

Parental Perceptions of Childhood Immunisation in the Context of the MMR Controversy

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Abstract

Background-Although immunisation against infectious diseases is an important aspect of public health policy and has played a significant role in controlling the threat of many once-common diseases, since the late 1990s it has been the focus of controversy. Much of this was fuelled by the publication in the *Lancet* of a paper based on a case series of 12 children. In this paper Wakefield and colleagues raised the possibility of a link between the measles, mumps, and rubella vaccine (MMR) and autism and bowel disease. Despite the fact that Wakefield's study has received little support from the scientific community these assertions have led to a decline in MMR uptake. Since then, few studies have examined parents' understandings, attitudes and experiences of childhood infectious diseases or of childhood immunisation. This qualitative study examines how parents have conceptualised the MMR controversy and offers an assessment of parents' perceptions of vaccine-preventable diseases and childhood immunisation.

Methods-Eighteen focus groups were conducted in central Scotland between November 2002 and March 2003, with a diverse range of parents to ensure maximum variation in terms of age, socio-economic circumstances, likely views about vaccination and family circumstances. Four focus groups were conducted with parents who were anticipated to have a particular interest in the debate: two groups with parents who had autistic children, and two with parents whose child had recently had a compromised immune system following chemotherapy.

Findings-There are some potentially serious misunderstandings and gaps in knowledge about many of the diseases, which generally led to a diminished sense of urgency for vaccination. Parents deciding about MMR vaccination have to balance the perceived risk of disease against the perceived risk of MMR, and the perceived ability of their child's immune systems to cope with the challenge of vaccines, or to fight the disease. Parents often questioned the safety of combining several antigens into one vaccine, as they were concerned it could be too potent for their child's immune system and could potentially



cause long-term damage. In some circumstances parents preferred to withhold MMR vaccination because it was easier for them to live with the risk of their child naturally contracting one of the diseases than with the risk of causing their child permanent damage as they perceived other parents may have unwittingly done.

Implications- There is a need for a campaign that concentrates on offering parents factual information about the risks, symptoms, potential complications and severity of some of the diseases included in the Childhood Immunisation Programme. However, it is recognised that simply targeting parents with the facts about diseases will not necessarily persuade them to immunise and that culture, economic factors, social and political values, trust, risk perception and world views are all important in influencing parents' attitudes towards immunisation. Nevertheless, it seems crucial to provide parents with accurate information so that they can assess the importance and relevance of current immunisation policy at a time when many are questioning whether children are becoming over-immunised against diseases that appear mild and of no real threat to their child's health. Parents' high level of understanding of the risks of meningococcal disease suggests that the high profile Men C vaccination campaigns may be a successful model to follow in communicating the risks of other vaccine-preventable diseases. Because of the complex role of personal and family experience in the acceptance or rejection of risk information about ill-health, it may be that these issues should also be explicitly addressed in vaccination campaigns. Further, whilst individual choice is important, so too are the community benefits of immunisation, and it may be time for such a campaign to embrace this aspect of immunisation more comprehensively and to recognise the public health contribution of immunisation more openly.

There is also a need for further research to investigate how parents caring for autistic children have been affected by the debate and to reassure parents based on sound evidence that giving these vaccines in a combined form is safe. Indeed, as the new pentavalent vaccine (DtaP/IPV/Hib) is introduced into the programme, it is crucial that these concerns about immune overload are taken into account to reassure parents in their wider reappraisal of vaccine risk.

Declaration

I declare that, except where acknowledged, all the work has been undertaken by myself.

A handwritten signature in black ink, appearing to read 'S. Hilton', written in a cursive style.

Shona M. Hilton M.Sc. B.Sc. RM. RGN

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Table of contents

Abstract.....1

Acknowledgements.....4

List of figures and appendices8

Chapter One: The MMR controversy a new era in childhood immunisation?9

1.1 Introduction... ..9

1.2 The literature review... ..10

1.3 Vaccine safety: speculation, scepticism and scientific evidence... ..12

1.3.1 A short history of vaccine controversy... ..13

1.3.2 The pertussis scare15

1.3.3 Events leading up to the MMR controversy... ..16

1.3.4 A review of the scientific evidence that sparked the controversy... ..18

1.3.5 Studies finding no support for the MMR, autism association... ..21

1.3.6 Support for the MMR, autism association.....24

1.3.7 MMR vaccination and adverse reactions.....25

1.3.8 Summary of the evidence.....26

1.4 Part Two: The public response: impact on MMR uptake27

1.4.1 Vaccine decision-making; the factors known to influence uptake.....29

1.4.2 Vaccination decision-making: seeking the best balance of risks and benefits.....32

1.4.3 Omission bias and vaccine decision-making.....33

1.4.4 Parents’ attitudes to the MMR controversy and to vaccination.....35

1.4.5 Are parents reappraising vaccine risk?.....37

1.4.6 Where are we now? Outstanding issues.....39

Chapter Two: Methodology43

2.1 Choice of study design... ..43

2.1.1 Why a qualitative perspective?.....43

2.2 The Pilot study... ..45

2.2.1 Sample selection.....45

2.2.2 Timing of the pilot study.....46

2.2.3 Main lessons learnt from the pilot study.....47

2.3 The Main study... ..47

2.3.1 Introduction to focus groups47

2.3.2 Why use focus groups?.....48

2.3.3 Developing a sampling strategy.....49

2.3.4 Sample selection for the main study.....50

2.3.5 Sample selection: limitations.....51

2.4 Group study design... ..53

2.4.1 Sample size: determining the number of groups..... 53

2.4.2 Determining the group size54

2.4.3 Determining the group composition.....55

2.4.4 Determining the level of group structure.....57

2.5 Ethical considerations... ..58

2.5.1 Informed consent.....58

2.5.2 Confidentiality.....59

2.6 Characteristics of participants... ..59

2.7 Conducting the study... ..61

2.7.1 Timing of the main study.....61

2.7.2 Access and recruitment.....61

2.7.3 Recruitment difficulties.....63

2.7.4	<i>Recording, transcribing and overcoming recording difficulties.....</i>	64
2.7.5	<i>Facilitating the groups.....</i>	66
2.7.6	<i>Facilitator skills, persona and reflexivity.....</i>	67
2.8	Focus group analysis	69
2.8.1	<i>Which analytical approach?.....</i>	69
2.8.2	<i>Group analysis: balancing the group picture against the voice of the individuals.....</i>	70
2.8.3	<i>Organising and coding the data using QRS Nvivo 2.0.....</i>	72
2.8.4	<i>Describing, interpreting and reporting the data.....</i>	74
 Chapter Three: Understanding, experiences and beliefs about childhood infectious diseases		76
3.1	Summary of literature on perceptions about childhood infectious diseases	76
3.2	Participants' accounts of vaccine-preventable diseases: From major to minor	79
3.3	Diseases considered: 'A major threat'	79
3.3.1	<i>Meningococcal disease group C: A tangible threat 'a killer'</i>	79
3.3.2	<i>'Rubella: is that the same thing as German measles?'</i>	87
3.4	Diseases considered: 'less of a major threat'	92
3.4.1	<i>Measles: 'itchy spots' and 'calamine lotion'</i>	92
3.4.2	<i>Whooping cough (pertussis): '...it hasn't done me any harm, that's the thing'.....</i>	98
3.5	Diseases considered: 'A minor threat'	101
3.5.1	<i>Mumps: 'bloated, big baw face, wi sore balls'</i>	101
3.5.2	<i>'Tetanus: is that like rabies'</i>	104
3.5.3	<i>Haemophilus Influenza type b: '...that one doesn't ring a bell'</i>	109
3.6	Diseases considered: 'No longer a threat'	112
3.6.1	<i>Diphtheria: 'Is it something out of the jungle?' 'Something that happened a long time ago?'</i>	112
3.6.2	<i>Polio: 'Cripples', 'calipers', and 'sugar lumps'</i>	115
3.7	Discussion of the findings	119
 Chapter Four: Parents' perceptions of the MMR controversy		125
4.1	Summary of literature on the MMR controversy	125
4.2	Perceptions of the MMR controversy: 'Who's got my wee boy's best interests at heart?'	128
4.2.1	<i>Participants' understanding of the evidence about the safety of the MMR vaccine: smoke without fire</i>	130
4.2.2	<i>Perceptions about the media's role in reporting the evidence.....</i>	135
4.2.3	<i>Perceptions about politicians and public health officials</i>	139
4.2.4	<i>Perceptions about Dr Wakefield and other medical and health care professionals</i>	144
4.3	Discussion of the findings	148
 Chapter Five: Parents' experiences of MMR decision-making		154
5.1	Summary of the literature on vaccine decision-making	154
5.2	Making the decision	158
5.2.1	<i>Weighing up the risks/benefits associated with diseases: assessing which diseases need immunising against.....</i>	159
5.2.2	<i>Assessing the risks and benefits associated with vaccines: fears of long-term damage..</i>	164
5.2.3	<i>Conceptualising immune overload.....</i>	168
5.2.4	<i>Fears about the MMR vaccine rendering the immune system unable to respond to other infections.....</i>	172
5.2.5	<i>Fears about vaccines not working, or not offering lasting protection.....</i>	174
5.2.6	<i>Immune vulnerability: assessing their child's immune system's ability to respond to the challenge of vaccination, or fight the disease.....</i>	176
5.2.7	<i>Deciding about MMR: disruptions to usual vaccine decision-making behaviour.....</i>	178

5.3 Discussion of the findings	182
Chapter Six: The MMR controversy from the perspectives of parents caring for autistic children and of immuno-compromised children	188
6.1 Introduction	188
6.2 The MMR controversy from the perspectives of parents caring for autistic children	189
6.2.1 <i>Overloading a deficient immune system and subsequent feelings of guilt.....</i>	189
6.2.2 <i>The MMR autism story: feeling guilt and trying to get answers.....</i>	193
6.2.3 <i>Views on the association between autism and bowel problems.....</i>	196
6.3 Discussion of the findings	198
6.4 The MMR controversy from the perspectives of parents caring for immuno-compromised children	199
6.4.1 <i>Views on the MMR controversy.....</i>	201
6.4.2 <i>The experience of protecting immuno-compromised children from contracting diseases.....</i>	204
6.4.3 <i>The challenge of re-integrating immuno-compromised children back into society.....</i>	206
6.4.4 <i>Educating people about the needs of immuno-compromised children.....</i>	209
6.5 Discussion of the findings	210
6.6 Conclusion	212
Chapter Seven: Conclusion	213
7.1 Part One: Reflections on the study	213
7.2 Part Two: Answering the study's research questions	215
7.2.1 <i>What are parents' knowledge, understanding and beliefs about childhood infectious diseases, and how do their experiences of disease affect their evaluations in the importance of preventing these diseases?</i>	215
7.2.2 <i>What are parents' views on mass childhood immunisation and of the vaccines included in the Childhood Immunisation Programme in the light of the MMR controversy?.....</i>	219
7.2.3 <i>What are parents' perceptions about the current MMR controversy and how do these perceptions translate into the parental decision-making process about whether to immunise, or not?.....</i>	222
7.2.3.1 Parents' perceptions about the MMR controversy	223
7.2.3.2 Parents caring for autistic children: perceptions about the MMR controversy	225
7.2.3.3 Parents caring for immuno-compromised children: perceptions about the MMR controversy	227
7.2.3.4 Parents' experiences of MMR decision-making and views on MMR	227
7.3 Part Three: Implications and recommendations	230
7.3.1 <i>Implications for policy</i>	230
7.3.2 <i>Implications for practice</i>	233
7.3.3 <i>Implications for future research</i>	235
7.3.4 <i>Dissemination of the findings</i>	236
Bibliography	237

List of figures

Figure 1.1: ‘The Cow Pock or the wonderful effect of the new inoculation’.

Figure 1.2: Graph showing MMR coverage in the UK for children aged 2 years, for each quarter since 1995.

Figure 2.1: Graph showing the areas in which participants lived.

Figure 3.1: Picture of Iron Lung machines.

Appendices

Appendix A1/A2: Tabulated summary of studies.

Appendix B: Childhood Immunisation Programme in December 2004.

Appendix C: Timeline showing major changes to the Childhood Immunisation Programme between 1940 and 2004.

Appendix D: Timeline showing relationship between key events in the MMR controversy and PhD study.

Appendix E: Topic guide.

Appendix F: Information sheet.

Appendix G: Consent form.

Appendix H: Characteristics of focus groups.

Appendix I: Cover letters given to potential participants.

Appendix J: Pre-focus group questionnaire.

Appendix K: Descriptions of the vaccine-preventable diseases included in the Childhood Immunisation Programme.

Appendix L: Childhood Immunisation Programme in December 2001.

Appendix M: Topic Guide used for focus groups with parents of autistic children.

Appendix N: Topic Guide used for focus groups with parents of immuno-compromised children.

Chapter One: The MMR controversy a new era in childhood immunisation?

1.1 Introduction

In Britain in October 1988, the combined measles, mumps, and rubella (MMR) vaccine was introduced into the routine childhood immunisation programme. Its introduction replaced the monocomponent measles vaccine in order to improve measles and rubella vaccination uptake, about which there had been widespread concern (Campbell, 1983; Miller and Miller, 1986; Walker et al., 1988). It also offered the opportunity to introduce protection against mumps into the programme for the first time in order to reduce the incidence of viral meningitis, a serious complication of mumps. By the early 1990s, MMR coverage for 2-year-old children exceeded 90% nationally and cases of measles fell to historically low levels (Hanratty et al., 2000).

However, just as rates of measles notification were reaching an all time low, speculation about the safety of the MMR vaccine began to emerge. In August 1997, Dr Andrew Wakefield, a consultant gastro-enterologist, and colleagues at the Royal Free Hospital, London, submitted a paper to *The Lancet* postulating the existence of a link between the MMR vaccine, bowel disease and autism (Wakefield et al., 1998). In 1995, *The Lancet* had published one of Wakefield and colleagues' earlier papers that had later been criticised in the *British Medical Journal* as 'flawed' (Metcalf, 1998). Nevertheless, after being peer reviewed and discussed by *The Lancet*'s editorial committee, the controversial paper was published in *The Lancet* on 28th of February 1998. On the day of publication, The Royal Free Hospital organised a press conference in which Dr Wakefield and four co-authors fielded questions and explained their findings. However, at the conference a divide in opinion became evident as Dr Wakefield suggested that there was a case for splitting the MMR vaccine into its three separate component parts, each given a year apart. Perhaps predictably, the paper and conference sparked near hysteria in the press. The following day a *Guardian* headline warned: 'Alert over child jabs' (Boseley, 1998). Unlike many other health scares that are short-lived, stories about the safety of the MMR

vaccine have made headline news over many years, and in common with other long-running public health scares the debate has been given a name by the popular media; in this case ‘The MMR Controversy’. It is against this background that this thesis aims to examine how parents have conceptualised the MMR controversy and to explore parental immunisation behaviours, in order to learn lessons that may assist future policy on childhood immunisation.

1.2 The literature review

This introductory chapter aims to provide the context for my study by critically examining the scientific evidence and events leading up to, and following, the publication of Dr Wakefield and colleagues’ paper. Studies reviewed in this chapter are tabulated in Appendix A1 and A2. The chapter is divided into two parts. The first part considers the scientific evidence, and the second part considers the impact the controversy has had on parents and their children. The review of the scientific evidence concentrates on the causal association postulated between the MMR vaccine, bowel disease and autism. Central to this critique are the studies of Dr Wakefield and colleagues at the Royal Free Hospital, and the studies that contest, or support, their theories. In order to develop an understanding of how the controversy has affected parents, the second part of the chapter reviews studies that have identified factors that influence vaccine decision-making behaviours, particularly when a vaccine is perceived by the public to carry a risk.

The level of coverage afforded to the MMR controversy means that this review inevitably provides a selection rather than exhaustive review of the studies. However, in order to be more systematic about the selection of these studies for the review, inclusion and exclusion criteria were developed. This process involved two stages. Firstly, a broad search on the Web of Knowledge and Medline databases was conducted using keywords and keyword combinations in their titles and abstracts from 1988 when the MMR vaccine was first introduced into the Childhood Immunisation Programme. Search keywords included: immunisation; childhood immunisation; vaccination; childhood immunisation programme; childhood infectious diseases; vaccine preventable diseases;

measles, mumps and rubella; MMR; vaccines; vaccine development; history and immunisation; vaccine decision-making; immunisation behaviours; parents and immunisation; attitudes and immunisation; herd immunity; and population immunity. This process produced a large number of studies. These papers were then assessed to determine whether they were applicable to the MMR debate and whether they should be included for a more thorough appraisal. At this stage the main criterion for exclusion was if they were irrelevant to the topic of childhood immunisation and MMR vaccination. For instance, even though there is a vast amount of literature on autism and inflammatory bowel disease, it was decided most of this was outwith the scope of this review. Similarly, literature examining the public's reactions to other high profile public health debates was only included if a parallel existed with the current controversy over MMR safety. As I became more familiar with the literature I refined my search terms and searched databases using the names of high profile authors in the MMR debate to find any articles or paper written by them. This search included the items (or words) Andrew Wakefield; Elizabeth Miller; Brent Taylor; David Elliman; Helen Bedford; and the Inflammatory Bowel Disease Study Group. Some of the older papers such as Asch's work on omission bias (1994), and Bogardus (1926), Merton and Kendall's (1946) focussed interview work were traced through the bibliographies of more recently published papers. Although the debate about the safety of the MMR vaccine is not confined to the shores of the United Kingdom, how parents conceptualise the debate here is likely to be shaped by political events, new stories and their experiences. Therefore, many of the papers that were assessed as being eligible for further appraisal were studies conducted in the United Kingdom. However, international studies (particularly those which focused on the evidence of a link between MMR, autism and bowel disease) were also included if they had had a direct impact on the debate about the safety of the MMR vaccine, or added something new to the wider debate on childhood immunisation.

The second stage in the process was to carry out a more detailed appraisal of each paper to assess its methodology and to decide whether it should be included in the final literature review. This appraisal involved assessing the selection and recruitment of the sample, the methods used and whether there was evidence of selection or measurement

bias, or if there was confounding or bias interpretation of the conclusions. The final selection in the review included a mix of large well-designed epidemiological studies given some prominence by the scientific community and small, in-depth qualitative studies offering important insights into parents' views on childhood immunisation. There was some variation in the quality of the studies included in the review, and attempts have been made to convey this in the chapter. In order to keep abreast of any new developments in the MMR debate, searches were repeated every three months; however, the newsworthy nature of this topic often meant that newspapers were the first to publish articles about newly published papers and this also proved a useful source.

1.3 Part One: Vaccine safety: speculation, scepticism and scientific evidence

Since the inception of immunisation in the late 19th century, it has widely been accepted that mass immunisation "has probably saved more lives than any other public health intervention, apart from the provision of clean water" (Bedford and Elliman, 2000 p. 240). Indeed, Stone (1995, p. 111) considers that without immunisation we in the Western world: "...would still be languishing in a 19th century nightmare of rampant epidemics of diphtheria, smallpox, tuberculosis and their ilk". This stance is not shared by McKeown (1976) who considers that, while immunisation has played a late and small role in the decline in mortality and morbidity from diseases, the dramatic improvements in health and decline in most infectious diseases during the 20th century have been largely due to improvements in housing, hygiene, sanitation and nutrition conditions. More recently Szreter (2002) has revisited McKeown's theory and suggested that this interpretation has failed to recognise the historical importance of an accompanying redistributive social philosophy and practical policies which characterised public health during its 19th century origins. Szreter argues that:

...political and ideological divisions and conflict and their subsequent resolution in favour of the health interests of the working-class majorities were key factors in determining whether industrialisation exerted a positive or negative net effect on population health (p. 75).

Although there is some debate about the degree to which immunisation can claim responsibility for the decline in diseases in the past, it seems likely that new developments in vaccines and vaccine delivery technology will fundamentally change how diseases are prevented and treated in the future. It is anticipated that over the coming years new vaccines will become available for use to treat and prevent a range of non-infectious diseases, including some cancers, diabetes, and Alzheimer's disease, and to treat autoimmune diseases and allergic disorders (Lambert and Siegrist, 1997). The progress in making vaccines aimed at controlling infectious diseases is equally impressive. For children living in developing countries work is underway to produce vaccines that protect against malaria, tuberculosis and diarrhoeal diseases (Lambert and Siegrist, 1997). For children living in industrialised countries new vaccines are being developed to reduce further the incidence of meningitis and severe lower respiratory infections (Poland et al., 2002) .

However, the paradox of the success of mass immunisation is that the huge decline in mortality and morbidity from infectious diseases in industrialised countries has meant that parents have less experience of those diseases (Bedford and Elliman, 2000). Perhaps for this reason, doubts about the efficacy, safety and necessity of childhood vaccinations have been brought into sharp focus. The most recent example of this phenomenon is the MMR vaccine, although controversy about the safety of vaccines is not an entirely new phenomenon; indeed opposition to mass childhood vaccination is a world-wide phenomenon and is as old as the vaccines themselves.

1.3.1. A short history of vaccine controversy

Perhaps unsurprisingly, speculation and scepticism surrounded the inception of vaccination. It is documented that in the mid-1770s, a Dorset farmer named Benjamin Jesty observed that the cowpox infection appeared to protect his milkmaids against the smallpox disease. Convinced that he could protect his family from the ravages of smallpox, Jesty transferred matter from a cowpox pustule on a cow onto a needle and from there to a scratch made on the arm of each member of his family (Horton, 1995). These crude inoculations were the first recorded (Horton, 1992).

Two decades later, in 1796, Dr Edward Jenner made the same observation during an epidemic of smallpox and published his findings in an article entitled: 'An inquiry into the causes and effects of the variolae vaccine'. He called his idea 'vaccination,' from the word 'vaccinia' which is Latin for cowpox (Henderson, 1994). Perhaps predictably this pioneering discovery was met with some degree of scepticism and opposition, and stories about its adverse side effects flourished. According to Beggs and Nicoll (1994) some extraordinary side effects were described: "A child ran upon all fours like a beast, bellowing like a cow, and butting with its head like a bull" (p. 1073). The artist James Gillray drew a cartoon showing cows coming out of various parts of people's bodies after they had been vaccinated, to illustrate some of the myths being circulated by opponents of Jenner's work (Figure 1.1).



Figure 1.1: 'The Cow Pock or the wonderful effect of the new inoculation' (1801). Photo, Wellcome Historical Museum.

Today, opposition to vaccination in industrialised countries mainly comes from groups of parents, or from individual spokespersons (Leask and McIntyre, 2003). Leask and McIntyre (2003) considered the case of Dr Viera Scheibner, a retired micropalaeontologist, with no formal training in medicine, who tours the world claiming that vaccines are ineffective and harmful to children, causing illnesses such as cancer and asthma. They highlight the fact that health professionals are concerned that these self-appointed and often non-medical spokespersons misrepresent the evidence on vaccine safety, potentially damaging public confidence in immunisation. However, perhaps such fears overstate the general appeal that such fringe spokespersons have on the public's trust in vaccination. For in recent years, vaccine controversies such as that of the pertussis vaccine and the MMR vaccine have stemmed from ordinary parents, experienced doctors, and respected academics whose public appeal may be greater.

1.3.2 *The pertussis scare*

In the case of the pertussis vaccine, speculation about its safety occurred within years of its introduction into the childhood immunisation programme in the early 1950s. Although the Medical Research Council's (1959) whooping cough trials found the vaccines to be safe, some adverse effects were subsequently reported. Anderson and Morris (1950) suggested a link between encephalopathy and the pertussis vaccine. Similarly, Miller and Stanton (1954) and later Berg (1958) reported serious neurological complications occurring in children following vaccination. According to Griffith (1981) these early reports in scientific journals had no perceptible effect on immunisation coverage in the UK, and received only sparse media interest. Griffith attributes this lack of negative impact to the fact that the Ministry of Health actively pursued a policy of encouraging parents to have their children immunised. However, in 1974, Kulenkampff and colleagues published a report postulating a link between the pertussis vaccine and neurological complications that was the subject of a television documentary (Griffith, 1981; Kulenkampff et al. 1974). The documentary featured two children severely brain-damaged following vaccination with the pertussis vaccine. The visible suffering of these children, the emotional turmoil faced by their parents and the split in medical opinion on the risks of neurological damage from the vaccine, fuelled media speculation and the

public lost confidence in the vaccine (Harding, 1985). By the late 1970s, the pertussis debate was exacerbated further by the claim from a prominent public health academic, Professor Gordon Stewart (University of Glasgow), that the protective effect of the vaccine was marginal because the epidemiology of pertussis had changed. He suggested that the disease had become less frequent, less severe, and therefore that the vaccine was largely ineffective (Stewart, 1977). In spite of the Ministry of Health's attempts to reassure the public that the vaccine was safe, the loss of confidence in the vaccine led large numbers of parents to refuse it. Church (1979) describes the effect on uptake levels of the vaccine as being instant and dramatic. McKinnon (1979), a specialist in community medicine, recalled:

...within days health visitors were reporting that mothers, having seen the television programme, were raising queries about whooping cough immunisation, and a significant number, who had brought their babies for immunisation appointments, were withdrawing previously given consent for whooping cough vaccine (p. 199).

Over the following years Koplan and Hinman (1987) reported that the vaccine coverage levels fell from approximately 80% to a low of approximately 30%. The decreased coverage of the vaccine in the UK led to the development of a large pool of susceptible people. The fall in uptake in Scotland resulted in four epidemics between 1977 and 1991, accounting for an estimated 100,000 notifications and up to 75 deaths (Health Education Board for Scotland (HEBS), and Scottish Centre for Infection and Environmental Health, (SCIEH), 2001). Nicoll et al. (1998) suggest a similar picture in England and Wales, estimating over 300,000 notifications and at least 70 deaths. According to Gangarosa et al. (1998) confidence in the vaccine was slowly restored by the publication of a national reassessment of the vaccine carried out by Salisbury (1992), and by the introduction of financial incentives to reward general practitioners who achieved government targets.

1.3.3 Events leading up to the MMR controversy

As with the pertussis vaccine, speculation about the safety of the MMR vaccine was also first presented in a television documentary. This programme aired in Denmark in 1993

and featured a mother of twins, one of whom had had the MMR vaccine and developed autism soon after. She believed that the MMR vaccine was the cause of her child's autism (HEBS and SCIEH, 2001). Whilst at that time in the UK no scientist had publicly suggested such an association, Dr Andrew Wakefield and other researchers collectively known as the Inflammatory Bowel Disease Study Group (IBDSG) were already theorising about a link between the measles virus and Crohn's disease.

In 1990, an hypothesis attracted the attentions of Dr Wakefield and colleagues of the IBDSG. Thayer (1990) questioned whether the aetiology of inflammatory bowel diseases (ulcerative colitis and Crohn's disease) could be attributed to a transmissible agent such as a virus. By 1993, Dr Wakefield and colleagues published a paper suggesting there was a resemblance between the Koplik's spots that are present on the skin during the early stages of measles, and the ulcers seen in Crohn's disease (Wakefield et al., 1993). Over the next few years the IBDSG, working with Swedish colleagues, reported a positive association between perinatal exposure to measles and the development of Crohn's disease in children (Ekbom et al., 1994; Ekbom et al., 1996). However, two larger epidemiological studies investigating a possible link between Crohn's disease and mothers infected with measles during pregnancy both failed to find any children who went on to develop Crohn's disease as a result of the measles infection. Therefore both studies concluded that no link existed between perinatal exposure to measles and the development of Crohn's disease (Jones et al., 1997; Nielsen et al., 1998).

Undeterred, Wakefield and colleagues expanded their theory in a paper published in the *Lancet* in 1995. From their original theory that wild measles virus could be a risk factor for the development of Crohn's disease, they raised the possibility that even the weakened (attenuated) live measles vaccine used in vaccines may also be a risk factor in the development of Crohn's disease (Thompson et al., 1995). They examined the impact of measles vaccination upon the incidence of Crohn's disease by comparing a cohort of children (n=3545) vaccinated with the single vaccine in 1964 as part of a randomised trial, with a group of unvaccinated children (n=11 407) recruited in 1958. From this they believed that they had found an association between measles vaccination, Crohn's disease

and ulcerative colitis and concluded that the measles virus had a role in the aetiology of inflammatory bowel disease. However, the researchers selected the cohorts using different methods, at different times, and from different areas, and did not adequately control for confounding factors. Indeed, in view of the study's lack of consistency and rigor Metcalf's (1998) stated in a critique of Wakefield and colleagues' study that:

...the theory of measles as a causative factor in the development of Crohn's disease therefore cannot be upheld and should remind us of the need for rigorous methodological review when causal associations are proposed (p. 167).

In an attempt to replicate Wakefield and colleagues' findings (Thompson et al., 1995), Feeney and colleagues at the East Dorset Gastroenterology Group conducted a case control study to compare measles vaccination rates in 140 patients with inflammatory bowel disease (83 with Crohn's disease) and 280 matched controls (1997). However, they found no association and concluded: "the cause of inflammatory bowel disease remains to be established" (p. 764). Likewise, a later study carried out by Davis and Bohlke (2001) did not support the theory. Indeed, a letter published in *The Lancet*, in 1995, commenting on a study that investigated trends in incidence of Crohn's disease, suggested that the rise in incidence started before 1968 when the monocomponent measles vaccine was introduced into the programme, thus shedding further doubt on the group's theory (Hermon-Taylor et al., 1995).

It is against this background that in 1998 *The Lancet* published Wakefield and colleagues' paper: 'Ileal-lymphoid nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children,' (Wakefield et al., 1998). In order to theorise about the role Wakefield and colleagues have played in what has become known as the 'MMR controversy' it is necessary to critically examine the paper that is at the centre of the debate.

1.3.4 A review of the scientific evidence that sparked the controversy

The hypothesis posed by Wakefield and colleagues was that the MMR vaccine causes inflammation of the gut which makes it more permeable and thereby to permit peptides to

leak out; in turn these toxins affect the brain causing serious developmental disorders (including autism). Wakefield and colleagues suggested a causal association between bowel disease, developmental regression and the MMR vaccine. In an attempt to infer causation between the MMR vaccine, bowel disease and developmental regression, Wakefield and colleagues describe the findings from their study based on a case series of 12 children with developmental and bowel problems. Published alongside the paper was a critical commentary of the study from respected specialists in the field (Chen and De Stefano., 1998). They reviewed the evidence to consider how well the features of the association reported by Wakefield and colleagues fit with criteria for causality, and warned that:

...because of inherent methodological limitations of epidemiological studies, biological plausibility, consistency, strength, and specificity of association must also be considered in inferring causation (p. 611).

In considering the biological plausibility of the findings from Wakefield's study, two problems can be identified. Firstly, although Wakefield reported finding viruses in the bowel tissues of children with inflammatory bowel disease, these findings have not been replicated by other investigators. In an attempt to reproduce Wakefield's findings, Afzal, et al. (1998) examined gut mucosal biopsies taken from 19 patients with inflammatory bowel disease. They concluded that even with the best available technology they had been unable to find vaccine viruses in the specimens taken from patients. The second problem relates to the biological plausibility. Serious vaccine reactions are usually characterised by specific laboratory or clinical findings. However, the non-specific nature of the symptoms described in the cases led Nicoll et al. (1998) to assert that the study is limited by the fact that no precise case definition is offered. In respect of this, it is of note that the sequence of events Wakefield postulates is that the MMR vaccine leads to inflammatory bowel disease, which results in toxins leaking out and causing neurological damage, and autism. However, Wakefield's study reports that the onset of behavioural symptoms occurred before the onset of bowel symptoms in almost all their

cases. This suggests that Wakefield's findings do not support the sequence of events he postulates.

Payne (1998) also noted that a weakness of the Wakefield study was that the sample was highly selected and suggested that a case control study would have reduced bias. According to Lee et al, (1998) attribution of causality requires (among other things) the use of patients and matched controls, and a sample size that is capable of detecting a statistically significant difference between the two groups. To reduce the risk of bias in the clinical assessments, investigators would have needed to be blinded to the children's clinical conditions. However, it is of note that in Wakefield's study there was no blinding of the investigators, no selection of patients with suitable matched controls, and a very small sample size (n=12). Indeed, following Wakefield and colleagues' earlier 1993 and 1995 publications, Nicoll et al. (1998) believed that patients would have been selectively referred to the Inflammatory Bowel Disease Study Group because of their research interest in MMR, inflammatory bowel disease, and autism, thus also introducing a strong selection bias.

Another problem with the study was the extent to which parents were able to accurately recall their child's developmental milestones. For example, in considering whether recall bias may have affected Wakefield's findings, Lee et al. (1998) suggest that developmental delay is likely to be detected slowly over a period of time, rather than on a particular day. However, according to Wakefield's study, in eight of the 12 children, either parents or the child's physician identified the MMR vaccine as the immediate precursor to the onset of behavioural problems. Furthermore, Wakefield et al. (1998) stated that in some cases children were as young as 12 months when they began displaying behavioural symptoms. However, Lee et al. (1998) suggest that autism is usually only diagnosed once a child is over the age of 18 months old, adding further doubts about how accurately events were being recalled. Furthermore, Wakefield and colleagues fail to acknowledge anywhere in their paper the possibility that the association between MMR and subsequent development of autism may be temporal rather than

causal. This criticism is based on the fact that the first dose of the MMR vaccine is commonly given when children are 12 to 15 months old, and autism is often detected after this time when children are around 18 months old. The temporal association between both these events means that MMR vaccination will often be given before autism first manifests itself. Le Page and Ainsworth (2001) suggest that by neglecting to acknowledge these facts the paper exaggerated the causal association between onset of behavioural symptoms and MMR vaccine. In consideration of this tenuous relationship, they state: “as persuasive as such cases might seem when looked at individually, they fall well within what would be expected by chance” (p. 8).

Flaws in the design of Wakefield’s study and questionable biological plausibility led Lee et al. (1998) to conclude that: “Wakefield’s study fails at every level to make a causal association” (p. 905). In an attempt to test Wakefield’s hypothesis, other researchers have been quick to try to replicate, contest or support their findings. Although the vast majority of studies have not supported Wakefield and colleagues’ research, there are a few studies that have. This review will now examine both sides of the argument.

1.3.5 Studies finding no support for the MMR/ autism association

Wakefield’s study has also largely been unsupported by other larger epidemiological studies. Several of these have examined whether there has been an increased incidence of autism in relation to the introduction of MMR. In the United Kingdom Taylor et al. (1999) conducted a well-designed epidemiological study to investigate trends in the incidence of autistic disorders before and after the introduction of MMR vaccine in October 1988. These investigators examined the immunisation records of 498 cases of autism, born between 1979 and 1998, to investigate whether there was any increase in the incidence of autistic disorders after the introduction of MMR vaccine in October 1988. They used a case series analysis method to test for clustering of onsets within defined post-vaccination periods. From this work they were unable to detect any change in the incidence of autistic disorders after the introduction of MMR and found no difference in the age at diagnosis of autism between vaccinated and unvaccinated children, or any

clustering of autism in the months following MMR vaccination. This led them to assert that they did not support the existence of a causal association between MMR vaccine and autism.

A second study was carried out in the United Kingdom using a time trend analysis to identify whether there were any changes in the diagnosis of autism recorded by general practitioners between 1988 and 1999 (Kaye et al., 2001). Using data from the UK's general practice database they identified 305 children aged 12 years or younger diagnosed with autism. They reported a marked increase in the incidence of autism among boys born between 1988 and 1993, but highlighted the fact that MMR uptake for successive annual birth cohorts remained consistently over 95%. This suggested that the MMR vaccine could not be responsible for causing the increase in autism as MMR uptake remained constant over the same time. However, they also stated that they were uncertain of the reasons for the marked increase in autism during this decade. In considering the unexplained rise in autism, Dr Fombonne, a specialist in the field of autism has suggested that one likely explanation may be that in recent years there have been changes to the classification, and diagnosis of autism (Fombonne, 2001). However, in a letter published in the British Medical Journal, Yazbak points out that the MMR vaccine was only introduced in 1988 and questions the validity of Kay's suggestion that MMR uptake remained consistently above 95% from its introduction in 1988 to 1999 (Yazbak 2001). Nevertheless, the rise in incidence of autism has not been confined to the UK, and Kaye's findings have been mirrored in other countries. For example, a Californian study compared the incidence of autism over time with MMR vaccine uptake rates (Dales et al., 2001). This study observed a marked and sustained increase in autism compared to a sustained level of MMR uptake. To investigate whether MMR vaccination is associated with an increase in autism Smeeth et al. (2004) conducted a study using the UK General Practice Research Database to identify people with autism who had first recorded diagnosis of autism between 1987 and 2001. They identified 1294 cases and 4469 controls, which they matched on age, sex, and general practice. They found that 1010 cases (78.1%) had MMR vaccination recorded before diagnosis, compared with

3671 controls (82.1%) before the age at which their matched case was diagnosed. This led them to conclude that MMR vaccination is not associated with an increase in autism.

Researchers have also examined whether there is any evidence of a new variant autism which may be induced by MMR. For example, Fombonne and Chakrabarti (2001) postulated that if a new 'autistic enterocolitis' syndrome exists, regression in the development of children with autism would become more common in MMR-vaccinated children. Their retrospective analysis of cohort data compared three groups of English children with autism. Ninety-six children immunised with MMR were compared with data from two previous clinical samples; one pre-MMR (n=98) and one post-MMR (n=68). They did not find any evidence that regression in the developmental course of autism was more common in children immunised with MMR. The rate of developmental regression reported in the post-MMR sample was 15.6%, compared to 18.4% for the pre-MMR sample. From this work they concluded that there was no evidence to support a distinct syndrome of MMR-induced autism or of autistic enterocolitis.

In a population-based study in the UK, Taylor et al. (2002) also examined whether there was any evidence of a new form of autism associated with MMR vaccination. They identified from computerised disability registers 278 children born between 1979 and 1998 with 'core autism' and 195 children with 'atypical autism'. Using information abstracted from the clinical notes on any change in the child's social and behavioural developments or any documented bowel problems investigators were able to link this to computerised vaccination records. They found no change in the proportion of children with developmental regression or with bowel disease, and no association between MMR, bowel problems and regression. From this they concluded:

These findings provide no support for an MMR associated 'new variant' form of autism with developmental regression and bowel problems, and further evidence against involvement of MMR vaccine in the initiation of autism (p. 393).

Researchers have also focused attention on trying to detect measles virus in the gut of children with autism. Thjodleifsson et al. (2002) tested the hypothesis that the measles vaccine virus moves into the intestinal tissue causing intestinal inflammation in the immediate period following vaccination. They did this by examining the intestinal inflammation response in 58 children before, and two and four weeks after immunisation with MMR. They found that MMR vaccination was not associated with any significant intestinal inflammation response, leading them to conclude there is no evidence of the hypothesised 'gut-brain' interaction central to Wakefield's 1998 theory. In a review of the evidence from the experimental work carried out to date Ghosh et al. (2001) concluded:

There is now enough experimental evidence to conclude that failure to detect measles virus genome in IBD tissue is not due to the inefficiencies of the PCR based detection systems but to the absence of measles virus particle (p. 752).

Likewise in a letter to the editor Afzal et al. (2001) suggested that Wakefield's findings were due to laboratory contamination, in view of the fact neither they nor other researchers have been able to identify measles virus persistence both in the specimens of people with IBD and non-IBD. This is despite the fact that more sensitive tests have now been developed (Iizuka et al., 2001). The fact that Wakefield's findings have been neither replicated, nor supported by the vast majority of studies has led to criticism of Dr Wakefield and colleagues. Nevertheless a small group of researchers continues to support his theories.

1.3.6 Support for the MMR/ autism association

Whilst most researchers have failed to find the measles or mumps virus in gut tissue, Professor O'Leary and colleagues continue to support Dr Wakefield's claims. In April 2000 Professor O'Leary and Dr Wakefield presented unpublished data to the United States Senate's congressional committee in Washington. At the hearing O'Leary and Wakefield explained the findings from their work with Kawashima and colleagues in which they had detected the measles virus in 24 of 25 autistic children's gut biopsies compared with one of 15 controls. These claims were later published, suggesting they

had detected measles virus in patients with inflammatory bowel disease and autism (Kawashima et al., 2000).

On 3rd February 2002, claims of new evidence from Dr Wakefield and Professor O’Leary were made public in a Panorama documentary. Following the documentary, a paper was published in the Journal of Clinical Pathology and Molecular Pathology (Uhlmann et al., 2002). The study examined 91 samples of ileal lymphoid tissue taken from children affected with inflammatory bowel disease. Seventy-five were found to be positive for measles virus compared to five of the 70 control patients. However, Morris and Aldulaimi (2002) commented that the interpretation of these findings is difficult and suggest it would be: “...wrong to jump to the conclusion that measles component of MMR causes the colitis or developmental disorder in these particular, or any other children” (p. 83). Indeed, they highlight the fact that causation is rarely simple and is often multi-factorial in nature (Morris and Aldulaimi, 2002).

1.3.7 MMR vaccination and adverse reactions

MMR has been used around the world for 30 years. Since its introduction in the UK in 1988, around 13 million doses have been given (HEBS and SCIEH, 2001). Although vaccines are subject to testing to demonstrate their safety, quality and efficacy before being licensed, less common adverse reactions may only become apparent once the vaccines have been widely used. In the UK, any adverse reaction to vaccines should be reported by doctors, nurses, pharmacists and parents to the Committee on the Safety of Medicines (CSM) using the Yellow Card Scheme. In turn, the CSM and Medicines Control Agency (MCA) investigate and assess all the reports to determine any safety issues associated with a vaccine. According to the CSM statistics, the MMR vaccine has received 3,453 Yellow Card Reports since 1988. Serious reactions include: 121 febrile convulsions, 42 reports of autism, 17 of autistic behaviour, 8 cases of meningitis/encephalitis, three of blood clotting disorders, three of bowel disease and two cases of anaphylactic shock (CSM and MCA, 2003). However, the success of this passive surveillance system relies on the early, complete reporting of any reactions and

on doctors being meticulous in obtaining the details and appropriate specimens in order to assist a thorough investigation. Critics of the scheme suggest that it is chaotic, misconceived and subject to underreporting, and have called for a critical appraisal of the scheme (Medawar and Herxheimer, 2004).

Studies investigating severe adverse reactions to the MMR vaccine have also been conducted in other countries. In Finland Peltola et al. (1998) conducted a large prospective study examining the medical records of 1.8 million children during a 14-year period in order to identify any severe adverse reaction within a three week period post-MMR vaccination. Investigators identified those children for whom gastro-intestinal symptoms were reported, and traced them to estimate the incidence of autism following MMR. Out of 31 children with gastro-intestinal symptoms none had gone on to develop autism. The study did not find any cases of autism or inflammatory bowel disease and concluded that: “serious events causally related to MMR vaccine are rare and greatly outweighed by the risks of natural MMR diseases” (p. 1127). However, one limitation of this study is the fact that investigators only examined a relatively short time frame of three weeks post-vaccination. A further limitation is that according to Lee et al. (1998) developmental delay is likely to be detected slowly over a period of time, rather than on a particular day. In consideration of this, Patja et al. (2000) used the same Finnish dataset to identify adverse drug reactions over a longer follow up period (1982-1996). Consistent with their earlier findings they found no case of inflammatory bowel disease or autism linked to the vaccine.

1.3.8 Summary of the evidence

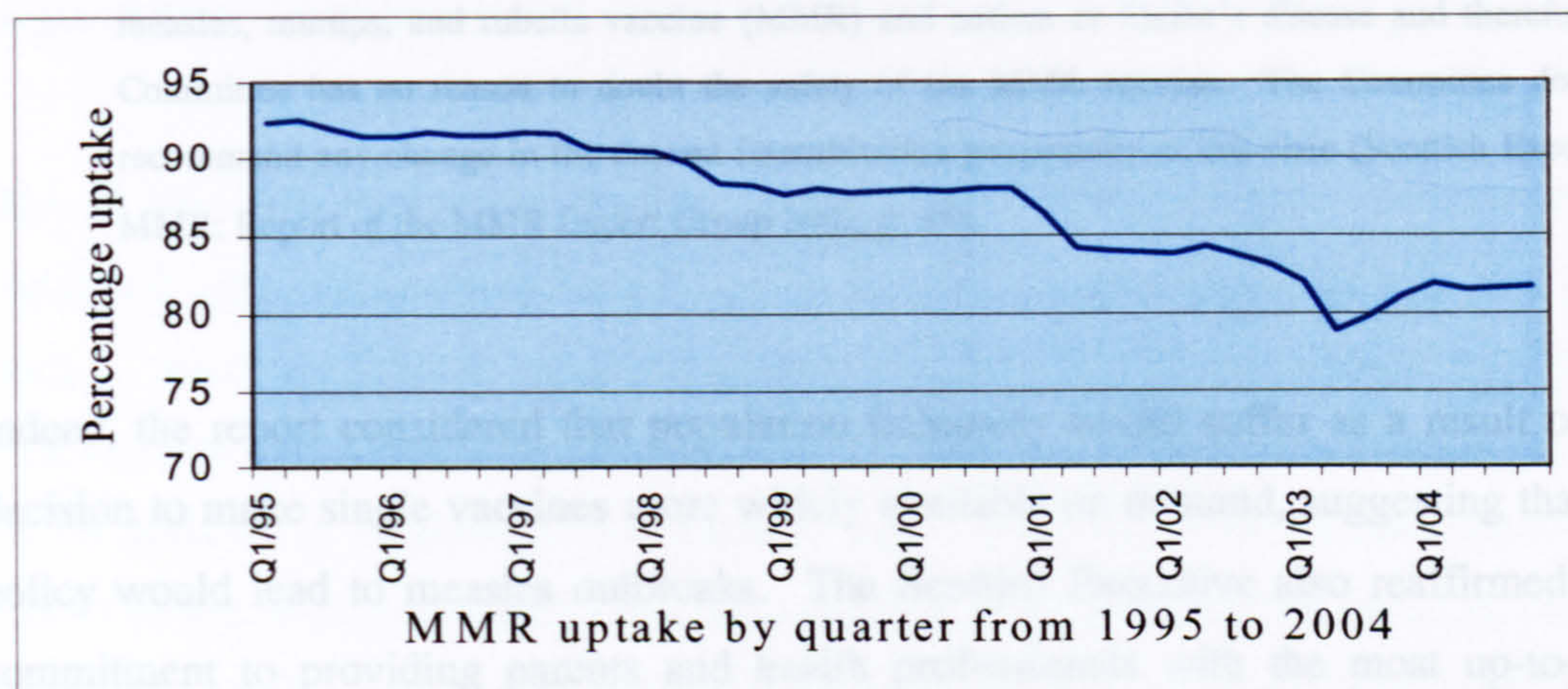
Researchers who have investigated the biological plausibility of Wakefield’s theory have identified an important flaw in the gut-brain part of the theory. Replications of Wakefield and O’Leary’s examination of intestinal specimens have not identified the measles virus. In addition, researchers have not identified a significant amount of inflammation in the intestine post MMR vaccination. This supports the findings of larger epidemiological studies which have investigated adverse reactions to the MMR vaccine and have not identified bowel problems post-vaccination. Taken together these findings

may account for why the symptoms described in Wakefield's study were non-specific, and wide-ranging, and why Wakefield and colleagues were unable to offer a specific case definition. Further, without this central link in the hypothesized MMR-autism chain, the entire theory is undermined. For this reason it is perhaps less surprising that large-scale epidemiological studies have not found any evidence of a new form of autism associated with MMR vaccination, or any evidence that trends in the increased incidence of autism are related to the uptake of the MMR or measles vaccines. Despite the evidence from these epidemiological studies refuting Wakefield's claims, Bedford and Elliman (2000) have observed that his research has received disproportionate publicity, giving the impression that a substantial body of opinion support his views. This is perhaps all the more confusing since Wakefield and colleagues did not suggest in their paper that they had proved an association between MMR and autism.

1.4 Part Two: The public response: Impact on MMR uptake

Despite the Government and public health officials acting quickly to reassure parents about the safety of the vaccine, parents' reactions to the controversy led to a drop in immunisation uptake. Between July and September 1998 there was a 1.4% drop in immunisation uptake in children aged 24 months, the largest fall since the programme began. In Scotland MMR uptake for 2 year olds for the first quarter fell from 94.1% in 1997 to 87.8% in 2003 (SCIEH, 2003) and in England, MMR uptake for 2 year olds for the first quarter fell from 91.4% in 1997 to 85.7% in 2003 (PHLS, 2003). Figure 1.2 shows MMR coverage in the UK for children aged 2 years, for each quarter, since 1995.

Figure 1.2: MMR coverage in the UK for children aged 2 years, for each quarter, since 1995



Data provided by the Public Health Laboratory Services: Communicable Diseases Surveillance Centre, COVER programme. Available at www.hpa.org.uk/cdr/archive.htm (December 2004)

The fall in MMR uptake in the months following the publication of Wakefield's paper led prominent virologists to issue warnings about impending measles outbreaks and to warn that the fall in MMR uptake would undo the recent near elimination of measles and rubella in the UK (Beggs et al., 1998). By 2002 these early predictions were realised when measles outbreaks occurred in London, Wales, and in Fife. Cases of mumps have also increased though mainly amongst a cohort currently aged between 13 to 22 years who did not receive MMR or only received one dose and confirmed cases of rubella remain low. According to the Health Protection Agency, during the first three-quarters of 2004, 3756 confirmed cases of mumps were reported, compared to 1529 cases in 2003, and 495 cases in 2002 (available at www.hpa.org.uk/hpa/news/articles/press) (December 2004).

In recognition of the falling uptake rates, growing public concern about the safety of the vaccine and calls for the single vaccine to be made available, the Scottish Executive established an 'MMR Expert Group' in August 2001. As part of their remit, the group

was asked to consider the public health consequences of pursuing alternative immunisation policies. In May 2002 the report was published. It recommended that:

...on the basis of currently available evidence, there is no proven scientific link between the measles, mumps, and rubella vaccine (MMR) and autism or Crohn's disease and therefore the Committee has no reason to doubt the safety of the MMR vaccine. The Committee does not recommend any change in the current immunisation programme at this time (Scottish Executive: MMR: Report of the MMR Expert Group 2002, p. 48).

Indeed, the report considered that population immunity would suffer as a result of any decision to make single vaccines more widely available on demand, suggesting that this policy would lead to measles outbreaks. The Scottish Executive also reaffirmed their commitment to providing parents and health professionals with the most up-to-date-assessment of the evidence surrounding the safety of the MMR vaccine in the form of 'The MMR discussion pack' and leaflets (HEBS and SCIEH, 2001).

1.4.1 Vaccine decision-making: The factors known to influence uptake

In the UK parents have the right to choose whether or not they wish to have their children immunised. The voluntary nature of immunisation means that the success of the Childhood Immunisation Programme relies on immunisation policy being an acceptable and more attractive option compared to opting not to immunise. Therefore understanding the factors that influence parents to accept or refuse immunisation for their children is important if parents are to be encouraged to comply with immunisation policy. Since the publication of 'The Black Report' (Townsend and Davidson, 1982) emphasis has been directed towards improving the uptake of child preventative health services, including that of immunisation, in socially and economically deprived areas. By the early 1990s the drive to improve childhood immunisation uptake levels heralded the introduction of target payments to general practitioners and the setting of a target of 95% uptake among children aged 2 year olds for all the vaccines in the Childhood Immunisation Programme. As a consequence of these new policies, the 1990s appears to be a period during which there were renewed efforts on the part of researchers to identify the factors that influence

parents' decisions about immunisation. Much of the research conducted during this period focused on those parents who decided to withhold immunisation, reflecting the fact that it was important to understand the view of this minority group of parents if the target of 95% was to be attained.

One of the first exploratory studies to investigate British mothers' experiences of childhood immunisation was carried out by New and Senior (1991) as part of a larger study. Participants were randomly selected from immunisation records held on the computerised Child Health System which collects data on the quarterly vaccine coverage for all children in England at two years of age. The study used an unmatched case-control design to include parents whose children were fully immunised (n=123), partially immunised (n=71) and parents who had defaulted on all their invitations to immunise (n=48). The main findings were that mothers rather than fathers were predominantly responsible for matters relating to immunisation and that they were reluctant to take ill children for vaccination even if the illness was minor. They found that in larger families there was a greater probability of the youngest being incompletely immunised, which they suggested may reflect the greater burden of childcare commitments. They also found that mothers with no formal educational qualifications at Advanced Level in the General Certificate of Education or above were more likely to have an incompletely immunised child, which they thought may account for lower vaccine uptake in deprived areas.

Two years later, Pearson et al. (1993) published the findings of their Liverpool-based study that aimed to identify the factors influencing parents to withhold immunisation. Using immunisation data held on the Child Health System, they used regression analysis to assess the association between parents' consent to immunise, and five sociodemographic factors: the child's gender, the child's position in the family, whether the family had one or two parents, migration into Liverpool since birth, and local deprivation, a factor identified as important in the earlier Peckham Report (Peckham et al., 1989). Of the cohort of 3585 children (1714 girls, 1871 boys), they found that

consent to immunise with pertussis was least likely to be given for boys, and for children with older siblings, and by single parents, and parents living in deprived areas. They suggested that health visitors should target parents living in deprived areas and families with two or more children and provide them with consistent advice and support.

In an attempt to identify the reasons why parents refuse immunisation, Simpson et al. (1995) also used the computerised Child Health System to identify parents whose children had not been immunised. They identified 106 children living in the Bath area of England who had received no immunisation between 1987 and 1993. The parents of these children were mailed a questionnaire, 87 of which were completed and returned giving a response rate of 82%. The most common reason for refusal to immunise was that they used homeopathy. This accounted for 22 parents' refusal. Religious beliefs accounted for a further 17 parents, five parents gave medical reasons for not immunising their children, and seven parents stated that they were in the process of having their children immunised. Seventeen parents were described as having various unidentified reasons for not immunising their children. The parents of the remaining 19 children gave no reason. The fact that 36 out of the 87 parents gave no reason prevents drawing firm conclusions about which groups of parents might benefit most from being targeted with more informed and accurate information about immunisation.

In 2001, Sporton and Francis published their small qualitative study. The study involved semi-structured interviews with 13 parents to explore the decision-making process of parents who had chosen not to immunise their children. They used purposive sampling to identify parents who had chosen not to immunise at least one of their children from an area of London with a high level of deprivation. They concluded that a major reason given by parents for choosing not to immunise was that they feared the risks of side effects from vaccines. Health visitors were not perceived as providing balanced information and this was identified as an impediment to decision-making. Consistent with Simpson et al's. (1995) earlier findings, they found that some parents refused immunisation because of religious beliefs or because they preferred to use homeopathy.

Although the publication of Sporton and Francis's study post-dated the publication of Wakefield's study, Sporton and Francis's paper does not mention the MMR debate. Therefore it is unclear whether Sporton and Francis's findings about parents' fears about side effects from vaccines specifically refer to the MMR vaccine, or to vaccines in general. The fact that the paper omits to mention the MMR controversy at all is puzzling given the context in which these findings were generated.

1.4.2 Vaccination decision-making: seeking the best balance of risks and benefits

Whilst most of these studies have been helpful in identifying factors that may influence parents' decisions, these factors alone do not fully explain vaccine decision-making outcomes. It is recognised that although parents make their own assessment of whether to immunise their child, immunisation is about more than just the individual and is a preventative measure that may sometimes bring more benefits to the community than to the individual. Rose termed this situation 'the prevention paradox' (Rose, 1981). Hershey et al. (1994) consider this conflict and suggest that when people choose among medical treatments they usually seek alternatives which appear to offer the best perceived balance of risks and benefits. They suggest that this is because this type of decision does not affect anyone else, and thus it makes sense for individuals to keep their own interests paramount. However, they point out that when people choose to become vaccinated, decisions do affect other people in that not only do they reduce their own chances of contracting the disease, but they also reduce their chances of carrying the disease or of transmitting it to others.

Recently, Hunt and Emslie revisited the prevention paradox and suggested that there may be an argument for acknowledging it more directly in health education materials, to stem the public's growing mistrust of science and health education (Hunt and Emslie, 2001). Indeed, past immunisation campaigns have not acknowledged the fact that immunisation has this dual role of protecting both the individual and those around the individual, despite the fact that decisions about immunisation may affect other people, and be influenced by the actions of other people. To assess the roles that altruism, free-riding,

and bandwagoning (copying others) play in vaccine decision-making, Hershey et al. (1994) asked 472 people to consider six hypothetical scenarios. Regression analysis provided evidence that altruism, free-riding and bandwagoning are significant motivators in the decision to undergo vaccination. This led them to propose that people factor the actions of others into their own decisions about whether to immunise or not. However, whilst Hershey and colleagues observed that some of the subjects in their study spoke as if they cared about the impact of their decisions on the well-being of others, they also appeared to act in their own interests. This suggests that they found some discrepancy between people's words and actions. On the other hand, they suggest that some individuals may undergo vaccination partly to help others. They warn that this gives rise to a situation whereby as herd immunity increases and diseases become well-controlled there is a decreased individual benefit from being vaccinated, compared with an unchanged risk of reaction to the vaccine. Hershey and colleagues consider that this scenario (free-riding) creates an ideal opportunity for some people to use herd immunity to gain benefit from an immunisation programme without accepting any personal risks.

However, free-riding to minimise personal risk is not a risk-free strategy as herd immunity is not constant. Indeed, the whooping cough epidemic of the 1970s is a testament to the fact that relying on herd immunity is inherently risky. Following adverse publicity about the safety of the pertussis vaccine in the mid-1970s, large numbers of parents decided not to get their children immunised, and the uptake rate of the vaccine plummeted and whooping cough rates soared (Meszaros et al., 1996). According to Preston (1980) population immunity was reduced to about 20-40% in some parts of the country. In these circumstances parents deliberately using herd immunity to offer protection to their child would have suddenly found themselves vulnerable to the resurgent whooping cough disease.

1.4.3 Omission bias and vaccine decision-making

The dramatic fall in pertussis uptake rates following adverse publicity is evidence that parents' usual patterns of immunisation decision-making behaviour were altered. In order

to gain a deeper understanding of the cognitive processes involved in decision-making, American psychologists Ritov and Baron (1990) conducted a study using a hypothetical vaccine scenario to consider the role that psychological bias, termed omission bias, plays in vaccine decision-making. Fifty-three undergraduate students were randomly selected on campus to consider scenarios and decide whether vaccination or potentially contracting a disease was in their hypothetical child's best interest. They found that some students considered that they would feel more responsible if their hypothetical child died as a result of a vaccination, than as a result of contracting a vaccine-preventable disease. They argue that this reluctance to act is an example of omission bias, whereby the person withholds vaccination because of the perception that action (commission) is more harmful than inaction (omission). Moreover, they suggest that when ambiguity exists in relation to the risks associated with the vaccine, it heightens the reluctance to vaccinate, even when the risks are small.

Similarly, Asch et al. (1994) investigated the role that omission bias played in American parents' decisions about whether to vaccinate their children against pertussis. They mailed 200 questionnaires to subscribers of a 'Parenting' magazine, which had previously published articles favouring and opposing pertussis vaccination. Parents were asked about their beliefs about the vaccine and the disease and whether they planned to, or had vaccinated their own children. They were given 11 different statements about whooping cough and pertussis vaccination, which they had to assess as either being true or false. One hundred and three questionnaires were completed and returned, of which 43% of the respondents reported they did not, or would not, allow their children to be vaccinated, and 57% respondents reported that they had, or would, vaccinate their children. Using logistic regression to determine the role omission bias played in parents' decisions about pertussis, Asch and colleagues found that parents who reported that they had not immunised their children were also more likely to believe that vaccinating was more dangerous than not vaccinating. They concluded that omission bias plays a role in decisions not to vaccinate with the pertussis vaccine, beyond the role played by belief about the risk of vaccination. They asserted: "... in some circumstances individuals favor

the choice representing inaction over that representing action, even when the latter is more likely to lead to better outcomes” (p. 121).

1.4.4 Parents’ attitudes to the MMR controversy and to MMR vaccination

Since the MMR controversy first began there have been several studies that have been particularly useful in gaining new insights into parents’ perceptions about MMR decision-making. Evans and colleagues (2001) recruited parents from the Avon and Gloucestershire area of the United Kingdom to take part in six focus groups. The focus of the discussions was on the influences on parents’ decisions to accept or refuse MMR. They used a purposive sampling strategy to include parents from a range of socio-economic backgrounds and different MMR decision-making outcomes. This study offered the first in-depth account of parents’ perspectives on MMR immunisation. Evans and colleagues found that parents are involved in a risk-benefit analysis and that for many parents it is easier to live with the risk of their child naturally contracting one of the diseases than with the risk of causing their child damage through vaccination, a finding reminiscent of Ritov and Baron (1990) and Asch and colleagues’ (1994) work on omission bias. Further, although these parents accepted that their unvaccinated children might contract a disease, they were optimistic that their children would make a good recovery. They concluded that the non-immunisers felt that the potential risks from MMR outweighed the potential risks of contracting the diseases, and were reluctant to comply with a policy that offered them no choice.

In another study, Ramsay et al. (2002) described trends in mothers’ attitudes to, and uptake of, MMR vaccine between 1995 and 2001. They utilised data from two sources, the computerised Child Health System, and the cross-sectional survey of attitudes towards childhood immunisation conducted in England bi-annually by all health authorities in England. Data were obtained from 26 English health authorities/trusts in 2001. The survey involved interviews with a random sample of 1000 mothers of children less than three years of age. From these routine data sources they found that, despite the adverse publicity surrounding the MMR vaccine, the fall in MMR coverage was small

(8.6% between 1995 and 2001) and that the vast majority of mothers (92%) would immunise future children with MMR. The interviews were structured and less well suited to exploring the views of the parents who declined MMR, or to drawing any conclusion about how they might be encouraged to immunise. Nevertheless, an interesting finding from this study was that the decline in acceptability of the MMR vaccine appeared to be greater among more socio-economically advantaged parents. This is in contrast to studies conducted in the late 1980s and early 1990s that reported lower vaccine uptake levels in more socially and economically deprived areas, with the exception of the pertussis vaccine, (Peckham et al., 1989; Pearson et al., 1993; Ramsay et al., 2002). This suggests that improving MMR uptake may require more than simply targeting parents living in deprived areas with more informed and accurate information about MMR.

A study by Smailbegovic et al. (2003) explored the attitudes and concerns about immunisation and vaccine-preventable diseases. They mailed questionnaires to 129 parents living in the London Borough of Hackney whose children had not completed the recommended course of immunisation (of children identified as having defaulted on one or more primary immunisation by 18 months of age). Ten were later interviewed. Consistent with the findings of Evans et al.'s (2001) study, they found that 23 out of 68 (34 %) responders perceived that having their child immunised with a particular vaccine was more risky than non-immunisation. They suggested that parents weigh up the perceived seriousness of a disease and the likelihood of catching it, against the perceived safety and efficacy of the vaccine. They assert that parents who consider that diseases pose a threat to their child's health and who consider immunisation to be both safe and effective are likely to have their children immunised. In contrast, parents who consider that the diseases pose little or no threat to their child's health, and who consider immunisation to be ineffectual or to pose a risk to their child, are more likely not to immunise their children.

Another study considered the views of parents who had opted to immunise their children in order to assess parents' perceptions about vaccine risk. Using convenience sampling

Raithatha et al. (2003) recruited parents from two nurseries in Norfolk with high vaccine uptake levels of over 90%. In addition to three parents who took part in pilot interviews, fifteen parents whose children were fully immunised agreed to take part in in-depth interviews. The authors proposed that parents weigh up the risks associated with vaccines against the risks posed by the diseases, and that this is influenced by parents' attitudes to the immunisation process and by their trust in government and health professionals. Findings from this study suggest that parents who immunise their children have concerns about the risks associated with vaccines and warn that it is vital not to assume that parents who at present immunise will continue to do so. They also found that the MMR vaccine scare may have triggered a reappraisal of vaccine risk, and propose that in order to address parents' fears about a causal link between autism and the MMR vaccine there is a need for further research into the aetiology of autism. Raithatha and colleagues recommend that parents are not pressurised to immunise, as this increases their feeling of lack of control, and that there is a need to improve parents' sense of trust. They concluded that: "Concentrating messages on the threat of infection for their own 'vulnerable' children may continue to help persuade parents to immunize" (p. 164).

1.4.5 Are parents reappraising vaccine risk?

The successful introduction of any new vaccine into the Childhood Immunisation Programme may depend on several factors, not least the capacity of the programme to include new vaccines. As Lambert and Siegrist (1997) note "the infant immunisation schedules are already quite full and may not readily allow the addition of many new vaccines" (p. 1597). Whilst combination vaccines offer greater scope for the introduction of new antigens, as more than one antigen can be given at any one time, a major obstacle to any introduction noted by Offit et al., (2002) is that an increasing number of parents are becoming concerned about the number of vaccines in the programme.

In comparing the numbers of vaccines included in the Childhood Immunisation Programme over the past century, it is clear that the UK programme has expanded. For example, in the 1900s a child would only receive the smallpox vaccine. Over the

following decades scientific advances, combined with the World Health Organisation's determination to set up mass immunisation programmes, meant that by the 1950s this had increased to five vaccines (diphtheria, pertussis, tetanus, polio and smallpox). Today the Childhood Immunisation Programme currently offers protection against nine diseases (See Appendix B). In September 2004 the new pentavalent vaccine (Dtap/IPV/Hib, brand name Pediacel) was introduced into the programme offering protection against diphtheria, pertussis, tetanus, polio and Haemophilus Influenza type b in one combined vaccine. This alteration to the programme does not add any new disease to the immunisation schedule and has been changed so that protection can be offered "in a slightly different, more acceptable, formation" (Bedford and Elliman, 2004 p. 411). See Appendix C for a timeline illustrating the major changes to the Childhood Immunisation Programme since the 1950s.

Although the debate about vaccine overload in the UK has largely been confined to the popular press, out-with the UK the scientific community have published several studies showing parents' concerns about this matter. For example, Bond et al. (1998) conducted a study in Melbourne, Australia to investigate mothers' perceptions of vaccine-preventable diseases and associated vaccines in terms of perceived susceptibility, severity, benefits and barriers. They used a purposive sampling strategy to include mothers of children with different decision-making outcomes and to include first-time mothers and more experienced mothers. Semi-structured interviews were conducted with 45 mothers. Bond and colleagues found that 'complete immunisers' believed that the risks associated with vaccines were lower than the risks associated with the diseases, and that the likelihood of contracting many of these diseases was low. In contrast, they found that incomplete immunisers perceived vaccines to be less effective in preventing diseases, and were often confused about which diseases the vaccines would protect against. They also suggested that non-immunisers were more concerned about unknown, long-term side effects of the vaccines than with the diseases, and that many mothers believed that vaccines place stress on the immune system rather than strengthening it.

Similarly, in a study conducted in the United States of America as part of a larger study on immunisation, Keane et al. (1993) explored parents' perceptions of vaccines. Forty parents participated in focus groups (they omit to state how many groups they conducted). They found that parents perceived vaccines to be only partly effective and did not consider immunisation to be a high priority in the broader context of parenting. Further, since fever was viewed as a primary indicator of illness this led some parents to suggest that vaccines caused, rather than prevented, illness and parents expected they would need to care for an ill child post-vaccination.

1.4.6 Where are we now? Outstanding issues

In February 2004 the General Medical Council conducted an investigation into Dr Wakefield's study following several allegations, brought by a journalist Brian Deer, of which the most serious was that Wakefield had been paid for a second study funded from the Legal Aid Board into whether children allegedly damaged by the MMR vaccine could sue. In response to these revelations, the editor of the Lancet, Richard Horton, stated that he would not have published the research in that form had he known about the conflict of interest and that he hugely regretted the adverse impact this paper had had, calling the paper 'fatally flawed'. In the March 6th edition of the Lancet, ten of Wakefield's co-authors formally disassociated themselves from the study in a 'retraction of an interpretation'. However, Dr Wakefield remains adamant that the scientific results of his 1998 study are still valid. After resigning from his job in December 2001, Wakefield moved to America to work for the International Child Development Resource Centre in Florida, a centre that is associated with the Good News Doctor Foundation, a Christian ministry.

In September 2004, Richard Horton has revisited the events surrounding this controversy in his book titled: MMR: science and Fiction. The book offers new and revealing insights into the debate from the perspectives of some of the scientists, physicians and politicians most closely involved in the controversy. Perhaps one of the most revealing

aspects of the debate is his view on the role of medical journal editors, on which he states:

...despite these uncomfortable events, medical journal editors must not refrain from publishing work that challenges mainstream scientific, clinical or public health opinion. There are now strong forces operating on journals to protect the system of health messages distributed to the public. The media is so voracious in its appetite for controversy, it is so merciless in its challenges to conventional opinion, that medical journals should, so many doctors will argue, avoid fuelling these fires. Journal editors should try to keep these difficult discussions within a closed professional circle. I simply do not accept this argument. It is the recipe for the stagnation of knowledge and the creation of a wholly undemocratic technocracy (p. 169).

However, many still question the Lancet's wisdom in publishing the paper and the case remains that there is still little known about some of the individuals most affected by the debate, namely the parents of young children. In particular it is of note that, as this PhD study is completed, no studies have been published presenting the views of parents of autistic children or parents whose children need to rely on immunisation as a consequence of having a compromised immune system due to the effects of chemotherapy, yet it seems likely that both these group of parents will have been affected by the controversy. The fact that researchers have largely focused attention on the scientific evidence appears to have unintentionally overshadowed the need to concentrate greater efforts on exploring parents' understanding of the scientific evidence and controversy surrounding the safety of MMR vaccination. Furthermore, the wider context within which parents were assessing the MMR controversy was one in which the public had recently witnessed several other public health scares such as BSE, Salmonella, genetically modified food, contraceptive pill scares, and failures in screening programmes. Perhaps for this reason, despite the growing body of scientific evidence overwhelmingly supporting the safety of the MMR vaccine, and Government and public health officials being quick to endorse its safety, their endeavors often seemed counter productive. Indeed, the longevity of the controversy may be testimony to a wider crisis in confidence that parents have in knowing who to look to for guidance and sound

judgment on health matters. This PhD study aims to offer a novel insight into the controversy by exploring it from the perspective of parents of young children.

Reviewing the literature also raises the question of whether parents have more general concerns about childhood immunisation. The fact that studies raising parental concerns about the safety of vaccines pre-date the publication of Wakefield's (1998) paper, and that they present the views of parents from a range of countries, suggests that concerns over vaccine safety are neither confined to the UK, nor limited to the MMR debate. However, the lack of recent literature exploring parents' views on childhood immunisation or how these relate to the decisions they make for their own children, offers this study the unique opportunity to provide a contemporary assessment on these aspects of childhood immunisation. Further, although there was general agreement in the literature that parents make decisions about immunisation by weighing up the risks associated with the diseases against those associated with the vaccine, no studies have been published offering an in-depth exploration of parents' knowledge, understanding or beliefs about childhood infectious diseases. This gap in the literature on disease perceptions seems particularly important to address, since the success and acceptability of immunisation may depend on parents' assessment of the diseases from which the vaccines aim to protect. This study aimed to fill this gap by conducting a thorough exploration of parents' understandings and beliefs about diseases and the perceived severity of these diseases, and the role first and second hand experience of diseases has on parents' evaluations in the importance of preventing certain diseases. This study aims to provide an original and far-reaching assessment of parents' perceptions about childhood immunisation, the MMR controversy and parental decision-making around vaccination, by answering the following questions:

- What are parents' knowledge, understanding and beliefs about childhood infectious diseases, and how do their experiences of disease affect their evaluations of the importance of preventing certain diseases?

- What are parents' views on mass childhood immunisation and on the vaccines included in the Childhood Immunisation Programme in the light of the MMR controversy?
- What are parents' perceptions about the current MMR controversy and how do these perceptions translate into the parental decision-making process about whether to immunise, or not?

The next chapter (Chapter Two) describes the methods used to explore parents' perceptions of childhood infectious diseases, childhood immunisation and vaccine decision-making. Chapter Three examines parents' understanding, experiences and beliefs about childhood infectious diseases. Chapter Four explores parents' perceptions of the MMR controversy. Chapter Five considers how parents' perceptions of the current MMR controversy have affected their perceptions about vaccines and of their decisions about whether or not to immunise their children with the MMR vaccine. Chapter Six explores the MMR controversy from the perspectives of two quite different groups of parents observed to have a special interest in the debate: parents caring for autistic children, and parents caring for children with a compromised immune due to the effects of chemotherapy treatment for cancer.

Chapter Two: Methodology

This chapter begins by describing the philosophic underpinnings that informed and shaped this qualitative inquiry. The chapter moves from description of the theories, to a detailed description of the design and conduct of the study with the aim of showing how subjectivity was managed and scientific rigour maintained. Consistent with this aim is the final section, which describes the problems encountered during the research process, reflects on my potential impact on the research as facilitator and details how analysis was carried out.

2.1 Choice of study design

2.1.1 *Why a qualitative perspective?*

The exploratory nature of the inquiry predisposed the study to the use of the inductive techniques used in qualitative research, rather than the deductive techniques of quantitative research. In deductive research, the researcher begins with the theory before empirical research and analysis. Using deductive reasoning, the researcher derives a testable proposition or hypothesis from the theory, in advance of the research process (Mason 2002). The researcher seeks to ‘transcend the particular by higher and higher reaching for abstraction, and in the end disclaim in principle any explanatory values at all where the particular is concerned’ (Bruner 1986, p. 56). Similarly, Seale (1999) describes deductive reasoning in these terms:

Propositions, logically deduced from theoretical statements, are operationalised in research projects, tested against the objectively observed, factual nature of the real world, thus determining the truth or falsity of propositions, which in turn influences the content of theories (p. 23).

In contrast, in inductive research the process of scientific discovery begins with data generation from which theory is then extrapolated. Mason (2002) considers that inductive reasoning develops ‘theoretical propositions or explanations out of the data, in a process which is commonly seen as moving from the particular to the general’ (p. 180). As such, inductive modes of thinking are particularly valuable when the aim is to

describe, explore, understand, or explain a particular phenomenon. It may consider the 'what', 'why' and 'how' of the phenomenon, but not in terms of 'how many' or 'how frequently' (Gantley et al., 1999). Maykut and Morehouse (1994) assert:

The goal of qualitative research is to discover patterns, which emerge after close observation, careful documentation, and thoughtful analysis of the research topic. What can be discovered by qualitative research are not sweeping generalizations but contextual findings. This process of discovery is basic to the philosophic underpinning of the qualitative approach (p. 21).

Therefore qualitative studies are designed to lead the researcher into unforeseen areas of discovery and are useful in exploring behaviour within specific social settings rather than broad populations. To explore and understand a particular phenomenon, Holliday (2002) distinguishes between two major paradigms of qualitative research, 'naturalism' and 'progressivism.' In naturalism the researcher becomes fully involved in the research setting either overtly or covertly for a lengthy period of time. Naturalists believe that substantiation is gained through establishing the 'real' nature of the social world through sufficient weight of description by 'being there' using an unobtrusive approach. In contrast, progressivists' argue that there is no 'there' until it is constructed and question the whole premise that a definitive picture of the 'truth,' or 'real' nature of the social world actually exists (Gubrium and Holstein, 1997). Holliday (2002) believes that the progressivists' break from naturalism enables "a far greater variety in procedure and scope, in which data is presented more creatively, with more openness about who the researcher is and how she spins validity through argument" (p. 21). Following a progressive paradigm would enable me to engage actively with parents to find out their views, beliefs and understandings about vaccines, diseases and the MMR controversy. Although this more activist approach would be at odds with a naturalist perspective that aimed to be unobtrusive, I felt it would offer more scope for understanding parents' feelings about childhood immunisation and diseases. To decide which method to employ and to develop a sampling strategy that would yield the most interesting data, I carried out a small pilot study that included five focus groups and four individual interviews.

2.2 The pilot study

2.2.1 *Sample selection*

The initial target population was parents from a range of socio-economic backgrounds with children under the age of five, to take account of the various ages at which children are offered vaccines in the Childhood Immunisation Programme.

Identification of areas of relative advantage and relative disadvantage was facilitated using Carstairs Deprivation Categories as a proxy indicator for socio-economic status (Carstairs and Morris, 1991). McLoone (1994) highlights the fact that the deprivation scores do not measure the extent of an individual's material well-being or relative disadvantage, but rather are measures applied to populations contained within small geographical localities. By targeting the most affluent areas with a DEPCAT score 1, and the most deprived areas with a DEPCAT score 7, there is an increased likelihood of recruiting people from different socio-economic backgrounds into the study. The extremes of the scores represent the increasingly homogeneous population that live in the areas and so recruiting from these areas also reduces the chances of focus groups containing a mix of people from vastly different socio-economic backgrounds.

The main criteria employed in the pilot-sampling frame included:

- Parents living in a range of socio-economic areas, including parents living in affluent (DEPCAT 1 or 2) and deprived (DEPCAT 6 or 7) parts of Glasgow and the surrounding areas.
- First-time mothers, as well as mothers with previous experience of motherhood, to identify any specific issues they may have about immunisation.
- Fathers as well as mothers.

2.2.2 Timing of the pilot study

The first tranche of pilot work was carried out over a six-week period from March 2002. This included three focus groups and four interviews. Two further focus groups were carried out in October 2002. The initial pilot work in March 2002 followed three months of intense media coverage about the safety of the MMR vaccine. Indeed, it has been estimated that of 561 stories involving MMR reported over a seven and a half month period, 56 per cent of the stories were reported between 28 January 2002 and 28 February 2002 (Hargreaves and colleagues, 2003). Three key events led to this increased interest in the MMR debate during this period. (See Appendix D, which shows a timeline of the key events in the MMR controversy and how these relate to the data collection for this study).

The first event was in December 2001, when media speculation about the safety of the MMR vaccine became front-page news when Tony Blair, the British Prime Minister, refused to reveal to the nation whether his son Leo (then aged 19 months) had had the MMR vaccine. Whilst Tony Blair implied that Leo had been immunised with the MMR vaccine, speculation continued for many months, fuelling calls for the introduction of single measles, mumps and rubella vaccines on the National Health Service. The second event that exacerbated demands for the introduction of single measles, mumps and rubella vaccines happened in January and February 2002 when outbreaks of measles were confirmed in London, Wales and Fife. Thirdly, on the 3rd February 2002 a Panorama television documentary was broadcast featuring Dr Andrew Wakefield defending his earlier paper that suggested a causal link between MMR, autism and bowel disease.

The culmination of these events meant that much of the discussion in these early focus groups tended to focus on the 'newsworthy' events of the preceding two months.

2.2.3 Main lessons learnt from the pilot study

Several key lessons emerged from the pilot groups. Firstly, on analysis it appeared that the group interactions within the focus groups yielded more interesting and varied data than did individual interviews. Secondly, it was clear that the sampling frame needed further refinement in order to capture a more diverse sample of parents into the main study. Thirdly, the pilot showed the media's influence and news events could be problematic in dominating focus group discussion and thus that it would be prudent to conduct the main study over as short a period of time as possible to minimise this risk. Fourthly, as data from two of the pilot focus groups were lost due to unreliable recording equipment, I reviewed and changed recording equipment to prevent further loss of data.

2.3 The main study

2.3.1 Introduction to focus groups

Contemporary focus groups have developed from well over half a century of evolving inquiry that had its origins in Bogardus' work in the 1920s and later Merton and Kendall's focussed interview work (Bogardus, 1926; Merton and Kendall, 1946). Market researchers have employed focus groups since the 1950s but during the 1980s there was a resurgence of interest among social scientists (Catterall and Maclaran, 1997). Kitzinger (1994) suggests that they have become more commonly used in popular communication research, such as in the evaluation of health education materials and in film and television reception studies. Focus groups have become popular as a means of exploring people's experiences of health services, such as health screening, and in action research projects involving grass-root participation.

In response to the growing popularity in the use of focus groups by researchers, and in an attempt to avoid social scientists uncritically adopting market researchers' models, Barbour and Kitzinger (1999) recently refined, and redefined, the role of contemporary focus groups. In their broadest sense, they define focus groups as "group discussions that explore a specific set of issues, and they are 'focused' in that they involve some kind of

collective activity” (p. 4). In attempting to distinguish focus groups from the broader category of group discussions, Barbour and Kitzinger (1999) state, “any group discussion can be called a ‘focus group’ as long as the researcher is actively encouraging of, and attentive to, the group interaction” (p. 4-5). Crucially, in refining focus group methodology, Barbour and Kitzinger (1999) explicitly identify the importance of using group interaction to generate data, and for the researcher to be attentive to those interactions. Whereas group interviews tend to involve question and answer exchanges between the researcher and participants, researchers facilitating focus groups encourage participants to exchange stories, and to talk between themselves. In this way, the participants create an audience for one another allowing the researcher to examine people’s different perspectives as they operate within a social network, and to explore how accounts are articulated, censured, opposed and changed through social interaction (Barbour and Kitzinger, 1999).

2.3.2 *Why use focus groups?*

The focus group method was selected for this study for the following reasons. Firstly, it offered a flexible approach to exploring parents’ experiences and views on childhood immunisation and diseases. It was anticipated that focus groups would enable parents to question each other, pursuing issues of importance to them, and thus encouraging a varied and in-depth dialogue between participants, rather than merely answering a pre-determined list of questions. Indeed, the emphasis that Barbour and Kitzinger (1999) place on group interaction suited the current research project which aimed to understand parents’ perceptions of diseases, immunisation and about the ongoing MMR safety debate, and how these views related to vaccine decision making. Such research objectives necessitated the use of an in-depth method that encouraged rich interactions between participants, and that was not too prescriptive in its focus.

Secondly, another advantage that focus groups have is that group interaction between participants can diminish the researcher’s power and influence. Wilkinson (1999)

suggests that the balance of power shifts away from the researcher ‘simply by the virtue of the number of research participants simultaneously involved in the research interaction’. Similarly, Morgan (1988) considers that participants’ interaction among themselves replaces their interaction with the researcher, leading to a greater emphasis on participants’ points of view. Wilkinson (1999) notes that in the group situation it is easier for participants to challenge views with which they disagree and to challenge or reject others’ assertions, including those of the researcher. This shift in the power dynamic between researcher and participant can mean that participants gain greater opportunity to set or challenge the research agenda, developing the themes that are important or salient to them (Copper et al., 1993). Thirdly, Bloor et al. (2001) argue that small groups are more typical patterns of interaction particularly for women and therefore may be productive for focus group purposes. The focus group method seemed particularly apt in relation to childhood immunisation because parents often set up their own parenting groups both formally and informally to give and receive support from one another on parenting and child health issues.

2.3.3 Developing a sampling strategy

Whilst statistical ‘representativeness’ is not an objective of qualitative research, sample selection is nevertheless important. Qualitative samples aim to encompass diversity. Mason (2002) suggests that the aim of the sampling strategy is to produce a relevant range of contexts or phenomena designed to encapsulate a diverse sample in relation to the wider universe, but not to represent it directly. In order to have as wide a spectrum of experiences and views on immunisation as possible, this study used a purposive sampling strategy in an attempt to capture the complexity that characterises vaccine decision-making. In order to incorporate new ideas and to enable the research questions to become more refined, the sampling frame was left flexible to allow the inclusion of new groups. In fact the sampling frame was adapted six times between the commencement of the pilot work in March 2002 and completion of the main fieldwork in March 2003.

2.3.4 Sample selection for the main study

The initial target population was parents with a child under the age of five years. This age range was chosen to reflect the complete pre-school immunisation programme offered to parents, including the first MMR (offered between 12-15 months) and the pre-school booster MMR (offered usually between 4-5 years of age). However, on two occasions in the pilot interviews parents indicated that the booster MMR vaccines had been delayed until the children were six years of age following a delay in the first MMR vaccine. Thus, the target population for the main study was changed to ensure the inclusion of children up to six years old. (The only exceptions to this were two groups with parents caring for children with compromised immune systems).

Almost without exception participants who took part in the pilot groups (including fathers themselves) considered that fathers played a secondary role in issues relating to childhood immunisation to that of mothers, a finding supported by Kilmartin et al. (1998). However, initial analysis of the pilot study data revealed that concerns over the safety of the MMR vaccine meant that 'normal' decision-making processes appeared to be disrupted, and that fathers appeared to be playing a more prominent role in the decision-making process about the MMR vaccine. Thus, it seemed wise to include some fathers in the study. Initially, the plan was to make contact with both fathers and mothers at the usual venues and groups that they frequent with their children. However, this strategy only resulted in the recruitment of five men into the study, of whom three appeared well-educated and lived in affluent areas. In order to recruit more men from less affluent areas, a group of fathers with sole responsibility for their children was recruited from a single fathers' group that is run in a deprived part of Glasgow.

As the study progressed it became clear that the sampling frame needed further refinement to include parents with less common vaccine decision-making outcomes. Target groups included parents who: had decided not to let their children have the MMR vaccine; were not planning to have any of the vaccines in the schedule; or had opted to pay privately for the single measles, mumps and rubella vaccines. Barbour and Kitzinger

(1999) consider that focus group guidelines often overemphasise the extent to which the researchers can control for all characteristics of participants which are likely to be relevant. They state: "...some details are likely to emerge only once discussion has been initiated and the precise composition of groups will often be a product of circumstance rather than planning" (p. 8). As this was my experience with some of the groups in the pilot study, this reaffirmed the need to purposefully target parents on their likely views and decisions about immunisation. The criteria used for the composition of each of these groups were not seen as fixed, inflexible or mutually exclusive. Rather, they aimed to include participants with a range of decision-making outcomes, and to bring together groups of parents with 'roughly' shared decision-making outcomes.

In an attempt to be more systematic in reflecting varying uptake levels within the Greater Glasgow National Health Service Board area, the Information and Statistics Division of the National Health Service was asked to supply a list of vaccine uptake rates by postcode sector. Using the Standard Immunisation Recall System (SIRS database) two groups from postcode areas with high MMR vaccine uptake rates were targeted (one an affluent area, DEPCAT 1 and 2, and one a deprived area, DEPCAT 6 and 7). Similarly two groups from postcode areas with low MMR uptake rates were sought (one an affluent area, DEPCAT 1 and 2 and one a deprived area, DEPCAT 6 and 7).

As the study progressed two special interest groups of parents were identified as having specific concerns relating to childhood immunisation. The first was parents of autistic children as the speculation about a causal link between autism and the MMR vaccine suggested that they would have a particular interest in immunisation and in the MMR vaccine. The second group of parents was those caring for immuno-compromised children. As I became increasingly aware that some parents questioned the need for immunisation, I wondered whether these parents were factoring the actions of others into their own decisions about immunisation, thus relying on herd immunity. To explore some of the issues relating to herd immunity further, the sampling frame was extended to include parents who had recently cared for a child with a compromised or deficient

immune system due to the effects of chemotherapy treatment for cancer. Additional criteria were developed with the help of a Cancer Support Worker. This meant that I only approached parents whose children were in the maintenance phase of their treatment, or had completely finished treatment. Including parents with children recovering from cancer meant they would be able to reflect on the problems that they encountered as a result of reintegrating children with compromised immune systems into mainstream society.

2.3.5 Sample selection: limitations

One limitation of the study was that, although the sample was diverse, some groups of participants were difficult to recruit. For example, it was difficult to obtain access to recruit parents who had opted for the single measles, mumps and rubella vaccines. Despite strenuous efforts, it was only possible to recruit three such parents into the study. (Box 2.1 shows the sampling frame).

Box 2.1: The sampling frame
First-time mothers, as well as mothers with previous experience of motherhood.
Fathers as well as mothers.
Parents living in affluent and deprived areas.
Parents with a range of vaccine decision-making outcomes.
Specific target groups
Parents of autistic children.
Parents with recent experience of caring for immunocompromised children following chemotherapy for cancer.

2.4 Group study design

2.4.1 Sample size: determining the number of groups

Since the aim of qualitative research is not to test for statistical significance, there is no formula for estimating sample size as is necessary in quantitative studies. Bloor et al. (2001) suggest that the appropriate number of focus groups will depend on the research plan including which sub-groups the researcher might want to target, which groups' views one might wish to compare, the variability of responses, and time and resource limitations. Zeller (1993) proposes that projects should consist of three to five groups. However, Barbour and Kitzinger (1999) suggest that the sample size in focus group studies can range from just three to over fifty depending on the scope of the study.

Whilst there is a range of opinions about how many groups are desirable, there is general agreement in the literature that it is wise to build in flexibility in the planning stage, and only to conduct as many groups as are required to provide a trustworthy answer to the research questions due to the costs involved. Morgan (1997) suggests that the most important factor in determining the number of groups is the "variability of the participants both within and across the groups" (p. 43). He considers that projects that bring together heterogeneous participants and projects that compare several distinct populations will typically require more groups in total because the diversity between and within groups "makes it more difficult to sort out coherent sets of opinions and experiences" (p. 44). He also suggests that lack of group structure and low levels of facilitator involvement increase the variability from group to group, and therefore the number of groups required.

Whilst aiming to provide trustworthy and full answers to the research questions, there was a need to be pragmatic about time and resources allocated for this study. The final number of focus groups conducted was 18 (excluding two pilot groups lost as a result of the recording equipment failing to work). This included three pilot groups and fifteen main study groups.

2.4.2 Determining the group size

Guidance on focus group methodology typically advises that the optimum number of individuals in a group should be between six and eight participants (Bloor, 2001) whilst market research literature tends to suggest larger numbers of between eight and twelve participants. Attempts to prescribe the ideal size of focus groups have led Barbour and Kitzinger (1999) to declare that: “Advice about group size and composition in existing guides to focus group research is often too didactic. This can seriously hamper imaginative, or even appropriate, application of focus group methods” (p. 8). The pilot work undertaken for this study suggested that much smaller groups with three and five participants were likely to be most suitable and productive for this study. Morgan (1997) highlights some of the advantages and disadvantages of running small focus groups. On one hand, he suggests that in some small groups it can be difficult to sustain active discussion because small numbers can be so sensitive to the group dynamics among the individuals. He also points out that ‘friendship pairs’, ‘experts’ or ‘uncooperative participants’ can easily disrupt the functioning of small groups (p. 42). Bloor et al., (2001) consider “...that small groups run the risk of cancellation if just one or two participants fail to turn up” (p. 27). On the other hand, Morgan (1997) suggests that small groups are useful when the researcher desires a clear sense of each participant’s feelings on a topic because each participant is given more time to talk. He suggests that small groups may be useful if the topic under discussion is a particularly complex one or if the participants are highly involved with topic. He concludes that: “small groups work best when the participants are interested and respectful of each others’ views” (p. 42).

Pilot work demonstrated that childhood immunisation and the ‘safety’ of MMR were topics that parents with young children were keen to debate with each other and most participants were quick to get involved in making contributions to the discussion. The larger groups of seven and eight participants presented problems because participants’ enthusiasm to express their views and opinions led to too many interruptions and too much ‘talk-over’. These groups were difficult to facilitate and there was a palpable sense

of frustration when participants did not feel they were given enough time to air their views. The persistent tendency of dominant participants to talk over other people meant that only a small proportion of those present were actually contributing to the discussion, and productive discussion was stifled. Attempts to bring in quieter members and to ask participants not to talk over one another made little difference. As a consequence these larger focus groups were difficult to transcribe, particularly when I was trying to attribute talk-over and sets of rapid interaction to specific members of the group. It was also difficult to analyse subtler group interactions. This led to the decision to use smaller groups for the main study. Smaller groups not only made it easier to encourage interrupted parents to return to any broken train of thought, but also allowed each participant to have enough time to explain themselves fully, so there were fewer interruptions and the discussions could be transcribed more accurately, allowing for more detailed analysis.

2.4.3 Determining the group composition

To determine the optimal focus group composition the researcher needs to consider two factors that may impact on the group dynamics. Firstly, whether to have homogeneous or heterogeneous groups, and secondly, whether to use pre-existing groups or whether to convene groups of individuals especially for the purposes of the study. In consideration of whether to have homogeneous or heterogeneous groups, Morgan (1997) suggests that participants must feel able to talk to one another, and warns that if the gaps in lifestyle or social background are too wide participants will not feel comfortable with each other. Similarly, Murphy (1992) considers that ‘to enhance freedom of expression, it is preferable that groups be homogeneous with respect to age, gender, and particular health problem or behaviour’. However, Kitzinger (1994b) takes a less prescriptive stance suggesting that whilst bringing together people on the basis of some shared experience is often productive, differences between participants can be illuminating. Morgan (1997) also warns ‘that if all the participants share virtually identical perspectives on a topic, this can lead to a flat, unproductive discussion’. In view of these recommendations I decided to aim to bring together participants from similar social backgrounds, and to try to avoid,

as far as possible, bringing together participants with opposing views on immunisation as this could result in high levels of conflict, and cause distress for parents.

In order to attempt to reduce variation within the groups, I recruited parents on the basis of a few key characteristics that were explicitly identified in the recruiting letters and posters. The careful planning that went into recruiting relatively homogeneous groups of parents meant that moments of conflict and upsetting situations that arose during discussion tended to be dealt with sensitively between participants, and participants were generally respectful of each others' opinions. This was particularly salient during discussions with parents of autistic children and parents caring for children recovering from cancer. However, even with careful planning there were still challenging moments. To illustrate; on one occasion members of a group were discussing what appeared to be a safe topic, when a young woman suddenly spoke of her wish for her severely handicapped sister to die. In response another woman spoke of her nephew's sudden death. These examples were not isolated and highlight how difficult it can be to anticipate the direction of discussion. What seemed to me to be an innocuous topic in fact triggered a series of sensitive revelations. Indeed, Farquhar and Das (1999) remind researchers that: "the sensitivity of a given research topic is not fixed, but socially constructed within a complex framework of taboos and norms, then sensitivity can be seen to be not only fluid, but highly unpredictable" (p. 51).

The other key consideration in determining the group composition was whether to use pre-existing groups or whether to bring together strangers. According to Bloor et al. (2001) market researchers have traditionally used groups of strangers, but the virtues of using pre-existing groups are increasingly being recognised. Indeed, Kitzinger (1994) argues that by using formed groups the researcher may tap into naturally occurring data and that they can provide one of the social contexts in within which ideas are formed and decisions made. Nevertheless, Agar and MacDonald (1995) warn that although acquaintances can converse more readily, this is often due to their ability to rely on the kind of taken-for-granted assumptions that are exactly what the researcher is trying to

investigate. Similarly, Barbour and Kitzinger (1999) consider that pre-existing groups are likely to have established their norms and to have hierarchies within the group. Nevertheless, they consider that using pre-existing groups can be a 'source of insight'.

This study consisted of focus groups that involved both some pre-existing groups, and some specially convened groups in order to answer the study's research questions. Sometimes it was impossible to recruit parents who were complete strangers because they were part of a wider support network; for example the groups run with parents with autistic children and children recovering from cancer. In other groups parents were familiar to each other only by sight because their children attended the same nursery or play scheme and there were also groups that brought complete strangers together who had never met, seen, or heard of one another. In consideration of the fact that it is sometimes impossible to recruit a full group of acquaintances and likewise that it is sometimes impossible to avoid it, Morgan (1997) advises that the decision should be based on the criterion of whether a particular group of participants can comfortably discuss the topic.

2.4.4 Determining the level of group structure

According to Morgan (1997) less structured approaches to focus groups are useful when the basic issues are poorly understood and when the goal is to learn something new from the participants. More structured approaches are useful when there is a strong pre-existing agenda for the research. This study used a less structured approach during the pilot work phase in order to reflect the exploratory nature of the initial enquiry and to allow participants the freedom to identify their own priorities for discussion. As the study progressed the approach became more structured, and my involvement as facilitator became a more prominent feature of the group discussion. A standardised topic guide was developed (see Appendix E) and several key questions were asked of each of the groups to make sure that all of the groups discussed these issues in a relatively comparable manner. However, participants were still encouraged to state their own views and where new ideas emerged participants were encouraged to explore them.

The key areas for discussion were:

- Understanding, experiences and beliefs about childhood infectious diseases.
- Perceptions about childhood immunisation and the vaccines within the programme.
- Perceptions about the safety of the MMR vaccine and current debate about it.
- Exploration of the factors that shape their decisions about vaccination, particularly in relation to the MMR vaccine.

2.5 Ethical considerations

Ethical approval for the study was obtained from the Glasgow University Ethics Committee.

2.5.1 *Informed consent*

Participants were provided with a simple but comprehensive information sheet (see Appendix F) either by myself or a gate-keeper usually a week before the focus group was held. Before commencing the focus group I checked that participants had read the information sheet and answered any questions they had about the study. Special care was taken to advise parents that it was unlikely that the study would be of direct benefit to themselves and that they were under no obligation to take part in the study, but that it was hoped that by participating in the study they might help future parents. Once this was explained they were each asked to sign a written consent form (see Appendix G) and advised that they could withdraw at any point from the session without giving a reason. At the end of the session participants were reminded that if they were interested in the findings of this study, a summary would be available to them on request once the study was completed.

2.5.2 Confidentiality

Before commencing the session I assured participants that: the data collected would be anonymised; pseudonyms would be used for participants and group location; and that only the members of the research team would have access to the tapes and transcripts. Participants were informed that all research documents would be kept secure for ten years and then destroyed in accordance with MRC guidelines on good practice. Once the transcripts were checked I immediately replaced the names of participants, their children, and partners with pseudonyms and logged the changes on a sheet of A4 kept separate from the transcripts in a locked drawer.

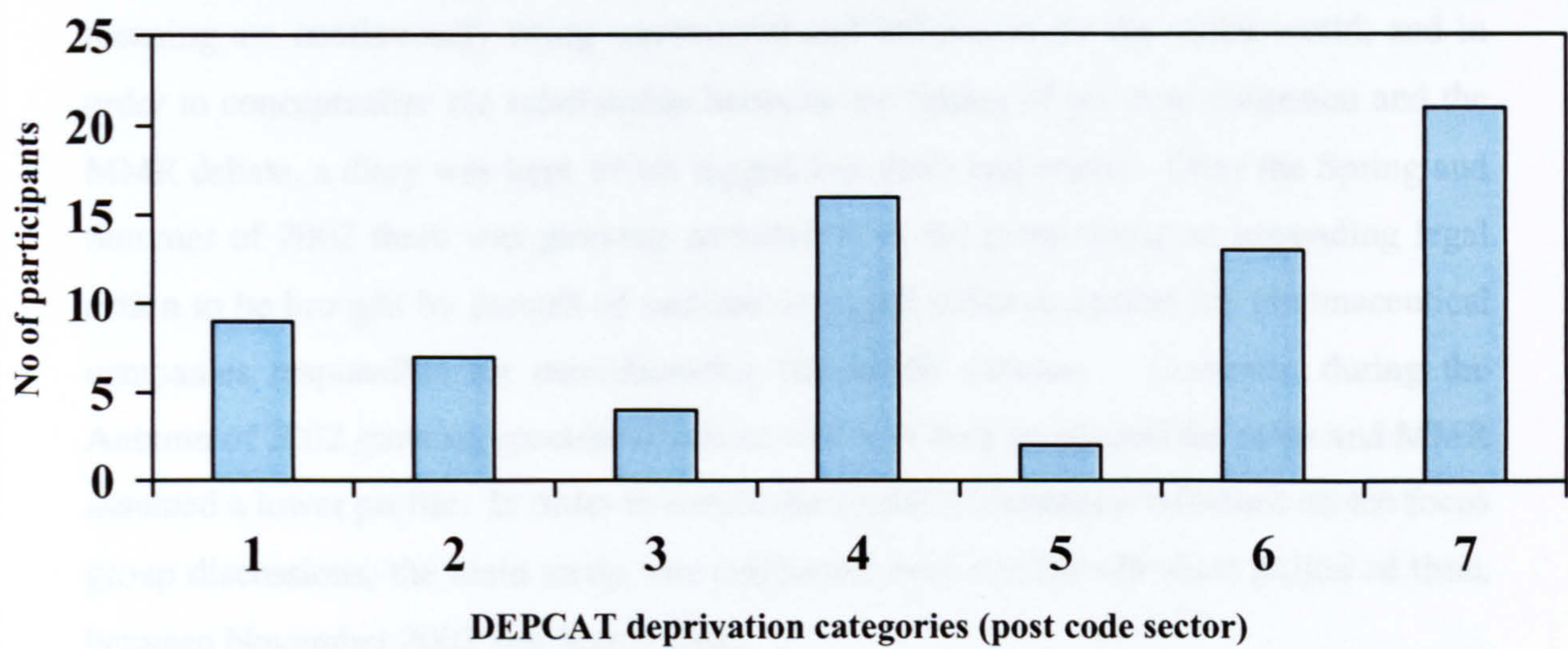
An ethical issue that arose during the course of the focus group work was that during discussions some participants misinformed the group on issues about immunisation or on particular vaccines. The dilemma I faced was that if I did not say anything participants might construe that I was legitimising inaccurate comments, but neither did I want to set myself up as an expert on immunisation. I occasionally felt it was appropriate to intervene during the discussion, to counteract the more potentially damaging comments. For example, one woman informed the group that a daughter's friend had contracted meningitis from the MMR vaccine and that experts were well aware of the link between MMR and meningitis. The horror on the other participants' faces indicated the need for clarity on this matter, but I generally refrained from intervening and used the debriefing session at the end of the focus group to clear up any misunderstandings. The debriefing session also offered the opportunity to hand out to parents immunisation contact details and leaflets produced by the Greater Glasgow National Health Service and the (then) Health Education Board for Scotland.

2.6 Characteristics of Participants

Seventy-two parents took part in the study. The sample included 64 mothers (age range 15 to 53 years, mean age 32 years), and eight fathers age (range 31 to 51 years, mean age 39 years). Forty-two parents described their marital status as 'married', fourteen as 'single', thirteen as 'co-habiting' and three as either 'separated' or 'divorced'. Appendix

H shows the characteristics of each of the 18 focus groups. Parents lived in a range of socio-economic areas. Figure 2.1 shows that the sample included more participants living in more socially deprived areas (DEPCAT 4 to 7).

Figure 2.1 The areas in which participants lived



Thirty-eight parents described their youngest child’s immunisation status as ‘complete’, that is, up-to-date for their age, having received all the recommended vaccines in the Childhood Immunisation Programme. Twenty-four parents described their child’s immunisation status as ‘partial’. This category included five parents who had fallen behind schedule with some of the vaccines, twelve parents who had decided not to have one or more of the recommended vaccines in the programme, and seven parents who were undecided about whether to immunise their child with the MMR vaccine. The third category, ‘none,’ comprised of six parents that did not plan to immunise their children with any of the recommended vaccines although two stated that they planned to use alternative homeopathic protection. The fourth category described as ‘other’ included two parents who did not know the immunisation status of their child because they were not living with the child, and two parents with children under eight weeks old who were too young to be immunised.

2.7 Conducting the study

2.7.1 *Timing of the main study*

Appendix D shows a timeline of the key events in the MMR controversy and how these relate to the data collection for this study. In recognition of the view that place and meaning are continuously being constructed and influenced by the social world, and in order to conceptualise the relationship between the timing of the data collection and the MMR debate, a diary was kept which logged key dates and events. Over the Spring and Summer of 2002 there was growing speculation in the press about an impending legal action to be brought by parents of vaccine damaged children against the pharmaceutical companies responsible for manufacturing the MMR vaccine. However, during the Autumn of 2002 growing speculation about war with Iraq dominated the news and MMR assumed a lower profile. In order to reduce the media's immediate influence on the focus group discussions, the main study was conducted over a relatively short period of time, between November 2002 and March 2003.

2.7.2 *Access and recruitment*

Recruiting participants for this study was a complex and time-consuming undertaking, primarily because eleven of the groups were specially convened for the purposes of the study. These groups took longer to organise than the seven pre-existing groups. Bringing participants together to form a group involved negotiating with different gatekeepers and required co-ordinating busy parents to co-operate in travelling to a common venue.

The decision mainly to bring together groups of parents for the purposes of the study, rather than to access only pre-existing groups meant that there was an increased dependency on gatekeepers. One of the difficulties of relying on gatekeepers highlighted by Barbour and Kitinger (1999) is that they may inadvertently or advertently screen potential participants. To minimise the influence they had in selecting potential

participants, I generally asked them to pass covering letters and information sheets to all the parents in their group, so that participants could decide themselves whether or not to participate. On several occasions gate-keepers played a minimal role and did not have any direct contact with the participants. However, they were still useful in giving me access to premises so that I could place posters advertising the study in strategic places, or in granting permission to conduct a focus group on the premises. There were also occasions when the knowledge and experience that gate-keepers possessed were useful in helping to screen potential participants. For example, it was advantageous to have gate-keepers to help screen participants for the immuno-compromised groups. In this group deliberate attempts were made to screen out parents with either very ill children in the middle of treatment, or parents whose children had died.

Once potential gate-keepers were identified, they were contacted by telephone to ask if they might be interested in helping me contact relevant parents. If they agreed, they were sent information about the study or a meeting was organised to discuss the study. The information sheets provided information about the study (see Appendix F), detailed the anticipated uses of the findings, and identified the Medical Research Council as the funder. They highlighted the number of participants required, the expected duration of the discussion, and the fact that the discussion was to be recorded. They also gave reassurances about confidentiality and anonymity, and my name and contact details.

Discussions that were organised with pre-existing groups were set up with relative ease once the gatekeeper had received the information sheet. Where possible I met with the group to hand out information sheets in person and to arrange when to carry the focus group. Where recruitment involved bringing together new groups, gate-keepers were either given brightly coloured posters inviting parents to take part, or given envelopes containing a study information sheet and cover letters to be handed to parents (see Appendix I). The cover letters were tailored to meet the individual requirement of the group. The letter included a short description of the study, an invitation to join a focus group and stated that participants would receive £10 towards any expenses incurred.

Once parents had received the letters and information sheets, it was up to them to make contact with myself.

2.7.3 Recruitment difficulties

Ensuring attendance is a problem facing researchers using focus group methods. Morgan (1995) asserts that inadequate recruitment efforts are the single most common source of problems in focus group research. Bloor et al. (2001) considers that it is standard practice to recruit more participants than required on the assumption that a number will not turn up on the day. However, following this suggestion meant that in one of my groups there were eight participants when I really only wanted four or five participants. On the other hand, because I preferred to use small groups, under-recruitment could have meant that nobody turned up. In order to recruit low numbers of participants for each group I realised that it was not just enough to simply locate participants and get them to agree to turn up, so I developed additional strategies for recruiting. Once participants agreed to take part I kept in contact with them via the telephone and email, contacting them the day before to check they were still available to attend. Whilst this meant that on a couple of occasions groups needed to be re-convened, it ensured that no group was cancelled at the last minute.

However, despite my best attempts some groups were difficult to set up. For example, setting up the Single Vaccine Group involved negotiating with two gate-keepers over an eight week period; these negotiations consisted of three letters, eight telephone conversations and one meeting. From this it was agreed that clinic staff would hand out 180 cover letters and information sheets to parents attending the private clinic for the single vaccines over a weekend. In the letter parents were asked to contact me if they were interested in taking part in a group discussion. Unfortunately, these efforts only resulted in three parents contacting me, which was puzzling given the fact that these parents were obviously motivated and concerned enough about the MMR vaccine to have sought three separate injections at considerable expense and inconvenience. On reflection, one explanation may be that the gate-keepers did not grant me access to speak

to the parents directly and therefore I had to rely on them contacting me and was not able to send a reminder letter. Nevertheless, it highlighted the important role gate-keepers can play in assisting recruitment.

The success of recruitment may also depend on the choice of venue. Known venues within easy access to the participants are generally advocated (Barbour and Kitzinger, 1999). Whilst I endeavoured to do this as far as possible, I found that for some of the more specific groups, (such as the 'single' vaccine group, the autism groups and one of the non-MMR groups) there was no obvious meeting place. These parents lived in different parts of Glasgow and the surrounding areas. Some of these parents travelled several miles in order to attend the group and I ensured travel expenses were fully reimbursed and encouraged transport by taxi where appropriate. Where possible, groups were convened in local community centres, churches, leisure facilities, schools or support centres, but where no mutual meeting place existed small conference rooms were booked in conveniently located hotels.

2.7.4 Recording, transcribing and overcoming recording difficulties

Audio-recording appears to offer the best possible method of ensuring an accurate record of focus group discussion (Bloor et al., 2001; Barbour and Kitzinger., 1999; Murphy et al., 1992). Initially I used a mini-disc recorder with an external flat microphone, but problems with the mike attachment meant that the recording for one pilot group was of such poor quality that the transcript was unreliable, and therefore not included in the study. Data from a second group were lost when the recorder failed to work. This led me to change recording equipment and instead to use a high-quality tape recorder with an external multi-directional flat mike. In addition to the tape recorder, and perhaps a reflection of my own growing paranoia, I used a discrete digital Dictaphone as a back up. The tape recorder was placed nearby under the table and the mike and Dictaphone were strategically placed on the table to ensure that all the members of the group were being adequately recorded. Before switching on the recording equipment I reminded

participants of the intent to record the group discussion and explained that the recording equipment was there to ensure that I would obtain an accurate account of what was said.

Comprehensive field notes were also recorded on the Dictaphone and logged in a diary. These data included observations on the characteristics of each participant in the group, and on participant exchanges and interactions and group dynamics. To aid voice recognition, I drew a sketch of the room including the participants' seating arrangements and assigned the more memorable comments or stories to the individual participant drawn on the sketch. The diary also included reflections and thoughts on the content of the discussion, my own feelings about 'how facilitating the group went' and any problems encountered.

There is agreement that the transcripts produced from focus group data are distinct from data collected by other qualitative methods, because of the emphasis placed on group interaction. Drawing on a study of AIDS media messages, Kitzinger (1994a) recalls the chaotic nature of focus group data, describing how participants brainstormed, argued, misunderstood and ridiculed each other. She details instances of over-talk and where sentences were unfinished, or where participants contradicted themselves and others. In a later text, Barbour and Kitzinger (1999) also reason that focus group transcription can be difficult to interpret because participants tend to make sudden, apparently 'illogical' leaps. All these traits of focus group transcripts were features of the transcripts in this study and meant that transcription was time-consuming. Barbour and Kitzinger (1999) suggest that focus groups should be carried out in rooms that are '...quiet, comfortable, and free from interruptions...' (p. 11), but in practice there were a few occasions when groups had to be held in less than ideal circumstances. There were times when nursing mothers needed to feed their babies or an older child being looked after in a nearby room was upset and wanted to rejoin their parent.

I transcribed the pilot groups myself but because of time constraints sent the main group tapes to be transcribed by a specialised audio-typist. Focus groups can generate large

amounts of data: for example, Bloor et al., (2001) estimates that a 90-minute session can create more than 100 pages of transcript. Whilst the duration of the groups in this study was shorter (lasting between 55 minutes and 82 minutes), these sessions could still generate transcripts of up to 56 pages in length. Despite the shorter transcripts and the assistance with transcription, the process of ensuring each transcript was accurate was time-consuming. Each transcript took between eight to twelve hours to check accuracy of dialogue, identify participants and to add in additional notes or impressions. Once participants were identified each participant was given a pseudonym and then the transcript was imported as a rich text file into NVivo.

2.7.5 Facilitating the groups

Generally the groups took place around a table, and chocolates or biscuits and teas and coffees were provided to create an informal setting and relax participants. Prior to commencing the discussion, participants were reminded that the discussion was expected to last approximately one hour and that they could withdraw from the group discussion at any time without giving a reason. Once consent forms were signed, a short questionnaire (see Appendix J) was handed to each participant to collect some basic demographic information including; name, post-code address, age, marital status, occupation and details on their children's immunisation histories. During the sampling phase this information assisted in monitoring sample socio-economic and demographic diversity and helped ensure that the sample contained a mix of parents with respect to vaccine decision-making outcomes. I reviewed the questionnaires briefly before commencing the discussion. The responses provided useful background information and I frequently noted remarks or interesting stories from participants on the back of their questionnaires to help with later identification.

The running order of the topics and questions generally involved starting with a broad question on immunisation, while more specific ideas about the MMR debate and childhood diseases were explored towards the end of the group. The decision to order questions this way was made to gently broach the subject of immunisation in a non-threatening way. On completion of the group discussion parents were also given contact details of support groups, the National Service Helpline and Immunisation Public Health

specialists working for Greater Glasgow National Health Service. In addition, parents were offered the opportunity to take away with them a selection of recently published leaflets on MMR and childhood immunisation, produced by the Health Education Board for Scotland and Greater Glasgow National Health Service Board. After the de-briefing session I generally stayed around so that participants could speak to me privately if they wished to do so. There were several occasions when participants wanted more information. For example, one parent with a child with autism wanted the details of a recently published report carried out by the Medical Research Council on autism, and I later sent her the report details. But there were many occasions when participants just wanted to talk about something they had said or felt during the discussion. These comments were logged in my field notes when appropriate. In order to ensure everyone had the opportunity to have their say, reply-paid envelopes were provided at the end of the discussion for those who wished to post further comments. In the event no one posted back any comments. Before leaving, parents were thanked and advised that if they kept my details they could request a summary of the findings once the study was completed.

2.7.6 Facilitator skills, persona and reflexivity

In contrast to the naturalistic paradigm defined by Holliday (2002) that suggests that substantiation is gained via minimal researcher interference using a 'fly on the wall approach' (p. 20), this study required that I intervene from time to time. An essential aspect of facilitating the groups was to ensure the validity of participants' responses, so that ambiguous statements could be clarified (where possible), incomplete sentences finished, and all participants got the opportunity to speak. Therefore during discussions I sometimes prompted participants to explain, confirm or justify their position so that their opinions could be examined in greater depth. However, the decision to intervene needed to be balanced with the need to keep quiet (Barbour and Kitzinger, 1999) and I tried to carry out any intervention in a non-threatening, non-judgmental manner, to avoid participants feeling under pressure. In general, I felt my role was to keep the group relatively focused on the topic areas, but to be a background figure in the group, keen to learn from them, rather than a controlling, knowledgeable foreground figure. Indeed,

Bloor et al. (2001) advise that a facilitator who seeks to control the group may be doing the study a disservice because the group norms and interactions may be distorted. However, despite my attempts, there were many occasions when parents asked me questions on the vaccines or on specific childhood infectious diseases, and I had to explain that I was not an expert on immunisation and would give them information on immunisation at the end of the session. I decided that I would not tell parents that I was a qualified nurse or midwife because neither training course included much education on childhood immunisation (work largely undertaken by health visitors, practice nurses and GPs). Less clear-cut in my mind was whether to tell participants that I was a parent. After careful consideration I decided that I would not tell participants that I have children to try to avoid taking on the role of an experienced parent. Nevertheless, there were several occasions when parents asked me if I had any children and whether I had had them immunised. In this situation I revealed that I did have children and that they were all fully immunised, however these conversations all occurred during the debriefing sessions after the focus groups were completed.

My prior experience in carrying out qualitative research using one-to-one interviews and focus groups was useful in developing group facilitation skills; however I probably drew on my wider life experiences equally. For example, in one group conducted with young mothers living in a deprived part of Glasgow one fifteen-year-old mother did not speak once during the whole session despite looking happy to be part of the group and keenly listening to what the other group members were saying. Perhaps previous experience of working closely with people meant that I felt acutely aware of her vulnerability and it felt appropriate to let her silently take part, rather than to focus any attention on her by encouraging her to talk. Importantly, in her silence she interacted with the other members of the group. On one occasion when her friend spoke she squeezed her friend's hand and smiled supportively and I felt sure that her presence was reassuring to her friends. At the end of the session when I was asking for everyone to fill in the receipt for payment forms her friend discreetly took her form and filled in the details on her behalf. Later it turned out that she was unable to read and write and had not spoken much since being in an abusive relationship that resulted in her becoming pregnant and having a son. I was glad

that the gate-keeper who had organised the group had told her about the discussion and felt sure that the discussion was richer for her presence.

2.8 Focus group analysis

2.8.1 *Which analytical approach?*

One of the advantages of using focus group methods is that it can generate rich and dynamic data by encouraging discussion between group members. However, whilst methodological textbooks often highlight that analysis of group interactions provides the researcher with unique and rich data, there is very little guidance on the analysis of group interactions. Perhaps the most insightful contributions on this were from the experiences of researchers in Barbour and Kitzinger's 'Developing Focus Group Research' (1999) book in which Frankland and Bloor suggest using deviant case analysis in the analysis of focus group data. They consider that the lack of detailed advice on the analysis of focus group data may be due to the fact that focus groups have developed from market research, where less emphasis has traditionally been placed on rigorous analysis. However, deviant case analysis often involves collecting and analysing simultaneously to explore new propositions and I was not able to either return to the participants for later clarification or to collect additional data. Nevertheless, reading about this approach heightened my awareness of the importance of concentrating on 'deviant' or contradictory cases to explore some of the less obvious aspects of parents' perceptions and decisions about immunisation. Another approach I drew upon to ensure that analysis was systematic was the constant comparative method. Although Glaser and Strauss (1967) developed this method for theory-building, Lincoln and Guba's (1985) later adaptations to the method meant that its use has become suited to other inductive approaches to data analysis. Although I was unable to find any real-life detailed examples of research using this method, textbooks such as Maykut and Morehouse (1994) offered useful step by step instructions. This approach was useful in highlighting how systematic and simultaneous comparison of all the units of data could be conducted to ensure that all the data from all the cases would contribute to some extent in the analysis, thus avoiding the selective use of data. It also proved useful in illuminating

silences in the data as the approach was ideal for comparing how discussion on similar topics varied between groups. Perhaps crucially there was a need to consider how to analyse group interaction.

2.8.2 Group analysis: balancing the group picture against the voices of the individuals

According to Catterall and Maclaran (1997) understanding group dynamics in focus group research is important for two reasons. Firstly, as discussed earlier in the chapter, understanding group composition helps researchers identify the conditions that promote interaction and open discussion amongst participants. Secondly, it helps them to appreciate what was happening in the group and why it might have been happening. It is the second aspect of group dynamics, often termed ‘group effect,’ that I wish to consider here. On one hand ‘group effect’ is to some extent viewed in negative terms, as a threat to the authenticity of individual participants’ views. The inference is that the group effect may distort the views of the individual members. On the other hand, the counter-argument is that the ‘group effect’ is a considerable resource in exploring how accounts may be altered, opposed or censured through group interaction, representative of real-life interactions. Indeed, Myers and Macnaghten (1998) challenge the idea that opinions and attitudes are attributes of research participants at all, and suggest that all conversation is influenced by the context in which it is generated. Barbour and Kitzinger (1999) consider that, in order to analyse focus group data, consideration needs to be balanced between looking at the picture provided by the group as a whole and recognising the individual voices within it. They suggest that the researcher should aim to:

...distinguish between opinions expressed in spite of, or in opposition to, the group and the consensus expressed or constructed by the group. Analysis will involve, at the very least, drawing together and comparing discussion of similar themes and examining how these relate to the variation between individuals and between groups (p. 16).

To enable me to become more familiar with the data and to construct an interpretive version of what I considered to be the interplay between what was said and the context in which it was said, I read my field notes of my observations on the group dynamics of each focus group. I also listened to the tape recordings whilst annotating the margins of the transcripts with thoughts about the group interactions between participants. Notes

were made about agreements and disagreements between group members and on how these arose or were modified by the group. This was a useful means of building a picture of the issues which participants disagreed on. It was often less apparent which issues participants agreed on from reading the transcripts, and the field notes made about participants' body language and facial expression proved particularly useful in this respect. At this stage it was also noted which participants remained silent and on which subject, and whether they appeared to be self-censoring an alternative point of view, or whether they appeared to have no view to offer on the subject. Indeed, knowing how to interpret passive voices was extremely difficult and whilst there were many times I intervened to encourage participation during the focus groups, at the analysis stage representing silence was done by annotating the margins of the transcript. Indeed, on reflection, this part of the process was one of the most challenging aspects of focus group analysis and striking a balance between analysing the content of what was said and determining how and sometimes why it was said, was far from straightforward. There were many instances when participants were interrupted or silenced by other group members, or when participants would not be drawn on a subject and seemed impartial to any viewpoint. These situations were difficult to interpret and I often inserted bold question marks in the text of the transcript to show my uncertainty. During this stage in the process short descriptions were added to the transcript on how sensitive moments were managed, how jokes were used, and how minds were changed or where participants contradicted themselves or each other. Key questions I asked of the data were: why did the participants say what they said? And what were the responses of the other group members? The outcome of this process was that each transcript seemed more complicated and unwieldy than it had before, and so began the process of organizing and coding the data to enable systematic comparisons to be made across all the data.

In an attempt to show that analysis was conducted systematically and rigorously, and that neither the content, nor the process were treated as separate units of analysis and to acknowledge the continuous interplay between these two levels of analysis, a more detailed account of the analytical process is now presented.

2.8.3 Organizing and coding the data using QSR NVivo 2.0

Despite concerns over the methodological implications of using software in qualitative analysis (Catterall and Maclaran, 1997) the use of Computer Assisted Qualitative Data Analysis Software (CAQDAS) has become a popular organisational tool for qualitative researchers. Concerns have largely centered on the extent to which the requirements of the software might alienate the researcher from their data and distort the underlying context and meaning of remarks (Kidd and Parshall, 2000). With respect to using software to organise focus group data this later concern may be particularly relevant in view of the complex group interactions. As Catterall and Maclaran (1997) have observed there is relatively little discussion in the social science literature on the use of CAQDAS with focus group data. In an attempt to identify issues specific to the computer-aided analysis of focus group data, they reviewed the literature and concluded that:

...the focus group is not simply a data gathering technique where data collected are analysed for their specific content such as all text relating to a particular theme. Important and potentially insightful communication and learning processes occurs in focus groups as a result of participant interaction. These processes in the data can only be identified by several readings of the whole transcript and tracing an individual's text in the context of other participants' text; this is difficult to effect on-screen. Thus, we recommend that transcripts are coded on-screen for content and off-screen for process (p. 1).

Nevertheless, with the new generation of more advanced computing packages the argument that the process of group interaction would be lost if coded electronically now seems outdated. Indeed, Richards (1999) asserts that the software package NVivo is designed to preserve and enhance richness of records, and that data can be connected electronically in many ways. Similarly, Kidd and Parshall (2000) used a software package to enhance rigour in the analysis of the large amount of data generated in their focus group study. In order to pay attention to the group interaction they suggest coding large chunks of narrative, including questions, comments, asides and elaborations, as well as the coding for content. In essence they used a combination of broad-brush coding for certain types of discourse, and fine-grained (line-by-line) coding of substantive content.

Feeling daunted by the amount of data, and persuaded that a software package could be used sensitively, I imported the transcripts into NVivo 2.0.

The first step in the process of analysis was to code pieces of transcripts thematically to allow for a full range of later possible interpretations of the data. These sections were commonly assigned several thematic codes in order to allow for a number of different interpretations. I used the speed-coding bar to attach codes to extracts of text pertinent to particular themes or topics. In an attempt to avoid hierarchical thinking and to keep the codes free of organisation, I decided to code the transcripts using the 'free-node' option. Richards (1999) suggests that free nodes are useful when categories are being created from the data early in coding. At this stage in the analytical process, thematic coding of the transcripts gave rise to 72 free nodes. However, as Bloor et al. (2001) advise, in the early stages codes should be kept quite broad, and become narrower as the study develops.

In order to check and compare all the text carrying the same code, I used the search tool to retrieve all the extracts of data that were pertinent to a particular free node. This allowed me to read and check that I had included all possibly relevant material, that the coding had been systematic and that I had not excluded relevant material. Once this check had been completed, I re-read the whole transcripts and using these nodes mapped out tentative relationships between them on pieces of A4 paper. This visual mapping of the nodes was transferred into a PowerPoint presentation and with the help of my two supervisors we identified key themes, and started to build a coding frame around the key areas of interest.

In order to avoid losing the richer picture of group interaction and conversation referred to by Reed and Roskell (1997), I worked between a version of the whole transcripts with the coding strips and group interactions on them, and the retrieved extracts of data pertinent to a particular free node. I decided not to follow Kidd and Parshall's (2000) suggestion of coding both content and group interaction separately as it would have been too time consuming with little benefit over the method I used. As I became more familiar

with the data new codes emerged and some of the old codes were changed. In this respect this part of the process was essentially inductive in nature and the process of reading, coding and describing the data was cyclical. Any changes to the codes were logged in my research diary and I then returned to earlier transcripts and made these new changes. As the coding frame became more refined the number of free nodes increased from 72 to 96.

2.8.4 Describing, interpreting and reporting the data

As I began to think and write about the data more conceptually, mapping codes on paper became a useful way of building up ideas and linking ideas into webs of theory. At this stage Richards (1999) suggests the re-coding of free nodes into tree nodes to help clarify concepts and illustrate relationships between codes and their sub-codes. However, I decided not to re-code the data on the grounds that it seemed to offer little analytical benefit to what already seemed a complex task. In this respect it could be argued that NVivo was not used to its full coding potential. Nevertheless, at this stage I felt NVivo had served its purpose in enabling me to code the data rigorously.

In the early descriptive stages I found it useful to count participants' comments to get an overall impression of the data. However, this approach was only useful where discussions had been quite structured. For example, this approach was useful in relation to the question and answer exchange that occurred across all the groups on participants' perceptions of the various childhood infectious diseases. However, most conversation was more unstructured, and crude strategies such as tallying-up would have been unhelpful in offering a realistic representation of the data. The only way I found to make sense of this more complex data was to compare and write interpretive and descriptive summaries of this data. However, in reviewing the methodology of over 40 published reports that purported to use focus groups, Kitzinger (1994) noted that none of the studies reported on the interactions between participants. She states that she "...could not find a single one concentrating on the conversation between participants and very few that even included any quotations from more than one participant at a time" (p. 139). To decide on

the best way of reporting participants' speech Myers and Macnaghten (1999) suggest that longer quotations should be given and that as a minimum the preceding turn of speech should be reported. However, in practice I felt the danger of uncritically adopting a set procedure in my writing was that it may become bland, and moreover the chaotic nature of focus group conversation meant that the preceding comments were not always relevant. Thus, I decided that the majority of quotes would reflect the discussion between participants, and that individual comments and the preceding turn of speech would only be included where appropriate. Similarly, a balance needed to be struck between offering a summary of the discussions and using direct quotes. I tended to use direct quotes that seemed important, or offered rich examples of the topic under discussion, and summaries of discussion that were either less important or more amenable to being condensed.

Another consideration in reporting the data related to the kind of language most appropriate to convey the varying levels of agreement or disagreement between the participants, and to offer an accurate representation of participants' opinions. Although occasionally participants' opinions on a given topic were counted, this was only used to give an initial and superficial impression of the data. In general I felt that employing numbers to portray an accurate picture of this complex data in the findings chapters would be inadequate. After reviewing several other researchers' theses, I decided that descriptive words such as some, commonly, rarely and exceptionally would be helpful in communicating this overall picture.

Following these principles, the next four chapters describe and explain the findings from the 18 focus groups.

Chapter Three: Understanding, experiences and beliefs about childhood infectious diseases

The purpose of this chapter is to describe and explain parents' understanding, experiences and beliefs about childhood infectious diseases.

3.1 Summary of literature on perceptions about childhood infectious diseases

Understanding parents' experiences and beliefs about childhood infectious diseases is important because the success and acceptability of immunisation may depend, to some extent, on parents' assessment of the diseases from which the vaccines aim to protect. As Dr David Salisbury, a leading specialist in infectious diseases in the Department of Health, observed:

If parents have fear of disease but no fear of vaccines, the argument in favour of vaccination is clear-cut. If they have no fear of disease but also no fear of vaccine, there may be inertia. When they have no fear of disease, but fear of vaccines, parents are likely to refuse immunization (Gellin et al., 2000 p. 1097)

Likewise, Bedford and Elliman (2000) have proposed that because many parents have no experiences of the diseases prevented by immunisation, they do not appreciate how damaging these diseases can be.

However, despite these assertions there are surprisingly few studies that have explored parents' perceptions of childhood infectious diseases in any depth. Typically, studies have tended to concentrate on parents' perceptions of the vaccines, rather than on the diseases (Klein et al., 1989; Raithatha et al., 2003) or alternatively to limit the focus to a few diseases, most recently measles, mumps and rubella (Pareek and Pattison, 2000). Where studies have considered parents' views on a range of vaccine-preventable diseases they have tended to focus on perceptions of disease severity and prevalence rather than

on describing parents' experience or beliefs about the diseases (Bond et al., 1998; Sporton and Francis, 2001). For example, Bond and colleagues (1998) conducted a study in Melbourne, Australia, to investigate mothers' perceptions of vaccine-preventable diseases in terms of perceived susceptibility, severity, benefits and barriers. They used a purposive sampling strategy to include mothers of children with different decision-making outcomes and to include first-time mothers and more experienced mothers. Semi-structured interviews were conducted with 45 mothers. Bond and colleagues found that mothers perceived poliomyelitis, diphtheria, tetanus, and meningitis as serious diseases that were life threatening, but with the exception of meningitis, considered that their children were unlikely to contract any of them. They also found that mothers assessed measles, mumps and rubella as not serious. In a recent UK study, Smailbegovic and colleagues (2003) explored parents' perceptions about vaccine-preventable diseases. They mailed questionnaires to 129 parents living in the London Borough of Hackney whose children had not completed the recommended course of immunisation. Parents were asked to rate the seriousness of each of the vaccine preventable diseases included in the Childhood Immunisation Programme as very serious, serious or mild. More than 50% of parents rated meningitis as the most serious and rubella as a mild disease. The fact that there are no in-depth studies that explore parents' understanding of, or beliefs about, the specific diseases suggests a need for further research in this area.

The current study set out to explore participants' perceptions and experiences of diseases more comprehensively by asking participants in each focus group to describe their images and experiences of each of the vaccine-preventable diseases included in the Childhood Immunisation Programme. In order to tap into participants' factual knowledge about each of the diseases, they were asked to describe how they would recognise it and how they thought it was transmitted. I was aware that by asking knowledge-based questions there was the risk that discussion could become derailed if participants did not know much about the diseases. So in order to make it as unthreatening as possible, this topic was introduced late in the discussion once the group members appeared comfortable with one another. Also, before beginning this more

structured part of the discussion, participants were reassured that all of their views about factual and non-factual issues were of equal interest and importance.

In fact, these question and answer exchanges led to enlightening and lively discussions and participants generally appeared to enjoy them. Perhaps most surprising was the fact that participants appeared comfortable admitting to one another that they did not know much about some of the diseases. There were no groups in which one person appeared to know vastly more than the other members of the group, and whilst some of the older participants in the groups had vague recollections of some of the diseases, younger participants appeared fascinated to hear their accounts. Further, even when participants had no direct experience themselves of the diseases this did not preclude them from describing vivid images of the disease, albeit sometimes inaccurately. Three key themes emerged from these discussions on disease perception:

- Understandings, images and beliefs about diseases
- Perceived threat of disease
- Experience of disease (both direct and indirect)

Guided by these themes this chapter presents an in-depth account of participants' understandings, beliefs and experiences of the individual diseases included in the Childhood Immunisation Programme. Each of the diseases is considered in order of perceived disease severity, as described by participants, so as to reflect their views on which of the diseases pose the greatest and smallest threat to their children's health. Participants' accounts of diseases are interspersed with factual textbook accounts of the diseases to enable some immediate comparison. However, for a more comprehensive clinical and epidemiological picture of each of the disease see Appendix K. Throughout the chapter data extracts are preceded, or followed, by discursive commentary to highlight the significance of participants' comments and to show where their comments link into the wider debate on immunisation. The chapter concludes with a summary of the main findings to have emerged from these discussions.

3.2 Participants' accounts of vaccine-preventable diseases: From major to minor

Within each of the groups participants were asked to identify which of the vaccine-preventable diseases covered by the Childhood Immunisation Programme they considered to be the most severe. From discussions on these topics it emerged that participants categorised diseases into three quite distinct groups, largely dependent on whether the diseases were perceived as a tangible or theoretical threat to their child's health. The first category consisted of diseases that participants categorised as posing a major threat to their child's health. These diseases included meningococcal disease and to a lesser extent measles and whooping cough. Although rubella was described as a mild disease, it was viewed as a major threat because of the serious harm that it could do to unborn babies. The general consensus that emerged from the focus groups was that meningococcal disease was perceived to be the most severe of all the diseases included in the programme. Participants appeared to find it easy to conceptualise what 'severe' meant and equated it with meaning 'life-threatening', or with having a long-lasting damaging impact on their child's health. Conversely, participants conceptualised 'minor' as being non life-threatening, and not causing long-lasting damage. Participants viewed mumps and haemophilus influenza as minor. The third category consisted of diseases that were described as no longer posing a threat to their children whilst living in the United Kingdom. Diphtheria and poliomyelitis were both viewed as 'no longer posing a threat'.

3.3 Diseases considered: 'A major threat'

3.3.1 Meningococcal disease group C: A tangible threat 'a killer'

In Scotland there are between 300 and 400 notifications of meningococcal disease each year, of which sero-type group C is most common, causing acute bacterial meningitis. The symptoms usually start abruptly and as the severity of the disease progresses the

outcome may be death or complications such as: septicaemia, neurological damage, or impaired hearing (see: www.show.scot.nhs.uk/scieh/surveillance).

With the exception of the Non-Vaccine Group, there was very little variation between the groups in suggesting meningococcal disease and its associated meningitis was the most severe of the diseases. Participants most often cited meningitis caused by meningococcal disease as ‘life-threatening’:

Facilitator: Which of those then do you think are the most severe, or which are the ones that you would worry about most. Is that the same thing?

Angie: I’d say personally the meningitis and measles.

Facilitator: What about everyone else, is that...?

Tracy: I’d say meningitis. (Everyone nodding yes)

Lydia: Meningitis.

Facilitator: What is it then, about that?

Angie: They can be life-threatening mair than anything else.

Facilitator: Mhm. Is that the same for everyone?

Samantha: Uhuh. (All the group agreeing-nodding heads)

Crafts Group: Angie aged 29; Tracy aged 32; Lydia aged 39; Samantha aged 24

Not only was there a high level of agreement between the groups that meningococcal disease was the most severe, but also within each of the groups. This agreement between participants was particularly noticeable in the Low Uptake Area Group:

Facilitator: So which of these ones do you think are severe and which would you say are mild? Are any of them mild, and are any of them severe?

Joan : They’ve all got different bad points.

Sheila: I think you think of the meningitis as being the...

Joan: The killer... (interrupted by Sheila)

Sheila: The killer. Aye. Definitely... (interrupted by Alan)

Alan : The killer aye. I would say that would be the worst. (All nodding their heads in agreement)

Low Uptake Area Group: Joan aged 20; Sheila aged 36; Alan aged 33

In this particular group, agreement between participants tended to be validated by group members using encouraging body language, such as approving nods of the head, by repeating the same words, and by rapidly completing each other's sentences.

Meningococcal disease was directly associated with meningitis. Participants almost without exception were able to accurately describe, in detail, the disease process from first signs of the infection to coma or eventual death. The symptoms they described included a red rash, severe headache, stiff neck and light sensitivity (photophobia). Perhaps unsurprisingly, meningococcal disease was described as "...your worst fear" (First-Time Mothers Group; Catrina aged 27) and was commonly associated with a speedy death. Participants spoke at length on this disease and attributed their knowledge to the high profile Men C publicity campaign. Jill described the posters advertising Men C vaccine as being "etched in ma brain" (Outpatient Cancer Group; Jill aged 38). Similarly, Aleena stated "well, it's a lot more publicised isn't it? You see the signs and symptoms of meningitis everywhere really. Don't you? It's well publicised" (Non-MMR Group; Aleena aged 35).

Whilst it was common for participants to be aware of the Men C campaign and knowledgeable about meningococcal disease, participants in the Non-Vaccine Group appeared oblivious to the campaign despite, as parents of young children, being a prime target of the 1999 campaign. Kitty reviewed the immunisation schedule handed out during the focus group and noted:

Kitty: Em, I don't really know anything about this meningitis C (pointing to schedule) to be honest, really, all I know is that it's something that students have been getting, or something. I don't really know anything.

Debbie: Big people. Small people don't get it.

Lola: You know, I didn't even realise that it was included in the 4 in 1 injection. It's just new, yeah. It wouldn't have applied when my children were born, em...

Molly: Well none are really life threatening as such now... (goes on to talk about diphtheria and whooping Cough).

Non-Vaccine Group: Kitty aged 37, three children younger than 6 years old; Debbie aged 33, four children younger than 5 years old; Lola aged 32, three children younger than 6 years old; Molly aged 37, two children younger than 5 years old

The comments made by the Non-Vaccine Group inaccurately suggested that students were the only people at risk from meningococcal disease. They also inferred that their own children were neither at risk from the disease, nor eligible for the vaccine. Despite these inferences and given the age range of their children, it is likely that they would have been offered the vaccine on several occasions. However, it is possible that they appeared less aware about meningococcal disease and Men C due to the fact that they preferred to seek alternative health care services, and may have been less exposed to the advertising campaign. Further, since none of them subscribed to orthodox immunisation practices, preferring to use homeopathic alternatives instead, such immunisation campaigns may have limited appeal and influence. For example, Debbie, a 33-year-old mother of four described herself as "anti-immunisation", and described immunisation advertising as "propaganda" and on vaccination felt that "the whole concept may be a bad idea". This group generally talked dismissively about the need for orthodox vaccines in a wealthy, healthy, Western society and suggested that none of the diseases really posed much threat to healthy children. Thus, Molly did not believe that immunisation was in her children's best interests and she displayed a degree of scepticism about the publicity about the Men C vaccine:

It's not the one that's the danger. The meningitis C is just the one that they've got the vaccination for so they're giving it to all these children and you don't get it (the vaccine) if you're a teenager so why are they vaccinating two month old babies who are already getting all these other, other 5 anyway, why are they doing that?

Non-Vaccine Group; Molly aged 37

Nevertheless, for the most part participants across the groups identified immunisation campaigns and media coverage as the key sources in raising their awareness about

diseases. Participants directly associated disease severity and prevalence with the level of publicity and attention afforded to a specific disease. Paradoxically, whilst the participants in the Non-Vaccine Group appeared sceptical about the motives behind immunisation campaigns, other participants viewed the Men C campaign as proof that health ‘experts’ were concerned about the risks posed by meningococcal disease. As William explained:

To me that's scary, (referring to meningococcal disease) you know what I mean? 'Cause that's in the newspapers and when somebody's got meningitis, whether it's meningitis C...that's the impression I get, it's meningitis C or it could be. You know what I mean? And as soon as somebody's got it, they're up in arms and they're trying to investigate it. Where did this come from and how many people have got it? So therefore to me, to me that's one of the major eh, diseases out of the group that's oot there.

Single Fathers Group: William aged 51

Similarly, the issue of the Men C campaign and its perceived relationship to disease severity was raised in a first-time mothers’ group:

Ros: It’s a severe one (referring to meningococcal disease).

Margaret: Ah widnae have known it wiz severe- know like when ye go intae the doctor's there's always posters and there's always...

Facilitator: Right.

Margaret: Ah widnae have known it was so severe if there wisnae aw that- know how their campaigns...

First-time Mothers Deprived Area: Ros aged 20; Margaret aged 20

Whilst the general consensus across the groups was that meningococcal disease was severe, there were no participants who had direct experience either themselves or as parents of their child contracting meningococcal disease or meningitis. However, across the groups, participants justified their decision for selecting meningococcal disease as the most severe disease by reasoning that they had either heard of, or knew of someone who had died or nearly died as a consequence of contracting meningitis. Discussions relating to meningococcal disease tended to produce rich descriptive anecdotes and indirect accounts of experiences of meningitis. Participants appeared to be particularly fearful of

meningitis because they had heard stories about it being misdiagnosed, or they were worried about the speed at which an individual could become seriously ill or die from it:

Facilitator: What diseases do you feel, most concerned about?

Joanne: Meningitis.

Facilitator: Why do you think that is?

Elaine: I think because the diagnosis of it is so difficult. It seems to strike so fast, so quickly and again I know someone who lost a baby at four months because of that.

Joanne: Yes, my husband got meningitis twice when he was a teenager, not the bacterial one, the other one. Also, someone at work had to rush their child into hospital recently. Just the thought of not knowing that the rash is the rash, or they have a temperature or that they have the symptoms and you didn't realise. You hear of stories of parents going to their doctors and the doctors telling them to go home, boom- next thing they are in hospital a few hours later.

Elaine: Well, my mum had an older brother who died of meningitis and my nanny was a nurse and it was exactly that, and God love her, she said she knew it was something else, but in those days especially- you didn't question the GP.

Joanne: Well, that's right you trust them don't you.

Elaine: Yes, within about a week of him (referring to own baby) coming home from hospital I was checking him.

New Mothers Group: Joanne aged 37; Elaine aged 34; Beathan aged 29

The Single Vaccine Group also expressed similar fears about the difficulty of diagnosis and the speed at which meningitis can affect an individual:

Dave: Meningitis, that's the one I worry about the most.

Facilitator: Why do you think you worry most about meningitis?

Joe: I think well that's probably one of the worst because... I know somebody that, you know, had had it and... he had it for two days and his dad was an ambulance driver and luckily they managed to sort of get it in, you know, get him in- in time and he was alright.

Jenny: I think the reason that I worry about it as well is that I know a wee girl who went to the church and she had it and was really ill with it. I think the reason why I worry about it most is it's the hardest to diagnose. And you know, you know, with the rash, when it forms, you know, if it doesn't go away but you know, sometimes that doesn't happen till it's too late so I think it's the... I think it's the fact that it's quite deadly and it's difficult to diagnose. Yeah, I mean that's the one

that any time my boy's ill, he might just have the cold but if he gets a rash with it, that's me - I'm out with the glass, you know? Checking-over.

Facilitator: Is there any other ones that you think are equally severe, like meningitis?

Joe: No, just meningitis. I think... I think it's a difficulty in diagnostics. I mean things like mumps, you know, you don't really hear – do you - people really dying with mumps, not really...

Single Vaccine Group: Dave aged 38; Jenny aged 19; Joe aged 36

Perhaps the most harrowing story demonstrating the speed with which meningitis can affect a child and, in this case, the slow response of the medical profession to a call for help, was told by Ros, when she recalled the night her boyfriend's nephew died:

Ros: Ah know somebody that had meningitis. Ma boyfriend's wee nephew.

Facilitator: Yeah?

Ros: He died wi it when he was four. In the hoose.

Natalie: Ah don't know anybody.

Ros: And the doctors, they were terrible that night.

Facilitator: Right.

Ros: Erm, he had a high, high temperature and he wiz sick a lot and they phoned the emergency doctor tae come oot tae him, and they took two oors tae come oot. And when they came oot they said it was jist a cauld. And he wiz tae lie up on the couch and if he got any worse tae phone them back. So they left and the wean was playing on the toybox oot in the hall wi ma boyfriend, munits latter the wean died in his arms and he brought him back, and then they had tae phone an ambulance and they took hauf an oor tae come, and when the ambulance came the wean had died and the rash had all come oot in him. But it never came oot until eftir he died.

Facilitator: Yeah.

Ros: So it wiz.

Facilitator: What is it about that do you think then? Is it the speed or is it the...?

Ros: It's jist how quick it affects them. Do ye know what Ah mean?

(over-talking)

Ros: Like as Ah says, his wee nephew wiz no well one minute and the next minute he had died.

Facilitator: Yeah.

Natalie: Ah know, like see...

Ros: Within an oor.

Young, Single Mothers Group: Ros aged 20; Natalie aged 18

What appeared to be particularly unsettling about meningitis, setting it apart from the other diseases, was the fact that so many participants knew of a harrowing story involving a young child where the outcome resulted in long-term damage, or was fatal. Therefore participants could appreciate how damaging the disease was, which in turn, made the disease a tangible threat to their own children. As such participants feared meningococcal diseases and often mentioned that they were glad their children were protected with the Men C vaccine. As Ros stated: “That was the one right, like, you would insist on getting” (Young, Single Mothers Group; Ros aged 20). Similarly, Michelle believed meningococcal disease was the most prevalent of the diseases and suggested: “The others are not so much about, but meningitis is bad if yer wean gets it. I think it kills most weans” (Multiple Parenting Problem Group; Michelle aged 21).

In summary, participants were knowledgeable about meningococcal disease and accurately described its symptoms. The main reasons why participants feared meningococcal disease was that they had read or heard about it leaving children with severe long-term neurological disability or causing death. Participants were also anxious about the speed with which meningitis can affect a child and about the difficulty in diagnosing it early enough to manage it effectively. These fears largely stemmed from hearing stories about the children of other parents. The fact that the Men C vaccine was so well publicised led participants to consider meningococcal disease posed a real danger to their children’s health and as such, most participants were keen to vaccinate and protect their children from it.

3.3.2 Rubella: 'Is that the same as German measles?'

Rubella is a mild disease characterised by a discrete macular rash. However, if rubella is contracted during early pregnancy it can result in fetal damage in up to 90% of cases (congenital rubella syndrome). The baby may be still-born or suffer from severe life-long handicap. Clinical diagnosis is unreliable since the symptoms are often fleeting and can be caused by other viral infections (Salisbury and Begg, 1996).

Rubella is commonly known as German measles due to the great interest German physicians had in the disease during the mid-18th to mid-19th centuries (Feigin and Cherry, 1998). However, its name caused confusion as participants were often unsure whether rubella was the same disease as German measles and whether measles was a slang term for German measles. For instance, Debbie implied that German measles was a separate disease from rubella when she stated:

Em, I remember em being... having spots, florid kind of rash but, em, you know, I was lucky, I think I was off school for a couple of weeks with... I had German measles and I had rubella as well and I don't remember it being particularly distressing but primary school, em... (interrupted)

Non-Vaccine Group, Debbie aged 33

Similarly, there was a degree of confusion among a group of participants whose children were recovering from cancer about the differences between German measles and measles:

Cara: I think I... I... my mum says she didn't know if I had measles or German measles, I don't know the difference between them.

Jill: German measles I think...

Cara: Is that rubella?

Jill: ...you can miss it cos it can come quickly, aye, well that's the...

(over-talking)

Cara: Is that one, you get the rubella injection, does it affect your fertility or something that you can damage your children if you're pregnant and you get German measles, doesn't it?

Jill: Mmm, you don't want to have German measles if you're pregnant.

Cara: Is it blindness it causes or something?

Jill: But you don't hear of people having it, so that's why... mostly why we're not too sure. I mean I'm not sure because I'm covering my mouth (covering her mouth with her hand, laughter). It's almost like you're telling a lie.

Cara: People don't have the confidence to say it because they don't really know.

Outpatient Cancer Group: Jill aged 38; Cara aged 36

The confusion some participants felt between measles and rubella may in part explain this story recalled by Sheila, which occurred during her second pregnancy:

... it was actually Jordan. And he was about a year old at the time. And I was bathing him and he was really blotchy and that and I phoned the doctor out. Eh and I was about 8 or 9 weeks pregnant. And he was just out the bath and he was sitting in his towel. She says "No he's got the German measles at the top and the measles at the bottom." And I thought 'fine'. And because I had, because I was pregnant em she basically said "there's no point, we can't give you the jag now against it. You should have had it at school." I said "I did have it at school".

Low Uptake Area Group; Sheila aged 36

Whilst the complexity of this story makes it difficult to interpret fully, it was interesting that nobody in the group questioned her report of her baby having the top half of his body infected with German measles whilst simultaneously having the bottom half infected with measles. The most likely explanation to account for this was the participants' difficulty in distinguishing between rubella and measles.

In the groups that were able to establish that rubella was the same disease as German measles, participants were usually able to describe accurately the mode of transmission and the long-term damaging effects of rubella on the foetus if contracted during pregnancy. The female participants often recalled having their rubella vaccination at

school and having their subsequent immunisation status checked during pregnancy. The fact that participants knew that contracting rubella during early pregnancy could result in long term foetal damage led this otherwise trivial infection to be generally viewed as a severe disease. However, this knowledge also led some participants to view rubella as a disease only affecting girls and women, and to question the need for boys to have the vaccine at all. As Sue, a mother of three boys, suggested:

Sue: I think you see, they give you this funny mixed message, em... they say 'the MMR, measles is a dreadful disease, you know, the effects of measles, there was an epidemic in Dublin, you know, the...' you know, all this sort of stuff. But then if you actually research into it a wee bit further, you'd discover... well I think what I've discovered is that it's not the measles that they're actually worried about, it's the German measles, rubella, that's what they really want you to take it for. But it's almost like they've got this scare tactic, we'll frighten them into getting it because of measles but it's because of rubella. They're not going to do it for rubella and that's what... because that's what they're really trying to immunise for, em, and they've combined it in this nice convenient package.

Facilitator: So you think part of it is that combining it encourages you to get ones that you might not get necessarily?

Sue: Yes, because they wouldn't get take-up because the parents of boys wouldn't take their babies to get immunised for rubella because the parents would consider it irrelevant and so in order to get the rubella vaccine out, em... they're sort of touting it basically as being measles. It's the scary one.

Non-MMR Group; Sue aged 36

These comments not only imply an understanding that rubella is a mild disease, other than if contracted during pregnancy by unvaccinated mothers, but also the fact that rubella vaccination of boys is a wholly altruistic act in that it has no direct benefit to the boy himself. Sue's assertions are interesting in that they highlight a dilemma faced by parents of boys. Sue was concerned about autism and aware that it affects more boys than girls, and so she perceived MMR to be additionally risky for her boys. Couple this with her perception that the rubella component may be irrelevant for her sons and it goes some way to explaining why she felt that the argument for getting MMR to confer immunity to others was not persuasive.

Another related idea that emerged from discussions on rubella was that instead of routinely immunising all children with rubella, women could be given it as part of pre-conceptual care. For example some participants thought rubella vaccine efficacy was limited and not long-lived and therefore suggested giving it to young children was of limited use. The following conversation occurred in a group of first-time mothers who were asked to describe their images of rubella:

Celia: Rubella? Oh that's just ...

Charlotte: Bad for girls to have. That's why girls got vaccinated.

Rhona: Birth defects in your baby if you catch it when you are pregnant because you checked birth defect that's why if you're, if you're planning a pregnancy they'll try and check you beforehand.

Charlotte: Because we all got done when we were at school about 13 years- that's why yeah.

Rhona: But a lot of people like don't keep their immunity and like throughout pregnancy they have got to be immunised again.

Catrina: They check you while you are pregnant I don't know why they bother because...I don't know why they bother.

Rhona: So you know if you come near anybody there's nothing they can do about it but if you go near anybody you know. Don't like to stay away from them because it can cause growth problems in the baby.

First-Time Mothers Group: Rhona aged 31; Katrina aged 27; Charlotte aged 34; Celia aged 33

In another debate about rubella vaccine efficacy, Aleena, a 35-year-old mother of three girls considered that:

...if girls got rubella when they were children, they would have life-long immunity, not just immunity until they're 12 or whatever, but they would have life-long immunity and eh...' (Interrupted by child screams).

Non-MMR Group; Aleena aged 35

Although the age range of the participants that took part in the focus groups meant that many of them thought that they had had rubella as a child, participants found it particularly difficult to recall their experience of having rubella. Often this led to

confusion about whether it was measles or rubella they had actually had. For example, William recalled:

I think it was German measles I had. There was a wee rash and...I think...noticed it, I was in ma pyjamas. I just thought it was a wee scab. And it was at the time there was an epidemic in the school, because everybody was aff a fortnight...

Single Fathers Group; William aged 51

William appeared unsure whether he had had rubella and the description given by him was vague so it is difficult to establish whether he was recalling rubella or some other viral infection. More precise accounts of rubella were offered by Jill, who warned: “you can miss it cos it can come quickly” (Outpatient Cancer Group; Jill aged 38). Similarly Rebecca recalled: “it’s sort of a...pinpoint rash and you’re not usually unwell with it particularly, I think” (Cancer Support Group; Rebecca aged 49). Although a few participants were able to recall the experience of having rubella, it was more often the case that participants were either unsure whether they had it, or knew they had had it but could not remember their experience of it. Perhaps the most likely explanation of this gap in memory lies in the mild nature of the disease itself. Since rubella is a mild disease often the only symptoms are a discrete rash and a feeling of generally being unwell and it is therefore not memorable. Indeed, Mandal and Mayon-White (1984) suggest that whilst many people will show serological evidence of previous infection they will not be able to recall a history of infection and so this disease can be difficult to diagnose clinically.

The participants’ silence on this matter is interesting because it feeds into a greater problem. Namely that since rubella symptoms are inconspicuous attempting to reduce the transmission of this disease from young children to pregnant women is difficult; this is one of the reasons why rubella was included in the Childhood Immunisation Programme in the first place. However, across the groups no one noticed that its mild nature and inconspicuous transmission could itself pose a problem. Ironically, it was suggested that the transmission of rubella was more controllable because women could

plan pregnancies and plan to have their immune status checked prior to conception. For example, Debbie reasoned:

...at least with the girls, they can choose their own course, you know, em, if they're going to start a family, they can make their own decision if they believe in vaccination, they can you know, get rubella vaccination then, but with boys, you know, I don't think it would be safe for them to get a mumps vaccination if that's what they wanted to do...

Non-Vaccine Group; Debbie aged 33

However, even disregarding its inconspicuous presentation and thus transmission, this argument ignores the fact that vaccines do not work one hundred percent of the time and some vaccinated individuals do not produce an adequate antibody response to offer protection to the disease.

In summary, participants appreciated that this otherwise mild disease had serious implications for pregnant women and their unborn children, and thus described it as a serious disease against which children should be immunised. However, a few participants questioned the need for boys to have the vaccine at all, believing girls should be the primary target, with women planning to become pregnant the secondary targets of the rubella immunisation programme. However, whilst participants implied that rubella symptoms are mild and inconspicuous, there was a lack of appreciation that this could pose a problem in preventing the transmission of this disease to pregnant women.

3.4 Diseases considered: 'Less of a major threat'

3.4.1 Measles: 'itchy spots' and 'calamine lotion'

Measles is a highly contagious viral disease transmitted by droplet infection. It is characterised by Koplik spots, fever, upper respiratory catarrh and conjunctivitis. Complications are reported in one in 15 notified cases and include: otitis media, bronchitis, pneumonia, febrile convulsion, encephalitis, subacute sclerosing

panencephalitis (a fatal degenerative neurological disorder) and death (Salisbury and Begg, 1996).

Participants generally described the symptoms accurately and associated measles with spots which were often described as 'itchy spots'. Some participants spoke of cold-like symptoms and mentioned that the eyes were affected, but there was a lack of consensus about whether the eyes were runny or dry. Measles was regarded by some participants as not serious whilst for others as a serious disease on the basis that in severe cases it could cause long-term sensory damage, or be fatal. For example, Judith considered: "measles has got like horrendous side effects. It can make you blind, it can make you ill...it can be fatal" (First-Time Mothers Group; Judith aged 34). Similarly, Lydia suggested that measles: "can make you go deaf and all that, you can go deaf wi that. It can affect your hearing and that..." (Crafts Group; Lydia aged 39). Likewise Rebecca and Pamela also mentioned that it could cause blindness and deafness (Cancer Support Group; Rebecca aged 49; Pamela aged 42).

It is not clear why this extremely rare complication was discussed in so many of the groups, because unlike meningococcal disease, no one mentioned that they knew of anyone that had suffered long-term damage as a consequence of measles. It seems unlikely that participants were simply confusing measles with the symptoms of congenital rubella because participants spoke passionately and unambiguously when discussing measles, in a way they had not done when discussing rubella. However, in the absence of any obvious explanation and in view of the fact that participants mentioned that they had gained much of their knowledge on matters of immunisation from the media, one explanation might lie in the way measles has been portrayed during the MMR debate. In response to poignant stories of children seemingly being adversely affected by MMR, media coverage about measles has often highlighted the more extreme complications of the disease. Emotive stories involving children who have developed rare complications of measles such as encephalitis, subacute sclerosing panencephalitis and associated subsequent long-term sensory damage, have had a more prominent place in the debate. These emotive media stories of measles causing severe and long-term

damage seem the most likely explanation to account for why these extremely rare complications appear to have taken such precedence in the minds of participants.

Out of all the diseases covered by the Childhood Immunisation Programme measles was the disease participants were mostly likely to report having had direct experience of as children themselves, and as parents with their own children. In contrast to meningococcal disease, in which having experience (albeit most commonly third-hand experience) made the disease a more tangible threat, experience of measles often made it less threatening. Whilst participants with no experience of measles tended to contemplate the long-term damage that it could inflict, those with experience of it tended to minimise these risks. For example, when asked: which of the diseases are mild? Hannah, replied:

For me I think ... the MMR, measles and mumps, I don't know about rubella but, you know. I've had measles and mumps when I've been ...I was younger and I've not had any ...and I don't know any... All my peers all had measles almost and have survived and I ...I'm not sure of the seriousness of it...

Non-MMR Group; Hannah aged 40

Remarkably, in light of the low prevalence rates of measles over the past few years, there were seven participants who reported that one or more of their children had had measles recently. The following story was recalled by Cara, whose daughter Emma was recovering from leukaemia:

Cara: Well, Emma had measles the last time. She had her MMR and then she got measles, em, it makes me wonder if I should have spotted something before she was actually diagnosed (referring to Leukaemia) as well, you know, but they've said 'No, there's no connection'.

Facilitator: What did you think the connection was?

Cara: It was just that there was something wrong with her system but that was only with hindsight. Because I remember taking her to the doctor and he said 'Oh it's measles,' I said 'How could she have measles when she's had her MMR,' and he said 'Oh there's 1 in 1,000 or something'.

Facilitator: And was it some time after it, she had measles?

Cara: No, it was within months of having the MMR, she got the measles, you know, but, em ...

Facilitator: And did you know anyone else that had measles?

Cara: No, no, no idea where it came from. I mean she wasn't really unwell and the doctor...

Facilitator: Did he diagnose it... did they take, you know, like a saliva test?

Cara: No. Just by looking at her, the GP just said, to him, it looked like measles.

Facilitator: Right.

Outpatient Cancer Group; Cara aged 36

Similarly, Anna, a mother of four, explained her third child's experience of measles:

I was delaying with Abby because I, well, firstly she's had measles and I had taken her to the doctor's and they said it was the first case in surgery in five years. And he had the health visitor out and a junior doctor in to have a look at her and the health visitor said well we'll come and take a test, they've got to come from, don't know the health board or whatever and she came about two weeks later, but the test came back inconclusive. They said that you know, they could determine whether she had it or not with a blood test and I felt by that, by that time well, the doctor said she had had it, I thought she had it, she looked, she had the same symptoms as a child with measles and I wasn't particularly bothered about getting her the blood test...

High Uptake Area Group; Anna aged 33

Of note was the fact that her youngest child (then aged 10 months) did not contract this highly contagious disease from her older sibling. Nevertheless Anna did not appear to have any doubts that Abby had had measles. For similar reasons Dawn, a mother of two, was convinced that both of her children had contracted measles, and she was therefore sceptical about media reports that suggested that an outbreak of measles in Fife in March 2002 were the first confirmed cases of measles in Scotland for some time. She said:

Dawn: Yeah, but the headlines saying first two cases is a lie. I can sit here and say it is an absolute lie, because of my two who caught it from nursery, and at the same time another nursery had it. I still knew of at least two other cases in Glasgow so I can't imagine that those were the only ones at the time. There must have been more.

Facilitator: Can you remember whether they were confirmed by bloods being taken, or saliva tests (interrupted)

Dawn: This is where it gets a bit confusing, because they were in contact with children in nursery and then we went on holiday to Australia. Two days after we got to Australia they both came down with measles. It was confirmed by a doctor in Australia, and that was it. When we came back we informed our GP, that's why mine weren't counted.

Facilitator: Do you know about the other people?

Dawn: I don't know really, but they must have told their doctor, because there was a notice up at nursery. I don't know what was done about that, but I do know they had very, very mild cases, and they definitely both had measles. The doctor out there said –they had a classic case. It just seems awfully convenient, a big newspaper headline at this particular moment in time.

Antenatal Group; Dawn aged 36

Dave, a father of two, who opted to pay for single vaccines for measles, mumps and rubella for his youngest daughter, also recalled a similar story concerning his older daughter. He stated:

When my daughter was very wee, she caught... well, we took her up, she basically woke up one morning and she had a rash all over. We took her up to Yorkhill. The doctor there said..., she had the runny nose as well, and all the symptoms and he said 'that's measles' and em... we went in, em... you know, we took her up and they said 'oh no, that's definitely measles'. So you know, we phoned all our friends and family and said 'don't come round for a few days' and my mum, em, you know, my wife's mum, they saw her and they said 'oh yeah, that's definitely measles, I remember, you know, what measles looks like' and em, but anyway, two weeks later, cos you know what it's like, you can't get an appointment for the doctor's, two weeks later we go to the doctor's and the doctor says 'no, there's no way that that was measles' and he wouldn't believe it, he never wrote it down. And you just think, you know, all the time it's like deny, deny, deny. Even the doctors, cos you know, they don't want to say that they have a confirmed case of measles. And yet, you know, I mean I don't ask my mum and my mother-in-law for much advice but on this one I'm sure they're right cos they'd seen measles before as well, you know? But no, the GP's surgery, not interested.

Single Vaccine Group; Dave aged 38

Similar accounts cropped up in several other groups. On closer examination there may be several possible explanations as to why there were so many accounts of children having had measles and it being denied or not reported by doctors. The first and perhaps the most likely explanation is the recent increased attention afforded to measles. As the MMR uptake rates declined this gave rise to an increasing number of forecasts of an impending measles epidemic both by public health officials and the media. These warnings to the public may have led some participants to have perceived measles prevalence to be far greater than it actually was, resulting in them taking their children to the doctors with measles-like symptoms. Indeed according to SCEIH the three

confirmed cases of measles in Fife in March 2002, which were widely reported in the media, along with a fourth case in Edinburgh, were the first cases in Scotland since April 2000. However, in 2002, 315 salivary samples were submitted compared to 147 the previous year. In this respect, participants in this study were acting like many other parents in taking their children with measles-like symptoms to the doctors. Participants reported that their doctors clinically diagnosed measles on appearance, with the exception of Anna, who recalled saliva tests being carried out but stated that the results were 'inconclusive'. Since confirmed cases are only counted when laboratory test results are positive, none of the participants' children were confirmed cases and would have been counted as notified cases.

However, the fact that many doctors did not carry out diagnostic tests raised another issue for some participants. It was explicitly suggested that doctors were contributing to the low numbers of confirmed cases. The fact that some doctors were viewed as actively denying or playing down the number of cases caused some participants to talk sceptically about the disease statistics. Further, some participants perceived doctors to be contradicting each other in their diagnosis of measles and this in turn led some participants to question doctors' clinical skills in identifying and thus monitoring its prevalence. Ambiguity about the actual prevalence of measles led to a degree of uncertainty which fuelled anxiety. As Ella observed: "uncertainty is fear and fear is uncertainty" (Saturday Club Group; Ella aged 45)

There is also another explanation. On further examination of the group dynamics and group interactions between members in some of the focus groups, it was noted that on occasions, participants appeared to be justifying their reasons for rejecting the MMR vaccine to other group members. This was particularly noticeable in Dawn and Anna's cases, both of whom appeared aware that they held views and had made decisions about MMR that were contrary to most of the other group members. By explaining their child's experience of measles to the group, they avoided potentially becoming marginalized or being seen as insensitive to other group members. Since they believed that their children had already had measles they were no longer a potential threat to others and by

explaining this to the group they effectively showed that they were acting in the best interest of their child, whilst remaining sensitive to the viewpoints of others. These interactions between participants highlight the importance that self-presentation plays in group situations and the impact of the group effect on individual accounts. This issue will be more fully explored in Chapter Five, which examines how parents' perceptions about the MMR controversy translate into their decisions about MMR vaccination.

In summary, some participants tended to view measles as a serious disease based on the long-term sensory damage that it could cause. However, other participants who had had measles as children themselves and had survived without any long-term damage contested the severity of measles. In this respect, there was a degree of ambiguity about the risk posed by measles to their children. There was also ambiguity surrounding the perceived prevalence of measles. On one hand, there was a surprising number of participants who reported that their children had had measles, leading some participants to be sceptical about statistics reporting low prevalence rates of measles. Indeed, it was suggested that measles was more prevalent than was admitted by the media, public health officials and doctors. However on the other hand, participants viewed measles as a rare disease and as such acknowledged that many doctors would have little or no experience of it and would not therefore be able to reliably diagnose measles. Despite this assertion, all of the participants who reported that their children had had measles had only received a clinical diagnosis, but seemed adamant the diagnosis had been accurate.

3.4.2 Whooping cough (pertussis): *'... it hasn't done me any harm, that's the thing'*

Whooping cough is a highly infectious bacterial disease of the respiratory tract. The disease is transmitted via droplets that are sneezed or coughed out and inhaled by others. It is characterised by violent coughing, often accompanied by high-pitched inspiratory 'whoop' sounds and vomiting. Complications of whooping cough may include convulsions, pneumonia, lung damage, temporary and/or permanent brain damage, subconjunctival haemorrhage or death. Complications and deaths from whooping cough are most prevalent in babies less than six months old. Whilst over the years there has

been a marked reduction in the incidence of whooping cough, in Scotland there were 109 notifications in 2002, 22 of which were children under one year of age (www.show.scot.nhs.uk/scieh/surveillance).

Perhaps unsurprisingly the descriptive name of the disease led participants to describe images of children coughing persistently and to mention that the cough had a 'whoop' sound. It was common for participants to accurately suggest that transmission was airborne and through saliva. Indeed, out of all the diseases considered by participants, whooping cough, along with meningococcal disease, generated the most accurate descriptions. Nevertheless, Mel, aged 35, suggested that it was related to croup (a mild viral infection) and likewise in the Young Single Mothers Group, Kate confused it with croup:

Facilitator: What about whooping cough? Does anyone know about...?

Kate: Aye, is that no that (she makes a whooping sound).

Unidentified: Aye.

Kate: Ye need tae take them into the toilets and run the hot tap so's that the steam goes in their mooth. Ah've had that.

(over-talking)

Lynne: Naw

Kate: Ah that's croup int it?

Young, Single Mothers Group; Kate aged 22

Participants were divided about whether they felt whooping cough was a severe disease or not. Some participants considered that it was severe and Stella described it as "nasty, aye that's a nasty one, that's a long horrible cough" (Autism Support Group; Stella, aged 37). Generally there was little mention of any long-term damaging consequences of whooping cough, and no participants mentioned the fact that it could be life-threatening. This was interesting given the fact that since the MMR debate the media and scientific community have highlighted the whooping cough controversy as a case in point for preventing deaths through preventing epidemics.

Nevertheless, whilst participants did not mention that whooping cough could be fatal, a few participants spoke fearfully about whooping cough, fearing the distressing nature of the disease. For example Aleena spoke about an immunisation talk that she had attended and recalled:

...there was a health visitor she got up and she showed a ...eh a videotape of a baby with whooping cough and the baby must have been about three months old and it was absolutely horrific and of course there were loads of nursing mothers and everything in the room and half of them had to get out, they were... it was so distressing.

Non-MMR Group; Aleena aged 35

The image of babies and young children violently coughing was a distressing image. As Rebecca recalls from personal experience: “the face goes blue and actually stops you breathing or stops you getting air into your lungs and your brain...” (Cancer Support Group; Rebecca aged 49). For some participants these images meant they appeared keen to prevent their children contracting whooping cough and thus to have them immunised with the pertussis vaccine.

When asked about whooping cough, a few participants spontaneously recalled the whooping cough epidemics in the 1970s and 1980s, as they had contracted whooping cough themselves as children during the outbreaks. Charolotte, a 29-year-old mother of one young baby, considered:

I just want to say something about whooping cough. It's funny because my mum said because I said what the first lot of immunisations were just for her (pointing to her daughter) and she said “oh” she said “she's so tiny, do I get them when I actually ask, you know, because she's so small does she still get them.” And they said “Oh I think you give it to premature babies.” So em and then fine. But my mum said “Oh you know, whooping cough is not so bad, you had whooping cough, you know. If there's any risk with the injections don't get it because whooping cough's fine, you've had it and you survived.” I think I probably didn't have a very nice time but that's my mum's perception of whooping cough. It wasn't very bad because I had had it. But then again I just wasn't ... (goes silent).

First-time Mothers Group; Charolotte aged 29

Similarly, Dave, a 38-year-old father of two, stated:

... I was one of the children that got whooping cough, but you know it hasn't done me any harm, that's the thing, and then there was all this query about did whooping cough cause, you know, mental problems? You know, em, for children, you know, brain damage, you know. And I thought it concluded really that for a small percentage there was that possibility, you know? And it's the same with MMR- is there a small possibility that for some children it causes damage but that nobody's acknowledging it, and if you think your child might be one you're not gonna take that risk.

Single Vaccine Group; Dave aged 38

These comments highlight the fact that experiencing a disease does not mean that a person will necessarily have a negative impression of it. In fact these comments highlight how complex the relationship is between participants' experiences of disease and their subsequent beliefs about its severity. Where participants experienced the disease and either fully recovered, or had difficulty remembering it, the risk may not be viewed as a threat to health.

In summary, whilst whooping cough was spoken about accurately and often as being a severe disease, participants did not talk about any long-term damage it could cause, or mention the fact that it could be fatal. Nevertheless, participants were keen to have their children immunised against whooping cough and some participants were aware of, or had been affected by the 1970s and 1980s whooping cough epidemics. For some participants the relatively recent epidemics appeared to serve as a reminder that whooping cough is a highly contagious disease and as such viewed it as a potential threat. However, as with measles, participants who had had whooping cough and survived without any long-term damage tended to view the disease as less severe than some of their counterparts with no experience of it.

3.5 Diseases considered: 'A minor threat'

3.5.1 *Mumps: 'bloated, big baw face, wi sore balls'*

Mumps is an acute viral disease characterised by localised inflammation and enlargement of the parotid, and or salivary glands. Complications include: viral meningitis (1 in 20

cases), encephalitis, orchitis, oophoritis, sensorineural hearing loss, pancreatitis and death. There is no evidence that mumps causes sterility (Salisbury and Begg, 1996).

Despite this, across the groups it was commonly thought to leave men sterile. Frank stated:

I think that's the wan Ah hud when I wis a wean. I think it wis like sore balls and it wis something that makes you no hiv weans, you know like you've been snazzled (castrated) and hiv no weans. But see it didnae affect me cos I've got the boys.

Multiple Parenting Problems Group; Frank aged 31

Similarly, Kenny suggested that mumps: "can make you infertile or something, can't it?" (Single Fathers Group; Kenny aged 43). Likewise, the Low Vaccine Uptake Group spoke about infertility resulting from mumps:

Sheila: It makes the men sterile, that's the only thing that...

Alan: That's what I look on it as.

Joan: Makes what?

Sheila: Makes the men sterile.

Joan: Oh, I never knew that.

Sheila: If they take it later in life, uhuh. I said I can always mind the old ones saying you're better, boys were better getting mumps early. That was the only thing that ever ...

Joan: I've never heard of that.

Low Vaccine Uptake Area Group; Joan aged 20; Sheila aged 36; Alan aged 33

While some participants explicitly spoke about the association between mumps and male infertility, it was more common for participants to merely imply an association by suggesting that mumps was only a problem for boys. Just as rubella was viewed largely as a disease affecting girls, mumps was viewed as a disease affecting boys. This gendering of the disease is perhaps best illustrated by Debbie, a mother of two girls and two boys:

I worry about my boys not catching mumps as a child because there's not so, so much around, em, and then them getting it as adults and I guess the same with the girls, with Rubella but at least with the girls, they can choose their own course, you know, em, if they're going to start a family, they can make their own decision if they believe in vaccination, they can, you know, get the rubella vaccination then and with the boys, you know, I don't think it would be safe for them to get a mumps vaccination if that's what they thought they wanted to do. So I feel, em, kind of responsible for my children's future in a way, that way, whether they might be into vaccinations, you know, but I made that choice as a parent.

Non-Vaccine Group; Debbie aged 33

It was extremely common for participants to associate mumps with male infertility and to mention that it was preferable for boys to contract mumps when they were young rather than as adults. Couple this notion with the fact that across the groups mumps was not associated with meningitis, despite this being the reason for its introduction into the programme, it is clear participants underestimated the severity of the mumps.

Participants across the groups viewed mumps as a mild disease, with little or no long-term implications if contracted as a child. William described mumps as: "...you know they might have a few spots, or a few more irritations and you know maybe be laid up for a few days" (Single Fathers Group; William aged 51). Similarly, Joe considered: "...you don't really hear people dying from mumps, not really" (Single Vaccine Group; Joe aged 36). Sue's assessment of mumps was:

It's not a serious one. People don't take it seriously I don't think, you know, or maybe it's because when we were wee, you knew people that had it and it's...it's as far as I'm aware, it's not particularly a life threatening thing, you know, what you would call...like chicken pox, it's like a childhood disease, it's like a rite of passage.

Non-MMR Group; Sue aged 36

Sue's comments that: 'people don't take it seriously' were borne out on several occasions during the focus groups. On being asked about mumps there were occasions when participants held their breath, puffed out their cheeks and burst out laughing. Similarly, in groups with male participants some of them puffed out their cheeks and crossed their legs clasping their hands over their groins as if in pain. To the amusement of

the other group members, Kenny took the opportunity to recount his brother's experiences of mumps:

The reason I said mumps was because I thought it was funny. Because I used, my young brother was a lot younger than me...and I used to drag my mates home from school to see him when he had mumps because his face was that thick (puffing out his cheeks- everyone laughing) you had big baws. My mates...(said laughing) it was, you need to come home to see my wee brother, he's got mumps. I used to bring all my pals in to see him. Just a big baw face' (said while puffing out his cheeks, tears in his eyes now and laughing- everyone else laughing uncontrollably).

Single Fathers Group; Kenny aged 43

The vivid images participants had of swollen faces appeared to be based on either having had mumps themselves or having witnessed a close member of the family with mumps. Samantha recalls:

Aye ma face was just a balloon, right up, (puffing out her cheeks) I mean my mum's got pictures of me and you would not even see me, imagine that it's me honestly. (Laughing) Cos I've always been quite thin, but when I had these I was just pure...puff, bloated right out. It was just mostly ma face.

Crafts Group; Samantha aged 24

In summary, across the groups participants considered that mumps was a mild and mildly funny disease. Amusing images and stories were commonplace and the more serious consequences - meningitis - were not mentioned in any of the groups. Just as rubella was seen as a disease concerning girls, mumps was viewed as a disease with negative health consequences for boys in relation to male sterility. This disease was largely viewed as a mild disease and participants appeared unconcerned about their children contracting it, provided boys caught it when young.

3.5.2 Tetanus: *'Is that like Rabies?'*

Tetanus is an acute disease caused by a spore-forming bacillus. In its spore form it is found in soil and animal faeces and it enters the body after injury through a puncture wound. Toxin from the tetanus bacilli causes painful muscle spasms. Complications

include lockjaw, painful muscular spasms or death. Although tetanus is extremely rare in the UK now, because it is found in the environment tetanus can never be eradicated and therefore remains a threat. Unlike the other diseases in the Childhood Immunisation Programme tetanus can not be spread from person to person (Salisbury and Begg, 1996).

Across the groups participants closely associated tetanus with the disease rabies and therefore considered it likely that tetanus would be contracted from a dog bite. Joanne, was unsure about tetanus and guessed: “Well, that would be rabies...frothing at the mouth being bitten by a dog...(starts laughing) I don’t know” (New Mothers Group; Joanne aged 37). A similar response was elicited from Trudie, who thought the symptoms of tetanus would be: “Frothing at the mouth, like rabies, I’m probably wrong, but...” (NCT Group; Trudie aged 38) In some cases tetanus was described as the vaccine for rabies:

Facilitator: Right. What about tetanus?

Alan: Tetanus, well that’s ...

Facilitator: What do you think on?

Joan: Rabies and stuff like that where you get your tetanus ...

Sheila: Jag aye.

Alan: Getting bit wi dogs and that.

Joan: Aye exactly. That’s what I think of them aye.

Alan: Bit wi cats and all that.

Low Uptake Area Group; Joan aged 20; Sheila aged 36; Alan aged 33

Another vivid image that participants commonly associated with tetanus was ‘rusty nails’:

Catrina: Well that’s.... yeah.

Facilitator: What did you say?

Catrina: Rusty nails.

Celia: Yeah. Is it in the soil and in dirty food.

Judith: Doesn’t it swell, doesn’t it give you swelling?

First-Time Mothers Group; Catrina aged 27; Judith aged 34; Celia aged 33

These two images were mentioned frequently, but it is unclear why the particular images of ‘dog bites’ or ‘rusty nails’ should so consistently come up across all the groups. It seems likely that they have something to do with images of the skin being punctured, but this still does not address why these specific sharp objects were mentioned over other potentially hazardous items.

Whilst some participants associated tetanus with rabies, dog bites and rusty nails, it is of note that they then went on to describe the signs and symptoms of tetanus reasonably accurately. The Non-Vaccine Group accurately described the symptoms of tetanus and was one of the few groups to accurately describe the transmission pathway:

Facilitator: What about tetanus and how would you catch tetanus and what is tetanus?

Molly: A deep puncture wound and I know that tetanus is in soil, you get through it to the inside, a deep puncture wound like an incision.

Facilitator: And what would be the symptoms if your child had that?

Kitty: Em, it’s lockjaw isn’t it? So kind of noticeable isn’t it?

Molly: It’s localised at first, stiff kind of muscles around the area first and I would imagine that would spread.

Non-Vaccine Group; Molly aged 37; Kitty aged 37

Similarly, Rebecca suggested that tetanus would present as:

The limbs are paralysed or something, something happens and your limbs get paralysed and you have to go em... I think you also have to have a respirator, you know, because your whole system shuts down. Your muscles are paralysed or something like that.

Cancer Support Group; Rebecca aged 49

Why participants should accurately describe the signs and symptoms of tetanus after so inaccurately describing its mode of transmission is puzzling and there is nothing in the data to explain why participants consistently confused these two diseases. However, the significance of this disparity is profound because it may explain why some participants dismissed the need for very young infants to be given tetanus. Further it may have also

influenced participants' decisions to assess tetanus as only carrying a minor threat to their children's health. During focus group discussions it was evident that some participants felt that their young children would be unlikely to be near rusty nails or dogs. Further it was suggested that even in the unlikely event that infection should occur there was still a course of action that they could take to prevent their child from becoming ill. Several conversations implied as much:

Anna: The tetanus one I'm not too sure because I remember like if you were bitten by a dog your mum took you to the hospital to get a tetanus injection so I don't know why... I don't know why you have to have that, I don't know what benefit...

Karen: ...how quickly you get it. Maybe there wasn't the accessibility to hospital at the time.

Anna: I just remember when we were young if a dog bit you, it was like, and did it break your skin? Yeah, right. Come down to the hospital for tetanus and that was it. It was like, it was just sort of routine it wasn't anything and then they asked when was the last time you had a tetanus so it seems you know, if they are injecting babies at two months with tetanus it's unlikely that they are going to... I mean they don't get to play with dirt....

High Vaccine Uptake Area Group; Anna aged 33; Karen aged 36

Similarly, Rhona mentioned:

...I was saying to Chris, why does he have to have tetanus when he is so little. You know, I mean he's not going to be cut in rusty nails, but Chris said, 'yeah, but if he's out in the garden picking up things like that then it get to that as well,' which I didn't realize you know, I didn't know the reason.

First-Time Mothers Group; Rhona aged 31

Although Rhona had been encouraged to rethink her views on tetanus, other participants had decided that they would only give the tetanus vaccine in an emergency. Dawn argued that she would know if her child had had an accidental injury that warranted the vaccine and felt comfortable with her decision not to have her son immunised with tetanus. However for the most part, participants merely questioned the need for the vaccine but preferred to err on the side of caution in having them immunised against tetanus.

Whilst participants often described the signs and symptoms of tetanus accurately, none of the participants knew anyone that had contracted tetanus. Nevertheless, there were many accounts of participants being given a prophylactic tetanus vaccine following accidental injury. Robert had worked on a building site previous to becoming unemployed, and recalled:

Aye. Could get lockjaw and heart problems...just....cause ...I carried on working. Then ma foot started swelling up, then I couldnae get ma boot back on. So I might have got, you know, poisoned from the nail and they said it could...the guys in the work at times says you end up with lockjaw and all that. So I got took to the hospital and just got another jag...but Ah've had the jag a few times for tetanus, just in case. Like you only need one every five year or something?

Single Fathers Group; Robert aged 27

Similarly in the Young, Single Mothers Group, participants remembered being given the tetanus vaccine for accidental injuries, one of which was a dog bite. They recalled their experiences:

Lisa: Aw, Ah've hid hunners eh them.

Margaret: Ah've had wan cos Ah got sick.

Facilitator: What's it for do you know?

Natalie: Well Ah got it when Ah split ma fit open. That's how Ah got it, cos Ah split ma fit open.

Lisa: Ah got bit on the arse. (Laughing) And two nurses had tae haud me doon. And then by the time Ah'd got the jag Ah'd fainted. Ah hate jags, Ah jist dae! Ah hid tae get it on the arse! Cos Ah got bit on the arse.

Natalie: Oh naw man, Ah got it on the arm.

Margaret: Ah canny even remember where Ah got it, ye know, cos Ah was sleeping by the time they gave me it.

Young, Single Mothers Group; Lisa aged 20; Margaret aged 20; Natalie aged 18

In summary, generally participants spoke accurately about the signs and symptoms of tetanus. It was often implied that puncture wounds were important in the transmission of the disease, but there was some ambiguity as to where the disease might come from and it was often confused with rabies. On several occasions the soil was mentioned as a possible source of transmission, but it was more often the case for participants to suggest that dog bites or rusty nails were the most likely sources. In turn, this led some

participants to consider that tetanus posed little threat to their children, as they were not considered to be in direct contact with any of these sources.

3.5.3 *Haemophilus Influenza type b: ‘... that one doesn’t ring a bell’*

This disease mostly affects children under the age of five and can cause meningitis and bacteraemia in up to 60% of cases. Thus, the signs and symptoms are similar to those seen in meningococcal disease group C. Complications include: septic arthritis, cellulites, osteomyelitis, pericarditis and empyema. Neurological damage may occur as a consequence of meningitis causing impaired hearing, mental retardation or death (Salisbury and Begg, 1996).

Initially it was thought that the organism was the cause of influenza and it was known as Pfeiffer influenza bacillus after Robert Pfeiffer isolated it from sputum of patients during the 1889-1892 influenza pandemic. Although there were doubts about its aetiology it was not until the 1918 pandemic that its true aetiology was understood. The organism was renamed haemophilus influenza to acknowledge its mistaken historic association with influenza, and to emphasise its requirement of blood factors for growth; ‘haemophilus’ from the Greek meaning ‘blood-loving’ (Feigin and Cherry, 1998).

Out of all the diseases included in the Childhood Immunisation Programme this was the disease participants knew least about, and its misleading name led participants to commonly reason that it was related to flu:

Facilitator: What about haemophilis influenza?

Charlotte: Would that be like, is that Spanish ‘flu or something is it? I don’t know.

Facilitator : Do you get that? Do your children get vaccinated does anyone know?

Charlotte: I’ve no idea.

Rhona: I don’t think so, I haven’t seen it on the lists.

Judith: No...that one doesn't ring a bell, no.

Facilitator: Hib?

Rhona: Yeah, he got the Hib. Is that what it is? Because I didn't even know that. I wondered what Hib was.

Facilitator: What do you think Hib is for? What are, what are the, what do you know about haemophilis influenza?

Judith: Nothing.

Rhona: Not a thing.

Facilitator: This is the one that nobody knows?

Judith: Only through work thinking about people coming in with chest, a chest infection is what I would associate it with. With community acquired infections em I think

First-time Mothers Group; Rhona aged 31; Judith aged 34; Charlotte aged 29

In the absence of any images or knowledge about haemophilus influenza Lauren, a 29-year old mother of one, asked: "...is that like a flu jab?" (High Uptake Group; Lauren aged 29). Similarly, Bob questioned: "was it the flu?" Dave stated: "No, I've never heard of that. Is that to do with, em...is that haemophilus to do with...you know, that blood clotting thing where your blood can't clot? Haemophilia?" (Single Vaccine Group; Dave aged 38).

By far the most common response in relation to haemophilus influenza was a shrug of the shoulders, blank expressions or participants simply saying that they did not know.

Facilitator: What about haemophilis influenza?

Fiona: Is that ...?

Anna: Don't know.

Alison: Really don't know. (Silence everyone looking blank)

Facilitator: Okay.

Anna: Is that short for something?

Facilitator: Yeah.

Anna: I don't even know what it's short for.

Facilitator: It's short for haemophilus influenza.

Anna: Ah ha, flu. (Laughing, everyone chants flu together)

High Uptake Area Group; Fiona aged 32, Anna aged 33, Alison aged 31

Almost all the participants stated that they had never heard of haemophilus influenza, leaving participants guessing. For example Kenny, a 43-year-old asked "Is that for HIV?" (Single Fathers Group). In fact there were only two participants in the study who knew about haemophilus influenza: one was a mother whose child had had haemophilus influenza, and the other was a nurse who was familiar with the disease through her work. The lack of any knowledge, images or experiences of this disease meant that discussion on this disease was short and swift. Ironically, it was viewed as only posing a minor threat because, unlike meningococcal disease with its associated meningitis, haemophilus influenza did not raise any negative associations in participants' minds.

After the focus groups were completed, participants were given immunisation leaflets that explained the different diseases. Some participants commented that they were surprised to read that haemophilus influenza could cause a number of major illnesses, including meningitis.

In summary, participants did not know about haemophilus influenza. Guided by its historically inaccurate name participants commonly guessed that it was to prevent flu. In turn this led participants to consider that this was not a disease that posed a threat to their children's health. However, on discovering that it was not related to the flu, but was in fact introduced to help reduce the prevalence of meningitis, participants seemed genuinely surprised that they knew so little about the disease and wondered why this was the case. Thus this disease was viewed as only posing a minor threat because as one

participant noted during the debriefing session “you don’t worry about things you don’t know about really” (High Uptake Group; Anna aged 33).

3.6 Diseases considered: ‘No longer a threat’

3.6.1 Diphtheria: ‘Is it something out of the jungle?’ ‘Something that happened a long time ago?’

Diphtheria is an acute infectious disease affecting the upper respiratory tract and occasionally the skin. It is characterised by a sore throat, pyrexia, general malaise, headache and vomiting and in severe cases by membrane formation in the larynx (throat) which can cause airway obstruction (Salisbury and Begg, 1996). Its effects are particularly severe in children and it was one of the most feared epidemic diseases of childhood, hence the name given in the late 19th century of the ‘strangling angel of children’ (Hendriksen 2000). In severe cases the absorption of exotoxin damages heart muscle and nerve tissue which can cause paralysis or death.

Across the groups diphtheria was commonly associated with a water-borne, cholera-like illness and thought to be transmitted by contaminated water.

Facilitator: What about diphtheria how do you think you catch diphtheria?

Charlotte: Well that is like...well that would be down to water.

Catrina: Unsanitary conditions down to water.

First-Time Mothers Group; Charlotte aged 29; Katrina aged 29

Similarly, Cassie guessed transmission was through water and suggested: “Water, infected water or something?” (High Uptake Area Group; Cassie aged 29) and Stella questioned “Well I just think diphtheria, I don’t know, do you get it from dodgy water or...” (Autism Support Group; Stella).

In the groups in which participants related diphtheria to water-borne transmission, this led some participants to think that the likely signs and symptoms might relate to the digestive system. For example Fiona wondered: “is it not like a being sick sort of thing? Like a sickness, no idea... like a stomach upset thing” (High Uptake Area Group; Fiona aged 32). Likewise, Dawn believed diphtheria was: “...a stomach infection, something really, really, nasty that you don’t get anymore” (Antenatal Group; Dawn aged 36). In fact, diphtheria is transmitted via droplet infection usually by coughing, sneezing or talking and in severe cases can cause airway obstruction. Perhaps for this reason Rebecca, an ex-nurse, related diphtheria to the respiratory system:

It’s a lung thing, isn’t it? You know, when it’s affected your, your lungs and your trachea and all these bits up here (pointing to neck and chest) I think doesn’t it? I can’t remember but something to do with that and people were seriously ill and had to go on respirators and iron lungs and all that stuff with diphtheria, I think.

Cancer Support Group; Rebecca aged 49

Diphtheria was one of the diseases that participants found most difficult to describe accurately; however they usually suggested that this was because they had no experience of it as the disease has not been prevalent in the United Kingdom for some time. Whilst there was a general perception that diphtheria was no longer a threat, Sue described a recent experience that had made her realise how severe and prevalent diphtheria once was. She recounted this discovery to the group:

... em, I’ve been researching my family tree and eh, one of the things that I have discovered, em, actually had me in tears when I did discover it was, em, my great, great, great grandfather’s, em, first wife and four of his five sons, they all died within two months of each other in 1863 of diphtheria and as I was just... as I found all these death certificates, I was in tears because it took me about... I was downloading it from the computer and I couldn’t believe it and I thought, you know, we just have no idea what these diseases do. We have no fear of them and that was a whole family wiped out including an adult and it was, it really made me reassess, you know, the whole... my whole position on this. So I’m kind of... after having been so sure that oh no, I’m not going to immunise and it’s dreadful this mercury, blah, blah, blah. I’m almost back to square one now because I’ve seen it, you know, and it meant something to me because okay, it was 1863 but it was really shocking to see it, you know? Child after child that I was looking up, the death was all... you know and it... and it was quite scary.’

Non-MMR Group; Sue aged 36

Sue felt the most likely reason for the lack of knowledge and fear of diphtheria was that it is extremely rare in the United Kingdom and stated:

The only thing I'd known about diphtheria before was I know my aunt had it when she was a child, em, and my... you know, she had to go to the fever hospital, eh... and this was, this must have been in the forties, em, but it's like... it's almost like a... to me now, it's almost like a sort of an ancient... it's like Latin, a dead language...

Non-Vaccine Group; Sue aged 36

Indeed, there were many comments that suggested that participants no longer thought that diphtheria was a threat to their children. Karen, for example, associated diphtheria with: "...something in London, and like the, the plague, that sort of thing" (High Uptake Area Group; Karen aged 36). Helen considered it was: "something in the past" (Saturday Club Group; Helen aged 39) and Stella said it reminded her of: "something that you seen happening years ago, you know, you see old films..." (Autism Support Group; Stella). Perhaps for similar reasons Jenny suggested the image of: "...overflowing, the Thames" (Single Vaccine Group; Jenny aged 19). Some participants thought of it as a disease affecting other countries; Rhona mentioned: "it's a Third World illness really, isn't it" (First-Time Mothers Group; Rhona aged 31). Similarly, it was associated with India and described as something to come from swamps in the jungle. Taken together these comments offer both historical and geographical reasons to explain why participants living in the United Kingdom felt removed from the threat of diphtheria. In turn this led some participants to question the need for the diphtheria vaccine to be included in the Childhood Immunisation Programme at all. It was proposed that it should just be given only if the family had plans to travel abroad. However, Karen feared that the recent increase in the numbers of asylum seekers to Glasgow vindicated the need to continue vaccination of diseases more prevalent in other countries, to avoid outbreaks occurring in the United Kingdom (High Uptake Area Group; Karen aged 36).

In summary, diphtheria was a disease that participants had great difficulty in describing. Generally it was incorrectly associated as being water-borne and causing problems in the digestive system. Participants acknowledged that their knowledge about diphtheria was limited, reasoning that this was because they had neither direct, nor much indirect,

experience of it because it has not been prevalent in the United Kingdom for some time. In turn, this led participants to view diphtheria as no longer posing a direct threat to their children's health. Nevertheless, generally participants felt that diphtheria was probably a severe disease in its time.

3.6.2 Polio: 'Cripples', 'calipers' and 'sugar lumps'

Poliomyelitis is an acute infectious disease spread via the faecal-oral route. The last notification of poliomyelitis in Scotland was in 1994, and was vaccine-associated rather than derived from wild-type polioviruses (see www.show.scot.nhs.uk/scieh/surveillance). In children most cases are sub-clinical or show as a mild febrile illness. However in a minority of cases the virus invades the nervous system, causing either aseptic meningitis or more rarely paralytic polio. Paralysis can be temporary or permanent, with lameness in mild cases and in severe cases paralysis of the respiratory muscles or death (Salisbury and Begg, 1996). In cases where the respiratory muscles were paralysed poliomyelitis patients were nursed in respiratory machines called 'Iron lungs'. Figure 3.1 depicts Iron Lungs in use in a ward in a Los Angeles Hospital during a poliomyelitis epidemic in the 1950s.

Figure 3.1 Iron Lung machines

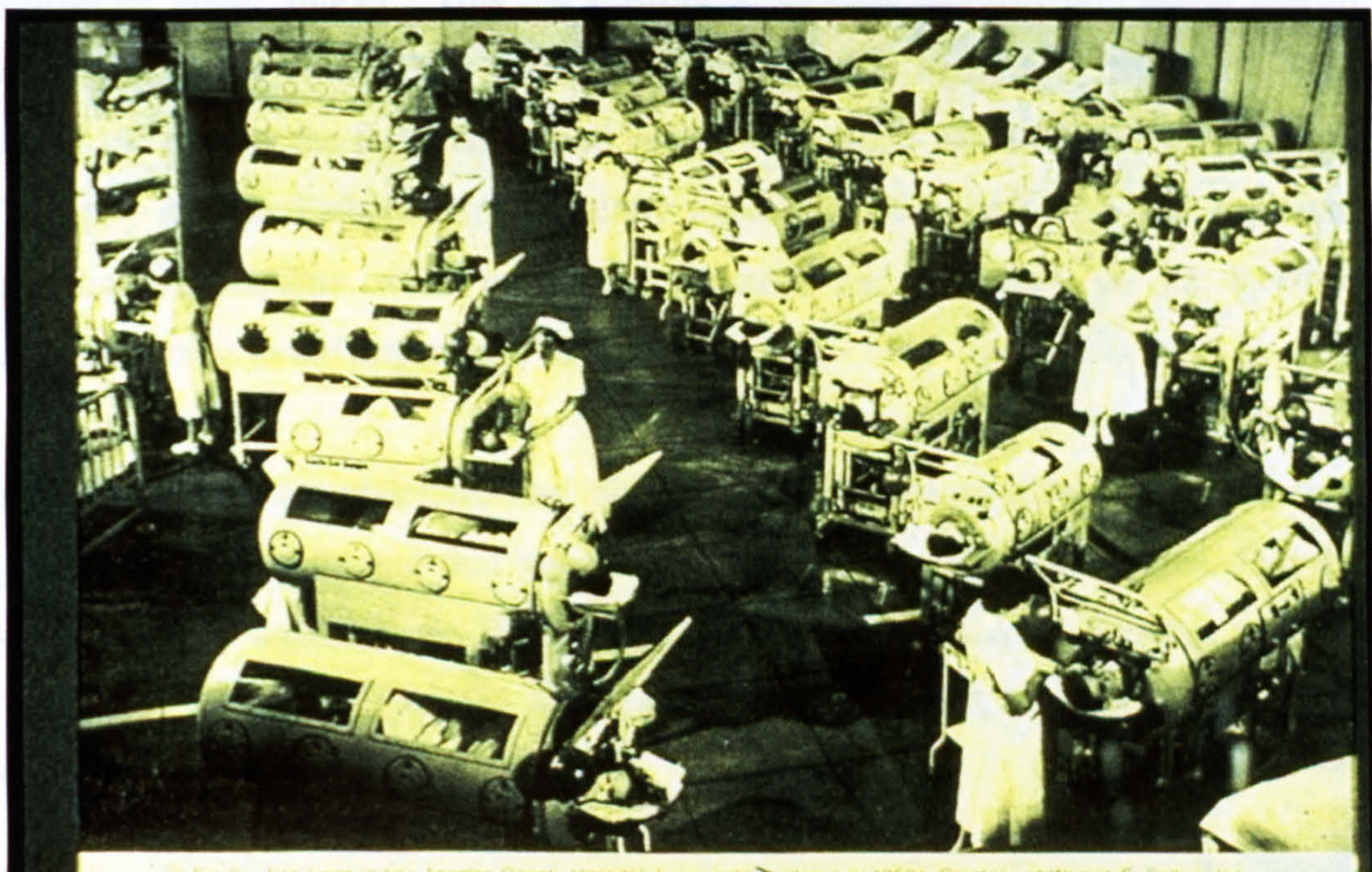


Fig. 3.1 Iron Lungs in Los Angeles County Hospital during polio epidemic in 1950s. Courtesy of Warren F. Cole, Inc.

The image of Iron Lungs came up in three groups; however, it was only associated correctly with poliomyelitis once and was associated with diphtheria and tuberculosis on two occasions.

A common image that participants associated with poliomyelitis was the vaccine itself. Participants often mentioned that polio was given orally and some participants recalled fondly stories of being given it in the form of a sugar cube at school. Margaret a 20-year old single mother remembered lining up outside the gym hall to receive the polio sugar lump. Similarly, Robert recalled:

...Ah've had. Cause when I was young...I was always off school at primary school. When you were getting all the immunisations. When I went back to go and see the nurse, 'cause I've missed getting the jags...and the, 'cause I always remember the teacher telling me to tell the class what I got and I got the wee lump of sugar.

Single Fathers Group; Robert aged 47

Some participants spoke of carefully washing their hands after changing their child's nappy in the weeks following getting the polio vaccine, but were not sure why they needed to do this and did not associate the mode of administering the vaccine with how poliomyelitis might spread. This led Catrina to wonder whether you could absorb it through your hands (First-Time Mothers Group; Catrina aged 27). Similarly, Kenny appeared puzzled by the fact that he had been told to wash his hands after changing his son's nappy (Single Fathers Group; Kenny aged 43). The lack of a full explanation meant that participants were unable to connect the relevance of its faecal-oral transmission route to the importance of hand washing.

In the absence of an understanding about how it is transmitted some participants suggested it was genetic and that you were born with it. Celia wondered: "maybe it was...from birth, maybe it was from the parents in the genes or something, something that the mother ate..." (First-Time Mothers Group; Celia aged 33). Similarly Margaret stated:

Margaret: Well Ah worry quite a lot about polio as well. Cos ma Da had polio when he was a wee boy.

Facilitator: Right.

Margaret: And he's got limps. His leg, he's nae muscles in his foot, so he limps noo...

Facilitator: Right.

Margaret: ...so Ah wiz quite worried about that as well, cos maybe it's hereditary and kind of stuff. Ah don't know if it is, but that was just cos ma Dad had it it was on my mind all the time.

Young, Single Mothers Group; Margaret aged 20

Although only one participant stated that you might ingest the virus, several participants implied that transmission was via the faecal-oral route. Participants in the Non-Vaccine Group felt concerned that the vaccine itself may infect unvaccinated individuals with the poliomyelitis virus, and discussed their fears about cross contamination of poliomyelitis at swimming pools:

Kitty: ...I was hearing that yeah, you can catch that you know in the swimming pool and I haven't taken my youngest son to the pool for that reason actually.

Facilitator: What age is he?

Kitty: Two and a half and I just wondered about that, but that was the first one that jumped out most... mostly to me. Em, and I have got, I've got the homeopathic alternative, as well, em, so I suppose. But I'm thinking well when can I take my son swimming, you know, when will it feel safe to do that, you know.

Non-Vaccine Group; Kitty aged 37

The conversation moved on to meningitis and pertussis, but later came back to the subject of whether polio can be transmitted via the water at swimming pools. Debbie stated:

Whereas I don't have a fear about polio because, apart from that the only polio in the western world seems to be from the vaccinations, you know, children passing it on through the vaccinations because it's live. But I have taken my children swimming quite young because there's chlorine in the water and they're getting, they're only getting rid of the amount that they've taken in and it's diluted by a whole swimming pool and I don't have any fear. I obviously did read something that was anti-vaccination that was saying that it's quite safe to take your children to the pool. So I've never really been bothered about that.

Non-vaccine Group; Debbie aged 33

Indeed, since 1993 there has only been an average of one case per year, of which two out of three were vaccine-related but these cases have mostly involved transmission between family members rather than at swimming pools (Mayon-White and Moreton, 1998). Whilst most participants appeared unsure as to how poliomyelitis was transmitted, participants had no difficulty in describing the visible disabilities that they associated with the disease. Most commonly mentioned was the fact that the disease affects the lower limbs, and a few of the older participants remembered seeing children at school that had had poliomyelitis and wore callipers as a consequence:

William: I remember a boy at school with it.

Robert: And his legs his legs crippled with it.

William: One boy in the class had, not in my class at school, had it. He could run about the Football pitch but he had a calliper.

Robert: I've seen when I was young, there was a few, a fair few, there was a few at my school as well with the callipers on. Aye that it, polio, aye.

Single Fathers Group; Robert aged 43; William aged 51

Even younger participants with no experience of the disease had no difficulty in describing some of the visible limb disabilities associated with poliomyelitis.

Facilitator: What about polio. What do you, what are your images of polio?

Catrina: Cripples.

Judith: Iron lungs?

Catrina: Iron lungs? What do you mean by ...?

Judith: (Nurse) the machines that we used to have.

Charlotte: Walking with a stick. Victorian children.

Catrina: Didn't they have like a club foot?

First-Time Mothers Group; Catrina aged 27; Charlotte aged 29; Judith aged 34

In summary, participants commonly mentioned that the polio vaccine was given orally and participants often recalled stories of being given it in the form of a sugar cube at school. Some participants spoke of carefully washing their hands after changing their child's nappy in the weeks following getting the polio vaccine, but did not associate either this, or the mode of administering of the vaccine, with how poliomyelitis might spread. Although there were a few participants who thought transmission was via ingestion, participants were generally unsure of how it spread. Concerns were raised that vaccinated individuals may infect unvaccinated individuals. One place that it was thought this could happen was in swimming pools. Across the groups, participants had no difficulty in describing the visible disabilities that poliomyelitis caused in its victims. Most commonly mentioned was the fact that the disease affects the lower limbs, and a few of the older participants remembered seeing children at school wearing calipers. Even younger participants with no experience of the disease had vivid images of poliomyelitis.

3.7 Discussion of findings

In order to compare and reflect the views from the wide range of participants who took part in the study, each focus group was asked to describe the images, experiences and knowledge of each of the vaccine preventable diseases included in the Childhood Immunisation Programme. To assess participants' knowledge of the diseases they were asked to describe how they would recognise the disease and how they thought it was transmitted. These discussions raised several important issues.

Of the vaccine preventable diseases included in the childhood immunisation programme, participants categorised meningococcal disease and its associated meningitis as the most severe. This finding is consistent with the findings of Bond et al. (1998) and with those of Smailbegovic et al.'s (2003) study; however neither of these studies offers any explanation as to why meningococcal disease was considered the most severe. In contrast, participants in this study identified several reasons to explain why they perceived meningococcal disease to be particularly threatening. Firstly, participants

appeared more knowledgeable about meningococcal disease than about the other diseases in the programme. They attributed their knowledge levels to the high level of publicity surrounding the Men C vaccine since its introduction into the Childhood Immunisation Programme in 1999. Secondly, participants considered that the high profile Men C campaign showed that public health experts were concerned about meningococcal disease. As such, participants viewed meningococcal disease as one of the more prevalent and severe diseases affecting children and in turn, judged it a more likely and grave threat to their children than any other disease vaccinated against in the programme. Thirdly, the perception that meningococcal disease was a severe and growing threat to their children seemed to be confirmed by having read or heard stories about children contracting meningitis. The main features of these stories that participants identified as being particularly alarming were: the speed with which meningitis can affect a child, the difficulty both parents and the medical profession have in identifying and diagnosing it during its early stages, and the perceived likelihood of the child having severe long-term neurological damage or of dying. These fears seemed to be largely derived from media coverage about meningitis and to be fuelled and corroborated by hearing other parents' experiences of meningitis, though these were more often third-hand accounts than first-hand experience. Indeed, on several occasions the focus group itself became the forum for the retelling of these third-hand accounts. These emotional and sometimes harrowing experiences appeared to serve as powerful reminders to participants not to be complacent about meningococcal disease. In this respect, Bedford and Elliman's (2000) assertion that if parents know about diseases they can appreciate how damaging these diseases can be, appears to be true in relation to meningococcal disease. A particularly striking feature of these discussions on meningococcal disease, which will be discussed in Chapter Seven, was the weight of evidence these anecdotal stories contributed in informing parents' perceptions about the disease.

The combination of the Men C campaign and the media's coverage of the disease acted as a powerful warning about the dangers of meningococcal disease and meningitis, and as a prompt to seek immunisation. However the sense of fear participants spoke of in relation to meningococcal disease was in stark contrast to their lack of concern about

haemophilus influenza. Participants knew very little about haemophilus influenza, leaving them to take clues, albeit misleading clues, from its name. Despite it also being associated with causing meningitis, no participant made this connection. Guided by its name, participants often suggested that it was a vaccine to prevent flu and thus perceived the disease as mild and as posing little threat to their children's health. Perhaps unsurprisingly no participants recalled any publicity about the Hib vaccine following its introduction into the programme in 1992, as most of the participants were not parents then. The complete lack of interest in, and understanding of, haemophilus influenza shown across all the groups was in stark contrast to their interest in meningitis, and suggests that immunisation education has been inadequate in explaining this disease to the public.

Likewise, although the mumps vaccination was introduced in 1988 into the Childhood Immunisation Programme as part of the MMR vaccine to reduce the incidence of viral meningitis, the more serious consequences of mumps as being viral meningitis was not mentioned in any of the groups. Participants generally considered mumps to be a mild disease and only harmful to boys if contracted when older as it was believed that it could make them sterile. This inaccurate belief led some participants to seek mumps protection for their sons and to view mumps immunisation as irrelevant for their girls. Similarly, some participants believed rubella immunisation was irrelevant for their boys on the basis that the disease only had serious implications for the unborn children of pregnant women. This led a few participants to question the wisdom of giving mumps and rubella vaccines to girls and boys and to view these 'blanket policies' as contributing to a state of over-immunisation of children. Although participants commonly suggested that rubella symptoms are mild and inconspicuous no participants raised the possibility that this could pose a problem in identifying and preventing the discrete transmission of this disease to pregnant women. Without such information, participants generally did not appreciate the importance of the role vaccination of boys play in reducing the numbers of potential carriers of the disease transmitting it to unprotected pregnant women. The significance of rubella infection of unprotected women (and thereby the risk to their unborn babies) highlights how important it is for parents to understand the factors that contribute to

controlling diseases, and the need for these factors to be communicated more effectively to parents.

Another disease some participants felt confused about was tetanus. Although participants generally spoke accurately about the signs and symptoms of tetanus, there was some confusion about where the disease might come from. On several occasions soil was correctly identified as a possible source of transmission. However, participants often suggested that rusty nails or dog bites were the most likely sources of infection. The most logical explanation to account for why these images came to so many participants' minds was that they would both cause puncture type injuries to the skin. However, the fact that participants thought dog bites were involved led them to suggest tetanus was the vaccine for preventing rabies. This is despite the fact that rabies and tetanus are unrelated diseases and the vaccine for rabies is not given routinely in the United Kingdom. This finding highlights the importance of educating parents about the diseases so that commonly-held misconceptions can be dispelled.

Further, as some participants thought it unlikely their children would be in direct contact with any of these sources of infection they assessed tetanus as only posing a minor threat to their children. This finding is consistent with Bond et al.'s (1998) study that found that mothers thought it unlikely their young children would contract tetanus. For some participants this risk appeared to be reduced further by the fact that, even in the unlikely event that their child should come into contact with these sources, they could still have the prophylactic tetanus vaccine to prevent them becoming ill. On this premise a few participants intimated that they had not given their child tetanus protection. A point worth noting is that no participant made any distinction between tetanus and the other diseases in relation to the fact that, unlike the other diseases, tetanus is not a communicable disease, and therefore does not pose a threat to those around an infected individual.

Diphtheria was another disease participants knew very little about, and incorrectly defined it as being a water-borne diarrhoeal disease. However, unlike haemophilus influenza, participants were able to offer an explanation as to why they knew so little about

diphtheria. Participants considered that their lack of knowledge was a consequence of neither having direct nor indirect experience of it, due to its low prevalence in the United Kingdom. Although a few participants appreciated that diphtheria could be imported into the United Kingdom from countries where there are still epidemics of the disease, many participants did not know this and therefore questioned the reason for its continuing inclusion in the Childhood Immunisation Programme. Similar to Bond et al.'s (1998) study, the participants in this study considered it unlikely that their children would come into contact with diphtheria or poliomyelitis living in the United Kingdom.

So far these findings seem to indicate that the less people know about the diseases the less they assess them as a threat. However, the relationship between people's experience of disease and their subsequent fear of the disease seems less obvious and their relationship is much more complex. For example, measles and whooping cough were the diseases that participants had the most direct experience of either as children themselves, or as parents. However, it was observed that having direct experience of a disease as children themselves did not necessarily mean participants would assess the disease as threatening to their child's health. This was especially true if they had cared for a child that had made an uneventful recovery, or had little or no memory of their own experience of the disease. Indeed, these participants tended to view the diseases as less severe than did some of their counterparts with no experience of it. In this respect the strategy of some public health officials in highlighting the whooping cough epidemic to persuade parents to avoid a similar pattern of events with measles, may lack persuasive power if parents have survived with little or no memory of ill effects of the disease. It also highlights a problem in that often the most severe reactions to the diseases are experienced by babies and very young children, who are too young to accurately recall their experiences. In general there seemed to be a lack of awareness that the effects of childhood infectious diseases may be worse if contracted as a baby than as older child, leading some participants to actually underestimate the potential risks associated with the disease to the more vulnerable members of society.

It seems highly debatable that any of the participants' children had actually contracted measles, as SCIEH reports state that in 2000 and 2001 there were no confirmed cases of measles in Scotland and that in 2002 none of the four cases of measles occurred in Glasgow (see www.show.scot.nhs.uk). However, several participants were adamant that their children had had measles and believed public health officials were underplaying the true incidence of measles in Scotland. This was despite the fact that these participants also questioned how accurately doctors could clinically diagnose measles as they felt many young doctors had little or no experience of it, and they had not had it confirmed by saliva test. In turn, this led to a sense of confusion among participants about the magnitude of the threat of measles and scepticism about the accuracy of information disseminated to the public.

The relationship between a person's experience of a disease and their knowledge and perceptions of that disease is complex. Despite the fact that participants had little or no experience of poliomyelitis they often described vivid images of the disease. The fact that participants found it difficult to describe diphtheria and easy to describe poliomyelitis suggests that even when parents have little or no experience of diseases themselves, some diseases appear to be more memorable. The physical impairment that poliomyelitis caused in its victims appeared to have created a lasting visual impression in many participants' minds. Perhaps for this reason, and because polio is a pain-free oral vaccine, participants did not question the need for its continuing inclusion in the programme.

The fact is that there is very little literature on people's understanding of the diseases prevented by immunisation programmes, which has made it difficult to compare and contrast these findings with other studies. Therefore these findings contribute original and highly policy-relevant research to the wider body of knowledge on childhood immunisation.

Chapter Four: Parents' perceptions of the MMR controversy

This chapter considers parents' perceptions of the MMR controversy. It begins by presenting a short review of the most relevant and up-to-date literature on parents' perceptions on MMR immunisation. It is of note that much of this literature has been published since fieldwork begun for this study. This short review is intended to recap and complement the more comprehensive review offered in Chapter One. At the end of the chapter a short conclusion draws together the most salient findings to have emerged on parents' perceptions of the MMR controversy.

4.1 Summary of literature on the MMR controversy

In recent years the public may have considered themselves to have been misled or offered incomplete information on a range of public health issues. These include the risks posed to humans from Bovine Spongiform Encephalopathy, Escherichia Coli, Salmonella infection, and from genetically modified food. This growing distrust of the Government in safeguarding public health is the backdrop against which parents have observed and assessed the speculation surrounding the safety of MMR. Across the United Kingdom the fall in MMR uptake rates provides evidence that some parents remain anxious about its safety. This is also suggested by the fact that before legal aid was denied in September 2003 there were more than 1000 claimants suing the pharmaceutical companies responsible for manufacturing the MMR vaccine. This suggests that there are thousands of parents convinced that MMR has damaged their children's health (Dyer, 2003).

Since the MMR controversy first attracted public attention in 1998 there has been huge interest in it from the media, politicians, health professionals, and parents alike. However, much of what has been written about parents' views on MMR has stemmed from media reports and newspapers, rather than from the scientific community. In recognition of this

fact researchers have begun to redress this imbalance and in the past few years there have been several papers that have considered how the controversy has been communicated to parents, and in turn, how parents have conceptualised it.

As described more fully in Chapter One, the studies by Evans et al. (2001) and Smailbegovic et al. (2003) are particularly important in offering an insight into parents' perceptions about the MMR vaccine and debate surrounding its use. The main findings from these papers were as follows. Evans et al.'s (2001) carried out a small qualitative study involving six focus groups and found that parents were not convinced by the Department of Health's reassurances that MMR was the safest and best option, and that on some occasions parents had accepted MMR unwillingly. They also suggested that many parents did not have confidence in the recommendations of health professionals because they were aware that GPs need to reach immunisation targets and that some parents experienced unwelcome pressure from health professionals to comply with immunisation policy. Similarly, a later study conducted by Smailbegovic et al. (2003) also found that parents considered the information provided by health professionals was biased, and that information about vaccine safety was withheld. They found that parents who rated immunisation information as poor were more likely to access Internet sites for information. They concluded that parents would benefit from more detailed factsheets given out by well-informed professionals. Flynn and Ogden (2004) conducted a study to find out parents' beliefs about the MMR vaccine. Five hundred and eleven parents living in East Sussex completed questionnaires prior to receiving a letter to attend for their child's vaccination. Attendance data were collected at follow-up by the age of two years in order to explore the best predictors of uptake by that age. They found that the uptake of the MMR vaccination was related to previous uptake of vaccination given to the child at 3, 4, and 5 months. Similar to Smailbegovic et al.'s study (2003) they also found that uptake was affected by parents' trust in the medical profession and that many parents held conflicting beliefs about the MMR vaccination and the doctors who administer it.

In an attempt to provide a contemporary assessment of the media's role in the public understanding of science, Hargreaves and colleagues at Cardiff University (2003) published an in-depth report that considered the MMR controversy amongst other public health debates. The study involved two nationwide surveys, both with representative samples of over 1000 members of the public, to explore what they knew and thought about MMR. In addition to this, they conducted a content analysis of 521 media reports on MMR over a seven and a half-month period, in order to explore exactly how MMR was reported, framed and interpreted. From this work they suggested that media coverage of the MMR debate was unintentionally misleading in creating the impression that the evidence for the link with autism was as substantial as the evidence against it. Although press reports often tried to make it clear that the bulk of evidence indicated that MMR was safe, what people appeared to have understood was that there were two sides to the debate. This led most respondents (53%) to assume that since both sides got roughly equal coverage, they must correspond to equal bodies of evidence. Similarly, Clements and Ratzan (2003) commented on the responsibility and role of the media in their reporting of the MMR debate and considered:

The British public have been fed by the media on a mixed diet of scientific evidence, theories, views, and other verbal roughage. Because of the huge amount of media coverage of the safety of MMR, the public, not unreasonably, have come to the conclusion that there is no smoke without fire; there must be some truth in all this alarmism... (p. 23).

Clements and Ratzan's suggestion is that once the public felt misled, they became suspicious and would no longer accept information unquestioningly. However, Bellaby (2003) pointed out that the public's reaction to the MMR debate should be viewed in a broader historical context. Bellaby suggested that in a democracy it should be expected that authority is challenged, and under these circumstances some people would choose not to comply with some public health measures. He considered that, if compliance is to occur, communicating risk effectively to the public is about more than providing information. However, he also acknowledged that a difficulty in communicating risk to parents is that "science cannot prove a negative, but where their children are concerned, parents want to be reassured that the risk is zero" (p. 725).

Indeed, Lewis and Speers (2003) suggested that there have been two key failures to communicate messages about MMR safety and risks to the public. Firstly, there was a failure to expose the limits of Wakefield's claims. This failure has been addressed to some extent by the partial retraction published in the Lancet in March 2004, in which ten of the co-authors of Dr Wakefield formally disassociated themselves from his hypothesis that MMR may cause autism. The second failure that Lewis and Speers highlighted was that there have been inadequate attempts to stress the risk of instituting an untested programme of three separate vaccines. In an attempt to draw lessons from the MMR controversy they advised that there is a danger in health professionals relying on government or established bodies to make the case for MMR, as it may lead to unwelcome comparisons with the BSE crisis. Lewis and Speers warn that the battle for public trust needs to be based on an understanding of the nature of public concern. Whilst recognition of this fact has led some researchers to focus their efforts on investigating parents' anxieties about MMR immunisation, the scope of these studies has often been limited. No published studies have included the diversity of parents that have taken part in the current study and none of the studies has included the views of parents with autistic children. Yet if, as Lewis and Speers suggest, the battle for public trust is to be won by understanding the nature of public concern, then it is clear that there is a need to hear from a greater diversity of parents affected by the debate. Indeed, in Horton's book published in September 2004, he notes that parents have been marginalised from the debate. With this in mind, this chapter aims to consider parents' perceptions about the evidence on MMR safety, and parents' beliefs about how the MMR controversy has been handled.

4.2 Perceptions of the MMR controversy: 'Who's got my wee boy's best interests at heart?'

Although one of the aims of this study was to explore parents' perceptions of the current MMR controversy there was a danger that this aspect of the focus group discussion could dominate the entire focus group session. Therefore I deliberately avoided using the word

MMR on any of the letters and information sheets handed out to potential participants. I also planned to introduce the topic of the MMR debate myself towards the end of the focus group if it had not already arisen during the course of the discussion. This was an attempt to try to control and manage the amount of discussion on the debate to avoid it dominating the whole session. In practice, this was naïve: MMR was often the first issue parents discussed and there was never a need for me to introduce it. Indeed, although MMR was not mentioned on the information sheets given to potential participants, it became clear that the MMR debate was the sub-text that drew participants into taking part in the study. Participants eagerly discussed the MMR debate and the volume of data generated on this topic was substantial. After much coding, re-coding and deliberation, four main themes were identified around which to present the data in this chapter. These themes reflect the main topics participants spoke about in relation to the MMR controversy.

- Participants' understanding of the evidence about the safety of MMR vaccine.
- Participants' perceptions of the role the media have played in reporting the evidence.
- Participants' perceptions of the role politicians and public health officials have played in the debate.
- Participants' perceptions of the role Dr Wakefield and other medical and health professionals have played in the debate.

Guided by these themes this chapter offers an insight into participants' perceptions of how the MMR controversy has been handled and of their understanding of the state of the scientific evidence about the safety of the MMR vaccine. The chapter concludes by discussing how the findings of this study compare with those of other studies and by summarising the main points to have emerged from discussions on the public health debate about the safety of MMR immunisation.

4.2.1 Participants' understanding of the evidence about the safety of MMR vaccine: 'No smoke without fire'

The general perception among participants was that the evidence of a causal link between MMR and autism was not convincing at the moment, but that in time further evidence may come to light that shows MMR is damaging for some children. In this respect there was a sense that for many participants the evidence of a link between MMR and autism is incomplete and uncertain at the moment. Indeed it was common for participants to demonstrate their uncertainty about the state of evidence by directing questions to each other, and to myself as the facilitator. Participants often sounded unconfident when they spoke, and talked hesitantly, using frequent pauses and unfinished sentences to encourage other group members to comment on their suggestions. Their body language tended to mirror this uncertainty, and participants encouragingly nodded their heads when other group members spoke and tended to use eye contact to show they were finding each others' point of view interesting. As such, participants did not tend to sound as if they were entrenched in their views on MMR safety, and they often appeared willing to consider the debate from various perspectives. However there were some notable exceptions to this. These exceptions included participants who had decided not to give their children MMR: the Non-Vaccine Group, the Single Vaccine Group and the two groups conducted with parents of children with autism. These four groups consisted of participants who had considered the debate and had made up their minds not to vaccinate their children with MMR; therefore they spoke with more conviction about MMR safety. The Non-Vaccine Group's concerns were about immunisation more generally and were not confined to the MMR vaccine, whereas parents in the Single Vaccine Group were primarily concerned with the MMR vaccine and their worry did not extend as much to the other vaccines in the programme.

In considering the evidence about MMR safety it was clear that many participants found it confusing to decipher what counts as evidence and to assess the trustworthiness of the studies being debated in the public domain. For example, Sue referred to a Finnish study:

Yes, uhuh, and this Finnish study as well, em, they always quote... this Finnish study only followed-... it didn't follow children up. It was something like, it was a month afterwards and they weren't looking for autism, it wasn't a study looking for autism, it was a study looking for reactions in... after your MMR after a couple of weeks. So you would have your initial temperature and all that, em, but no, there's no proved link with autism because they weren't looking for autism. That wasn't what that study was about and that keeps continually being... touted and trotted out and it's almost like false information because the study wasn't to do with that as far as I'm aware. You know, the autism wouldn't develop within the first four months although I know somebody that said, you know, some people who've had the injection, something's happened to their child but there has... but as far as I'm aware, there has not been a study done that follows up children specifically looking for autism from MMR.

Non-MMR Group; Sue aged 36

Sue's comments were interesting because, by referring to a specific research study, she, like other participants, demonstrated how highly involved parents have become in trying to comprehend the evidence. However, despite her efforts she appeared to feel sceptical about the evidence, sensing that studies are selectively chosen to be communicated to the public and that, as yet, research attempts have been inadequate in addressing the real issue of a link between MMR and autism. Likewise Trudie considered that she had tried to gather as much information as she could. She stated: "I didn't really get very far, I was quite confused and I don't have the scientific, medical sort of background to be able to understand the information that I need in order to understand, to make a decision. It is all kind of anecdotal and quite emotive the way it is presented..." (NCT Group; Trudie aged 38). Even, Bob, a father of two, who talked about specific authors and studies, considered that the studies he had read about in the press were difficult to assess. He summed up his feelings thus: "I have no way of knowing that that paper is any more relevant in any way to the greater good. There's no way of knowing that one paper is... is the method used to test the hypothesis is in any way rigorous..." (Saturday Club Group; Bob aged 31).

A common view expressed by participants was that in order to reassure parents that MMR has no risks associated with it there is a need for further research to show that there is no link between MMR and autism. For Joanne, the lack of research made her feel that the Government was not taking her concerns seriously (New Mothers Group; Joanne aged 37). The NCT Group also debated the issue of the lack of research and thought:

Trudie: I just don't think enough research has been done really, one way or the other, to say whether it is completely safe.

Mel: I still feel as if there is something underlying, something there, you know these children were they (interrupted)

Violet: You know though that these parents weren't just making it up, I don't think, you know.

Mel: No, I know.

Violet: 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.

Trudie: That's true.

They then moved on to talk about feeling misinformed about BSE, before Violet summed up her assessment of the evidence on MMR safety:

Violet: I don't think you can just keep saying to parents, it's safe, it's safe, it's safe, and you are putting your child at risk if you don't give it. They are not really allowing anything of the other side of the story. I don't think that Dr Wakefield has ever said he can prove a link. I think his research has been validated as research. There is nothing wrong with the processes he has gone through, and I think parents would be more comforted if they would allow the other side of the story to come out a bit more...

NCT Group; Mel aged 35; Violet aged 36; Trudie aged 38

This conversation is interesting because it highlights some of the difficulties participants had in trying to interpret the language used by politicians and scientists to convey messages about MMR safety to the public. Participants were often dismissive of phrases such as 'no proven risk,' and 'minimal risk,' and of blanket messages that MMR is safe, as they felt that the lack of research contributed considerably to the difficulty they experienced in assessing MMR safety. Participants appeared to interpret these messages from politicians and scientists as meaning that they are not aware of any risk 'at the moment'. For example, Patsy stated that as far as she was concerned until scientists get the proof to show there are absolutely no risks associated with MMR they are experimenting with children's health (Multiple Parenting Problem Group; Patsy aged 23).

In the absence of feeling able to make sense of the biological plausibility of Wakefield and colleagues' theory, participants tended to focus their attention on what they considered to be the facts about the epidemiology of autism. Participants often speculated about why the incidence of autism seems to be increasing, and about which children they thought might be at most risk of developing autism. For example, in the First-Time Mothers Group when Celia stated that she felt worried about her daughter receiving MMR, Charlotte tried to reassure her by saying:

I think actually as a girl, you've got hardly any chance of them becoming autistic because it's about... almost every autistic baby is a boy. It's not, I mean it does happen to girls, I mean every so often we get a girl but it's really very, very low percentage that we see.

First-Time Mothers Group; Charlotte aged 29; Celia aged 33

Charlotte's attempts to reassure Celia were mirrored by comments from participants in other groups. Whilst this appeared to be reassuring for those participants with girls, those with boys found it worrying, and this was evident when they talked about the factors that influenced their decisions about MMR. Indeed, on closer examination of the data, it is of interest to note that the participants who opted to take part in the study were more likely to have boys than girls. Collectively they had 78 sons compared to 51 daughters. One possible explanation for this may be that participants with boys were keener to volunteer to take part because many of them were aware that there is a higher incidence of autism among boys. This knowledge may have led them to consider that their boys were at greater risk from developing autism after receiving MMR. In fact, reviewing the responses from the short questionnaire completed by participants, it is interesting that out of the 78 boys, 34 of them had either not had their MMR, were not going to be given their MMR, or were having their MMR delayed; this compared to only seven of the 51 girls. This finding supports the need for further research into the aetiology of autism as it is of concern that parents of boys to be particularly worried about the causal link between MMR and autism.

Another group of children that some participants felt future research might reveal to be at risk from having an adverse reaction to MMR were children with vulnerable immune systems. Some participants identified childhood illnesses (such as recurrent ear and chest

infections, or asthma, eczema or allergies) as being indicative of a slightly deficient immune system. This led some participants to fear that future MMR research might suggest that these children should not be immunised with the combined MMR vaccine. For example, in the New Mothers Group, Joanne wondered whether her son's eczema might be an indication that he could be vulnerable to having an adverse reaction to MMR:

Well, I'm a journalist so I've been reading quite a lot about it- though, I must admit I'm not entirely convinced that I want him to have the MMR. Six months ago I'd have probably said yes, I wouldn't have had any problem with it, but I just think the lack of the Government's...not allowing a study to be done into whether there is any definite effect. I don't think MMR causes autism as Wakefield suggested, but I think if there is enough mothers that are worried to think that there is something there, to think that if their child has asthma or eczema or whatever that it could act as a trigger. The fact that the Government won't do anything about studying whether that is a possibility or not, I just think just makes me worried, you know. He has actually got baby eczema, so could MMR could be a trigger? I don't know whether it is true or not, but it just makes me think the single vaccines would be better.

Conversation moves on to the single vaccines, before Joanne sums up her feelings:

... I am only concerned because I read somewhere about possible triggers. I read that asthma and eczema are possible triggers and I would never forgive myself if that was a trigger and I went ahead and got him jabbed. Are they triggers that cause autism? But there again, he could end up autistic anyway. So I don't know, I just feel completely confused about the whole thing.

New Mothers Group; Joanne aged 37

Joanne clearly felt apprehensive about her son and used rhetorical questions to demonstrate to the other group members that she considered there to be many unanswered questions about the safety of MMR. By introducing herself as a journalist and referring to Wakefield's study, she immediately let the other group members know that she was an educated professional. But by then admitting that she found the debate complicated, she endeared herself to the other group members who also went on to talk about finding the evidence confusing. This subtle interaction was noticeable because it was one of several conversations in which Joanne appeared to hold court over the other group members. On one hand, it may be that because Joanne stood out as the most vocal and confident member of the group, her comments directly influenced the other group members' comments. There is no doubt that Barbour and Kitzinger's (1999) suggestion that data are influenced by the context in which they are produced holds true here.

However, one of the useful aspects of keeping the transcripts intact and writing field-notes on to them was that it offered greater insight into the group dynamics. It was observed that when participants agreed with each other for the sake of group consensus, these participants often affirmed their position or contradicted themselves in later discussions. This was not a feature in the New Mothers Group and therefore it seems likely that the high level of agreement that the evidence was confusing and incomplete was genuine.

Although the general feeling among participants was that further research would help clear up some of the confusion surrounding MMR and thus dispel parents' fears, not all the participants felt concerned about MMR safety. Some participants were quite dismissive of the evidence of a link between MMR and autism. Margaret, a mother of one boy, stated: "...fur aw the children in the world that has had MMR there's only like a small minority that have maybe got it and it's no even proven is it? That they've actually got autism because o' that jag, so ye don't know..." (Young, Single Mothers Group; Margaret aged 20). Although Catrina, a mother of one girl, mentioned that she was concerned about MMR, she also made reference to the pertussis controversy in the 1970s and 1980s. She considered that: "...in 20 years time it will be a different one that they, you know, that's in the press and they are creating fuss over" (First-Time Mothers Group; Catrina aged 27). Similarly, whilst Angie, a mother of two boys, urged the need for further research, she felt convinced that the higher incidence of autism in boys was evidence that genetics would eventually be cited as a major factor in the development of autism, and took solace from the fact that she had no family history of autism (Crafts Group; Angie aged 29).

4.2.2 Perceptions about the media's role in reporting the evidence

Participants' views on the role that the media have played in the MMR controversy varied enormously. Some participants viewed them as scaremongers, only interested in selling newspapers, whilst others thought of them as valuable information providers. For example, Ellen thought that they were useful in raising the public's awareness of issues

(Saturday Club Group; Ellen aged 45). Likewise, Frank considered: "I think the newspapers are trying to let the everyday people know the inside story" (Multiple Parenting Problems Group; Frank aged 31). In contrast, Cathy denounced the media's involvement in the MMR controversy, stating:

...it's, it's just the media being the media. You know, we've got to have something to sort of ... the minute a bit of scandal comes along they just sort of, you know, they just go mad with it. I think they take it out of all contexts. Yeah, I think we do have a right to know if there are problems with it. But there again, it's like Helen said, it's kind of blanket everything, you know, it's just too blanket.

Saturday Club Group; Cathy aged 29

Likewise, the participants in the Crafts Group considered:

Angie: ...they make it into a big issue an just get a wee bit carried away.

Mary: Aye (group members nodding heads).

Tracy: Aye the usual.

Angie: It is. It is but that's their policy, they dae that anyway, I mean. As long as they're getting the weans they're no caring, I mean, cos that's all it is really. Just, dunno, they dae it all the time, they just over-dramatise it, if you could call it that.

They went on to discuss the media's role in other public health scares, before coming back to talk about the MMR controversy.

Mary: It's ridiculous, and then people... are unsure about going in to buy eggs and ... what do we dae? Do we buy them or do we no buy them? And again the same wi the CJD an beef.

Angie: Doesnae matter what you eat don't eat this and don't eat that.

Lydia: Autism and stuff like that.

Angie: If we didnae eat anything we wouldnae survive, know what I mean?

Mary: Just say, as long as the media attention and they're getting the ratings they're fine init?

Crafts Group; Angie aged 29; Mary aged 43; Tracy aged 32

Indeed, when some participants spoke about the media's involvement in the debate, it was almost with a sense of resignation that the media can be expected to act

unscrupulously in sensationalising stories in order to sell papers. Some participants looked dejected when they spoke about the media, and talked about being tired of the spin that the media put on stories about health. It was implied that the competitive nature of newspapers and journalists to sell newspapers may have played a substantial role in creating much of the furore about MMR safety. A few participants sounded fed up with this state of affairs and occasionally spoke angrily about the media's antics. For example, Iona demanded that: "...the media have a responsibility to stop just taking bits of research and throwing it into the press to alarm us" (Antenatal Group; Iona aged 39). Participants talked about the fact that health stories, especially those involving children, are of huge interest to the general public and that the media are acutely aware of this fact. The Single Fathers Group considered that this interest in health in the media has grown over the years. They said that when they were young, their parents did not have access to the level of information that today's parents have, and questioned whether the information on MMR had helped or hindered parents' assessment of MMR safety. William summed up the current situation as he saw it, stating: "there was no controversy to the amount there is today" (Single Fathers Group; William aged 51). Similarly, Joan considered "it's never off the television" and Alan later replied to Joan's point stating:

I feel as if the media has got a lot to play in everything. They've got...because you would never really hear about this if it wasn't for the media. The media is...you just take it in...how many papers is there now to before? There wasn't as many papers before as what there is nowadays. You know you go into the shop and you've got a choice of maybe 20 or 30 papers. And the TV, the TV, there's news on all the time and I feel, you feel as if they're just searching for something.

Low Uptake Area Group; Joan aged 20; Alan aged 33

Indeed, whilst some participants considered that they would not know anything about the MMR debate if it were not for the media's involvement in it, they often considered that media involvement had confounded rather than illuminated their understanding of the MMR issue. This led a few participants to state that they had stopped reading the articles on MMR in newspapers. Nevertheless, other participants had found it difficult to distance themselves from the debate and spoke of feeling particularly drawn to

newspaper stories that involved the personal stories of other parents. They suggested this was because they could relate to them more as parents than they could to commentary by scientists and politicians with whom they felt they had less in common. Parents' stories were also viewed as being more impartial and as having no hidden agenda. In addition they were able to relate to these stories easily, and this seemed to make this kind of evidence very persuasive. For example, Dave thought:

... I think there's a sense that there's a kinship with other parents that you just don't have with, you know, doctors and you know, the reason why it was moving, the article that Quentin had written, was because he was a parent writing about his son. But you know, if that was just a journalist writing about autism, it wouldn't have the same impact because you're not relating experiences as parents. And I think as well, you know, that the evidence that scientists use, it's just stuff that just goes in and out your ears. You just can't comprehend it. It's 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.

Single Vaccine Group; Dave aged 38

In this respect these personal stories appeared to carry as much, if not more, weight of evidence than research studies or comments from politicians and public health officials. This was because participants could relate to this kind of evidence compared to research studies which many participants felt ill-equipped to assess for themselves. However, a few participants complained that newspapers and television programmes have tended to contrast the scientific and anecdotal evidence alongside each other, leaving a confusing picture that did not assist them to come to any conclusions about the safety of MMR. For example, Joanne mentioned that the Daily Mail is a health newspaper, and she went on to make an important point about the way that the media presents stories:

Well, newspapers have different agendas anyway; I mean the Daily Mail is normally the health newspaper. They ran an article on the MMR story and they had a page for and a page against it. But again, like the Panorama programme there is nothing in the middle saying - the conclusion is you've got to make your own mind up. In the end it comes down to you as a parent, you decide one whether you think it is a risk, then whether it is it is a risk you want to take, or whether you don't think the disease is a risk worth vaccinating against.

New Mothers Group; Joanne aged 37

The interest that participants appeared to have in reading and hearing other parents' experiences of MMR, and the level of media coverage paid to the debate, appeared to have influenced participants' assessment of the evidence. It was implied on several occasions that the level of attention afforded to the MMR debate and the fact that some stories involved parents who were adamant that MMR had caused their child's autism, was evidence enough for them to conclude that MMR is unsafe. "No smoke without fire" was a term used and Angie expanded on this when she said "obviously there is something, there is something that links it or it wouldn't be going on, do you know what I mean, all the discussion about autism" (Crafts Group; Angie aged 29).

4.2.3 Perceptions about politicians and public health officials

The general consensus among participants about how politicians and public health officials were perceived to be handling the MMR debate was that politicians were untrustworthy, and that public health officials were not persuasive. Participants talked about public health officials and politicians interchangeably and they rarely differentiated between the two. In this respect any announcement of reassurances about the safety of MMR from public health officials were subjected to the same critical appraisal as that from politicians. Alison considered that the attempts by politicians and public health spokespersons to discredit Dr Wakefield and co-authors were not reassuring (High Uptake Area Group; Alison aged 31). A few participants implied that as doctors, Wakefield and co-authors were more likely to be acting in the public interest and thus were more trustworthy than politicians, who were often viewed as acting primarily in their own interests. This was interesting because when participants later came to discuss the role of GPs and other health professionals in the MMR debate, they often talked about not being able to trust them either. The general feeling was of mistrust. For instance in relation to public health spokespersons, there was a sense that they were speaking on behalf of the Government and thus were not viewed as impartial. This led participants to dismiss messages from them about MMR safety. For example, when the Low Uptake

Area Group were asked if they felt that the Government and public health officials had reassured them, the question was interrupted by Sheila:

Sheila: No I think they've just said its safe, that's it.

Joan: It's always the same thing. It's always the same statement you read that its' safe. There's no evidence.

Facilitator: Does that reassure you? Or does that not reassure you?

Alan: No.

Sheila: No it doesn't reassure me.

Alan: See really afore this all came out, surely they should have had their facts perfect, the facts that they should have been right before they came away out with all this. It just seems as if they've blew it all out of proportion and then they retract some of it.

Low Uptake Area Group; Joan aged 20; Alan aged 33; Sheila aged 36

A key reason given by participants for not feeling reassured by the Government and public health spokespersons was that participants recalled their handling of the recent BSE crisis. Dawn felt that since then the public has become less trusting of Government reassurances, and stated:

I think throwing blanket statements at you, we are right and you are wrong, is not very helpful and the big studies, you know they have just said we are going to look at autism, but we are not going to look at MMR because that is not the reason. It is like ...it is just treating us like... It reeks of all the other health scare scandals. Where we are told, there is not a problem, not a problem –oh whoops! There is a problem.

Antenatal Group; Dawn aged 36

It was commonly mentioned that the Government had failed the public during the BSE crisis, and so could not be trusted to accurately communicate risks to the public. Participants were of the view that the Government's reassurances of the minimal risk posed to human health by BSE greatly underplayed the actual risk. In turn, just as the image of John Gummer the Minister of Agriculture feeding his daughter a hamburger during the BSE crisis was mentioned by participants as symbolising the Government's handling of the crisis, the image participants associated with the MMR debate was of Tony Blair, the British Prime Minister, refusing to confirm whether his son Leo had had

MMR. This image was discussed within many of the groups and participants often debated at length the rights and wrongs of Tony Blair's decision not to disclose this information to the public. (See Appendix D for MMR events/ PhD study timeline). For example, Violet considered:

...I think Tony Blair, I mean, I don't really think it is an issue of the baby's privacy, either he has had it, or not. It is not going to make any difference to anybody one way or the other. He should come out and say, particularly if these recent stories are true that he delayed getting it till Leo was 19 or 20 months. Because it is unfair to be saying to parents it is safe for your child to have it at 13 months.

NCT Group; Violet aged 36

Similarly, the Single Fathers Group discussed it and they considered:

Kenny: See a, the thing that annoyed me as well with the...the media. The way it's brought across the media. If I'm correct em...when eh, Tony Blair's kid, was to get a jag...it wasn't made public knowledge at the time. Whether he went for it or not. Whereas if they were pushing policies and especially with him being head of government, he should have made it public knowledge.

Robert: Practice what he preached.

Kenny: Their choice. They're pushing a programme and what better to push a programme than the head of state having their kid...disclose whether they've had it or not. Because the fact that he didn't disclose that...put a lot of fear into parents. Because he doesn't go...he's being cagey with us. He may be pushing a programme he doesn't believe in because he's not made it public knowledge about his own kid. So I think that caused a bit of hysteria as well.

Single Fathers Group; Kenny aged 43; Robert aged 47

Participants were asked to expand on why they thought these two images were particularly memorable. The response usually was because they both involved children. However a few participants also drew some interesting parallels between the two images. For example, Charlotte considered that the image of John Gummer and his daughter represented the fact that his daughter probably did not have any choice as to whether she wanted to eat the hamburger in front of the assembled press. She sympathised with his daughter's predicament, as she felt that whilst not overly concerned herself, other parents were being denied the right to choose between the single vaccines and the MMR vaccine (First-Time Mothers Group; Charlotte aged 29). Likewise Sue compared the two images, she stated: "I think it's a whole... it's like a metaphor for the way the Government treats

the public...(spoken in loud commanding voice) ‘I know what is best for you’ – have a burger sort of thing public.” She later expanded: “...I’m a dad, this is my child, I’m the Government and you’re the public and it’s that relationship I think that it illustrates.” (Non-MMR Group; Sue aged 36).

Another incident that many participants also mentioned as having dented their confidence in the Government and in public health officials’ abilities to communicate health risks to the public was the cryptosporidium incident that occurred in Glasgow in the summer of 2002. Many of the participants who took part in this study were directly affected by having their water cut off during the outbreak and many of them were pregnant, and or had young children at the time. Rhona, who was pregnant at the time, considered that the public health officials were slow to respond and were deliberately selective in the information they gave to the public (First-Time Mum Group; Rhona aged 31). Similarly, Karen who had just recently given birth to a baby boy recalled: “...when it came to that breakout in the news I was really upset, I think I was hormonal, but I was very upset you know? I just bathed my baby that morning, you know...” (High Uptake Area Group; Karen aged 36).

Between and within the groups there was a high level of agreement among participants that the handling of these public health debates had contributed to their lack of trust in politicians on the MMR debate. The general view expressed by participants was that politicians serve their own interests and those of their party before that of the public. Joanne summed up what many participants implied when she said: “...there is a lack of trust in prime ministers, health ministers, food ministers, politicians generally” (New Mothers Group; Joanne aged 37). Debbie and Molly both believed politicians would readily manipulate statistics and tell the public half truths and Kitty considered that this and being brought up around Members of Parliament had influenced her and made her think that politics was quite corrupt (Non-Vaccine Group; Molly aged 37; Debbie aged 33; Kitty aged 37).

The distrust with which politicians were regarded spilled over to a distrust of their motives for supporting the combined MMR in preference to the single measles, mumps and rubella vaccines. It was common for participants to consider the wider public debate about the pros and cons of making the single measles, mumps and rubella vaccine available on the NHS alongside the MMR vaccine. On one hand, some participants were content to accept the Governments' recommendations that the MMR vaccine is the most effective means of protecting a child from measles, mumps and rubella. However, it was more common for participants to focus attention on the fact that, by not allowing parents the right to choose between the vaccines, the Government was denying parents the fundamental right to follow their own preferences as parents. This view was expressed both by participants who had and had not opted for MMR alike. However, the tone of the conversation among those participants living in socially and economically deprived areas sounded a particularly aggrieved note. For these participants being able to afford to pay privately for single measles, mumps and rubella vaccines was not an option. They felt that the Government's policy on MMR was harsh and penalised parents like them in particular, putting their children at greater risk of either contracting an infectious disease through opting not to immunise with MMR, or from having an adverse reaction following receiving MMR. Kenny spoke angrily on the predicament that he considered the policy put his son in, stating: "...so...is he not to get the jags? And it's not the wean's fault. I mean he can't even talk, and he's probably, he's probably got his wee thoughts in his heid about that, naebody knows. So he, he's getting punished..." (Single Fathers Group; Kenny aged 43).

Some groups discussed the reasons for the Government's policy on MMR and the decision not to give parents the choice between MMR and the single vaccines. The main reason participants gave for the Government's stance on MMR policy was financial. Participants considered that the Government was motivated by saving money and thought that the single vaccines would be more expensive to produce and more time consuming for health professionals to administer. A less commonly cited reason was that the separate single vaccines take a comparatively longer time to protect children, leaving these children exposed for a long period to the risk of contracting a disease. However,

there was disagreement among participants about this, as some participants considered the incidence of measles, mumps and rubella to be low and therefore dismissed this reasoning as irrational and as evidence of the Government bullying frightened parents into having MMR. Lastly, a few participants suggested that some parents might not complete the course of single vaccines. This reason was usually given by participants living in affluent areas, and whilst they considered this a possibility, they were always quick to discount the possibility that they themselves would default on any appointment, implying that people living in more deprived areas would be the more likely to do so (First-Time Mothers Group; New Mothers Group).

4.2.4 Perceptions about Dr Wakefield and other medical and health care professionals

There was quite a mixed response to the role the medical and health professionals have played in the MMR controversy. As mentioned earlier, some participants spoke positively about the individual doctors involved in the debate. For example, Andrew Wakefield and colleagues were viewed by some participants as being on the side of ordinary parents. However, interspersed between occasional positive remarks were more subtle and disparaging remarks about him. For example he was often referred to as “that doctor” implying that he should shoulder much of the blame for causing the uncertainty surrounding MMR safety. When participants talked more generally about the medical and health professions, they tended to speak of them with caution. The dilemma that many participants appeared to face was one of knowing who to trust to give them impartial advice. For example, Lesley a mother of a boy with autism questioned:

What do you do as a parent? You don't know who to trust. Because these are the people- you're meant to trust your doctor implicitly and yet people are saying well, you know, they're getting paid for having so many people vaccinated and all this and you start thinking 'well, who's got my best- who's got my wee boy's best interests at heart?'

Autism Club Group; Lesley

Similarly, Helen questioned the extent to which parents can rely on the medical profession to give them impartial advice. Helen stated that she felt: "...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?" (Saturday Club Group; Helen aged 39). Central to this dilemma about trust seemed to be the fact that the MMR debate has heightened parents' awareness of the fact that GPs receive payments for meeting Government immunisation targets. The issue of immunisation targets appeared to have forced some participants to question the motives and integrity of their own GP and health visitor on the question of MMR safety. A common theme was that participants did not know to what extent they could trust their own GP and health visitor to act in their child's best interest, as opposed to their public health role as advocates of public health policy. For example, Joanne recalled:

... I saw my health visitor the other day. I just wanted to get some honest advice. You know- I said, I know you're supposed to recommend MMR and all the rest of it, but they just won't, they just can't get involved so you're left. Who do you go to for advice? You're just completely stuck. You know you're relying on doctors and health professionals to help you with the help of your child, but they're just touting the government line, unless they are this surgery in Edinburgh or whatever. They know they will lose money for the number of vaccines they carry out. They have to reach government targets, so they are not going to say don't have it done, go and have your single jabs.

New Mothers Group; Joanne aged 37

For Sue, the MMR debate had highlighted the close relationship between the Government and the medical and health professions. This had made her adamant that health professionals are biased. She stated: "...they are part of the system of dispensing it; they're not there to question. They don't know..." (Non-MMR Group; Sue aged 36). Likewise, Debbie was not impressed with the health and medical profession's role in immunisation. She considered:

I think the medical profession believe that they're fantastic and they are so narrow-minded and single focussed that they come up with this idea and they think it's great and they go... they run with it and it's not until it's fully established and they've been telling everybody how great it is that they think, ohhh... maybe it's not that great and so, either they cover it up or they say, well, we'll just invent a new one that is great instead of thinking, well, is the whole concept may be a bad idea in the first place. I think they just... I don't necessarily believe that they're doing it on purpose to... to... oh let's not worry about how we're going to get something out of this, I do

think that they believe that they're so fantastic that they're not prepared to step back and have a look at the whole picture and say, you know, what – is this really as valuable as we're making it out to be.

Non-Vaccine Group; Debbie aged 33

Although her views were unorthodox and were mainly held by other participants like herself who had chosen not to immunise their children, some of the sentiment of what she said was shared more generally. Despite the reservations many participants expressed about the medical and health profession's role in the debate, there were occasions when participants talked about their own experiences of asking their GP and health visitor to give them advice on MMR. This was particularly noticeable among the less experienced first-time parents, compared to their more experienced counterparts, who rarely mentioned asking their GP or health visitor for advice. A few participants felt their concerns about MMR safety were dismissed out of hand by their own GP, and that there was little room for discussion about the pros and possible cons of MMR. However, as indicated in Joanne's (New Mothers Group) comments earlier, other health visitors gave ambiguous answers. On the other hand, when Louise told Joanne that her health visitor was adamant about the safety of MMR, she ended up having to defend her health visitor's categorical response on MMR safety:

Louise: ...my health visitor is completely pro it, the two of them stood there and said there is no link at all. They are so adamant.

Sally: But how do they know? If the experts don't know - how do they know? Do they not lose credibility by saying that so adamantly?

Louise: No, because one of them is well respected in the group and she was annoyed about kids not getting vaccinated.

New Mothers Group; Joanne aged 37; Louise aged 29; Sally aged 34

This discussion in the New Mothers Group highlights the difficult task that health visitors face. Some participants appeared to want someone to air their worries to about MMR, whilst others wanted their health visitors to take a more pro-active advisory role. When health visitors sounded too resolute about the safety of MMR, some parents questioned their motives and knowledge, but when they sounded too vague, some parents interpreted

this uncertainty as concern that MMR is unsafe. However, what was clear was that participants did not appreciate being pressurised into making decisions in order to keep to the allotted timetable of the Childhood Immunisation Programme. Several of the participants who had either decided to delay, or had 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. For example, Jenny and Dave who had opted to have single measles, mumps and rubella vaccines, talked about feeling 'blackballed':

Jenny: ...I come from a village, I'm the only person in the village who has decided to get single vaccines, but see the pressure I've had and you know... in the village I've had the health visitors, you know, they've been phoning me non-stop and, em, I went down because there was someone else in one of the other villages in one of the surgeries was giving, em, rubella to them. They'd gone through to Edinburgh and they were getting their jags done through in Edinburgh in one of the other clinics, well, she was giving rubella out. So I said to my health visitor 'could I not get rubella cos obviously that would save me a bit of money if I got rubella done on the NHS?' and they said 'no' and I've been like shunned ever since. You know, I can't get appointments and I feel like, you know, I feel almost like I've been blackballed.

Dave: That's right. I mean it's... that's right. She's right, because it's just like us. We've had so many phone calls you know, every time like phone calls, come down and get your MMR, come down and get your MMR from the health visitor and it's just wee subtle things, you know. It's not overt, it's actually quite covert, you know? Yeah, like you say, you can't get an appointment. You know, there's such pressure put on and you just think, you know, these are people that are supposed to be, you know, on your side and you just don't feel that they are. You know, they're not there for you. They don't give you the information that you ask for. And you wonder, you know, who is it that's... who is it that's actually benefiting out of all of this? All this pressure? You know, is it the drug companies? No, I mean you don't make huge profits from vaccines. I mean antibiotics, yeah, you make big profits but not, you know, Glaxo Smith and Kline aren't making big profits from vaccines. You know, you think who is making all the gains here? You know, why is there such pressure?

They go on to expand on the pressure they felt was exerted on them.

Facilitator: So how does this all make you feel?

Dave: Suspicious, very suspicious.

Jenny: Well, it just makes you wonder, you know. Is it all just to do with GPs and health visitors trying to meet their targets? The way I feel about it is that I was looking out for my boy and I just felt he... he's already allergic to that much and I just thought well, is one person gonna make that much difference, but you know...

Single Vaccine Group; Dave aged 38; Jenny aged 19; Joe aged 36

Although there were other participants who spoke of relentless phone calls and messages being left on their answer machines, the participants who had opted to have the single vaccines appeared to feel particularly aggrieved by this unwelcome pressure as they felt they were acting responsibly, and ultimately in their own child's best interest.

4.3 Discussion of the findings

Generally participants did not feel there was enough evidence to prove that there was not a link between the MMR vaccine and the subsequent development of autism in children. Some participants cautioned that in time further evidence may come to light that shows that for some children the MMR vaccine might be damaging. In this respect they spoke about the 'jury still being out'. Other participants were unsure of the link because they found it difficult to understand the scientific and anecdotal evidence and come to any firm conclusion. This led them to feel unconvinced about the safety of the MMR vaccine and these participants often delayed having it given to their children. Indeed, despite participants being extremely interested in the debate and in trying to understand Wakefield's claims, the overriding feeling was that the evidence was difficult for lay people to understand.

In the absence of feeling well equipped to make a sound judgment about the scientific plausibility of Wakefield's theory, there was a tendency for participants to focus their attention on what they considered to be the facts about the epidemiology of autism. Participants often mentioned the fact that autism was becoming more prevalent, and talked speculatively about which children they thought might be at most risk from developing the disorder. Participants identified two groups of children to be at greater risk of developing autism. Firstly boys were considered to be at greater risk than girls based on the fact that they were aware that there is a higher incidence of autism among boys. This meant that parents of boys seemed particularly anxious about the MMR vaccine and amongst participants' children there were more boys who had their MMR vaccine delayed or not given than girls. The second group that some participants felt

future research might reveal as being at risk of developing autism were children with deficient immune systems. Participants identified childhood illnesses such as multiple allergies; recurrent ear and chest infections, and asthma and eczema as indicators of a slightly deficient immune system. This led some participants to consider that future immunisation research might eventually suggest that children with severe cases of these conditions should not be immunised with combined vaccines such as MMR. Participants often expressed these concerns hesitantly and for the most part without conviction; however participants also identified a need for more research to be conducted into the causes of autism and into whether children with multiple allergies, asthma and eczema or recurrent ear and chest infections are susceptible to it. Participants also suggested a need for further research to confirm or refute Wakefield and colleagues' theory of a causal association between MMR and autism and for this to be written in a way that parents can understand. The general perception was that there was a lack of research in these areas and this made participants feel as if the Government was not taking their concerns or those of Dr Wakefield seriously.

Participants were often dismissive of messages from politicians and scientists such as 'no proven risk,' 'minimal risk,' and of blanket assurances that MMR is safe, as untrustworthy. Participants interpreted messages of 'no proven risk,' or 'minimal risk' as tantamount to saying 'no risk known at present'. One of the problems with using language such as 'minimal' to convey messages about the risks posed by the MMR vaccine was that participants had difficulty in deciphering how minimal, minimal was. Indeed terms such as 'probable', 'unlikely', 'rare' and so on have been shown to convey 'elastic' concepts and thus to mean different things to different people depending on their interpretation of these concepts (Cohn et al., 1995; Edwards et al., 2002). For similar reasons, it was clear that participants in this study found the subjective term 'minimal' unhelpful in enabling them to assess the extent of the risk posed by the MMR vaccine. However, it may also be the case that participants felt uneasy and even sceptical about the use of language to convey 'elastic' concepts because they recognise that this language also allows the person communicating the risk greater scope for being able to mask what participants viewed as the actual risk. This observation is based on the fact that

participants often drew parallels between the unsettling dialogues used to reassure the public about the risks posed by BSE and that of MMR. Participants commonly mentioned that during the BSE crisis the Government had failed to accurately communicate risks to the public. Participants were of the view that the Government's reassurances about the risk being so infinitesimally small that it could be said that there was no risk posed to humans by BSE greatly underplayed the actual risk.

Just as the image of John Gummer feeding his daughter a hamburger during the BSE crisis came to symbolise the Government's handling of the crisis, the image participants associated with the MMR controversy was of Tony Blair refusing to confirm whether his son Leo had had MMR. This image was seen to be a metaphor for the way the Government treats the public and for the 'nanny state' mentality at odds with providing information in a healthy democracy. The close comparisons participants drew between these two public health scares and images was interesting because participants did not differentiate between the fact that they were handled by two different administrations, suggesting politicians were being viewed generically. Indeed, perhaps Tony Blair's refusal to publicly endorse the MMR vaccine through his son was an attempt to learn lessons from John Gummer's public discredit, both as a politician and perhaps more importantly as a parent, following the announcement that scientists had discovered a link between BSE and a new variant of CJD. The sentiment behind much of the conversation about John Gummer's actions was that he was seen to have put politics before parenting. Nevertheless, Tony Blair may have not only misjudged an opportunity to be seen as a parent rather than as a politician, but also he may have contributed to the uncertainty about MMR. By refusing to disclose to the public whether his son had had MMR on the grounds of it being a private matter, he had chosen to act in his role as a politician rather than as a parent. Unsurprisingly many participants questioned his motives for doing so and some concluded that he had done so because his son Leo had not had MMR vaccination. Indeed, despite Bellaby's (2003) assertion that parents want to be reassured that the risk is zero, Whitfield (1997) believes that of all the lessons to be drawn from the BSE crisis, the most important is not to comfort the public with messages of no risk. However, in relation to the MMR controversy, although public health officials and

politicians have avoided offering reassurances that there are no risks, elastic terms such as 'minimal' risk appear to have added to rather than reduced the sense of uncertainty surrounding the safety of the MMR vaccine. Notably absent were any discussions about the risk of instituting an untested programme of three separate vaccines. This was only referred to briefly, and supports Lewis and Speers' (2003) suggestion that scientists and public health professionals have failed to communicate this fact to the public.

Participants were divided about the role that the media has played in the MMR controversy. Some participants viewed the media as pivotal players in much of the unsettling dialogue played out in news reports in newspapers and on the television. This finding is consistent with Clements and Ratzan's (2003) suggestion that the media have been alarmist. In contrast, other participants viewed the media as useful in providing information to the public and seemed quite unquestioning about some of the stories they heard and read. A few participants commented on the way newspapers and television programmes have reported the MMR controversy. These participants were concerned that reports tended to contrast the scientific and anecdotal evidence alongside each other and spoke of feeling particularly drawn to anecdotal stories involving real people. Participants suggested that as parents they found other parents' stories more convincing than the statistics, comments and reassurances from scientists and politicians who they felt they had less in common with and who may have ulterior motives. In contrast, parents' stories were viewed as being impartial and as having no hidden agenda (ironic since they are probably the most partial, but then this is probably part of their appeal). These attributes seemed to make this kind of evidence very persuasive and in turn these anecdotal stories often appeared to carry a disproportionate weight. Indeed, this supports Hargreaves and colleagues (2003) assertion that media coverage has given a misleading impression that the evidence for the link was as substantial as the evidence against it. It was also observed that for many participants the level of media coverage afforded to the MMR controversy became tantamount to evidence itself that MMR is unsafe. Hence any story about autism or MMR vaccination appeared to be newsworthy and to perpetuate the public's interest in the debate.

There was quite a mixed response in parents' perceptions about the role that the medical and health professionals have played in the MMR controversy. Whilst few of the experienced first-time parents spoke about finding health visitors helpful, the more experienced parents were less positive. Participants spoke about health visitors offering ambiguous advice and seeming ambivalent about their position on MMR safety, a finding consistent with Smailbegovic et al.'s (2003) study. A few participants felt their concerns about MMR safety were dismissed out of hand by their own GPs, others spoke about being pressurised into making decisions about MMR, and in a few cases participants felt ostracised for not complying with the recommended vaccines. An important theme to have emerged in relation to the medical and health professions was that many participants appeared to face the dilemma of not knowing whom to trust to give them impartial advice. Some participants were suspicious of their GPs' motives and viewed them as part of the system of dispensing MMR rather than as having an impartial role, a finding consistent with Evans et al. (2003) and Flynn and Ogden (2004). This sense of mistrust and suspicion seemed to be exacerbated by the fact that GPs receive payments for meeting government immunisation targets. This issue, more than any other, seemed to have forced some participants to question the extent to which they could trust their GP to act in their child's best interest, as opposed to acting as advocates of public health policy.

There were also conflicting beliefs about the roles that Dr Wakefield and his colleagues have played in the debate. Participants were divided about Dr Wakefield's character and whether he was a courageous individual standing up for his beliefs and those of ordinary parents in his care, or whether he was to blame for causing all the uncertainty surrounding the safety of the MMR vaccine. However, even when participants felt he was responsible for much of the furore surrounding MMR, they often tempered negative comments by mentioning that there was already a climate of mistrust following the BSE crisis. In this respect participants believed that any attempt to exaggerate his role in the MMR controversy would be to misrepresent the facts. Attempts by politicians and public health spokespersons to discredit Dr Wakefield and his co-authors were viewed as political manoeuvring, and were not seen as reassuring to participants. Indeed, a few participants even implied that, as doctors, Wakefield and co-authors were more likely to

be acting in the public interest and thus more trustworthy than politicians, who were often viewed as acting primarily in their own interests.

Chapter Five: Parents' experiences of MMR decision-making

This chapter explores parents' experiences of making the decision about whether or not to vaccinate their children with the MMR vaccine, at a time when there was still speculation and concern about its safety. It begins by briefly examining the literature on vaccine decision-making, before presenting the views of the parents who took part in the focus groups. The chapter concludes by considering how these parents' experiences of MMR decision-making compare with findings from the literature on vaccine decision-making. It also highlights findings that may be useful in guiding strategies for improving MMR uptake.

5.1 Summary of literature on vaccine decision-making

As suggested in Chapter One, there are many factors that influence parents' decisions about immunisation. It has been suggested that some parents forgo immunisation because of practical, social, or economic difficulties or because of cultural or religious beliefs (Peckham et al., 1989; New and Senior, 1991; Pearson et al., 1993; Simpson et al., 1995). It has also been suggested that the information parents receive from health professionals and from the media exerts an influence on their decisions (Sporton and Francis, 2001). Parents may also be influenced by the decisions that other parents make for their children (Meszaros et al., 1996). For example, they may choose to vaccinate their children to ensure that their own child is protected against infectious diseases. In doing so, they contribute to maintaining high levels of uptake in the population, thus conferring protection to those around the individual, termed 'herd' or 'population' immunity. It is this second form of protection that prevents the outbreaks of diseases that Hershey and colleagues (1994) focused on. Their work led them to suggest that people factor the actions of others into their own decisions about whether or not to vaccinate. Thus, Hershey and colleagues believe that some people seek immunisation partly to contribute to the overall control of diseases within their community. However, they also

suggest that a high uptake of immunisation creates an opportunity for some individuals to use herd immunity to gain the benefits of an immunisation programme without taking any of the perceived risks associated with the vaccines.

As noted in Chapter One, studies by Ritov and Baron (1990) and Asch et al. (1994) have been useful in gaining a deeper understanding of the cognitive processes involved in vaccine decision-making. They have shown that if parents believe the risk of harm from the vaccine is greater than that from the disease then they may refuse immunisation, believing that doing nothing is less harmful. This action termed 'omission bias,' was observed to have occurred during the pertussis controversy in the 1970s when many parents preferred to take the risk of their children contracting whooping cough than to intervene and potentially cause damage through vaccination. Whilst it is likely that there are some valuable parallels between the decision-making behaviours of parents during the pertussis controversy and during the current MMR debate, there may be some important differences, not least because the context in which parents make those decisions has changed.

Since the publication of Dr Wakefield's paper (1998) cast doubt over the safety of the MMR vaccine, several studies have been particularly useful in gaining new insights into understanding parents' decisions about the MMR vaccine. For example, Ramsay et al. (2002) described some of the trends in mothers' attitudes to the MMR vaccine. They observed that, unlike other vaccines in the programme, the decline in acceptability of MMR appeared to be greater among more socio-economically advantaged parents. Evans et al.'s (2001) study offered the first in-depth account describing the decision-making processes parents used to decide whether or not to have their children vaccinated with the MMR vaccine. Similar to other observations during the pertussis controversy (Ritov and Barron, 1990; Asch et al., 1994), Evans and colleagues found that parents try to weigh up the risks and benefits. They found that for many parents it is easier to live with the risk of their child naturally contracting one of the diseases than with the risk of causing their child damage through vaccination. Further, although these parents accepted that their unvaccinated children might contract a disease, they were optimistic that their

children would make a good recovery. From this they concluded that the non-immunisers felt that the potential risks from MMR outweighed the potential risks of contracting the diseases, and were reluctant to comply with a policy that offered them no choice. Raithatha et al. (2003) also proposed that parents weigh up the risks associated with vaccines against the risks posed by the diseases. They found that parents who immunise their children have concerns about the risks associated with vaccines and warn that it is vital not to assume that parents who at present immunise will continue to do so. They suggested that the recent MMR vaccine scare might have triggered a more widespread reappraisal of vaccine risk. In 2004 Flynn and Ogden published their findings from a study which aimed to identify the best predictors of uptake of MMR by the age of two years. They found past vaccination history predicted MMR vaccination uptake. This led them to suggest that doctors should encourage the uptake of earlier less controversial vaccines and use these vaccines as an opportunity to encourage the uptake of MMR by creating a culture of vaccination uptake. However, McMurray et al. (2004) also explored parents' accounts of MMR decision-making in order to identify determinants of uptake and suggested that the opportunity for primary care providers to encourage the uptake of MMR is limited by the fact that parents do not view them as financially or politically impartial. They suggested that there is a need for new approaches to increase parents' understanding of medical science in order to secure more informed decisions in the face of health controversy. They went on to warn that at present, for most parents, scientific and medical evidence plays little role in that decision.

To date these studies have been useful in gaining a better understanding of the cognitive processes involved in MMR decision-making and in identifying that parents weigh up the risks and benefits they associate with the vaccine and diseases. However, they have often fallen short of describing the risks, and of exploring parents' beliefs about how these risks may damage their children's health. At the time of planning and conducting this study there was little debate about whether children's immune systems could be overwhelmed by receiving too many vaccines combining too many antigens. Indeed, as yet no studies have been published that specifically explored parents' views on this issue. This gap in the literature means that it is unclear what role parents' views about their

child's immune system play in relation to forming opinions about vaccines or about the notion of immune-overload. The lack of research on this topic offered an opportunity for this study to explore how parents conceptualise their child's immune system and relate these concepts to their own children, not least because it may affect the decisions they make about immunisation in the future.

To date the only paper to have touched on this aspect of the debate has been that by Miller et al. (2003). They challenged the claim that the MMR vaccine induces immunosuppression, thus causing increased susceptibility to infection in the post-vaccination period. Using computerised discharge records from several hospitals in the Thames region of England they identified 436 cases of children aged between 12 and 23 months, admitted to hospital between 1991 and 1995 with a bacterial infection. After reviewing each child's clinical and medical histories, children with any underlying disorders predisposing them to bacterial infection were excluded. They tested for clustering of bacterial infection in the 12 week period post-MMR vaccination in the 395 children identified as eligible to be included in the case series. Since the incidence of bacterial infection varies with age and by season these factors were adjusted for by stratifying the analysis by calendar month and by age in 26 two-week intervals. None of the post-vaccination risk periods showed a relative incidence significantly greater than 1.0, thus suggesting that MMR vaccine does not impair the ability to respond to the immune challenge of infection. One potential criticism of the study may be that one of the funders of this research was the pharmaceutical company, GlaxoSmithKline, one of the manufacturers of the MMR vaccine that parents are planning legal action against. The obvious conflict of interests may make this research newsworthy for the wrong reasons, alienating rather than persuading anxious parents that the scientific community is attempting to provide them with balanced and unbiased information.

In summary, although there have been new papers published on MMR decision-making since fieldwork for this thesis commenced, there is still a need for a more in-depth research that focuses attention on exploring and describing how parents conceptualise putative MMR associated risk as damaging their children's health. This study attempts to

build on the work of other researchers, but also recognises that the MMR controversy does not exist in a vacuum and that parents' concerns about vaccines may not be confined to the MMR vaccine. As such, although the focus of this chapter is on parents' experiences of making the decision about the MMR vaccine, their discussions also involved other vaccines in the Childhood Immunisation Programme. Without viewing MMR decisions in this broader context, it is difficult to ascertain whether the current reappraisal of vaccine risk that Raithatha and colleagues highlight is, as they suggest, a consequence of the recent MMR debate, or whether it is part and parcel of a wider sense among parents that children are becoming over-immunised against diseases that pose little threat. With this in mind, I will now consider the views of the participants that took part in this study.

5.2 Making the decision

To date it has been suggested that when parents make decisions about whether or not to immunise their children, they carry out a risk assessment that is based on two key factors: their assessment of the risk posed by the diseases, and of the vaccines aimed at preventing these diseases (Smailbegovic et al. 2003). However in relation to MMR decision-making my research has identified three factors that appeared to play equally important roles in influencing whether participants will seek or withhold MMR immunisation.

- The perceived seriousness of a disease and the likelihood of catching it.
- The perceived safety and efficacy of the vaccine.
- The perceived ability of their child's immune system to cope with the vaccine, or fight the disease.

Conversations about the seriousness of the diseases and beliefs about the vaccines were topics I included in the topic guide. However, conversations about the ability of their child's immune system to cope with the vaccine, or fight diseases, were topics that participants themselves identified when asked to recall the main factors that had influenced their decision about MMR. Participants often talked about weighing up these

factors in order to come to a decision about MMR. In this respect it appeared that they were carrying out an informal risk-benefit assessment to help process these factors into an equation with the aim being to minimise risks to their child's health.

At this stage it may also be useful to be aware of the difference between two closely related terms, immune-overload and immune-vulnerability, liberally referred to by participants in this chapter. For the purposes of clarity I interpreted and thematically coded the two concepts separately after considering the context in which participants used these terms. I observed that immune-overload was used to describe the notion that the immune system is overwhelmed by receiving too many antigens. By contrast when participants spoke about their children's immune system being vulnerable they were usually referring to their assessment of how well their child's immune system seemed to cope with the invasion of pathogens generally, and not just with the antigens contained within vaccines.

5.2.1 Weighing up the risks/benefits associated with diseases: assessing which diseases need immunising against

As suggested in Chapter Three, participants' perceptions of the severity and prevalence of the diseases informed their assessment of which diseases posed the greatest and least threat to their children, and, in turn, which diseases to vaccinate against. These factors appeared to be influenced by participants' knowledge, experience, and beliefs about the diseases but, as highlighted in Chapter Three, participants' knowledge about some of the diseases were quite limited and they were often ambivalent about the threat posed by them. For example participants were unsure whether measles and whooping cough were severe and knew very little about mumps, haemophilus influenza or diphtheria. Perhaps for this reason they considered mumps and haemophilus influenza to pose little threat, deeming them mild and fairly innocuous diseases. Likewise, diphtheria and polio were viewed as posing little threat to children living in the UK because for some years these

diseases have been almost completely eradicated. In contrast, participants had a clear sense that meningitis posed a major threat to their children based on the fact that participants perceived the disease to be severe and prevalent.

In the context of this chapter, I wish to consider the extent to which participants' beliefs and descriptions of the diseases related to the decisions they had made about the vaccines, paying particular attention to decisions made about MMR. First it is important to note that it was more common for participants to consider several diseases together, rather than as separate entities. For example, in the Low Uptake Group Joan, a 20-year-old, spoke about being undecided about the severity and prevalence of measles, mumps and rubella. But in order for her to make a decision about MMR, she felt she needed more information on the diseases and so asked her health visitor for advice. She recalled her meeting with her health visitor:

Joan: Em... well the health visitor, she had showed me pictures of children who had measles and the mumps and whatever, side effects they had like sick children were disabled and that through it.

Facilitator: Right.

Joan: And I thought, oh God not that. I wouldnae forgive myself if she got older, had children, took the mumps and measles and it affected her children or that. I wouldn't forgive myself if it turned out like that so...

Low Uptake Area Group; Joan aged 20

The experience of being shown pictures of children with these diseases had shocked her and persuaded her that opting not to immunise her daughter with MMR was putting her daughter and even her grandchildren at risk. Although she assumed incorrectly that it was measles or mumps that could have implications for her daughter's children instead of rubella, the end result was that she felt concerned enough to take her daughter along for MMR. In contrast, the association that many participants made between mumps and male infertility meant there was a tendency for parents of boys to worry more about mumps. The MMR vaccine was unusual in this respect, because whilst parents of boys seemed more anxious about mumps, parents of girls worried more about rubella and therefore MMR seemed relevant to parents of children of both genders. As such, many

parents spoke about using MMR to protect their children against one disease in particular and viewed the additional protection for the remaining two diseases as an added bonus of combined vaccines. The direct approach used by Joan's health visitor appeared to work best with younger participants. Older participants were less appreciative of this approach. A few participants recalled a similar situation in which a health visitor had shown a group of mothers a video of a child who was extremely distressed as a consequence of coughing with whooping cough. This approach seemed to backfire as they viewed it as a desperate measure, described as 'scaremongering' (Non-MMR Group: Non-Vaccine Group).

Nevertheless, it was common for participants to mention that they were more likely to immunise their children if they perceived the disease to be severe. For example, Dawn, pregnant with her third child, stated that her criterion for deciding whether or not it is important to vaccinate her children is whether the disease could kill them. If not, then she was not keen on them being vaccinated (Antenatal Group; Dawn aged 36). Dawn stated that she did not perceive whooping cough to be severe, or for rubella to be important if boys contracted it, and thus had not vaccinated her youngest boy against either disease. She also assessed that tetanus was not a threat to a young baby and had decided that her unborn child would not require it until he, or she, was at least a year old. In this respect Dawn's assessment of the severity of each of the diseases was quite consistent with the decisions she had made about vaccination. However, Dawn's decision-making strategy was quite unusual and it was uncommon for participants to assess diseases separately. Indeed, making decisions about the vaccines based on assessing individual diseases is problematic for two reasons. Firstly, it requires an accurate assessment of the diseases, which, as indicated in Chapter Three, is not always the case. Secondly, it ignores the fact that the Childhood Immunisation Programme includes combined vaccines (DTP, MMR)* to offer immunisation against three diseases in one vaccine. The way some parents addressed this problem was to pay privately to have single vaccines.

*Modifications to the UK Childhood Immunisation Programme announced from September 2004 include the introduction of a new pentavalent vaccine (DtaP/IPV/Hib) brand name Pediacel.

For example, Anna, a mother of four, had decided in relation to MMR to withhold it for both her two youngest girls. This decision was based on the fact that she considered that they had already contracted wild measles, and that mumps was irrelevant for her daughters to have. She stated that she planned to pay privately for them to have the single rubella vaccine because she feared rubella could be harmful if contracted whilst they were pregnant (High Uptake Group; Anna aged 33). In contrast, Dawn mentioned that she did not plan to pay for the rubella vaccine for her boys, but planned to pay for the mumps vaccine because she feared mumps could be harmful to her sons' fertility if contracted in adolescence (Antenatal Group; Dawn aged 36). However, it is of note that the reason mumps was introduced into the Childhood Immunisation Programme was to reduce the incidence of viral meningitis. Indeed, the general medical consensus is that it is not thought that mumps causes any infertility problems. Further, Dawn's suggestion that the rubella vaccine was irrelevant for her boys caused Fiona, a midwife and mother of two girls, offense. Fiona looked and sounded irritated as she reacted to Dawn's comments, and retorted that rubella vaccination is important for all children to have in order to reduce the incidence of congenital rubella.

The fact that some health visitors showed videos or pictures of the diseases to participants may have been because they believed that the more experience that participants had of the diseases causing harm, the more likely they were to view them as risky, and therefore to seek vaccination. For example, Karen, a mother of three, had heard from her sister about a friend whose child had contracted measles and had been left with long-term damage. Although she did not know this child, her reservations about the safety of MMR were overshadowed by the fear that measles could cause long-term damage, and this fear had influenced her to act and have her son immunised with MMR (High Uptake Group; Karen aged 36). Likewise, Charlotte in the First-Time Mothers Group, and Dave in the Single Vaccine Group had both had whooping cough as children, but neither considered it to be severe, nor remembered being particularly ill with it. As a consequence both of them questioned whether whooping cough should be included in the immunisation programme at all. However, despite their reservations, all of their children had been

immunised with pertussis as part of the DTP combined vaccine. On one hand this may seem like a contradiction, but alternatively, this could be another demonstration of how participants make decisions about vaccines based on the assessment of several diseases rather than on individual diseases. This highlights how complex the relationship is between participants' experiences of disease and their subsequent decisions about the vaccines aimed at preventing it. Past experience of a disease does not necessarily mean that a person will have a negative impression of it, particularly if the person made an uneventful recovery, or finds it difficult to remember. In these cases, having experienced the disease may make the disease seem more familiar and less formidable. This may lead some participants to underestimate the potential risks associated with the disease.

Whilst it was generally common for participants to make decisions about immunisation by weighing up the risks of the disease, the few participants who preferred to use homeopathic and herbal alternatives to orthodox medicines did not appear to view the diseases as risky. Indeed, the participants in the Non-Vaccine Group did not appear to believe it was necessarily advantageous to avoid diseases altogether. These participants frequently questioned the wisdom of avoiding diseases by vaccination, on the basis that a healthy individual may benefit from contracting a disease and developing life-long immunity to it. This was deemed to be particularly beneficial to women in relation to the rubella vaccine, as it was believed they would pass on some of this immunity to their children. Further, these participants often cited the fact that as disease prevalence has reduced over the years, so too has disease threat, and for them the need for a continuing immunisation programme in the UK seemed to have become out-dated. However, this group of participants also tended to under-estimate the contribution mass immunisation has made in bringing about reduced disease prevalence, preferring to attribute it solely to improved sanitation, water supply and living conditions. These participants generally perceived disease threat to be low and appeared to play down the severity of the diseases. These findings are consistent with much of the literature on vaccine decision-making that suggests that parents who consider the diseases to pose little or no threat to their child's health are more likely not to vaccinate. However, it is also worth noting that this particular group of participants held quite different beliefs about the risks posed by

diseases as they felt that there were benefits to allowing healthy children to contract them. In this respect any immunisation campaign aimed at encouraging these particular parents to immunise seems likely to fail, as they question the whole premise that mass childhood immunisation still has a role to play in contemporary Britain.

5.2.2 Assessing the risks and benefits associated with vaccines: fears of long-term damage

The second part of the risk assessment that participants discussed related to assessing the risks associated with the MMR vaccine. The controversy surrounding MMR safety meant that it was widely viewed as being a particularly risky vaccine. As suggested in Chapter Four, participants' assessment of MMR appeared to have been informed by their assessment of the current state of evidence about its safety, and their assessment of the roles the Government, the media, and the medical and health professions played in the handling of the MMR debate. However, perhaps one of the most interesting and surprising aspects of these discussions was the way participants spoke about their concerns about autism. When participants were asked to describe their main concerns about vaccines, participants rarely identified autism as being their main worry; instead they spoke about their fears that over-immunising young children by giving them too many vaccines might result in long-term damage to their child's immune system. In fact, although autism was clearly a concern because participants occasionally recounted stories to each other of children they knew with autism, and on several occasions spoke about the rise in incidence of autism, they tended to speak about autism using more generic terms such as having 'long-term damage'. For instance, towards the end of one focus group in which the participants had been very informed and opinionated, I noticed that the group had not specifically mentioned autism, and questioned them further on this:

Facilitator: ...The only thing that hasn't really come up that was interesting to me is autism, it hasn't really come up and I was wondering why...if you had any images about autism what it is. And what you feel about that whole link with MMR that's been made?

Hannah: I think I mentioned earlier about that ... is it this Finnish study I think? There's no link between MMR and Crohn's disease or autism. So that...

[People talking at same time]

Sue: (spoken in high surprised sounding voice) I never mentioned autism because I took it as read that that was part of it, if you see what I mean. I didn't specifically mention it because I assumed that's what were talking about and we... all knew about it.

Non-MMR Group; Sue aged 36; Hannah aged 40

It was clear from their faces that this question seemed slightly foolish to them and that they worried that I had not really been listening or fully understanding their concerns about vaccines. With hindsight it would have been useful to probe participants more on what they meant when they spoke about 'long-term damage' in order to gain a deeper understanding of their fears about the MMR vaccine. It seems likely that when participants were talking about 'long-term damage' they were actually speaking about autism, and in this respect long-term damage was a euphemism for autism. Indeed, this is evident in some of the comments made by participants on MMR decision-making. For instance, Violet thought:

...before the MMR thing, a side effect was a mild fever, I don't think of long-term problems that you were going to have to cope with for the rest of your child's life probably ever crossed your mind. I think now whatever your child is immunised against, I would certainly be looking for much more information than the standard leaflet that comes out from the manufacturer's instructions

NCT Group; Violet aged 36

Similarly, William also spoke about the fact that the MMR debate has raised questions more generally over vaccine safety. He considered that before the MMR controversy parents were unaware that there were any risks attached to immunisation and the possibility of long-term damage was not something parents confronted whilst making their decisions. However, he felt that since the MMR debate had begun, parents had become more questioning and they now faced a dilemma about whether to immunise or not (Single Men's Group; William aged 51).

The fear of long-term damage arose spontaneously in all the groups. The main concern appeared to centre on the fact that participants were anxious that too many antigens given together could potentially overwhelm the child's immature immune system, causing health problems at a later date. This fear led Anna to refuse MMR. She stated: "the worry is putting all three in at one time, into that wee body. Individual ones for me is, it makes sense to not bombard it with too much chemicals all at one go" (High Uptake Area Group; Anna aged 33). Indeed, the three participants who had sought single vaccines for their children had done so partially to space out the vaccines and to reduce this perceived risk of overwhelming their children's immune systems. Joe explained:

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 gonna 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?

Single Vaccine Group; Joe aged 36

But this reasoning is inherently illogical in that many of the participants who talked about increasing the time between the MMR vaccine components, had already given their children combined DTP vaccines at two, three and four months of age, and seemed quite unconcerned about it. These inconsistencies in their argument were evident throughout the discussion and reflect the fact that many participants seemed ambivalent about the nature of the link between their child's state of health and immune overload. This rather obvious inconsistency was even noticed by a few participants themselves. For instance, Cassie observed:

Cassie: I was actually going to say that because the diphtheria and the one that they get when they are so young is actually a combined...because I remember somebody said that you have already given her a combined injection and I hadn't really thought about it like that.

Facilitator: So why is that then that you haven't thought about it?

Cassie: I never thought (unintelligible), but then sometimes you wonder if that's because it's done so young ...and you have not had a chance to think...

High Uptake Area Group; Cassie aged 29

Likewise, Joanne, a first-time mother, considered the immunisation schedule and stated: “funny enough we are all just in the middle of our first jabs and suddenly with the MMR thing- I thought heck- I didn’t even really think about what the side effects were of those” (New Mothers Group; Joanne 37).

The only explanation to be given by participants to account for this inconsistency was that these first combined vaccines are given at a time when parents are overwhelmed with the new task of parenthood and as such have not had an opportunity to fully consider the various arguments about immunisation. For example, Violet reflected back on her earlier decisions about immunisation and believed that she had not had time to assess the risks of the combined DTP vaccines. She spoke about just emerging from a ‘state of not knowing whether it was night or day’ when she was told her daughter should have DTP. She went on to assert: “I’m sure if the timing of diphtheria, tetanus, whooping cough and HIB was later like MMR, there would be a lot more discussion about it” (NCT Group; Violet aged 36). However another explanation to account for why so many participants only attributed immune damage to the combined MMR vaccine may be due to the press release that accompanied publication of Wakefield’s paper. This press release stated that Dr Wakefield was of the opinion that there is a case for separating the three vaccines into separate measles, mumps, and rubella components and administering them individually spaced by at least one year. Across the groups many participants felt that, if given the choice by the NHS, they would follow Dr Wakefield’s advice and opt to space the vaccines out and give their children the single vaccines in favour of the combined MMR vaccine.

On the whole, participants’ concerns about vaccines tended to focus on the MMR vaccine and less on the other vaccines in the programme. Participants often changed their minds, contradicted themselves and spoke with uncertainty and ambiguity on matters of vaccine safety. Nevertheless, there were a few participants whose children were fully immunised (or planned to have all the vaccines given to their children) who voiced concerns about the number of vaccines given to young babies. For example, Joanne, looked at the Childhood Immunisation Schedule handed out (Appendix L) and asked: “ ...you are told

you need all these injections, but like you say (looking at Sally) we didn't need these injections, you know are we over immunising our kids? I don't know...I just feel they are putting all these drugs into the kids and at some stage you have to say stop, that's enough, they don't need any more vaccinations..." (New Mothers Group; Joanne aged 37).

The most vocal groups to speak critically about the MMR vaccine and vaccination in general were the Non-Vaccine Group and the Non-MMR Group. In the Non-Vaccine Group, Molly, a herbalist, argued that administering three antigens in one vaccine is an unnatural way of encountering diseases. She stated:

Well from what I've heard, em, it's like a sudden onslaught, 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 those defences and the body just gets a shock, where did this come from?

Non-Vaccine Group; Molly aged 37

In the Non-MMR Group Aleena, a stay-at-home mother of four, also mentioned that she feared long-term damage and stated that: "I don't think they know enough about the immune system when they're two months old, it's still developing..." (Non-MMR Group; Aleena aged 35). Both these groups represent some of the least enthusiastic voices on immunisation and unlike most participants their concerns about the risks associated with vaccines were not confined to MMR.

5.2.3 Conceptualising immune overload

Despite fears about some children being prone to 'immune overload', getting participants to articulate this fear more specifically in the groups was quite difficult. When participants were asked to describe what they meant by 'overloading' the immune system, the question was often met by silence. Nevertheless, the Low Uptake Area Group attempted to explain what they meant by this term:

Sheila: You can just overload their immune systems.

Facilitator: What does that mean?

Sheila: They'd probably become immune to jags eventually I think.

Alan: I feel as if their immune systems would go to pot. You can only immunise so much.

Low Uptake Area Group; Alan aged 33; Sheila aged 36

Words like 'go to pot' and 'knacker' the immune system did not really shed light on the precise mechanisms of overloading the immune system. William, Kenny and Robert tried to illuminate the problem and explained their fears about over-immunisation by reflecting back on their respective experiences of immunisation:

William: ...I think sometimes that you can clean up things so well, that the body breaks down in its immune system, you know? As this, as an old wives tale says, a happy kid's a dirty kid. And you'd go out and...you would rummage the bins when you were young and everything else. And you didn't catch diseases. (People talking at the same time)

Robert: Right, right? And you didn't catch diseases.

Kenny: They made themselves immune.

William: So in those days you had a bath once a week or something, right?

Robert: Still dae.

William: Right? But, nowadays all the emphasis is on cleanliness and no-one's actually telling us that if you're not getting attacked by germs, then when you do get attacked by deadly germs, your immune system breaks down.

Robert: Aye, 'cause... You know... I've drunk water out of empty cans...

Facilitator: So what are you saying here... though, what are you saying about immunisation?

William: What I'm saying is...are we over doin'it, you know? If you're having a... if you're having a major breakdown, if there's measles coming in, in the corner, right? Okay, fair enough. In my days, kids had measles, right? So therefore, why prevent measles? It was part and parcel 40 year ago. Okay, the policies are changed now and they're saying okay, rather than have it. But as Kenny says, your system builds up its immune system because you do get attacked by viruses, germs and eh, eh...

Kenny: Bacteria?

William: ...eh...illnesses. You know? So you're breaking, so you're breaking down your body's defences.

Kenny: Every weans catch wee illnesses a lot easier now. (People talking over each other)

William: They were hardier in those days. Right? We were hardier 40 year ago than what they are today, right? Know?

Single Vaccine Group; William aged 51; Kenny aged 43; Robert aged 47

This perception was interesting. On one hand, it would be easy to dismiss the idea that children were healthier 40 years ago, simply by comparing the morbidity and mortality rates of childhood infectious diseases over the past few decades. However, to consider only epidemiological data may be to miss the point. I think that implicit in this conversation is the perception that environmental sterility may itself breed new risks. The risk that William, Robert and Kenny identify is that they feel children's immune systems nowadays are less well equipped to cope with illness. In effect when William asks: "are we over doin' it?" he is questioning whether vaccines could have played a role in bringing about this situation as he perceives it. They did not appear to be talking about the perils of over-immunising with any sense of conviction, but rather there was an unmistakable undertone of uncertainty running through this conversation. They phrased their comments on this subject as questions to each other and used the word 'right?' repeatedly as if to look for reassurances from each other.

Joanne also mentioned that 'too sterile an environment' may breed new risks. She feared that, by over-immunising children, we in the West are modifying our children's immune systems, making them more vulnerable to contracting diseases in the future (New Mothers Group; Joanne aged 37). Both Kenny and Joanne mentioned the unexplained rise in the incidence of childhood asthma and allergies as evidence, that children in the 21st century face new health threats. Nevertheless, there were a few participants who did

not share this concern about over- immunisation. Margaret, a 20-year-old took a different stance. She stated:

Margaret: See Ah think a jist think a lot mair because ma wee boy's always no well. Fae the day he's been born he's just been constantly no well.

Facilitator: Right.

Margaret: And there's been like hunners of different things wrang wi him, like he's spewing constantly and things like that, and Ah always worry about everything wi him so Ah dae...

Facilitator: Yeah.

Margaret: ...it could be anything at aw, but Ah'm right doon the doctor's wi him jist in case.

Facilitator: So if you've got a child that's not really that well, do you think that that makes you feel more like you want to get them immunised or less?

Margaret: Aye, mair.

Facilitator: Right.

Margaret: Cos Ah feel as if like- if they get aw the jags then like, because he is no well aw the time...

Facilitator: Yeah.

Margaret: ...then maybe if he gets aw these jags it might prevent him fae getting so no well, do you know what I mean? He might feel a bit better eftir getting them.

Facilitator: Yeah.

Young, Single Mothers Group; Margaret aged 20

Margaret's viewpoint that her son appeared to contract infections easily, and thus would benefit from the added protection of immunisation was unusual as participants often viewed their child's ability to avoid, or quickly fight, infection as evidence that their child's immune system was robust and healthy. However, more puzzling was the fact that the same logic did not appear to be applied to children deemed to have healthy immune systems. Indeed, some participants who believed that their children were healthy with robust immune systems suggested that this meant they would be unlikely to benefit from immunisation. For example, Dawn considered:

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. But where I start to worry is when you know, my wee boy is up at the crèche at the moment- what if he is playing with some other child less fortunate than he is that is when it starts to bother me. It is all very well me saying, I'm not going to bother, they will be fine, there are big issues there.

Antenatal Group; Dawn aged 36

Therefore for some participants childhood immunisation seems to be a 'no-win' situation, their argument being if your child is unhealthy, or seen as vulnerable, then you don't want MMR; and if they are healthy they don't need it.

5.2.4 Fears about the MMR vaccine rendering the immune system unable to respond to other infections

Whilst many participants feared that MMR could cause long-term damage to the immune system, there were only a few participants who had had any direct experience of any adverse reactions (excluding the parents of children with autism, see Chapter Six). Participants generally spoke of their children having had a mild reaction post-vaccination. However, two members of the Saturday Club Group related how their children experienced more severe and unexpected reactions. Cathy recalled her daughter's experience of MMR and Bob recounted his older son's reactions.

Cathy: Annabel got her first MMR, and it turned out it was an ear infection in both ears, went into her throat and everything. And that was a week after her MMR.

Bob: And what did they say?

Cathy: She just- it was actually my health visitor, my GP kept on shrugging it off- 'oh yeah, it's just a bug' you know and I spoke to my health visitor at the time and she was a fabulous woman. Kept me so informed, and she actually did say to me at one time you know, 'you ask so you get to know more', you know, whereas other people are just basically left alone.

Facilitator: Did that ear infection affect how you thought about your decision with your son, or?

Cathy: I don't think so, I just thought that was, well, it was an ear infection and... a course of antibiotics cleared it up, you know, it wasn't- but I did know that it was the MMR that caused it because my health visitor told me.

(Over-talking)

Ella: Did you say it was about a week after and then it went away.

Bob: And is this... going into the data, I'd like to know whether anyone records it in the data...

Cathy: Yes, of course, I mean is it?

Ella: That's quite common cos any vaccination you're getting a dose of the problem, what you're actually...

Facilitator: What about anyone else?

Bob: He (referring to older son) was in hospital for, for 8 days after the MMR. 8 days. His whole system closed down and we were told he was brain damaged. At three o'clock in the morning by a staff nurse- no, a staff doctor who was the ward doctor, who was just qualified. And she told my wife at half past three in the morning that he was brain damaged, his, his heart rate had halved, his temperature was, went up to a fever and went down to a ridiculously low, say 20, and they couldn't understand why his lips weren't blue. I mean, the only person monitoring him for the whole time was me, because nobody else was looking at his stats and his- his blood oxygen levels had halved as well, so he wasn't getting any oxygen into his blood. And I, and obviously we all said 'well, MMR?' And they went 'no'. And as I said that's not gone into any of the studies, so are they doing a study that when they collect data, are they ticking like MMR, had the MMR- any bad response afterwards?

Saturday Club Group; Cathy aged 29; Bob aged 31; Ella aged 45

Not only did Bob's experience of seeing his son so unwell colour his views about the potential harm of MMR, but it also led him to question how accurately adverse reactions to vaccines are recorded. Whilst a few participants associated vaccination with having an extreme reaction in their child, it was more common for participants to offer third-hand accounts of other parents' experiences of adverse reactions. Alison spoke about hearing about a child who developed lumps in their neck after receiving the vaccine. To the disquiet of the other group members she then went on to tell them that her cousin's daughter developed meningitis a week after receiving MMR. Although she diluted the story by implying that it could have been a coincidence and that the child may have caught it from a cup at nursery, the sceptical looks on the faces of the other group members suggested that they did not subscribe to this explanation. Indeed, Anna seemed compelled to offer a more plausible explanation to the other group members. She stated: "but her immune system's maybe down a bit because she had had the injection and that just triggered it" (High Uptake Group; Alison aged 31; Anna aged 33). Anna's explanation appeared to be a more acceptable account of what had happened, as the other group members nodded approvingly. This was an interesting response by the group because it highlighted the fact that the participants were more inclined to believe the

explanation of a parent, in preference to that given by the health professionals investigating the meningitis outbreak at the nursery.

5.2.5 Fears about vaccines not working, or not offering lasting protection

Concerns about the efficacy of vaccines arose in almost half the groups. These discussions tended to focus on either how effective some vaccines were in offering long-term protection to an individual, or on what percentage of the population are protected by each vaccine. For instance, Aleena was concerned that rubella efficacy might not be long-lasting and she and Sue both questioned the accuracy of data on vaccine efficacy in general:

Aleena: ...Do they know how effective it is? Do they ever take blood and... and see how the antibodies levels are, and also I read somewhere that just because you've got the antibodies in your blood, doesn't particularly mean you're immune to it, you know, you can still have, I think there have been cases of people having high antibodies against particular diseases and they still get them.

Sue: Do you think...that's right! Do you remember that case a year ago or so in Dundee and there was two children who had got measles? Both of them had had the MMR, you know, so its all a bit vague who becomes immune and who doesn't.

Non- MMR Group; Aleena aged 35; Sue aged 36

Rhona also questioned the efficacy of the rubella part of the vaccine, believing it was not long-lasting (First-time Mothers Group; Rhona aged 31). Likewise, Ella had felt confused about why some vaccines needed to be followed by a booster, and had asked her health visitor to explain this to her. From this explanation Ella had understood that:

Ella: ...it's because they don't know if the first one is effective or not. They don't- the only way they could know if it was effective would be to give it to every child and do a blood test.

In a later conversation she was asked:

Facilitator: So you're not planning to ...then get the booster at the moment?

Ella: I don't really see the point, because if he's immune you know, I'm thinking about asking for a blood test to check if he is, or not.

Saturday Club Group; Ella aged 45

Bob, who worked as a researcher, had recently been listening to a radio programme about the rising incidence of tuberculosis in the United Kingdom; he felt confused about what the professor taking part in the discussion was saying about the efficacy of the BCG vaccine, and stated:

...he was only telling us that it's effective for 20 years and that you can't have it again because it doesn't work like that, you can't have it again and it'll only last 20 years. And none of this has been told to me, well, I can't remember, I'll have to talk to my parents. And then he said it's only 75% effective. Now, I couldn't work out whether that was 75% of the sample that are given it, or 75% effective as in you've got a 25% chance, 25% chance of getting it. So he didn't explain it, so you can immunise 100% of the people or everybody, true- is one person still going to get it? Or are we saying that everybody's 75% you know, only immunised?

Saturday Club Group; Bob aged 31

Although some participants felt confused about the efficacy rates of vaccines, Dave who also worked as a researcher, questioned whether vaccines work at all, stating:

I used to work, you know, when I was working as a biochemist I was working with this guy and I needed to go over to Turkey and I needed to get the typhoid jab and anyway I was working with this guy, you know, it was quite a long time ago but I was working with this guy who actually developed the typhoid jabs and he said, you know, I was ill for three days after, it was like oh, I just felt awful. Anyway, after I got back from this holiday, you know, I was talking one time to him and he said 'you know, we know it doesn't work, the jab, we know it's the best that we've got at the moment but we know it's not really all that good' and it makes you think, well... you know, and that was then. That was the people that had developed it and they're telling me it's not worked, it hasn't worked...

Single Vaccine Group; Dave aged 38

Many of parents' fears about the vaccine efficacy appeared to stem from their feelings that they were inadequately informed about how vaccines' efficacy rates are calculated or monitored. This fear seemed to be exacerbated by hearing or reading anecdotal accounts of where vaccines had failed. Although several participants recalled these stories, there was only one participant who mentioned that a vaccine had not worked. Cara spoke about her daughter developing measles a few months after being vaccinated with MMR (Outpatient Cancer Group; Cara aged 36). Despite these concerns about the efficacy of some vaccines, there was little mention of whether the issue affected making decisions about vaccines. Ella was the only participant who explicitly spoke about it being factored into her decision not to vaccinate. Whilst Dave and Bob raised concerns over efficacy,

neither of them suggested that this had influenced their decisions. In fact the general consensus across the groups was that vaccines must be effective because diseases in general are well controlled. Nevertheless, the fact that the issue of efficacy was discussed in almost half the groups suggests that it was an issue even if participants were unsure as to how to address it.

5.2.6 Immune vulnerability: assessing their child's immune system's ability to respond to the challenge of vaccination, or to fight the disease

The third influence that participants identified on their decisions about MMR immunisation was their assessment of their child's ability to cope with vaccines, or fight disease. As yet, researchers have not explored this aspect of vaccine decision-making. Nevertheless, this topic arose in all the groups and participants spoke at length about factoring their child's state of health into their decisions about immunisation. Participants 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 to vaccination even if the illness was slight. However, there were many instances where participants spoke about deciding not to immunise with MMR on the grounds that they believed that their child's immune system was unable to cope with the stress of receiving several antigens at once. Across the groups participants mentioned that common colds, recurrent ear and chest infections, urinary tract infections, eczema, asthma, and allergies were signs of a child with a more fragile immune system. The main concern that participants expressed was that, for some children who already appear to have difficulty coping with common infections, the MMR vaccine could overwhelm their already fragile immune system potentially causing long-term damage. These participants often described their children as being particularly susceptible to damage. Indeed, all three participants who opted to pay privately for the single measles, mumps and rubella vaccines did so because of this fear. Jenny spoke about her reasons for opting for the single vaccine. She stated:

Jenny: Well, my boy, he has been ill, see from day one he has been ill with everything, everything.

Facilitator: What kind of things?

Jenny: Everything. You name it... he's had colds, just one after the other, he's got eczema all over him and then just allergies, everything. When he had the meningitis jag, his legs all blew up and he was really ill with it. I went... I went to the doctor and they said no, that wasn't to do with meningitis C but I knew it had to do with meningitis C and I just thought no, what's in that?
Single Vaccine Group; Jenny aged 19

It was common for participants to mention that they felt children's immune systems varied greatly, and that some children were better at fighting infections or more susceptible to contracting infections. Participants with several children spoke about the differences they had noticed between their children. For example, Sue, a mother of three, explained her reasons for deciding not to immunise her middle child with MMR. She stated:

...the second one had lots of colds, he had allergies and eczema, and em, it just seemed to be too much on his wee immune system and I just felt it was too risky, whereas the third one is a much more robust child...

Non-MMR Group; Sue aged 36

She later mentioned that she had given what she considered was a less potent homeopathic alternative, and was surprised that he had had quite a severe reaction to it. This reinforced her opinion that this son's immune system was more susceptible and more delicate than both her other sons, and she spoke about feeling reassured that she had made the right decision for her son (Non-MMR Group; Sue aged 36).

Likewise the Non-Vaccine Group participants spoke about the belief that a healthy child would be better equipped to fight disease and they rejected the whole premise that diseases are caused by micro-organisms. Fundamental to this group's belief was the idea that a healthy body can resist disease. Molly and Debbie both believed that disease only invades the body when there is already an illness causing disruption to the body's normal ecology. These participants considered that receiving three antigens at once would disrupt the body's normal functioning and that this could be harmful. Molly stated:

...the body does not encounter these pathogens directly into its bloodstream and certainly not in a combined way, you know, it's highly unlikely to encounter all these pathogens at the same time. Plus the immune system does not stop developing until you're about 18 years old, not 18 months

old, 18 days old or 18 weeks old and em the human body is not designed for this kind of onslaught of pathogen invasion...

Non-Vaccine Group; Molly aged 37

Molly and Debbie's ideas are more in keeping with traditional Chinese medicine where disease is mainly thought of as disharmony within the body, than with orthodox medicine, which is largely based on Pasteur's nineteenth century germ theory of disease.

5.2.7 Deciding about MMR: disruptions to usual vaccine decision-making behaviour

Participants were asked to describe how they had arrived at a decision about whether to vaccinate or withhold MMR immunisation. Although the decision had been easy for some participants, it was more common for participants to describe MMR decision-making as being difficult and as having risks attached to it. For instance, Kenny compared it to gambling:

Doesn't matter how small. If it's only one percent...I'll still question it...should you, you throw the dice and get the jag. You throw the dice and get the jag for that small percentage. You know? A gamble, 'cause before, you didn't know so it wasnae a gamb...if that gamble wasn't there the fact that you've got your, got to gamble with your kids life is unfair. Because you're put under that pressure of gambling, where before you weren't. You weren't. So if something did happen, right? You'd take that part and parcel an' take the blame, even though you're cornered by a no choice situation.

Single Fathers Group; Kenny aged 43

Ella also considered that she was gambling with her son's health and she recalled seeing her son having his MMR:

...I remember when they put the needle in his arm when he was, he looked at me, he was only a wee baby, and he looked at me like that, and I felt I am taking a risk with your life even though I'm trying to protect your life. And that, it's, you know, it's a lottery, I felt as if I was taking risks, it was like, what's that game you play with the gun? Russian roulette.

Saturday Club Group; Ella aged 45

In making the comparison with gambling both Kenny and Ella suggest that they are taking an unknown risk with their children's health. For this reason they both mentioned

that they felt particularly anxious about having their sons vaccinated with MMR. This anxiety was evident not only in what participants said about MMR, but also in what they said about the decisions they had made about the other vaccines in the programme. For example, it was common for mothers to refer to themselves as being the decision-makers and their partners as having a secondary role in decisions about vaccination in general. However, in relation to the MMR vaccine, it was noted that fathers appeared to play a more prominent role in the decision. Indeed, when mothers spoke about deciding about MMR they often mentioned that they had sought the support of their partners, a fact not mentioned when discussing decisions about other vaccines in the programme. In this respect, the debate surrounding MMR safety appeared to have disrupted normal decision-making patterns. Whilst mothers spoke about ultimately having the final say, they appeared keen to have the support of their partners in the decision and, in turn, fathers appeared keen to take a more active role in weighing up the advantages and disadvantages of MMR immunisation. The members of the NCT Group debated this issue and Mel mentioned that although she was the “driver in the decision,” she had sought her husband’s approval because she did not want to shoulder all the responsibility, or guilt, if things went wrong. Likewise, Trudie also referred to herself as being the “driving force,” but spoke about her and her partner making the decision together. However, trying to come to a joint decision had caused Violet and her husband some difficulty. Violet explained:

Violet: ...if it was left up to him, I don’t think Annabel would have the MMR. Which is quite difficult because...because I think he does now agree that she should have it (interrupted)

Mel: Because of the egg allergy?

Violet: Well, partly because of that, and partially because he just feels very strongly that ‘there is no smoke without fire’ and he thinks parents know their children better than anybody. So if all these people are saying they saw a perfectly healthy child up to that point, then they had the injection and suddenly they were not well. If he totally didn’t agree with it I wouldn’t go for it because – what if something did happen to her. But then ...so we have discussed it ‘up hill and down dale’ finally I think we are agreed. We’re going for it.

NCT Group; Violet aged 36; Mel aged 35; Trudie aged 38

Another interruption to normal patterns of vaccine decision-making behaviour was caused by the high profile nature of the public health debate surrounding MMR, which had forced participants to engage more actively in the decision-making process. Indeed, whilst it was not uncommon for participants to describe some of their earlier decisions as being almost an automatic response to receiving the letter to attend for immunisation, this was not the case for MMR. The only group of participants who seemed quite passive about MMR was the Young, Single Mothers Group. They recalled:

Kate: Just get em done, don't really think about whit it is ...well I donnae anyway. Ah never sat and read the leaflets that they gave you on your jags and a' that.

Lisa: Naw, see ah never either. And the doctor says they've to get their jags like every couple of months...

Kate: ...and Ah wiz just like that, 'just get em dun'. If they need them, just get them dun.

Facilitator: Is that how you feel about the whole thing?

Kate: The only reason wi the MMR, the only reason Ah kinda thought mair intae it wiz because o' the stuff that's been on telly about it and a' that.

Facilitator: Right.

Kate: That's the only reason that Ah really worried about it a wee bit more, but the rest eh them's fine. But Ah'll get it done. Ah will get it done. Jist thought about it a wee bit more...Ah didnae think twice about it, Ah jist went and got them.

Other: Aye.

Facilitator: Mmm.

Kate: There's nae point in thinking twice. If MMR was something they didnae need done, why the hell dae they have the jag fir it?

Young, Single Mothers Group; Kate aged 22 ; Lisa aged 20

Deferring MMR immunisation was common, and participants gave several explanations to account for this action. A few participants spoke about delaying because they wanted to wait until their children were beyond the age at which autism first shows signs of developing. For example, Cassie and Alison both mentioned that they were waiting until their children were past eighteen months old in order to ensure that they first met the expected developmental milestones (High Uptake Area Group; Cassie aged 29; Alison aged 31). Likewise, Mel in the NCT Group explained:

Well, I have an older son who is now four, and I waited until he was about 18 months before I gave it to him. I just had reservations about giving it, there was just something telling me not to give it so early. So this time with Lousie she is already 15 months and has been called three times for it, but I have just told the doctor - I'm putting it off again. And also when I spoke to the doctor recently she said ... She said 'you are quite right not to give it initially when they call you up for it. Wait till they are 18 months, they are a bit more mature, you can see them walking, talking and all the things they are meant to do at that stage'. So I'm just going to do that, I'll wait till early September before I give it to her. They have been fine, I think you just have to go with your gut reaction really.

NCT Group; Mel aged 35

Although Mel does not specifically refer to autism, her comments suggest that her decision to defer vaccination was based on her fear that her daughter could develop autism. Indeed, it was common for participants who opted to delay MMR immunisation to do so because they believed that doing nothing was better than doing something that could have negative repercussions later. For example, Michelle and Patsy reasoned:

Michelle: Well I havnae had it done, I put it off cos I couldnae cope on ma own wi a mentally handicapped wean. It's too much o a risk especially wi boys.

Patsy: Aye that's right it's too risky. You know when you have a perfectly healthy wean. You'd be mad tae take the chance tae loose them tae this mad autism disease ...

Multiple Parenting Problems Group; Michelle aged 21; Patsy aged 23

Likewise in the High Uptake Group, Anna spoke about there being too much uncertainty and conflicting evidence to make a decision, and said that she had opted to do nothing at the moment and review the evidence in a year or two because she felt this to be a safer option (The High Uptake Group; Anna aged 33). However, there were also several participants who considered this action to be dangerous. For instance Kate suggested:

Kate: If you miss wan eh they jags, do you know what Ah mean? Yer gonny feel Ah think a lot of people would feel guilty for no getting their wean that jag if they end up wi wan o' they, know how, diseases?

Facilitator: Yeah.

Kate: And they could have prevented it. Ah wid, Ah wid feel dead guilty so Ah wid. If Ah never got aw they vaccinations and then wan day if ma wean does end up wi- and Ah could have prevented, do you know whit Ah mean? Ah would feel dead guilty.

Natalie: Ah would feel dead guilty.

Young, Single Mums Mothers group; Kate aged 22; Natalie aged 18

Similarly Alan had delayed taking his son for the MMR vaccine, but had felt anxious about delaying. He argued: "I think if you get the chance to give them.... the jag and you decided not to give them it, you would feel worse if they caught it". However, he also mentioned that he had waited until a friend had had his child immunised with the MMR vaccine and seen for himself that the child did not have a bad reaction before taking his son for his vaccine (Low Uptake Group; Alan aged 33). Indeed, it was common for participants to want to hear what their friends and other parents had decided for their own child because they were seen as facing the same dilemma and as having no hidden agenda.

5.3 Discussion of the findings

In summary, it was clear that the debate surrounding the safety of the MMR vaccine had made participants extremely anxious about making a decision about whether immunisation was in the best interests of their children. Participants commonly spoke about ensuring that their children were in good health on the day of immunisation and similar to the findings of New and Senior (1991), reported that they were reluctant to take ill children for vaccination even if the illness was minor. In particular it was noticed that participants' thinking about MMR vaccination had altered several aspects of their usual vaccine decision-making behaviours. Firstly, consistent with New and Senior's (1991) finding, the mothers in this study spoke about being predominantly responsible for matters relating to immunisation. However, in relation to the MMR vaccine it was observed that fathers appeared to play a more prominent role in the decision than for the other vaccines in the programme. One possible explanation for this change in behaviour was that mothers may have considered the vaccine to be too risky to make the decision on

their own, fearing guilt or reprisal if anything should go wrong. Secondly, it was noted that, while some participants spoke of having an automatic response to taking their children along for immunisation following receiving notification that their child was due his or her vaccines, this was generally not seen in the case of the MMR vaccine. Therefore although some participants described taking a more passive role in vaccine decision-making, in general in respect of the MMR vaccine it was more common for them to describe becoming involved in weighing up the evidence and trying to come to a decision about it. Nevertheless, after considering the evidence, these participants tended to opt to have their children immunised. The third alteration to parents' usual decision-making behaviours was that some participants had difficulty reaching a decision at all. In the event, they opted to defer the decision by delaying it, an option rarely spoken about for any other vaccine in the programme. Two reasons were given by participants to account for this action. Firstly, participants wanted to wait until their child had passed the age at which autism first appears so that should their child become autistic they would know that they themselves had not contributed to their child's condition. Secondly, by delaying the decision some participants considered that it gave their child's immune system time to develop and thus less likely to be overwhelmed by the combined antigens within the MMR vaccine. Many participants considered that it was preferable not to act, than to act and cause long-term damage as this action was viewed as being less risky and as having less guilt attached to it. This finding is consistent with Ritov and Baron's (1990) observations about the vaccine decision-making behaviours of parents during the pertussis controversy, which they termed omission bias.

To date, much of the literature on vaccine decision-making has identified two factors that play an important role in assisting parents to decide whether or not to immunise their children. These are the perceived seriousness of a disease, and the likelihood of catching it, and the perceived safety and efficacy of the vaccine (Hershey et al., 1994; Evans et al., 2001; Sporton and Francis, 2001; Smailbegovic et al., 2003). However, in relation to the MMR vaccine my study identified three factors that appeared to play equally important roles. In addition to their assessments of the diseases and of the vaccines, participants in

this study spoke about assessing the ability of their child's immune system to be able to cope with the challenge of combined vaccines, or to fight the disease.

Consistent with the findings in Chapter Three, there was evidence that the relationship between parents' experience of disease and decision-making outcomes appears complex and not always predictable; experiencing the disease first-hand did not necessarily mean participants would decide to immunise. This was particularly the case when participants remembered their experience of a disease as innocuous and had an uneventful recovery from it. Such participants often seemed more likely to underestimate the risks associated with the disease and in some cases to withhold vaccination. Similarly, there were instances where participants had no experience of the disease but had heard stories about a disease causing harm or death and this anecdotal evidence had acted as an incentive to immunise.

This study found that when deciding about a combined vaccine, participants often considered all the diseases it protects against at the same time, rather than as separate entities. This makes sense given the fact that most of the diseases in the Childhood Immunisation Programme are prevented by combined vaccines in which several antigens are given in one vaccine. However, it was observed that for some parents the fact that they decided about a combined vaccine by assessing the diseases together produced a situation whereby each of the diseases became less well defined, and seemed to create a level of ambiguity about which disease caused which health problem. This may contribute to poor understanding of the diseases.

When participants spoke about their decision-making outcome in relation to the MMR vaccine, it was noted that there were some notable divisions between the parents of boys and girls. For instance, some participants who spoke about deciding not to immunise their boys with rubella appeared to cause offense to parents of girls who viewed their decision as potentially putting their girls at risk. The parents of boys seemed less offended by the decisions of parents of girls, who mentioned that they did not think

mumps was relevant for girls. One explanation for this may be that on several occasions participants questioned the efficacy of the rubella component of the MMR vaccine. These concerns seemed to stem from hearing or reading anecdotal accounts about vaccine failure, and feeling inadequately informed about how vaccines' efficacy rates are calculated or checked. This finding highlights the importance of reassuring parents about the efficacy of the MMR vaccine and in particular about the rubella component of the vaccine.

Raithatha and colleagues (2003) have suggested that the MMR controversy may have triggered a more widespread reappraisal of vaccine risk and there was some support for this idea in my data. Although many participants tended to focus attention on the MMR vaccine and less on the other vaccines in the programme, some participants were concerned about combined vaccines more generally. However, participants often changed their minds, contradicted themselves and spoke with uncertainty and ambivalence on matters of vaccine safety. For example, although many of the participants talked negatively about the fact the MMR vaccine combines three antigens into one vaccine, many of these parents had already given their children combined DTP vaccines at two, three, and four months of age and did not seem unduly concerned about them. These inconsistencies between participants' views and actions were evident throughout conversations on this matter, and reflect the fact that many participants seemed anxious, and confused about the whole concept of combined vaccines overwhelming the immune system. In this respect participants did not confine their concerns about the safety of MMR to fears about autism. Although participants were clearly concerned about autism, they tended to speak about it in terms of worrying about immune damage. Participants seemed particularly anxious about the possibility these combined vaccines could be detrimental to their child's health in the long-term. This fear appeared to centre on the concern that too many antigens given together could potentially overwhelm the immature immune system causing long-term damage. This fear led three participants to pay privately to have single mumps, measles and rubella instead of MMR and lead many participants to refuse, or delay MMR. In fact it was common for participants to believe that immunisation initially suppresses rather than boosts the

immune system, making children more vulnerable to contracting diseases. This idea was interesting in that this is the exact opposite of its intended effect. Indeed a recent study suggests that immediately post-MMR vaccination the immune system is not compromised and is able to respond to fight other infections (Miller et al., 2003). However, although many participants feared MMR could cause damage, there were only a few participants who had had negative experiences with it, which led them to view MMR as dangerous. It was more common for participants to offer third-hand accounts of other parents' experiences of adverse reactions and these stories acted as powerful reminders that vaccines have risks attached to them.

Consistent with the findings of Offit et al. (2002) and Miller et al. (2003) participants in this study feared their child's immune system might be vulnerable to the stress of receiving several antigens at once. Participants commonly spoke about deciding not to immunise with MMR on the basis that they considered their child's immune system to be vulnerable to the stress of receiving several antigens at once. Across the groups participants mentioned that common colds, recurrent ear and chest infections, urinary tract infections, eczema, asthma, and allergies were symptoms of a deficient immune system. The main concern that participants expressed was that for some children with deficient immune systems, the MMR vaccine could be harmful and could potentially cause long-term damage. It was common for participants to mention that they felt children's immune systems varied greatly and for participants with several children to compare and talk about the differences between their children. More puzzling was the fact that the same logic did not appear to be applied to children deemed to be healthy with robust immune systems. Indeed, some participants who believed that their children were healthy suggested that this meant that they would be unlikely to benefit from immunisation. However, these ideas tended to be expressed by participants who rejected the whole premise that diseases are caused by micro-organisms and who considered that it is not necessarily advantageous to avoid diseases altogether. They believed that a healthy individual may benefit from contracting a disease and developing life-long immunity to that disease, and suggested that mass immunisation in the UK has become out-dated.

An important and as yet relatively unexplored aspect of the debate was the fact that participants' fears about their children having deficient immune systems was a common reason for participants to delay or withhold MMR immunisation. It seems likely that concern about immune overload may have stemmed from the press release that accompanied the publication of Wakefield's paper. Although no participants recalled this event, it seems possible that issuing this statement has increased concerns that the combined MMR vaccine might place too much stress on the immune system.

The findings in this chapter are particularly relevant because in August 2004 the government announced plans for the introduction of a new five-antigen vaccine into the Childhood Immunisation Programme. Although Bedford and Elliman (2004) have been quick to point out that this change to the programme is "...a natural progression in the light of changes in the epidemiology of polio and advances in vaccine technology developments" (p. 411) it seems likely that in the coming years this aspect of the debate about vaccine safety will take precedence over any concerns about MMR causing autism. It therefore seems wise for policy makers to address these concerns to persuade parents that combined vaccines are safe. Until further work is directed at educating parents about their children's immune systems and dispelling parents' fears about immune-overload, this misconception may continue to seriously undermine the efforts to improve MMR uptake and may leave parents casting a more critical eye over the entire programme.

Chapter Six: The MMR controversy from the perspectives of parents caring for autistic children and of immuno-compromised children

6.1 Introduction

This chapter investigates the experiences and views of the MMR controversy as expressed by parents caring for autistic children or immuno-compromised children. I anticipated that both these groups of parents would have a particular interest in the debate and in the public's response to it, for quite different reasons. Firstly, the speculation in the media surrounding Wakefield's theory about a causal link between MMR and autism suggested that, in order to understand the various dimensions of the MMR controversy, it was important to include parents of children with autism in the study. As yet no research has been published on how the MMR controversy has affected these parents, despite autism playing a central role in the debate. In contrast, parents whose children have compromised immune systems have had no such obvious role in the debate, but I wondered what effect the reduced MMR uptake was having on these parents whose children are dependent on high population immunity to offer them protection. Again, as yet no research has been published on this aspect of the debate. Yet, it seemed likely these parents were also being affected by the way the MMR controversy has unfolded and impacted their on lives, and this seemed like an original aspect of the debate worthy of investigation.

This exploratory chapter is based upon analysis of the discussions in four focus groups. Two groups were conducted with parents whose children have autism, and two with parents caring for children with compromised immune systems due to the effects of chemotherapy treatment for cancer. The topic guides used for these groups were adapted from the main guide (See Appendix M and N). These guides were kept brief in order to encourage participants to take charge of much of the direction of the discussion and to explore the issues important to them. In the event, this meant that some of the data

generated were outwith the scope of this thesis. However, encouraging participants to set the agenda led to some unforeseen and original issues being raised,. Further, as no papers have been published specifically examining the MMR debate from the perspectives of either of these groups of parents, it offered an ideal opportunity to let these participants take the lead in shedding some light on these less obvious aspects of the debate.

6.2 The MMR controversy from the perspectives of parents caring for autistic children

All six participants in these two focus groups had sons with autism. Four participants who were part of the legal action felt certain that MMR was responsible. The remaining two participants felt unsure whether MMR had caused their child's autism, although neither of them ruled out the possibility of a link. In order to protect the identity of these participants and any children involved in legal action their ages and those of their children are omitted from this thesis in addition to being given pseudonyms. Both these focus groups turned out to produce extremely moving and often emotional accounts of parents trying to come to terms with their child's diagnosis of autism, against a backdrop of growing speculation that MMR may have triggered it. All of them had received their son's diagnosis of autism since Wakefield's paper was published in 1998. In order to do justice to these very personal accounts, slightly longer extracts have been used to let them tell their story in their own words. However, in order to condense some of the longer discussions into a more manageable size, summaries are also included.

6.2.1 Overloading a deficient immune system and subsequent feelings of guilt

An important theme to have emerged from these discussions was that participants considered that with hindsight their children should never have received any combined vaccines, and they felt guilty about having made the decision to have them vaccinated. This sense of guilt seemed to centre on the fact that all of the participants except Lesley felt that from a young age their child displayed signs of having a deficient immune

system, and that as parents they had ignored these signs. For example, Dianna asserted that her son Jack should not have received any vaccines:

... he had like chest infections, coughs, colds. I was at the doctor twice, maybe three times, every month. And he was on all these antibiotics and that. He really shouldnae have had his vaccine, but no only his MMR. Em... I'm sure they should be, they should be three month clear at least o antibiotics. For Jack's second DTP he had these coughs and colds and UTI (urinary tract infection). I don't know how many times that's wrote in his medical record. Em, after his first vaccination that's where they started, so his, like, immune system was assaulted. This is the way I've looked at it. This has come in, assaulted his immune system and he cannae cope, so he's getting all these coughs, colds, you're thinking it's away- two days later it's back, you're back at the doctors. 'Try these antibiotics', so he got antibiotics for a week. Went back the following week and the antibiotics hadnae worked, so, 'try these ones'. So that's like two courses o antibiotics. Go back the following week and the cough and cold's cleared, OK for immunisation. So I mean his system was totally oot anyway wi one course o antibiotics but he had two and I believe that this is when it started... by the time it got to the MMR it was like over.

She later commented:

See, if my boy's immune system cannae throw a scab oot? Cannae... get into gear and send the immune army up there to clear that wee scab, what chance did he have against measles, mumps, rubella, all the chemicals, the animal proteins and the polio and everything else that he was given?

Autism Club Group; Dianna

In the same group Jacqueline was also adamant that MMR had caused her son's autism. Like Dianna she felt that she should not have had her son immunised, and later said that she regretted not paying more attention to 'warning signs' that his immune system was deficient. She recalled Max's health in his first year:

Max was just one of these typical wee boys that you were never away from the doctor with. Snottery noses, coughs, colds, chest infections... everything, absolutely. If you gave me a list of things that Max could have had, he had them. He was also very badly affected with eczema. So he had a very low immune system, so low that... I feel a doctor, a health visitor and a nurse should have had the common sense to say this child isn't fit enough for any of these vaccinations, because he wasn't fit. He had so so much... never off antibiotics.

Autism Club Group; Jacqueline

A similar picture was presented in the Autism Support Group. Stella, Caroline and Alison all recalled the medical histories of their children. Stella mentioned the fact that

her family has a lot of allergies, asthma, eczema and ME, and Caroline talked about her son having had many recurrent chest infections and colds as a baby. Alison also blamed herself.

Alison: ...if I had researched to any extent I would have found out that my children were so susceptible.

Facilitator: Mmhm. So why do you think they're so susceptible?

Alison: Because there's an auto-... I had an auto-immune disorder. Eh ...

Facilitators: You, yourself?

Alison: I have uhuh, when I had the children eh I had...chronic ME for 15 years.

Facilitator: ME, right.

Alison: and eh I suffered really badly with migraines, my brother is hospitalised twice a year with migraines, eh, my sister has eczema and irritable bowel syndrome, all the kind of susceptible family traits we had in abundance in, in the 3 children in my family. You know, and I... I mean independently I'm doing research into how many parents of children with autism have any ME connection and it's huge.

Autism Support Group: Alison

Lesley was the only participant in either of the groups who spoke about her son being a healthy baby, or of feeling uncertain as to whether MMR had contributed to her son's autism. Nevertheless she did not discount the possibility that MMR may have triggered it, and found all the speculation surrounding MMR upsetting:

Lesley: It makes you feel pretty damn rotten. I feel as if at the time I did the best for my boy, I believe... I believe at the time, I wouldn't have put my child through anything that I think would harm him, so if the doctor who I implicitly trust tells me that my child needs an MMR, I go to my doctor and at that time I would say 'you know best, I'm gonna give it...' I don't blame myself at all if that's... (all talking at once)

Autism Club Group; Lesley

It was interesting that Lesley was the only participant who talked about not blaming herself for her son's autism. All the other participants talked about feeling responsible and spoke angrily about MMR. In contrast, Lesley spoke with composure and talked

about not looking to blame anyone, but on focusing her efforts constructively on looking to her son's future and what is best for him. A major factor in her not feeling to blame seemed to be the fact that Lesley was able to look back on her son's early development safe in the knowledge that he had always seemed healthy. This seemed to console her: as a parent she had done her best for her son. However, the other participants were not able to rationalise their actions so easily. The anguish and turmoil they felt about the fact that they had ignored early signs that their children were not healthy and then sanctioned a vaccine that may have caused autism placed an unbearable burden of guilt on them. This guilt was evident throughout the discussions. Participants spoke about feeling inadequate as parents, and talked almost confessionally about having let their children down. For instance Alison stated:

Alison: ...I feel like just I've failed my children so badly by not researching that. I feel as though I've bought organic food, I bought organic jars of food, I breastfed for as long as I could, I did everything, you know, I'd Dettol every fuckin' surface, nothing would get into them. And then I never questioned what was in the vaccine...and I know, you know everyone always says 'oh, you know, you can't blame yourself' but I do blame myself. And I should blame myself because I should have looked into that, I should have questioned that before I took my child along and got them injected (tears in her eyes).

Stella: You weren't to know (touches Alison's shoulder).

Autism Support Group: Alison

The distress these participants felt occasionally spilled over into tears, and whilst other participants often tried to find words of comfort, these words often seemed hollow as they too appeared to share in this same sense of guilt. One particular event that participants seemed to feel guilty about was the day they took their children to receive MMR.

6.2.2 The MMR autism story: feeling guilt and trying to get answers

Jacqueline spoke about the day that she took her son Max to a major children's hospital to have an egg-free MMR, due to allergies. She referred to it as "the day that changed her and her wee boy's life forever", and recalled: "...I'll never forget the day we took

him". She goes on to state in a happy care-free voice: "Taking him in, oh yes, he's getting his MMR. They give him it, you wait an hour and you take him home. And then...(spoken in low grave voice) your life changes so much... so, so much" (Autism Club Group; Jacqueline). She talks about him deteriorating before her eyes, and recalls:

It was his speech that really went first and then the whining started, and the whining never stopped. And he whined for everything. He used to hang upside-down, obsessive about videos, he used to want to watch the same video 1500 times a day and he screamed when you were rewinding it. I felt as if all I was doing as a mother was screaming at him, shouting and bawling at him, wanting to absolutely kill him but not realising that he's in absolute agony to everything...

Autism Club Group; Jacqueline

The passion with which Jacqueline spoke about her son's sudden deterioration was moving and even compelling. She realised when looking at video footage of him how quickly he had deteriorated after his MMR, and became convinced that MMR had triggered his autism. In the Autism Support Group, Alison also told a similar story about her son being immunised with MMR, and described how she noticed an immediate deterioration in him. She recollected:

Alison: ...he missed the first call for his vaccination, at 18 months he was ill or 19 months. So I don't think he got the vaccination to 21 months and by 22 months he couldn't speak and all he did was smash his face off concrete.

Facilitator: So was it very quickly then?

Alison: Uhuh. (Nodding head yes)

Facilitator: Did you associate it yourself?

Alison: No, cos I didn't know there was any risk involved so I would have associated it as much as giving him the cream egg the day before, do you know what I mean? I had no idea there was a potential. So my... my... my... I wasn't affected at all at that point.

Facilitator: When did you associate it? When ...?

Stella: I think it was in the media when it came out.

Alison: No, because you see ... uhuh, but he took very ill after the, the vaccination.

Facilitator: Right, what kind of ill?

Alison: He just... he was just ... ill. He, he, just as if, you know, when they're really, really poorly and they're pure... temperature and they've just got that look of, I'm not here, just that scary as a parent, you're scared. And then when he finally kind of awoke, you know, during that time, he had the deadest eyes, it was like all the life had gone from his eyes, all this... but I know that sounds really...

Stella: No, Ewan has been like that as well.

Alison: It was like before he was like wee boy, twinkly eyes and after it, it was just like the same eyeballs but as if, the glare had been taken out of them or something and he just...

Autism Support Group: Stella; Alison; Caroline

Alison, like Jacqueline, was adamant that her son's adverse reaction to MMR and subsequent sudden deterioration was evidence that MMR had triggered her son's autism. Although Alison also talked about feeling sure that MMR was responsible, she also mentioned the fact that at the time she was not aware of any risk associated with MMR. According to Alison it was only when her daughter developed severe eczema immediately after receiving her MMR that she began to become convinced that MMR was not safe. Dianna told a similar story and had also become increasingly convinced of the link. Her fears seemed to be confirmed when sifting through her son's health records and video footage of him as a baby and young toddler. Both groups spoke about realising that MMR had been the trigger and then having to deal with their son's diagnosis. For example Jacqueline and Lesley reflected on their experience of coming to terms with having a child with autism, and stated:

Jacqueline: ... We'll never have the child that we lost.

Lesley: Absolutely.

Jacqueline: And that's a process that we've been through as well. You grieve for that child.

Lesley: Oh, absolutely.

Jacqueline: A grieving process.

Lesley: Well I mean cos you've got your own idea how your child is gonna be like- I mean you always want better for your children, same as my mum wanted better for me and all the rest of it. You want your child to do the best that they can and you don't want ?? (all talking at once)

Autism Club Group; Lesley; Jacqueline

Jacqueline, Alison and Dianna stood out as being the parents most affected by Wakefield's theory. Indeed, on comparing their sons' histories with major events in the MMR debate it was interesting to note that the period during which their sons were beginning to display signs of severe autism coincided with the publication of Wakefield's study in 1998. These participants may therefore have been more sensitised to and influenced by the debate than they now consider themselves to have been. Indeed, these three participants talked about searching for answers, and Dianna and Jacqueline both spoke of travelling down to London's Royal Free Hospital in the hope of understanding more about the bowel problems their sons had. Dianna and Jacqueline also spoke about travelling to hear Dr Viera Scheibner speak on one of her tours.

I mean we went to, we went to hear this woman speaking, a lovely woman. Bulgarian, Hungarian-Dr Viera. She was absolutely superb. She's right up on these vaccines and she's from the old school, you know. She's Hungarian I think she is. And all these studies on baby's breathing and all that. She's done studies on baby's breathing, she developed this map cos she was fed up of hearing of children dying of cot death in her native country. But when she studied these children, see as soon as a baby died, she was chapping on the mother's door. 'Can't help your child but I can help somebody else's... will you please help me doing this study?'. Now, you're talking twenty, thirty years ago where... you know, you're intruding on grieving parents, but... her persistence and her energy was amazing. She done studies that showed...that specifically showed that between, what was it... the twelfth and the sixteenth day after vaccination is when a cot death occurs...

Autism Club Group; Jacqueline

In searching for answers to their son's condition, these participants spoke of reading anti-vaccination articles and of becoming interested in hearing the stories of people who oppose immunisation. Like Dr Viera Scheibner, Dr Andrew Wakefield was viewed as being on the side of ordinary parents and standing up to authority on their behalf.

6.2.3 Views on the association between autism and bowel problems

All of the participants were convinced of a connection between their child's bowel symptoms and worsening behaviour and talked at great length on the subject. For

example, Jacqueline spoke about her second visit to the Royal Free Hospital in 2001. She recalled the experience:

... 'you need to get doon here. His condition merits, what we've found in his blood merits, em, further... investigation'. He went down the following month and got a colonoscope and an endoscope and when he was in the recovery room Dr X who is... is em... Andrew Wakefield's sidekick sort of thing- he came in and he produced these photos but you're no really taking these photographs in cos you're worried about your child lying there full o' anaesthetic, which an autistic child shouldnae even get anyway. It buggers them up, you know, it just- it's no good for them. So you're worried about the anaesthetic, blah blah, blah, and he come in and he said well 'Max basically... he's got cysts, he's got pockets of inflammation, he's producing too much acid in his gullet, he has got polyps, he has got a... a misshapen colon obviously due to the compacted constipation over the years, he's got... infection, inflammation, blah blah blah, inflammation'. Em... so that's fine, he goes away and, you know, the next day he comes in before you're going home and I said 'right, how do we treat this?' and again he told us exactly what he had found. But while he was in the recovery room I said well 'how did he get all this?' and he mentioned MMR before I did because we still hadn't mentioned anything to do with MMR just because I was determined.

Dianna: Not to mention it.

Jacqueline: I was not going doon that road. Em... he said 'well, you know, it's some parents' belief that the MMR caused this and we really don't know yet' and I said 'well, we believe it was the MMR'. Might as well tell him now, you know? So the next day he came in... and there was loads, loads of people in with Max He was... I got the impression that the doctor was very, very excited about what he'd found in Max.

Autism Club Group; Jacqueline; Dianna

Dianna and Jacqueline both spoke about wanting to get some answers about their sons' autism and bowel problems, but instead felt let down by the medical team at the Royal Free Hospital. Jacqueline believed that the medical team looking after Max felt they had found something exciting, and she went on to describe travelling home feeling delighted and hopeful that her son's autism might improve if his bowel problems were treated. However, she went on to say that when she visited her GP she was bitterly disappointed to find that the hospital had sent a discharge letter. She described how this could have been written for 'Joe Bloggs', and how subsequently she has received no assistance with his condition, other than a course of laxatives. On this subject she spoke angrily, concluding that there had been a clampdown on the medical team investigating the link between bowel disease and autism since Dr Wakefield's departure in 2001. Dianna also considered:

...one minute there are all these open people and then they're no wanting to say nothing to you. They're going fae that side o' the fence to that side o' the fence, but in the middle is these parents who are daeing their damndest to try and find something to help their kids, because in the hoose could be this wee boy, could be a wee boy in a corner spinning plates still, you know... but I'm quite lucky that I got my wee boy out o' that foetal position.

Autism Club Group; Dianna

In retelling her story Jacqueline highlighted an important aspect of the debate which may have been over-shadowed by the furore about a possible causal association between MMR and autism; that is, of Wakefield and colleagues' observation that there may be an association between autism and inflammatory bowel disease. Indeed, both Dianna and Jacqueline implied that the MMR debate had been unhelpful in their quest for help for their sons' bowel problems, because they perceived that the medical profession appeared to be trying to distance itself from Dr Wakefield's work. In this respect, they considered that politics was interfering with their ability to manage their sons' conditions, and that the medical establishment had turned their backs on them. In turn, they spoke optimistically about the possibility of the pending legal case obtaining answers for them.

In the absence of orthodox medicine recognising and treating their sons' bowel problems all of the participants had turned to homeopathic alternatives, with the exception of Caroline, who stated that she was not able to afford this treatment. Indeed, Lesley also felt concerned about how expensive these alternatives are, mentioning that she pays £79 every time she goes to see that her homeopath, in addition to the cost of all the medication that they prescribe as well. Despite the expense she felt that she needed to get this help for her son, and asserted: "...you know, if someone's had a really positive response, you look into it hoping...you try things" (Autism Club Group; Lesley). However, Lesley stated that she was not sure whether she had seen a change in her son, and stated: "...I mean they play on your fears. Everybody plays on your fears". All of the participants talked quite extensively and positively about their experiences with homeopaths, and felt that their children were improving as a consequence of homeopathy. This was in stark contrast to their experience of and comments on mainstream autism care which seemed to them to be woefully inadequate in addressing the problems they

faced and in caring for and treating children with autism (an area outwith the scope of this thesis).

6.3 Discussion of the findings

In summary, the sense of grief that these participants felt was unmistakable, and during conversations it seemed apparent that the MMR controversy had added to this sense of grief and guilt. One of the most striking features of these focus groups with parents caring for children with autism was the level of agreement between them. This was particularly evident in their descriptions about finding out their sons had autism, and in the search for treatment to reverse their sons' cognitive and social deterioration. All the participants told heartrending stories and appeared to have been served badly by the MMR controversy.

An important theme to have emerged from these discussions was that, with hindsight, participants considered that their children should never have received any combined vaccines because they now believed in retrospect that their children had displayed signs of having a deficient immune system from a young age. Participants recalled their children's medical histories and family histories of conditions such as allergies, asthma, eczema, ME and recurrent ear and chest infections. They considered that giving combined vaccines had overloaded their immune systems, causing irreparable damage and the subsequent development of autism. As such they displayed a mix of emotions including anger at the medical profession for failing to give them better advice for their children, guilt that as parents they felt that they had ignored signs that their children's immune systems were deficient and sanctioned a vaccine condemning their children to a life with autism, and dismay at the Government for stopping research that might help them to discover and treat their children's bowel problems. They were particularly anxious about what they perceived to be a clampdown on research into the link between bowel disease and autism as researchers tried to distance themselves from Wakefield's work. Recognition and subsequent treatment of their sons' bowel problems had ceased.

Participants spoke about turning to the legal profession to build a case against the pharmaceutical companies responsible for manufacturing the vaccine. However, for some participants in this study, gathering evidence and viewing hours of video footage of their child's development was a sobering experience that confirmed their worst fears, that as parents they might not have protected their child from MMR. In the absence of help from orthodox medicine, most of the participants had turned to homeopathic alternatives and opponents of vaccination for answers. Although their experiences of homeopathy were generally positive, they considered it to be expensive, but they felt they had no alternative because mainstream autism care was inadequate.

6.4 The MMR controversy from the perspectives of parents caring for immuno-compromised children

The second and less obvious group of parents that were identified as having specific concerns given the falling rate of MMR uptake was those caring for immuno-compromised children due to the effects of chemotherapy treatment for cancer. Intensive chemotherapy regimes cause a decline in leucocytes and antibody levels acquired from immunisation. Consequently, during and immediately after chemotherapy treatment these immuno-compromised children are at increased risk from an array of bacterial, fungal and viral pathogens, some of which are particularly hazardous. Whilst the outcome for many of these children has improved considerably over the past 30 years, and at present, 70 -90% of children are cured with appropriate chemotherapy treatment (Patte, 1998; Pinkerton, 1999), as more children recover from their cancer and re-integrate back into their normal life there is a greater need to consider the immune status of these children post chemotherapy treatment. In recognition of this fact the Royal College of Paediatrics and Child Health published a Best Practice Statement on the immunisation of the immuno-compromised child in February 2000. Although the

publication offers detailed guidance on the re-vaccination of children post-chemotherapy treatment, it also warns:

...there is a clear and important need for further research in immunocompromised children concerning immunisation in general, and specific vaccines in particular (p. 4).

A German study investigated the impact of chemotherapy treatment on levels of vaccine antibodies before, during and after chemotherapy (Reinhardt et al., 2003). The authors recommended the re-vaccination of children 3 to 5 months after the cessation of chemotherapy, although they also observed that re-vaccination failed in some children. They suggested that these children may have a decreased reactivity to vaccination, indicating they would remain vulnerable to diseases such as measles and chicken pox. Accordingly, these children are forced to rely on high population immunity to offer them protection.

Reviewing the literature suggests that little is known about parents' experiences or the problems they face integrating their child back into society post-chemotherapy treatment. I decided to carry out two focus groups with parents whose children had recently recovered from cancer to explore their experiences of caring for a child with a compromised immune system. In particular, I hoped to explore some of the issues parents encountered in trying to protect and integrate their children back into mainstream society at a time when MMR uptake rates were well below the 95% target level required to sustain population immunity.

The main criterion for inclusion was that participants' children had completed their chemotherapy treatment for cancer within the past four years and were considered to be fully recovered, or in remission from cancer. At this stage I did not think the age of the child was particularly relevant, and participants with children under the age of sixteen years old were eligible to take part in the focus groups. However analysis did suggest that the age of the child was important particularly in relation to the problems they encountered when trying to re-integrate their children back into their normal lives, as will

be discussed in the chapter. Similar to the groups conducted with parents of autistic children, the sensitive subject matter and the need to ensure that each participant would have enough time to speak about their experiences meant that the groups were kept small, with three participants in each. In the event, all six participants gave lengthy, extremely poignant and highly personal accounts of their experience of living with a child with cancer. Although all of their discussions were interesting, for the purposes of this chapter I have focused on the most relevant aspects to immunisation. These aspects are: participants' views on the MMR controversy; their accounts of trying to protect their vulnerable child from infections and diseases; the issues they encountered trying to re-integrate their child back into mainstream society; and how they think the problems they encountered could be overcome.

6.4.1 *Views on the MMR controversy*

The groups were asked what they thought about the MMR vaccine and the debate surrounding its use. These participants were unconvinced of a causal link between MMR and autism based on the current evidence, but felt wary of reassurances from politicians and stories in the media as they thought these sources were often biased and inaccurate. In particular, they were anxious to highlight the fact that their children's needs had not been mentioned in anything they had read or heard about MMR. For example, Pamela, a mother of three whose youngest daughter developed leukaemia four years earlier when she was four years old, believed that her daughter's needs had not been considered. She stated:

I don't know, in all the recent talk to do with MMR, I don't remember hearing very much about if you didn't get your child vaccinated, you know, the problems it can be for other people. It was all about the children with autism, you know...

Cancer Support Group; Pamela aged 42

Likewise, Sally, a mother of three whose son had developed leukaemia and had a bone marrow transplant at six-years-old, agreed and questioned:

...I mean it is such a major issue. Why is it never been... I mean you see an advert on the TV or something, you know, 'get your child immunised'. I mean there was a lot o' adverts at the time when there was a big hype about it. I mean there should have been part of that saying 'if you don't get your child immunised, this is what they'll be like, they'll have... they'll be ill for a few days but this could stem onto all these people in all different walks of life and ages'. You know, you're gonna infect all them and possibly kill half o' them as well just because you chose not to have your child immunised.

Cancer Support Group; Sally aged 45

Similarly the participants in the Out-Patient Cancer Group also considered that the needs of their children were not considered when parents make decisions about the MMR vaccine. Jessie, a mother of three whose son developed leukaemia three years earlier when he was thirteen years of age, seemed more sympathetic to the situation that parents with autistic children face. She spoke about relating to these parents' need to search for answers about the cause of their child's autism. She felt that she, too, had done this when her son was first diagnosed with cancer, and that this was a 'normal' response. However, she also suggested that the general population should be given more balanced information so that they know about the needs of other more vulnerable children.

...You know, I know it's difficult for people making the decision, but you do see it differently when your own child's... in this kind of thing... affected. When you know other people could protect, could do something to help yours and they're openly going against the advice.

Out-Patient Cancer Group; Jessie aged 53

Cara, a mother of two whose daughter developed leukaemia when she was four, also spoke about feeling upset with parents who were opting not to immunise their children with MMR. She believed that the benefits of MMR immunisation outweigh the small risks of any side effects, and summed up immunisation as: "...there for the greater good of the health of the nation..." (Out-Patient Cancer Group; Cara aged 36). Jill, a mother of three whose sixteen-year-old daughter had just completed chemotherapy treatment for Non-Hodgkins Lymphoma, was also less sympathetic. She suggested that immunisation should be compulsory, but then seemed to backtrack slightly by stating that she was only

taking such an extreme stance because of her experiences with her daughter (Out-Patient Cancer Group; Jill aged 38).

Participants were asked to elaborate on their experiences of caring for a child with cancer. One of the problems they highlighted was that in their experience most other parents were oblivious to the fact that children with cancer are vulnerable to infections and diseases, and that these diseases could be life-threatening to their children. This meant that, in relation to the MMR debate, these participants had on occasion to listen to other parents speaking about the rights of parents to choose not to immunise their children with MMR. For example, Cara spoke about a conversation with a parent who was adamant she would not have her child immunised with MMR. She recalled the conversation:

...Em, one of my friends is adamant. I mean I didnae fall out with her about it but I just didnae say anything, inside I could feel myself getting kinda angry cos her view is, 'well I'm no risking ma child having the MMR, em, in case there's any adverse reaction' and I said 'Well, that means that, you know, you could be contributing to an outbreak of measles or mumps or whatever, if she's not protected, if everybody thought like that, we'd be back to where we were years ago'. And her attitude was, 'well, you know, you look out for number one, your own family, I don't really care about other people's kids', even though it was going to affect Emma (Cara's daughter) and it was... I could feel my hands... (wringing them in anger).

Out-Patient Cancer Group; Cara aged 36

Later Cara mentioned that she has not spoken to this woman since. Although Cara spoke about being aware that parents make decisions about immunisation on the basis of doing what is best for their own child, she felt frustrated by some parents' lack of sensitivity to her daughter's predicament. This frustration may have been exacerbated by the fact that she, like all the other participants who took part in these two groups, had played their part in contributing to population immunity when they had had the choice (all their children were fully immunised). However, it was also very evident that the problem of people being insensitive to or ignorant of the needs of their children on post-chemotherapy treatment went beyond any issues arising from the MMR debate. Indeed, for these participants the fear of their children contracting infections or diseases was something they spoke about with a real sense of foreboding, particularly in relation to chickenpox.

6.4.2 The experience of protecting immuno-compromised children from contracting diseases

One of the most important and relevant aspects of these discussions was participants' experiences of protecting their immuno-compromised children from contracting infectious diseases. Unprompted, participants reflected back on some of the practical ways that they had tried to protect their children from coming into contact with diseases or infections during the time that their children were most vulnerable. For example, the Cancer Support Group spoke about the fact that they had completely stopped allowing visitors to the house. Sally stated that she had no visitors for more than two years, during and in the months following her son's bone marrow transplant and intensive chemotherapy regime. Likewise, Pamela stated that to avoid her daughter contracting a disease or infection she would have "...locked Nicola in a room for two years I would have, you know?" (Cancer Support Group; Pamela aged 42). Jill described this period when her child was on treatment and particularly vulnerable to infections as 'mind-blowing' (Out-Patient Cancer Group; Jill aged 38). Cara recalled: "...everything just stopped for me, social life, everything stopped" (Out-Patient Cancer Group; Cara aged 36). Participants in the Cancer Support Group spoke about some of the emotions they experienced during this period when a key objective was to protect their child from infectious diseases and infections. For example, Sally recalled her experience to Rebecca, a mother of four whose eight-year-old daughter was diagnosed with a tumour when she was four.

Sally: I was petrified, yes. Well, I mean it's potentially life-threatening. I mean you're not... there's nothing we can do for the cancer... I mean OK, the leukaemia is life-threatening and I just had to trust that they gave him and did everything that could to help that and I had no control over that, but I did have control over people coming with any kind o'diseases or ...

Rebecca: Infections.

Sally: Yeah. You know, and I mean imagine him fighting the leukaemia, getting through that and because somebody came to my house with something that I allowed them in and... and he died. Because of that, you would never forgive yourself, especially knowing how dangerous it was, so I just felt it was easier to say to people 'please don't come' and everybody respected that.

Rebecca: I think in a sense, really, you know so much, but because you're not medical and you're just a parent, you know, you take the information that they get and you can't really decipher it, you know, you can't think... OK, I think that's maybe OK, but maybe it'll not be quite OK, you actually just take a more a blanket view on it, don't you? And you think... right, I just know that that's potentially dangerous, I'm not quite sure whether it's here, here or here, or what exactly that means, so I'm just gonna take the whole thing...

Cancer Support Group: Sally aged 45; Rebecca aged 49

Rebecca's comment that parents take a 'blanket view' that all infections and diseases should be avoided is supported by the fact that all six participants decided to isolate their children completely from having contact with people outside the family. However, both groups also went on to identify measles and chickenpox as being diseases that they felt particularly concerned about. Jill stated that just hearing the word 'chickenpox' made her panic. She also mentioned the fact that her job as a schoolteacher brought her into contact with lots of children and that she continuously worried about transmitting a disease to her daughter when her daughter was neutropenic (Out-Patient Cancer Group; Jill aged 38). Likewise Pamela recalled an incident in which she found out that her daughter may have come into contact with someone with measles:

When Nicola was at nursery, the nursery again was like Sara's, very good, and they sent notices out to all the parents and the same when Nicola went to school as well. They were excellent. But when Nicola was at nursery, I got a phone call one day to say that somebody had phoned in to say their child had measles and it had just been confirmed by the doctor it was measles and I was straight up, you know, took Nicola out and we were straight into Sick Kid's to get a jag and I remember cursing the parents of the child for not having their child immunised, but it turned out they had had them immunised and it was just, you know, it's no guarantee they're not gonna get it, they were just unlucky. Well, unlucky for us.

Cancer Support Group: Pamela aged 42

As Pamela spoke about rushing Nicola up to the hospital she looked anxious and patted her heart as if indicating to the other participants that her heart was pounding. Both Sally and Rebecca nodded their heads indicating empathy with Pamela's predicament.

6.4.3 The challenge of re-integrating immuno-compromised children back into society

Although participants deemed the protective action of isolating their child as necessary during and immediately following intensive chemotherapy, they also spoke about finding it difficult to relinquish this protection. Participants spoke at length about finding this period of adjustment very difficult and about it creating new anxieties. The main challenge participants identified was that as their children began to feel better and wanted to participate more in usual everyday activities, this increased contact with people and also increased their likelihood of contracting an infection or disease. During this period, participants spoke about the difficulty of making sound judgments about how contagious the different diseases were, and of assessing the suitability of some activities that their children wished to partake in. For example, Sally recalled her experience of her son first being discharged from hospital after completing an intensive course of chemotherapy:

You just want to sit at your child's bedside and protect them. ... You know... I mean as I say, we were in for seven month, so going out wasnae a problem, but they were only coming in for a couple of days treatment and then going home or sometimes even a couple o' hours treatment and going home and you did have to think about these things, and to be told 'oh don't go in enclosed places, em... stay away fae chickenpox' and you go home, you think 'what did they mean by that?', em, you know, and 'did they mention such and such?' or 'I hear that somebody's child up the road's got such and such, do you think that would be harmful?...' And you dinnae want to phone the hospital, you dinnae want to be a pest and... you say what do I do about it?...

Cancer Support Group: Sally aged 45

Both groups identified that for quite long periods of time they avoided taking their children near large groups of people, or to enclosed areas with air conditioning. Cara mentioned that she stopped going out altogether. For example, she stopped going to the supermarket, to restaurants, to activities such as swimming with her younger son, and took a year off her work to stay at home with her daughter. Looking back, she stated: "...I just stopped taking any risks at all, em, and I didnae really notice at the time because you're still kinda in shock in the beginning but now, I realise how much more we're doing now". She later stated: "You know, you feel as though you're kind of out on a limb, but now we're coming, or I'm coming back in again" (Out-Patient Cancer Group; Cara aged 36).

Participants were asked whether they found people understanding and helpful when they were trying to re-introduce their child back into mainstream society. Both groups mentioned that generally other parents, school teachers and nursery teachers were sympathetic and tried to cooperate with them. However, there was one exception. Sally recounted her experience of her son Robert returning to school following a period of time during which he was educated by a tutor at home. She described the headmaster as 'horrible,' 'ignorant,' and 'uncooperative'. The main problem was that the headmaster at her son's school would not accept the fact that following Robert's bone marrow transplant and chemotherapy he was more vulnerable to the side effects of diseases such as chickenpox. As such, he refused permission to have letters distributed to other parents asking them to notify the school should their child have chickenpox, to enable Sally to seek medical advice for her son. She recalled:

Well, I tried to explain to him, you know, 'this is life-threatening to my son', especially when he first went back, em... but he just would not take it on board. He says 'no, I have never heard of it, it's utter nonsense' and it didn't matter what I said to him, you know? I mean a couple of years later when I did meet him one day and I said, you know, 'it was alright for you not to know about that, but it wasn't alright for you not to want to know'. You know, he didn't want to know. It was just... you know, 'go away, you're a paranoid mother' and that's the way he looked at it. And Robert did take shingles and he was very very ill. He had to go on ... go on a drip. He had to go on the drip and things, he was very ill. It was right round his waist. And then he took it a second time a few months later.

She later went on to state that eventually she took control and began informing parents herself, and involved the hospital liaison nurse.

By the time we got the liaison nurse down it was after Robert had had shingles twice, you know, and we were like demented because we thought how many more times is he gonna get... and this headmaster still wouldn't inform the parents and so by the time... that took months to get all sorted out. She came down, we all went into a meeting and I thought 'thank God, at last we're gonna get this sorted out' and the headmaster said 'is Robert at risk?' and she said 'well, this far on, no, not really'. And that was it because by this time he was... oh, he was months, months after his treatment and he'd been given the okay that his immune system could cope. About eight months I think. Wasn't as much as a year, I'd say about eight months. Even still you don't feel sure...and you worry.

Cancer Support Group; Sally aged 45

Sally's experience was in stark contrast to the experience of the other participants. They had found their liaison nurses to be highly involved in the process of educating both teachers and parents, and had found teachers and parents to be extremely receptive to assisting them in any way they could. Nevertheless, Sally's experience unintentionally highlighted another important aspect mentioned by other participants. Namely, that even after they were told by their child's paediatric oncologist that their son or daughter's immune system would be able to cope with infections and diseases, parents continued to feel concerned about the risks posed by diseases. Indeed, all of the participants identified that they still felt anxious about their children contracting a childhood infectious disease. For example, Cara illustrated the point by recalling an event that had happened that day.

...Emma had spots on her legs tonight, I turned round and looked at her in the car, she had spots all down her thighs and then her forearms but they were wee tiny spots and I said (spoken in a loud panicky voice) 'What's that on your arm? Why have you got all those spots?' and she says 'I don't know, didn't have them' she's kind of looking about and she said 'Do you think it's chickenpox?'. So it's been on her mind as well although we don't talk about it often. And I said 'No, I don't think it is, what were you doing at Calum's?' 'We were just playing oot'. I said 'Were you in bushes?' 'Yeah, I was because the wall went in' and I thought, well it's just like a wee prickly rash and it went away after about an hour I checked, I didn't want to make a big fuss. I thought, I'm not having her panicking cos of me, because that would be the question she would ask then is, 'Do I have to go up to the hospital?' She still thinks that's what going to happen when she's ill.

Out-Patient Cancer Group; Cara aged 36

Although Cara knew her daughter was fully recovered from leukaemia, she seemed less sure about how well her immune system would cope with fighting an infection or disease. This fear may have stemmed from the fact that all the participants spoke about feeling unsure of their child's immune status, post chemotherapy. The participants seemed unsure to what extent the chemotherapy had destroyed their child's immunity gained from immunisation, or if they were to be re-vaccinated against these diseases at a later date. This ambiguity may explain why participants continued to feel anxious about these diseases, despite feeling confident about the cancer.

Another factor that seemed to affect the experience of re-integration seemed to be the age of the child. For example, Jill felt that her sixteen-year-old daughter, Laura, was able to

detect potentially hazardous situations and diseases herself. Jill stated that this helped her enormously when Laura first returned to school (Out-Patient Support Group; Jill aged 38). In contrast, Pamela, Cara and Rebecca all spoke about the difficulties they faced in trying to re-introduce their young children back into nursery. They identified two main problems. Firstly, the increased incidence of chickenpox amongst very young children made it difficult to find a time when it was safe to let their children return to nursery. This was especially difficult during the winter months when chickenpox prevalence rates are generally higher. Secondly, participants felt more anxious because their children were wholly reliant on others, being too young to detect potential signs of infection themselves. Both these problems meant that all their children missed out most of their pre-school year at nursery and some of their early years at school.

6.4.4 Educating people about the needs of immuno-compromised children

Both groups considered that people generally underestimate the severity of childhood infectious diseases and are unaware of the damage these diseases can do to immuno-compromised children. For instance, in the case of chickenpox Rebecca considered:

Rebecca: ...I think people actually even kids who have it, and you can see them maybe out and about in the community and clearly they're still infectious because you can see the spots are not scabbed over or whatever.

Sally: That's right. But all they're thinking about is 'och, my poor wee boy, he's been in his bed for three days, he needs to get out and get some fresh air, granny said it' but I mean, you know, infecting all our kids that potentially is life-threatening.

Rebecca: People I think are ignorant actually. People generally don't know that people with diseases are dangerous... I mean not just to cancer, but other diseases actually lower your immune system and you're more susceptible to catching it.

Sally: I wouldnae have thought about it years and years ago. I wouldn't have thought about it.

Facilitator: Why do you think people are ignorant about it?

Sally: I don't think there's enough... I mean, have you ever read anything anywhere, publicly, that says if your child has a disease... you know, stay indoors, you know, or please think if you ever have any disease about children who... or anybody wi' a low immune... I mean you don't think o' things like that and unless somebody tells you, you're no gonnae work it out yourself...

Cancer Support Group; Rebecca aged 49; Sally aged 45

In light of these comments, and in view of the fact that participants had found that other parents were keen to co-operate once they were made aware of the situation, they suggested that there is a need for a poster and leaflet campaign every couple of years. They also suggested that general practitioners and health visitors could play a more prominent role in educating parents by using immunisation clinics and consultations about childhood infectious diseases to highlight the needs of immuno-compromised children. Cara also believed there was a need to educate parents more generally about children with cancer. She mentioned that she had overheard a conversation in which another parent was telling their child to keep away from her daughter, whose appearance had been altered by chemotherapy, in case they contracted an illness from her. She stated: "...they see the kids with, you know, wi' no hair and looking bloated or looking really... looking ill, it's like, you know, 'Steer clear of them or you'll catch something' although it's the other way round" (Out-Patient Support Group; Cara aged 36).

6.5 Discussion of the findings

In relation to the MMR controversy parents of immuno-compromised children were keen to highlight that the needs of their children had been overshadowed by debates on the rights of parents to have choices about immunisation. Despite participants showing some sympathy for parents who feel their child's autism may have been caused by the MMR vaccine, they felt concerned that more generally parents who decide to withhold the MMR vaccine from their children are unaware that their actions put other children's health at risk. During the process of integrating their child back into their daily routines participants had generally found other parents to be ignorant of the fact that their children were more susceptible to contracting infections and diseases post-chemotherapy. They suggested that there was a need to educate parents so that they can make informed decisions about immunisation taking account of the fact that their decisions may affect other children. Both groups suggested that future immunisation campaigns should emphasise the role that population immunity plays in protecting the more vulnerable

members of society who are unable to protect themselves. However, participants also acknowledged the limitations of such campaigns in an increasingly choice-driven society where some parents will choose to opt out of any immunisation if there is doubt over its safety, and thus opt out of a public health intervention which is intended to benefit the wider population. In these circumstances participants recognised that parents had the right to decide to opt out, in favour of pursuing a more parent-centered approach to protect their own individual children. However, they suggested that they should only do so after considering the wider implications of their decisions. This is not the case at present.

In the initial period following their child's return home after intensive chemotherapy, participants described taking a blanket approach to avoiding all infections and diseases by isolating their child in the house, including isolating them from contact with people outside the family. However, as their child began to recover and gained the strength and desire to re-join their normal activities, participants described facing several difficulties. It was noted that the experience of re-integration raised different problems depending on the age of the child. In relation to avoiding infections and diseases older children were considered to be better able to protect themselves, as they were able to detect and avoid potentially hazardous situations and diseases themselves. However, participants with younger children attending nursery and primary school spoke about the difficulties they faced trying to re-introduce their younger children into nursery and school. They suggested that the increased incidence of chickenpox amongst this age group and, the fact that, in the days before the first spots appear apparently healthy children are infectious make it impossible for parents to detect and the children are too young to detect signs of infection themselves. The fact that chickenpox can be life-threatening to these children made it difficult to re-introduce their children into their nursery or primary schools, and thus they had missed long period of schooling.

It seemed that another difficulty they were implying was that it was difficult to assess how contagious and severe different diseases were, and to assess when to seek medical

advice. In part, a general lack of knowledge about the severity and modes of transmission of diseases may explain this. However, participants also mentioned that they were unsure how well their children's immune systems would cope with fighting an infectious disease, even when their child had long completed chemotherapy and recovered from cancer. None of the participants knew their children's immune status to vaccine preventable diseases, and they continued to feel anxious about these diseases long after feeling reassured about the cancer. These anxieties suggest that there is a need for parents to receive greater reassurance and information about the long-term implications of having undergone chemotherapy in relation to their child's vulnerability to childhood infectious diseases.

6.6 Conclusion

This exploratory work on parents caring for autistic children or immuno-compromised children was intended to identify how the MMR controversy had impacted on their lives. At the outset this work was speculative and the small number of groups conducted reflects this. However, the fact at the time of writing up this chapter almost seven years had passed since Wakefield's paper was published and no studies have been published considering either group of parents' views illustrates how limited the focus has been to date. It is clear that there is a need for research with both groups of parents. In particular this research highlighted some of the problems faced by parents trying to integrate their child back into mainstream society because people often underestimated how devastating diseases might be to their child. But perhaps the most overlooked aspect of the debate has been the views of parents with autistic children. There is an urgent need for a larger exploratory study to investigate how parents caring for autistic children have been affected by the debate, for without hearing the stories of these parents how can the full extent of the MMR controversy truly be assessed and appreciated.

Chapter Seven: Conclusion

This study aimed to examine how parents have conceptualised the MMR controversy and to explore parental immunisation behaviours, in order to provide an assessment of parents' perceptions about childhood immunisation. A thorough review of the literature was conducted to ascertain what work had been done in this area and to provide the context for this study. This review critically examined the scientific evidence and events leading up to, and following, the publication of Wakefield and colleagues' 1998 paper. The review examined the impact that the long-running controversy about the safety of the MMR vaccine has had on parents and reviewed studies on vaccine decision-making behaviour. From this, several gaps in the literature were identified and research questions were developed to address these gaps. This chapter revisits and answers these questions. It is divided into three parts. The first part reflects on the study and on the exploratory approach used which allowed me to uncover new ideas and novel insights into parents' perceptions about childhood immunisation. The second part answers the study's research questions by highlighting the main findings from this study and by comparing them to the findings from other studies. The final part sets out key implications and recommendations from this research, and suggests a plan for the dissemination of these findings.

7.1 Part One: Reflections on the study

A great strength of this study has been that it provides a much broader assessment of parents' perceptions about childhood immunisation than previously available. For example, by comparing parents' understanding and experience of the diseases covered by the childhood immunisation programme with their beliefs about the importance of preventing these diseases, a greater understanding has been gained about parents' immunisation behaviours. Similarly, exploring parents' views on the different roles people and key agencies have played in the MMR controversy allows lessons to be highlighted that may be important for shaping future immunisation policy and practice. These findings are considered later in the chapter. Another strength of this study was that

it included a diverse range of parents. This included parents from varied socio-economic backgrounds and with different levels of experience of parenting, including first-time parents and more experienced parents. The study also included parents with different views on immunisation and with different vaccine decision-making histories. One of the most original aspects of this study is that for the first time the MMR controversy has been considered from the perspectives of parents caring for autistic children and immuno-compromised children. To date both these groups of parents have been marginalised from the debate about vaccine safety and their stories offer new and important perspectives. I would argue that the wide range of topics considered and the diversity of the parents included sets this study apart from other studies and creates new opportunities for understanding and learning lessons about the MMR controversy and about immunisation more generally.

However this PhD study was not without problems. In addition to the methodological limitations discussed in Chapter Two, I also faced the problem that this research was being carried out concurrently with the public debate about the safety of the MMR vaccine. This meant that I had to keep abreast of new developments and newly published findings to ensure the continuing relevance of the study. For instance, the focus of this research was determined by the fact that when I began this study in December 2001, there was very little exploratory work published which explored the perspectives of parents. This gap has recently begun to be addressed (Raithatha et al., 2003; Smailbegovic et al., 2003 and McMurray et al., 2004). Another problem facing this study was the possibility that major policy changes might be introduced (such as the single measles, mumps or rubella vaccine being introduced), or that new media revelations could inflame, or even extinguish the debate. Indeed perhaps the greatest achievement of this study is that it seems more relevant now, three years on, as the scientific community begins to reflect on the lessons that can be learnt from the MMR controversy. Indeed, in this respect it is anticipated that this study has the potential to make a genuine and original contribution to future research, practice and policy on childhood immunisation in the UK.

7.2 Part Two: Answering the study's research questions

The first research question which I sought to answer was:

7.2.1 What are parents' knowledge, understanding and beliefs about childhood infectious diseases, and how do their experiences of disease affect their evaluations of the importance of preventing these diseases?

The literature on vaccine decision-making suggests that when parents decide whether to vaccinate their children, they do so by weighing up the risks associated with the diseases against those associated with the vaccines (Raithatha et al., 2003). However, I found no studies that provided an in-depth assessment of parents' knowledge about vaccine-preventable diseases. Further, the few studies to examine parents' understandings and beliefs about childhood diseases in any detail have tended to focus on perceptions about the severity of diseases, and often report contradictory findings. For example, Flynn and Ogden (2004), Pareek and Pattison (2000) and Smailbegovic et al. (2003) found measles to be considered as 'severe' or 'serious', while participants in other studies assessed it as 'mild' or 'less serious' (Gellin et al., 2000; Bond and Nolan, 1998; Sporton et al., 2001). Similarly mumps and rubella have been reported as both 'serious' (Flynn and Ogden, 2004; Pareek and Pattison, 2000) and 'mild' (Bond and Nolan, 1998; Sporton et al., 2001) and no studies have considered parents' views on haemophilus influenza. One further limitation of these studies is that they tend to offer a one-dimensional account of parents' assessments of the diseases, without any explanation of the underlying beliefs that may have informed these assessments.

In contrast, my study offers a much more comprehensive picture, exploring parents' knowledge, beliefs and experience about each of the vaccine-preventable diseases included in the programme. This research found that parents' knowledge about vaccine-preventable diseases was limited. Parents often had serious misunderstandings about the mode of transmission, severity and prevalence of diseases and this limited their ability to

make informed decisions about vaccination. Mumps infection was widely associated with male infertility, tetanus was confused with rabies, and diphtheria was confused with cholera-like illness. Parents' knowledge about meningococcal disease and its associated meningitis was the exception, as parents described the signs and symptoms and potential consequences of this disease accurately. Similar to the findings of Bond and Nolan (1998), this research found that parents assessed meningococcal disease and its associated meningitis as the most severe and life-threatening of all the diseases they were asked to consider. Parents associated meningitis with the potential to cause death or long-term damage to their child's health, even though no parents had had direct experience of meningococcal disease either themselves, or as a parent.

So why was meningococcal disease perceived to be the most severe by parents in this study? Two reasons were identified: firstly, the popular media's interest in meningitis and other parents' harrowing stories about children dying or being left with long-term damage from meningitis together contributed to parents' views of this disease as a major and tangible threat to their child's health. Secondly, this view was reinforced by the high profile Men C campaign. The campaign seemed to signal to parents that the 'experts' were particularly concerned about the threat posed by this disease. The Men C poster campaign appeared to have been particularly successful, as parents described seeing it in their GPs' surgeries. The cumulative effect of the media's involvement, other parents' stories and the Men C campaign was that most parents concluded that it was important to protect their children with the Men C vaccine.

A compelling reason why haemophilus influenza might be perceived as a threat to a child's health is that it, too, can cause meningitis. However, in contrast to parents' concerns about meningococcal disease, most parents knew very little about haemophilus influenza and, on the basis of its name, often guessed that the disease was related to the flu, and that the Hib vaccine was a flu vaccine. In turn this led to concerns being raised that children are becoming vaccinated against mild infections. Although these misunderstandings could be addressed in the debriefing sessions that followed the focus

groups, it was interesting to observe how parents constructed descriptions and what they considered to be plausible explanations for diseases they knew little about.

The lack of knowledge about haemophilus influenza led some parents to underestimate the threat posed by it. In contrast, other parents overestimated the extent to which they could control the threat posed by other diseases. For example, the fact that tetanus cannot be eradicated because it exists in the soil and therefore poses a constant threat makes it unrealistic for parents to protect their children by limiting contact with the source of this infection. Many parents thought that a child would be most likely to contract tetanus from rusty nails and dog bites which they believed very young children would be unlikely to encounter. Further, the fact some parents knew they could seek tetanus vaccination post- infection appeared to diminish any sense of urgency or need for tetanus vaccination as a prophylactic measure. Similarly, some parents questioned the need for very young children to have rubella vaccination, believing that they could prevent its transmission to pregnant women by isolating any infected child. However, this belief fails to recognise the fact that the signs and symptoms of rubella infection are often mild and inconspicuous, making its transmission difficult to contain effectively without the mass immunisation of young children who are often in close contact with pregnant women.

This research also found that parents had little direct experience of most of the diseases prevented by the immunisation programme. Bedford and Elliman (2000) have proposed that, because many parents have little or no experience of the diseases prevented by immunisation, they do not appreciate how damaging these diseases can be. This study supports Bedford and Elliman's observation and suggests that as parents become less familiar with the diseases and, more importantly, less knowledgeable about them, growing numbers of parents are questioning the need for so many vaccines to be included in the Childhood Immunisation Programme. However, the association between personal experience of the disease and subsequent assessment of the importance of preventing it appears complex. Even parents who have experienced diseases such as measles, mumps, rubella and whooping cough often underestimated their severity. This may be because they felt that modern medicine is now so advanced that serious complications of these

diseases can be treated, or because they feel less daunted by the prospect of their children encountering it having successfully fought off the disease themselves. In fact not only did this research find that experiencing a disease themselves (either as a parents caring for a child or as a child themselves) does not necessarily make that disease more threatening, but it also found that hearing second or even third-hand accounts of stories of other children suffering serious complications was often a more frightening prospect. For this reason although no participants had experienced meningococcal disease themselves, stories of other people's children having long-term damage from meningitis meant parents feared their own child contracting it.

Parents seemed to find other parents' anecdotal evidence and personal stories very persuasive. This may be one of the reasons why parents appear to have had such difficulty in assessing the threat posed by measles, mumps and rubella compared to that posed by the MMR vaccine. On the one hand, parents have read and listened to stories of seemingly-well children becoming autistic after receiving MMR vaccination, whilst on the other, they have read or been told of children developing long-term damage from contracting measles infection. The point here is that anecdotal evidence is extremely persuasive and is capable of swaying parents in a way scientific evidence often seems powerless to do. Perhaps this is one of the reasons why Wakefield's research was so amenable to translation by journalists into stories that ordinary parents could relate to, and why it had an appeal and impact disproportionate to the weight of scientific evidence presented by the study. Indeed, as more parents currently assessing the importance of preventing diseases have less and less experience of those diseases it is likely that their views will rely more heavily on the stories, including the 'horror stories', of other parents and media reports. The challenge facing health educators is that they need to find a way to educate parents about diseases in a responsible and persuasive way.

The second major research question was:

7.2.2 What are parents' views of mass childhood immunisation and of the vaccines included in the Childhood Immunisation Programme in the light of the MMR controversy?

The public's reaction to the MMR debate should be viewed in a broader historical context. The MMR controversy followed the foot and mouth crisis, the BSE crisis and scares caused by salmonella and *Escherichia coli* 0157 food poisoning in which the Government and Government agencies responsible for food safety were perceived to have put the interests of food producers before those of consumers. More recently, the public have witnessed debates over the safety of genetically modified food. This growing distrust of Government in safeguarding public health is the backdrop against which parents have assessed the MMR controversy. One of the most important lessons to be drawn from the MMR controversy is that the public find it difficult to know who to trust to offer balanced and accurate information on which they can make sound judgments. As such the publication and subsequent publicity surrounding Wakefield's paper provoked immediate anxiety among parents, leading to a decreased MMR uptake which remains well below the ideal 95% target rate (Wakefield et al. 1998). The consequences have been a rise in the incidence of mumps since the late 1990s and clusters of measles cases. It is possible both may grow if greater numbers of children remain unvaccinated.

Like many medical interventions, vaccination is not entirely free from risk. Usually any adverse reactions are minor, although they may be more severe in a minority of cases. The publication of Wakefield's paper provoked considerable anxiety among parents, leading to a decreased MMR uptake which remains well below the 95% target rate (Wakefield et al. 1998). Indeed, there has been a dramatic rise in the incidence of mumps since the late 1990s and there is likely to be a growing number of measles cases in the next few years as greater numbers of children remain unvaccinated with MMR. Like many medical interventions, vaccination is not entirely free from risk. Usually any adverse reactions are minor, although they may be more severe in a minority of cases.

This study found that parents are tending to focus attention on the more serious and long-term consequences perceived to be associated with immunisation and supports, to an extent, Raithatha et al.'s (2003) claim that the MMR vaccine scare may have triggered a wider reappraisal of vaccine risk. However, it is clear from the literature review (Chapter One) that parental concerns about the safety of vaccines pre-date the publication of Wakefield's controversial paper (Lambert and Siegrist, 1997), and that they are neither confined to the UK (Offit et al., 2002) nor to the MMR vaccine (Bond and Nolan, 1998). In this respect, there is a limit to which Wakefield's paper can take responsibility for claims of a vaccine reappraisal by parents. Perhaps a fairer assessment of the situation is that the MMR controversy appears to have added to parents' growing concerns that too many vaccines could do more harm than good, and Wakefield has offered parents a plausible explanation for their fears. Indeed, it is arguable whether Wakefield's paper would have been able to create the uncertainty it did had better attempts been made to educate the public about the diseases prevented by vaccines, and about the benefits and safety of combined vaccines. Nevertheless, Wakefield's comments at his press conference and subsequently about splitting the MMR into three separate vaccines undoubtedly added to parents' concerns. What parents seemed to have understood from Wakefield's statement was that some children could be more vulnerable to immune damage from vaccines, of whom those who later manifested autistic syndromes could be one example. Unfortunately, no research has been published to date that focuses on these concerns of parents, so there is little to compare these findings with although Miller et al.'s (2003) study has been useful in refuting Wakefield's claims of immune overload. My research suggests that parents were struggling to identify other signs that their child might be amongst a group of potentially vulnerable children; children with asthma, multiple allergies and recurrent infection were all thought to be potentially more susceptible to immune damage from vaccines. Parents whose children had any of these conditions seemed to have had a particularly difficult time making the decision about MMR vaccination. However, it was also evident that parents were inconsistent in their thinking about combined vaccines, as they almost exclusively focused these concerns on the MMR vaccine and seldom on the combined DTP vaccine. Nevertheless, if these concerns extend to the new pentavalent vaccine (introduced into the Childhood

Immunisation Programme in September 2004), or if any side-effects from the new vaccine are perceived to exist, this research suggests that parents may defer or refuse vaccination as they have done when the safety of the pertussis vaccine and MMR vaccine has been in dispute.

Both mumps and rubella vaccination were found to be strongly gendered; the mumps component of the MMR vaccine was viewed as irrelevant for girls and the rubella component as irrelevant for boys. Current health education materials aim to persuade parents that immunisation is in their own child's best interest by concentrating messages on individual risk. The main problem with this approach is that it unwittingly sends out mixed messages which add to a sense of mistrust and confusion. If most parents believe that mumps was introduced into the programme to reduce the risk of male sterility and parents are being told that seeking immunisation is in their own child's best interest, parents of girls may conclude that policy makers have overlooked their daughter's needs. Focusing so much attention on individual risk to the exclusion of community risk distorts the actual risk, alienating some parents and adding to a growing sense that blanket policies are responsible for children becoming over-immunised. Although research suggests that parents make decisions on the basis of their own individual child, rather than being motivated to immunise for the benefit of others (Hershey et al., 1994), it seems possible that confused messages about immunisation hinder parents' decisions. There is a need for greater transparency in health education material and immunisation campaigns about who benefits from immunisation. For instance, tetanus is not a communicable disease and therefore in the UK tetanus vaccination largely benefits the individual child. By contrast, rubella is a mild disease for most children and rubella vaccination of children largely provides protection for the babies of pregnant women from developing congenital abnormalities associated with rubella infection. Whilst immunising pre-pubertal girls will protect any future pregnancies of their own in the future, immunising boys is largely for the benefit of others (including, of course, their own future children). As such, boys play an equally important role in reducing the spread of rubella infection.

Parents who choose not to immunise their children were more concerned about unknown, long-term side-effects of the vaccines than about the diseases, and many believed that vaccines place stress on the immune system rather than strengthening it. These findings are consistent with those of Bond et al. (1998). Some of these parents who subscribed to alternative health care beliefs and choose not to immunise at all considered mass immunisation to be an out-dated public health intervention in the face of low disease threat. These parents were ideologically anti-immunisation. Indeed, it is questionable how successful any attempts might be to persuade these parents of the benefits of immunisation. Nevertheless, the current system that places the emphasis on the individual child seems particularly problematic and unlikely to encourage them to immunise. Any more effective approach would have to embrace a more holistic stance that places greater emphasis on the importance of community benefits and on reducing the spread of disease to more vulnerable members of society. In this respect, Hunt and Emslie's (2001) argument for acknowledging the prevention paradox more directly in health education materials may offer one means of making vaccination campaigns more open and acceptable.

The third major research question I sought to answer was:

7.2.3 What are parents' perceptions about the current MMR controversy and how do these perceptions translate into the parental decision-making process about whether to immunise, or not?

This question is answered by considering parents' perceptions about the MMR controversy, including the perceptions of parents caring for autistic children and those caring for immuno-compromised children, and by considering parents' experiences and views on MMR decision-making.

7.2.3.1 Parents' perceptions about the MMR controversy

Parents generally viewed Andrew Wakefield as a 'good' doctor who was revealing startling new evidence to parents. He was viewed as an 'insider' (as an NHS consultant) who was standing up to politicians and public health officials because he believed it his duty, both as a parent himself and most importantly as an advocate of autistic children. Indeed, this gave him an unrivalled standing with parents compared with the perceived hypocrisy of public health officials and politicians, exemplified by the British Prime Minister Tony Blair's refusal to let the public know his son's MMR immunisation status. However, not all the parents in this study were positive about Andrew Wakefield. Some parents considered he was a scaremonger, to blame for causing parents to lose confidence in an important public health intervention. Ironically, parents in this study, including those with autistic children who were perhaps the most affected by the debate, were less vicious in their attack and more forgiving than many of his more public opponents. Indeed, in his book Richard Horton (2004) acknowledges the often extreme reaction of Wakefield's opponents and states there was something deeply unpleasant about Wakefield's public humiliation, and about protagonists openly stating their intention to 'rub out' Wakefield (p. 13). Nevertheless, at the height of the controversy this kind of excessive reaction from opponents appeared to have been unhelpful to parents trying to make sense of the debate. This is because parents see politics and political manoeuvring taking over from the real issues, such as the need for further research into the aetiology of autism and the safety of the MMR vaccine. In effect, these political point scoring exercises marginalise parents from the debate, and in turn, they become more sceptical that their or their children's needs are considered important.

Parents in this study found that the language used by politicians and public health spokespersons to convey messages about the risks posed by the MMR vaccine did not help them assess these dangers. Elastic concepts such as 'minimal', 'probable', 'likely', and 'rare', meant different things to different people. Parents felt that politicians could use ambiguous language deliberately to mask and underplay the actual risk. In this respect parents drew parallels between the dialogue used to reassure the public about the risks posed by BSE, and MMR. Parents wanted to know how many children had a

serious adverse reaction following MMR vaccination, and how many children had had a serious complication following measles infection, so that they could weigh up the risks of MMR against the risk posed by the diseases. However parents also questioned how accurately adverse reactions are monitored and wanted more information on this.

Although parents were unsure about the link between MMR and autism, they were under the impression that there was as much evidence showing a link, as showing no link. This finding parallel Hargreaves et al.'s (2003) observation that the media coverage of MMR has given a misleading impression that the evidence 'for' a link with autism was as substantial as the evidence 'against' it. The key sources from which parents obtained information about the safety of MMR were the popular media, health professionals and other parents. However parents often questioned the motives of health professionals such as GPs and health visitors, who were viewed as maintaining the status quo on childhood immunisation policy and were held to be part of the system of dispensing it rather than questioning it. Perhaps inadvertently the MMR controversy has drawn health professionals into the debate because GPs receive payments if they meet Government vaccination targets, set at 70% and 90%. The fact that GPs and health visitors (who are often attached to GP practices) are primary providers of immunisation advice makes it difficult for parents to trust that this advice is completely impartial. This supports Sporton and Francis's (2001) finding that health visitors were not perceived as providing balanced information, and this was identified as an impediment to parental decision-making. It also explains why parents in this study were often scathing and dismissive of their health visitors' and GPs' attempts to encourage immunisation, and suggests that this incentive scheme could be potentially damaging to the patient-doctor/nurse relationship.

Issues about the rights of parents to choose dominated the single-vaccine-versus-MMR-vaccine debate, and there was an absence of any discussion about the risk of instituting an untested programme of three separate vaccines. This suggests that politicians, scientists and public health professionals have failed to communicate this fact effectively to the public. In turn, parents opted to delay or refuse immunisation altogether rather than opt

to immunise with what many perceived to be an unsafe vaccine. However, this research suggests that the Government may have been wise not to introduce the single vaccines as an alternative to the MMR vaccine, as some parents may not have protected their girls against mumps, or boys against rubella.

7.2.3.2 Parents caring for autistic children: perceptions about the MMR controversy

In December 2002, when I conducted the two focus groups with parents caring for autistic children, Wakefield had already resigned from his post at London's Royal Free Hospital and had moved to the USA to continue his work on autism. Parents in this study were anxious that Wakefield's research into the link between autism and bowel disease should continue. However, they also were keen for researchers in the UK to continue to be supported in their work in this field, and were concerned that funding might be stopped. Some of these parents with autistic children were also part of a pending legal action against the pharmaceutical companies responsible for manufacturing the MMR vaccine, and felt hopeful they would win their High Court case. However, in October 2003 the Legal Services Commission decided to remove funding for the MMR litigation on the grounds that there was a lack of evidence of a link between the MMR vaccine and autism.

The fact that no studies have been published that considers the views of parents of autistic children is an omission that needs to be addressed as a matter of urgency. Although I only had a limited number of parents' experiences to draw on, in-depth analysis of their six stories suggests that the impact has been immense. In particular parents felt guilty that they may have inadvertently caused their child's condition by agreeing to have them immunised. This guilt seemed to be increased because, with hindsight, they believed that at an early age their child displayed signs that their immune system was inadequate. Recurrent ear, eye, chest and urinary infections along with multiple allergies and asthma were described as early warning signs, that they felt should have alerted them to the possibility that their child's immune system may not have been able to cope with combined vaccines.

In this respect Wakefield's comments about the combined vaccine needing to be split into three separate parts made great sense to them. However, they failed to recognise the inconsistency in this 'immune-overload' argument since all their children had already received the triple DTP vaccine, yet they only suggested that the overload happened post-MMR vaccination. Nevertheless, in the absence of any other plausible explanation for their child's developmental regression, they seemed relieved to have someone (i.e., Wakefield) identify a possible cause of their child's condition. Perhaps for this reason these parents were positive about Wakefield and felt that he, unlike many other doctors and scientists, took their concerns seriously. Indeed, they all believed that there is a link between autism and bowel disease on the basis of their experiences with their own children. All six parents spoke of the difficulties they faced in dealing with their child's bowel and dietary problems, and that this aspect of their child's needs is often overlooked. These difficulties included incontinence, diarrhoea, constipation, and bowel pain and these aspects of their child's health often dominated their already complicated and stressful lives. The fact that these parents' children had bowel problems and that Wakefield was one of the first doctors to recognise a possible link between autism and bowel problems convinced them that he was correct in his assertion that MMR is linked to autism. However, this belief led them to feel immensely guilty that they had allowed their children to be vaccinated, and they spoke of feeling a loss almost akin to bereavement.

If anything, Dr Wakefield seemed to represent to these parents a means of obtaining answers to the complex problem that is autism, in contrast to the perceived lack of understanding and willingness on the part of the medical establishment, scientists, politicians and public health officials to offer explanations about its causes. These parents considered that they had generally been served poorly by the medical profession and as a result some had turned to alternative health care, which was often extremely expensive. However, whilst alternatives such as homeopathy and herbal remedies appeared to have offered some hope to these parents, and some spoke of seeing improvements in their child's health, these parents seemed extremely vulnerable to

exploitation. These desperate, guilt-ridden groups of parents appeared to be frantically trying to prevent any further developmental regression and convinced that vaccination had damaged their child's fragile immune system, were keen to prevent any further damage.

7.2.3.3 Parents caring for immunocompromised children: perceptions about the MMR controversy

Another group of parents completely marginalised from the MMR debate has been parents of immunocompromised children, whose children rely on herd immunity for protection. As yet, no research have been published that explore these parents' views or consider how their children's lives may have been affected by the MMR controversy. This is despite the fact that these parents have much to lose should there be an epidemic of measles. These parents were keen to highlight the fact that the needs of their children had been overshadowed by debates on the rights of parents to have choices about immunisation and they felt hugely saddened that in their experience parents tend to only take into account their own children's needs. During the process of integrating their children back into their daily routines these parents had generally found other parents to be ignorant of the fact that their children were more susceptible to contracting infections and diseases post-chemotherapy. They suggested that there was a need to educate parents so that they could make informed decisions about immunisation, while taking account of the fact that their decisions may affect other more vulnerable children. As such, they were keen that any future immunisation campaigns should emphasise the role that population immunity plays in protecting those more vulnerable members of society who are unable to protect themselves.

7.2.3.4 Parents' experiences of MMR decision-making and views on MMR

The fall in MMR vaccination uptake rates following adverse publicity about MMR safety is evidence that parents' usual patterns of immunisation decision-making behaviour were altered. This study identified two alterations to the usual patterns of behaviour that have important implications for the way vaccine information is targeted at parents. Firstly,

fathers appeared to play a more prominent role in the decision about the MMR vaccine than for other vaccines in the programme. This suggests that for many couples both parents are actively involved in trying to assess the evidence. Therefore it may be useful for health professionals to be aware of this when offering advice about MMR vaccination. Secondly, parents were more likely to delay MMR immunisation and found pressure from health professionals to immunise, unhelpful. This is consistent with Raithatha et al.'s (2003) recommendation that parents are not pressurised to immunise, as this increases their feeling of lack of control. Parents preferred to withhold MMR vaccination because of the perception that the action of MMR vaccination (commission) may cause long-term damage and be more harmful than deferring vaccination or inaction (omission). This finding is reminiscent of Ritov and Baron (1990) and Asch and colleagues' (1994) work on omission bias, and suggests that omission bias has played an important role in parents' decisions about MMR vaccination. The horrendous stories of children suffering from autism and the unimaginable guilt faced by their parents meant that the decision about MMR was extremely difficult. For many parents deciding about MMR, it was easier to live with the unlikely risk of their child naturally contracting one of the diseases than with the risk of causing their child permanent damage, as they perceived other parents may have unwittingly done. Therefore this research supports the more recent findings of Sporton and Francis (2001) and Evans et al. (2001) which suggests that parents choose not to immunise because they fear the risks of side-effects. Both these studies found that parents considered that it was preferable not to act, than to act and potentially be responsible for causing long-term damage.

Indeed, Hershey et al.'s (1994) claim that people usually seek medical interventions which appear to offer them the best perceived balance of risks and benefits, holds true for MMR vaccination. Consistent with Smailbegovic et al.'s (2003) findings, the current research found that parents were weighing their child's likelihood of catching a disease and the perceived seriousness of the disease, against the perceived safety and efficacy of the vaccine. When parents considered that the diseases posed a tangible threat to their child's health, and when they considered immunisation to be both safe and effective they were unwavering about the need to have their children vaccinated. This was the case

with Men C vaccination. In contrast, when parents considered that the diseases posed little or no threat to their child's health, and when they considered immunisation to be ineffectual or risky, they were more likely not to immunise their children, as was sometimes the case for MMR vaccination. This research found that in addition to weighing up the risks and benefits associated with the diseases and with the vaccines, parents assessed the ability of their child's immune systems to cope with the challenge of vaccines, or fight the disease. Parents feared that combining the antigens causes the vaccine to become too potent for young children whose immune systems are not fully developed, and feared that for some children the vaccine could cause long-term damage.

7.3 Part Three: Implications and recommendations

7.3.1 Implications for policy

The fact that parents' knowledge about and understanding of the transmission of most of the vaccine-preventable diseases was often so poor suggests that there is a need for a renewed campaign to educate parents about the diseases. This recommendation stems not only from a need to equip parents with information in order to make informed decisions, no matter whether the outcome is to immunise or not, but also from an obligation to explain and justify immunisation policy to parents so that they, in turn, can assess its importance and relevance. Indeed, whilst recommending a need for a renewed education campaign, I also acknowledge that merely targeting parents with information about the diseases will not necessarily have the effect of persuading parents to immunise, consistent with assumptions underpinning the deficit model (Irwin and Wynne 1996). Indeed, in Sturgis and Allum's (2004) critique of what they describe as the "rather simplistic deficit model" of health information they state: "it is quite clear that culture, economic factors, social and political values, trust, risk perception, and worldviews are all important in influencing the public's attitude towards science" (p. 58). A key factor identified in this suggestion is the belief that knowledge of science is influenced by the level of trust that the public places in the institutions and experts that are imparting the information. On one hand, many parents in this study spoke of mistrusting the Government and government spokespersons defined as public health officials. On the other hand they also spoke about trusting immunisation 'experts' that had identified the need for the Men C campaign because they perceived the campaign as evidence that experts were worried about the risks posed by this disease. Clearly parents were making some distinction between the various information providers and this highlights what Sturgis and Allum (2004) describe as the 'complex and interacting nature of the knowledge-attitude interface'. It also highlights the fact that parents are not passive receivers of information and that they will take different meanings from the same information. A more comprehensive critique of audience reception and the deficit model of health information is outwith the scope of this thesis, but would be central to any

campaign aimed at educating parents about the diseases. This study aimed to investigate parents' knowledge in order to offer guidance on the content of such a campaign, rather than on the most effective methods of communication in future campaign. Clearly any campaign should draw on current theories of trust, risk perception, communication and the public's understanding of science.

In consideration of the content of a campaign this study recommends there is a need to educate parents about modes of transmission and the potential threats they pose, and to challenge some of the myths surrounding these diseases (for instance that mumps is causally associated with male infertility, that Hib is a flu vaccine, that rubella is unimportant for boys or that rabies is associated with tetanus). It is important to tackle these inaccurate beliefs, not only so that parents can make more informed decisions, but also because these unchallenged myths appear to be contributing to a wider sense that children are being over-immunised against diseases that are mild and of no great threat.

There is also a need to educate parents about the importance of maintaining high vaccine uptake levels even when disease prevalence in the UK is minimal. In this respect it seems advisable that greater efforts are concentrated on persuading parents of the constant threat posed by the resurgence of 'old' diseases. For example, modern lifestyles mean that global travel provides greater opportunities for diseases such as diphtheria and polio to be reintroduced back into the UK from parts of the world in which these diseases still remain endemic. (Most parents were unaware of this, which meant they often questioned the need for the continuation of these vaccines in the programme). There is also a need for parents to be encouraged to be realistic about their own ability to control disease. For instance, tetanus cannot be eradicated because the spores exist in the soil and therefore poses a constant threat. Parents should also be made aware that seeking tetanus vaccination after an injury has occurred is not a safe strategy for preventing tetanus infection.

The scope for improving parents' knowledge through a campaign similar to the Men C campaign appears to be considerable. The high level of understanding of the risks of meningococcal disease and their positive attitude to Men C vaccination suggests that the Men C campaign may be a successful model to follow in communicating the risks of other vaccine-preventable diseases. It was clear that the poster campaign had been a particularly successful aspect of this campaign. These findings suggest that a similar follow up campaign with a central focus on reducing the prevalence of meningitis may be equally successful as a means of educating about haemophilus influenza and mumps infection. Both these diseases were considered to be minor because parents misunderstood them. By building on the success of the Men C and by adding these two vaccines into the new campaign parents could be educated about the fact that Hib was introduced to reduce the incidence of meningitis (among other conditions), and that mumps vaccination was introduced into the programme to reduce the incidence of viral meningitis. This has the two-fold benefit of challenging the myths about mumps and Hib vaccines and thus educating parents about the rationale for their inclusion in the programme, and perhaps reducing parents' concerns that children are becoming over immunised against diseases that pose little risk.

The findings from this research also suggest that, since parents seem to find personal stories very persuasive, these may have a role to play in health education materials and campaigns. It seems that any future campaign would be wise to encompass accurate and factual information about the diseases, with a campaign that places an appropriate level of emphasis on the important community benefits of immunisation as well as those pertaining to the individual. One benefit of increasing the emphasis on the community benefits of immunisation is that it recognises the public health contribution of immunisation more openly. In the case of rubella vaccination this would challenge the view held by some parents that rubella immunisation is irrelevant for boys since it is their sisters, aunts, future female partners and potentially their own children who could benefit from the protection. Acknowledging the dual role of immunisation more openly would more accurately reflect the fact that vaccines offer both individual and community protection. It would also allow more debate about the important role vaccination plays in

reducing the spread of disease to more vulnerable members of society, such as people with compromised immune systems due to a range of illnesses, or brothers and sisters who are too young to be vaccinated. Whilst the current climate of individual choice is important, so too is responsibility and it may be time for health education to embrace this aspect of immunisation more comprehensively.

But perhaps the most pressing and urgent need of any immunisation campaign is the need to address parents' growing concerns and fears about over-immunisation. At present parents are anxious and confused about whether combined vaccines do overwhelm the immune system. Whilst educating parents about the individual diseases may help parents appreciate the need to include each of the vaccines in the current programme, parents also need reassurances based on sound evidence that giving these vaccines in a combined form is safe. As the new pentavalent vaccine (DtaP/IPV/Hib) is introduced into the programme, it is crucial that parents' concerns about immune overload are taken into account to reassure parents in their wider reappraisal of vaccine risk.

7.3.2 Implications for practice

In this study, health professionals, particularly GPs and health visitors, were often viewed by parents as offering ambiguous advice and being ambivalent about MMR safety. This added to parents' sense of uncertainty about the safety of MMR and about whether MMR immunisation was in their child's best interest. Some parents spoke of their concerns about the MMR vaccine being dismissed out of hand by health professionals, or of feeling pressurised into making quick decisions. Parents found this kind of pressure unhelpful and were resentful of it when trying to make such a difficult decision. It is imperative that health professionals are sensitive to parents' needs and that they receive up-to-date assessments of the evidence about MMR safety and any new developments in autism research to assist them in supporting parents to reach an informed decision.

Some parents were also suspicious of the motives of GPs and health visitors because they were aware that they receive payments from the Government to reach immunisation targets. This target payment scheme appears to be undermining the very programme it seeks to promote, and may be potentially damaging to the parent-practitioner relationship.

Parents appeared to find negative comments about Wakefield unhelpful. They also found the fact that the aetiology of autism is still not fully understood unsettling and added to their general sense of uncertainty. Therefore it may be wise for health professionals to distance themselves from politicians by avoiding using the kind of rhetoric they have used to discredit Wakefield and his findings. Instead health professionals could concentrate on the positive messages such as the good safety record of the MMR vaccine and the overwhelming support from the scientific community for the MMR vaccine as the safest vaccine available for preventing measles, mumps and rubella infection.

The MMR controversy appears to have increased parents' fears about combined vaccines potentially overwhelming and damaging their child's immune systems. Health professionals may need to offer greater reassurance and advice on this aspect of immunisation to parents who are worried, or whose children have asthma or multiple allergies. As such, health visitors, GPs and practice nurses need to be provided with up-to-date information and be prepared to discuss this topic with parents. Health professionals may need to reassure parents that their own child's immune system is capable of coping with multiple antigens, and to discuss the benefits combined vaccines offer their child. They may also need to advise parents that combined vaccines offer their child protection against several diseases at once, and at a younger age than would be possible if given separately, and that this is important because many infectious diseases are most dangerous to very young children. However, some parents may continue to have reservations about vaccines and may still decide not to immunise. The decisions of these parents should be respected and they may need to be encouraged to learn about the signs and symptoms of the diseases so that they could recognise early infection and seek medical assistance.

7.3.3 Implications for future research

This research suggests that parents are anxious that combined vaccines could be detrimental to their child's health both immediately following vaccination and in the long-term. Further research in these areas could help alleviate some of these anxieties and return greater confidence to the use of combined vaccines. This is essential as new combined vaccines are introduced into the programme.

This study also highlighted a need for further research with parents caring for immunocompromised children and immunisation. It seems sensible that the wider community benefits of immunisation should receive more consideration than at present. Further research is warranted to determine how this could best be incorporated into an immunisation campaign.

The anguish and grief that the MMR controversy has caused for parents who believe they are in part responsible for their child's autism is so unimaginable that it is imperative that lessons are drawn from this whole unfortunate affair. The need for further research with these parents is central to this process of learning. In particular there is an urgent need for a larger exploratory study to investigate how parents caring for autistic children have been affected by the debate, so that the medical and health professions can address these needs more effectively.

Parents also want more research into the aetiology of autism, into the relationship between autism and the immune system, and whether immunisation is safe for autistic children. It is essential that this research is done and that the findings are disseminated quickly to parents so that they have closure on the MMR controversy. The Government's pledge in February 2002 of £2.5 million towards further autism research effort is a positive step in this direction.

7.3.4 Dissemination of findings

This study has provided an original and unique insight into perceptions of the MMR controversy, and on parents' views on childhood immunisation and vaccine-preventable diseases. It is anticipated that the findings from this PhD research will be relevant to public health policy on immunisation and will be presented in scientific medical journals (a paper has been submitted) and at public health conferences. Indeed, as the MMR controversy slowly fades, this research suggests that new debates may emerge that will focus attention on whether children are becoming over-immunised against diseases perceived to pose no real threat. Although many parents will continue unquestioningly to accept immunisation, it is possible that growing numbers will not. It is therefore important that future immunisation policy takes a proactive stance in educating parents about the diseases. Parents need to be given clear and accessible public health information about the vaccines and diseases included in the programme as this will determine the future success of the Childhood Immunisation Programme. The completion of this PhD study coincides with a more reflective period in the MMR controversy, at a time when scientists, journalists, policy makers, public health officials and health professionals are beginning to ponder on the lessons that may be learned from this public health scare. It is hoped that this research will usefully contribute to this process of reflection.

Bibliography

- Afzal, M. A., P. Minor, J. Begley, M. Bentley, E. Armitage, S. Ghosh and A. Ferguson (1998). "Absence of measles-virus genome in inflammatory bowel disease." The Lancet 351: 646.
- Afzal, M. A., P. Minor and S. Ghosh (2001). "Letter to the editor: Measles virus persistence in specimens of inflammatory bowel disease and autism." Digestive Diseases & Sciences 46(3): 658-660.
- Agar, M. and J. MacDonald (1995). "Focus Groups and Ethnography." Human Organization 54: 78-81.
- Anderson, I. M. and D. Morris (1950). "Encephalopathy after combined diphtheria and pertussis inoculation." The Lancet 537-539.
- Asch, D. A., J. Baron, J. C. Hershey, H. Kunreuther, J. Meszaros, I. Ritov and M. Spranca (1994). "Omission Bias and Pertussis Vaccination." Medical Decision Making 14(2): 119-123.
- Barbour, R. and J. Kitzinger (1999). Developing Focus Group Research: Politics, Theory and Practice. London, Sage Publications 8,11,16.
- Bedford, H. and D. Elliman (2000). "Concerns about immunisation." British Medical Journal 320: 240-243.
- Bedford, H. and D. Elliman (2004). "Misconceptions about the new combination vaccine." British Medical Journal 329: 411-412.
- Beggs, N. and A. Nicoll (1994). "Myths in Medicine: Immunisation." British Medical Journal 309: 1073-1075.
- Beggs, N., M. Ramsay, J. White and Z. Bozoky (1998). "Media dents confidence in MMR vaccine." British Medical Journal 316: 561.
- Bellaby, P. (2003). "Communication and miscommunication of risk: understanding UK parents' attitudes to combined MMR vaccination." British Medical Journal 327: 725-727.
- Berg, J. M. (1958). "Neurological complications of pertussis immunisation." British Medical Journal 2: 24-27.
- Bloor, M., J. Frankland, M. Thomas and K. Robson (2001). Focus Groups in Social Research. London, Sage Publications 26-27.
- Bogardus, E. (1926). "The Group Interview." Journal of Applied Sociology 10: 372-82.
- Bond, L., T. Nolan, P. Pattison and J. Carlin (1998). "Vaccine preventable diseases and immunisations: a qualitative study of mothers' perceptions of severity, susceptibility, benefits and barriers." Australian and New Zealand Journal of Public Health 22: 440-446.
- Boseley, S. (1998). 29-2-98 Alert over child jabs. The Guardian.
- Bruner, J. (1986). Actual Minds, Possible Worlds. Cambridge, MA, Harvard p56.
- Campbell, A. G. M. (1983). "Measles immunisation: why have we failed?" Archives of Disease in Childhood (58): 3-5.
- Carstairs, V. and R. Morris (1991). Deprivation and Health in Scotland. Aberdeen, Aberdeen University Press.

- Catterall, M. and P. Maclaran (1997). "Focus Group Data and Qualitative Analysis Programs: coding the moving picture as well as the snapshots." Sociological Research Online 2(1).
- Chen, R. T. and F. De Stefano (1998). "Vaccine adverse events: causal or coincidental?" The Lancet 351: 611-612.
- Church, M. A. (1979). "Return of whooping cough." British Medical Journal 1: 195.
- Clements, C. J. and S. Ratzan (2003). "Misled and confused? Telling the public about MMR vaccine safety." Journal of Medical Ethics 29: 22-26.
- Cohn, L., M. Schydlower, J. Foley and R. Copeland (1995). "Adolescents' misinterpretation of health risk probability expressions." Pediatrics 95: 713-716.
- Cooper, P., I. Diamond and S. High (1993). "Choosing and using contraceptives: integrating qualitative and quantitative methods in family planning." Journal of the Market Research Society 35(4): 325-39.
- Craft, A. W. (2000). "Childhood cancer- mainly curable so where next?" Acta Paediatrica 89: 386-392.
- Dales, L., S. J. Hammer and N. J. Smith (2001). "Time Trends in Autism and in MMR Immunization Coverage in California." Journal of the American Medical Association 285: 1183-1185.
- Davis, R. and K. Bohlke (2001). "Measles vaccination and inflammatory bowel disease - Controversy laid to rest?" Drug Safety 24(13): 939- 946.
- de Boer, A. W. and G. de Vaan (1989). "Mild course of mumps in patients with acute lymphoblastic leukaemia." European Journal of Paediatrics 148: 618-619.
- Dyer, C. (2003). "Commission withdraws legal aid for parents suing over MMR vaccine." British Medical Journal 327: 640.
- Edwards, A., G. Elwyn and A. Mulley (2002). "Explaining risks: turning numerical data into meaningful pictures." British Medical Journal 324: 827-830.
- Ekbom, A., P. Daszak, K. Wolfgang and A. J. Wakefield (1996). "Crohn's disease after in-utero measles virus exposure." The Lancet 348: 515-517.
- Ekbom, A., A. J. Wakefield, M. Zack and H. Adami (1994). "Perinatal measles infection and subsequent Crohn's disease." The Lancet 344: 508-510.
- Evans, M., H. Stoddart, L. Condon, E. Freeman, M. Grizzell and R. Mullen (2001). "Parents' perspectives on the MMR immunisation: a focus group study." British Journal of General Practice 51: 904-910.
- Farquhar, C. and R. Das (1999). Are focus groups suitable for sensitive topics? Developing focus group research: Politics, Theory and Practice. In: R. Barbour and J. Kitzinger. London, Sage Publications.
- Feeney, M., A. Clegg, P. Winwood and J. Snook (1997). "A case-control study of measles vaccination and inflammatory bowel disease." The Lancet 350: 764-766.
- Feigin, R. and J. Cherry (1998). Textbook of Pediatric Infectious Diseases. London, WB Saunders Company.
- Flynn, M. and J. Ogden (2004). "Predicting uptake of MMR vaccination: a prospective questionnaire study." British Journal of General Practice 54(504): 526-530.
- Fombonne, E. (2001). "Is there an epidemic of autism?" Pediatrics 107: 411-413.

- Fombonne, E. and S. Chakrabarti (2001). "No evidence for a new variant of measles-mumps-rubella-induced autism." Pediatrics 108(4): e58.
- Frankland, J. and M. Bloor (1999). Some issues arising in the systematic analysis of focus group materials. Developing Focus Group Research: Politics, Theory and Practice. R. Barbour and J. Kitzinger. London, Sage Publications.
- Gantley, M., G. Harding, S. Kumar and J. Tissier (1999). An Introduction to Qualitative Methods for Health Professionals. No 1 Master Classes in Primary Care Research Series. H. Carter, S. Shaw and C. Thomas. London, Royal College of General Practitioners.
- Geiger, R., F. M. Fink, B. Solder, M. Sailer and G. Enders (1995). "Persistent rubella infection after erroneous vaccination in an immuno-compromised patient with acute lymphoblastic leukaemia in remission." Journal of Medical Virology 47: 442-444.
- Gellin, B. G., E. W. Maibach and E. K. Marcuse (2000). "Do Parents Understand Immunizations? A National Telephone Survey." Pediatrics 106(5): 1097-1102.
- Ghosh, S., E. Armitage, D. Wilson (2001) "Detection of persistent measles virus infection in Crohn's disease: current status of experimental work." GUT 48; 748-752
- Glaser, B. G. and A. L. Strauss (1967). The Discovery of Grounded Theory. Chicago, IL, Aldine.
- Griffith, A. H. (1981). "Medicine and the media-vaccination against whooping cough." Journal of Biological Standardization 9: 475-482.
- Gubrium, J. F. and J. Holstein (1997). The New Language of Qualitative Research. New York, Oxford University Press.
- Hanratty, T., T. Holt, E. Duffell, W. Patterson, M. Ramsay, J. M. White, L. Jin and P. Litton (2000). "UK measles outbreak in non-immune anthroposophic communities: the implications for the elimination of measles from Europe." Epidemiology and Infection 125: 377-383.
- Harding, C. M. (1985). "Whooping cough vaccination: the case presented by the British national press." Child: care, health and development 11: 21-30.
- Hargreaves, I., J. Lewis and T. Speers (2003). Towards a better map: Science, the public and the media. Cardiff, Cardiff University Press.
- Health Education Board for Scotland & Scottish Centre for Infection and Environmental Health (2001). The MMR discussion pack: an information guide for health professionals and parents. Edinburgh, Health Education Board for Scotland.
- Henderson, R. (1994). Vaccination: successes and challenges. Chichester, John Wiley & Sons.
- Hendriksen, C. (2000). Vaccine development: past, present and future. Fighting infection in the 21st Century. In: P. Andrew, P. Oyston, A. Smith and D. Stewart. London, Blackwell Science: p61-71.
- Hermon-Taylor, J., J. Ford, N. Sumar, D. Millar, T. Doran and M. Tizard (1995). "Measles virus in Crohn's disease." The Lancet 345: 922-923.
- Hershey, J. C., D. A. Asch, T. Thumasathit, J. Meszaros and V. V. Waters (1994). "The Roles of Altruism, Free-Riding, and Bandwagoning in Vaccination Decisions." Organizational Behaviour and Human Decision Processes 59: 177-187.

- Holliday, A. (2002). Doing and Writing Qualitative Research. London, Sage Publications 20-21.
- Horton, R. (1992). "Jabs." London Review of Books: 22-3.
- Horton, R. (1995). "Myths in medicine." British Medical Journal 310: 62.
- Horton, R. (2004). "MMR: Science and Fiction- for parents and health professionals." London. Granta.169
- Hunt, K. and C. Emslie (2001). "Commentary: The prevention paradox in lay epidemiology- Rose revisited." International Journal of Epidemiology 30: 442-446.
- Iizuka, M., H. Saito, T. Shirasaka, M. Chiba, T. Fukushima and S. Watanabe (2001). "No evidence of persistent mumps virus infection in inflammatory bowel disease." Gut 48(5): 637-641.
- Irwin, A. and B. Wynne (1996) "Misunderstanding Science?" The public reconstruction of science and technology. Cambridge, Cambridge University Press
- Jewell, D. (2001). "MMR and the age of unreason." British Journal of General Practice 1: 875.
- Jones, P., P. Fine and S. Piracha (1997). "Crohn's disease and measles." The Lancet 349: 473.
- Kawashima, H., T. Mori, Y. Kashiwagi, K. Takekuma, A. Hoshika and A. J. Wakefield (2000). "Detection and sequencing of measles virus from peripheral mononuclear cells from patients with inflammatory bowel disease and autism." Digestive Diseases & Sciences 45(4) 723-729.
- Kaye, J., M. del Mar Melero-Montes and J. Hershel (2001). "Mumps, measles, and rubella vaccine and the incidence of autism recorded by general practitioner: a time trend analysis." British Medical Journal 322: 0-2.
- Keane, V., B. Stanton, L. Horton, R. Aronson, J. Galbraith and N. Hughart (1993). "Perceptions of Vaccine Efficacy, Illness, and Health Among Inner-City Parents." Clinical Pediatrics (1): 2-7.
- Kidd, P. and M. Parshall (2000). "Getting the Focus and the Group Enhancing Analytical Rigor in Focus Group Research." Qualitative Health Research 10(3): 293-308.
- Kilmartin, M. R., D. R. Woodward, C. L. Blizzard and K. Turner (1998). "Immunisation of babies." Australian Family Physician 27(Suppl 1): 511-514.
- Kitzinger, J. (1994a). Focus Groups: Method or madness? Challenge and Innovation. Methodological Advances in Social Research on HIV / AIDS. M. Boulton. London, Taylor and Francis.
- Kitzinger, J. (1994b). "The methodology of focus groups: The importance of interaction between research participants." Sociology of Health and Illness 16(1): 103-121.
- Klein, N., K. Morgan and M. H. Wansbrough-Jones (1989). "Parents' beliefs about vaccination: the continuing propagation of false contradictions." British Medical Journal 298: 1687.
- Koplan, J. P. and A. R. Hinman (1987). "Decision Analysis, Public Policy, and Pertussis." Medical Decision Making 7(2): 71-73.
- KulenKampff, M., J. S. Schwartzman and J. Wilson (1974). "Neurological complications of pertussis inoculation." Archives of Disease in Childhood 49: 46-49.
- Lambert, P. and C. Siegrist (1997). "Science, medicine and the future: vaccines and vaccination." British Medical Journal 315: 1595-1598.
- Le Page, M. and C. Ainsworth (2001). "MMR Vaccine : A parents' dilemma." New Scientist: 8-9.

- Leask, J. A. and P. B. McIntyre (2003). "Public opponents of vaccination: a case study." Vaccine 21: 4700-4703.
- Lee, J. W., B. Melgaard, C. J. Clements, M. Kane, E. K. Mulholland and J. M. Olive (1998). "Autism, inflammatory bowel disease, and MMR vaccine." The Lancet 351: 905-916.
- Lewis, J. and T. Speers (2003). "Misleading media reporting? The MMR story." Nature Reviews: Immunology 3: 913-918.
- Lincoln, Y. S. and E. G. Guba (1985). Naturalistic Inquiry. Beverly Hill, CA, Sage Publications.
- Mandal, B. and R. Mayon-White (1984). Lecture notes on infectious diseases. London, Blackwell Scientific Publications 49.
- Mason, J. (2002). Qualitative Researching. London, Sage Publications.
- Maykut, P. and R. Morehouse (1994). Begining qualitative research: A philosophic and practical guide. London, Routledge / Falmer.
- Mayon-White, R. and J. Moreton (1998). Immunizing children. Oxfordshire, Radcliffe Medical Press.
- McKeown, T. (1976) The role of medicine: dreams, mirage or nemesis? London, Nuffield Provincial Hospital Trust.
- McKinnon, J. A. (1979). "The impact of the media on whooping cough immunisation." Health Education Journal 37: 198-202.
- McLoone, P. (1994). Carstairs Scores for Scottish Post-code Sectors from the 1991 Census. Glasgow, Social and Public Health Science Unit.
- McMurray, R., F. Cheaters and I. Alders (2004). "Managing controversy through consultation: a qualitative study of communication and trust around MMR vaccination decisions." British Journal of General Practice 54(504): 520-525.
- Medawar, C. and A. Herxheimer (2003) "A critical appraisal of the yellow card scheme" The Pharmaceutical Journal 271 (7276) 703.
- Medical Research Council (1956). "Vaccination against whooping cough." British Medical Journal 2: 454-462.
- Medical Research Council (1959). "Vaccination against whooping cough." British Medical Journal 1: 994-1000.
- Merton, R. (1987). "The Focused Interview and Focus Groups: Continuities and Discontinuities." Public Opinion Quarterly 51(4): 550-566.
- Merton, R. and P. Kendall (1946). "The focused interview." American Journal of Sociology 51: 541-557.
- Meszaros, J. R., D. A. Asch, J. Baron, J. C. Hershey, H. Kunreuther and J. Schwartz-Buzaglo (1996). "Cognitive Processes and the Decisions of Some Parents to Forego Pertussis Vaccination for Their Children." Journal of Clinical Epidemiology 49(6): 697-703.
- Metcalf, J. (1998). "Is measles infection associated with Crohn's disease?" British Medical Journal 316: 166-167.

- Miller, C. and E. Miller (1986). "Rubella vaccination in the UK: time for a complete strategy." The Lancet 732.
- Miller, E., N. Andrews, P. Waight and B. Taylor (2003). "Bacterial infections, immune overload, and MMR vaccine." Archives of Diseases in Childhood 88: 222-223.
- Miller, H. G. and J. B. Stanton (1954). "Neurological sequel of prophylactic inoculation." Quarterly Journal of Medicine 23: 1-27.
- Morgan, D. (1988). Focus Groups as Qualitative Research. London, Sage Publications.
- Morgan, D. (1997). Focus Groups as Qualitative Research. London, Sage Publications.
- Morris, A. and D. Aldulaimi (2002). "New evidence for a viral pathogenic mechanism for new variant inflammatory bowel disease and development disorder?" Journal of Molecular Pathology 55: 83.
- Murphy, B., J. Cockburn and M. Murphy (1992). "Focus groups in health research." Health Promotion Journal of Australia 2(2): 37-40.
- Myers, G. and P. Macnaghten (1998). "Rhetoric of environmental sustainability: commonplace and places." Environment and Planning 30: 333-353.
- New, S. J. and M. L. Senior (1991). "I don't believe in needles": qualitative aspects of a study into the uptake of infant immunisation in two English Health Authorities." Social Science and Medicine 33(4): 509-518.
- Nicoll, A., D. Elliman and E. Ross (1998). "MMR vaccination and autism." British Medical Journal 316: 715-716.
- Nielsen, L. L. W., N. M. Nielsen, M. Melbye, M. Sodermann, M. Jacobsen and P. Aaby (1998). "Exposure to measles in utero and Crohn's disease: Danish register study." British Medical Journal (316): 196-197.
- Offit, P. A., J. Quarlest, M. A. Gerber, C. J. Hackett, E. K. Marcuse, T. R. Kollman, B. Gellin and S. Landry (2002). "Addressing parents' concerns: do multiple vaccines overwhelm or weaken the infants immune system?" Pediatrics 109(1): 1124-129.
- Pareek, M. and H. M. Pattison (2000). "The two-dose measles, mumps, and rubella (MMR) immunisation schedule: factors affecting maternal intention to vaccinate." British Journal of General Practice 50: 969-971.
- Patja, A., I. Davidkin, T. Kurki, M. J. T. Kallio, M. Valle and H. Peltola (2000). "Serious adverse events after measles-mumps-rubella vaccination during a fourteen-year prospective follow-up." Pediatric Infectious Disease Journal 19: 1127-1134.
- Patte, C. (1998). "Non-Hodgkin's lymphoma-paediatric update." European Journal of Cancer 34: 359-363.
- Payne, C. (1998). "Correspondence. Autism, inflammatory bowel disease, and MMR vaccine"; The Lancet 351: 907.
- Pearson, M., K. Makowiecka, J. Gregg, J. Woollard, M. Roger and C. West (1993). "Primary immunisation in Liverpool. Who withholds consent?" Archives of Disease in Childhood 69: 110-114.
- Peckham, C., H. Bedford, Y. Senturia and A. ades (1989). The Peckham Report: National Immunisation Study : factors influencing immunisation uptake in childhood. Horsham, Action for the Crippled Child.

- Peltola, H., A. Patja, P. Leinikki, M. Valle, I. Davidkin and M. Paunio (1998). "No evidence for measles, mumps, and rubella vaccine-associated inflammatory bowel disease or autism in a 14-year prospective study." The Lancet 351: 1327-1332.
- Pinkerton, C. R. (1999). "The continuing challenge of treatment for non-Hodgkin's lymphoma in children." British Journal of Haematology 107: 220-234.
- Poland, G., D. Murray and R. Bonilla-Guerrero (2002). "Science medicine and the future: New vaccine development." British Medical Journal 324: 1315-1319.
- Preston, N. (1980). Whooping cough immunization : fact and fiction. London, Public Health: 94 350-355.
- Public Health Institute for Scotland www.show.scot.nhs.uk/PHIS
- Raithatha, N., R. Holland, S. Gerrard and I. Harvey (2003). "A qualitative investigation of vaccine risk perception amongst parents who immunise their children: a matter of public health concern." Journal of Public Health Medicine 25(2): 161-164.
- Rajouria, V. P. and J. H. Johnston (1982). "Tetanus complicating acute leukaemia- a case report." Annual Review of Tropical Medicine 76: 247.
- Ramsay, M., J. Yarwood and D. Lewis (2002). "Parental confidence in measles, mumps and rubella vaccine." British Journal of General Practice 52(484): 912-916.
- Reed, J. and V. Roskell (1997). "Focus groups: issues of analysis and interpretation." Journal of Advanced Nursing 26: 765-771.
- Reilly, A. (2003). "Infections in children with cancer." European Journal of Cancer 39: 652-653.
- Reinhardt, D., K. Houliara, A. Pekrun, M. Lakomek and B. Krone (2003). "Impact of conventional chemotherapy on levels of antibodies against vaccine-preventable diseases in children treated for cancer." Scandinavian Journal of Infectious Diseases 35: 851-857.
- Richards, L. (1999). Using NVivo in Qualitative Research. London, Sage publications.
- Ritov, I. and J. Baron (1990). "Reluctance to Vaccinate: Omission Bias and Ambiguity." Journal of Behavioral Decision Making 3: 263-277.
- Rose, G. (1981). Strategy of prevention: lessons from cardiovascular disease. British Medical Journal. 282; 1847-1851.
- Royal College of Paediatrics and Child Health (2002). Immunisation of the Immunocompromised child: Best Practice Statement. London Royal College of Paediatrics and Child Health.
- Salisbury, D. M. (1992). The immunization program in England: 25th National Immunization Conference Proceedings 1991. Centers for Disease Control and Prevention, Atlanta, GA.
- Salisbury, D. M. and N. Begg (1996). Immunisation against infectious diseases. London, HMSO.
- Scottish Centre for Infection and Environmental Health. Surveillance report: vaccine-preventable and childhood diseases. SCIEH Weekly Reports 2003; 35.
- Scottish Executive: Report of the Expert Group (2002). MMR: Report of the MMR Expert Group. Edinburgh, Scottish Executive.
- Seale, C. (1999). The Quality of Qualitative Research. London, Sage Publications.

- Simpson, N., S. Lenton and R. Randall (1995). "Parental refusal to have children immunised: extent and reasons." British Medical Journal 310: 225-227.
- Smailbegovic, M. S., G. Laing and H. Bedford (2003). "Why do parents decide against immunization? The effect of health beliefs and health professionals." Child: care, health and development 29: 303-311.
- Smeeth, L., Cook, C., Fombonne, E., Heavey, L., Rodriques, L., Smith, P., and A. Hall (2004) "MMR vaccination and pervasive development disorders: a case-control study." The Lancet 364: 963-969
- Sporton, R. K. and S. Francis (2001). "Choosing not to immunise: are parents making informed decisions?" Family Practice 18(2): 181-188.
- Stewart, G. (1977). "Vaccination against whooping cough." The Lancet i: 234-37.
- Stone, D. H. (1995). "The difference between ideological and intellectual dissent." Journal of Health Care Analysis 3: 111-113.
- Sturgis, P. and N. Allum (2004). "Science in society: re-evaluating the deficit model of public attitudes." Public Understanding of Science 13. 55-74.
- Szreter, S. (2002) "Rethinking Mckeown: The relationship between public health and social change." American Journal of Public Health 92(5): 722-725
- Taylor, B., E. Miller, R. Lingham, N. Andrews, A. Simmons and J. Stowe (2002). "Measles, mumps and rubella vaccination and bowel problems or developmental regression in children with autism: population study." British Medical Journal 324: 393-396.
- Taylor, B., E. Miller, C. Paddy Farrington, M. Petropoulos and J. L. Favot-Mayaud (1999). "Autism and measles, mumps, and rubella vaccine: no epidemiological evidence for a causal association." The Lancet 353(20): 2026-2029.
- Thayer, W. (1990). The aetiology of inflammatory bowel disease: the role of infectious agents. Inflammatory bowel diseases. R. Allan, M. Keighley, J. Alexander-Williams and C. Hawkins. Edinburgh, Churchill Livingstone.
- Thjodleifsson, B., K. Davidsdottir, U. Agnarsson, G. Sigthorsson, M. Kjeld and I. Bjarnason (2002). "Effect of Pentavac and measles-mumps-rubella vaccination on the intestine." Gut 51: 816-817.
- Thompson, N. P., S. M. Montgomery, R. E. Pounder and A. J. Wakefield (1995). "Is measles vaccination a risk factor for inflammatory bowel disease?" The Lancet 345: 1071-1074.
- Townsend, P. and N. Davidson (1982). Inequalities in health: The Black Report. Harmondsworth, Penguin.
- Uhlmann, V., C. Martin, O. Sheils, L. Pilkington, I. Silva, A. Killalea, S. H. Murch, J. Walker-Smith, M. A. Thomson, A. J. Wakefield and J. J. O'Leary (2002). "Potential viral pathogenic mechanism for new variant inflammatory bowel disease." Journal of Molecular Pathology 55: 84-90.
- Wakefield, A. J., S. H. Murch, A. Anothony, J. Linnell, D. M. Casson, M. Malik, M. Berelowitz, A. P. Dhillon, M. A. Thomson, P. Harvey, A. Valentine and S. E. Davies (1998). "Ileal-lymnhoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children." The Lancet 351: 637-641.
- Wakefield, A. J., R. M. Pittilo, R. Sim, S. Cosby, J. R. Stephenson, A. P. Dhillon and R. E. Pounder (1993). "Evidence of persistent measles virus infection in Crohn's disease." Journal of Medical Virology.

Walker, D., H. Carter and I. Jones (1988). "Measles, mumps and rubella: the need for a change in immunisation policy." British Medical Journal 292: 1501-1502.

Whitfield, A. (1997). Mad cows or crazy communications? Mad Cows and mother's milk. D. Powell and W. Leiss. London, McGill-Queen's University Press: 3-25.

Wilkinson, S. (1999). How useful are focus groups? Developing Focus Group Research: Politics, Theory and Practice. R. Barbour and J. Kitzinger. London, Sage Publications: 64-78.

Yazbak, F. (2001). "Measles, mumps, and rubella (MMR) vaccine and autism: MMR cannot be exonerated without explaining increased incidence of autism." British Medical Journal 323(7305): 163-164.

Zeller, R. (1993). Combining qualitative and quantitative techniques to develop culturally sensitive measures. Methodological issues in AIDS behavioural research. D. Ostrow and R. Kessler. New York, Plenum.95-116.

Appendices

Appendix A1: Tabulated summary of Wakefield's studies and related studies.

Appendix A2: Tabulated summary of studies related to perceptions about immunisation, vaccine preventable disease and the MMR vaccine.

Appendix B: Childhood Immunisation Programme in December 2004.

Appendix C: Timeline showing major changes to the Childhood Immunisation Programme between 1940 and 2004.

Appendix D: Timeline showing relationship between key events in the MMR controversy and PhD study.

Appendix E: Topic guide.

Appendix F: Information sheet.

Appendix G: Consent form.

Appendix H: Characteristics of focus groups.

Appendix I: Cover letters given to potential participants.

Appendix J: Pre-focus group questionnaire.

Appendix K: Descriptions of the vaccine-preventable diseases included in the Childhood Immunisation Programme.

Appendix L: Childhood Immunisation Programme in December 2001.

Appendix M: Topic Guide used for focus groups with parents of autistic children.

Appendix N: Topic Guide used for focus groups with parents of immuno-compromised children.

Summary of Wakefield's studies and related studies

Authors/ Date/ Place	Aim	Participants & Method	Authors Findings/ Conclusions
Wakefield et al. (1989) (Inflammatory Bowel Disease Study Group) UK	To describe the pathogenetic process of Crohn's disease.	Design: Case series. Sample: Fifteen patients with Crohn's disease in which specimens of intestinal tissue were examined. Main outcome measured: Pathological changes in the intestinal tissue.	Findings: A pathogenetic sequence of events in Crohn's disease was seen- vascular injury, focal arteritis, fibrin deposition, arterial occlusion followed by tissues infarction or neovascularisation. Conclusion: This finding has important implications for the identification of the primary causes of Crohn's disease and for its clinical management.
Wakefield et al. (1993) (Inflammatory Bowel Disease Study Group) UK	To investigate whether there is any evidence of persistent measles virus in infection Crohn's disease.	Design: A case-control study Sample: Intestinal tissue from 9 patients with Crohn's disease and 4 patients with non- inflammatory were compared using transmission electron microscopy Main outcome measured: Evidence of persistent measles virus in intestinal tissue	Findings: All nine patients with Crohn's disease were found positive for paramyxovirus- like particles. No evidence of paramyxovirus-like particles was found in the control groups. Conclusion: This observation suggests that measles virus is capable of causing persistent infection of the intestine and that Crohn's disease may be caused in response to this virus.
Ekbom et al. (1994) (Inflammatory Bowel Disease Study Group) Sweden	To investigate whether there is an increased incidence of Crohn's disease among people born during measles epidemics.	Design: A cohort study. Sample: All individuals born between 1945-54 in four countries in central Sweden (that had five measles outbreaks) and individuals who had Crohn's disease diagnosed before the age of 30 years. Main outcome measured: The number of individuals with Crohn's disease compared to the total number of births used to calculate the	Findings: The number of people with Crohn's disease significantly exceeded that expected. Conclusion: These findings strengthen the hypothesis that measles is related to Crohn's disease and that the perinatal period is a time of vulnerability.

		expected number of patients to have Crohn's disease or ulcerative colitis following the peaks of the epidemics.	
<p>Ekbom et al. (1996)</p> <p>(Inflammatory Bowel Disease Study Group)</p> <p>Sweden</p>	<p>To determine whether exposure of mothers to measles virus in-utero is a risk factor for Crohn's disease in their children.</p>	<p>Design: Retrospective cohort study.</p> <p>Sample: Maternity records for all 25,000 deliveries at a maternity hospital were reviewed between 1940 and 1949 to identify all cases of measles infection in the mothers during pregnancy; four cases were identified.</p> <p>Main outcome measured: Subsequent development of Crohn's disease after exposure to measles virus in-utero.</p>	<p>Findings: Of these four children, three had undergone multiple intestinal resections and had been found to have Crohn's disease.</p> <p>Conclusion: The data indicate that exposure of mothers to measles virus in utero is a risk factor for Crohn's disease in their children.</p>
<p>Feeney et al. (1997)</p> <p>(East Dorset Gastroenterology Group)</p> <p>UK</p>	<p>To assess the risk of inflammatory bowel disease (IBD) associated with vaccination against measles in early childhood.</p>	<p>Design: A case-control study.</p> <p>Sample: The study included 140 patients with IBD (83 of which had Crohn's disease) and 280 controls matched for age, sex and general practice area with no IBD. Both samples were born during, or after 1968 to 1991 (in 1968 the measles vaccine was introduced in the UK). Childhood vaccination histories for each patient were reviewed from GP and community health records.</p> <p>Main outcomes measured: Difference in the rates of measles vaccination between the IBD and non-IBD groups.</p>	<p>Findings: Measles vaccination rates were 56.4% in patients with IBD and 57.1% among controls. Odds ratios for measles vaccination were 1.08 (95%CI 0.62-1.88) in patients with Crohn's disease, 0.84 (0.44-1.58) in patients with ulcerative colitis, and 0.97 (0.64-1.47) in all patients with IBD.</p> <p>Conclusion: These findings provide no support for the hypothesis that measles vaccination in childhood predisposes to the later development of either IBD overall, or Crohn's disease in particular.</p>

Nielsen et al. (1998) Denmark	To investigate whether an association exists between exposure to measles in-utero and Crohn's disease.	<p>Design: Retrospective cohort study.</p> <p>Sample: Hospital records for 1915-1966 were screened to identify pregnant women aged 15-43 years with measles. Their children were identified through the civil register and linked with the national inflammatory bowel disease registries. During this period 472 women were admitted with measles of which 33 were pregnant and 26 children were subsequently identified to take part.</p> <p>Main outcomes measured: Subsequent development of Crohn's disease.</p>	<p>Findings: None of the 26 children traced from these pregnancies were registered as having Crohn's disease and this was confirmed by their GPs.</p> <p>Conclusion: Exposure to measles in-utero does not seem to be strongly associated with the development of Crohn's disease later in life.</p>
Wakefield et al. (1998) (Inflammatory Bowel Disease Study Group) UK	To describe the clinical findings of 12 children with chronic enterocolitis and regressive developmental disorder.	<p>Design: A case series study.</p> <p>Sample: Twelve children consecutively referred with developmental and bowel problems.</p> <p>Main outcomes measures: 1) Evidence of chronic enterocolitis (this assessment included a detailed examination which included having an ileocolonoscopy and biopsy sampling) 2) the range and onset of behavioural symptoms (parents were interviewed about their child's development and about their child's immunisation history and exposure to infectious diseases).</p>	<p>Findings: In 8 of the 12 children, the onset of behavioural symptoms was associated by parents or GPs to the MMR vaccine.</p> <p>Conclusions: Gastrointestinal disease and developmental regression was identified in a group of previously normal children, which was generally associated in time with possible environmental triggers.</p> <p>In most cases, onset of symptoms was after MMR immunisation. Further investigations are needed to examine this syndrome and its possible relation to this vaccine.</p>

Taylor et al. (1999) UK	To investigate whether measles, mumps and rubella vaccine (MMR) be causally associated with autism.	<p>Design: Time trend analysis.</p> <p>Sample: Children with autism born between 1979 and 1998 were identified from special needs/disability registers and special schools in eight North Thames health district. From this 498 cases of autism were identified. Information from clinical records was linked to immunisation data.</p> <p>Main outcomes measured: Evidence of a change in trend in incidence or age at diagnosis with the introduction of the MMR in 1988.</p>	<p>Findings: No difference in the age at diagnosis of autism between vaccinated and unvaccinated children. No clustering of autism in the months following the introduction of the MMR vaccine.</p> <p>Conclusion: These findings do not support a causal association between MMR vaccine and autism. If such an association occurs it is so rare that it could not be identified in this large regional sample.</p>
Patja et al. (2000) Finland	To identify any severe adverse reactions which might be due to MMR vaccination.	<p>Design: Prospective cohort study.</p> <p>Sample: Medical records of 1.8 million children over a 14-year period from 1982.</p> <p>Main outcomes measured: Subsequent development of autism.</p>	<p>Findings: No cases of autism were associated with MMR vaccination.</p> <p>Conclusion: There is no evidence of onset of autism within a short period following vaccination.</p>
Kaye et al. (2001) UK	To estimate changes in the risk of autism and assess the relation of autism to the measles, mumps, and rubella vaccine.	<p>Design: Time trend analysis study.</p> <p>Sample: Using UK general practice research database 114 boys born between 1988 and 1993 and diagnosed as autistic between the ages of 2 and 5 years of age were identified.</p> <p>Main outcomes measured: The incidence of autism between 1988-1999.</p>	<p>Findings: The results showed that diagnosis of autism increased sevenfold, from 0.3 per 10 000 person years in 1988 to 2.1 per 10 000 person years in 1999. However, the MMR vaccine coverage remained steady, at over 95%.</p> <p>Conclusion: This indicates that no correlation exists between the prevalence of MMR vaccination and the rapid increase of autism over time. The explanation for the marked increase in autism in the past decade remains uncertain.</p>

<p>Kawashima et al. (2000)</p> <p>(Wakefield co-author)</p> <p>Japan</p>	<p>To identify which, if any, strain of the measles virus is present in intestinal tissue.</p>	<p>Design: Case control study</p> <p>Sample: Eight patients with Crohn's disease, three with ulcerative colitis, nine with autistic enterocolitis and eight control healthy patients.</p> <p>Main outcome measured: Presence of measles genomic in intestinal tissue.</p>	<p>Findings: The measles genomic was detected in one patient with Crohn's disease, one patient with ulcerative colitis and three patients with autistic enterocolitis. The controls were all negative. Both genomic strains from wild and vaccine strains were identified.</p> <p>Conclusion: Persistence of measles virus was confirmed. The mechanism of persistent measles virus infection in patients with chronic intestinal inflammation is complex and requires further study</p>
<p>Fombonne and Chakrabarti (2001)</p> <p>UK</p>	<p>To investigate whether there is any evidence of a new phenotype of autism involving regression and gastrointestinal symptoms.</p>	<p>Design: Study comparing three samples of autistic children</p> <p>Sample: One sample comprised 95 children immunised with MMR (epidemiologic sample), sample two comprised 68 children immunised with MMR (post-MMR sample). Sample three comprised 98 children that had not been immunised with MMR (pre-MMR sample).</p> <p>Main outcomes measured: The age that parents became concerned about their child's behaviour. The rate of developmental regression reported in each group, and the rate of gastrointestinal symptoms and inflammatory bowel disease reported by parents.</p>	<p>Findings: No difference in the age at which parents became concerned about their child's behaviour between the groups. Thus, immunisation was not associated with a shift toward an earlier age for first parental concerns. The rate of developmental regression reported in the post-MMR samples was not different to the pre-MMR sample. In the epidemiologic sample gastrointestinal symptoms were reported in 18.8% of children and no inflammatory bowel disease was reported.</p> <p>Conclusion: No evidence was found to support a distinct syndrome of MMR-induced autism or of 'autistic enterocolitis'.</p>
<p>Thjodleifsson et al. (2002)</p> <p>Iceland</p>	<p>To assess if MMR vaccination is associated with subclinical intestinal inflammation, which is central to the autistic 'enterocolitis' theory.</p>	<p>Design: Study comparing stool for faecal calprotectin.</p> <p>Sample: The sample consisted of 109 children attending two vaccination centers in Iceland.</p> <p>Main outcome measured: Presence of intestinal inflammation (faecal calprotectin), before, two and four weeks after immunisation with MMR and Pentavac vaccines.</p>	<p>Findings: Neither vaccination was associated with any significant increase in faecal calprotectin concentrations.</p> <p>Conclusion: The failure of the MMR vaccination to cause an intestinal inflammatory response provides evidence against the proposed gut-brain interaction that is central to the autistic 'enterocolitis' theory.</p>

<p>Uhlmann et al. (2002)</p> <p>(Wakefield co-author)</p> <p>UK</p>	<p>To investigate the presence of persistent measles virus in the intestinal tissue.</p>	<p>Design: Case control study.</p> <p>Sample: Ninety-one children with inflammatory bowel disease and 70 control patients with no inflammatory bowel disease.</p> <p>Main outcome measured : Presence of persistent measles virus in intestinal tissue.</p>	<p>Findings: Out of the 91 sample, 75 were positive for measles virus, compared with five out of the 70 control patients.</p> <p>Conclusion: The data confirm an association between the presence of measles virus and gut pathology in children with developmental disorder.</p>
<p>Smeeth et al. (2004)</p> <p>UK</p>	<p>To investigate whether MMR vaccination is associated with an increased risk of autism or other pervasive developmental disorders (PDD).</p>	<p>Design: Case control study.</p> <p>Sample: Individuals born in 1973 or later who had first recorded diagnosis of pervasive developmental disorder while registered with a contributing general practice between 1987 and 2001. 1294 cases and 4469 controls matched on age, sex, and general practice.</p> <p>Main outcome measured: Diagnosis of PDD following MMR vaccination.</p>	<p>Findings: There were 1010 cases (78.1%) had MMR vaccination recorded before diagnosis, compared to 3671 controls (82.1%) before the age at which their matched case was diagnosed.</p> <p>Conclusion: MMR vaccination is not associated with an increased risk of pervasive developmental disorders.</p>

Appendix A2

Summary of studies related to perceptions about immunisation, vaccine preventable disease and the MMR vaccine

Authors/ Date	Aim	Participants & Method	Authors Findings/ Conclusions
Klein et al. (1989) UK	To assess parents' reasons for refusing immunisation and beliefs about vaccination and diseases.	<p>Design: Survey</p> <p>Sample: Parents (n=173) were randomly selected to be interviewed following their child's admission to hospital.</p> <p>Main outcomes measured: Reasons for refusing immunisation.</p>	<p>Findings: Thirty-eight percent of parents stated that the reason their child had missed immunisation was due to infection or atopy. (This was similar to the percentage accounted for by parental apathy and objection 42%).</p> <p>Conclusion- If these two misunderstandings about infection and atopy were specifically targeted, uptake of more than 80% might be achieved.</p>
Ritov & Baron (1990) USA	To investigate the role omission bias and ambiguity play in decisions about vaccination.	<p>Design: Survey.</p> <p>Sample: Fifty-three undergraduate students were randomly selected to take part in an interview.</p> <p>Main outcomes measured: Omission bias and ambiguity in decisions, by assessing the answers students gave to hypothetical vaccine scenarios in which they had to decide whether to vaccinate their (hypothetical) child.</p>	<p>Findings: Some students considered that they would feel more responsible if their (hypothetical) child died as a result of a vaccination, than as a result of contracting a vaccine-preventable disease. This reluctance to act is an example of omission bias, whereby the person withholds vaccination because of the perception that action (commission) is more harmful than inaction (omission).</p> <p>Conclusion: When ambiguity exists in relation to the risks associated with the vaccine, it heightens the reluctance to vaccinate, even when the risks are small.</p>

<p>Pearson et al. (1993)</p> <p>UK</p>	<p>To investigate who withholds primary immunisation in Liverpool.</p>	<p>Design: Cross-sectional study.</p> <p>Sample: The immunisation records of 3585 children born between April and October 1988 were obtained from immunisation data held on the Child Health System.</p> <p>Main outcomes measured: The association between parents' consent to immunise with pertussis, and five socio- demographic factors; the child's gender, the child's position in the family, whether one or two parent family, parents' migration to Liverpool since birth and local deprivation.</p>	<p>Findings: Consent to immunise with pertussis was least likely to be given for boys, and children with older siblings, by single parents and those living in deprived areas.</p> <p>Conclusions: To achieve improved immunisation uptake, a more flexible and targeted approach is required of health professionals.</p>
<p>Keane et al. (1993)</p> <p>USA</p>	<p>To explore parents' perceptions of vaccines and immunisation.</p>	<p>Design: Qualitative study using focus groups.</p> <p>Sample: Forty parents/guardians of infants aged 18 to 24 months.</p> <p>Focus: Discussions focused on perceptions of disease severity, vaccine efficacy, and the tasks of parenthood.</p>	<p>Findings: Parents considered vaccines only partly effective and did not consider immunisation to be a high priority in the broader context of parenting. Some parents believed immunisation caused rather than prevented illness or that vaccines were ineffective.</p> <p>Conclusion: Future interventions should be aimed at changing parental perceptions of vaccines as ineffective and of fever after immunisation as an indicator of illness. Immunisation should be made easily available, even during clinic visits for a child's illness.</p>

Hershley et al. (1994) USA	To assess the roles that altruism, free-riding and bandwagoning play in vaccine decision-making.	<p>Design: Survey.</p> <p>Sample: All patients (n=472) presenting to a university student health service completed a questionnaire. Participants were asked to consider whether they would agree to be vaccinated against a contagious disease under six hypothetical scenarios.</p> <p>Main outcomes measured: The roles that altruism, free-riding and bandwagoning play in vaccine decision-making.</p>	<p>Findings: Regression analysis provided evidence that altruism ($p<.001$), free-riding ($p<.001$) and bandwagoning ($p<.001$) are significant motivators in the decision to undergo vaccination.</p> <p>Conclusion: These findings suggest that public health programmes to increase vaccine usage should stress high vaccination rates.</p>
Asch et al. (1994) USA	To assess the role that omission bias plays in parents' decisions whether to vaccinate their children against pertussis.	<p>Design: Postal survey.</p> <p>Sample: Parents subscribing to a parenting magazine (n=200). The questionnaires asked parents to consider 11 statements about the vaccine and disease and whether they had vaccinated their own children, or planned to.</p> <p>Main outcomes measured: Omission bias in their reasoning.</p>	<p>Findings: Response rate: 43%. Regression analysis showed that respondents who were not or did not plan to vaccinate were more likely to believe that vaccinating was more dangerous than not vaccinating ($p=<.001$). They were also more likely to exhibit omission bias ($p=<.004$).</p> <p>Conclusion: These findings suggest that omission bias plays a role in decisions not to vaccinate with the pertussis vaccine, beyond the role played by belief about the risk of vaccination.</p>
Simpson et al. (1995) UK	To investigate why parents whose children receive no immunisation make this choice.	<p>Design: Postal survey.</p> <p>Sample: One hundred and six children were found to have no immunisation (study omits to state how many parents) and their parents were sent a questionnaire.</p> <p>Main outcomes measured: Reasons for not immunising.</p>	<p>Findings: Response rate: 82%. The most common reasons for refusal were homoeopathy (21%), religious beliefs (16%) and medical reasons (5%). 'Other reasons' accounted for 17% these were not given by the authors.</p> <p>Conclusion: One way in which the prevalence of non-immunised children might be reduced is through improved communication of consistent and up-to-date advice to parents.</p>

Bond et al. (1998) Australia	To investigate mothers' perceptions of vaccine-preventable diseases and immunisation.	<p>Design: Qualitative study using semi-structured interviews.</p> <p>Sample: Purposive sampling was used to select mothers whose only or youngest child was either completely or incompletely immunised, or not immunised at all.</p> <p>Focus: The interviews explored mothers' perceptions of vaccine-preventable diseases and associated vaccines in terms of perceived susceptibility, severity, benefits and barriers.</p>	<p>Findings: Complete immunisers believed that the risk of vaccines was lower than the risk from disease and that the likelihood of contracting many of these diseases was low. Incomplete immunisers perceived vaccines to be less effective in preventing disease and were often confused about which diseases the vaccines would protect against. Non-immunisers were more concerned about unknown, long-term side effects of immunisation.</p> <p>Conclusion: Parents need more detailed information about the diseases. Health providers need to show that they appreciate and treat seriously parents' concerns and questions about immunisation.</p>
Gellin et al. (2000) USA	To assess parents' understanding of vaccine-preventable diseases.	<p>Design: National telephone survey.</p> <p>Sample: Parents and pregnant women (n=1600) with children under the age of six years.</p> <p>Main outcomes measured: Parents' understanding of vaccine-preventable diseases, vaccines, immunisation practices, and policies.</p>	<p>Findings: Most parents (87%) deemed immunisation an extremely important action in keeping their children well. However, 25% believed that their child's immune system could be weakened as a result of too many immunisations, and 23% believed that children receive more vaccines than are good for them. Children's health care providers were cited as the most important source of information.</p> <p>Conclusions: Many parents have important misconceptions that could erode their confidence in immunisation. There is a need for better education and nurses, physicians and other providers of primary care are best placed to do this work.</p>

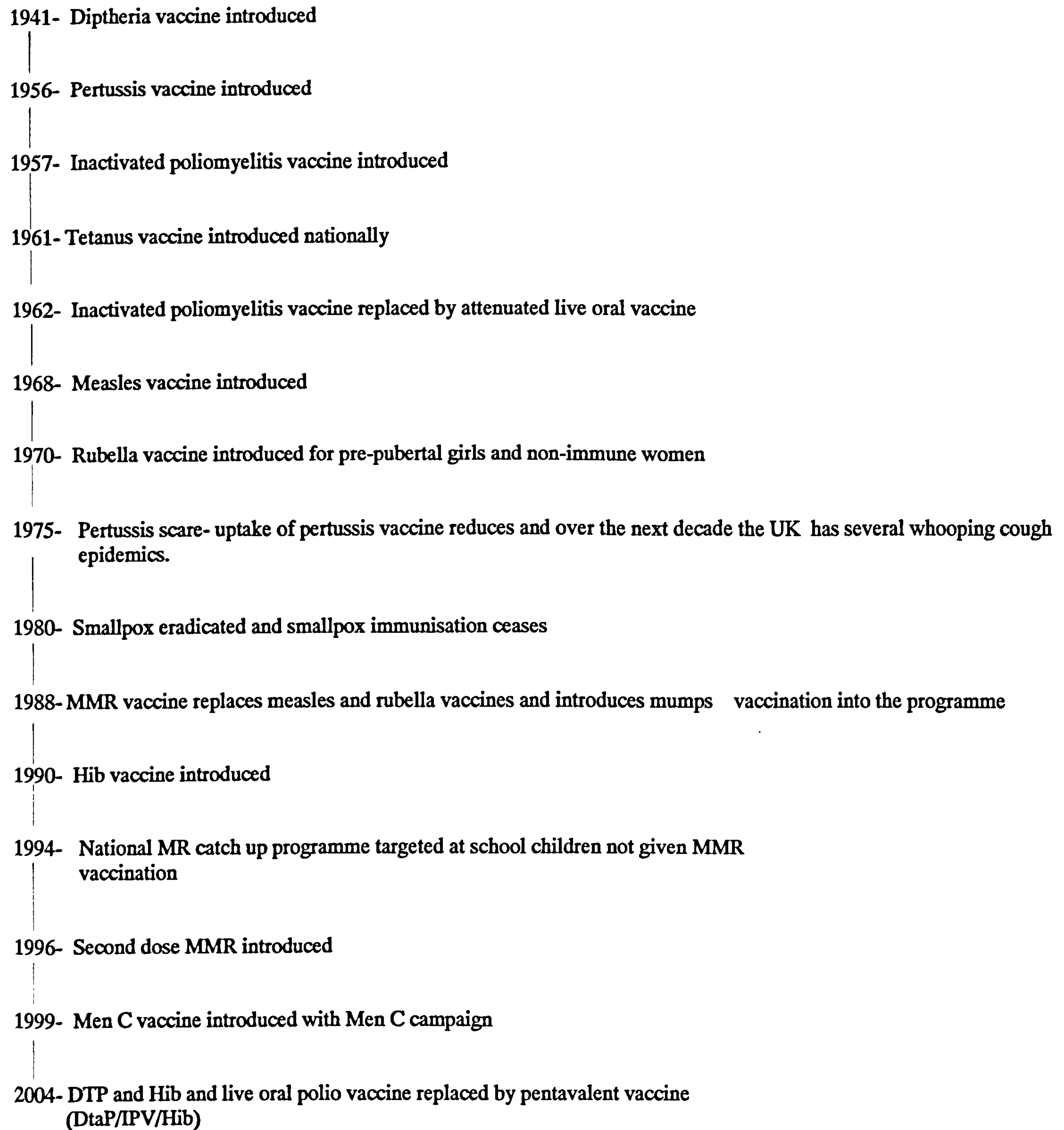
Pareek and Pattison (2000) UK	To investigate the factors that influence mothers to vaccinate with MMR.	<p>Design: Survey.</p> <p>Sample: Mothers (n=300) due to be offered MMR vaccination for their child were sent a postal questionnaire.</p> <p>Main outcomes measured: Intention to vaccinate, knowledge of the vaccine, and socioeconomic status.</p>	<p>Findings: Response rate: 59%. The commonest side-effect was general malaise, and 29.8% cited autism. The most trusted source of information was the general practitioner but the most common source of information on side-effects was television (34%).</p> <p>Conclusions: A major reason for the low uptake of the MMR vaccination is that it is not perceived to be important for children's health, particularly the second dose. Health education material from GPs is likely to have considerable impact.</p>
Sporton and Francis (2001) UK	To explore the decision-making process of parents who have chosen not to have their children immunised.	<p>Design: Qualitative study using semi-structured interviews.</p> <p>Sample: Thirteen parents whose children were not immunised.</p> <p>Focus: Parents discussed their perceptions of childhood diseases and immunisation.</p>	<p>Findings: All parents identified the risk of side effects as a reason for choosing not to immunise. Three actions were described by parents: a routine response, an emotional response and delaying the decision. Health visitors were perceived to provide unbalanced information that was an obstacle to decision-making.</p> <p>Conclusion: It is important that parents have easy access to accurate information concerning the pros and cons of vaccination, and have the opportunity to discuss their concerns with health professionals.</p>
Evans et al. (2001) UK	To investigate what influences parents' decisions on whether to accept or refuse the primary MMR immunisation and the impact of the recent controversy over its safety.	<p>Design: Qualitative study using focus groups.</p> <p>Sample: Purposive sampling was used to identify parents from varied socioeconomic backgrounds. Three groups comprised parents that had accepted MMR vaccination, and three groups comprised parents that had rejected MMR vaccination for their youngest child.</p> <p>Focus: Discussions focused on the factors influencing MMR decision-making and parents experiences of the MMR decision-making process.</p>	<p>Findings: All parents felt that the decision about MMR was difficult and stressful, and experienced unwelcome pressure from health professionals to comply. Parents were not convinced by the Department of Health's reassurances that MMR was the safest and best option for their children and many had accepted MMR unwillingly.</p> <p>Conclusions: Parents wanted up-to-date information about the risks and benefits of MMR. Many parents did not have confidence in the recommendations of health professionals as they were aware that GPs need to reach immunisation targets. Most parents would welcome more open discussion about immunisation with health professionals.</p>

Ramsay et al. (2002) UK	To describe the recent trends in parental attitudes to, and coverage of, MMR vaccine.	<p>Design: Routine surveillance of vaccine coverage and cross-sectional survey of parental attitudes.</p> <p>Sample: Quarterly MMR vaccine coverage for all two year olds resident in England and data from 1000 mothers that took part in interviews as part of a national survey.</p> <p>Main outcomes measured: The MMR uptake between April and June 1995 compared to between April and June 2001. Mothers' attitudes and beliefs about MMR vaccination.</p>	<p>Findings: MMR coverage at two years of age fell 8.6% between April and June 1995 and between April and June 2001. In September 67% of mothers reported that the MMR vaccine was safe or carried only a slight risk and 92% of mothers suggested they would continue to immunise all their children against all childhood diseases.</p> <p>Conclusion: Despite the adverse publicity, the fall in MMR coverage has been relatively small. Mothers' attitudes to MMR remain positive and most plan to have future children fully immunised.</p>
Smailbegovic et al. (2003) UK	To explore the knowledge, attitudes and concerns with respect to immunisation and vaccine-preventable infections in parents whose children have not completed the recommended course of immunisation.	<p>Design: Postal survey.</p> <p>Sample: Children whose parents had defaulted on one or more primary immunisation by 18 months of age were identified from the child health database. After validation 129 parents were sent questionnaires. Ten parents from this sample were also interviewed.</p> <p>Focus: Parents' knowledge, attitudes and concerns about immunisation and vaccine-preventable diseases.</p> <p>Design: An in-depth interview study.</p> <p>Sample: Parents with pre-school age children (n=15) attending two nurseries were invited to take part in an interview.</p> <p>Focus: Topics related to parents' vaccine risk perceptions.</p>	<p>Findings: Response rate 69%. MMR and Men C vaccines were most frequently refused, usually because of concerns about vaccine safety. Twenty-three respondents perceived that having their child immunised with a particular vaccine was more risky than non-immunisation. Those who were interviewed were concerned about the MMR vaccine but not immunisation in general.</p> <p>Conclusion: The decision-making process around childhood immunisation is complex. Parents require information that is up-to-date, tailored to their individual needs and provided by health professionals who are well informed.</p>
Raithatha et al. (2003) UK	To assess their vaccine risk perception and thereby to identify strategies to prevent further deterioration in uptake.	<p>Design: An in-depth interview study.</p> <p>Sample: Parents with pre-school age children (n=15) attending two nurseries were invited to take part in an interview.</p> <p>Focus: Topics related to parents' vaccine risk perceptions.</p>	<p>Findings: Risk characteristics associated with MMR vaccination were feeling of dread, lack of control, doubt in scientific knowledge, lack of trust in government agencies and doubts in the medical profession as the 'managers' of vaccine risk.</p> <p>Conclusion: There is an urgent need to address concerns amongst parents who immunise, to ensure they continue to immunise.</p>

<p>Miller et al. (2003)</p> <p>UK</p>	<p>To assess whether MMR vaccination induces clinical immunosuppression.</p>	<p>Design: Time series.</p> <p>Sample: Children admitted to hospital with a bacterial infection over a 90 day period post-MMR vaccination (n=436).</p> <p>Main outcomes measured: The relative incidence (RI) of admission for bacterial infection within 90 days of MMR vaccination and in the month before vaccination. The 90 day period was divided into three contained 30 day periods to test for clustering in pre-defined post-vaccination periods.</p>	<p>Findings: There were 116 children that had a diagnosis of invasive bacterial infection, 279 that had lobar pneumonia, 25 were admitted with an underlying disorder and 16 were considered repeat admissions for the same illness. None of the post-vaccination risk periods showed an RI significantly greater than 1.0 including the prevaccination period.</p> <p>Conclusion: MMR vaccination did not increase the risk of hospitalisation with invasive bacterial infection in the three month period post vaccination. These results provide no support for the concept of 'immunological overload' induced by multiple antigen vaccinations, nor support for calls for single antigen vaccines.</p>
<p>McMurray et al. (2004)</p> <p>UK</p>	<p>To explore parents' accounts of decision-making relating to the MMR vaccine controversy, identifying uptake determinants and education needs.</p>	<p>Design: Qualitative study using semi-structured interviews.</p> <p>Sample: Parents of children aged between 4 and 5 years (n=69), and 12 interviews with primary care practitioners, managers and immunisation coordinators.</p>	<p>Findings: For most parents the evidence of science and medicine plays little role in the decision. The influence of primary care providers on the decision is limited by concerns over financial and political partiality.</p> <p>Conclusion: Parents and practitioners need to be supported in order to increase understanding of medical science and secure more informed decisions in the face of health controversy.</p>
<p>Flynn and Ogden (2004)</p> <p>UK</p>	<p>To describe parents' beliefs about MMR vaccination and to explore the best predictors of uptake by the age of 2 years.</p>	<p>Design: Survey.</p> <p>Sample: Parents (n=898) of children due to receive an invitation for the MMR vaccination were mailed a questionnaire.</p> <p>Main outcomes measured: Respondents beliefs about MMR vaccination and previous vaccination history compared to attendance data checked at two years of age.</p>	<p>Findings: Response rate 56.9%. Parents were ambivalent about the benefit of vaccinations and were unsure whether to trust either the medical profession or the media. Uptake of vaccination at follow-up was related to previous uptake for vaccination, increased faith in the media, and a lower belief that vaccination is unhealthy and can harm the immune system.</p> <p>Conclusion: Many parents hold mixed beliefs about the MMR vaccination and the doctors who administer it. Uptake relates to past experience and more positive beliefs.</p>

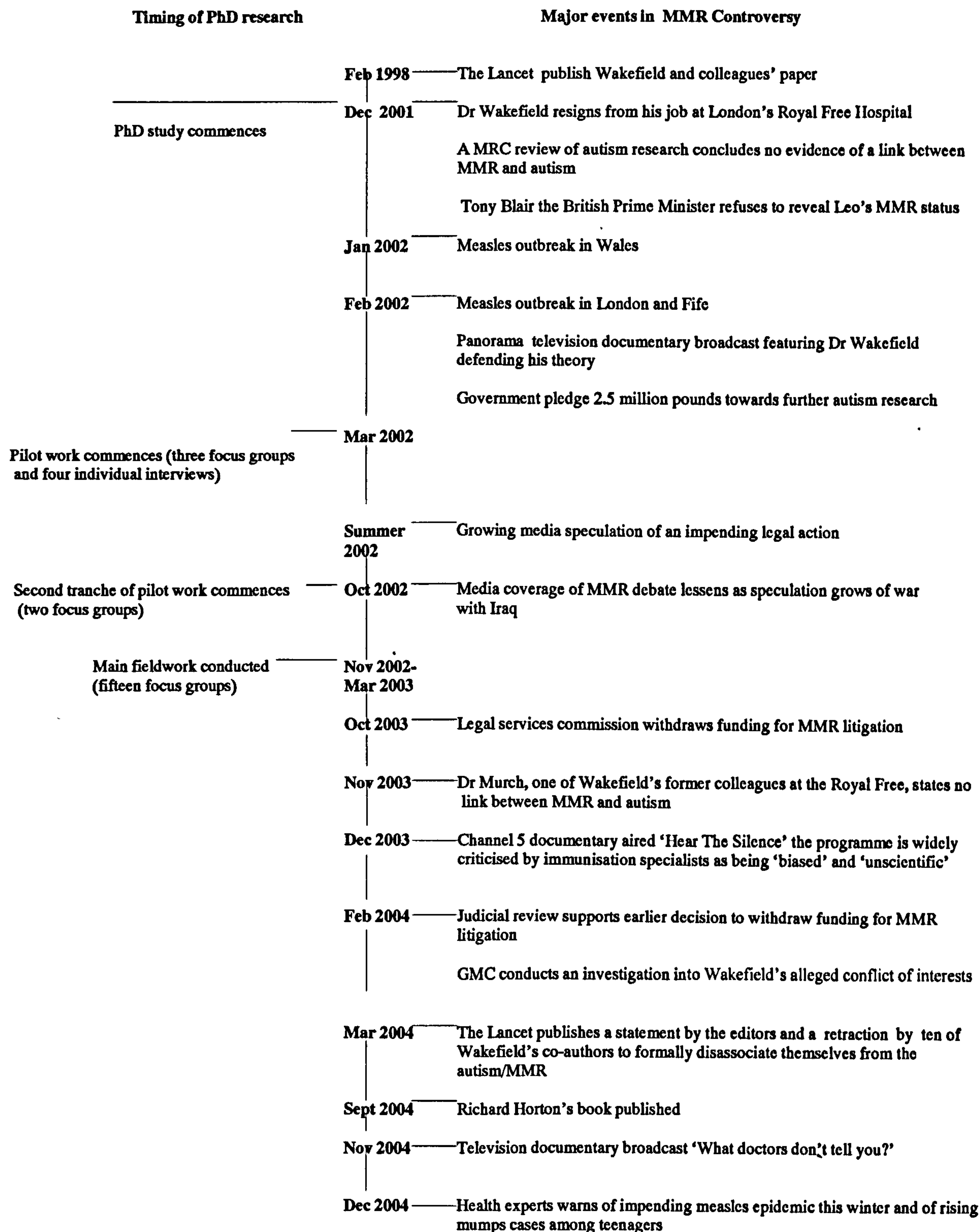
United Kingdom Childhood Immunisation Programme		
VACCINE/ DISEASE	HOW IT IS GIVEN	AGE VACCINE GIVEN
Diphtheria/tetanus/ Pertussis/ Hib & polio (DtaP/IPV/Hib)	Combined 5 in 1 injection	2 months
Men C	One injection	2 months
//////////////////// ////////	////////////////////	////////////////////
Diphtheria/tetanus/ Pertussis/ Hib & polio (DtaP/IPV/Hib)	Combined 5 in 1 injection	3 months
Men C	One injection	3 months
//////////////////// ////////	////////////////////	////////////////////
Diphtheria/tetanus/ Pertussis/ Hib & polio (DtaP/IPV/Hib)	Combined 5 in 1 injection	4 months
Men C	One injection	4 months
//////////////////// ////////	////////////////////	////////////////////
Measles/mumps/ rubella (MMR)	Combined 3 in 1 injection	12 to 15 months
//////////////////// ////////	////////////////////	////////////////////
Diphtheria/tetanus/ Pertussis & polio (dTaP/IPV or DtaP/IPV)	Combined 4 in 1 injection	3 to 5 years
Measles/mumps/ rubella (MMR)	Combined 3 in 1 injection	3 to 5 years

Timeline showing the major changes to the Childhood Immunisation Programme between 1940 and 2004 (not to scale).

- 
- 1941- Diphtheria vaccine introduced
 - 1956- Pertussis vaccine introduced
 - 1957- Inactivated poliomyelitis vaccine introduced
 - 1961- Tetanus vaccine introduced nationally
 - 1962- Inactivated poliomyelitis vaccine replaced by attenuated live oral vaccine
 - 1968- Measles vaccine introduced
 - 1970- Rubella vaccine introduced for pre-pubertal girls and non-immune women
 - 1975- Pertussis scare- uptake of pertussis vaccine reduces and over the next decade the UK has several whooping cough epidemics.
 - 1980- Smallpox eradicated and smallpox immunisation ceases
 - 1988- MMR vaccine replaces measles and rubella vaccines and introduces mumps vaccination into the programme
 - 1990- Hib vaccine introduced
 - 1994- National MR catch up programme targeted at school children not given MMR vaccination
 - 1996- Second dose MMR introduced
 - 1999- Men C vaccine introduced with Men C campaign
 - 2004- DTP and Hib and live oral polio vaccine replaced by pentavalent vaccine (DtaP/IPV/Hib)

Timeline showing the timing of PhD fieldwork in relation to major events in the MMR controversy

Appendix D



CHECK LIST

- 1. Check has everyone received and read the information sheet?**
- 2. Introduce self and research.**
- 3. Re-state the following:**
 - Length of time (approx 1 hr).
 - Voluntary nature of participation.
 - Recording the group discussion.
 - Confidentiality – (information kept in locked drawer in MRC unit & not disclosed to anyone outside the research team).
 - Anonymity- (all documents and data identifiable only through ID number and any extracts used in presentations or publications given pseudonyms to protect identity).
 - Expenses.
- 4. Check if there are any questions or concerns about the study.**
- 5. Get the consent form signed and personal detail form completed.**
- 6. Give out discussion material.**
- 7. Switch on microphone and recorder.**
- 8. Map positions of participants – (name, no of children & age of children).**

TOPIC GUIDE (not in order)

EXPERIENCES OF CHILDHOOD IMMUNISATION/ PERCEPTIONS ABOUT VACCINES

- Words / images associated with immunisation.
- Experience of immunisation so far.
- Views on the current Childhood Immunisation Programme.
(Hand out Immunisation Programme see Appendix L)

PERCEPTIONS ABOUT CHILDHOOD INFECTIOUS DISEASES

- Words / images associated with: - Diphtheria, tetanus, whooping cough (or pertussis), meningococcal disease, mumps, poliomyelitis, measles, rubella and haemophilus influenzae (or Hib).
- Find out which disease's parents' feel **most** and **least severe**?
- Find out which disease's parents' feel **most** and **least prevalent**?
- Find out which disease's parents' feel **threatens** their child's health **most** and **least** ?
- Explore parents knowledge/ understanding about how they think each disease is transmitted.
- **Do parents have any direct experiences** of any of the diseases either as parents themselves or as children?
- **Does this affect their perceptions about the disease and in what way?**
- **If parents have no direct experience** of childhood infectious diseases, what or who has helped them make their assessments of these diseases?

BELIEFS ABOUT HEALTH & THE IMMUNE RESPONSE

- How- vaccines works / explore parents' understanding of the body reaction to vaccination or to disease?
- Explore notions of 'healthiness' with immunisation and perceived threat of disease.
Is there any relationship between -general health and need for immunisation?
-general health and threat of disease?

BELIEFS ABOUT CHOICE & RESPONSIBILITY

- Individual choice V's societal responsibility. Is it okay to opt out? & When?

PERCEPTIONS ABOUT THE MMR VACCINE / DEBATE

- Feelings about the MMR vaccine?
- Feelings about the MMR debate?
- Beliefs about the 'state of the evidence.'
- Feelings about the Dr Wakefield?

THE EXPERIENCE OF DECIDING ABOUT MMR

- MMR decision making experiences. Was it an easy or difficult decision?
- Influential factors in the 1st & 2nd MMR dose. Were they different?
- Identify other people involved in the decision. Any informal support?
- Explore which of the other vaccines easy / difficult to decide about? Why?

If autism brought up by group-

- Explore words / images/ fears about autism.
- Experience of autism.
- Feelings / perceptions re: 'the evidence'.

CHECK

1. Ensure each person given list of contacts & reply paid envelopes.
2. Expenses given.
3. Thank parents.

Parents' perceptions of childhood infectious diseases, MMR and other childhood immunisation.

- What is this study about?**

I would like to talk to parents about their experiences and beliefs about childhood infectious diseases and childhood immunisation. I am interested in hearing about your experiences of the immunisation service, of the current immunisation programme, what you feel about the measles, mumps and rubella vaccine (MMR) and what factors influence your decisions about whether to get your child immunised, or not.

- Why are your views important?**

I am carrying out a small number of discussion groups with parents of young children in various parts of Glasgow and surrounding areas. Whilst the study is unlikely to be of direct benefit to yourselves and there is, of course no obligation to take part in the study, it is hoped that your participation in the study will help future parents. If you are interested in the findings of this study, a summary will be available to you on request once the study is completed.

- What do you have to do?**

The group discussion today will take approximately one hour and will be recorded to ensure I get an accurate account of what is said. If you are willing to take part, you will be given a consent form to sign and details of when and where in the clinic the group discussion is planned to take place.

- What will the data be used for?**

The Medical Research Council is funding this research project. The information collected from all the groups will be studied and the findings used as the basis of a PhD, published in academic journals and presented to policy makers.

- Will the information provided be kept confidential?**

Yes, short quotes of what you say may be used in articles in research journals, but I will not use your name or anything that could identify you, so that you remain anonymous. Only members of the research team will have access to the tapes and written material relating to the tapes and the Medical Research Council requires us to keep all research documents in a locked drawer for ten years, in accordance with the MRC guidelines on good practice.

- What should you do if you wish to take part or want more information?**

Please let me know if you have any questions about the study, or wish to take part. If you decide that you would like a summary once the study is completed my contact details are as follows:

Direct line 0141 357 7537

Email shona@msoc.mrc.gla.ac.uk

Address MRC, Social & Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow, G12 8RZ.



Parents' perceptions of childhood infectious diseases, MMR and other childhood immunisation.

The purpose of this agreement is to ensure that your contribution to the above research project is in strict accordance with your wishes.

Please tick as appropriate :-

- ☐ I have read the information sheet that describes this study, and agree to take part in a group discussion.
- ☐ I give permission for brief extracts of what I say to be used for research purposes (including research publications and reports), with strict preservation of anonymity. I understand that the recorded discussions will remain confidential and become the property of the MRC Social & Public Health Sciences Unit.

I understand that I do not need to answer all the questions if I do not wish to and that I may leave the discussion at any time.

I am aware that any information I provide will be treated in the strictest of confidence. Tapes and transcripts will be locked away and only available to the research team.

Signed..... Date.....

Name (Block capitals please).....

Address.....

Group Characteristics

The sampling frame included a diverse range of parents to ensure maximum variation in terms of age, socio-economic circumstances (including deprived and more affluent communities), likely views about vaccination (including parents living in high and low uptake areas, as well as with groups of parents who had opted for single measles, mumps and rubella vaccines instead of MMR, parents who rejected the MMR, and rejected all vaccination) and family circumstances (including first-time mothers, more experienced mothers, single parents and parents with multiple social problems). Four focus groups were conducted with parents who were anticipated to have a particular interest in the debate: two with parents who had autistic children and two with parents whose child had recently had a compromised immune system following chemotherapy.

The profile of the 18 focus groups is represented below

GROUP 1: NCT GROUP (PILOT)

Recruited from the National Childbirth Trust (pre-existing group)

Participant’s Pseudonyms	Trudie	Violet	Mel
Participant’s Age	38	36	35
Occupation by social class	11	1	At home full-time
1 st Child’s gender, age, immunisation status	Girl, 8 yrs, fully immunised	Girl, 2yrs, partially immunised-delayed 1 st MMR (egg allergy)	Boy, 4yrs, fully immunised – delayed MMR until he was 2yrs old
2 nd Child’s gender, age, immunisation status	Girl, 7mths, fully immunised	-	Girl, 15mths, partially immunised–plans to delay MMR until she is 2 yrs old

GROUP 2: NEW MOTHERS GROUP (PILOT)

Recruited from a postnatal support group (pre-existing group)

Participant’s Pseudonyms	Joanne	Elaine	Louise	Beathan
Participant’s Age	37	34	29	29
Occupation by social class	11	1	11	11
1 st Child’s gender, age, immunisation status	Boy, 5mths, fully immunised	Boy, 4mths, fully immunised	Boy, 5mths, fully immunised	Girl, 6mths, fully immunised

GROUP 3: ANTENATAL GROUP (PILOT)

Recruited from an antenatal group for second time mums (pre-existing group)

Participant's Pseudonyms	Sian	Dawn	Ruth	Beatrice	Iona
Participant's Age	32	36	29	29	39
Occupation by social class	Did not complete	At home full-time	1	11	11
1 st Child's gender, age, immunisation status	1 st child died at birth	Boy,4yrs, partially immunised-not given MMR	Boy, 12mths, fully immunised	Boy,18mths, partially immunised-not given MMR	Boy, 12yrs, fully immunised
2 nd Child's gender, age, immunisation status	-	Boy, 3yrs, partially immunised-not planning to give pertussis or MMR	-	-	Girl, 7yrs, fully immunised
3rd Child's gender, age, immunisation status	-	-	-	-	Girl, 5yrs, fully immunised
4th Child's gender, age, immunisation status	-	-	-	-	Boy, 3yrs, fully immunised

GROUP 4: LOW UPTAKE AREA GROUP (deprived area)

Recruited from a recreational centre in DEPCAT 7 area with low MMR uptake rate less than 75% (specially convened group)

Participant's Pseudonyms	Joan	Sheila	Alan
Participant's Age	20	36	33
Occupation by social class	At home full-time	At home full-time	111M
1 st Child's gender, age, immunisation status	Girl, 20mths, fully immunised	Boy, 21mths, fully immunised	Boy, 2yrs, Partially Immunised -not had 1 st MMR.
2 nd Child's gender, age, immunisation status	-	Girl, 10yrs, fully immunised	-
3rd Child's gender, age, immunisation status	-	Girl, 3yrs7mths, fully immunised	-

GROUP 5: HIGH UPTAKE AREA GROUP (affluent area)

Recruited from a private nursery in DEPCAT 1 area with high MMR uptake rate greater than 95% (specially convened group)

Participant's Pseudonyms	Fiona	Alison	Lauren	Cassie	Karen	Anna
Participant's Age	32	31	29	29	36	33
Occupation by social class	111M	At home full-time	1	11	11	At home full-time
1 st Child's gender, age, immunisation status	Girl, 6yrs, fully immunised	Boy, 15mths, partially immunised delaying 1 st MMR	Boy, 14mths, Partially immunised delaying 1 st MMR	Girl, 3yrs, fully immunised	Girl, 7yrs, fully immunised	Girl, 7yrs, fully immunised
2 nd Child's gender, age, immunisation status	Boy, 5mths, fully immunised	-	-	Boy, 9mths, fully immunised	Girl, 4yrs, fully immunised	Boy, 4yrs, partially immunised not given 2 nd MMR
3 rd Child's gender, age, immunisation status	-	-	-	-	Boy, 4mths, fully immunised	Girl, 3yrs, Partially immunised no MMR
4 th Child's gender, age, immunisation status	-	-	-	-	-	Girl, 1yr 2mths partially immunised no MMR

GROUP 6: SATURDAY CLUB GROUP (deprived area)

Recruited from a Saturday club in DEPCAT 6 area with low MMR uptake rate less than 75% (specially convened group)

Participant's Pseudonyms	Cathy	Bob	Ella	Helen
Participant's Age	29	31	45	39
Occupation by social class	11	1	Self-employed	11
1 st Child's gender, age, immunisation status	Girl, 3yrs 6mths, fully immunised	Boy 3yrs 2mths, fully immunised- but not getting 2 nd MMR (adverse reaction to 1 st MMR).	Boy, 5yrs, partially immunised (only had DTP)	Girl, 4yrs 7mths, fully immunised
2 nd Child's gender, age, immunisation status	Boy, 2yrs 1mth, fully immunised	Boy, 7mths, fully immunised not planning to give MMR	-	Boy, 2yrs 7mths, fully immunised

GROUP 7: CRAFTS GROUP (deprived area)

Recruited from a crafts group in DEPCAT 6 area with high MMR uptake rate greater than 95% (pre-existing group)

Participant's Pseudonyms	Tracy	Samantha	Lydia	Angie	Mary
Participant's Age	32	24	39	29	43
Occupation by social class	Unemployed	Unemployed	111N	111M	At home full-time
1 st Child's gender, age, immunisation status	Boy, 10yrs, fully immunised	Boy, 16mths, Boy	Boy, 6yrs, fully immunised	Boy, 5yrs, fully immunised	Girl, 5yrs, fully immunised
2 nd Child's gender, age, immunisation status	Girl, 4yrs, fully immunised	-	-	Boy, 18mths, fully immunised	-
3 rd Child's gender, age, immunisation status	Girl, 2yrs 2mths, fully immunised	-	-	-	-

NB: Lydia mentions that she has six children, but only fills in details for her youngest.

GROUP 8: YOUNG SINGLE MOTHERS GROUP (deprived area)

Recruited from a family resource unit in DEPCAT 7 area with MMR uptake rate approx. 85% (pre-existing group)

Participant's Pseudonyms	Kate	Margaret	Lisa	Ann	Lynne	Natalie	Ros	Lucy
ParticipAge	22	20	20	16	20	18	20	15
Occup by social class	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed
1 st Child's gender, age, immunisation status	Boy, 2yrs, fully	Boy, 2yrs 3mths, partially immunised not had 1 st MMR	Girl, 2yrs 11mths, fully immunised	Boy, 6mths fully immunised	Boy 13mths fully immunised	Boy, 15mths, fully immunised	Boy, 20mths, fully immunised	Boy, 11wks, fully immunised
2 nd Child's gender, age, immunisation status	-	-	Boy, 1yr 11mths, fully immunised	-	-	-	-	-

GROUP 9: FIRST-TIME MOTHERS GROUP (affluent area)

Recruited from a baby massage class in a DEPCAT 1 area with MMR uptake rate 89% (pre-existing group)

Participant's Pseudonyms	Rhona	Catrina	Judith	Charlotte	Celia
Participant's Age	31	27	34	29	33
Occupation by social class	At home full-time	At home full-time	11	At home full-time	At home full-time
1 st Child's gender, age, immunisation status	Boy, 11wks, fully immunised	Girl, 11wks, fully immunised	Girl, 11wks, fully immunised	Girl, 5mths, fully immunised	Girl, 6mths, fully immunised

GROUP 10: SINGLE FATHERS GROUP (deprived area)

Single fathers group recruited from a family resource unit in DEPCAT 7 area with MMR uptake rate approx 85% (pre-existing group)

Participant's Pseudonyms	William	Kenny	Robert
Participant's Age	51	43	47
Occupation by social class	Unemployed Sole Carer	Unemployed	Unemployed Sole Carer
1 st Child's gender, age, immunisation status	Girl, 12yrs 11mths, fully immunised	Boy, 3yrs, immunisation status unknown	Girl, 17yrs, fully immunised
2 nd Child's gender, age, immunisation status	Girl, 5yrs 2mths, fully immunised	Boy, 3mths, fully immunised	Boy, 6yrs, fully immunised

NB: William also has three older boys who have left home (aged 17, 19 and 21).

GROUP 11: MULTIPLE PARENTING PROBLEMS GROUP (deprived area)

Parents with drug addictions recruited by snowballing through a community project from derived area DEPCAT score 7 (specially convened group) Michelle was certain her young 6mth baby had had four DTP's.

Participant's Pseudonyms	Sheena	Michelle	Patsy	Frank
Participant's Age	24	21	23	31
Occupation by social class	Unemployed	Unemployed	Unemployed	Unemployed
1 st Child's gender, age, immunisation status	Girl, 7yrs, fully immunised	Boy, 2yrs 2mths, fully immunised but delayed MMR	Boy (twin) 3yrs, fully immunised but delayed MMR	As for Patsy
2 nd Child's gender, age, immunisation status	Boy, 6yrs, fully immunised	Girl, 6mths, fully immunised- stated she had 4 DTP's	Boy (twin) 3yrs, fully immunised but delayed MMR	As for Patsy
3rd Child's gender, age, immunisation status	Boy, 2yrs, fully immunised, but delayed 1 st MMR	-	Boy, 2mths no immunisation given yet but plans to immunise	As for Patsy

GROUP 12: SINGLE VACCINE GROUP

Recruited from a private health care clinic (specially convened group)

Participant's Pseudonyms	Dave	Jenny	Joe (male)
Participant's Age	38	19	36
Occupation by social class	11	At home full-time	At home full-time
1 st Child's gender, age, immunisation status	Girl, 7yrs 7mths, fully immunised-given single measles, mumps and rubella vaccines	Boy, 2yrs 1mth, partially immunised in the process of getting single measles, mumps and rubella vaccines	Boy, 2yrs 3mths, partially immunised- in the process of getting single measles, mumps and rubella vaccines
2 nd Child's gender, age, immunisation status	Girl, 1yr 9mths, partially immunised- in the process of getting single measles, mumps and rubella vaccines	-	-

GROUP 13: NON-MMR GROUP

Recruited from the National Childbirth Trust, homeopathic and herbal shops (brought together group)

Participant's Pseudonyms	Sue	Aleena	Hannah
Participant's Age	36	35	40
Occupation by social class	11	11	At home full-time
1 st Child's gender, age, immunisation status	Boy, 6yrs 6mths, partially immunised- not given 2nd MMR.	Girl, 5yrs 6mths, no immunisation given at all.	Boy, 4yrs 3mths, partially immunised- not given MMR
2 nd Child's gender, age, immunisation status	Boy, 4yrs 8mths, partially immunised –not given MMR. Given homeopathic alternative	Girl, 3yrs 4mths, no immunisation given at all	Boy, 2yrs 8mths, partially immunised- not given MMR
3 rd Child's gender, age, immunisation status	Boy, 13mths, fully immunised, but plans to delay MMR	Girl, 5mths, no immunisation given at all	-

GROUP 14: NON-VACCINE GROUP

Recruited from alternative parenting organisations (specially convened group)

Participant's Pseudonyms	Molly	Kitty	Lola	Debbie
Participant's Age	37	37	32	33
Occupation by social class	11	11	At home full-time	11
1 st Child's gender, age, immunisation status	Boy, 5yrs 10mths, no immunisation given, homeopathic alternative given instead.	Boy, 6yrs, partially immunised - not given Men C or MMR	Boy, 6yrs 6mths, partially immunised-not given Men C	Boy, 5yrs 4mths, partially immunised
2 nd Child's gender, age, immunisation status	Boy, 2yrs 9mths, no immunisation given, homeopathic alternative given instead.	Boy, 4yrs, partially immunised - not given Men C or MMR	Boy, 4yrs 10mths, partially immunised-not given Men C	Boy, 3yrs 6mths, no immunisation given or planned
3rd Child's gender, age, immunisation status	-	Boy, 2yrs, no immunisation given or planned	Boy, 2yrs 5mths, no immunisation given or planned	Girl, 1yr 11mths no immunisation given or planned
4th Child's gender, age, immunisation status	-	-	-	Girl, 4wks, no plans to immunise

GROUP 15: AUTISTIC CLUB GROUP

Recruited from a club for autistic children (specially convened group)

Participant's Pseudonyms	Lesley	Dianna	Jacqueline
Participant's Age	omitted	omitted	omitted
Occupation by social class	omitted	omitted	omitted
1 st Child's gender & immunisation status	Boy, fully immunised	Boy, partially immunised omitted	Boy, partially immunised
2 nd Child's gender & immunisation status	Boy, partially immunised not given 2 nd MMR	Boy, no plans to immunise	Boy, partially immunised

GROUP 16: AUTISM SUPPORT GROUP

Recruited from the National Autistic Society (specially convened group)

Participant's Pseudonyms	Stella	Alison	Caroline
Participant's Age	omitted	omitted	omitted
Occupation by social class	omitted	omitted	omitted
1 st Child's gender & immunisation status	Boy, fully immunised	Boy, partially immunised	Boy, partially immunised
2 nd Child's gender & immunisation status	Boy, partially immunised	Boy, partially immunised	Boy, partially immunised

GROUP 17: CANCER SUPPORT GROUP

Recruited through a parent support group (specially convened group)

Participant's Pseudonyms	Sally	Rebecca	Pamela
Participant's Age	45	49	42
Occupation by social class	11	At home full-time (used to be a nurse)	11
1 st Child's gender, age, immunisation status	Girl, 25yrs, fully immunised	Boy, 21yrs, fully immunised	Boy, 13yrs, fully immunised
2 nd Child's gender, age, immunisation status	Boy, 20yrs, fully immunised	Girl, 17yrs, fully immunised	Girl, 11yrs, fully immunised
3rd Child's gender, age, immunisation status	Boy, 9yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated	Girl, 12yrs, fully immunised	Girl, 8 yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated
4th Child's gender, age, immunisation status	-	Girl, 8yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated	-

GROUP 18: OUTPATIENT CANCER GROUP

Recruited through snowballing from parents knowing each other from out-patient clinics at hospital visits (specially convened group)

Participant's Pseudonyms	Jill	Cara	Jessie
Participant's Age	38	36	53
Occupation by social class	11	11	At home full-time
1 st Child's gender, age, immunisation status	Girl, 16yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated	Girl, 8yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated	Girl, 25yrs, fully immunised
2 nd Child's gender, age, immunisation status	Boy, 14yrs, fully immunised	Boy, 6yrs, fully immunised	Girl, 19yrs, fully immunised
3rd Child's gender, age, immunisation status	Boy, 14yrs, fully immunised	-	Boy, 16 yrs, no known antibody immunity due to treatment for cancer. Not re-vaccinated



**UNIVERSITY
of
GLASGOW**

MRC
Medical Research Council

**Social and Public Health Sciences Unit
University of Glasgow
4 Lilybank Gardens
G12 8RZ**

Dear Parent,

My name is Shona Hilton. I am a researcher at Glasgow University carrying out a study on parents' perceptions of childhood infectious diseases, MMR and other childhood immunisation.

At present I am recruiting parents with different views and experiences of childhood immunisation. I plan to hold a discussion group with parents who have children with autism here inCommunity Centre in November. If you would be willing to take part in a group discussion on immunisation I would be happy to hear from you.

Further details of the study are attached along with my contact details. However, if you prefer you can send me with your contact details in the attached envelope and I will make contact with you.

If you are willing to take part I would be very grateful. Thank you very much for your help.

Yours sincerely

Shona Hilton



Parents’ perceptions of childhood infectious diseases, MMR and other childhood immunisation.

Name:..... Age:.....

Address.....

Post-code:..... Occupation.....

Marital Status (please tick)

- ☐ Married
- ☐ Cohabiting
- ☐ Single
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

Please fill in the grid below using a new row for each of your children.

Child's age	Boy or Girl	Immunisation status
Example: 1yr 2mths	Girl	Tick box if your child has had each vaccine, if not please state whether you plan to have it, or not.
		<div><input type="checkbox"/> DTP/Hib/Men C 1st @ 2mths</div> <div><input type="checkbox"/> DTP/Hib/Men C 2nd @ 3mths</div> <div><input type="checkbox"/> DTP/Hib/MenC 3rd @ 4mths</div> <div><input type="checkbox"/> Polio 1st @ 2mths</div> <div><input type="checkbox"/> Polio 2nd @ 3mths</div> <div><input type="checkbox"/> Polio 3rd @ 4mths</div> <div><input type="checkbox"/> MMR 1st between 12 and 15mths</div> <div><input type="checkbox"/> MMR 2nd pre-school booster</div> <div><input type="checkbox"/> DTP/Hib pre-school booster</div> <div><input type="checkbox"/> Polio pre-school booster</div>
		<div><input type="checkbox"/> DTP/Hib/Men C 1st @ 2mths</div> <div><input type="checkbox"/> DTP/Hib/Men C 2nd @ 3mths</div> <div><input type="checkbox"/> DTP/Hib/MenC 3rd @ 4mths</div> <div><input type="checkbox"/> Polio 1st @ 2mths</div> <div><input type="checkbox"/> Polio 2nd @ 3mths</div> <div><input type="checkbox"/> Polio 3rd @ 4mths</div> <div><input type="checkbox"/> MMR 1st between 12 and 15mths</div> <div><input type="checkbox"/> MMR 2nd pre-school booster</div> <div><input type="checkbox"/> DTP/Hib pre-school booster</div> <div><input type="checkbox"/> Polio pre-school booster</div>
		<div><input type="checkbox"/> DTP/Hib/Men C 1st @ 2mths</div> <div><input type="checkbox"/> DTP/Hib/Men C 2nd @ 3mths</div> <div><input type="checkbox"/> DTP/Hib/MenC 3rd @ 4mths</div> <div><input type="checkbox"/> Polio 1st @ 2mths</div> <div><input type="checkbox"/> Polio 2nd @ 3mths</div> <div><input type="checkbox"/> Polio 3rd @ 4mths</div> <div><input type="checkbox"/> MMR 1st between 12 and 15mths</div> <div><input type="checkbox"/> MMR 2nd pre-school booster</div> <div><input type="checkbox"/> DTP/Hib pre-school booster</div> <div><input type="checkbox"/> Polio pre-school booster</div>
		<div><input type="checkbox"/> DTP/Hib/Men C 1st @ 2mths</div>

		<input type="checkbox"/> DTP/Hib/Men C 2 nd @ 3mths <input type="checkbox"/> DTP/Hib/MenC 3 rd @ 4mths <input type="checkbox"/> Polio 1 st @ 2mths <input type="checkbox"/> Polio 2 nd @ 3mths <input type="checkbox"/> Polio 3 rd @ 4mths <input type="checkbox"/> MMR 1 st between 12 and 15mths <input type="checkbox"/> MMR 2 nd pre-school booster <input type="checkbox"/> DTP/Hib pre-school booster <input type="checkbox"/> Polio pre-school booster
		<input type="checkbox"/> DTP/Hib/Men C 1 st @ 2mths <input type="checkbox"/> DTP/Hib/Men C 2 nd @ 3mths <input type="checkbox"/> DTP/Hib/MenC 3 rd @ 4mths <input type="checkbox"/> Polio 1 st @ 2mths <input type="checkbox"/> Polio 2 nd @ 3mths <input type="checkbox"/> Polio 3 rd @ 4mths <input type="checkbox"/> MMR 1 st between 12 and 15mths <input type="checkbox"/> MMR 2 nd pre-school booster <input type="checkbox"/> DTP/Hib pre-school booster <input type="checkbox"/> Polio pre-school booster
		<input type="checkbox"/> DTP/Hib/Men C 1 st @ 2mths <input type="checkbox"/> DTP/Hib/Men C 2 nd @ 3mths <input type="checkbox"/> DTP/Hib/MenC 3 rd @ 4mths <input type="checkbox"/> Polio 1 st @ 2mths <input type="checkbox"/> Polio 2 nd @ 3mths <input type="checkbox"/> Polio 3 rd @ 4mths <input type="checkbox"/> MMR 2 nd pre-school booster <input type="checkbox"/> DTP/Hib pre-school booster <input type="checkbox"/> Polio pre-school booster

If none of the above apply, please describe your children’s immunisation status
overleaf... ..

THANK YOU

Any further comments

**Descriptions of the vaccine preventable-diseases included in the Childhood
Immunisation Programme**

Source: www.scieh.org.uk

Diphtheria

Causative Agent

Corynebacterium diphtheriae (toxin producing strains).

Clinical Description

Diphtheria is an acute bacterial disease resulting from toxigenic *C. diphtheriae* or more rarely *C. ulcerans* infection of the upper respiratory tract and occasionally the skin. An inflamed thick greyish adherent membrane forms at the site of infection, which, in severe cases, may cause respiratory obstruction (croup). Other severe complications can include toxin-induced myocarditis and peripheral neuritis. The case fatality ratio for respiratory diphtheria is 5-10%.

Transmission

Respiratory transmission through contact with an infectious individual, or, rarely, indirectly via fomites. The incubation period is usually two to five days. A patient with clinical diphtheria is infectious for two to four weeks after onset, although rarely chronic carriers may shed bacteria for up to six months.

Surveillance In Scotland

Laboratory reports of toxigenic *Corynebacterium diphtheriae*.

Statutory notification of respiratory diphtheria by clinical diagnosis. (The disease is also statutorily notifiable under its previous nomenclature of membranous croup).

Definition for Surveillance

Notification (suggested)

Any person with:

- laryngitis

or

- pharyngitis

or

- tonsillitis

and

adherent membrane of the tonsil(s), pharynx, and/or nose. (CDC/WHO)

Laboratory Report

Laboratory reports of toxigenic *Corynebacterium diphtheriae* or *Corynebacterium ulcerans*

Incidence

Recently there have been very few notifications for diphtheria and laboratory reports of toxigenic *C. diphtheriae* are extremely rare. There have been only four notifications of diphtheria and no laboratory reports of toxigenic *C. diphtheriae* during the decade 1990-99. However the threat from imported organisms remains, most notably, in recent years, from the former Soviet Union states.

2001 zero notifications

2001 zero laboratory reports

Prevention

Vaccination against diphtheria was introduced in the 1940's. Diphtheria vaccine is still included in the UK childhood immunisation schedule, with routine primary vaccination recommended at two, three and four months, a booster dose at three to five years and a low dose booster at 13-18 years.

Further information on diphtheria can be found on **page 4** of the [Review of Communicable Diseases in Scotland 1999](#) (pdf document - Acrobat Reader required)



Haemophilus influenzae type b

Causative Agent

Haemophilus influenzae type b.

Clinical Description

Invasive infection with *Haemophilus influenzae* type b (Hib) most commonly presents as meningitis and bacteraemia (approximately 60% of cases), followed by epiglottitis (15% cases) and septicaemia (10% cases). Cases of Hib pneumonia, septic arthritis, cellulitis, osteomyelitis, pericarditis and empyema also occur. Prior to the introduction of Hib vaccine, rates of disease were highest in children under the age of one. Neurological complications of Hib meningitis occur in 15-30% of survivors and include deafness, convulsions and learning disabilities and mental retardation. The case fatality ratio is approximately 5%.

Transmission

Respiratory transmission from infectious carriers, usually asymptomatic individuals. The incubation period is short, probably two to four days.

Surveillance in Scotland

Laboratory reports for *Haemophilus influenzae* type b.

Definition for Surveillance

Notification

Not notifiable.

Laboratory Report

Laboratory reports of *Haemophilus influenzae* type b from a normally sterile site.

Incidence

Hib disease is not notifiable, so incidence is indicated by laboratory reports. The number of laboratory reports fell dramatically after vaccine introduction. The marked reduction is not just in the vaccinated high-risk age group (less than one year), but also in older age groups. This effect is because the vaccine not only protects the vaccinated individual against disease, but also prevents carriage of the organism, decreasing transmission of the organism in the wider community.

2001 13 laboratory reports.

Prevention

Hib vaccine was introduced in 1992, making it the first vaccine available to protect very young children (less than two years) against bacterial meningitis. Hib vaccine is included in the UK Childhood Immunisation schedule, with routine vaccination recommended at two, three and four months.

Further information on *haemophilus influenzae* type b can be found on page 5 of the [Review of Communicable Diseases in Scotland 1999 \(pdf document - Acrobat Reader required\)](#)

Measles

Causative agent

Measles virus

Clinical description

Measles is an acute viral disease resulting from infection with measles virus. There is prodromal fever, malaise, conjunctivitis, coryza, cough and Koplik spots. A maculopapular rash spreads from the head to the body and limbs. Complications of measles occur for around one in 15 notified cases and include otitis media bronchitis, pneumonia, convulsions and encephalitis. A rare complication of measles is subacute sclerosing panencephalitis (SSPE), a fatal degenerative neurological disorder. Measles is more severe for infants and adults than children. The case fatality ratio is approximately one to two deaths per 1000 cases. The case fatality ratio is highest for children under one year of age.

Transmission

Respiratory transmission from infected individuals. The incubation period is about 10 days and usually 14 days until the appearance of rash. A measles case is infectious from four days before the appearance of rash (ie one day before prodromal phase) to four days after its appearance.

Surveillance in Scotland

Statutory notification of measles by clinical diagnosis

Laboratory reports for measles virus

Laboratory confirmation of notified cases by salivary testing

Definition for surveillance

Notification (suggested)

Any person with:

- fever ($= 38.3^{\circ}\text{C}$)

and

- maculopapular (i.e. non-vesicular) rash lasting ≥ 3 days

and

cough, coryza (i.e. runny nose) or conjunctivitis (i.e. red eyes) (CDC)

Laboratory report

Laboratory reports for measles virus, excluding those following vaccination

Incidence

Vaccination has led to a dramatic decrease in measles notifications, with only 315 received during 2001. This is in marked contrast to the nearly 25,000 notifications received in 1970. No laboratory reports were received for measles in 2001, this first year for this to happen. A salivary surveillance scheme exists in which all notifying GPs are strongly encouraged to submit a salivary sample from all notified cases for laboratory confirmation. Additional epidemiological information such as vaccination history, recent international travel and contact with similar illness is requested for all confirmed cases. Genotyping to determine the possible origin of the virus is also attempted. In 2001, of the 147 salivary samples submitted for measles confirmation, none was consistent with recent measles infection. However, three cases of measles were confirmed in Fife in March 2002, the first since April 2000. Scotland had recently been fortunate in not having any outbreaks of measles similar to those seen in England and the Republic of Ireland. However, small localised outbreaks are an inevitable consequence of reduced uptake of MMR.

2001 315 notifications

2001 zero laboratory reports

Prevention

Vaccination against measles was introduced in 1968. The measles antigen was combined with mumps and rubella with the introduction of the combined MMR vaccine in 1988. Increased incidence of measles in 1994 prompted, later that year, mass schools vaccination with measles and rubella (MR) vaccine for all children aged five to 16 years, as mathematical modelling predicted more cases in the future. A second dose of MMR was introduced for pre-school children in 1996, as a one dose programme would not support eventual measles elimination. The second dose protects children who may not have responded to the first dose, and offers a further opportunity to those who may not have received the first dose. Measles vaccine is included in the UK childhood immunisation schedule, with routine vaccination recommended at 12-15 months and three to five years.

Further information on polio can be found on p1 of the [Review of Communicable Diseases in Scotland 1999](#).

Meningococcal Infection

Causative Agent

Neisseria meningitidis, of which there are a number of different sero-groups, is classified according to its outer membrane characteristics, the most common in Scotland and the UK being sero-groups B and C. Sero-groups Y, W135, and X are also regularly encountered.

Clinical Description

Meningitis: includes meningitis of any infectious cause but excluding meningococcal septicaemia. Enquiries are often aimed at meningococcal infection rather than all causes of meningitis. Meningococcal infection refers exclusively to invasive infections of *Neisseria meningitidis*, whether of CSF, blood or other sterile sites, plus meningococcal conjunctivitis.

Transmission

Neisseria meningitidis is a very common infection of the respiratory tract and carriage rate is of the order of 10% or higher. The vast majority of individuals who are colonised remain asymptomatic and invasive cases invariably acquire their infection from non symptomatic carriers.

Surveillance in Scotland

Enhanced surveillance data as recorded jointly by SCIEH and by the Scottish Meningococcal & Pneumococcal Reference Laboratory (to which all hospitals in Scotland send their samples) is used for the most up to date recent notifications and laboratory confirmed cases as well as for more complex analyses (age groups, sero-groups, deaths etc).

Trends in Scotland (1995-2000)

Notifications of meningococcal infection (meningitis, septicaemia, infection of normally sterile sites, conjunctivitis) remained fairly stable at between 100 and 200 cases per year from 1977 until the late 1990's, when the increase in 1997 was sustained throughout 1998 and 1999. An unusually large influenza outbreak in 1999/2000 brought about a further increase, the association of flu outbreaks (particularly influenza A) and meningococcal infection being well recognised.

There has been a striking oscillation in the predominant serogroup causing meningococcal disease in Scotland, with Group B and Group C contributing almost equally over the past few years. Group C infections were more common in 1998, and in the first part of 1999 prior to the MenC conjugate meningococcal vaccine programme being commenced in November 1999. Group A infections have effectively been unknown in Scotland for many years. There has also been a shift in recent years towards the disease affecting older age groups.

Incidence and Risk

Between 300 and 400 notifications of meningococcal disease are currently notified in Scotland each year, with the majority of cases in children and young adults. There has been a shift towards older age groups in recent years with an increasing proportion of infections in the over 21's.

Prevention

Since the bacteria do not survive long outside the body, prolonged and close contact with an infected individual who is either ill or a carrier is required to transmit the germ. Widespread preventative measures are therefore generally not indicated. Antibiotics (one dose or a very short course) are recommended for close contacts of a case in order to prevent further spread from potential carriers.

Mumps

Causative agent

Mumps virus

Clinical description

Mumps is an acute viral disease resulting from infection with mumps virus. Clinical features include fever, headache swelling of one or both cheeks or sides of the jaw and swollen glands. The fever usually lasts for 1 to 6 days and the parotitis for up to 10 days, or more. Mumps can have serious complications, including aseptic meningitis (4-6 % cases), encephalitis (1 in 1000 cases), inflammation of the testes (orchitis), pancreatitis, oophoritis and permanent deafness. Neurological involvement occurs in 10-20% of cases and may precede or follow parotitis, and can also occur in its absence. Orchitis is the most common complication of mumps in adult males (4 out of 10 cases). Fulminant encephalitis is rare, but a potentially fatal complication of mumps.

Transmission

Respiratory transmission from infected individuals. The incubation period ranges from 12-25 days, and is usually about 18 days. A mumps case is infectious from about 6-7 days before onset of parotitis until 9 days after, although clinical inapparent cases can also be communicable.

Surveillance in Scotland

Statutory notification of mumps by clinical diagnosis

Laboratory reports for mumps virus

Laboratory confirmation of notified cases by salivary testing

Definition for surveillance

Notification (suggested)

Any person with:

acute onset of unilateral or bilateral tender, self-limited swelling of the parotid or other salivary gland, lasting ≥ 2 days, and without other apparent cause (CDC)

Laboratory report

Laboratory reports for mumps virus, excluding those due to vaccination

Incidence

Mumps became a notifiable disease in October 1988, with the introduction of MMR vaccine. There were 3095 notifications in 1989. Just over a decade later, in 2001, there were only 155 notifications and 6 laboratory reports of confirmed infections. A salivary surveillance scheme exists for mumps, in which all notifying GPs are strongly encourage to submit a salivary sample from all notified cases for laboratory confirmation. Additional information such as vaccination history, recent international travel and contact with similar illness is requested for all confirmed cases. Genotyping to determine the possible origin of the virus may also be attempted. In 2001, of the 54 samples submitted for mumps confirmation, only one was consistent with recent mumps infection. In the first half of 2002, there has been a localised outbreak of mumps, in Dumfries and Galloway Health Board, mostly in teenagers and young adults. An increase in the number of mumps case was also been observed in England, Wales and Northern Ireland in 2001. The age cases in these, largely schools-based outbreaks, indicated that many may have received only one dose of mumps-containing vaccine, or none at all.

2001 155 notifications

2001 6 laboratory reports

Prevention

Protection against mumps was first offered with the introduction of MMR vaccine in October 1988. Mumps vaccine is included in the UK Childhood Immunisation schedule, with routine vaccination recommended 12-15 months and 3-5 years.

Further information on polio can be found on p1 of the Review of Communicable Diseases in Scotland 1999.

Poliomyelitis

Causative agent

Polioviruses types 1, 2 and 3 (wild type)

Clinical description

Poliomyelitis is an acute infection caused by any of the three wild type polioviruses. Over 90% of infections are asymptomatic. The remainder of infections result in clinical illness, which can range from non-specific febrile illness (5% of infections), aseptic meningitis (1% of infections) to flaccid paralysis (<1% of infections). The risk of paralytic poliomyelitis varies with age, rising from approximately 1 in 1000 infections in infancy to up to 1 in 10 infections for adults. Paralysis is more likely to affect the legs than the arms, but can involve all four limbs. Recovery may be complete or only partial and post-polio syndrome, a deterioration of the originally affected muscles has been reported to occur 30-50 years later in many patients. If the paralysis also affects muscles for breathing and swallowing, poliovirus infection is life threatening .

Transmission

Primarily person-to-person transmission through the faecal-oral route. The incubation period is usually 7- 14 days for paralytic cases, but with a reported range of 3 - 35 days. An infected person may transmit virus in throat secretions for 3 - 10 days after exposure and in the faeces for up to 6 weeks, but is most infectious in the few days before and after onset of symptoms. As humans are the only reservoir of infection, eradication, through vaccination is possible.

Surveillance in Scotland

Statutory notification of poliomyelitis

Laboratory reports for wildtype polio virus.

Definition for surveillance

Notification

Any person with:

acute onset of a flaccid paralysis of one or more limbs with decreased or absent tendon reflexes in the affected limbs, without other apparent cause, and without sensory or cognitive loss (CDC)

Laboratory report

Laboratory reports for wild type polio virus (as opposed to live attenuated oral polio vaccine virus)

Incidence

There have been no cases of indigenous wild type polio in the UK for over 15 years now. The last notification of polio in Scotland was in 1994, and was vaccine-associated paralytic poliomyelitis, rather than derived from wild type virus. The patient (male, age 62 years) had been in close contact with a recent recipient of oral polio vaccine. The European Region of the World Health Organisation was certified polio-free in June 2002, having been free of indigenous polio for over three years. However, poliovirus imported from polio-endemic countries remains a threat.

2001 zero notifications

2001 zero laboratory reports

Prevention

Polio vaccination was introduced in the UK in 1956, in the wake of dramatic paralytic

poliomyelitis epidemics. Injectable inactivated polio vaccine (IPV) was used initially, but this was replaced with oral live attenuated vaccine (OPV) in 1962. OPV is included in the UK Childhood Immunisation schedule, with routine primary vaccination recommended at 2, 3 and 4 months, and booster doses at 3-5 years and 13-18 years.

Further information on polio can be found on p4 of the Review of Communicable Diseases in Scotland 1999.

Rubella

Causative agent
Rubella virus

Clinical description

Rubella is an acute viral infection caused by rubella virus. It is generally a mild illness, but if acquired by women in early pregnancy can have devastating effects on the unborn child, leading to congenital rubella syndrome. The virus affects all fetal organs and can lead to serious birth defects. These include learning difficulties, cataracts, deafness, cardiac abnormalities, retardation of intrauterine growth and inflammatory lesions of the brain, liver, lungs and bone marrow. Non-fetal complications include arthritis and arthralgia in adults, especially women, and encephalitis (approximately 1 in 6000 cases), which can be fatal.

Transmission

Respiratory transmission from infected individuals. The incubation period is usually 14 to 21 days. A rubella case is infectious for about 1 week before to at least 4 days after the onset of rash.

Surveillance in Scotland

Statutory notification of rubella by clinical diagnosis

Laboratory reports for rubella virus

Laboratory confirmation of notified cases by salivary testing

Definition for surveillance

Notification (suggested)

Any person with:

- acute onset of generalized maculopapular rash

and

- temperature ($>37.2^{\circ}\text{C}$)

and

arthralgia/arthritis or lymphadenopathy or conjunctivitis (CDC)

Laboratory report

Laboratory reports for rubella virus, excluding those due to vaccination

Incidence

The introduction of MMR vaccine in October 1988 led to a marked decrease in the incidence of rubella, as the previous policy of selective immunisation had little impact on the circulation of rubella in the community. There were only 234 notifications for rubella in 2001 and two laboratory confirmed cases, compared to 6628 notifications and 356 laboratory confirmed cases in 1989. A salivary surveillance scheme exists for rubella, in which all notifying GPs are strongly encourage to submit a salivary sample from all notified cases for laboratory confirmation. Additional information such as vaccination history, recent international travel and contact with similar illness is requested for all confirmed cases. Genotyping to determine the possible origin of the virus may also be attempted. In 2001, of the 113 samples submitted for rubella confirmation, only one was consistent with recent rubella infection. The small number of laboratory confirmed cases still occurring indicate that females of child bearing age remain at risk of infection through circulating virus, unless protected by vaccination.

2001 356 notifications

1999 2 laboratory reports

Prevention

The primary aim of rubella vaccination is to protect pregnant women from rubella infection, resultant congenital infection, and fetal damage. This is why UK policy, when the vaccine was originally introduced in 1970, was for selective immunisation of pre-adolescent girls and non-immune women of child bearing age. However, as this strategy has little impact on the circulation of rubella virus in the community, rubella vaccination was offered to both boys and girls with the introduction of MMR vaccine in 1988. Rubella antigen was also include in the 1994 schools campaign against measles, as MR vaccine, with the specific aim of reducing susceptibility among young men, who may be in close contact with pregnant women. Rubella vaccine is included in the UK Childhood Immunisation schedule, with routine vaccination recommended 12-15 months and 3-5 years.

Further information on polio can be found on p1 of the Review of Communicable Diseases in Scotland 1999.

Tetanus

Causative Agent
Clostridium tetani

Clinical Description

Tetanus is an acute disease induced by the toxin of *Clostridium tetani*, a bacterium that grows anaerobically after being introduced by injury. The neurotoxin causes muscular rigidity and agonising contractions. These tend to begin as spasms in the masseter and neck muscles (lockjaw), progressing to the trunk and extremities. Reported case fatality ratios range from 10-90%, with highest ratios for infants and the elderly.

Transmission

Wound colonisation by tetanus spores, which are present in soil, and animal faeces. The incubation period is usually three to 21 days, but may range from one day to several months, depending on the type of wound.

Surveillance in Scotland

Statutory notification of tetanus by clinical diagnosis.
Laboratory reports of toxigenic *Clostridium tetani*.

Definition for Surveillance

Notification (suggested)

Any person with:

acute onset of hypertonia and/or painful muscular contractions (usually of the muscles of the jaw and neck) and generalized muscle spasms without other apparent medical cause (CDC).

Laboratory Report

Laboratory reports of *Clostridium tetani* (NB laboratory tests are not normally performed).

Incidence

Tetanus is now extremely rare. During the years 1990-99 there were only seven notifications and one laboratory report. Nevertheless, vaccination against tetanus must be maintained, as the continued presence of the causative organism, toxigenic *Clostridium tetani* in the environment makes eradication impossible. This is highlighted by a clinical case of tetanus in Glasgow in April 2002 ([View Current Note - pdf](#)). The patient (male, age 26 years) reported sustaining a mild arm wound, but was also known to be a current injecting drug user.

2001 zero notifications

2001 zero laboratory reports

Prevention

Tetanus vaccination has been offered on a national scale since the 1960s, before which it was offered only to men during their period of National Service. Tetanus vaccine is included in the UK Childhood Immunisation schedule, with routine primary vaccination recommended at two, three and four months, and booster doses at three to five years and 13-18 years. Patients who have had clinical tetanus need to be immunised before discharge.

Further information on tetanus can be found on page 5 of the [Review of Communicable Diseases in Scotland 1999](#) (pdf document - Acrobat Reader required)

Whooping Cough (Pertussis)

Causative Agent

Bordetella pertussis and, occasionally, *B. parapertussis*.

Clinical Description

Whooping cough is an acute bacterial disease of the respiratory tract, resulting from infection with *Bordetella pertussis*, or occasionally milder disease with *B. parapertussis*. Onset is insidious with an initial catarrhal stage causing an intermittent irritating cough that gradually becomes paroxysmal within one to two weeks. Paroxysms comprise a series of coughs, without opportunity for inspiration, followed by the characteristic inspiratory 'whoop'. The paroxysmal phase may last for two to three months, and apnoea, cyanosis, and post-tussive vomiting may occur. Complications of whooping cough include bronchopneumonia, acute encephalopathy, and long-term brain damage as a result of cerebral hypoxia. Complications and deaths from whooping cough are most frequently seen in infants less than six months of age; this prompted the introduction of an 'accelerated' UK primary immunisation schedule for vaccination at two, three, and four months of age. Those too young to be vaccinated continue to be at highest risk of severe disease. The disease is generally mild in adolescents and adults.

Transmission

Respiratory transmission through contact with an infectious individual. The incubation period is between six and 20 days, usually seven to ten days. Infected individuals are most infectious in the initial catarrhal phase, before onset of paroxysms. Communicability then declines, and by three weeks after onset of paroxysms an individual may be considered non-infectious for non-household contacts.

Surveillance in Scotland

Statutory notification of whooping cough.

Laboratory reports for *Bordetella pertussis* and *B. parapertussis*.

Definition for Surveillance

Notification (suggested)

Any person with cough, illness lasting two or more weeks with one of the following:

- paroxysms (i.e. fits) of coughing,
- inspiratory 'whoop,'
- or post-tussive vomiting,
- without other apparent cause

Laboratory Report

Laboratory reports for *Bordetella pertussis*, or *B. parapertussis*.

Incidence

Prior to vaccine introduction, large epidemics of whooping cough occurred every three to four years, and in 1951 there were nearly 23,000 notifications. Marked reductions in vaccine uptake in the 1970s, as the result of unfounded public and professional anxiety about the safety of pertussis vaccine, led to three epidemics of the disease. It has only been in the last decade that the incidence of whooping cough has returned to levels occurring before adverse publicity. Whooping cough continues to show an epidemic cycle, but with much smaller peaks. The last period of increased incidence was in 1997-98.

2002 103 notifications (provisional)

2002 109 laboratory reports for *Bordetella pertussis*

Prevention

Immunisation against whooping cough was introduced in the UK in the 1950s. Whole cell pertussis vaccine is still included in the UK childhood immunisation schedule, with routine primary vaccination recommended at two, three and four months. A pre-school booster of acellular pertussis vaccine was recently added to the UK Childhood Immunisation Schedule, with effect from January 2002 in Scotland. The booster was introduced as there was evidence that infants, too young to be protected through vaccination, may be catching pertussis from older siblings, or parents with waning immunity. Chief Medical Officer letter, 9 November 2001, Current pre-school acellular pertussis booster:
[http://www.scot.nhs.uk/sehd/publications/CMO\(2001\)16.pdf](http://www.scot.nhs.uk/sehd/publications/CMO(2001)16.pdf)

Further information on pertussis (whooping cough) can be found on page 4 of the Review of Communicable Diseases in Scotland 1999 (pdf document - Acrobat Reader required)

United Kingdom Childhood Immunisation Programme		
VACCINE/ DISEASE	HOW IT IS GIVEN	AGE VACCINE GIVEN
Polio	By mouth	2 months
Diphtheria/tetanus/ pertussis (DTP) & Hib	Combined 4 in 1 injection	2 months
Men C	One injection	2 months
////////////////////	////////////////////	////////////////////
Polio	By mouth	3 months
Diphtheria/tetanus/ pertussis (DTP) & Hib	Combined 4 in 1 injection	3 months
Men C	One injection	3 months
////////////////////	////////////////////	////////////////////
Polio	By mouth	4 months
Diphtheria/tetanus/ pertussis (DTP) & Hib	Combined 4 in 1 injection	4 months
Men C	One injection	4 months
////////////////////	////////////////////	////////////////////
Measles/mumps/ rubella (MMR)	Combined 3 in 1 injection	12 to 15 months
////////////////////	////////////////////	////////////////////
Polio	By mouth	3 to 5 years
Diphtheria/tetanus/ pertussis (DTP)	Combined 3 in 1 injection	3 to 5 years
Measles/mumps/ rubella (MMR)	Combined 3 in 1 injection	3 to 5 years

Source: Department of Health 2001 see www.immunisation.nhs.uk

CHECK LIST

- 1. Check has everyone received and read the information sheet?**
- 2. Introduce self and research.**
- 3. Re-state the following:**
 - Length of time (approx 1 hr).**
 - Voluntary nature of participation.**
 - Recording the group discussion.**
 - Confidentiality – (information kept in locked drawer in MRC unit & not disclosed to anyone outside the research team).**
 - Anonymity- (all documents and data identifiable only through ID number and any extracts used in presentations or publications given pseudonyms to protect identity).**
 - Expenses.**
- 4. Check if there are any questions or concerns about the study.**
- 5. Get the consent form signed and personal detail form completed.**
- 6. Give out discussion material.**
- 7. Switch on microphone and recorder.**
- 8. Map positions of participants – (name, no of children & age of children).**

TOPIC GUIDE/ PARENTS OF AUTISTIC CHILDREN (not in order)

EXPERIENCES OF CHILDHOOD IMMUNISATION/ PERCEPTIONS ABOUT VACCINES

- Words / images associated with immunisation.
- Experience of immunisation so far.
- Views on the current Childhood Immunisation Programme.

(Hand out Immunisation Programme see Appendix L)

PERCEPTIONS ABOUT CHILDHOOD INFECTIOUS DISEASES

- Words / images associated with: - Diphtheria, tetanus, whooping cough (or pertussis), meningococcal disease, mumps, poliomyelitis, measles, rubella and haemophilus influenzae (or Hib).
- Find out which disease's parents' feel most and least severe?
- Find out which disease's parents' feel most and least prevalent?
- Find out which disease's parents' feel threatens their child's health most and least ?
- Explore parents knowledge/ understanding about how they think each disease is transmitted.
- Do parents have any direct experiences of any of the diseases either as parents themselves or as children?
- Does this affect their perceptions about the disease and in what way?
- If parents have no direct experience of childhood infectious diseases, what or who has helped them make their assessments of these diseases?

BELIEFS ABOUT HEALTH & THE IMMUNE RESPONSE

- How- vaccines works / explore parents' understanding of the body reaction to vaccination or to disease?
- Explore notions of 'healthiness' with immunisation and perceived threat of disease.
Is there any relationship between -general health and need for immunisation?
-general health and threat of disease?

BELIEFS ABOUT CHOICE & RESPONSIBILITY

- Individual choice V's societal responsibility. Is it okay to opt out? & When?

PERCEPTIONS ABOUT THE MMR VACCINE / DEBATE

- Feelings about the MMR vaccine?
- Feelings about the MMR debate?
- How the MMR debate has affected them?
- Beliefs about the 'state of the evidence.
- Feelings about the Dr Wakefield?
- Are they part of any legal action?

THE EXPERIENCE OF DECIDING ABOUT MMR

- MMR decision making experiences. Was it an easy or difficult decision?
- Influential factors in the 1st & 2nd MMR dose. Were they different?
- Identify other people involved in the decision. Any informal support?
- Explore which of the other vaccines easy / difficult to decide about? Why?

LIVING WITH AUTISM

- Getting their child diagnosed with autism
- Daily living
- Other parents understanding of autism
- Autism health care/ education

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TOPIC GUIDE/ PARENTS OF IMMUNO-COMPROMISED CHILDREN (not in order)

EXPERIENCES OF CHILDHOOD IMMUNISATION/ PERCEPTIONS ABOUT VACCINES

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- Experience of immunisation so far.
- Views on the current Childhood Immunisation Programme.

(Hand out Immunisation Programme see Appendix L)

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PERCEPTIONS ABOUT THE MMR VACCINE / DEBATE

- Feelings about the MMR vaccine?
- Feelings about the MMR debate?
- How the MMR debate has affected them?
- Beliefs about the 'state of the evidence'.
- Feelings about the Dr Wakefield?

LIVING WITH A CHILD WITH A COMPROMISED IMMUNE SYSTEM

- Getting their child's cancer diagnosis
- Critically ill period in hospital-preventing disease and infections
- Initial recovery period- preventing disease and infections
- Re-integrating their child back into society-problems faced and why they managed the situation
- Other parents, school, nursery school's understanding of their child's needs

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