation is a limitation of this work. Despite these unexpected shortcomings of the objective outcome data, they did add some value to the work: using official records facilitated detailed analysis of differences between parents who obtained MMR on-time and parents who postponed MMR. This had not been possible in many previous studies which had obtained simple binary uptake outcomes through parent report (MMR received versus MMR not received), and it provided good evidence on ways in which parents might be encouraged to give their child timely protection.

The second part of the research programme (Chapters 5, 6, 7 and 8), which explored decision-making about hypothetical vaccine and disease scenarios, took parent-reported intention to accept the vaccine as its outcome, rather than behaviour. Although this approach is a common, established practice in pure behavioural science (Baron, 2008), in the context of my applied research programme it was not ideal, as intention is an imperfect predictor of behaviour (Sheeran, 2002). It was, however, unavoidable in these studies as the vaccine in question was hypothetical, therefore no actual uptake (parent-reported or objectively assessed) could be obtained. These studies could have been made more robust by assessing participants' intentions and actions for related behaviours (e.g. receipt of real-life vaccines for their child or for themselves) in order to calculate their individual intention-behaviour gaps; however practical constraints precluded this addition to my own research programme.

9.3 Personal and professional development

In addition to my novel scientific contribution, a key aim of my Doctoral training was to develop the professional skills and personal attributes required for me to become an independently practising behavioural scientist. Here I reflect on my professional and personal development during my Doctoral studies.

9.3.1 Academic achievement

My PhD research programme provided numerous opportunities to improve my skills in study design, conduct, analysis, writing and presentation. For the first time in my career I have obtained funding

and ethical approval for studies. Conducting semi-structured interviews was also a new experience for me. I have learned new analytic techniques and become much more confident in interpreting analyses which I had used before. Through writing articles for peer-reviewed publications and completing grant applications I have developed a more concise and clear writing style. In addition, presenting my work at national and international conferences and symposia with academic and clinical audiences has refined my public speaking skills. I have also enjoyed teaching research methods to a range of student groups. However, I am still striving toward publication in high impact factor journals including British Medical Journal and The Lancet, and I am trying to be more confident when inviting and responding to questions during presentations and teaching sessions.

9.3.2 Project management

Completing the programme of research required a range of project management skills. Creating and maintaining relationships with GP surgeries and PCTs opened my eyes to their problems with data quality, and their failure to follow my instructions for identifying cases (as discussed above), therefore I learned to double-check data from these secondary sources in future. Despite the challenges of multidisciplinary working, were I to begin my programme over again I would certainly seek more input from professionals 'on the ground' in immunisation – the shape of my Thesis may have been different had I had my own clinical experience, or taken more advantage of the clinical experience of others. I also trained and supervised three research assistants who distributed questionnaires for the MMR decision-making study (Chapter 4) and the student study (Chapter 5). I found relinquishing control over minor details quite difficult initially and was prone to micro-managing my team, but came to understand the benefits of a more collaborative style in which I encouraged them to strive toward the wider goals of the project and manage their own workload. This is a highly transferable skill which I will apply when supervising researchers and postgraduate students in future.

9.3.3 Personal skills

My confidence as a researcher has improved substantially during my PhD. I have worked hard to become more professionally assertive and to trust in (but know the limits of) my expertise. Achieving publication in peer-reviewed journals and being selected to present my work at high-profile conferences has been central to this. Perhaps paradoxically, having articles rejected by high-profile journals has also developed my ability to use constructive criticism to improve my work and to cope with professional disappointment. My PhD has, as I expected, been the most challenging stage of my professional life so far, but without doubt the most personally rewarding.

9.4 Directions for further research

My PhD research programme has clarified several key issues around parents' immunisation decision-making, however some original questions remain unanswered, and some new questions have arisen. Therefore in this final section I outline some new research directions indicated by my findings.

9.4.1 Improving research methodology

My systematic review (Chapter 2) provided vital direction for my own studies by identifying conceptual gaps to fill and methodological weaknesses to overcome, however I was unable to address all of the issues which emerged in the review. Poor participation in immunisation decision-making research remains a particular problem, and is one which I failed to overcome in my own work, therefore understanding and reducing non-response is a priority for further exploration. As my evidence-based practical strategies to improve response (e.g. incentives, multiple response formats,

and language support; Dormandy, Brown *et al*, 2008; Edwards, Roberts *et al*, 2009; McColl, Jacoby *et al*, 2001) met with limited success, further research may explore wider issues around trust in research impartiality and confidentiality (which emerged anecdotally as a reason for apprehensiveness about participating in my interview and MMR questionnaire studies), simple lack of interest in the topic, and doubt that research findings will translate to personally relevant changes to practice or policy. Studies of immunisation decision-making research participation will probably need to be separate from studies of immunisation decision-making itself.

9.4.2 Developing the attitudes and demographics measurement tool

The MMR attitudes and demographics assessment instrument (Chapter 4) is a key output from this programme of research and a valuable contribution to the knowledge base, therefore refining this tool and encouraging its wider application is a key future research and practice direction. The above points about increasing research participation and assessing the prevalence of concerns about GP targets and incentives are central to the development of the tool. Further modifications may include the addition of an appropriate parent-reported uptake measure (given the limitations in objective MMR uptake data observed here), revisions to item wording to reduce ambiguity (e.g. 'I do not believe newspaper and TV stories about MMR' could be amended to 'I do not believe newspaper and TV stories about MMR being dangerous'), expansion of the practical barriers scale to include contraindications on appointment day, translation, and adaptation for other vaccines.

9.4.3 Evaluating the ecological validity of hypothetical decision models

A central area for expansion on my present findings is exploration of how parents' decisions about hypothetical scenarios compare with their decisions about real-life vaccines. Understanding why the MMR questionnaire and the hypothetical scenario study provided different regression models is vital

to understanding whether and under which circumstances hypothetical modelling can provide an appropriate basis on which to plan strategies for promoting new vaccines. Parents could be recruited to complete both the MMR questionnaire and the hypothetical scenario questionnaire, and then any discrepancies between models could be explored through qualitative interviews. However, as discussed, if MMR decisions are different from other real-life immunisation decisions, they are likely also to be different from hypothetical immunisation decisions. Therefore the hypothetical model should perhaps be tested against decisions about a comparably less contentious vaccine (e.g. DTaP/IPV/Hib). Further, the hypothetical scenarios should be refined such that each aspect of each factor is manipulated independently, and realism should be improved through use of more varied stimuli including mocked-up newspapers and leaflets, rather than written vignettes alone.

9.4.4 Further exploring how to communicate risks and norms in immunisation

As the risk communication study in this programme (Chapter 8) was only a small-scale pilot, replicating and extending this work with a larger sample and more detailed communication scenarios is a clear future research direction. Exploring whether parents are able to comprehend, trust and make use of odds ratios would be a useful addition to this strand of research, as this would indicate whether official information materials could usefully communicate to parents the likelihood of developing autism with and without MMR (Smeeth, Cook *et al*, 2004). Several parents in my interview study stated that such a statistic would be central to their decision were it readily available, and accordingly measles factors were less pertinent than MMR factors among parents in my questionnaire study. This suggests that some parents made their decision by weighing autism against no autism, rather than by weighing no autism against measles, effectively considering autism a reality of MMR despite the lack of evidence for such a link. The odds ratio for autism with or without MMR would support decisions made on this basis without giving credence to the purported MMR-autism link. A hypothetical scenario analogous to the MMR situation could be used to test the

impact of communicating this information in a 'safe' way before any real-life intervention is attempted.

9.5 Implications for policy and practice

The research reported in this Thesis indicates a number of possible methods by which parents may be encouraged to accept immunisation for their children, on the basis of informed decision-making. These potential implications for policy and practice are summarised below.

9.5.1 Improving trust in immunisation providers and policy

My systematic review (Chapter 2) and interview study (Chapter 3) demonstrated that mistrust in the entire immunisation system is prevalent among parents rejecting MMR; my MMR questionnaires revealed trust in GP/practice nurse to be a factor on which MMR acceptors and MMR rejectors differed in univariate analyses; and my experimental study with parents (Chapter 7) indicated that such mistrust may compromise use of evidence during decision-making. These findings indicate that improving trust in immunisation providers and policy is likely to be central to increasing immunisation uptake and to facilitating informed decision-making. Interventions to improve trust in health professionals and organisations are surprisingly few (McKinstry, Ashcroft *et al*, 2006), but current evidence suggests that patient-focused intervention (rather than practitioner training) may be more effective in improving trust.

My systematic review and interviews indicated that disclosure of financial incentives and performance targets for immunisation providers may be central to improving trust around

immunisation. Disclosure of financial incentives in relation to treatment choices has also been associated previously with increased trust (Hall, Dugan *et al*, 2002). Trust interventions for immunisation could usefully incorporate a financial disclosure component, perhaps first at individual level, whereby practitioners are encouraged to be open about their targets/incentives with parents who express an awareness of these issues. If further research indicates that concerns about financial incentives are pervasive, official DH leaflets could usefully incorporate relevant information for a wider audience. One approach may be to contrast the financial benefits which NHS MMR providers receive with the financial benefits which private clinics providing separate measles, mumps and rubella vaccines receive, thus acknowledging the existence of these providers without sanctioning their practice. This would simultaneously highlight the comparative lack of profiteering within the NHS, and address the criticism (voiced in my qualitative study) that GPs and DH make single vaccine clinics appear 'seedy' by withholding information about them.

My interview study also suggested that communicating effectively about disease severity and susceptibility, therefore clarifying the clinical need for immunisation, may improve trust in vaccine providers and policy. Parents may perceive their clinician to have other motives in recommending a vaccine to them (e.g. desire for financial reward) if they do not agree that there is a clear clinical need for that vaccine. In this way, effective communication of disease risks may serve a dual purpose, both in facilitating basic risk/benefit analysis around the vaccine decision, and in improving trust in the source of information.

9.5.2 Highlighting positive social consequences of immunisation

My questionnaire studies exploring predictors of MMR uptake indicate that highlighting the social benefits of immunisation (peer approval and community benefit of herd immunity) may be particularly effective in interventions to improve both routine and catch-up MMR uptake. Social marketing strategies may be useful in promoting this message. Local champions who are willing to

discuss and recommend MMR to peers (and crucially, who are not seen to have any vested interest in improving MMR uptake) could be usefully involved, as could methods which contextualise MMR as something which 'good parents' do, just as commercial marketing contextualises particular product choices as emblematic of desirable lifestyles.

Clarification of social norms around MMR in this way may also serve to promote MMR acceptance as normal behaviour, and rejection as deviation from that norm. This may effectively reframe which course of action parents consider to be the omission and which they consider to be the commission, thus any bias toward omissions over actions may result in vaccine acceptance rather than rejection. The frequency of MMR uptake in the local population will likely be best demonstrated using percentages, as the small pilot study in Chapter 8 demonstrated that this presentation method was linked to more positive outcomes on a number of dimensions.

9.5.3 Addressing anticipated regret

Immunisation providers should become aware of the potential impact of anticipated regret (as a consequence of vaccine reaction) on parent's immunisation decision-making, as this emerged as a key predictor of MMR uptake in my questionnaire study (Chapter 4). They could consider using Baron's 'Golden Rule' (Baron, 1992) when consulting with a parent who anticipates regret as a consequence of vaccine reaction. The Golden Rule suggests that the parent will be less influenced by their anticipated regret if they acknowledge that their child would simply want them to take the least risky option, and if the child became sick through either option, the source of that sickness (vaccine versus disease) would probably not matter to him/her. This may highlight to the parent that their regret considerations are about primarily about protecting themselves from guilt, rather than protecting their child from harm. Practitioners could usefully encourage parents to think in these terms about their decision where appropriate. Highlighting the possibility of regret as a consequence of disease may also provide balance for some parents.

9.5.4 Screening for active resistance to immunisation

My MMR attitudes/demographics assessment tool (Chapter 4) and provider/policy trust scale (Chapter 7) may be usefully employed to 'screen' parents during pregnancy or at early postnatal healthcare appointments for risk of vaccine rejection. As advance thinking about immunisation was linked with eventual vaccine rejection in my systematic review, early intervention with parents expressing doubts at this stage may be particularly useful. Responses to these scales could be assessed anecdotally at first, with interventions delivered on a parent-by-parent basis, perhaps by health visitors, as they are a trusted source of immunisation information with which parents have frequent contact at this early stage. In future, longitudinal studies plotting attitudes against eventual vaccine uptake should be able to identify scale score ranges which correspond reliably with eventual uptake behaviour, and on this basis more widespread interventions could be targeted and delivered.

A similar approach could be used with parents who have already rejected vaccines, using these assessment tools to explore their views and identify areas for personalised intervention. Again, with further research, score ranges for these tools which correspond with eventual behaviour can be identified. These ranges can be used both to identify parents for whom continued efforts to encourage vaccine uptake may be useful, and parents for whom such efforts are unlikely to have an impact (and may in fact damage relationships between the parent and their healthcare provider). In addition, these tools may be usefully employed to regularly monitor predictor factors at local or national level, thus to inform the content of interventions responsive to current concerns, and to evaluate the impact of those interventions on subsequent cohorts.

My experiment with parents also indicated that increased general anxiety may also compromise comprehensive use of information during immunisation decision-making. Therefore screening

parents for anxiety, and seeking to reduce that anxiety in advance of providing detailed information for risk-benefit analysis, may facilitate more informed decision-making.

9.5.5 Providing appropriate information, and tailoring to specific populations

My systematic review and interview study showed that DH leaflets are typically provided around the time of the primary immunisation schedule, therefore some parents do not use these leaflets during their MMR decision-making many months later. These studies also indicated that many parents consider their health professional(s) the best source of information around immunisation. These findings in combination indicate that health professionals should reinforce key messages from DH leaflets in their MMR consultations, or at least provide further copies of the leaflets at this time.

Being of black or minority ethnicity (BME) was an independent predictor of routine schedule MMR uptake in my questionnaire study. This may indicate that white British parents take into account a different profile of factors than do BME parents when making their decisions (and that the factors which BME parents use were not measured in my questionnaires), that BME parents adhere to health professionals' recommendations with less resistance than do white British parents (hence their 'decisions' were not explained by our measured attitudinal factors), or that white British parents face greater practical barriers to uptake than do their BME counterparts. In order to support equality of informed decision-making, interventionists could perhaps seek to ensure that BME parents are not failing to question their health professionals' recommendations simply because they lack relevant information, for example by actively providing translated information at every stage of the immunisation process – however of course this may result in decreased uptake in this currently compliant group and the risks and benefits of this at public health policy level must be carefully considered.. Further research is required to inform national policy around this issue, however at

individual level practitioners should be sensitive to cultural factors possibly influencing immunisation uptake in the communities which they serve.

My questionnaire studies also indicated that parents of children past routine schedule age (i.e. older than 5 years) may be motivated to immunise for different reasons than are parents of children still within the routine schedule window. Whilst beliefs about the social implications of immunising were key predictors of uptake in both populations, MMR beliefs were not independently influential in catch-up decisions, though they were central to routine schedule decisions. This may indicate that catch-up campaigns and routine campaigns require different information materials and overall different approaches to target the factors salient to their different populations. School-based catch-up programmes appear to have a better record of success than PCT-based programmes, therefore this may be a key element of future catch-up campaigns.

My experimental study with young adults indicated that young parents (who are less experienced with proxy decision-making and are unfamiliar with the disease and vaccine) may make more evidence-based decisions when presented only with information on vaccine and disease characteristics. Providing information beyond that required for simple risk-benefit analysis may overload this population, or alert them to complexities which they had not yet considered. This effect may be compounded if risk-benefit information detail is sacrificed in order to make way for information on other factors. Health professionals should perhaps focus primarily on effectively communicating this basic information to less experienced parents, escalating their information provision only if the parent requests it.

9.6 Concluding remarks

The programme of research reported here has employed a range of methods to explore the complex process of parental decision-making about childhood immunisation. My work has identified and explored the predictive value of five key dimensions on which parents accepting vaccines tend to differ from parents rejecting vaccines: perceived vaccine safety and efficacy; perceived disease severity and susceptibility, perceived implications of the decision for social relationships and community; trust in vaccine providers and policy; and satisfaction with immunisation information.

The work has found that parents tend to make real-life MMR vaccine decisions in line with their attitudes relating to these dimensions, and that perceived social implications and trust in providers/policy may be more influential than simple vaccine versus disease risk/benefit analysis. However, the work also showed that MMR decisions are made differently from hypothetical decisions about hypothetical vaccines, which may present problems for generalising the MMR model to other vaccines. Hypothetical immunisation decision modelling may be useful for producing generalisable models and for testing the impact of novel interventions in a 'safe' way, if their ecological validity can be demonstrated. My research programme also identified methodological limitations to the current immunisation decision-making literature, and offered some novel solutions to pervasive problems.

My programme of work was inevitably not without conceptual and methodological limitations. However, it has been a wonderful learning experience for me, and has contributed to the knowledge base a number of interesting directions for further research, and ideas for practical interventions to improve the quality and outcomes of parents' immunisation decisions.

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11 Appendices

Figure 11.1: Systematic review search terms

#	Search terms	Hits
1	((mothers\$1 or father\$1 or parent\$3 or guardian\$ or (care adj giver\$) or caregiver\$ or family) adj5 (decid\$3 or decision-making or (decision adj making) or choos\$ or reason\$ or belief\$ or perception\$ or choice\$ or attitude\$ or decision\$ or barrier\$ or action\$ or behavio\$3 or knowledge or understanding\$ or ((vaccin\$ or immuni\$) adj5 (deci\$ or choice\$))))).ti,ab.	93325
2	(parents/ or fathers/ or mothers/ or legal guardians/ or caregivers/) and (decision making/ or decision theory/ or choice behaviour/ or uncertainty/ or risk/)	5243
3	1 or 2	97361
4	(((((child\$ or baby or babies or infant\$1 or pre-school or preschool or toddler\$1) adj5 (vaccin\$ or immuni\$ or booster)) or MMR or (vaccine adj safety)) not (infant adj pain)).ti,ab.	31339
5	(child/ or child, preschool/ or minors/ or infant/) and (vaccines/ or bacterial vaccines/ or viral vaccines/ or immunization/ or immunization schedule/ or immunization, secondary/ or mass immunization/ or injections/)	19773
6	4 or 5	44144
7	3 and 6	899
8	limit 7 to abstracts	850
9	limit 8 to English language	801
10	limit 9 to human / humans	785
11	limit 10 to yr="1987-2008"	760
12	remove duplicates from 11	440

Table 11.1: Detailed associations between predictor factors and vaccine uptake in comparison studies

Study Factor	Alfredsson (2004) ⁺	Bardenheier (2004) ^{†‡}	Bond (1999) ⁺	Casiday (2006) ⁺	Cassell (2006) ⁺	Flynn (2004) ⁺	Gellatly (2005) ⁺	Impicciatore (2000) ⁺	Lewis (1988) [‡]	MacDonald (2004) ^{†‡}	Petrovic (2003) ⁺	Trauth (2002) [‡]	Wroe (2005) ⁺
Vaccine causes side effects / is unsafe ^b	↘ 53% ng	↘ OR 2.8* [†] OR 2.5* [†]	↗ OR 0.98 ns	↘ 21.45% ***	↘ 14.3% ***	↘ OR 0.48 **	↘ OR 0.65 *		↗ 5.1% ***	↘ 7-35% * _ **	↘ OR 2.19 *	↘ OR 1.15 ns	
Parental education ^a		↗ ng ^{†‡} ns ^{†‡}	↗ OR 1.07 ns	↔ X ² 0.89 ns	↘ ng ns			↗ OR 2.25 *				↗ OR 1.05 ns	↔ ng ns
Parental income/occupation ^a		↗ ng ^{†‡} * ^{†‡}	↗ OR 0.97 ns	↔ X ² 9.76 ns		↗ OR 1.05 ns		↗ OR 1.67 *		↘ ng ng		↗ OR 1.37 ns	
Vaccine is effective ^b	↗ 27% ng	↔ 0% ^{†‡} ns ^{†‡}	↗ OR 2.39 *	↗ 6.7% ng		↗ OR 1.02 ns		↗ OR 1.86 **	↗ 2.9% ng				↗ 0.41 *
Family size ^a				↗ OR 0.71 *				↘ OR 1.39 ns		↘ ng ns		↘ OR 3.05 *	↔ ng ns
Disease is serious ^c	↗ 12 – 6% ng	↗ OR 4.5 ^{†‡} * ^{†‡}	↘ OR 0.94 ns	↗ 10.9% ng	↗ 13.1% ***			↗ OR 1.20 ns			↘ 7.4% ng		
Parental age ^a		↗ ng ^{†‡} * ^{†‡}		↔ t -0.49 ns	↘ ng ns	↘ OR 0.96 ns							
Disease is likely ^c		↗ 0.3% ^{†‡} ns ^{†‡}	↗ OR 2.63 *	↗ 36.5% ***		↗ OR 1.18 ns						↘ OR 1.28 ns	
Trust in healthcare system/Government ^d				↗ 13.1 – 44.1%***	↗ 30.1 – 37%***	↗ OR 1.78 *	↗ OR 1.90 ns			↗ ng ng ↗			
My information/ knowledge is adequate ⁱ					↗ 39.2% ***		↗ OR 3.27 *	↗ OR 3.27 *		↗ 18% ng		↗ OR 0.27 *	

Study Factor	Alfredsson (2004) †	Bardenheier (2004) ††	Bond (1999) †	Casiday (2006) †	Cassell (2006) †	Flynn (2004) †	Gellatly (2005) †	Impicciatore (2000) †	Lewis (1988) ‡	MacDonald (2004) ††	Petrovic (2003) †	Trauth (2002) ‡	Wroe (2005) †
Number of parents in family ^a		↗ ng ^{††} ↘ ng ^{††}				↗ OR 0.73 Ns				↕ ng ns ↘ 20% ng ↗ ng * - ***			↕ ng ns
Vaccine causes autism ^b		OR 4.7* [†] ns [‡]		↘ 51.5% ***	↘ 48% ng								
Satisfactory discussion with HCP ^d	↗ 14% *		↗ 34.9% ***				↗ OR 0.60 ns						
Media reports are trusted or influential ^g					↘ 28.7% ***	↗ OR 2.37 *			↘ ng ng	↘ OR 3.52 *			
Ethnicity (African-American) ^a		↗ ng ^{††} ng ^{††} ↘ ns [†]										↘ OR 1.58 ns	↔ ng ns
Experience of vaccine adverse events ^b		OR 1.9* [‡]			↘ 26.15% ***	↘ OR 0.86 ns							
Single vaccines are safe ^b				↘ 30.8% ***	↘ 27.2% ***		↘ OR 1.6 ns						
Concern about immune overload ^b					↘ 64.2% ***		↘ OR 0.65 *				↘ 16.6% Ng		
Vaccination is a social responsibility ^e				↗ 19% ***	↗ 29.9% ***		↗ OR 2.42 *						
Have vaccinated previously ^f	↗ 22% ***	↗ OR 2.9* [†] OR 2.7* [‡]				↗ OR 4.24 ***							
Plan to vaccinate future children ^f		↗ OR 0.2* [†] OR 0.5 ^{ns‡}							↗ 14.5% ***		↗ 44.9% ng		

Factor \ Study	Alfredsson (2004) †	Bardenheier (2004) ††	Bond (1999) †	Casiday (2006) †	Cassell (2006) †	Flynn (2004) †	Gellatly (2005) †	Impicciatore (2000) †	Lewis (1988) ‡	MacDonald (2004) ††	Petrovic (2003) †	Trauth (2002) ‡	Wroe (2005) †
Anticipated regret as a consequence of not vaccinating ^j					↗ 28.5% ***	↔ OR 1.01 ns							↗ OR 0.28 *
Child's birth order ^a		↘ ng ^{††} ng ^{††}			↘ ng **								
Membership of "at-risk" group ^a		↗ ng ^{††} ng ^{††}								↘ ng *			
Thinking about vaccine before time it was due ^b	↘ 17% *				↘ 34.4% ***								
Natural immunity is preferable ^c	↘ 44% ng				↘ 35.2% ***								
Current research is adequate ^d				↗ 19.7% ***	↗ 50.9 ***								
HCP supports decision ^d					↗ 81.6 – 84.4%***		↗ OR 1.40 ns		↗ 1% ng				
Parents' right to make the choice is important ^e				↘ 23.7% ***	↘ 87.9% ***								
Peers support or concur with decision ^e					↗ 27.1% ***	↗ OR 1.51 ns							
Legal issues influence decision ^e		↘ OR1.9 ^{ns†} OR2.1 ^{ns‡}							↘ 3.4% ng				
Children receive too many shots ^b		↘ OR 4.0* [†] OR 7.5* [‡]											

Study Factor	Alfredsson (2004) †	Bardenheier (2004) †‡	Bond (1999) †	Casiday (2006) †	Cassell (2006) †	Flynn (2004) †	Gellatly (2005) †	Impicciatore (2000) †	Lewis (1988) ‡ ^z	MacDonald (2004) †‡	Petrovic (2003) †	Trauth (2002) †	Wroe (2005) †
Outbreaks influence decision ^c				↗ 16.1% ng									
Parents share responsibility for vaccination decisions ^e					↔ 0.5% ns								
Engagement in personal research ^e					↘ 11% * _ ***								
Plan to postpone vaccination ^f		↔ OR2.5 ^{ns†} OR0.7 ^{ns‡}											
Financial costs are a problem ^f		↔ ns ^{†‡} ns ^{†‡}											
Organised groups and the internet influence decision ^g										↘ OR 3.52 *			
Immune systems differ by child ^h					↘ 16.4% ***								
Post-decisional satisfaction ^j					↗ 2.2% *								
Favours non-medical approaches to healthcare ^k					↘ 22.5% ***								
†: MMR/MCV; ‡: DTP/ DTaP ↗: increase in “score” on factor = increased likelihood of vaccination OR factor applicable to higher proportion of vaccine acceptors than decliners ↘: increase in “score” on factor = decreased likelihood of vaccination OR factor applicable to higher proportion of vaccine acceptors than decliners ↔: no relationship between factor and vaccine uptake				* : p <0.05; **: p <0.01; *** : p < 0.001 %: percentage difference vaccinators versus non-vaccinators OR: odds ratio ng: data/statistics not given ns: not significant X ² : chi-squared test statistic t: t-test statistic						a: Demographics; b: Vaccine factors; c: Disease factors; d: Healthcare system/Government; e: Parenting/social context; f: Practicalities; g: Non-official sources of information; h: Individual differences; i: Information needs; j: Decision-making; k: Lifestyle factors z: Fully vs partially immunised			

Table 11.2: Percentages of respondents citing predictor factors in cohort studies

Factor	Study	Binkin (1994)	Dannetun (2005)	Jones (1992)	Lawrence (2003)	Lieu (1994)	Murphy (1994)
		Unvaccinated	Unvaccinated	Unvaccinated	Unvaccinated	Vaccinated DTP	Unvaccinated
Vaccine causes side effects / is unsafe ^b		8.1	64.0		5.6	59.0	
Vaccine is effective ^b				85.7	91.9		
Disease is likely ^c			81.0				
My information/ knowledge is adequate ⁱ			76.0	55.0	71.2	92.0	
Satisfactory discussion with HCP ^d			66.0			66.0	
Experience of vaccine adverse events ^b						13.0	
Have vaccinated previously ^f						86.0	
Natural immunity is preferable ^c		8.9	50.0				
HCP supports decision ^d		6.1					
Parents' right to make the choice is important ^e						13.0	
Outbreaks influence decision ^c			51.5				
Vaccines are given at too young an age ^b			55.0				
Contraindications precluded vaccination ^f		16.0		27.0	18.0		42.0

b: Vaccine factors; c: Disease factors; d: Healthcare system/Government; e: Parenting/social context; f: Practicalities; i: Information needs

Figure 11.2: Qualitative data on predictor factors

Vaccine side effects and safety^b

- "I read that they carried out a survey on children who had been breastfed for the first six months, and half of them were vaccinated and half of them hadn't, and they found that the ones who had been vaccinated were five times more likely to get asthma. Which is quite considerable really"
- "You have this doubt in your mind, however small I may feel it may be... autism... Crohn's disease..."
- "...expose his immune system at the age of whatever, a year, to something [vaccination] that may or may not have serious effects on the system itself"
- ... an increased susceptibility to allergies, asthma and eczema... potential for developing autoimmune diseases, cancer and AIDS
- "...a kind of half-hearted thing after the vaccination which does happen"
- The vaccine itself and 'swimming pools' were most often raised as potential sources of infection [with poliomyelitis]
- ...some parents cited the unexplained rise in the incidence of childhood asthma and allergies as evidence of possible long-term damage resulting from immune overload
- "Well from what I've heard, combined vaccines are like a sudden onslaught to the body's immune system, normally you would catch it through the mouth and there are so many defences that it goes past before it gets there. But when they inject them, it goes straight into the bloodstream and it doesn't pass all these defences and the body just gets a shock, where did this come from?"
- "... By over-immunising children, are we in the West modifying our children's immune system, making them more vulnerable to contracting diseases in the future and damaging them in some way?"
- "I would be very worried about giving them the jab, all three in one, because a bloke I work with, his brother had it and his brother has got autism. He swears it was something to do with it"
- "They actually give them a bit of the disease don't they and that's what goes up their immunise system against the disease. So you know, in actual fact they are given a bit of it, erm so you know they're gonna be poorly, you know"

Vaccine effectiveness^b

- All groups... were concerned about the duration of protection from MMR, with the need for an MMR booster raising doubts about its long-term effectiveness
- "I would prefer to give my child protection against MMR naturally through catching the disease than have to keep boosting him for however long it takes"
- Vaccine effectiveness was generally accepted by immunisers, despite some knowing immunised people who had developed the diseases
- Some parents thought that the efficacy of the rubella vaccine was limited and not persistent, and questioned whether there was any point giving it to young children
- ... incomplete immunisers spoke of older children who had been immunised, yet had still caught whooping cough: immunisation was therefore, in their opinion, a pointless exercise

Disease severity^c

- Some parents' memories of measles being a common childhood illness made this prospect less frightening
- ...parents...were more likely to accept [multiple vaccines routinely given to younger infants]... because the diseases being immunised against, especially polio and meningitis, were particularly frightening
- "I mean in the third world it's obviously a killer, I don't believe that measles is a killer here, I haven't heard of anybody dying"
- "...the chances are so small of any serious complication"
- ...diseases in general (were perceived to be) a necessary part of the spectrum of life and the balance of nature...
- ...no parents mentioned that they knew of anyone who had suffered long-term damage. Indeed their experiences of measles often rendered it a *less* threatening disease
- ... A degree of uncertainty about how serious a threat measles really was to their child's health, fuelling anxiety
- "[Measles] can make you go deaf and all that, you can go deaf wi' that. It can affect your hearing and that..."
- Some parents regarded it as serious and potentially fatal or leading to serious complications (emphasizing the rare possibility of long-term sensory damage rather than other complications, possibly reflecting media coverage of measles)
- "[Mumps is] like a childhood disease, it's like a rite of passage"
- The diseases were seen as relatively mild, treatable and natural

-
- "I think there can be positive things about them catching measles, mumps and rubella. They're not as serious as the government makes out"
 - "...[Parents] don't realise how serious measles is and can be as a disease"
 - "...whooping cough was seen to be bad enough even when a child had been immunised - how much worse it must be if a child had no protection at all"
 - "With all these diseases they're just not heard of nowadays and that does kind of push your mind to well what's the point, you know?"
 - "[Meningitis] they're making it more aware to you through the news and everything, 'cos it is a very deadly illness or serious illness if they get it, you know"
-

Trust in healthcare system/Government^d

- "I felt that 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"
 - "I think just from hearing doctors in interviews and health officials kind of saying that it was safe, and it's a really difficult thing because as a parent you want to make your decisions based on what medical experts say"
 - "...they've been trained to do their job and they're a lot more qualified than I am...I'm putting my children in their trust"
 - "...advice from healthcare practitioners without such trusting relationships was often said to be "biased". Distrust in the government and in government medical authority was widespread (because of perceived conflicts of interest and mishandling of previous risk issues like BSE)
 - Governmental policy-makers were accused of colluding with pharmaceutical companies, pushing immunisations for the manufacturers' financial gain rather than for the health of the nation's children
 - "All credit to health visitors but they toe the government line, there's no choice about it"
 - "...some suggested that doctors were now reluctant to diagnose measles, contributing to low numbers of confirmed cases. This led to scepticism in some groups about the validity of official statistics, and led to uncertainty for some parents about the prevalence of measles"
 - "It's almost like they've got this scare tactic, we'll frighten them into getting [MMR] because of measles"
 - "[Scientific evidence is] not written for parents, and then when they do write it for parents you just wonder, you know, what their motives are because there are so many big players, so many people with their own interests that it's easier to believe other parents. You want to believe other parents."
 - "...I know that doctors and health professionals have to give the government line, so I'm not expecting an unbiased discussion"
 - "Well, you have to put your trust in doctors"
 - Local practitioners were identified as the most trusted source of information in principle
 - Four other women gave examples of incidents in their dealings with the health service that had served to put them off to some extent: one child... had suffered severe hair loss in the few days following immunisation... another...had been given one too many doses due to his records being mislaid
 - All the groups expressed concern that the Prime Minister refused to say whether his son had had the MMR - the fact that he had not raised suspicion that there is something wrong
 - "They know about the science not me"
 - The Department of Health emerged as the most trustworthy source of information on MMR
 - Among the mothers were several health professionals; they did not all accept vaccination unquestioningly, but also narrated their increased awareness of iatrogenic disorders, medical mistakes and possibilities of error. Some (other mothers) are suspicious of drug companies' involvement in vaccination programmes. The other three mothers [who expressed total confidence in the MMR, saying they always knew their children would be vaccinated] distinguished themselves in their trust of professionalism
 - Six parents reported distrust in professional advice: "I expect to get the official line from the doctor and health visitor, and the real picture from the internet"; "I mean, you know, infant mortality is at its lowest ever and we're coming up with this vaccine. You know, I just really think that the Government and the pharmaceutical companies are in bed together"
 - "I think my trust is in the fact that they've been doing MMR for a number of years now. Erm and if they... I can't imagine that the Government and NHS etc would be so daft if there was a problem with it to continue using it"
 - "I would be happy to take the advice of my GP and my health visitor as to which route to go down. And if that's what they're advising then at the end of the day they're the professionals who know far more about it than I do"
-

Information/knowledge adequacyⁱ

- The balance [between risk of vaccinating and risk of not vaccinating] was determined not only by assessing statistical probabilities - although parents often stated that they would like better information about those
-

statistics

- "I might not have had the MMR vaccination, I was given the fact sheet AFTER my son had it, which I was a bit cross about"
- ...For a majority of parents, the decision on whether to vaccinate did not reflect an informed choice. Most parents received no information prior to appointment for second dose vaccination on the rationale, benefits and risks of immunisation or the diseases...
- Many felt that there should have been much more advice available to them from the professionals
- At the beginning of the group discussions it was common to hear assertions that there is "no information out there" on MMR, particularly in the Asian and also the lower socio-economic groups
- "I don't feel we have enough information. I sway one way then the other. Single vaccinations concern me too. Confusion really"

Vaccine causes autism^b

- ... For [some parents] even an extremely slight risk of autism was too great
- "You have this doubt in your mind, however small I may feel it may be... autism... Crohn's disease..."
- "My husband is deaf in one ear and that happened, they're almost certain, after he had the measles as a child and so he felt it was far more important that they did [get vaccinated] and run a very small risk of autism."
- "I would be very worried about giving them the jab, all three in one, because a bloke I work with, his brother had it and his brother has got autism. He swears it was something to do with it"
- "It's what you want for your children, whether you can cope with a bit of autism or blind and deafness, it's pot luck then at the end of the day"
- Half the [vaccine-accepting] families had personal contact with the parents of children who were autistic and suspected a link between MMR and autism

Discussion with HCP^d

- "...We brought it up with the nurse before we had it"
- (Parents) sought recognition of their good intentions of behalf of their children's health; when these intentions were recognised and respected, parents entered into trusting relationships[with health professionals] that fostered dialogue and co-operative decision making
- ...advice that did not clearly seem to represent the considered personal and professional opinion of a trusted professional was often perceived as simply "toeing the government party line" about MMR
- ...medical practitioners' advice was generally trusted when they showed concern for the individual child, as opposed to merely protecting the population or their own professional reputations
- ...health visitors and doctors who discussed immunisation issues openly with parents were highly valued
- "You're conscious that there's a waiting room outside of children coming to have the same injection and... So you know there's pressure on you don't you? I suppose you're at the doctor's surgery... You're [feeling] a bit alien anyway. You just want to be in and out and you don't want to be causing a nuisance"
- "The GP was very good. Very good, very clear in her advice. But not dictatorial. She just sort of presented me with the facts and with the information"
- There was reported frustration that professionals in the health service did not have time to relay information
- ...Doctors "Having no time for them [Asian mothers]: "You can't just ask for information, you only go to see your GP when you are ill"
- "The MMR really worried me. He [GP] spent an hour and a quarter with me going through the statistics and just generally putting my mind at rest"
- Many mothers confirmed that they did not raise their questions with GPs, seeing them as time-constrained
- For some, having a supportive health professional lends momentum to the process of research and of acquiring confidence in one's judgement
- Many mothers confirmed that they did not raise their questions with GPs...because of a sense of unequal power relations, invoking worry about appearing ignorant
- The participants also reported that they would have liked an opportunity to discuss their concerns with health professionals in more detail
- Health professionals' neutrality was seen as unhelpful
- Two mothers stated they would not contact healthcare professionals with questions or concerns about immunisation due to the time constraints of general practice

Media^e

- ...Parents also queried the multiple immunisations routinely given to younger infants, but were more inclined to accept those vaccines because there was less media attention challenging their safety
- "It was because of the media and press that I looked into the MMR and decided well whoa, I'm not having that you know, otherwise, before, I just didn't think anything of it"

-
- "The newspapers are trying to let the everyday people know the inside story"
 - "There's no smoke without fire"
 - "The media have a responsibility to stop just taking bits of research and throwing it into the press to alarm us"
 - ...It was more common for parents to speak negatively about the media's involvement in the MMR debate
 - The mass media raised concern and initiated information search
 - ...All the participants were aware of the problems with MMR being suggested in the media
 - "If you had not seen anything or heard anything in the press you would have just gone and done it like all the other jabs"
 - Only in the fathers group was it pointed out that media reporting had been beneficial in raising important questions
 - [Parents] language was often accusatory, characterising reporting as 'hype' or 'sensationalism'
 - "It is scary that reading newspapers can cause this much harm"
 - The other three mothers [who expressed total confidence in the MMR, saying they always knew their children would be vaccinated] distinguished themselves in their suspicion of the media
 - 13 parents referred to lack of adverse publicity in the media compared with MMR: "I've never heard anything adverse about the five-in-one on the tele or... you know, not like MMR is constantly in the press. I never really hear about the five-in-one being bad, so erm I don't have an issue"
 - "I don't trust all the Government says, but I do think it's been researched and there's some sort of validity to it. Whereas the internet, I know some of those are the same no matter what site you go to, so I would probably take that more with a pinch of salt and that's probably why I didn't go to the other one...I'd go to the Government's site if I wanted some more information to trust"
 - "I do read the newspapers, but I don't necessary take information to be honest from the newspapers, just because I'm aware of... I mean I just think it is very... it's like scare tactics and we've all seen it before with other things that I know are not really as they seem"
-

Vaccine experience^b

- "... a friend of mine, a speech therapist, and she deals with two children whose parents are convinced that their child's had problems since having the MMR. Even though you can't prove it, to know someone who actually knows children who have changed quite dramatically was quite scary"
 - ...it was more common for parents... to offer third-hand accounts of other parents' experiences of adverse reactions. These indirect accounts of adverse reactions ranged from hearing about a child who developed a lump on her leg at the injection site to contracting meningitis and being hospitalised in intensive care following MMR vaccination
 - Parents who declined vaccination in whole or part had seen children with autism first-hand through family, friends or work, or believed their own child to be autistic (though not all cases were medically confirmed)
 - "The thing that clinched it was just [name of partner] and his like, sensible everyday comment, not rooted in medical history that 'well do we know anybody who's had an adverse reaction?'"
 - One mother... Had been put off taking her children for vaccination because her eldest son had developed an allergy in reaction to his first injection. Eleven full immunisers said that their parents had had them immunised as infants...
 - "I would be very worried about giving them the jab, all three in one, because a bloke I work with, his brother had it and his brother has got autism. He swears it was something to do with it"
 - Eight parents across five groups spoke in detail about friends whose children had experienced onset of speech or behavioural problems after receiving MMR. In contrast Debbie (9 month old son, in Group 8) recounted how two of her friends had young sons who had had MMR and were 'fine' and how their mother had made the decision taking advice from their mothers, from GPs and from the information. The evidence of the two boys' health was clearly compelling for her, but she admitted that she was 'still in two minds'
 - Half the families had personal contact with the parents of children who were autistic and suspected a link between MMR and autism
 - ...negative experiences with immunisation discouraged parents from immunising
 - Trust in vaccine safety was also based on parents' experiences with immunisation, such as having no previous adverse reactions or history of allergies in the family. For example, six parents reported being happy to have their baby immunised because they were vaccinated themselves as children
 - "I would feel a lot happier had I and my partner had these vaccines then at least I could sort of say in my mind oh well we're alright, she's got a good likelihood of her being alright. But the fact is we weren't immunised with these combination vaccines, erm therefore I don't really know, you know, how she would react"
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Single vaccines^b

- Parents who chose separate vaccines (i.e. three single-antigen vaccines administered at different times) felt that they offered the benefits of MMR while reducing the likelihood of problems caused by interaction of the three
-

components

- ... the three separate vaccines for measles, mumps and rubella were seen as a safer option and one which placed less stress on the immune system
- "We were angry that we were not given a choice, that it had to be the combined three together, why they couldn't split it"
- "I only hope that if we do make a stand they [Department of Health] will release a single one"
- "I mean but you think about it, you know, if you were given a shot of caffeine and it was just caffeine with no water in it, you know, that's going to be far more potent for your body than you know, giving it with water, caffeine with water. You know, so why would you not expect your children to have a bad reaction if they're given something that's so potent?"
- "My friend has let hers have it and she kept asking the doctors if she could have it separately and they just said they didn't do it"
- "The thing is how much is it [single vaccinations] and where can you get it done, and what are the risks of having them separately?"
- Eight parents reported that they would prefer to have their baby immunised with single-antigen vaccines. Their decision [to give the five-in-one] did not necessarily reflect acceptance of their safety, but lack of choice and perceptions of the importance of immunisation: "I think single injections are always preferable, but if you can't actually get them then you've got to go down the route of having the combined ones"

Immune overload^b

- Allowing children's immune systems to 'develop' meant that they would be less susceptible to side effects or 'immune overload'
- "Since giving her the single [measles vaccine] we've spoken to a geneticist who says 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"
- "The worry is putting all three in at one time, into that wee body. Individual ones for me is the way, it makes sense to not bombard it with too much chemicals all at one go"
- Most of those concerned about the MMR suggested that three vaccines were too much for the immune system to cope with and could 'knock back' a child
- ...nine parents expressed concerns that the five-in-one may place stress on the baby's immature immune system. Fears centred on the vulnerability of a young baby: "I think it's a lot to erm put on a little baby"; "When it first came out and they said they were doing five-in-one, I must admit I thought oh God you can't put any more. It's just horrific when you think of taking five different tablets together and it is... I just thought I'd hate to do that, that's just too many"

Social responsibility^e

- "My own children's health and safety is more important than the impact on the population... I don't want you to think that I'm not putting my children first that I'm putting the population first because that's not the case. But I feel by protecting them I'm also protecting the population. But by protecting the population I'm also protecting them. It's sort of two ways"
- "The government aren't worried about my child, they're actually worried about protecting pregnant women [from rubella infection]"
- "[The Government] are making decisions for what they see as society as a whole and we're making decisions for our individual children so we are polarised to start with"
- "I resent being told by a GP that I have to have something done because it's better for the population and I want to challenge that somehow"
- "I think primarily your first thought is, oh yes, my child and I want to protect them and then as a knock-on effect, as a secondary effect, if you like, the fact that it's going to help everybody is a great - that's good, that's a bonus - but I think the primary thought is - how it will benefit your child"
- 13 parents referred to the importance of immunisation for the population, believing they had a social responsibility to protect children and eradicate diseases from society: "Protecting the child, but protecting all the other children as well. Yeah, I think that's a good benefit to have"

Anticipated regret^f

- "If it's going to happen [vaccine damage] it will do - not that I want it to happen, but I think it's better they're protected against it. I couldn't live with myself if anything happened through not being vaccinated"
 - "I suppose if anything does happen to them and you had a choice to immunise them and you didn't you could only blame yourself really"
 - "You can't put your highly opinions on them [friends who come to you for advice], otherwise if they did what you did and they did catch something they could blame you, couldn't they?"
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- "The acceptance of personal responsibility is manifest in the recurring statement 'I couldn't forgive myself if [my child became autistic; my child developed complications from measles]"
-

Natural immunity^c

- It's very healthy to have them and it's a positive benefit to the child to actually have those illnesses properly, not a kind of half-hearted thing after the vaccination which does happen"
 - Parents generally thought it was important to develop their child's 'natural immunity' through exposure to mild infections
 - "If girls got rubella when they were children, they would have life-long immunity, not just immunity until they're 12 or whatever"
 - They believed that a healthy individual may benefit from contracting a disease, thus developing life-long immunity to that disease, and suggested that mass immunisation in the UK has become out-dated
 - "... If children get measles, mumps and rubella it helps build up their natural immunity, and that's better than the immunity built up by vaccines"
 - Thus, whooping cough itself was regarded as a 'natural' intervention, whilst vaccination to prevent whooping cough was regarded as an unnatural - any by implication, negative - intervention
 - ...The value of natural immunity and of supporting it with nutrition
-

Research adequacy^d

- "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]. Hands on, you know... rather than the sort of broad things"
 - "They still cannot categorically say the vaccine is safe and until, however small the doubt in my mind is, I feel probably it is safe but I can't live with that and until someone can categorically say that it's going to be all right, it's not going to be acceptable to me"
 - "I don't think they [doctors] know enough about the immune system when they're 2 months old, it's still developing"
 - "I just don't think enough research has been done really, one way or the other, to say whether it is completely safe"
 - "I think to say there is no evidence that it causes harm, is not comforting, because that just means there has not been the research done on it. You could say that about virtually anything practically"
 - But common to all groups was the fact that expressed concerns extended beyond MMR itself to the level of scientific/expert knowledge about the risks, with understanding that not even 'the experts' are certain. Some were suspicious that the knowledge of scientists and doctors did not extend to all possible diseases
 - [Parental rating of information as 'poor'] was because of inadequate information about vaccine testing and, in particular, research relating to the MMR vaccine
-

HCP support for decision^d

- Narratives indicate how some mothers actively choose between health professionals, seeking out those who will support their particular perspective on vaccination
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Parents' right to decide^e

- Parents...felt that a separate injection should be a matter of parental choice
-

Peers support for decision^e

- It is the rare mother who has not been drawn into a particular way of discussing MMR along with other issues of concern (sleeping, feeding, behaviour) in the many groups most mothers participate in with their children
-

Outbreaks^c

- Even parents who did not plan to immunise their children said that they might reconsider their decision if measles emerged locally
 - A reported measles outbreak in the area - not confirmed by microbiological testing - was sufficient for some mothers to go and seek MMR
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Responsibility for decision^e

- "My partner and I decided together."
 - All but three interviewees stated that both parents were involved in the decision-making process
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Personal research^e

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- ...Vaccination has become a subset of expected personal research into parenting options and advice of all kinds
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Postponing vaccination^f

- As long as there was no apparent urgency to vaccinate (for example a local outbreak of measles), their reluctance to take a decisive action they might later regret prevailed. Furthermore, some parents chose to wait until their children had passed the age at which autistic symptoms were said to become manifest before allowing them to receive the MMR
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Financial costs^f

- ...As the surgery was two bus journeys away and she (mother of three young children, pregnant again) had no money for taxis, she just didn't bother to go
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Organised groups and the internet^g

- ... The same sort of trust [used to reduce decision complexity by allowing the dismissal of conflicting viewpoints] was also sometimes invested in anti-vaccine groups or private clinics administering separate vaccines
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Immune systems differ by child^h

- ...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... 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
 - Additionally, boys were sometimes seen to be at greater risk, because the prevalence of autism is greater among boys
 - ...Some parents expected their children to cope well with such an exposure [to infectious diseases] because their environment, diet and overall health were very good
 - The ideas about vulnerability that parents expressed served to distinguish one's own child from an otherwise impossible array of contradictory information and uncertainty
 - "Well, my boy, he has been ill, see from day one he has been ill with everything, everything"
 - "I'm really lucky because my two are extremely healthy, you know, look up the dictionary, the word 'healthy' there would be pictures of my two in there... I think they are strong and could fight these infections"
 - [Parents suggested that] any information provided... should seek to relate the risks and benefits of the intervention to the parent's local circumstances and individual child
 - It was no comfort to be told that the risk was slim, as "my child might be the one in a thousand". One mother commented that, "until they find a safe vaccine, 1: 300,000 is still too large; I wouldn't play Russian roulette with my child"
 - ...The particularity of individual immunity, sometimes linked to hereditary factors
 - ...Some parents... regard the MMR as appropriate for most people, but not for their own child because of a particular weakness or susceptibility
-

Non-medical approaches to healthcare^k

- Several mothers who later rejected MMR had sought 'natural' or active birth
 - It also appears from our narratives that informed rejection of the Vitamin K injection at birth may be a good predictor of future concern with MMR
 - Several mothers suggested, however, that more experience of alternative medicine might encourage rejection of the MMR
 - Only three parents were undecided and, of these, two discussed alternatives, such as homeopathy or diet
-

Misconceptions about vaccination^b

- "I've just been told that...breast feed... you get immunity so I wonder why the pressure. I feel that the medical profession can't have it both ways, they say breastfeed because the baby gets your immunity therefore well, why have vaccinations then until you stop"
 - [that participants knew that contracting rubella in early pregnancy could result in foetal damage] led some parents to question the need for rubella vaccination for boys. Some queried the need for girls to receive the mumps vaccine as they perceived mumps to be a disease that affected boys
 - Not all participants fully understood the purpose of MMR - for example, in the two lower socio-economic groups (2 and 4) two mothers asked what the initials meant, although both had already had one child vaccinated
 - Three mothers strongly argued that conditions such as eczema, asthma, allergies and learning disorders - of parent or child - predispose a child to suffer serious effects from the MMR vaccine
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- ..19 parents believed that a vaccine contained 'a little bit of the disease' it was protecting the child against: "They actually give them a bit of the disease don't they and that's what goes up their immune system against the disease. So you know, in actual fact they are given a bit of it, erm so you know they're gonna be poorly, you know"
 - "The thing about boosters is I don't know if there's a way that his immunity could be checked prior to having a booster. Because if he was immune anyway, I don't see the point in him having a booster and bombarding his immunity again with something he doesn't need"
-

Vaccines are provided at too young an age^b

- Older, bigger children were presumed to be more capable of handling a challenge to the immune system
 - Vaccines in general were perceived ... as placing stress on a child's immature immune system
 - "They're too young and helpless"
 - ...[some parents] referred to the vulnerability of a young child: "It's just seeing her little tiny legs and putting a great big needle in it"
 - "I'd be more worried about her now because when she's older she can speak and she can say if she's hurting or something, or if she doesn't feel well. At the moment it worries me 'cos she can't tell me what she can feel"
-

MMR-specific issues

- "I'm not actually anti-vaccines, I'm quite sort of pro-vaccines, it's MMR in particular that I have a problem with"
 - Another explanation parents gave for their attribution of greater potential for immune damage to MMR than to DTP was that parents understood that Wakefield appeared to be specifically identifying the need for the MMR vaccine to be administered through three separate vaccines
 - Two women who had lived abroad (India and the USA) when their older child was immunised noted MMR had not been a public issue
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Financial incentives for HCPs^d

- "Because the GP's funding is based on their quota of immunised children that's something that made me very suspicious about the whole thing. I've got to have immunisation for my child otherwise they won't get their funding, that's already weighted isn't it"
 - "...suspicious of some of them, I just sort of don't know their motives, so you know, that does concern me, because you know is there profit involved in it?"
 - "My problem with the advice coming from the GP is that I know that GP practices are paid a bonus for having so many patients vaccinated, so how can their advice be impartial? They're running a business at the end of the day"
 - ...[trust in GPs] was often mitigated by issues of access and concerns that surgeries had financial incentives to promote MMR to the extent that some participants held GPs to be untrustworthy
 - Many mothers confirmed that they did not raise their questions with GPs, seeing them as... probably partial in their advice (not least because of their financial gain from meeting vaccination targets)
 - Parents expressed scepticism about the government's policy on single vaccines, claiming that it was based on financial reasoning
 - "...as long as it's not because they're cutting corners to save money, erm which some people think, you know some of these injections are when they chuck them all in together"
 - "Erm I do think Governments put money and finances erm before human beings. Erm... so yeah I am kind of sceptical and yes I do have concerns"
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Pressure from HCPs to vaccinate^d

- "When [the GP] found out that I wasn't going to have Sara immunised...she really put this huge guilt trip on me... So, I felt quite dejected when I came out and felt I was a bad parent"
 - "Sometimes the doctors and nurses at the surgery can be too much you know, you must have it, you know? And that's what puts a lot of people's backs up doesn't it really, your choice is gone a bit isn't it"
 - However, for non-immunisers, this pressure to comply made them more resistant to having the immunisation
 - These parents gave the explanation [for not citing the "immune overload" theory about DTP] that DTP is given when a baby is only 2, 3 and 4 months old at a time when parents are overwhelmed with the new task of parenthood and have not had an opportunity to fully consider the various arguments about immunisation
 - Several of the parents who had either decided to delay, or opted not to have MMR, spoke of their health visitors applying unwanted pressure and in some cases ostracising them for not complying with the recommended vaccines
 - Effectiveness of consultation was further diminished where practitioners were felt to be unwilling to engage in discussion of concerns, or were dismissive, condescending or coercive
 - Her health visitor, she [incomplete immuniser] said, had 'given up' on her
 - The concept of choice was sometimes discussed in the context of feeling pressurised by government to have MMR
-

as no alternatives were readily available

- "Oh no I love it, honestly. You're sucked into the system and you just get this little note through saying X should be here at this time, this day, for this vaccine, and I just laughed. I just called up and said no, we won't be doing that"

Personal testimony from HCPs^d

- Personal relationships with medical professionals were extremely important for parents' trust
- Parents often felt reassured to learn that the health professional had given his or her own children the MMR vaccine
- "I felt that 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"
- When doctors...shared their own stories about making such decisions as a parent or about positive experiences of MMR vaccination, parents were reassured that their concerns had been taken seriously
- ...Trust was heightened when participants felt that those giving information had had direct experience of the MMR - "we see they have had their children vaccinated and maybe that could promote more confidence"

Impartiality of informationⁱ

- "There doesn't seem to be anything balanced does there, there's either the government sort of, yes, you know it's definitely very safe and every child should have it or there's the other side where, you know, they shouldn't have any etc, and it's very hard to try and work out from those two what to do"
- "It is impossible to get figures that we know are objective and trustable"
- A few parents complained that the media presented the evidence in such a way that it was difficult to derive clear messages about the safety of MMR
- Parents highlighted a need... for facilitated access to independent third parties who could be trusted to provide balanced accounts of the controversy and underlying science
- "I'm not aware of any independent place where they could go and get independent advice."
- Dissatisfied parents believed that NHS information was biased: "I don't think it gives you the whole picture. It gives... the profession what the parents need to know, which is have your children immunised... and this is what happens if you don't. But it doesn't give you the rest of the picture."

Experiences (own and others) of diseases^c

- "Things like mumps and measles I had them when I was little, and so I was fine"
- Many knew or had heard of people who suffered blindness or other complications of measles
- "I had measles at six or something and it allegedly damaged my eyesight very badly but, and I wear lenses now, I'm very blind but, I would still rather run the risk that G catches it sometimes and we catch it quickly enough to put him in bed and so on, than expose his immune system at the age of whatever, a year, to something [vaccination] that may or may not have serious effects on the system itself"
- ...[Parents] with experiences of it [measles] tended to minimise these risks
- "I was one of the children that got whooping cough, but you know it hasn't done me any harm"
- While parents with no experience of measles entertained the long-term damage it could inflict, those with experiences of it tended to minimise these risks
- "My husband is deaf in one ear and that happened, they're almost certain, after he had the measles as a child and so he felt it was far more important that they did [get vaccinated] and run a very small risk of autism."
- Another incomplete immuniser... Said that she had never been immunised against whooping cough herself and had not suffered for lack of being immunised (a comment echoed by several other women)
- Eleven full immunisers said that their parents had had them immunised as infants or that they had been poorly with whooping cough as children...Moreover, at least 35 full immunisers reported having seen cases of whooping cough first hand or knew of children who had been left with a range of health problems following exposure to whooping cough
- "Well we didn't have mumps did we, and we didn't have the jab"
- Several parents were familiar with children who had been brought up unvaccinated with, they perceived, little ill effect: "My mum thinks that in the past when there was no midwives and health visitors they just got on with it. Mum thought she didn't think it would work for us, she thought if we were ill we would be ill"
- Experiences of oneself or others catching childhood diseases with few serious effects or, less frequently, with complications, also feed into people's perspectives on vaccination
- ...Parents who had experience of a disease, whether personal or through others, were more likely to report that it was serious
- "A friend of mine who I worked with lost her baby erm at about eight weeks from meningitis, which was just

awful. So I mean that may have been something that's influenced me to make sure that they get the Hib and stuff 'cos it was just so tragic. It was awful"

Knowledge about diseases^c

- By far, the most common response to questions about haemophilus influenzae was a shrug of the shoulders, blank expression or participants simply saying that they did not know
 - Moreover, she [incomplete immuniser] was unaware of the dangers of the disease whooping cough
 - Although parents could identify some of the diseases [protected against by the five-in-one DTaP/IPV/Hib vaccine], only four could list diphtheria, tetanus, pertussis, polio and Hib
 - In terms of specific diseases, while parents had limited knowledge of diphtheria, tetanus, pertussis and polio, half could describe the symptoms of meningitis
 - "{Diphtheria} I'm just completely ignorant about that, about the risks or, you know, what it is or anything like that, so I've just not thought about it at all"
-

Parents can protect their children from diseases^e

- 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
 - Children attending nursery or school were more likely to be exposed to infectious diseases
 - "The vulnerable children are the one who don't have good diet or who are from, you know, poorer backgrounds and who obviously are more open to infection in the first place if there are epidemics"
 - "G catches it... and we catch it quickly enough to put him in bed and so on"
 - Perhaps...because parents felt they could protect their children from dog bites and nail injuries, many dismissed the need for young infants to be vaccinated against tetanus
 - ...The value of natural immunity and of supporting it with nutrition
 - They [mothers who chose to avoid or postpone vaccination] saw their child's vulnerability to serious effects as depending on the strength of their immunity as acquired through nutrition and appropriate nurturing
 - One mother believed it was unlikely that her child would get tetanus because it was her 'job to keep him out of harm'. She and another mother also believed their babies were at low risk of disease because they were breast-feeding
-

Vaccination is a routine procedure or "the done thing"^e

- "When [the GP] found out that I wasn't going to have Sara immunised...she really put this huge guilt trip on me... so, I felt quite dejected when I came out and felt I was a bad parent"
 - ...For parents who were unsure about their decision or placed a high value on being respected by health workers, feeling that they would be viewed as bad parents did make them more likely to comply with medical advice
 - The majority of full immunisers felt that it was only right and proper to avail oneself of all the preventive services on offer - 53 women specifically mentioned this as one of the main reasons why they had attended the appointment
 - Several recounted how the norm at the time [of vaccinating their older children] was to 'turn up and get it done' or 'it was just another one on the list'
 - ...Others come from families with a history of compliance born of economic need that makes them ill prepared either to research or to feel confident to criticize
 - Twelve parents, particularly first-time mothers, reported that they would take their baby for their immunisations because it was 'the normal thing to do': "Cos I'm a sheep and that's what you do. You know, I just... it's just another thing that you do, you know. You fall pregnant, you go through this whole regime of things you do, and that you have to do, and that's one of them I mean"
-

Trusting your instinct as a parent^e

- Many of the non-immunisers had had their older children immunised, but had changed their views over time as they reported feeling more confident about questioning professional recommendations and exploring alternatives as their experience as parents grew
 - ...Some parents felt a need to apologise for having made a rational rather than emotional response to the controversy that surrounded MMR, with one parent commenting that at some level it 'sounds awful' to be reliant on scientific information, the implication being that as a mother she should just know what is best
-

Social support

- "Had all of the baby jabs done. Because being on my own, as I said my mum wasn't down here and I hadn't established a group of friends down here, I felt really vulnerable. The responsibility of looking after him was extremely overwhelming"
 - On this account, vulnerability was a reason for vaccination, or at least for handing over judgement about it to
-

health professionals

- "I think people should look into it, but when you've got a six week old baby, you've got a job to even like get enough rest for yourself, let alone going to look on the internet and your baby's injection is due in two weeks time"

Contraindications^f

- Mothers commonly spoke about ensuring that their children were in good health on the day of immunisation and about how they would not take an ill child for vaccination even if the illness was minor
- Illness in the child to be immunised was most frequently mentioned - by 26 of the 46 incomplete immunisers - as the chief reason for non-attendance
- "He's full of cold and teething - I'm a bit biased about letting him have it"
- "She never seems well enough to go..."
- Some mothers who mentioned contraindications in their narratives postponed vaccination until they felt their child's constitution had strengthened, or a period of particular susceptibility had passed.
- "Erm if he's ill... you know, if he has a cold or anything then his immune system's gonna fight it anyway, so that might be compromised if he has a vaccine, especially five vaccines in one"

Childcare^f

- ...The presence of older children...[was] seen to be of some significance
- ...Seven parents, particularly those with older children, discussed commitments that might get in the way of timely immunisation: "If you've got children it is a hassle going and having them done at a set time and etc. because, you know, people have got other things to do..."

Time^f

- For women in full-time employment, attendance more often than not necessitated taking formal leave, whilst even those women employed part time did not find it easy to attend appointments
- Parents expressed a lack of control in accessing information and lack of time to find it
- "Well it's all over and done with then isn't it [with five-in-one vaccine]. It's all out the way, so you haven't got to think I've got an injection this week and another one next week"
- "Because I'm not working erm then [when on maternity leave], you know, nothing would... I think it would have to be something pretty major for me to then not take her when it's necessary, so it's going to be very easy for me"

Physical pain of vaccination^f

- Several parents acknowledged particular personality quirks or phobias that made them apprehensive of biomedical intervention, however mild
- Several mothers only consented to vaccination once the child's father finally agreed to take the children, claiming that they could not bear to see their children suffer
- "Well it's obviously beneficial for the child in that they only have to go through one jab as it were, so it would be less painful, more humane really"
- "'Cos he's older and they know what's going on, whereas when they're at this age they just don't know what's coming. I think as soon as he sees that needle he's going to have a fit"

Clinic factors^f

- ...Complete immunisers tended to highlight difficulties relating to dissatisfaction with the services available once having arrived at clinics and surgeries, such as lengthy waiting times, overcrowding and the inflexibility of clinic hours. [Incomplete immunisers cited] associated mobility difficulties, that is, problems of actually reaching the clinic

Knowledge of vaccine arrangements^f

- Eight parents reported uncertainty about the organisation of immunisation appointments: "I'm not sure whether or not I'm supposed to phone the doctor's to get the appointments or whether or not they phone me"

Influence of friends, family and other parents^g

- "And to me the clinching thing on why I wanted the single vaccines was the parents on the television that were showing their children... That these parents were so convinced that it was the MMR... They truly believed that, do you know what I mean?"
- "You know where you are with other parents. They don't have any reason to make things up or like any hidden agenda so to speak, so you feel you can believe other parents"
- ...Anecdotal accounts from other parents appeared to carry as much, if not more weight than either evidence from epidemiological studies or assurances from politicians and public health officials [or] research studies, which

many participants felt ill-equipped to assess [in terms of credibility] for themselves

- ...A third of incomplete immunisers said that their relatives had advised against vaccination
 - Full immunisers, however, were more likely than incomplete immunisers to have received pro-vaccination advice from family and friends
 - ...Their mothers had therefore recommended that they consider full protection for their own children
 - "It does influence your decision I must admit, particularly when it's your mum who's saying it. Erm... she was very... particularly with MMR... she was very nervous about it and offered to pay for [three year old daughter] to have it done"
 - "I think probably friends' experiences as well. And I think they play an important role in erm new mothers because they're always listening to other people, trying to take on board tips and things"
-

Decision balance/weighing risks^j

- ... For others [parents] even an extremely slight risk of autism was too great
 - "If there's any risk with the injections, don't get it because whooping cough's fine"
 - These parents perceived that the disabling long-term impact of the disorder [autism] was far worse than the mumps, measles or rubella diseases
 - "We'd decided that whatever the risks were of having the vaccination, of possible problems, we still felt it was just better for them to have the injections than run the risk of any of the diseases"
 - "If he has whooping cough, he catches it and that's that - but if he had the injection, I'd feel responsible. If anything happened as a result of vaccination, I would always blame myself. If she catches whooping cough, it's an act of God and out of our hands, but if she was brain damaged, that would be our responsibility... we wouldn't want to bring it on ourselves"
 - "If it is going to happen [vaccine damage] it will do – not that I want it to happen, but I think it's better they're protected against it. I couldn't live with myself if anything happened through not being vaccinated"
 - "I think that the risks that he gets ill without having it are worse than the ones if he doesn't and as far as I am concerned I want to protect my son as much as I can"
 - "If she doesn't have it, she could get very ill, she could die. Then realistically, I'd rather she be autistic"
 - There's a fine line to tread. It's what you want for your children, whether you can cope with a bit of autism or blind and deafness, it's pot luck then at the end of the day"
 - "When I do it, and I probably will, it will be closing my eyes, running and jumping"
 - "I wouldn't wanna put a death sentence on them for the sake of having one jab"
-

Moral/religious reasons^k

- Non-immunisers also cited the process of vaccine production and the use of animal products as further disincentives to immunise
 - In one group of Asian women the impact of religious beliefs was discussed suggesting a lack of personal control over their child's health – "if it is meant to happen it will"
 - Some mothers claimed political or philosophical attitudes that make them suspicious of or offended by what they experience as heavy-handed or patronising denials of their ability to choose for themselves
-

a: Demographics; b: Vaccine factors; c: Disease factors; d: Healthcare system/Government; e: Parenting/social context; f: Practicalities; g: Non-official sources of information; h: Individual differences; i: Information needs; j: Decision-making; k: Lifestyle factors

Figure 11.3: Qualitative study invitation to participate



**Imperial College
London**

Ealing 
Primary Care Trust



Dear Parent,

The DeCIDE study: Understanding how parents decide whether to give their child the Measles, Mumps and Rubella (MMR) vaccine

You are invited to take part in a research study. The study aims to find out what parents think about when they are deciding whether or not to give their child the MMR vaccine.

We are inviting all parents of MMR-age children in the borough of Ealing to take part in this study. The study is run by Imperial College London, with the support of Ealing Primary Care Trust.

Taking part in the study will involve you talking to our researcher **confidentially** for **between 30 minutes and 1 hour**. Where and when this happens is up to you:

- The researcher could come to you at home or work (any time)
- You could come to us in Paddington (we will pay for travel)
- You could talk to the researcher on the phone (any time)

We can arrange an interpreter if you would like this.

You will receive a **£10 Boots or Wilkinson's voucher** to thank you for taking part.

Please find attached an information sheet telling you more about the study. Please read the information sheet before you decide whether you would like to take part in the study.

If you are interested in taking part in this study, please contact Katrina Brown, our researcher. Contact her in any of these ways:

Telephone: 020 7886 6567
Email: Katrina.Brown@imperial.ac.uk
Post: return the response slip below, using the enclosed freepost envelope

Please also contact Katrina if you have any other questions about the study.

We look forward to hearing from you.

Yours sincerely,

Katrina Brown

Katrina Brown

V2 Dec 10 07

Please contact me about taking part in the DeCIDE study.

My name is.....	My phone number is.....
My address is.....	My email address is.....
.....	My language is.....
.....	
.....	

Please return this slip in the freepost envelope

www.decidestudy.co.uk

Figure 11.4: Qualitative study participant information sheet

Can everyone take part?

We may not be able to talk to everyone who wants to take part in the study. If we are not able to talk to you, we will write and let you know.

What if there is a problem?

We do not expect that any part of this study will cause harm or worry for anyone taking part in it. Standard NHS and Imperial College procedures for potential compensation are in place for all participants.

Who is organising and funding this study?

The study is organised and managed by psychologists at Imperial College London. The study is funded by the Health Protection Agency.

The study has been reviewed and approved by an NHS Research Ethics Committee (Ealing & WLMHT, ref. 08/H0710/06) and by Ealing Primary Care Trust.

Would you like to take part in this study?
Would you like more information before you decide?

Please contact Katrina Brown

Telephone: 020 7886 6567
Email: Katrina.Brown@imperial.ac.uk
Post: return the response slip on the letter that comes with this leaflet – a freepost envelope is provided

Thank you

With your help, we can understand how parents make decisions about MMR and how to support them in those decisions

Participant information leaflet

Imperial College London
Ealing NHS Primary Care Trust

Understanding how parents decide whether to give their child the Measles, Mumps and Rubella (MMR) vaccine

Parents receive a lot of information about the MMR vaccine. We need to know if parents have the information they need to help them decide whether to give their child MMR.

We need to find out what parents think about when they are making their MMR decision.

We want to talk to parents of MMR-age children in the borough of Ealing.

We want to talk to you.

This leaflet tells you more about the study and how you can take part in it. Please read the leaflet carefully.

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Why have I been invited to take part in this study?

Every parent in Ealing whose child has been invited to have the MMR vaccine will be invited to take part in this study. We will talk to about 40 parents. You can participate in the study if you have already decided about MMR, or if you are not sure yet.

Do I have to take part in this study?

No. It is completely up to you to decide whether you want to take part. If you decide not to take part, it will not affect the care which you or your child will receive from your doctors. If you decide to take part and then change your mind, you can stop taking part in the study at any time without giving a reason.

What will happen if I take part?

We will make an appointment to talk to you about your MMR decision. Where and when we have this talk is up to you:

- We can talk on the phone (any time)
- We can come to you (at your home or at work)
- You can come to us (Imperial College, Paddington)
- Weekend, evening or working hours appointments

If you need to travel to us, we will refund your fares or mileage.

You can have an interpreter to help you when you talk to us.

Your appointment will last for between 30 minutes and 1 hour. The researcher will ask you to talk about the things you have been thinking about when deciding about the MMR vaccine. You don't have to answer any questions that you don't want to.

We will record what you say to the researcher on a digital voice recorder. This is so that we don't miss anything that you say. We might miss things out if we just took notes.

We will give you a £10 Boots or Wilkinson's voucher to thank you for taking part in the study, when you have talked to us.

We will ask your permission to look at your child's immunisation record to check when they had MMR. Using official records like this means that our results will be taken more seriously. This means our study is more likely to help parents like you in the future.

We may also ask you to check our results to make sure you are happy with the way that your views are represented.

Is taking part confidential and anonymous?

Yes. We will only keep a record of your contact details if you ask to receive results from the study. Only members of the research team will ever have access to information like this. Your information will be stored in accordance with the Data Protection Act 1998 (DPA). Your doctor will not know whether you take part in the study.

We will not link your name or other personal details to anything that you say in your interview

I do not speak much English. Can I still take part?

Yes. We can send you a copy of this leaflet in your own language. Contact us to request this: (020 7886 6567 or Katrina.Brown@imperial.ac.uk). You can also have an interpreter to help you.

What are the possible benefits of taking part in this study?

There may not be any direct benefit to you of taking part in this study, though you may find that talking about your MMR decision helps to make your thoughts clearer. The information we get from this study will help parents like you making MMR decisions in the future.

What are the possible risks of taking part in this study?

There is a small chance that talking about your MMR decision will make you a bit worried. If you feel worried, we can put you in contact with a specialist Doctor to talk about this.

What will happen after the study?

We hope that the results will help provide the right information to parents making MMR decisions. The results will be published in journal articles. We can send you a summary of the results of the study when they are ready. We will ask you at the appointment if you would like to see these results.

Figure 11.5: Qualitative study participant consent form

Consent Form		Imperial College London		Ealing NHS Primary Care Trust
--	---	--------------------------------	--	---

Title of study
 The DeCIDE (Describing Childhood Immunisation Decisions) study: Understanding how parents decide whether to give their child the Measles, Mumps and Rubella (MMR) vaccine

Name of Researcher
 Katrina Brown

Participant ID number for this study

Instructions for participant
 Please read each of the sections below. In the box next to each section, please write your initials to show that you agree with what the section says.

If there is anything that you do not understand, please contact Katrina Brown: 020 7886 6567 or Katrina.Brown@imperial.ac.uk

When you have written your initials in all of the boxes, please write clearly your name, today's date, and your signature, in the spaces at the bottom (the ones marked with an X).

1 I confirm that I have read and understand the information sheet dated 19 th February 2008 (version 1.5) for the above study.	INITIALS
2 I have had the opportunity to think about the information and to ask questions about it if I want to. If I have asked questions, I am happy with the way that my questions have been answered.	INITIALS
3 I understand that I do not have to take part in this study and that I am free to stop taking part in this study at any time without giving any reason.	INITIALS
4 I understand that if I stop taking part it will not affect the medical care of me or my child. I understand that if I stop taking part, my legal rights will not be affected.	INITIALS
5 I understand that the research team will look at my child's official record to find out when he/she had the MMR vaccine. I give permission for the research team to access my child's record for this purpose only.	INITIALS
6 I understand that what I say to the researcher will be recorded using a digital voice recorder and saved on a computer at Imperial College. I understand that parts of what I say may be used anonymously in the results of this study.	INITIALS
7 I would like to receive a summary of the results of this study.	INITIALS
8 I agree to take part in this study.	INITIALS

X _____ NAME OF PARTICIPANT	X _____ DATE	X _____ SIGNATURE
_____ NAME OF PERSON TAKING CONSENT	_____ DATE	_____ SIGNATURE

When completed: 1 copy for participant; 1 copy for researcher

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Figure 11.6: All studies translation sheet

Would you like information about this study in your own language?
Please contact Katrina Brown – her details are below.

If you phone, an interpreter can help you during the call. If you email or return the card by post, please write your language.



Soomaali (Somali)

Hadaad doonayso fahfaahin ku hadlaya AfSomali? Fadlan Laxidhiidh Katrina Brown - Ciwaankedu wuxuu ku qoranyahay xaga hoose.
Hadaad Telefonka soo dirto waxaa ku caawin kara Turjume intaad telefonka ku jirtid.
Hadii aad Email ama warqad boosta kusoo dirto waxaad kusoo qortaa inaad ubaahan tahay Somali.

தமிழ் (Tamil)

இந்த ஆய்வின் விளக்கங்கள் உங்களுக்கு தேவைப்பட்டின் கற்றினா பிறவுண் (Katrina Brown) உடன் தொடர்பு கொள்ளவும். தொடர்பு கொள்ள வேண்டிய விபரம் கீழ் தரப்பட்டுள்ளது. தொலைபேசியில் தொடர்பு கொண்டால் தமிழ் மொழி பெயர்ப்பாளர் உங்களுக்கு உதவி செய்வார். தபால் பதில் அட்டை மூலமோ, தொலை நகல் மூலமோ (e-mail) தொடர்பு கொள்வதென்றால், தமிழ் மொழியில் விளக்கம் தேவை என்று தயவு செய்து குறிப்பிடவும்.

ਪੰਜਾਬੀ (Punjabi)

ਕੀ ਤੁਸੀਂ ਇਸ ਘੋਖ ਸ਼ਾਵੇ ਜਾਣਕਾਰੀ ਪੰਜਾਬੀ ਵਿਚ ਚਾਹੋਗੇ? ਕਿਰਪਾ ਕਰਕੇ ਕੈਟਰੀਨਾ ਬਰਾਊਨ ਨਾਲ ਸੰਪਰਕ ਕਰੋ- ਉਸਦਾ ਵੇਰਵਾ ਹਲੇ ਹੈ।
ਜੇ ਫੋਨ ਕਰੋ ਤਾਂ ਟੁਰਜਮੀਆ ਤੁਹਾਨੂੰ ਮਦਦ ਕਰੇਗਾ। ਜੇ ਤੁਸੀਂ ਈ ਮੇਲ ਜਾਂ ਕਾਰਡ ਭਾਵ ਵਿਚ ਭੇਜੋ। ਕਿਰਪਾ ਕਰਕੇ ਲਿਖੋ ਕਿ ਪੰਜਾਬੀ ਚਾਹੀਦੀ ਹੈ।

język polski (Polish)

Jeśli chcecie Państwo informacje o tej ankiecie po polsku, proszę skontaktować się z Katrina Brown - szczegóły poniżej.
Dysponujemy tłumaczem, który może Państwu pomóc podczas rozmowy telefonicznej. W przypadku kontaktu przez e-mail lub przez zwrot tej kartki, proszę dopisać ze potrzebują Państwo

اردو (Urdu)

کیا آپ اس تعلیم کی معلومات اردو زبان میں حاصل کرنا چاہیں گے؟ براۓ مہربانی کٹرینا براؤن سے رابطہ کیجئے، رابطے کیلئے تفصیلات نیچے موجود ہیں
اگر آپ فون کریں گے تو ایک ترجمان گفتگو کے دوران آپ کی مدد کر سکتا ہے۔ اگر آپ ای میل کریں یا ڈاک کے ذریعے پیکارڈ واپس بھیجیں تو براۓ مہربانی لکھیے کہ آپ کو اردو کی ضرورت ہے

فارسی (Farsi)

اگر علاقمند می باشید که در این رابطه اطلاعات به زبان فارسی در اختیار تان قرار گیرد؟ در این صورت می توانید با خانم کاترین براون تماس حاصل نمائید، مشخصات او در زیر آمده است.
اگر با تلفن با ما تماس بگیرید در زمان تماس مترجم ما میتواند به شما کمک نماید.
در صورت فرستادن ایمیل و یا فرستادن فرم با پست لطفا در ان تاکید نمائید که به زبان فارسی نیاز دارید.

العربية (Arabic)

هل ترغب بمعلومات عن هذه الدراسة باللغة العربية؟ ألهجاء الإتصال بـ كاترينا براون- تفاصيل الإتصال مذكورة أدناه.
لو إتصلت، سيساعدك مترجم خلال الإتصال. لو أرسلت بريد الكتروني أو أعدت إرسال البطاقة بالبريد فالرجاء أن تكتب بأنك محتاج الى اللغة العربية.

☎ 020 7886 6567

✉ Katrina.Brown@imperial.ac.uk

Figure 11.7: Qualitative study interview schedule



Study 2: Interview Schedule

1. Let's begin by talking a bit about you:

Prompts: age – education – employment – number of children – birth order of child currently called for MMR – ethnicity – *religion** – access to healthcare (travel, childcare) – general feelings about vaccines – previous vaccination behaviour

2. Do you think you will give your child the MMR?

Prompts: timeframe – reasons for timeframe – *factors which might change plans* – “CONFIDENCE INTERVAL”

3. What things have you thought about when making your decision about MMR?

KEEP THIS QUESTION VERY OPEN INITIALLY, GIVE PARTICIPANT SPACE TO BRING UP TOPICS BEFORE PROMPTING

Prompts: VACCINE – are there risks (what are they, likelihood, seriousness) – comparison of vaccine risks with disease risks – media portrayals – friends/family views – personal experience of vaccine side effects – procedural issues – schedule (satisfaction with) – efficacy of vaccine – *vaccine overload* – difference between MMR and other vaccines – natural versus artificial immunity

Prompts: DISEASES – prevalence (*outbreaks*) – susceptibility (own ability to protect child) – seriousness – complications – personal experience

Prompts: YOUR CHILD – birth order (what you did with previous children) – sex – health to date (“*longed-for baby*”, “too strong to need MMR”, “too weak to cope with MMR”) – uniqueness of child (in relation to research findings – “one in a million”) – contraindications – TRACING OUTCOMES: WHY IS THIS IMPORTANT (SELF BLAME OR TREATMENT) – child’s feelings about procedure

Prompts: YOUR ROLE AS A PARENT – self blame (what is worse – blame re VAE or blame re complications from VPD?) – social norms (what are peers doing, what do HCPs expect) – moral norms (responsibility to child) – *political/philosophical/religious beliefs* – preference for “the natural” (GM crops, childbirth)

Prompts: INFORMATION – type – amount – where from (who sent info) – did it meet your needs – timing (enough time to digest info) – how long have you been thinking about MMR – source of info (trust, motives) – celebrity endorsement (would that work for you, which celebrity) – did you seek out your own information – “MMR mentors” (would that be useful) – change from “MMR: The Facts” leaflet to “Immunisations at 12 and 13 months” (did you notice, did that make MMR seem like less of an issue)

Prompts: ACCESS – appointments (convenient, fitting around work or childcare) – “bad timing” (child illness)

Prompts: THE HEALTHCARE SYSTEM – trust in HCPs (and variation by type of HCP) – perceived agenda – perceived skill/knowledge of HCPs – actual discussions with HCPs – consistency (comparison with experience in other countries) – HCP supports decision or feeling need to justify choice

Prompts: THE IMPORTANCE OF CHOICE – autonomy (in your culture) – your views vs family views vs HCP views – is MMR a choice for you (was it presented as a choice by HCPs, balance of evidence)

Prompts: PREPARING FOR THE UNEXPECTED – “leap of faith” – *local outbreaks*

4. Finally, which of the issues that we’ve talked about are the ones that you’d say really “drive” your decision? If you had to pin your decision down to one or two factors, what would they be?

Prompts: recap factors which participant went into detail about earlier, ask why those factors and not the others – distinction between feelings and facts – justifying decision (to whom)

* Italicised prompts might not always be appropriate to bring up – exercise caution.

Figure 11.8: MMR catch-up study invitation to participate

Imperial College London		NHS Halton and St Helens
Parent/guardian of «Child_Forename» «Child_Surname» «addr1» «addr2» «town» «county» «postcode»		Katrina Brown Imperial College London St. Mary's Hospital Medical School Norfolk Place LONDON W2 1PG
		<<DATE>>
Tell us what you think about MMR!		
We would like to find out what parents in Halton & St Helens Primary Care Trust (PCT) think about the measles, mumps and rubella (MMR) vaccine. You have been chosen at random to receive this short survey about MMR. We are sending this survey to over 2400 parents in your PCT.		
Please complete and return this survey within the next week – freepost envelope enclosed.		
Halton & St Helens PCT records show that your child is not up-to-date for their age with the MMR vaccine*. Your child should by now have received one dose.		
This survey is run by Imperial College London, sponsored and funded by the Health Protection Agency, and has the full approval of Halton & St Helens Primary Care Trust. You do not have to complete and return this survey, but if you do your response will be anonymous and confidential, and you can ask us to remove your response at any time if you wish. If you do not participate, your child's health care will not be affected. Your GP will not know whether or not you participate.		
By completing and returning this survey you will help Halton & St Helens PCT understand how parents feel about MMR. This will help GPs in your PCT give parents the information and support they need to make the decision which is right for them.		
If you have any questions about the survey, please telephone or email us: 020 7594 3062 or Katrina.Brown@imperial.ac.uk		
Thank you in advance for your help.		
Yours sincerely,  Katrina Brown, Principal Investigator		
<i>*If you believe Halton & St Helens PCT's MMR record for your child is wrong, please fill in the survey ticking the box to show your child is up-to-date, and we will advise the PCT to update your child's record.</i>		
«id»		Version 1.3 September 2009

NB: PCT logo and PCT references in text were appropriate to PCT with which letter recipient was registered. Third paragraph and corresponding footnote omitted for cases CHIS-recorded as up-to-date with MMR.

Figure 11.9: Young adults Study 1 questionnaire

VACCINATION DECISION-MAKING STUDY	Age: years Gender:
<u>Instructions</u> You are the parent of a one-year-old child. You are considering whether to give your child a vaccine to protect them against a disease. The details about the disease and vaccine are as follows: - Disease A is a moderately severe childhood illness. Symptoms last 3-5 days and include fever, vomiting and fits - Vaccine B offers effective protection against Disease A - Vaccine B can have moderately severe side effects, lasting 3-5 days and including fever, vomiting and fits Your child's chance of catching Disease A, or having side effects from Vaccine B, can vary. The scenarios below describe some of these variations. Read each scenario and rate how likely you are to give your child Vaccine B, in each case.	
There is a 1 in 10,000 chance that your child will catch disease A. There is also a 1 in 10,000 chance that your child will experience side effects from Vaccine B. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
- Chance of catching Disease A: 1 in 10,000 - Chance of side effects from Vaccine B: 1 in 50 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
- Chance of catching Disease A: 1 in 10,000 - Chance of side effects from Vaccine B: 1 in 10 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
- Chance of catching Disease A: 1 in 50 - Chance of side effects from Vaccine B: 1 in 10,000 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
- Chance of catching Disease A: 1 in 50 - Chance of side effects from Vaccine B: 1 in 50 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	

- Chance of catching Disease A: 1 in 50 - Chance of side effects from Vaccine B: 1 in 10 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will												
- Chance of catching Disease A: 1 in 10 - Chance of side effects from Vaccine B: 1 in 10,000 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will												
- Chance of catching Disease A: 1 in 10,000 - Chance of side effects from Vaccine B: 1 in 50 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will												
- Chance of catching Disease A: 1 in 10 - Chance of side effects from Vaccine B: 1 in 10 How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will												
What most influenced your decisions about giving your child Vaccine B? Tick the box next to your choice ☐ The chance of catching Disease A ☐ The chance of side effects from Vaccine B ☐ Other (please state).....												
<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding-bottom: 5px;">What do you consider to be a low chance of catching a disease? (Write in here)</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> <tr> <td style="padding-bottom: 5px;">What do you consider to be a medium chance of catching a disease?</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> <tr> <td style="padding-bottom: 5px;">What do you consider to be a high chance of catching a disease?</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> <tr> <td style="padding-bottom: 5px;">What do you consider to be a low chance of having side effects from a vaccine?</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> <tr> <td style="padding-bottom: 5px;">What do you consider to be a medium chance of having side effects from a vaccine?</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> <tr> <td style="padding-bottom: 5px;">What do you consider to be a high chance of having side effects from a vaccine?</td> <td style="padding-bottom: 5px; text-align: right;">1 in</td> </tr> </table>	What do you consider to be a low chance of catching a disease? (Write in here)	1 in	What do you consider to be a medium chance of catching a disease?	1 in	What do you consider to be a high chance of catching a disease?	1 in	What do you consider to be a low chance of having side effects from a vaccine?	1 in	What do you consider to be a medium chance of having side effects from a vaccine?	1 in	What do you consider to be a high chance of having side effects from a vaccine?	1 in
What do you consider to be a low chance of catching a disease? (Write in here)	1 in											
What do you consider to be a medium chance of catching a disease?	1 in											
What do you consider to be a high chance of catching a disease?	1 in											
What do you consider to be a low chance of having side effects from a vaccine?	1 in											
What do you consider to be a medium chance of having side effects from a vaccine?	1 in											
What do you consider to be a high chance of having side effects from a vaccine?	1 in											
Thank you for completing this questionnaire!												

NB: Vignettes randomised to different orders in other versions of this questionnaire.

Figure 11.10: Young adults Study 2 questionnaire

VACCINATION DECISION-MAKING STUDY	Age:	Gender:
<u>Instructions</u> You are the parent of a one-year-old child. You are considering whether to give your child a vaccine to protect them against a disease. The details about the disease and vaccine are as follows: - There is a 1 in 400 chance of your child catching Disease A - Vaccine B offers effective protection against Disease A - There is a 1 in 7,000 chance of your child having side effects from Vaccine B The severity of Disease A, and the severity of side effects from Vaccine B, can vary. The scenarios below describe some of these variations. Read each scenario and rate how likely you are to give your child Vaccine B, in each case.		
Disease A causes a low fever and a rash. Side effects of Vaccine B are also a low fever and a rash. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		
→ Symptoms of Disease A: low fever, rash → Side effects from Vaccine B: vomiting, diarrhoea How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		
→ Symptoms of Disease A: low fever, rash → Side effects from Vaccine B: paralysis, brain damage How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		
→ Symptoms of Disease A: vomiting, diarrhoea → Side effects from Vaccine B: low fever, rash How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		
→ Symptoms of Disease A: vomiting, diarrhoea → Side effects from Vaccine B: vomiting, diarrhoea How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		
→ Symptoms of Disease A: vomiting, diarrhoea → Side effects from Vaccine B: paralysis, brain damage How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← → 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Definitely will		

→ Symptoms of Disease A: paralysis, brain damage	→ Side effects from Vaccine B: low fever, rash
How likely is it that you will give your child Vaccine B? Circle a number on the scale	
Definitely won't ← → 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
→ Symptoms of Disease A: paralysis, brain damage	→ Side effects from Vaccine B: vomiting, diarrhoea
How likely is it that you will give your child Vaccine B? Circle a number on the scale	
Definitely won't ← → 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
→ Symptoms of Disease A: paralysis, brain damage	→ Side effects from Vaccine B: paralysis, brain damage
How likely is it that you will give your child Vaccine B? Circle a number on the scale	
Definitely won't ← → 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
→ Symptoms of Disease A: paralysis, brain damage	→ Side effects from Vaccine B: death
How likely is it that you will give your child Vaccine B? Circle a number on the scale	
Definitely won't ← → 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
→ Symptoms of Disease A: death	→ Side effects from Vaccine B: paralysis, brain damage
How likely is it that you will give your child Vaccine B? Circle a number on the scale	
Definitely won't ← → 0% 100% 10% 20% 30% 40% 50% 60% 70% 80% 90% Definitely will	
What most influenced your decisions about giving your child Vaccine B? Tick the box next to your choice	
☐ The severity of Disease A ☐ The severity of side effects from Vaccine B ☐ Other (please state).....	
How severe do you believe the following symptoms/side effects are? Tick one box for each symptom	
	Mild Mild-moderate Moderate Moderate-severe Severe Don't know
Low fever	☐
Rash	☐
Vomiting	☐
Diarrhoea	☐
Paralysis	☐
Brain damage	☐
Death	☐
Thank you for completing this questionnaire!	

NB: Vignettes randomised to different orders in other versions of this questionnaire.

Figure 11.11: Young adults Study 3 questionnaire

VACCINATION DECISION-MAKING STUDY														
You are the parent of a one-year-old child. You are considering whether to give your child a vaccine to protect them against a disease. The details about the disease and vaccine are as follows: • There is a 1 in 400 chance of your child catching Disease A. Disease A causes fever and rash • Vaccine B offers effective protection against Disease A • There is a 1 in 7,000 chance of your child having side effects from Vaccine B. These are vomiting and diarrhoea														
1. Based upon this information only, how likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
GPs provide varying advice and information about Vaccine B to parents. The relationship between GP and parent can also vary. The scenarios below describe some of these variations. Read each scenario and rate how likely you are to give your child Vaccine B, in each case.														
2. Your GP encourages you to give your child Vaccine B. She gives you some NHS leaflets about vaccine B and disease A. You feel that she is an average communicator, and you did not specifically choose her over another doctor. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
3. Your GP encourages you to give your child Vaccine B. She tells you about her personal experience of deciding about Vaccine B. You feel that she is a good communicator, and she was recommended to you by a friend. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
4. Your GP gives you neutral advice about Vaccine B. She tells you about her personal experience of deciding about Vaccine B. You feel that she is an average communicator, and you did not specifically choose her over another doctor. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
5. Your GP gives you neutral advice about Vaccine B. She tells you about her personal experience of deciding about Vaccine B. You feel that she is a good communicator, and she was recommended to you by a friend. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
6. Your GP encourages you to give your child Vaccine B. She gives you some NHS leaflets about vaccine B and disease A. You feel that she is a good communicator, and she was recommended to you by a friend. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														
7. Your GP encourages you to give your child Vaccine B. She gives you some NHS leaflets about vaccine B and disease A. You feel that she is an average communicator, and you did not specifically choose her over another doctor. How likely is it that you will give your child Vaccine B? Circle a number on the scale Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will														

8. Your GP **encourages you** to give your child Vaccine B. She tells you about her **personal experience** of deciding about Vaccine B. You feel that she is a **good communicator**, and she was **recommended** to you by a friend.

How likely is it that you will give your child Vaccine B? Circle a number on the scale

Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will

9. Your GP **encourages you** to give your child Vaccine B. She tells you about her **personal experience** of deciding about Vaccine B. You feel that she is an **average communicator**, and you **did not specifically choose her** over another doctor.

How likely is it that you will give your child Vaccine B? Circle a number on the scale

Definitely won't ← 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% → Definitely will

10. Have you or anyone close to you ever experienced side effects from a vaccine? Please tick all that apply

☐ No ☐ Yes, moderate (e.g. vomiting, diarrhoea) ☐ Not sure

☐ Yes, mild (e.g. fever, rash) ☐ Yes, severe (e.g. paralysis, brain damage) ☐ Other (please explain)

11. Have you or anyone close to you ever contracted an illness which could have been prevented by a vaccine, but the vaccine wasn't available at the time? Please tick one option only

☐ No ☐ Yes ☐ Not sure ☐ Other (please explain)

12. Have you or anyone close to you ever contracted an illness which could have been prevented by a vaccine, but you/they (or someone acting on your/their behalf, e.g. a parent) chose not to take the vaccine? Please tick one option only

☐ No ☐ Yes ☐ Not sure ☐ Other (please explain)

13. How do you feel about your GP? Please tick only one option which best describes the extent of your agreement with each statement

	Never	Rarely	Sometimes	Often	Always
I trust my GP's advice on treatment decisions	☐	☐	☐	☐	☐
I follow my GP's advice on treatment decisions	☐	☐	☐	☐	☐

14. How **directive (pressurizing)** do you think the following **GP behaviours** are, in the context of vaccination decisions? Please tick only one option for each behaviour

	Not at all directive	A little directive	Completely directive	Unacceptably directive	Don't know
Encouraging a parent to vaccinate their child	☐	☐	☐	☐	☐
Giving neutral advice about a vaccine	☐	☐	☐	☐	☐

15. How **useful** do you think the following types of information are, when deciding whether to vaccinate a child? Please tick only one option for each type of information, and explain in the end box your reason(s) for ticking this option

	Not at all useful	Slightly useful	Quite useful	Very useful	Don't know	Why? (Please write in, i.e. "trustworthy"; "biased"; "comprehensive"; "selective")
NHS / Government material	☐	☐	☐	☐	☐	
GP's personal testimony / experience	☐	☐	☐	☐	☐	

16. How much would you **trust** a GP with the following characteristics, in the context of vaccination decisions? Please tick only one option for each characteristic

	Mistrust	Slightly mistrust	Neither trust nor mistrust	Slightly trust	Trust	Don't know
Good communicator	☐	☐	☐	☐	☐	☐
Average communicator	☐	☐	☐	☐	☐	☐
Recommended by friend	☐	☐	☐	☐	☐	☐
Not specifically chosen	☐	☐	☐	☐	☐	☐

Sex: M / F Age: years Student: Yes / No Course: Year: Please circle or write in

NB: Vignettes randomised to different orders in other versions of this questionnaire.

Figure 11.12: Omission bias study invitation to participate

Title: 10-minute survey on immunisation decisions: Parents of children aged 5-7 years required

Dear Parents,

We are running a study to find out exactly how parents make decisions about immunisations for their children. It is important to know what information parents use, and how they use it, to ensure that information is made available in an appropriate way.

We need to use information in this study which is relevant and makes sense to parents. The best way for us to get that information is by asking parents. This is where you come in!

We are asking parents of 5-7 year-olds on a number of online forums to complete a short questionnaire, which takes about ten minutes to complete. The questionnaire asks what you consider to be good (would make you want to accept a vaccine), bad (would put you off accepting a vaccine) and neutral (would neither make you want to accept a vaccine, nor put you off accepting a vaccine) characteristics in a hypothetical (imaginary) immunisation scenario. These characteristics cover the vaccine, the disease, and issues in accessing healthcare. There are no right or wrong answers – we just want to know your opinion. We will average out all the responses to get information which should be relevant for most parents.

The questionnaire is completely confidential. It is run by a team at Imperial College London, is funded by the Health Protection Agency, and has received full ethical approval (<<ICREC ref to follow>>)

The questionnaire is available at: www.decidestudy.co.uk

If you have any questions about this study, please contact Katrina Brown, study co-ordinator:

Telephone: 020 7594 3062
Email: Katrina.Brown@imperial.ac.uk

Thank you in advance for your help with this study!

NB: This invitation was posted on discussion forums on a number of parenting websites.

Figure 11.13: Information sheet for omission bias study participants

This survey explores which factors would make you want to accept or decline a vaccine for your child. It contains 20 questions and should take about ten minutes to complete.

Please read each question carefully, as some questions look very similar but have slight differences in the wording. For most questions you are asked to choose options from drop-down menus. When answering the questions, please think about your own child aged 5-7 years.

All the information in this survey is hypothetical (not real). Please try not to let your real-life feelings about a specific vaccine or disease influence your answers to this survey.

There are no right or wrong answers – we just want to know your opinion. Your responses are completely confidential.

We will average out all the responses so your individual answers will not be studied. We will use the information we get from this survey to explore how parents prioritise information in vaccine decision-making.

This study is run by a team at Imperial College London, and is funded by the Health Protection Agency. It has full ethical approval (ICREC_9_2_2).

If you have any questions about this survey, please contact Katrina Brown, study co-ordinator:

Katrina.Brown@imperial.ac.uk
020 7594 3062

Please now hit the "Next page" button below to proceed to the first question.

NB: This information was provided on the first page of the online questionnaire.

Figure 11.14: Example questions from omission bias study questionnaire

Likelihood

What do you consider a small, medium, and large chance of your child REACTING TO A VACCINE?

A small chance of reaction means reactions are less common; a large chance of reaction means reactions are more common. Please select an option from the drop-down menus for each one

- 100,000 in 1 million children will have a reaction (10%)
- 10,000 in 1 million children will have a reaction (1%)
- 1,000 in 1 million children will have a reaction (0.1%)
- 100 in 1 million children will have a reaction (0.01%)
- 10 in 1 million children will have a reaction (0.001%)
- 1 in 1 million children will have a reaction (0.0001%)

Severity

Please choose two VACCINE REACTION symptoms which you consider to be mild, two which you consider to be moderate, and two which you consider to be severe.

Please select an option from each of the drop-down menus

- Crying/irritability
- Loss of appetite
- Joint pain
- Low fever (<37.5°)
- Vomiting and diarrhoea
- Small pink rash on arms
- Blotchy red rash all over body
- High fever (>37.5°)
- Seizure or convulsion (fit) which is new or unusual for the child
- Anaphylaxis (swelling of body tissues causing breathing problems)
- Paralysis
- Brain damage

Duration

What do you consider the minimum and maximum lengths of a short-term, medium-term and long-term duration of a VACCINE REACTION in your child?

Please select an option from the drop-down menus for each one

- < 5 minutes
- 5 minutes

- 30 minutes
- 1 hour
- 24 hours
- 48 hours
- 1 week
- 1 month
- 1 year
- Lifelong

NB: These example questions all relate to vaccine reaction, corresponding questions for disease episode were identical except all references to vaccine reaction were replaced with appropriate reference to disease episode. For severity questions, two drop-down menus were provided, with identical response options in each one, but different menu headings ('Symptom 1' and 'Symptom 2'). For duration questions, three drop-down menus were provided, with identical response options in each one, but different menu headings ('short-term', 'medium-term', and 'long-term'). Demographics were assessed in this study exactly as they were assessed in the MMR questionnaires (Chapter 4).

Figure 11.15: Experimental model study invitation to participate

Title: Survey on immunisation decision-making: Parents of children aged 5-7 years required

Dear Parents,

We are running a study to find out exactly how parents make decisions about immunisations for their children. It is important to know what information parents use, and how they use it, to ensure that information is made available in an appropriate way.

We are asking parents of 5-7 year-olds on a number of online forums to complete a short questionnaire, which takes about twenty minutes to complete. In total about 250 parents will complete this questionnaire.

The questionnaire asks you to read a number of pieces of information about a hypothetical (not real) vaccine and disease, then to state how likely you would be to accept that vaccine for your child, and how that decision makes you feel. We will analyse responses to find out which bits of information are most important, which will enable GPs and nurses provide the right information to help parents make their decisions with less anxiety and uncertainty.

When you complete the questionnaire you can enter a prize draw to win a voucher for the shop of your choice. There are three prizes in this draw:

First prize: £100 shopping voucher
Second prize: £50 shopping voucher
Third prize: £25 shopping voucher

The questionnaire is completely confidential. It is run by a team at Imperial College London, is funded by the Health Protection Agency, and has received full ethical approval (<<ICREC ref to follow>>)

The questionnaire is available at: www.decidestudy.co.uk.

If you have any questions about this study, please contact Katrina Brown, study co-ordinator:

Telephone: 020 7594 3062
Email: Katrina.Brown@imperial.ac.uk

Thank you in advance for your help with this study!

NB: This invitation was posted on discussion forums on a number of parenting websites. A modified version, including information on returning a hard copy of the questionnaire by post, was sent to parents recruited through schools.

Figure 11.16: Information sheet for experimental model study

Why have I been invited to take part in this study?

Parents of children in the first three years of primary school (Reception, Year 1 and Year 2) will be invited to take part in this study via online groups and a number of schools. We need 250 parents, from across the UK and Republic of Ireland, to participate.

Do I have to take part in this study?

No. It is completely up to you to decide whether you want to take part. If you decide not to take part, it will not affect your child's schooling or health care. If you decide to take part and then change your mind, you can stop taking part in the study at any time without giving a reason, just by contacting us.

What will happen if I take part?

Taking part in this study just involves completing this online survey, which will take about 15 minutes.

The survey asks questions about a hypothetical (not real) illness and vaccine. It also asks questions about you and your family, and your real-life immunisation views and behaviour.

You may feel some questions are quite personal – for example, we ask about ethnicity and income - but you are free to leave these questions blank if you wish.

You can speak to a researcher about the study before you complete the survey if you would like.

On the last page of the survey you can enter a prize draw to win a voucher (£100, £50, £25) for a shop of your choice. You can also receive results from the study.

If you would like to enter the draw or receive results, you will need to give us your contact details. We will only use these details for the prize draw and/or the results. You do not have to give us your contact details if you do not want to enter the prize draw or receive results.

After you complete the survey, we will only contact you again if you have agreed to this. You can contact us at any time after you have completed the survey.

I do not speak much English. Can I still take part?

Yes. We can send you a copy of all the study documents in your own language. Contact us to request this. We can arrange an interpreter for your call.

Is taking part confidential and anonymous?

Yes. We will only keep a record of your contact details if you ask to enter the draw or receive results from the study. Your contact details will be stored securely and separately from your survey responses. Only members of the research team will ever have access to your information. Your information will be stored in accordance with the Data Protection Act 1998 (DPA). Your child's school and teacher will not know whether you take part in the study.

Will everyone get the same survey?

No, we use several versions of the survey which are very slightly different from one another in terms of the information they contain about the hypothetical illness and vaccine. We will change the version

available online periodically. You need only complete one version of the survey.

How will the prize draw be done?

When we have received completed surveys from 250 parents, we will de-activate the online survey. We will then allow two weeks for parents recruited through schools to send back paper copies in the post. Then we will make the draw. A senior member of Imperial College academic staff (independent to the research team) will draw out the names of three survey completers, at random. The first drawn will win the £100 voucher, the second will win the £50 voucher, and the third will win the £25 voucher. If we cannot make contact with any winner within two weeks after the draw, we will draw another winner to take that person's prize.

If surveys are completed at the rate we expect, we should be making the draw around late July 2009

What are the possible benefits and risks of taking part in this study?

Taking part in this study may not be of any direct benefit to you, unless you are one of the three participants who win shopping vouchers in the prize draw. We do not believe that taking part in this study poses any risks to you.

What if there is a problem?

We do not expect that any part of this study will cause harm or worry for anyone taking part in it. Standard Imperial College procedures for potential compensation are in place for all participants.

What will happen after the study?

We hope that the results will help provide the right information to parents making immunisation decisions. The results will be published in journal articles and reported directly to GPs, practice nurses and policy makers at national conferences

We can send you a summary of the results of the study when they are ready. Tick the box at the end of the survey to request this.

You can also join our Parent Panel for further information on our immunisation decision-making research, if you would like. If you join the Panel, you will be updated regularly about our new research studies, and invited to participate in those that interest you. We will also hold events where you can meet the research team and other Panel members. All this is completely voluntary and you can leave the Panel at any time. Tick the box at the end of the survey if you would like to join the Parent Panel.

Who is organising and funding this study?

The study is organised and managed by researchers at Imperial College London. The study is funded by the Health Protection Agency. The study has been reviewed and approved by Imperial College Research Ethics Committee (Ref. ICREC 9_2_2).

If you have any questions about this study, please contact Katrina Brown, study co-ordinator:

Katrina.Brown@imperial.ac.uk, 020 7594 3062

Figure 11.17: Example questions from experimental model study questionnaire

Scenarios

ImmunoBUG would probably be **more serious and more likely**/no more or less serious or likely/**less serious and less likely** for your child than for other children. The clinic where your child will receive ImmunoVAX is **less than 5 minutes**/20-30 minutes/**more than 30 minutes** away, and convenient appointments are **usually**/**sometimes**/**rarely** available. On the day ImmunoVAX is due your child is **completely well**/**has a low fever (less than 38.5 degrees)**/**has a high fever (more than 38.5 degrees)**.

There is a **1 in 1 million (0.0001%)**/10,000 in 1 million (1%)/10,000 in 1 million (1%) chance that your child will have an adverse reaction to ImmunoVAX, typically causing **irritability and crying**/**high fevers (more than 38.5 degrees)**/**brain damage** for **24 hours**/**between 24 hours and 1 week (on-and-off)**/**the rest of his/her life**. **1 in 1 million (0.0001%)**/10,000 in 1 million (1%)/10,000 in 1 million (1%) children who are given ImmunoVAX go on to catch ImmunoBUG.

Your GP and the UK Immunisation Board (A Government body) advise all children should receive ImmunoVAX. Thousands of children have taken part in independent research into the vaccine.

Your family and friends **think you should accept**/**do not have any opinion about**/**think you should refuse** ImmunoVAX. Many of your friends **have given their child**/**are deciding whether to give their child**/**have not given their child** ImmunoVax. Newspaper and TV reports about ImmunoVAX are **positive**/**mixed**/**negative**.

There is a **100,000 in 1 million (10%)**/10,000 in 1 million (1%)/1000 in 1 million (0.1%) chance that your child will catch ImmunoBUG if they are not vaccinated against it. ImmunoBUG typically causes **brain damage**/**high fevers (more than 38.5 degrees)**/**loss of appetite** for **the rest of his/her life**/**between 48 hours and 1 month (on-and-off)**/**24-48 hours**.

Would you give your child ImmunoVax on the day it is due?

- Definitely not
- Probably not
- Maybe not
- Don't know
- Maybe yes
- Probably yes
- Definitely yes

Trust in providers/policy

These questions ask how you feel about immunisation in real life.

Tick one box for each statement to show how much you agree with the statement.

- Most vaccines currently given to children are safe
- Most vaccines currently given to children protect against disease

- Most diseases children are vaccinated for are serious
- Most diseases children are vaccinated for are common
- I trust immunisation advice from my GP/Practice Nurse
- I trust immunisation advice from NHS/Government
- I trust research into immunisation safety and effectiveness
- I have accepted every vaccine available for my children

Response options for all items:

- Not at all agree
- Moderately agree
- Somewhat agree
- Very much agree

Anxiety

These questions ask how you feel about life in general. We ask these questions to see how general personality factors affect the decisions you are making about the information sets.

Please answer these questions in relation to how you feel on a normal/typical day for you. Tick one box for each statement to show how much the statement applies to you.

- I feel calm
- I feel tense
- I feel upset
- I feel relaxed
- I feel content
- I feel worried

Response options for all items:

- Not at all
- Moderately
- Somewhat
- Very much

NB: In the example scenario, coloured text denotes manipulated elements. Each section of coloured text shows all three levels of manipulation for that element (**pro-vaccine/neutral/anti-vaccine**). Order of the five paragraphs was randomised in each scenario. In the questionnaire, each scenario paragraph contained only one of the three levels. Demographics were assessed in this study exactly as they were assessed in the MMR questionnaires (Chapter 4).

Figure 11.18: Risk communication methods study invitation to participate

Subject line: Immunisation decision-making study – how to present risk to parents

Dear parent,

You recently completed our survey about immunisation decision-making, in which you rated your likelihood of accepting a vaccine (ImmunoVAX) against a hypothetical illness (ImmunoBUG). At the end of that survey you ticked a box to join our “Parent Panel” – a group of parents which we invite to participate in our immunisation-related research. This email is to invite you to participate in our newest survey.

The purpose of this new survey is to find out the best way to present probabilities of illness and vaccine risk to parents making decisions about immunisation. The aim is to find the presentation format which maximises comprehension and satisfaction with decisions. We are using hypothetical scenarios to investigate this.

The survey is available here: <<LINK>>.

It takes about 5-10 minutes to complete the survey. If you have any questions about this survey, please contact me (Katrina.Brown@imperial.ac.uk; 020 7594 3062).

Thank you in advance for taking the time to participate our survey. Your contribution helps us to find the best way to support parents making immunisation decisions.

Yours faithfully,

Katrina Brown (study co-ordinator)

Figure 11.19: Information sheet for risk communication methods study

Why have I been invited to take part in this study?

Parents who completed our original survey about immunisation decisions will be invited to take part in this study. We need 50 parents, from across the UK and Republic of Ireland, to participate.

Do I have to take part in this study?

No. It is completely up to you to decide whether you want to take part. If you decide not to take part, it will not affect your child's health care. If you decide to take part and then change your mind, you can stop taking part in the study at any time without giving a reason, just by contacting us.

What will happen if I take part?

Taking part in this study just involves completing this online survey, which will take about 15 minutes. The survey presents information about a hypothetical (not real) illness and vaccine, and asks you whether you would accept the vaccine based on that information, and how you would feel about your decision. It also asks questions about you and your family, and your real-life immunisation views and behaviour.

You may feel some questions are quite personal – for example, we ask about ethnicity and income - but you are free to leave these questions blank if you wish.

You can speak to a researcher about the study before you complete the survey if you would like. On the last page of the survey you can tick a box to request results from this study.

If you would like to receive results, you will need to give us your contact details. We will only use these details to send you the results, and will not share them with any third parties. You do not have to give us your contact details if you do not want to receive results.

After you complete the survey, we will only contact you again if you have agreed to this. You can contact us at any time after you have completed the survey.

I do not speak much English. Can I still take part?

Yes. We can send you a copy of all the study documents in your own language. Contact us to request this. We can arrange an interpreter for your call.

Is taking part confidential and anonymous?

Yes. We will only keep a record of your contact details if you ask to receive results from the study. Your contact details will be stored securely and separately from your survey responses. Only members of the research team will ever have access to your information. Your information will be stored in accordance with the Data Protection Act 1998 (DPA).

What are the possible benefits and risks of taking part in this study?

Taking part in this study may not be of any direct benefit to you. We do not believe that taking part in this study poses any risks to you.

What if there is a problem?

We do not expect that any part of this study will cause harm or worry for anyone taking part in it. Standard Imperial College procedures for potential compensation are in place for all participants.

What will happen after the study?

We hope that the results will help inform plans to present information to parents making immunisation decisions in the best way. The results will be published in journal articles and reported directly to GPs, practice nurses and policy makers at national conferences

We can send you a summary of the results of the study when they are ready. Tick the box at the end of the survey to request this.

Who is organising and funding this study?

The study is organised and managed by researchers at Imperial College London. The study is funded by the Health Protection Agency. The study has been reviewed and approved by Imperial College Research Ethics Committee (Ref. ICREC 9_2_2).

If you have any questions about this study, please contact Katrina Brown, study co-ordinator:

Katrina.Brown@imperial.ac.uk / 020 7594 3062

NB: This information was provided on the first page of the online questionnaire.

Figure 11.20: Example questions from risk communication methods study questionnaire

Scenarios

ImmunoBUG (the illness) causes high fevers (more than 38.5 degrees) on-and-off for between 48 hours and 1 month. ImmunoVAX (the vaccine) reaction causes high fevers (more than 38.5 degrees) on-and-off for between 24 hours and 1 week.

- 0.0001% (99.9999%)/1% (99%)/10% (90%) of vaccinated children have a reaction (no reaction) to ImmunoVAX
- 10% (90%)/1% (99%)/0.1% (99.9%) of unvaccinated children do not catch (catch) ImmunoBUG

Would you give your child ImmunoVAX?

- Definitely not
- Probably not
- Maybe not
- Don't know
- Maybe yes
- Probably yes
- Definitely yes

How sure are you about this decision?

- Rate how sure you are on a scale of 1 to 7, where 1 = Extremely unsure, and 7 = Extremely sure

How worried/relaxed are you about this decision?

- Rate how worried/relaxed you are on a scale of 1 to 7, where 1 = Extremely relaxed, and 7 = Extremely worried

How easy was it to understand the probabilities in this question?

- Rate how easy it was on a scale of 1 to 10, where 1 = Extremely difficult, and 10 = Extremely easy

NB: In the example scenario, coloured text denotes manipulated elements. Each section of coloured text shows all three levels of manipulation for that element (pro-vaccine/neutral/anti-vaccine). Material in brackets denotes the gain-framed equivalent of each manipulation. Examples of the graphics conditions are shown in Chapter 8.

