

MMR Uptake in Somerset following the 2009 national catch-up campaign: factors affecting parents' decisions to accept or decline immunisation

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Declaration

I declare the work in this thesis to be my own, except where otherwise stated

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ABSTRACT

Introduction and Background

Measles, mumps and rubella (MMR) are infectious diseases, primarily of childhood, which cause significant mortality and morbidity globally. These infections are, however, vaccine preventable and there is potential for them to be eradicated worldwide through the strategic use of organised population immunisation programmes.

Following the introduction of the MMR vaccination in the UK in 1988, uptake was initially good and a high level of population vaccination coverage was achieved. This was sustained until 1998 when a study by Dr Wakefield and colleagues was published in the Lancet suggesting the theoretical possibility of an association between MMR and Autism /bowel disease. Intense media coverage followed, uptake of MMR vaccine fell to less than 80% in Somerset, and community outbreaks of measles, which had almost been eliminated in the UK, began to reappear. The Wakefield study was subsequently discredited and was eventually retracted by the Lancet in 2010.

In August 2008 the Chief Medical Officer announced a national MMR catch-up campaign, targeting all children between the age of 13 months and 18 years who had either not been vaccinated against measles, mumps and rubella, or had only partial immunisation. These children were invited again for vaccination and the campaign was completed in January 2009.

This study was undertaken to explore, in depth, the quantitative data available in respect of the uptake of MMR at the time of the 2009 campaign, and also to provide new qualitative data in relation to the attitudes, beliefs and experience of MMR and immunisation services of parents who continued to decline MMR for their children after the 2009 campaign, in order to identify factors which affected parental decision-making, add to the wider knowledge base,

and to use this knowledge to improve the future development of immunisation services in Somerset.

Methods

The overall objective of the study was to investigate a number of social, demographic and geographic characteristics of parents and children associated with MMR uptake, to compare these characteristics within and between defined sub-sets of the Somerset population, and to explore the basis on which parents in Somerset make decisions in relation to MMR immunisation.

The study design adopted was a 'mixed methods' approach comprising of a cross-sectional design with three sequential phases - an exploration of baseline epidemiological data; a survey conducted with parents of children who remained unimmunised after 2009; and finally, semi-structured interviews with a sub-set of these parents.

Results

The key findings from the study are:

Parents who decline MMR for their children are not a homogenous group, but consist of a number of sub-groups each of which have different motives, decision pathways and predicted outcomes in relation to potential to change their mind and accept MMR

There are differences in geographic distribution between the two age groups investigated

Whilst the 'Wakefield' study did, and still does have, an impact, it is not the only or most important factor in their continuing decision-making.

There is evidence that health professionals have a key role in addressing parental concerns in respect of immunisation. GP practice was the most significant factor associated with uptake in the Phase 1 study, and this was further confirmed in interviews with parents.

Parents make decisions through engagement, through communicating and relating to others and this offers a potential mechanism for health professionals to influence decisions through open engagement with parents.

Discussion and Conclusions

Three parent sub-groups were identified (Single Vaccines; Medical Comorbidities and Natural Health). These sub-groups were further investigated and factors associated with the decision-making pathways of each group were identified. This resulted in the development of the 'MMR Parent Engagement Framework' as a tool for use by professionals in planning their interactions with parents to improve and encourage more open dialogue in order to positively influence parental decision-making in relation to accepting MMR or other vaccinations.

From a commissioning perspective, embedding frameworks such as this in service specifications offers a more cost-effective approach to improving immunisation uptake than funding large, poorly targeted catch-up campaigns. It is therefore recommended that further research is undertaken to provide evidence of the effectiveness of the approach in practice, and to inform future commissioning decisions.

Additional recommendations to improve the effectiveness and delivery of immunisation services are also made in respect of GP Practice specific factors, independent schools, ethnic minority communities, vaccine overload, media, and data validation.

The study has already directly influenced changes in current practice at both a local and a national level.

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LIST OF ABBREVIATIONS

BCG	Bacillus Calmette–Guérin vaccine
BIG HIT	Bristol Immunisation Group Health Integration partners Team
BME	Black and Minority Ethnic
BMJ	British Medical Journal
CC	Children’s Centre
CDC	Centres for Disease Control
CHIS	Child Health Information System
CHRD	Child Health Records Department
CFR	Case Fatality Rate
CMO	Chief Medical Officer
COREC	Central Office for Research Ethics Committees
COVER	Cover of Vaccination Evaluated Rapidly
CRS	Congenital Rubella Syndrome
DPH	Director of Public Health
DTP	Diphtheria Tetanus Polio vaccine
EU	European Union
GMTV	Good Morning Television
GP	General Practitioner
HPA	Health Protection Agency
IMD	Index of Multiple Deprivation
KC50	Adolescent (13 – 19) immunisation data collection
LSOA	Lower Super Output Area
MEDLINE	Medical Research online database
MeSH	Medical Subject Headings (used for indexing articles for MEDLINE)

MHRA	Medicines and Healthcare Regulatory Agency
MMR	Measles, Mumps and Rubella vaccine
MOSAIC	Geo-demographic segmentation system for classifying populations
MSOA	Middle Super Output Area
NICE	National Institute for Health and Care Excellence
NHS	National Health System
NPSA	National Patient Safety Agency
NS-SEC	National statistics – Socio Economic Classification
ONS	Office of National Statistics
PALS	Patient Advocacy and Liaison Service
PCT	Primary Care Trust
PhD	Doctor of Philosophy Degree
Q & A	Questions and Answers
RCV	Rubella Containing Vaccine
R & D	Research and Development
RNA	Ribonucleic acid.
SAGE	Strategic Advisory Group of Experts
SOA	Super Output Area
SQL	Structured Query Language
SREC	Somerset Race Equality Council
SSPE	Sub-acute Schlerosing Pan Encephalopathy
WHA	World Health Assembly
WHO	World Health Organisation

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CHAPTER 1: INTRODUCTION AND OVERVIEW OF THE THESIS

1.1 Background to the Thesis

Measles, mumps and rubella are infectious diseases, primarily of childhood, which at 2013 continued to cause significant morbidity in the UK, and high morbidity and mortality globally (Ramsay, 2013). These infections are, however, vaccine preventable and there is considerable potential for them to be eradicated worldwide through the strategic use of organised population immunisation programmes.

Measles vaccine was first introduced in the UK in 1968, but coverage for this initial programme was not high enough to interrupt disease transmission (Department of Health, 2013, Ch. 21). The introduction of a combined Measles, Mumps and Rubella (MMR) vaccine in 1988 proved far more effective. It was initially well received by parents and resulted in a significant decline in measles notifications (Ramsay, 2013). However, in 1998, there was controversy over the use of MMR vaccine resulting from speculation (in a now discredited research paper published in the *Lancet*) that the vaccine might be associated with inflammatory bowel disease and developmental disorders, such as autism (Wakefield et al, 1998). MMR uptake declined to less than 80% in England by 2003/04, and in some areas 44% of pre-school and 22% of primary school aged children remained unimmunised. Uptake remained under 90% up to 2008, resulting in a gradual increase in the number of susceptible individuals in the population which could potentially sustain prolonged outbreaks of these diseases (Health Protection Agency, 2013) (See Appendix 1).

In August 2008, prompted by an increase in the number of cases of measles, the Chief Medical Officer announced a national MMR catch-up campaign targeting all children between the ages of 13 months and 18 years who had either not been vaccinated, or who had only partial immunisation, against measles, mumps and rubella (CMO, 2008).

These children were invited again to attend for vaccination. It was a resource intensive programme involving the issuing of invites to 13,800 children in Somerset, and was completed by March 2009.

This thesis documents the design and implementation of a research project that was undertaken to explore, in depth, the quantitative data available in respect of MMR in Somerset at the time of the 2009 MMR Catch-up Campaign, and to provide new qualitative data in relation to the attitudes, beliefs and experiences of MMR and immunisation services of a sub-set of parents' who, at the end of March 2009, continued to decline the vaccination. The aim of the study was to identify the characteristics of parents who continued to decline MMR and any factors which influenced parental decision-making within this sub-set of parents; to add to the wider knowledge base in this area of inquiry; and to use this knowledge to improve local immunisation services.

1.2 Purpose and Rationale for the Study

In 2009, there was a requirement for Primary Care Trusts (PCTs) to achieve 95% uptake of two doses of MMR in children aged five years; this was a core public health target in 2009 and remains one of the current national public health outcome measures (Public Health England, 2015). Achieving the 95% target was considered particularly challenging for NHS Somerset which had one of the lowest rates of MMR uptake in the South West with uptake of first dose of MMR (MMR1) at only 87% at Q4 2009 (NHS Information Services, 2009) (See Appendix 2),

A review of the literature, particularly the unpublished documents obtained from the national immunisation team, provides evidence of considerable efforts by national health protection and immunisation leads, governmental departments, and researchers, to explore parental attitudes and improve communication in relation to the

risks and benefits of MMR with parents of children aged under five throughout the 2000's (Martin & Sandson, 2003; Yarwood et al, 2006; Scottish Health Feedback, 2008). Maternal tracking studies undertaken annually by the Department of Health had begun to indicate a small but steady increase in acceptance of MMR by mothers of children aged up to five years of age in 2009 and this progress has continued (Cragg Ross Dawson, 2010; BMG Research, 2015). However, uptake of a complete course of two doses of MMR at age five continues to lag behind this improvement in primary course uptake, resulting in a pool of susceptible children of school age which increases year on year (Ramsay, 2013).

The maternal tracking surveys referenced above focus specifically on parents of children aged less than five years. In addition, many of the previous studies have explicitly excluded 'confirmed rejectors' of MMR and those clearly opposed to immunisation from study samples, believing that divergent views were unhelpful, or had a tendency to create group conflict, or that recruiting 'refusers' was more difficult (Hershey et al, 1994; Martin & Sandson, 2003; Yarwood et al, 2006; Scottish Health Feedback, 2008). As a result, parents who continue to decline MMR for their school aged children are, by default, a somewhat ignored and poorly understood group within the wider parent population.

Evidence obtained from personal communications with Mary Ramsay and Jo Yarwood of the national Immunisation Team, and with health professionals at the national 'Fundamentals of Immunisation Course' 2013, also suggest that a number of assumptions have been made by health professionals about this group of parents. These assumptions are that they form a single homogenous core of 'refusers' who, after many previous approaches, are unlikely to be persuaded to accept MMR under any circumstances in future. Many professionals therefore feel that there is limited value in engaging with them further. Parents who continue to decline MMR are also

assumed to be likely to have 'alternative health beliefs'; and to have been primarily influenced in their decision-making by the 'Wakefield MMR controversy'. There are, however, very few studies that explore parental attitudes to and experiences of immunisation beyond the primary schedule (Tickner, 2008). I was only able to identify one published study which focussed specifically on the attitudes and beliefs of parents of school aged children (Salmon et al, 2005) and this paper appeared to challenge these assumptions, but the research was undertaken in the USA and it is therefore unclear whether the findings are applicable to other populations or healthcare systems. This lack of evidence highlights the need for further investigation.

An understanding of the reasons for parents persisting to decline MMR, years after the evidence presented by Wakefield et al (1998) was discredited and beyond the age that autism is clinically agreed to develop; or of what influences them to change their minds and accept MMR at a later date where they do so, are also significant gaps in the present evidence, but an understanding of these factors is essential if uptake is to be improved and outbreaks of disease minimised in this group of young people.

'Choosing Health' the Public Health White Paper (2004) highlighted the need for PCTs to examine immunisation uptake rates and identify the differences between population groups and geographical areas in terms of immunisation completion rates and access, suggesting that closer examination of local data might reveal hidden variation and might help improve the situation for those most in need of vaccination. The publication of Public Health Guidance 21 'Reducing the difference in childhood immunisation uptake' (NICE, 2009) added further recommendations to enable PCTs to reduce variations in uptake, and also provided evidence of the cost-effectiveness of efforts to increase uptake rates for measles vaccination programmes, especially if targeted at low uptake groups.

A detailed examination of immunisation uptake in Somerset had not previously been undertaken. In addition, it was identified that data collected by the Health Protection Agency (HPA), although useful in terms of national benchmarking, did not utilise all of the information that was potentially available at PCT Child Health Records Department or General Practice level. I considered that using this data to more accurately identify factors affecting these persistent decisions to decline MMR could contribute to the redesign and more effective targeting of immunisation services, and therefore to increasing MMR uptake locally. It also offered the potential for the more effective use of NHS resources as well as the reduction of vaccine preventable diseases (measles, mumps and rubella) and their consequences.

The present study was designed to capture both quantitative and qualitative data in relation to the uptake of MMR uptake in Somerset, and to identify factors affecting parents' continuing decisions to decline the vaccination. The aim of this study was to chart potentially modifiable factors associated with low uptake, and thereby to identify interventions which could be implemented to achieve improvements in MMR uptake and coverage.

Any information which makes possible the identification of factors which encourage acceptance of MMR immunisation, particularly amongst those who remain unimmunised, could enable more effective, equitable and cost-effective services to be developed locally (and potentially more widely) which is both ethically desirable and increasingly necessary at a time of financial constraint. Identification of factors contributing to persistent decline of MMR and recommendations for changes to clinical practice to improve uptake were therefore agreed priorities for NHS Somerset in 2009, and I was supported to complete the research study by the Director of Public Health, the Director of Nursing and Patient Safety and the Somerset R&D Consortium.

The Phase 1 baseline epidemiological study of MMR uptake in Somerset was a necessary precursor to the development of the Phase 2 survey, and was intended to provide a framework for the subsequent qualitative elements of the research. Phase 1 compared the demographic characteristics of accepting and declining families (parents and children) across two age groups of children, to see if any were associated with the decline of the offer of MMR in Somerset.

The Phase 2 and 3 studies were then designed to be built upon this baseline review, with the objective of exploring the reasons why parents in these two groups continued to decline MMR after 2009; and to attempt to discover what had influenced them to accept MMR, if they had, at the time the survey and interviews with parents were undertaken in 2012. These qualitative elements focussed on a sub-set of parents of children who were offered MMR as part of the 2009 campaign, but who continued to remain unvaccinated after March 2009. The Phase 1 study is therefore reported in the thesis as an essential and integral part of the work I have undertaken as part of this research process.

1.3 Research Questions

The following research questions were posed:

- What were the social, demographic and geographic characteristics of parents / children who had accepted and declined MMR in Somerset in 2009?
- Are parents who persist in declining MMR a single homogenous group?
- Does the 'Wakefield study' remain a primary factor influencing parents' of school age children to decline MMR in Somerset, or are there other factors at play?
- How have parents' early experiences, attitudes and behaviours in respect of MMR and wider immunisation services influenced their longer term decision-

making? Have their attitudes and behaviours changed over time, or as new experiences occur?

- Why do some parents persist in declining MMR, despite having information and experiences which appear to counteract the basis on which their initial decision was made?
- What factors influence parents who have persistently declined to change their mind and accept MMR for their school-age children?

1.4 Overview of the structure of the Thesis

Within this first chapter of my thesis I have outlined the background and structure of my study. The contextual factors underpinning my thesis are further explored in Chapter 2. In particular, the scientific evidence demonstrating the clinical significance of measles, mumps and rubella are reviewed to establish the relevance of this subject, and of maintaining uptake within the MMR immunisation programme, within the wider context of public health. This chapter includes detail of the epidemiology of the diseases, the contribution of measles and rubella to childhood mortality, the potential for the eradication of these diseases, and the history of measles, mumps and rubella control in the UK and Europe.

The evidence related to parental attitudes and behaviours in respect of immunisation decision-making, and specifically in respect of MMR decision-making, is reviewed in Chapter 3. The initial scope of this review was considerable and the resulting body of social science, medical and psychological literature (published and unpublished) vast. As a result I have focussed on reviewing evidence in the main areas of parental attitudes and beliefs (in relation to both MMR and immunisation per se); decision-making and MMR; factors affecting or influencing uptake; and specifically, autism / bowel problems and MMR. Additional searches in respect of herd immunity, individual

freedom and collective responsibility and immunisation, vaccine overload, and compulsory vaccination were also included as these themes emerged within the data.

In Chapter 4, the methodological approach and specific research methods underpinning my research are presented. The rationale for the mixed methods approach is described, as is the rationale for the use of the survey as the basis for both the collection of data and the development of a framework to support the subsequent qualitative elements of the study. The three stages of the research design are described and the interaction between these illustrated. The process for data collection and analysis is explored as are ethical aspects of the research.

In chapter 5, the results of the analysis of the Phase 1 and Phase 2 categoric data are presented. These findings relate primarily to research question one and illustrate the social and demographic characteristics of parents who declined the offer of MMR in Somerset in 2009 and their children.

Chapter 6 presents the results of the thematic analysis of the qualitative data obtained from Phase 2 and 3 - the parent census survey (free text comments), and semi-structured interviews with a sub-set of parents who responded to the survey and who had indicated that they would be willing to participate in further research. Nine themes, arising from this analysis are described in depth. The findings described within this chapter provide evidence in respect of research questions two to six.

Whilst much of the analysis presented in chapter 6 provides evidence which confirms previous research findings in relation to the beliefs and attitudes of parents, and the factors that influence parental decision-making in respect of MMR, new evidence is presented in relation to the identification of three sub-sets of parents within the population of persistent decliners, each with different characteristics. The information obtained from the thematic analysis, is then applied to develop a Parent Group

Framework, which it is proposed could be used to improve parental engagement with immunisation services. This proposition is further developed in Chapter 7 where the development of an overarching strategy for communicating with parents, and of parent group-specific actions to improve engagement and uptake, the 'MMR Parent Engagement Strategy', is presented.

Finally, Chapter 8 presents the key findings and recommendations arising from this thesis, and concludes with an examination of the strengths and limitations of the study, and of the actual and potential impact of this study on current and future immunisation services and clinical practice.

CHAPTER 2: ASPECTS UNDERPINNING THE RESEARCH - THE PUBLIC HEALTH SIGNIFICANCE OF MEASLES, MUMPS AND RUBELLA

2.1 Background

Measles, mumps and rubella are childhood infections which cause significant morbidity and mortality in the UK and globally. The purpose of this chapter is to outline the current evidence in relation to disease epidemiology and clinical significance for each of these infections, in order to highlight their importance in terms of impact on wider public health. The rationale for implementing population-based vaccination programmes is also explored, together with the cost-benefit analysis in relation to implementation of MMR programmes, in order to further justify this study. This rationale includes consideration of measles, mumps and rubella as total contributors to childhood mortality (worldwide and in industrialised countries); of global initiatives to reduce measles mortality and the incidence of congenital rubella syndrome; and of the potential to eradicate measles and congenital rubella syndrome.

The history of Public Health interventions to reduce the incidence of measles, mumps and rubella infections in Europe and the UK; and the impact of the 'Wakefield controversy' are also briefly examined to establish both the relevance and necessity for undertaking this study.

2.2 Disease Epidemiology and Clinical Significance

2.2.1 Measles

Measles virus (genus *Morbillivirus*, family *paramyxoviridae*) is an enveloped, single-stranded RNA virus (Hawker et al, 2012). It is one of the most highly contagious viruses known and remains one of the leading causes of death among young children globally, despite the availability of a safe and effective vaccine, with approximately 158,000 deaths from measles occurring in 2011 (Strebel et al, 2011), mostly in children

aged under 5 years. Measles occurs primarily in humans; other animals are generally not susceptible. Prior to vaccines becoming widely available, more than 90% of individuals would become infected before the age of 10 years, with most cases being symptomatic. The measles virus is transmitted by direct contact and via respiratory droplet spread. These droplets can also spread to surfaces where the virus can remain transmissible for up to two hours (Perviz and MacMahon, 2006).

The incubation period for measles is 10 – 14 days (range seven – 18 days) from time of exposure to onset of rash. Individuals become infectious from about four days before the rash appears, until four days after becoming symptomatic (Choi et al, 2008). At the onset of the rash, small red spots with bluish-white centres, known as 'koplik's spots' can be seen on the buccal mucosa. These are a diagnostic feature of measles. Onset of the rash is also often accompanied by a very high fever, peaking at >40 C, swelling around the eyes, and photophobia (Department of Health, 2013, Ch. 21).

The severity of measles varies widely, and depends on a number of host and environmental factors. The risk of developing measles increases for those aged under five years, those living in overcrowded conditions, malnourished individuals (especially those who have vitamin A deficiency), and in those with severe chronic conditions, including immunosuppression (Cochi / WHO, 2011).

In industrialised countries, deaths from measles are rare, whilst case fatality rates of 5 – 10% are commonly seen in developing countries. However, severe forms of the disease, and even death, can occur even in previously healthy individuals. Death occurs in 1/5000 cases in the UK. The case fatality ratio is age-related, being high in very young children (<1 year), lower in those aged 1 – 9 years, and then rising again for teenagers and adults. Pregnant women are also at risk of severe complications, miscarriage, or preterm delivery (Maya et al, 2011a)

Otitis media, laryngo-tracheobronchitis and pneumonia are all relatively common complications of measles. Otitis media occurs in approximately 7 – 9% of cases; pneumonia 1 – 6%; and convulsions in 1 / 200 children. Measles encephalitis, blindness and diarrhoea are other potential complications. Persistent diarrhoea, with protein-losing enteropathy can occur, particularly in infants and is significant contributor to mortality in developing countries (Maya et al, 2011b).

2.2.1.1 Measles encephalitis is probably the most significant complication associated with measles infection. There a number of forms which occur at different times in relation to the onset of the rash, as follows:

- Post infectious encephalitis occurs at around one week after the onset of the rash in about 1/1000 measles cases. It is associated with demyelination and is thought to have an auto-immune basis (Department of Health, 2013 Ch.21).
- A delayed type of acute measles encephalitis occurs in immune-compromised patients. In these patients there may not be a preceding measles-like illness, but there may be a history of exposure to measles several weeks or months previously. These patients suffer acute neurological compromise, deterioration of consciousness, seizures and progressive neurological damage (WHO, 2009).
- Subacute sclerosing panencephalitis (SSPE) is a rare, often fatal, late complication of measles infection, occurring in 1/25,000 cases. However, in children aged under two years the case rate for SSPE is around 1/8,000 cases and for those aged under 1 year the rate is 16 times greater than those infected when over five years of age (Jin et al, 2002). This complication of measles infection often occurs many years after the onset of the original symptoms. The median interval from measles infection to onset of symptoms of SSPE is around seven years, but can be as long as two to three decades. It may also

follow an unrecognised measles infection (WHO, 2009; Department of Health, 2013 Ch. 21). There is no specific antiviral treatment for measles infection.

2.2.2 Mumps

Mumps is an acute viral illness caused by a paramyxovirus. It is characterised by the presence of parotitis (parotid swelling which is usually bilateral, but can occur unilaterally). This symptom is usually preceded by several days of non-specific symptoms, such as fever, malaise, myalgia and anorexia. Mumps can also occur as an asymptomatic infection, and commonly does so, particularly in children (Department of Health, 2013, Ch.28).

Before MMR vaccine was introduced in 1988, more than 85% of adults had evidence of mumps infection. Mumps occurred as a common infection amongst school-aged children and was the cause of around 1200 hospitalisations per year in England and Wales; and was the most common cause of viral meningitis in children (Morgan Capner et al, 1988). Neurological complications, including meningitis and encephalitis, can occur or after the parotid swelling appears, and can also occur in the absence of any obvious swelling (Plotkin and Orenstein, 2004).

Other common complications of mumps infection include pancreatitis (4% of cases); oophoritis (in 5% of cases in post pubertal women); orchitis (in 25% of post pubertal cases in men; subfertility is also a rare complication of bilateral orchitis); sensorial deafness (bilateral or unilateral, in 1/3400 to 1/20,000); and less commonly, nephritis, arthropathy, cardiac abnormalities, and death (Falk et al, 1989; Plotkin and Orenstein, 2004). There is no specific antiviral treatment for mumps.

2.2.3 Rubella

Rubella is caused by a single stranded RNA togovirus and is transmitted via respiratory droplet spread (Roitt et al, 1994). Although rubella has a worldwide distribution, it was first described in Germany and is also commonly known as 'German measles' (NaThNac, 2013). It is generally a mild, self-limiting infectious illness with an incubation period of 14 to 21 days. Individuals with rubella are infectious from one week before symptoms appear, until four days after the onset of the rash. The rash itself is transitory, erythematous and occurs mainly behind the ears and on the face and neck, both the rash, and many of the prodromal symptoms are not specific for rubella, and so clinical diagnosis is generally considered unreliable. 20 – 50% of all rubella infections are also subclinical (Miller et al, 1982; Hawker et al, 2012).

Complications of rubella include thrombocytopenia (1/3000 cases) and post-infectious encephalitis (1/6000 cases). In adults, arthritis, arthralgia (mostly affecting the wrist and the joints of the hands) and, rarely, chronic arthritis have been reported (Plotkin and Orenstein, 2004). However, if rubella is contracted in pregnancy it is indistinguishable from parvovirus B19 (Hawker et al, 2012) and can cause miscarriage, stillbirth and the risk of multiple birth defects (Congenital Rubella Syndrome (CRS)) in up to 90% of affected children (Miller et al, 1982). There is no specific antiviral treatment for rubella infection.

2.2.3.1 Congenital Rubella Syndrome (CRS)

CRS often presents with multiple defects, which can be transient, developmental or permanent. If rubella infection occurs in the first 8 – 10 weeks of pregnancy, it results in significant damage in up to 90% of surviving infants. The risk reduces to 10 to 20% between 11 and 16 weeks of pregnancy, and by 16 weeks of pregnancy foetal damage is rare (Hawker et al, 2012). Transient effects of maternal rubella infection in infants include intrauterine growth retardation; thrombocytopenia purpura (25% have

'blueberry skin'), haemolytic anaemia, hepatosplenomegaly, jaundice, radiolucent bone disease (20%), meningitis-encephalitis (25% of cases – with or without other neurological sequelae) (Heymann, 2004).

The most common developmental effect in infants is sensorial deafness, which occurs in 80% of cases and can be bilateral or unilateral. Rubella is the most common cause of congenital deafness in the developed world. In addition, 55% of affected infants will have a significant learning disability; 20% will have immune-mediated insulin dependent diabetes (although this may be delayed until adolescence or adulthood).

'Late onset' disease can also occur at 3 -12 months, and this presents with rash, diarrhoea, pneumonitis. Mortality from late onset disease is high (Bantavala and Brown, 2003). Congenital heart disease (patent ductus arteriosus or peripheral pulmonary artery stenosis), eye defects (cataracts, congenital glaucoma, pigmentary retinopathy, severe myopia, microphthalmia) and microcephaly are also additional permanent disabling consequences of rubella infection in infants (Best, 2007).

The World Health Organisation estimates that there are 700,000 deaths from CRS every year, the highest risk being in regions where there are high rates of susceptibility among women of child-bearing age. In relation to the UK population, this is significant in terms of risks associated with overseas travel. Rubella vaccination makes CRS a completely preventable condition, and the primary purpose of rubella vaccination programmes is therefore to prevent congenital rubella infections (WHO, 2008).

2.3 Measles, Mumps and Rubella as total contributors to Childhood Mortality

(worldwide and in industrialised countries)

2.3.1 Avoidable Mortality

The Centre for Health Economics describes the concept of 'avoidable mortality' as 'all those deaths that, given current medical knowledge and technology, could be avoided

by the healthcare system through either prevention and / or treatment' (Castelli and Nizalova, 2011).

The earliest studies associated with the concept of the 'avoidability' of death are the 'confidential enquiries' which involved the investigation of maternal deaths in the UK (MacFarlane, 2004) and the USA (Holland, 2009). During the 1970s, however, Rutstein et al (1976) brought together experts from medicine, epidemiology, public health and other related disciplines to work together in a systematic way to identify conditions for which it could be agreed that death or disability should not occur if timely and effective medical care had been administered (Charlton et al, 1983). These investigators identified 91 conditions (termed 'sentinel health events') which were considered to be 'clear-cut immediate use' indices of the quality of healthcare, and which by definition should not occur in effective modern healthcare system. Death due to measles in children aged 1 – 14 years was included as one of the original 'single case indexes' due to the availability of a relatively safe, effective vaccine (even in the 1970s) which confirmed it as a preventable infectious disease (Wolfson et al, 2008;Castelli and Nizalova, 2011).

2.3.2 Measles Case Fatality Ratios

Global and UK deaths from measles have decreased significantly over the past few decades as a result of improved immunisation coverage and also as a result of decreases in measles case fatality ratios – that is, the numbers of individuals who die from measles or its complications as a proportion of all those who acquire measles infection. Studies do consistently document that cases fatality ratios for measles are highest in unvaccinated children under the age of five years, and in outbreaks. The lowest case fatality rates occur in vaccinated children, regardless of setting (Maya et al, 2011a; Wolfson et al, 2007; Centres for Disease Control and Prevention, 2009).

Risk factors for measles deaths include diarrhoea, respiratory complications (including pneumonia), otitis media and encephalitis. Respiratory complications are more directly associated with risk of death than diarrhoeal infections, and one study found that pneumonia occurred more frequently in 'mild', unvaccinated cases, than among severe cases (Department of Health, 2013, Ch. 21; WHO, 2009).

The majority of studies also suggest that in vaccinated children milder disease is associated with lower CFRs and fewer complications than in unvaccinated children (Wolfson et al, 2007; Maya et al, 2011a).

2.4 The Potential for the Eradication of Measles and Congenital Rubella Syndrome

2.4.1 Eradication of Measles

Control of infectious diseases through the strategic use of population immunisation programmes is a key public health priority (CMO, 2008; CMO, 2013). Successful immunisation programmes can result in diseases being eliminated or even, ultimately, being completely eradicated. Measles elimination refers to the interruption of measles virus transmission within a defined geographic area, such as a country or a region of the WHO, whereas measles eradication is the global interruption of measles virus transmission such that control efforts could be completely stopped in all areas (Keegan et al, 2011).

Success in measles mortality reduction since the 1960s has mainly been due to increased vaccination coverage, which interrupts transmission of the virus between susceptible individuals and has been made possible by the availability of relatively safe and effective vaccines. Following systematic reviews of this evidence, the World Health Organisation (WHO) initiated a programme of work to evaluate the feasibility of achieving the global eradication of measles (Cochi / WHO, 2011) and following this

evaluation, the 2010 Global Consultation on the feasibility of Measles Eradication concluded that there are currently no known technical barriers to measles eradication; that measles can and should be eradicated; and that 'global eradication by 2020 is feasible given (the then) measurable progress towards the 2015 targets' (Moss and Strebel, 2011).

2.4.2 Eradication of Congenital Rubella Syndrome

Several safe and effective rubella vaccines have been licensed for use since 1969, however, use of Rubella Containing Vaccines (RCVs) was primarily limited to industrialised countries until the 1990s (Department of Health, 2013, Ch. 21/Ch. 28). Significant morbidity and costs result from infants born with Congenital Rubella Syndrome and there is much evidence that this can be avoided by the introduction of RCV into the routine immunisation programme, particularly when combination vaccines are used. The greatest decrease in rubella cases has, for example, been seen in the Americas, which have also succeeded in sustaining elimination of measles, where cases decreased almost 100% from 39,228 to 18 between 2000 and 2009 (Strebel et al, 2011). In Europe, the number of cases decreased by 98% over the same period, from 621,039 to 11,623 as coverage of RCV improved across the region (WHO Europe, 2003).

In light of these issues, the evidence suggests that any programme of eradication of measles should also be used to accelerate rubella control and the prevention of Congenital Rubella Syndrome. The WHO Strategic Advisory Group of Experts (SAGE) and the World Health Assembly (WHA) both endorse the use of safe and effective combination vaccines, such as MMR, to achieve these goals. (WHO, 2010).

2.5 Public Health interventions to reduce the incidence of Measles, Mumps and Rubella infections in Europe and the UK

2.5.1 Introduction of Measles vaccines

Notification of measles infections began in 1940 across the UK, at which time notifications were running at between 160,000 and 800,000 per year. Peaks occurred every two years, with around 100 deaths being attributed to measles each year (Osbourne et al, 2000) (See Appendices 3 and 4)

Measles vaccine was first introduced in the UK in 1968, but coverage remained low up to the late 1980s, and was not high enough to interrupt disease transmission (Vyse et al, 2002). Annual notifications remained at around 50 – 100,000, and morbidity and mortality remained high (Ramsay et al, 2003). It is reported that on average 13 acute measles deaths occurred each year between 1970 and 1988. Whilst this had a significant impact on those who could not be immunised, such as children in remission from acute lymphatic leukaemia, more than half of these deaths occurred in previously healthy unimmunised children (Department of Health, 2013, Ch.21).

MMR was introduced in 1988, for children aged 18 months. Coverage rose to above 90%, transmission was interrupted, and notifications dropped to very low levels (de Melker et al, 2001). As previously described, this reduction in measles transmission meant that children were no longer exposed to wild-type measles infection, and, if unimmunised, remained susceptible. Sero-prevalence studies in 1993 confirmed that a higher proportion of school-aged children were susceptible to measles than in 1986/87, raising the possibility of the resurgence of measles infection in this age group (Ramsay et al, 2003). In 1993/94, a measles outbreak in Scotland resulted in 138 children being admitted to one hospital, and this prompted the implementation of a national vaccination campaign to prevent a further epidemic.

Following this campaign, measles transmission fell seven fold in this age group and endemic measles transmission was effectively interrupted (Gay, 2000). Between 1995 and 2003, there were just 12 confirmed deaths attributable to measles and all were the result of the late effects of measles acquired before 1995. The reduced incidence of measles also brought about the almost complete disappearance of SSPE in England and Wales (Jin et al, 2002).

2.5.2 The Development of Effective MMR Immunisation Strategies

There are a number of considerations when developing effective MMR immunisation strategies. These include timing of the immunisations, the possibility of vaccine failure, and also the need for any immunological 'boosting'. The development of high avidity antibody response is also essential for the development of protective immunity to measles. If 95% of individuals are immunised and 95% seroconvert, the population protective effect is 90%. Any lower vaccination coverage further reduces this protective population effect (Carabin et al, 2003).

Scheduling of immunisations therefore has to reflect a balance between leaving a period when the individual may no longer have passive immunity (for example from maternal antibodies), when he or she may therefore be susceptible to natural wild type virus, and the timescales required for effective sero-conversion to provide protective effect (Roitt et al, 1994). Current UK scheduling of MMR immunisation at 12-13 months reflects the assessment of these factors (Department of Health, 2013, Ch.11).

Following vaccination there is evidence of the long-term persistence of neutralising antibodies and long lasting protection against measles (Janeway and Travers, 1994). However, it is recognised that 5-10% of children fail to respond to the first dose of MMR. Studies on revaccination of these children, however, show that over 97% develop immunity after a second dose (interquartile range 87 – 100%) (Pebody et al,

2002). For these reasons a delivery strategy involving two routine doses of MMR is used in almost all national campaigns globally. Second doses are also a key element of supplementary immunisation activities, such as catch-up campaigns (Pebody et al, 2002; Carabin et al, 2003; Gay, 2004).

A two-dose MMR schedule was introduced in the UK in 1996. Coverage remained at sufficiently high levels following introduction of the second dose and it appeared that the UK was on target to achieve indigenous elimination of measles (Stage III) by 2010, as planned (WHO, 2009).

2.5.3 The impact of the 'Wakefield' controversy

In the late 1990s, controversy over the safety of the MMR vaccine resulted from speculation, in a now discredited research paper, that measles vaccine given as MMR might be associated with inflammatory bowel disease and developmental disorders, such as autism (Wakefield et al, 1998). These were only speculations based on observations of a very small sample of 12 children, but the study received very wide media coverage. In addition, Dr Andrew Wakefield added a suggestion at the press conference that accompanied the release of his research, again without any evidence, that he would recommend that parents seek single (monovalent) vaccines in preference to MMR until any potential link could be discounted.

MMR uptake subsequently declined to 80% in England in 2003/04, and in some areas 44% of pre-school and 22% of primary school children remained unimmunised. Uptake remained under 90% up to 2008, resulting in a gradual increase in the susceptible individuals in the population to levels which could sustain prolonged outbreaks of the disease (CMO, 2008).

Monovalent (single) vaccine was not available, and was not supplied as part of the national programme. Parents were, however, able to acquire monovalent vaccines from private healthcare providers, many of whom were set up opportunistically to provide this service. The current recommendations remain that children who have received single vaccines should also be immunised with MMR to ensure adequate protection against measles, mumps and rubella (Department of Health, 2013, Ch.11). This is because it is difficult to be confident that children who have received single vaccines have been given a product of equivalent safety and efficacy. In particular, the MHRA have objected to the importation of some poor quality single mumps vaccines during this period. In addition, many single vaccine providers were not licensed with the Healthcare Commission, and legitimate concerns were raised about the storage and mixing of vaccines of one very large provider (Ramsay, 2013). As MMR can safely be given to children known to be immune to any of the antigens, it is recommended that two doses of MMR are given to any child with an incomplete history of immunisation to provide long lasting protection against measles, mumps and rubella.

2.5.4 The history of Mumps and Rubella control in the UK

Rubella vaccine had been given as part of a selective UK immunisation programme to teenage girls and to women of childbearing age, from 1970, to prevent rubella infections in pregnancy. Although the initial selective programme was effective in reducing the number of cases of CRS and terminations due to CRI, rubella in pregnancy continued to occur because a small number of unimmunised women could still acquire rubella infection predominantly from their own, or their friends', young children, but also from imported cases, or from overseas travel, or from other unimmunised individuals (Department of Health, 2013, Ch.23). The universal MMR programme, introduced in 1988, aimed to interrupt the circulation of rubella among both male and female young children, preventing exposure of susceptible women to the most common source of infection (Strebel et al, 2011).

Cases of CRS in the UK and Ireland are monitored via the National Congenital Rubella Surveillance Programme (University College London Institute of Child Health, 2015). Since 1991, only 1/3rd of CRS infants have been born to UK women who acquired the infection in the UK. The remainder were born to women from overseas who acquired rubella in their country of origin, or to women who acquired the infection whilst travelling to other countries (European Centres for Disease Control and Prevention, 2013). Recent reports of two new cases of CRS in UK born women have raised further concerns. These cases occurred in 2015 in unimmunised UK born young women, one of who acquired the infection whilst on holiday abroad and the other who acquired rubella from a male sibling who had himself become infected whilst travelling (Public Health England, 2015b). All of these young people were in age groups eligible for MMR immunisation and these cases were therefore entirely preventable.

A single dose of mumps vaccine confers 60 – 90% immunity against mumps infection. Two doses are therefore necessary to achieve effective individual and population immunity (Health Protection Agency, 2005). Between 1999 and 2008, the number of confirmed mumps cases increased, mostly in adolescents or young adults who were too old to have MMR in 1988, or to have been offered a second dose in 1996 (Ramsay, 2010). Outbreaks frequently occurred in higher education establishments, with most of these individuals believing that they had been immunised with a mumps containing vaccine in the past (CMO, 2008).

However, there was no routine mumps immunisation programme before 1988, and the 1994 MR campaign was not able to include mumps because of problems with MMR vaccine supply. These individuals, therefore, may either have had two doses of MCV, one of rubella, but no mumps vaccine. Others may have had only one MMR (therefore one mumps vaccine) which did not provide sufficient protection. During the mid-1990s there were also additional issues with both availability of the Leningrad strain of

vaccine, and efficacy concerns with the Rubini mumps vaccine strain, which also further impacted on coverage and population immunity to mumps (Strebel et al, 2011).

These events mean that there are a considerable number of older children and young adults within the UK population who are not immune to mumps or rubella and who require immunisation to ensure adequate protection. MMR catch-up campaigns have a primary aim of increasing coverage of measles vaccine, however, the use of combination vaccines have the added advantage of also increasing population immunity to both mumps and rubella at the same time, further increasing the clinical and cost-effectiveness of these programmes.

2.6 The Cost Effectiveness of MMR Immunisation Programmes

The NHS has to take cost-effectiveness, equity and access in to account when setting priorities. The NHS is committed to promoting access to services, reducing inequalities in health, and to using its resources in the most cost-effective ways.

There is robust evidence to confirm that measles immunisation is one of the most cost-effective public health interventions. Studies in the Americas, where coverage of >95% was achieved in both routine programmes and catch up campaigns, show that considerable cost savings were achieved when compared with moderate coverage (85%) using routine programmes alone (Zhou et al, 2004). Immunisation with either two routine doses, or two doses with a catch up campaign, have also been found to have a cost to benefit ratio >1 in Canadian, US and Japanese studies (Pelletier et al, 1998; Zhou et al, 2004; Takahashi et al, 2010), and the authors of these studies have all concluded that, in general, programmes that provide two doses of measles vaccine have been found to be highly cost-effective, regardless of the method of delivery of these doses, and that good measles control is likely to save money, when compared with poor control (Choi/WHO, 2011). It has also been found that the addition of a one-

off catch-up campaign to reduce susceptibility in pre-adolescent and adolescent age groups is cost-saving when past coverage is low (<70%), and even where past coverage is >90% for more than a decade, it is suggested that this strategy could be implemented at acceptable cost to the individual and with net savings to society (Beutels and Gay, 2003).

Zwanziger, Szilagyi and Kaul's (2008) economic evaluation of 14 primary studies, however, concluded that supplementary immunisation programmes (catch up campaigns) designed to control measles are unlikely to be cost-effective unless an outbreak is taking place. This conclusion is particularly relevant in areas where pre-school immunisation rates exceed 70% and suggests that any such immunisation programmes must have a focus other than just increasing immunisation rates – for example, identification of hard to reach populations, or areas with very low immunisation rates.

The 2011 WHO evaluation of the cost-effectiveness of measles eradication (Strebel et al) provided an economic analysis at both country and global levels for the ultimate goal in measles control. These studies demonstrate that measles eradication is highly cost-effective regardless of country income levels; is cost-saving in those countries that have already eliminated indigenous measles transmission; and compares favourably with almost any other investment in health. The use of combination vaccines, such as MMR, further increase the potential cost-effectiveness of these programmes, through the additional benefit of preventing CRS and mumps infections (Carabin et al. 2003; Carabin and Edmunds, 2003).

Keegan et al (2011), also reporting for the WHO, estimated that global eradication of measles would cost \$5 – 8 billion. This is less than the cost of eradicating polio and malaria, but more than the Yaws, Smallpox and Guinea Worm eradication

programmes. However, the financial crisis that started in 2008, poses significant challenges to financing a measles eradication programme at this time. This means that the threat of imported cases will remain, and high coverage rates will therefore need to be maintained in the UK to avoid sustained outbreaks and epidemics for the foreseeable future.

2.7 Summary – why the research is needed

The evidence provided in this chapter has clearly demonstrated that measles, mumps and rubella are childhood infections which cause significant morbidity and mortality in the UK and globally. All three of these diseases are vaccine preventable and deaths and serious illnesses that result from these infections should be considered avoidable. Vaccinated children have lower Case Fatality Ratios for measles, and where disease does occur vaccinated children have milder illness and suffer fewer complications. Global initiatives exist to reduce measles mortality, and to reduce the incidence of congenital rubella syndrome, and it is biologically feasible to eradicate these diseases – however these initiatives will potentially be de-railed if immunisation coverage continues to fall.

There is a large body of evidence (both historical and clinical) to support the use of MMR vaccine, and effective organisational infrastructures in the UK to deliver, monitor and evaluate the effectiveness of national and international MMR immunisation programmes. These programmes are highly cost-effective, but cost and clinical effectiveness both depend on maintaining high population uptake and coverage. Evidence from recent outbreaks highlights the potential consequences of failing to maintain uptake and coverage at sufficiently high levels to prevent community transmission, and confirms the relevance of this topic as a contemporary public health priority. Immunisation uptake, specifically requirements for Primary Care Trusts (PCTs), and now NHS England local teams, to achieve 95% uptake rates for childhood

immunisations such as MMR, therefore remains a core measurement of public health performance in the UK (NHS England, 2013; Health Protection Agency, 2013).

The development of MMR immunisation programmes in the UK reflects progress in both applying the approaches described in the WHO Plan and in working towards the overarching goal of eliminating indigenous transmission of measles and rubella. This national organisational infrastructure has delivered vaccine uptake rates which have generally remained high across the majority of programmes. However, offers to provide vaccination via these programmes are not universally accepted by parents (Yarwood et al, 2005) and, in addition, events have occurred periodically which have resulted in falls in uptake for specific programmes, most recently the 'Wakefield controversy' and MMR.

The number of measles and mumps cases remained at high levels during 2007 and the MMR Catch-up Campaign, was initiated following a series of outbreaks of measles in an attempt to return to Stage III levels of control, in 2008 / 09. Significant progress is still required, even in 2013, for the UK to move from the current stage of 'approaching measles and rubella control', to the WHO goal of achieving elimination. As part of this, developing a better understanding of 'hard to reach' groups, such as those who have persistently declined MMR beyond school entry age, will be key if services are to be managed more effectively and communication materials and activities are to be produced which better meet the needs of these populations.

Chapter 3 provides an overview and critique of the current evidence in relation to parental beliefs, attitudes, experiences, and other factors affecting parental decision-making in respect of MMR, which add to the scientific and epidemiological evidence presented in this chapter to underpin this area of inquiry.

CHAPTER 3: LITERATURE REVIEW AND AREAS FOR FURTHER RESEARCH

3.1 Introduction

The national and international public health significance of measles, mumps and rubella infections as important causes of childhood morbidity and mortality, and the potential for these diseases to be eliminated if appropriate strategies are employed to achieve the required levels of population immunisation uptake, has been clearly demonstrated in the previous chapter.

There is a wide body of UK and international evidence examining parental uptake of childhood immunisations. This includes both qualitative and quantitative studies exploring attitudes and beliefs, and other factors, which may influence parental decision-making in relation to immunisation, and specifically the MMR vaccine. This chapter provides a comprehensive review of the existing evidence, with the specific aim of outlining the context and further justification for the present research.

Refusal to accept vaccination (and under-vaccination) may theoretically occur for a number of reasons. Firstly, this could be related to logistical barriers, such as lack of support, childcare or transport – factors which may prevent parents from physically accessing these services (Morrow et al, 1998). Secondly, it might be related to parental concerns about the safety of vaccines, or a particular vaccine (Mills et al, 2000). Finally, there could be other, currently unrecognised, reasons why parents do not accept these offers. The existing evidence for each of these propositions will be explored.

This literature review is divided into sections, each designed to add evidence to underpin the framework upon which my thesis is developed. The evidence in respect of parental attitudes and beliefs (for immunisation per se and more specifically in relation to MMR) is examined in Section 3.3. Evidence in respect of immunisation decision-making, and specifically how parents make decisions to accept or decline MMR, is explored in Section 3.4. Section 3.5 provides a summary of the available evidence base in respect of any other factors that have been identified that may affect or influence uptake. The relevance of this evidence to the Somerset context is explored in Section 3.6, as is evidence of any previous methodologies used to investigate this area of inquiry. The limitations and gaps in the current evidence base are discussed in Section 3.7 in order to demonstrate the relevance of the research questions which underpin the current study. The chapter then concludes, in Section 3.8, with a summary of the rationale for the current study based on the evidence reviewed.

3.2 Search Strategy & terminology

The initial scoping search included very broad topics, such as the psychological theory underpinning parental health beliefs, health belief scales or models, health locus of control, normative theories of decision-making, cognitive psychology, social cognition and informed decision-making, as well as an investigation of the literature relating to the diseases themselves. It is recognised that there is a large body of literature related to parental decision making in general, however, in order to manage the scope of the review the search was narrowed and was focused on evidence related to parental attitudes, beliefs and decision-making and immunisation. It is acknowledged that a narrative literature review was completed and that there may be limitations as a result.

The search terms were then refined and specific searches related to immunisation uptake and MMR were undertaken using the Cochrane Database of Systematic Reviews; ScienceDirect; PubMed; AMED; EMBASE; MEDLINE; PsychINFO; British

Nursing Index and CINAHL. Searches were restricted to English language publications dating from 1980 to present.

Original studies, reports, evaluations and systematic reviews in English were included in the review of published literature and those which only provided secondary reviews or commentary on other articles were excluded. All methods and types of research evidence were included. The articles were then filtered and all duplicates removed. The organisation of immunisation services in the UK, and the specific social, demographic and environmental characteristics of the county of Somerset were also considered. See Appendix 5 for MeSH terms used within the search strategies, and the search results.

The original searches were run in December 2009 and repeated periodically as the study progressed to identify additional papers published during the course of the research. The final search was completed in December 2014 prior to submission.

All available English immunisation data sources (McKesson Careplus, COVER, ImmForm, Open Exeter) were reviewed and additional searches were also performed as the study progressed in relation to:

Personal / Individual freedom and MMR

Rurality and Immunisation / MMR

Collective responsibility and MMR

Herd Immunity and MMR

Vaccine Overload and MMR

Compulsory vaccination

The information obtained from these later searches was used to explore evidence in relation to the themes which emerged from the preliminary qualitative data analysis

and to support the development of codes to inform the final framework for the thematic analysis described in Chapter 5.

Hand searches of the articles and resources were undertaken to identify any additional secondary sources for inclusion. Unpublished academic and policy documents were identified via conference proceedings; via recommendations from researchers in the field; and via a search for previous post-graduate / PhD research on the subject. Dr Mary Ramsay and Jo Yarwood, of the Public Health England National Immunisation Team, kindly provided access to internal departmental documents relating to research evaluations of the Childhood Immunisation Programme Communication Campaigns; the tracking surveys of mothers' attitudes to childhood immunisation (1991 to present); Health Education Authority England meeting notes and presentations; and the evaluations of the NHS Scotland 'MMR Discussion Pack'.

Whilst the information contained within the academic and policy documents remains unpublished, these studies involved relatively large, matched and segmented national samples of parents and the authors and investigators followed robust qualitative methodologies to obtain the data presented. These documents therefore provided an extremely valuable additional source of data on the subject.

It is acknowledged that a number of potentially influential 'anti-vaccination' groups exist within the UK and on social media, however, very few resources promoted by these groups are published in academic publications. Searches were undertaken of eGroups and websites such as 'JABS' and 'What the Doctors Don't tell You' to identify any potentially relevant themes arising from these sources. It should be noted that, although there appeared to be potential for themes to be identified from these sources, much of the information supporting these themes was found to be anecdotal and / or subjective in nature, or related to single incidents or individual cases, without the

application of any robust methodology. This prevented any critical analysis or assessment of the wider relevance of these materials and therefore, whilst these sources are acknowledged, they are not included further within the evidence described within this thesis.

3.2.1 Clarification of terminology used within the evidence and in this thesis

The research presented within this thesis focusses on a group of children whose parents have persistently declined the offer of MMR beyond school entry age. These children and parents are referred to using a variety of terms in both the published and grey literature. These terms include 'confirmed rejectors', 'refusers', 'non-acceptors', 'unimmunised children' and 'persistent decliners'. Whilst these terms are reported within this review as they appear in the evidence referenced, it should be clarified that these are the same population group as studied within the present research and who are referred to by the researcher as 'unimmunised' or as 'persistent decliners'.

3.3 Parents Attitudes and Beliefs about Immunisation

The next sections provide an overview of evidence obtained in respect of parental attitudes, beliefs and decision-making in relation to immunisation (and specifically to MMR) and consideration of other factors which may impact on parents' decisions to accept or decline MMR vaccination.

Childhood immunisations are not mandatory in the UK, they are recommended by the NHS and are provided free of charge, but it remains a parent's choice whether to accept or decline this offer for their child. Parents' attitudes and beliefs therefore have the potential to play an important part in determining the outcome of that choice and exploration of these parental attitudes and beliefs subsequently forms the basis of a

large segment of the literature reviewed relating to parents' acceptance or rejection of immunisation.

Examination of the literature, and most specifically the unpublished government policy documents, resulted in the identification of a number of themes associated with parental attitudes and beliefs in respect of immunisation. These included: vaccine safety; parental knowledge of immunisation and the diseases they protect against; the risks and benefits of immunisation; and in relation to MMR, assessment of specific risks associated with autism and bowel disease. These themes will now be explored.

3.3.1 Balancing vaccine safety and the risk of disease

3.3.1.1 Vaccine safety

In England, tracking surveys of mothers' attitudes, experiences and beliefs about immunisations, undertaken for the Department of Health, provide a unique body of evidence. The information obtained from these surveys has been based on nearly 30,000 interviews used to gather regular feedback from parents and to inform the strategic planning of the childhood immunisation programme in England from 1991, and has been continued on an annual basis to the present day. The outputs from these large population studies suggest that whilst the majority of parents consider immunisation to be generally safe, the decline in the incidence of the childhood diseases they protect against may have resulted in an increased focus on vaccine safety and distortion of the relative assessment of risks and benefits (Keane et al, 2005; Yarwood et al, 2005).

Smailbegovic, Laing & Bedford (2003) identified that MMR and MenC vaccines were the most frequently omitted due to concerns over vaccine safety. A systematic review of 15 qualitative studies exploring parental beliefs and attitudes by Mills et al (2005)

reported that concerns about adverse effects of vaccines were consistently identified as a barrier to childhood immunisation. Studies conducted in Sweden (Dannentum et al, 2001), New Zealand (Hamilton et al, 2004) and Italy (Impicciatore et al, 2000) have all cited similar results adding to the robustness of this assertion.

A variety of methodologies have been used to explore parents' perceptions of vaccines and vaccine safety. Streefland et al (1999) and Streefland (2001), for example, drew on ethnographic material from six countries to examine 'vaccine acceptability' as perceived by parents and other stakeholders; Evans and Bostrom (2002) highlighted the importance of personal factors and cognitive processes, such as beliefs and 'decision-making shortcuts', in a review of immunisation risk communication in the USA; and in a large prospective UK study, Samad et al (2006) found that (inaccurate / negative) maternal beliefs about vaccines and immunisation were, the predominant reason for infants not receiving any vaccinations at nine months of age. These studies each provide evidence confirming the role of parental attitudes, perceptions and beliefs in respect of the assessment of the relative benefits and risks associated with immunisation, factors which appear to be highly significant in enhancing, or conversely reducing, parents' willingness to accept vaccinations such as MMR.

In addition, evidence suggests that immunisation, as a policy, appears to be generally trusted in the UK and that most parents believe in both the value and the importance of the national programme (Gellin et al, 2004; Wardle McLean, 2004; Keane et al, 2005). This is important because other authors have suggested that national policies and legal frameworks can directly influence parental health beliefs in both positive and negative ways – for example, by encouraging them to think of immunisation as necessary and beneficial, or alternatively as being something that is forced on them, and/or deserving of parental resistance (Sturm et al, 2005).

Ramsay et al (2002) reported that whilst an increase in mothers' concerns about MMR safety was identified, the majority of those interviewed in 2001 still intended to fully immunise another child in the future. Evaluations of health education immunisation communication campaigns in England (Malam & Muir, 2002; DDB, 2004; Wardle McLean, 2004; Wardle & Sancho, 2004) also appear to confirm, however, that whilst the 'silent majority' of parents are still immunising, parents are generally now sensitised to potential problems with immunisations. It is suggested that many parents remain anxious about vaccine safety, especially in relation to MMR, and 1 in 5 parents believe that the MMR vaccine poses a greater risk than the diseases it protects against (although it appears that this concern reducing over time) (Yarwood, 2005; BMG Research, 2015).

Whilst the tracking surveys have shown that in recent years there has been a gradual and sustained increase in parents' confidence in the safety of MMR, the responses continue to remain below the confidence levels seen in 1998 (Yarwood et al, 2007; BMG, 2015). MMR also remains the vaccination that is most often delayed – with concerns about safety remaining the most frequently cited reason for the delay (Cragg Ross Dawson, 2010).

Concern about vaccine safety is not confined to the UK, but it does appear to be a more significant factor for UK parents than for parents in other countries. In a large international survey of lay and professional attitudes and beliefs, conducted in six European countries (Pasteur Merieux MSD, 1998) the British public were found to be more interested in the features of vaccines than the diseases they protected against or disease epidemiology; they had more concerns about the general side effects of vaccines, and had less enthusiasm for the development of future vaccines than members of the public in any of the other countries. This survey was undertaken before the MMR controversy became widely reported in the media and suggests that

there may have been pre-existing concern and suspicion about vaccine safety on the part of the British public. This may explain, in part, firstly why controversies, such as that relating to Wakefield's 1998 publication, may have had a much more significant impact in the UK than in other countries, and why, despite considerable evidence refuting any links between MMR and autism, parental concerns still persist within the UK. These issues will therefore be investigated further within this study.

The evidence reviewed appears to suggest that parental fear about vaccine safety forms a barrier to high immunisation uptake. What these studies do not reveal, however, is what strategies might contribute to allaying these fears and act as reassurance to parents and encourage them to change their minds and accept immunisations such as MMR. The present study aims to explore these questions.

3.3.1.2 Parental perceptions of the relative risks of immunisation and the diseases they protect against

Socio-environmental factors include culturally based beliefs about the nature of diseases and immunisation and encompass factors such as parents' knowledge of the relevant diseases, or their perceptions of the child's susceptibility to those diseases (Mays et al, 2004). Whilst a positive attitude may be associated with higher uptakes of childhood immunisations, Impicciatore et al (2002) found that the most common reason for not immunising was the belief that it was not considered important. Parents' perceptions of the importance of immunisation, and therefore of the relative risks associated with vaccination or disease, relates to their knowledge about infectious diseases and understanding of how immunisation works.

Perceptions of the risks of disease and disease severity appear to be important, but vary widely. Whilst some focus group studies have found that most parents were poorly informed about the diseases that their children were being vaccinated against

(Cotler et al, 2003), there does appear to be considerable evidence that parents are more accepting of vaccines that offer protection against diseases which are perceived to be 'serious' than those that are perceived to be less serious (Smailbegovic et al, 2003; Yarwood et al, 2005; Bedford & Lansley, 2007). Whilst there is some evidence to suggest that parents may be concerned about measles, for example, other research has indicated that parents generally do not consider the diseases that MMR protects against to be serious. Parents appear to be more strongly influenced by the perceived risks carried by vaccines, rather than balancing the overall risks and benefits of vaccinating against not vaccinating, and this may significantly impact on parental decisions relating to risks and benefits associated with these immunisations (Pareek & Pattison, 2000; Yarwood et al, 2005; Bedford & Lansley, 2007).

Parents perceptions may develop or be reinforced by a number of factors. Reviews of sociological theory and social cognition models in the wider literature refer to constructs underpinning preventive health behaviours, some of which may be relevant to interventions such as immunisation. Within models, such as the Health Belief Model (Rosenstock, 1959), social norms – such as the opinions held by peers, or groups that are important to the person making the decision – significantly influence the outcome of the decisions, to the extent that people will 'have their children vaccinated (or not) because everyone else does and it seems the right thing to do' (Streefland et al, 1999). Social group norms, therefore, form an intrinsic part of the constructs as applied to immunisation (Anderson et al, 1997; Prislin et al, 1998) and may also be relevant to the current investigation.

The evidence to support the theory that perceived risks associated with vaccines are far more likely to be the focus of parental anxiety than any risks associated with specific diseases (Chen, 1999) appears to be robust. Mathematical modelling approaches have also been used to demonstrate that the impact of any such perceived

risk is likely to persist long after a vaccine 'scare' has occurred (Baush & Earn, 2004). These findings may be particularly relevant to identifying persistent parental attitudes affecting uptake of MMR in populations reviewed several years after the impact of the initial Wakefield publication, and these parental perceptions will be explored in the present study.

3.3.2 Vaccine overload and the challenge to immature immune systems

A further concern about MMR appears to centre on speculation that giving children three antigens in a single vaccination is 'too many for the immune system to cope with' (Poltorak et al, 2005). Pettigrew & Hunt (2006) also found that parents were likely to delay their child's MMR if they had a minor illness, largely due to the belief that the vaccination would 'overwhelm the child's already compromised immune system'. Concerns that the vaccine places stress on the child's 'immature' immune system; whether a child's immune system is mature enough to 'cope' with this combination; and whether some children's immune systems are less able to cope, making them more prone to long term damage from the vaccines, were common themes in previous UK focus group studies involving parents who had refused MMR (Evans et al, 2001; Hilton et al, 2006). Parental concerns relating to perceptions of their child's ability to cope with vaccination appear common and this is further supported by the findings of ethnographic research, undertaken amongst mothers in Brighton, which confirmed the importance of lay theories of immunisation, particularly with regard to 'vaccine overload' in the context of individual 'weakness' (Cassell et al, 2006).

Corr Willbourn's 'Conceptual Framework Research Among Mothers' (2004), undertaken to inform the Department of Health immunisation communication strategy, confirmed that parental knowledge of how immunisation works was generally poor. This study (involving both interviews and focus groups with parents across the UK) found an almost universal belief that immunisation was a process of giving the child 'a

little bit of the disease'. Whilst there is some logic to this, the principles of immunisation are far more complex and this explanation is too simplistic to be technically correct.

The parents within the Corr Willbourn (2004) study were found to have a deep commitment to their child's welfare and were doing what they considered was best for them, but this analogy was problematic and contributed both to misunderstanding and to perpetuating the concept that the body was being challenged or overloaded with 'lots of little bits of disease' when multi-valent vaccines were used. This then resulted in 'vulnerability to disease' and 'vulnerability to immunisation' being conflated in parents' minds and a 'degree of free-floating anxiety' remaining which the authors suggest could easily attach to another issue (or another multi-valent immunisation) even if concerns about MMR were attenuated. The authors concluded that this is of particular importance given the volatile nature of parental perceptions in this area, and also provides evidence of the potential dangers of trying to over-simplify explanations when attempting to reassure parents, since these explanations themselves can be misinterpreted and can add to the complexity of evidence that parents' themselves have to consider when making decisions on behalf of their children.

There do, however, appear to be some inconsistencies between parents' views and actions in respect of immunisation, perhaps associated with the poor levels of parental knowledge and understanding of both the vaccines and of vaccine preventable diseases previously identified. Hilton et al (2006) in Scottish focus group studies, for example, found that parents who were concerned about vaccine overload in relation to MMR had, in the main, taken their child for the combined DTP vaccine at 2, 3 and 4 months and seemed unconcerned about the multi-valent nature of these vaccinations or of any potential for these to 'overload' the immune systems of very young infants.

Both vaccine safety and parental perceptions of the relative risks associated with vaccination and diseases / disease severity appear to be significant factors of relevance to the present investigation. A limitation of the evidence reviewed so far, however, is that the studies almost universally provide a 'snap-shot' of parents' attitudes and beliefs at just one particular point in time, that is, around the time of the original offer of the primary immunisations at 13 months (first dose) or 31/4 – five years (second dose).

Whilst samples are matched across the waves of the tracking surveys, for example, these studies involve a different group of parents, approached at the same defined decision point, for each new round of the survey. This is useful for providing trend data and comparators, but does not provide any evidence in relation to the persistence of these parental attitudes, or of whether and how these attitudes may change over time. Further research to gain insights into whether these concepts continue to influence parents' decisions longer term, and for older children, is of particular relevance to prevent the development of susceptible pools of unimmunised children and young people as the childhood immunisation programme continues to develop. The present study therefore aims to explore whether similar attitudes and perceptions persist for parents of older, school-aged children.

3.3.3 Perceived risks related specifically to MMR - the 'Wakefield controversy'

In 2009, a significant theme within the literature related to a hypothesis proposing the possibility of a 'new variant' of autism involving developmental regression and bowel problems, temporally associated with administration of MMR vaccine. Originally published as a study in the *Lancet*, a highly respected and influential medical publication, '*Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children*' (Wakefield et al, 1998) triggered a wave of public concern and media interest and this widely regarded as the primary cause of the rapid

and persistent fall in MMR uptake in subsequent years. The potential impact of this, particularly on parents making decisions about MMR at that time, cannot be underestimated, but further research is required to explore whether it remains a key contributory factor influencing parents of older, school age children who continue to persistently decline the MMR vaccine many years after this event.

Wakefield's research was formally retracted by the Lancet in 2010 and there is now considerable evidence refuting any link between MMR, autism and inflammatory bowel disease. This evidence will now be examined to further understand the potential influence of this episode on parental perceptions in relation to MMR.

Following the publication of the Wakefield research in 1998, a number of theories of immunisation as a risk factor, and/or theories of autoimmunity as a predisposing genetic risk, were proposed to explain the perceived correlation between the use of MMR and the rapid increase in cases of autism over time (Borchers et al, 2002; Mehta & Munir, 2003; Chez et al, 2004).

Whilst a very small number of molecular studies have suggested that such a development – or, more specifically, the possibility of the involvement of an environmental risk factor or an autoimmune mechanism – is biologically plausible and cannot be ruled out in a very small number of cases of autism (Singh et al, 2002), there is no significant evidence to demonstrate a specific link with MMR (Taylor et al, 2002; Smeeth et al, 2004). Any biological link would be equally applicable to other viruses, for example rubella, and would have to relate to any measles-containing vaccine, not solely the measles component of MMR. Such a link would therefore also contraindicate the use of single vaccines as a safer alternative. More recent studies, using the most sensitive techniques, have failed to detect vaccine virus in biological assays from children with autism (Afzal et al, 2006; D'Souza et al, 2006).

Conversely, this review identified a large body of accumulated evidence, from molecular biology to complex epidemiological studies, matched case-control studies, comparative, prospective and retrospective cohort studies, clinical trials, reviews of unintended adverse events in healthy young people, case note reviews / linked hospital discharge studies, ecological studies, and time trend analyses, all conducted by independent researchers, that have been unable to establish a causal link between MMR and autism (Fombonne & Chakrabati, 2001; Kye et al, 2001; Coffin, 2002; Makela et al, 2002; Masden et al, 2002; Phelan, 2002; Taylor et al, 2002; Thjodleifsson et al, 2002; Smeeth et al, 2004 Chen et al, 2004). In addition, systematic reviews of the literature have failed to identify any links between Crohn's Disease, ulcerative colitis, autism or aseptic meningitis and MMR (Jeryl-Lyn strain) (Jefferson et al, 2003; Miller E et al, 2005; Demecheli et al, 2005).

Additional compelling evidence is obtained from a whole population study undertaken in Japan, where MMR was withdrawn in 1993, effectively creating a large natural experiment (Honda et al, 2005). The series of studies that followed found that there was no effect of the withdrawal of MMR on subsequent rates of autism over time (Takahashi et al, 2003). There has also been found to be no correlation between the rate of autism and MMR vaccine coverage in the UK or the USA (Dales et al, 2001; Kaye et al, 2001) and there is no evidence of a clustering of the onset of symptoms of autism in the period following MMR vaccination (DeWilde et al, 2001; Makela et al, 2002). There is, however, some evidence of recall bias in cases where parents retrospectively attribute causation to MMR (Andrews et al, 2002; Lingham et al, 2003), and also evidence that the likelihood of parents reporting a link with administration of MMR increased significantly after 1998 (Lingham et al, 2003).

There is no doubt that the recorded rates of autism have increased over the past 30 years, and that there is an urgent need for research into the causes and potential

treatment for this lifelong condition. However, whilst the research is not able to definitively rule out a potential environmental or autoimmune mechanism for all cases of autism, cases of regressive, degenerative autism are very rare, and there do not appear to have been any increase in rates of this specific form as a proportion of all diagnosed cases over time (Al-Ayadhi, 2005). Whilst this provides good evidence that this cannot be the explanation for the large increase in cases of autism in recent years, the fact that these are very rare occurrences means that they would be too small in number to be identified in epidemiological studies (Lingham et al, 2003). Consequently, the possibility remains technically open, and the debate in respect of causation cannot be concluded for this extremely small group of children. Unfortunately, these children continue to remain the subject of case reports in online media and grey literature sources, particularly those associated with 'anti-vaccination' groups.

An exploration of the wider literature, however, does provide credible alternative explanations for the increase in autism, not least that the increase is most likely to have resulted from increased public and professional awareness following better recognition and assessment, and the broadening of diagnostic criteria for the disorder (DeStephano, 2002; Wing & Potter, 2002; Rutter, 2005). Greater public awareness is also reflected in increased media coverage; but, unfortunately, studies which have reviewed this coverage tend to conclude that there is significant negative stereotyping of the disorder and of individuals affected by it, and that there is a lack of support available for parents of these children (O'Dell & Brownlow, 2005). This, in turn, is shown to affect parents' concerns about the possibility of having an autistic child, especially in relation to the safety of the vaccine and them making an active decision to accept this for a child who is apparently healthy and unaffected (Speers & Lewis, 2004).

Some authors also conclude that the lack of a robust defence of MMR, until the publication of the second Cochrane Review in 2005, acted to further undermine public confidence and that *'the media's critical scrutiny of those supporting MMR was not matched by a critical examination of the case against it, and that the public was, as a consequence, often misinformed about the level of risk involved'* (Speers & Lewis, 2004, p. 175).

Research published since 2009, including a further Cochrane Review and a meta-analysis both published in 2012 (Demecheli et al; Hobson et al), confirm the absence of any causal link, and in fact suggest that the odds of being diagnosed with ASD are substantially smaller for those who receive MMR. There has also been significant coverage of failed legal cases and professional action against Dr Wakefield by the GMC, which resulted in the subsequent retraction of the original article by the Lancet in 2010.

Given the substantial body of published evidence demonstrating that MMR is not correlated with the development of autism, the ages of the children, and the time elapsed since the initial offer and the new evidence refuting this link, a key question remains of relevance to the current study – was this still the key contributory factor influencing the parents' decisions to decline MMR in Somerset after 2009?

3.3.4 Summary of evidence relating to parental attitudes and beliefs

From the studies reviewed so far, it is reasonable to suggest that scientific and medical evidence appear to play little part in parents' decisions in respect of MMR, with parents' own assessments of the relative acceptability of the vaccination and possible outcomes being of far greater significance. Previous experience – either of the diseases or of children with autism – was also found to be a significant factor and whilst some parents have reported that they did not receive information on the

rationale, benefits and risks of MMR; many felt that the information they did receive from the NHS did not bear any relation to their real life local circumstances MacDonald (2004),

The cultural context of MMR rejection is another key concept highlighted. In the ethnographic study undertaken in Brighton (Cassell et al, 2006) for example, the authors concluded that decision-making in respect of immunisation was a complex culturally rooted activity, and that parental attitudes and beliefs were poorly understood. It has also been suggested that research in this area holds great promise for promoting the public health of children and their families, but that there is little or no information on how these attitudes change over time or what influences these changes where they occur (Sturm et al, 2005). Further research may provide insights into these factors and in doing so provide direction to guide how the providers of these services can effectively engage with parents, thereby bridging the gap between policy recommendations and parents' actual decisions. This is particularly important at a time when there are so many new vaccines in development.

The present study will explore socio-environmental, parent-specific and personal characteristics (such as beliefs and attitudes) in relation to immunisation in general, and specifically in relation to MMR, in order to establish whether the same characteristics – health beliefs, social norms, and perceived risk – apply equally to a population of parents in Somerset who are, by default, 'persistent decliners' of MMR vaccine.

3.4 Parental decision-making and MMR

3.4.1 Conflicting evidence and 'decisional conflict'

The evidence explored in the previous sections of this literature review suggests that immunisation decisions almost inevitably involve the weighing up of the risks and

benefits of vaccinating the child, against not doing so (Cassiday, 2007). There are, however, considerable inconsistencies and contradictions within the evidence.

Parents' consistently report that the potential to cause physical pain to their child through the process of immunisation is considerably distressing and anxiety provoking (Bennett & Smith, 1992; Harrington, Woodman & Shannon, 2000; Smailbegovic et al, 2003; Mills et al, 2005). Combination vaccines, such as MMR, offer a potential solution to this and to the addition of new vaccines to the national schedule (Kaslap-Petraco & Parsons, 2003) by reducing the number of clinic visits and the distress of multiple injections. It may also increase vaccine coverage and reduce the potential for the child acquiring serious disease in the intervals between single doses (Andeae, Freed & Katz, 2004; Bedford & Lansley, 2007). However, despite these advantages, and their acknowledged distress and anxiety in respect of causing pain, parents' concerns when assessing the initial offers of MMR appear to continue to centre on the simultaneous administration of the three antigens and this creates a dilemma for parents when making decisions for their children (MacDonald, Henderson & Oates, 2004).

Leach et al (2006) suggest that this 'decisional conflict' appears to be a key factor, which is only resolved by parents in reference to considerations of either the specific vulnerability of the child to the diseases, the effects of the vaccine, a desire for choice, or to what parents regard as values in respect of 'good' parenting. Other authors have suggested that the suggestion of harm, occurring as a result of immunisation ('commission'), may be less acceptable to parents than harm occurring as a result of not immunising ('omission') (Wroe et al, 2005). This possibility of 'omission bias', may be one of a number of 'emotion-related' variables which are currently poorly understood and require further exploration in order to establish what motivates parents when deciding to accept or decline immunisation for their children. The literature also suggests that parents use a number of different strategies to make sense of risk issues

in health, particularly in respect of MMR, and that this may involve roles for both social networks and the media as sources of information and in reinforcing parental understanding and belief (Cheater, 2006).

3.4.2 The role of past experience in immunisation decision-making

Weighing up risks and benefits may also rely to some extent on personal experience. Qualitative interview studies, undertaken in Scotland, have identified prior experiences of disease as the primary determinants of MMR decisions, with parents who had direct experience of autism, or who believed their child to be autistic, more likely to decline and those who had observed the negative impact of vaccine preventable diseases more likely to accept vaccination (McMurray et al, 2004). Ethnographic studies by Poltorak et al (2004) provided further evidence that mothers bring to parenthood very diverse experiences and found that parents drew on the history of immunisation decisions, and their experience of this within their own family and in other families known to them, when making decisions about MMR. Both studies were, however, small in scale and it is unclear whether these findings can be more widely generalised.

Published research in respect of the role of immunisation services in relation to uptake appears to be even more limited, but there is some evidence to suggest that adverse experiences of immunisation services can result in deferral of future visits or in defaulting and non-attendance (Harrington et al, 2000). Cassell et al (2006), however, suggest that, whilst previous negative experiences may discourage parents, for some 'non-compliers', the decision to refuse all immunisations is made very early on, perhaps even before their baby is born. For this group of parents, refusal appears to be completely unrelated to their experience of or satisfaction with the immunisation service. This suggests that there may be differences within the group of parents currently identified as a single group of 'persistent decliners' and this warrants further investigation.

Past experience, both positive and negative, may play an important part in parents' decision making, however, what remains unclear, is whether the influence of these experiences or behaviours, persists long term; and whether this then changes over time, or as new experiences occurs? In addition, why do some parents persist in deferring, despite having experiences which counteract the decisions previously made?

A final consideration relates to findings by Evans et al (2001), who identified that, in UK focus group studies, because responses relied on self-report, personal experiences were not necessarily 'good predictors' of immunisation status. They report that quantitative research using objective measures is needed to enable further clarification. These issues have been considered when designing the present study.

3.4.3 Other factors influencing parental decision-making

3.4.3.1 The influence of the media

As stated previously, adverse publicity about MMR has been shown to raise doubts in the minds of people who had not previously questioned the safety of immunisation (Evans et al, 2001; McMurray et al, 2004). Pareek & Pattison (2000) found that mothers obtained information from the media, especially from magazine style TV programmes such as GMTV. However, Mac Donald et al (2004) found that parents who declined MMR were more likely to rely on information from the internet, than from health care professionals or other media sources. In an Australian study, Bond et al (1998) reported that anti-vaccination material reported in the media caused mothers to question their decisions and contributed to feelings that important information was being withheld from the public. There is robust evidence from multiple sources of the significant influence of both print and digital media on parental attitudes towards acceptance or refusal of immunisation from the earliest points of programme

introduction (Davies et al, 2002; Leask & Chapman, 2002 and Wolfe et al, 2002).

However, parents' views of the media vary widely.

In a Scottish focus group study, for example, whilst some parents viewed journalists as important providers of information, others viewed them as 'scaremongers' (Hilton, Pettigrew & Hunt, 2007). Attention surrounding MMR therefore appears to have highlighted to some extent the negative role of the media in vaccine scares. These studies provide further evidence of the difficulties parents find in identifying reliable sources of information on risks and benefits and of then balancing these to be able to make the required decisions about immunisation (Petts et al, 2003).

Social media has also now become integral part of modern communications. Parents do not just use the internet to acquire information; they also use it to share their opinions and concerns through social conversations. Skea et al (2008), in a review of online chat room discussion confirms that 'avoiding harm to others' is an important consideration for parents. However, this is again couched in terms of individual susceptibility: a clear distinction is made between vulnerable and healthy children, and this has implications for which children should 'bear the burden of vaccination'. Parents were, for example, very critical of those who did not vaccinate healthy children.

There is also a need for more research in respect of how parents make the distinction between vulnerable and healthy children, since there has been some evidence of uptake being negatively impacted where parents and professionals had misconceptions about the risk of adverse events, or where 'spurious contraindications' to immunisation, including concerns about concurrent respiratory conditions, allergies, or minor illnesses, have been applied (Watson et al, 2007; Ozkaya, 2011; Fox et al, 2012; Munro, 2013; Parella et al, 2013). It should also be noted that, in many of these studies, parents who were critical of the decisions of other parents were equally able to

rationalise why their particular child (and decision) were acceptable exceptions, based on perceived individual vulnerability factors.

3.4.3.2 Distrust in the Government

A review of the chronological history of vaccine development (Warren, 2000) confirms that anti-vaccination attitudes existed many years before the MMR controversy. The 1802 caricature of Jenner inoculating patients in Figure 1 below, for example, demonstrates the early concerns of patients when Jenner first proposed vaccination against smallpox using cowpox vaccine that it would make them sprout cow-like appendages:



Figure 1: "The cow pock" by James Gillray - Library of Congress, Prints & Photographs Division, LC-USZC4-3147 (colour film copy transparency), archival TIFF version

Reviews in relation to media coverage of vaccines in Australia in the 1990s have identified several key anti-vaccination themes. These included conspiracy theories of 'cover-ups' relating to the withholding of information from the public, portraying vaccines as dangerous chemicals or toxins which poison the body, or regarding

vaccines as a form of Governmental control, or a threat to civil liberty (Leask & Chapman, 1998).

There is also evidence to suggest that distrust in the UK government, and consequently a lack of confidence in statements issued by the Government about the safety of MMR, may have more recently adversely impacted on parental decision-making, particularly among parents who refuse MMR. (Evans et al, 2001; Cassell et al, 2006; Cassiday et al, 2006; Hilton et al, 2007).

3.4.3.3 The role and influence of Health Care Professionals

In terms of trust, whilst some parents remain sceptical about reassurances of MMR safety made by the Department of Health (Evans et al, 2001), the tracking surveys undertaken between 1996 and 2006 provide robust evidence that mothers were more likely to trust information given by health care professionals and the NHS than the Government and that they continue to see Health Care Professionals (HCPs) as a key source of information and advice about immunisation (Impicciatore et al, 2000; Smith et al, 2001; Smailbegovic et al, 2003; McMurray et al, 2004; Heininger, 2006).

However, if doctors or nurses appear to lack confidence in the programmes, there is evidence that this is likely to be reflected in reduced uptake. The complexity of the current schedule and negative publicity, particularly in respect of MMR is, however, reported to have resulted in a reduction in professional confidence, and knowledge in this area of work (Smith et al, 2001), which consequently may have an effect on parents' experience of the process.

In two focus group studies undertaken in Australia, Leask et al (2006) found that the family doctor was considered an integral point of reference in both immunisation decision-making and in the 'negotiation of risk messages'. Bond et al (1998) found that

mothers valued doctors who took the time to explain procedures and discuss risks and appreciated staff that listened to them and 'credited them with common sense'. Evans et al (2001) also found that doctors and health visitors who discussed immunisations openly were highly valued, whilst those who 'sat on the fence' were viewed most negatively by parents.

Parents frequently report that HCPs are the most helpful source of advice, however, a significant number remain dissatisfied with some aspect, for example believing the information to be biased, or lacking objectivity, or that some information may be being withheld (Smailbegovic et al, 2003). Others, particularly those who decline MMR, remain concerned about GPs receiving payments for immunisations or them having to meet targets for uptake (Evans et al, 2001; Sporton & Francis, 2001). The same studies identified a desire for HCPs to provide more balanced information for parents, with many finding it difficult to have an open discussion with professionals about the risks and benefits of immunisation.

Poor communication and unpleasant staff have therefore been identified as barriers to immunisation (Mills et al, 2005). Qualitative interviews have also revealed that a lack of empathy from doctors involved in immunisation was considered unacceptable and that mothers valued attempts by them to acknowledge the pain and to engage with the child (Harrington et al, 2000).

Given this evidence, it is likely that issues of trust and parental satisfaction with both the amount and the quality of information received are key factors in determining whether or not parents will take their children for their immunisations. Similarly, the 'MMR contact' with health care professionals appears to be of crucial importance in determining outcome and therefore needs to be effective since Martin et al (2001) also found that:

“If a parent remains undecided after a discussion with a health professional, it is likely that this will not change and there is little gain in referring them to someone else. This may be counter-productive and, at worst, stiffen resolve not to vaccinate and, at best, maintain the parent in a state of continuing indecision” (p 38).

To date, the Government’s responses to falling immunisation uptake rates appear to have been based on providing more information to the public, overtly using language of risk. These strategies are apparently based on a number of assumptions which may not be entirely valid (Hobson-West, 2003). For example, it is assumed that individuals make decisions through a comparison of individual relative risks, that the current public concern is due to misunderstanding or miscalculation of risk, and that therefore reducing these knowledge deficits by providing more information is the best response to improve vaccine acceptance (Cunliffe, 2004). The evidence presented here suggests that the process may be far more complex and may therefore require a different approach, particularly for those parents who persistently decline.

Whilst professionals do need to be accurately informed, in order to be able to assist parents in making their decisions, they also need a better understanding of the dynamic nature of immunisation decision-making, so that they can help to identify more effective methods of promoting childhood immunisation to groups at risk of non-compliance. Streefland (in Vernon, 2003) suggests that immunisation policy needs to move from the current situation, which largely assumes passive population compliance, to a policy where people are actively involved and their views are respected. This can only be achieved where these views are better understood by policy makers and this study aims to provide further evidence to improve that understanding.

Between 2009 and December 2013, there was an increase in the number of studies investigating parental attitudes and beliefs, and in using new models to develop predictors of vaccination outcomes (for example, Tickner et al, 2010 – Immunisation Beliefs & Intentions Measure, based on the theory of planned behaviour; and Schultz & Nakamoto's Extended Health Empowerment Model, Diviani et al, 2012). These studies appear to confirm the strong influence of parental attitudes on vaccination intention.

The most significant new area of investigation over the past three years, however, relates to studies exploring the role and impact of HCPs, and the development of potential interventions to improve access and delivery of immunisation information. Whilst it appears generally acknowledged (and is evidenced in this review) that HCPs can be a credible source of information for parents seeking informed decision-making, and are well-placed to challenge myths and promote the benefits of immunisation (Kassianos, 2010; Schonberger, 2012; Hill & Cox, 2013), Simone (2012) identified that gaps in health care professionals' knowledge and poor communication could actually be detrimental to achieving high uptake, while Redsell et al (2010) found that the approach of some professionals could act as a psychological barrier to accepting vaccination. This author also suggested that further work to identify parental factors that may point to ways of making positive adjustments to these approaches – such as the research undertaken within this thesis – could help to facilitate more effective MMR promotion activities in future.

There is, however, no consensus about how best to alter current approaches in order to address falling uptakes. Some investigators have continued to focus on the need to overcome potential barriers by improving the knowledge of both parents and professionals through better education and provision of information (Anderberg et al, 2011; Fox et al, 2012; Harrisen et al, 2012). Others have investigated specific interventions to improve uptake, with a focus predominantly on structural changes to

improve the organisation of immunisation services, including provision of improved call/recall, leaflets and parent meetings, telephone follow-up of postal invites, commissioning of care packages, development of incentivized GP practices and networks, and innovative use of information technology (Jackson et al, 2011; Cockman et al, 2011; Goodyear-Smith et al, 2012).

New and potentially interesting areas of study include development of the ideas around communicating concepts of 'benefit to others' and 'herd immunity' in ways that are understandable and compelling to parents, and using this as a motivational tool to increase uptake (Quadri-Sheriff et al, 2012). Equally, there is the exploration of concepts of health literacy, health empowerment and information searching behaviour in relation to immunisation (Diviani et al, 2012) which also has the potential to be incorporated and further explored in this study.

Several studies have suggested that parents may benefit from social engagement with professionals, and that attention should be paid to parental 'storytelling' when making policy decisions (Vernon, 2003; Leach et al, 2006). Since there were only a small number of such studies identified, further research is needed to confirm the validity of these concepts, and to ascertain whether these ideas can be extrapolated to other contexts and populations. The integration of qualitative and quantitative approaches, as proposed in this study, may produce a richer vein of evidence about factors, such as these, which may be associated with parental decision-making.

3.5 Evidence of other factors affecting or influencing uptake of immunisations

Whilst some authors conclude that parental attitudes, and perceptions of control, are significantly associated with immunisation uptake (Prislin et al, 1998), or are sufficiently reliable to be used as predictors of completion of childhood immunisation programmes (Gore et al, 1999), others have highlighted limitations in the use of these models

suggesting that socio-demographic and financial factors, or access / barriers to care, may be more predictive of immunisation outcome (Strobino et al, 1996; Bates & Wolinsky, 1998).

From the evidence reviewed to date it is possible to identify six consistent and interacting factors related to acceptance of childhood immunisation, as follows:

Parent - specific personal factors (e.g. attitudes, beliefs, social group norms, geographic, demographic and social characteristics, including religious and moral objections) (Streefland, 1999; Evans & Bostrom, 2002; Leask & Chapman, 2002; Sturm et al, 2005; Cassell et al, 2006)

Attitudes and practices of healthcare providers (e.g. whether providers recommend vaccination or not; whether there has been effective risk/benefit communication with the parents; whether phone or other reminders are given) (MacDonald, 2004; Fitzpatrick, 2004; Deady & Thornton, 2005; Rosen-Schikuta et al, 2007)

Access to healthcare (e.g. vaccine cost and availability, transport, convenient clinic hours) (Strobino et al, 1996; Bates & Wolinsky, 1998; Harrington et al, 2000; Niroshan et al, 2003; Henderson et al, 2004; McMurray et al, 2004; Yarwood et al, 2005).

Policies, interventions and action at political and societal level (e.g. legal mandates to immunise) (Sporton & Francis, 2001; Smith et al, 2001; McMurray et al, 2004; Wood-Harper, 2005)

The physical environment such as background prevalence of the disease & history of previous public health efforts (e.g. the length of time since a disease last caused significant outbreaks, or whether there is effective medical treatment for the disease) (Bond et al, 1998; Fitzpatrick, 2004; Petts & Niemeyer, 2004; Cameron et al, 2007).

The issue of balancing individual freedoms and collective responsibility (Vernon, 2003; Skea et al, 2008; Perisic & Bauch, 2009)

Two large UK population based studies published around the time of the MMR debate and subsequent 'Catch-up campaign' (Friederichs et al, 2006; Bedford et al, 2009) have indicated that there may also be specific social or demographic factors associated with partial or no immunisation. For partial immunisation, factors include lone parents, large family size, residing in a disadvantaged area, smoking in pregnancy, ethnicity, teenage mothers, or a history of the child having at least one hospital admission. For no immunisations these include older (> 40 years) mothers and more highly educated mothers. These findings are also supported by further research (Reading, Surridge & Adamson, 2004; Cassidy et al, 2006; Hawker et al, 2007).

For MMR, studies suggest that the pattern is slightly different, in that the factors below are actually more likely to result in no immunisation:

Mother more highly educated

Mother over 34 years of age

Larger family size

Mother under 20 years

Lone parent

Maternal smoking in pregnancy

Of these factors, mothers who are highly educated and those over 34 years of age appeared to be of greatest significance (Friederichs et al, 2006; Samad et al, 2006; Hilton et al, 2007; Bedford et al, 2009). These additional social and demographic factors are explored in the context of the population of Somerset, within this thesis.

3.6 Gaps in the current evidence base and areas for further research

3.6.1 Evidence from a UK context

Much of the published evidence examined in this review predominantly originated from the US, Australia, New Zealand, or Europe. Searches in relation to parents' attitudes

towards MMR yielded very few original UK published studies. Five UK studies were identified which were of particular relevance, and these were reviewed in detail. These included a focus group study undertaken in Avon and Gloucestershire (Evans et al, 2001), a study using parental questionnaires in Hackney, London (Smallbegovic, 2003), a qualitative interview study undertaken across five GP practices in Leeds (McMurray et al, 2004), an ethnographic survey of mothers in Brighton (Cassell et al, 2006), and a focus group study undertaken in Scotland (Hilton et al, 2006). A review of previous PhD theses (Hilton, 2005; Tickner, 2008; and Kaur, 2011) provided useful additional insights; and evidence from the 'Millenium Study' (Bedford et al, 2005), from Health Education England, Scottish Health Feedback, and the evaluations of the Department of Health campaigns were also reviewed in detail. Whilst these studies used robust methodologies, and have identified some apparent themes, the sample sizes in many of the studies were relatively small (particularly in the published studies), or the contexts limited, and the evidence produced may not therefore be more widely generalisable.

Searches in relation to rurality ('rural' AND 'immunization' or 'MMR') produced even fewer UK studies, instead primarily yielding evidence from developing countries, the findings of which are not easily applicable to modern developed administrations. This is relevant because Somerset is a rural county in England, and there is very little evidence relating to the rural UK context. However, studies undertaken in Ireland did suggest that there may be a potential link between mothers living in rural areas and lower uptake rates for childhood immunisation, and therefore a need for further investigation (Lowery et al, 1998). Additional research is therefore required within the UK context to confirm and add robustness to the findings of these previous studies, particularly in rural UK contexts.

3.6.2 Evidence in relation to populations who decline immunisation

The studies noted in 3.6.1 above differ from the present study in that they all focus on whole populations of parents (that is they included both those who have accepted and those who have not yet accepted the offer of MMR) rather than focussing on those who had persistently declined the offer of immunisation. In fact, within the majority of studies reviewed (including the national policy sources) ‘confirmed rejectors’ and those clearly opposed to immunisation were almost universally explicitly excluded from the study samples – the most common justification being that divergent views were unhelpful and had a tendency to create group conflict (Corr Willbourn, 2004) and/or that recruiting ‘refusers’ proved more difficult, with parents of these children being considered less likely to complete the surveys (Hershey et al, 1994; Martin & Sansom, 2003; Scottish Health Feedback, 2008).

Gust et al (2005) highlighted a further common feature of surveys and other research in relation to attitudes in respect of MMR and immunisation, that is, the tendency to categorise parents in a dichotomous way – either for or against immunisations. Communication and marketing campaigns, however, depend on effective audience segmentation. Audience segmentation is the process of dividing people in to groups based on shared characteristics so that interventions can be tailored to best address their needs (Gust et al, 2005). Gurnig (1989) suggests that the same criteria for segmenting populations for marketing can also be used to address and target public health efforts, however, for this ‘social marketing’ to be successful:

‘In general, segments must be definable, mutually exclusive, measurable, accessible, pertinent to an organisational mission, reachable with communication in an affordable way and large enough to be substantial and to service economically’ (p.203).

Investigation of the beliefs and attitudes of parents who persistently decline may therefore yield important insights that may have been omitted from previous research and which may be of significance in identifying the differential effect of current universal interventions aimed at increasing uptake across different groups and also the most effective and cost-effective ways of modifying existing services to increase vaccine uptake particularly among children and young people whose parents have persistently declined the offer of MMR. This will be vital if uptake is to be improved within this group in future (NICE / Department of Health, 2009).

3.6.3 Evidence in relation to school-age children of parents who persistently decline MMR

A further finding is that the majority of studies which have explored parental factors (including the unpublished communication research evaluations and the national tracking surveys) have done so with parents of very young children (under 5 years of age and typically 12 – 39 months) who remain in the age groups for primary courses of immunisation. There appear to be very few studies which have specifically followed-up cohorts of older children of parents who declined the initial primary schedule offer of MMR, and who continue to remain unvaccinated a number of years later, or those which explore what influenced these parents to change their mind and accept MMR at a later date, where they did so.

A single study focussing on school age children was identified in the current literature review (Salmon et al, 2005). This study appeared to confirm that parents of these older children shared the same concerns in respect of vaccine safety / overload; ethical, moral and religious issues related to vaccine development (aborted cell lines, animal testing, etc); difficulties in assessing relative risk; and lack of trust in drug companies, professionals and government. However, the study was conducted in the US where a very different healthcare system and mandatory immunisation programme exists.

Further studies are therefore needed to establish if these findings are applicable to other populations and health systems, including the UK.

In the absence of this evidence, there is currently no distinction in terms of current professional understanding between those who are delayed – since most parents do accept immunisation by the time children enter school – and those who remain unvaccinated beyond school entry and into young adulthood. This is of particular importance because of the potential for clustering of susceptible older children at secondary school, colleges and universities. In addition, there are suggestions that concern and mistrust may persist beyond the initial offers of MMR, creating a brief but significant cohort effect which may impact on public health across future generations.

As parents who continue to decline MMR, especially those with children above school entry age, appear to have been excluded from most of the existing evaluations and published research to date, existing knowledge about them is quite limited and there is a tendency to group them together as a single entity. However, given the cumulative nature of unvaccinated populations, they have over time become a significant group both in number and in consequence for the development of susceptible populations. Existing knowledge of audience and population segmentation, as described in 3.6.2, suggests that this group of parents can, very likely, be categorised beyond this. Identifying any potential sub-groups within group would offer the potential to improve communications and tailor interventions more effectively to address specific concerns and needs of these parents (Gust et al, 2005). It is therefore important to establish whether this is a single homogenous group or whether sub-groups exist within this population which can then be categorised and targeted more effectively.

3.7 The local context - why is this relevant to Somerset?

Somerset is a rural county in the South West of England. It borders Bristol and Gloucestershire to the North, Wiltshire to the East, Dorset to the South East and Devon to the South West. Agriculture is a major business in the county. Unemployment is lower than the national average, with the largest employment sectors being retail, manufacturing, tourism and health and social care. Population growth in the county is also higher than the national average, although the greatest increase in population age groups aged over 75.

The population predominantly lives in small market towns, across a geographical area covering 1332 square miles and environments which range from remote moorland (Exmoor), to open agricultural land (South Somerset), and wetland (the Levels). There are also three main urban centres in Taunton, Yeovil and Bridgwater. Whilst indicators of population health for Somerset generally rate above national average, there are significant pockets of deprivation. These are associated with the urban centres and also, less easily identified areas of rural deprivation. Families tend to have high levels of car ownership, which tends to skew traditional measures of deprivation; however, car ownership is generally a necessity rather than a luxury because of poor local infrastructure, and especially access to public transport.

A number of these factors may be related to the levels of immunisation uptake in Somerset – for example, by impacting on parents' ability to access immunisation services, or by influencing decisions about whether to accept or refuse it. Somerset has relatively low levels of uptake of childhood immunisations, including MMR, when compared with other areas in the South West (See Appendix 2).

General Practice is the cornerstone of childhood immunisation service delivery in the UK, and it has a good record of delivering high levels of vaccine uptake across most

programmes. However, wide variations in immunisation uptake exist between general practices in Somerset, as in other PCTs, and an initial review of local data had indicated that some practices maintain remarkably high uptake for all immunisations, including MMR, despite the generally low overall uptake figures for the county. In some cases, however, even practices in very close proximity to each other (adjoining premises) have been found to have very significantly different uptake rates (Lamden and Gemmell, 2008; Somerset Joint Strategic Needs Assessment, 2008; Glastonbury and Street Needs Assessment, 2009). It is therefore crucial to identify whether these variations can be attributed to any of the characteristics previously described – and, if not, what other characteristics are salient – to be able to develop appropriate interventions to address these issues.

Uptake within Somerset does not, on initial review, seem to be linked to deprivation, practice size, or the number of staff (GPs or Practice Nurses) that are available; and there are no easily identifiable characteristics of high uptake practices or areas (Somerset JSNA, 2008). Studies have, however, previously demonstrated a strong negative association not only between uptake and professional confidence, but also between uptake and access to housing and /or other services; and this may be particularly relevant in large rural counties such as Somerset (Peckham et al, 1989; Samad et al, 2006). It is not known whether the association with the specific factors cited above is the same for rural populations, or those in areas with less ethnic and economic diversity, such as Somerset and this requires further investigation.

3.8 Concluding the case for the research

High coverage of population childhood immunisation programmes, such as MMR, are both clinically and cost-effective. The challenge for the NHS is therefore to identify potentially modifiable factors associated with low uptake, and then to implement interventions to achieve improvements in both uptake and coverage. This can only be

achieved if there is a very good local understanding of the reasons why parents do not accept this immunisation for their children.

Parents' interactions with health professionals appear to be crucially important in terms of addressing parental concerns and also in motivating hesitant parents towards immunisation. At a time of increasing personalisation in healthcare (when 'informed patients' are to be considered to be the norm) and in recognition of a shift in power relationships between patients and health care providers which encourages patients to become equal partners in decisions about their health (Dixon-Woods, 2005; Leask et al, 2012), it seems reasonable to assume that new ways of communicating and interacting with parents might be needed to help guide them towards making quality decisions. However, in order to develop these new ways of interacting, and to be able to recognise and respond to different perspectives, it is first essential to understand the particular characteristics of the populations that you need to reach.

The conclusion that can be drawn from this critique of the literature is that there are significant gaps in the current understanding of parental decision-making particularly in relation to those parents who persistently decline immunisations such as MMR and in respect of the experiences and decision-making that occurs for parents of school age children as sub-sets of the general parent population. In addition, the limitations of current knowledge also include a lack of information in respect of the impact of contextual issues of relevance to Somerset, such as, the rural nature of the county.

This thesis aims to address some of these gaps by focussing on exploring the factors influencing the decision-making of two groups of parents of school-age children who were invited to have MMR as part of the 2009 MMR Catch-up Campaign and who remained unimmunised after this offer, within Somerset, a rural county in the South West of England, through a series of quantitative and qualitative studies. Having

provided the context and further justification for the current research, the rationale for the study design and methodology used to achieve these aims, along with important ethical considerations of relevance to the research, is explained and critiqued in the next chapter.

CHAPTER 4 RATIONALE FOR THE METHODOLOGY AND THE APPLICATION OF RESEARCH METHODS WITHIN THIS THESIS

4.1 Introduction

Previous chapters have highlighted the importance of understanding the factors that may contribute to the uptake of MMR. Any information which makes possible the identification of factors which encourage acceptance of MMR immunisation, particularly amongst those groups who have previously declined or failed to attend, could enable the development of more effective, equitable and cost-effective local (and potentially wider) services, which is both ethically desirable and increasingly necessary at a time of financial constraint.

This thesis aims to improve the current understanding of characteristics contributing to the uptake of MMR, and the influence of these on parental decision-making in Somerset, by addressing the following research questions:

What were the social, demographic and geographic characteristics of parents / children who had accepted and declined MMR in Somerset in 2009?

Are parents who persist in declining MMR a single homogenous population sub-group?

Does the 'Wakefield study' remain a primary factor influencing parents' of school age children to decline MMR in Somerset, or are there additional factors at play?

How have parents' previous experiences, attitudes and behaviours in respect of MMR and wider immunisation services influenced their longer term decision-making? Have their attitudes and behaviours regarding immunisation changed over time, or as new experiences occur? Are there any consistent differences in the experiences of parents who decide to decline MMR vaccination?

Why do some parents persist in declining MMR, despite having information and experiences which counteract the basis on which their initial decision was made?

What factors influence parents who have persistently declined to change their mind and accept MMR for their school-age children?

The present research aims to address these questions by exploring baseline epidemiological data, conducting a survey of parents and undertaking semi-structured interviews with a sub-set of these parents. This chapter provides the rationale for the study design, and outlines important ethical and methodological factors that were considered when conducting this research.

4.2 Rationale for using a 'mixed methods' approach

The review of the literature in Chapter 3 identified a number of methodologies that have previously been used to investigate immunisation uptake. These included survey, case studies, cohort studies, qualitative interviews and questionnaires, ethnographic and epidemiological studies. (Streefland et al, 1999; Streefland, 2001; Prislin et al, 1998; Briss et al, 2000; Sturm et al, 2005; Weinkunat et al, 1998; Henderson et al, 2004; Wood-Harper, 2005). The present study employed a mixed methods design in order to address the research questions outlined above.

The overall objective of the present study was to investigate a number of social, demographic and geographic characteristics of parents and children associated with MMR uptake, to compare these characteristics within and between defined subsets of the Somerset population, and to explore the basis on which parents in Somerset make decisions in relation to MMR immunisation. It is also of interest to compare the findings from this study with those of the previous studies described (Friederichs, 2006; Bedford et al, 2009). The review, in Chapter 3, provided an indication of potential approaches which might be useful in providing evidence to answer some of the research questions. However, there was no evidence of studies previously undertaken that had achieved all of these objectives. In order to obtain sufficient evidence, both in breadth and depth, to effectively answer the research questions posed and to make full

use of the strengths of each research methodology, the design adopted was therefore a cross sectional study consisting of three sequential phases as outlined below:

Phase 1: A preliminary epidemiological baseline review of MMR immunisation data for Somerset. This initial phase underpinned the remainder of the research and was used: to determine any differences in demographic and geographic characteristics between children whose parents accepted and those who declined the offer of MMR as a sampling frame to identify a subset of children whose parents had continued to decline the offer of the MMR vaccine in March 2009

This epidemiological baseline review involved quantitative analysis of routine immunisation data held on the local McKesson CarePlus Child Health Information System (CHIS), extracted using Business Objects into a standard excel database.

Phase 2: A cross-sectional census distributed as a postal survey to the parents of all the children identified in the subset in (b) above. This study integrated both deductive and inductive methods and involved collection of quantitative (categorical) data via multiple choice / tick box questions and also the collection of free text (codable) data, which was later collated and analysed as one of the qualitative data sources within the present research. The information obtained was intended to validate the evidence on factors associated with declining immunisation as identified in the literature review (Chapter 3) within the context of Somerset, and to support the development of an initial framework for the thematic analysis of the semi-structured interviews

Phase 2 was also used as a sampling frame for Phase 3, with parents opting to consent to be invited to participate in semi-structured interviews by completing the contact details section at the end of the survey.

Phase 3: Semi-structured qualitative interviews conducted with a sub-set of parents who had completed and returned the census survey and had provided consent and contact details to enable the researcher to make contact with them. The purpose of this component of the research was to explore and compare themes arising from these narratives and to use these to explore how parents make decisions about MMR immunisation and whether this can information can be used to influence parents' decision-making in future.

The three phases were designed to be linked via the use of a unique identifier for each child within the study populations (linked within the original database to the child's NHS number). This was to enable information for each child / parent to be added to, and / or referred back to (to check validity of responses within each subsequent study) and to build a more complete dataset for comparison between groups within the population of parents being studied.

The quantitative elements of the study provided access to information on geographic location, immunisation status and demographics for the population of children in Somerset within the two age groups included in Phase 1, and also to the complete dataset of children within the unimmunised subset of this population later investigated in Phase 2. The respondents to the Phase 2 survey then provided a sampling frame for, and an initial framework for the analysis of, the final Phase 3 study. The qualitative, Phase 3, elements then performed a role in 'validating' the quantitative research and

also in providing a different 'perspective on the same social phenomena' (Pope & Mays, 2006a) through the identification of patterns and themes within the data which could be used to derive possible explanations for the factors identified in the earlier phases of the research.

The insights gained from the qualitative interviews also provided challenge to the researcher's own assumptions and resulted in a periodic return to reconsider previous interpretations of the data during the course of the study and therefore to a fuller understanding of the findings of the initial quantitative studies.

It is therefore argued that using a 'mixed methods' approach offered a more informative means of establishing the range of factors that may influence parental uptake of childhood immunisations such as MMR and of providing possible explanations for how these factors may interact to influence parental decision-making. The findings from each phase, undertaken using different methods, were then compared and convergence is sought in the final discussion of this thesis.

4.3 Phase 1 Study Design: Cross-sectional review of routine immunisation data for Somerset in 2009

4.3.1 Study aims and rationale for the use of a cross sectional survey method

The aims of this study were:

To investigate the distribution of a number of variables relating to factors associated with MMR uptake in Somerset

To compare these factors within and between defined subsets of the Somerset population

The Phase 1 study aimed to provide answers to the following research question:

What are the social, demographic and geographic characteristics of parents / children who had accepted and declined MMR in Somerset in 2009?

The rationale for the use of a cross-sectional design for Phase 1 and Phase 2 is as follows. The main designs in quantitative health based research are cross-sectional, prospective longitudinal and experimental (Sutton & French, 2004). In a cross-sectional study, data are collected on the whole study population, or a representative subset of a population, at a single point in time, to examine the relationship between disease (or other health related state) and other variables of interest, allowing conclusions about phenomena to be drawn across a wide population (Shuttleworth, 2010). Cross-sectional studies therefore provide a 'snapshot' of the frequency of a disease or other health related characteristics in a population at a given point in time (Hennekens & Buring, 1987). This methodology can be used to assess the burden of disease or the

health needs of a population, for example, and is therefore particularly useful in informing the planning and allocation of health resources (Shuttleworth, 2010).

In experimental designs, including randomised control trials and case-control studies, researchers randomly assign individuals to one or more independent variables and then measure the effect of the independent variable on one or more dependent variables (measured outcomes). This ensures that every participant has an equal chance of being selected to each of the experimental conditions and improves the likelihood that there is not a third variable causing any associations, and therefore enables the strongest causal inferences to be made (Tickner, 2008).

Cross-sectional studies differ from case-control studies in that they aim to provide data on the entire population under study, whereas case-control studies typically include only individuals with a specific characteristic. Cross-sectional studies may also be described as censuses and they often rely on the use of data originally collected for other purposes. Longitudinal studies differ from both of these designs as they involve making a series of observations more than once on members of the study population over a period of time. (Tickner, 2008).

Henneken & Buring (1987) have outlined a number of strengths and weaknesses of cross-sectional studies. They acknowledge that this type of research is relatively easy to conduct as there are no long periods of follow-up, data on variables is only collected once, and you are able to measure prevalence for all the factors under investigation or study multiple outcomes and exposures. This is important because prevalence of disease or other health related characteristics are used in public health for assessing

the burden of disease on a specified population and in planning and allocating health resources. These studies are therefore good for producing descriptive analyses and for generating hypotheses. It can, however, be difficult to determine whether the outcome followed exposure in time, or the exposure resulted from the outcome in these studies. As a result these designs are not suitable for studying rare diseases with a short duration, they cannot be used to measure incidence, and any associations identified can be difficult to interpret.

In summary, advantages of this methodology include the fact that the use of routinely collected data allows large cross-sectional studies to be made at relatively little expense. In reality it is often impossible to survey the entire population of interest and cross-sectional studies therefore have a major advantage over other forms of epidemiological study. A further advantage relates to the fact that most case-control studies collect specifically designed data on all participants, including data fields designed to allow the hypothesis of interest to be tested. However, in issues where strong personal feelings may be involved, specific questions may be a source of bias. For example, past MMR decision-making may be inaccurately reported by a parent wishing to reduce their personal feelings of guilt. Such bias may be less in routinely collected statistics, or effectively eliminated if the observations are made by third parties, for example by reviewing routine immunisation records by area.

A disadvantage, however, is that the available routine data sources may not be designed to answer the specific question being asked. In addition, routinely collected data does not normally describe which variable is the cause and which the effect, in a particular situation. Cross-sectional studies using data originally collected for other

purposes are therefore often unable to include data on confounding factors, other variables that affect the relationship between the putative cause and effect.

In the present research a cross-sectional design was employed for both of the quantitative Phase 1 and Phase 2 components. The factors outlined above were considered when assessing the use of these methods within this thesis and the studies were designed to try to minimise the disadvantages and weaknesses associated with the method, for example, by using routine data that could be identified at individual level as well as community level, and by then linking all data subsequently obtained back to this original data to both supplement and validate the dataset.

4.3.2 Study design

The purpose of an epidemiological review is to study the patterns, causes and effects of health, and disease conditions, in defined populations (Porta, 2014). Key features of this type of study design are that all findings must relate to a defined population; it must be oriented to groups rather than individuals; and the conclusions of the study are based on comparisons (BMJ, 2010). This phase therefore involved the comparison of routine data held on the Somerset McKesson CarePlus Child Health Information System for a defined population of children resident in Somerset in 2009 as detailed below.

4.3.2.1 Population and Sample

41,767 children aged between six and 15 years were identified on the Somerset Child Health Information System (CHIS) as at 31 March 2009. These children formed the study population for the baseline epidemiological review of data in relation to MMR uptake. Analysis (comparison of proportions) was undertaken on data relating to the

whole of this study population to provide information on factors associated with both accepting and declining MMR and to compare any differences between children in the accepted and declined groups.

The study population was divided in to two age groups as follows:

Age group 1 (Primary School Age) - children aged six to 10 years of age on 31/01/2009 (birth dates 30/01/1998 – 31/01/2003)

Age Group 2 (Secondary School Age) - children aged 11 to 15 years of age on 31/01/2009 (birth dates 31/01/1998 – 31/01/1994)

The rationale for choosing these two age cohorts was as follows:

Children aged six years and over should have completed their full primary course of two MMR immunisations, and would have received repeated invitations for their parents to consent for them to receive MMR as part of the routine offer within the UK Immunisation Schedule.

Children aged 16 years and over are capable of making the decision to accept or decline immunisation independent of parental decision-making, and may have done so in the period after the 2009 catch-up campaign

Children aged six to 10 years would have been born between 1999 and 2003 and their parents would have been those most exposed to negative media and public interest following the publication of Andrew Wakefield's research (Wakefield et al, 1999) at the time of their first offer of MMR vaccine for their child

Children aged 11 to 15 years were born before the publication of the Wakefield paper and at a time when acceptance of MMR by parents was considered to be relatively high and improving.

4.3.2.2 Inclusion and Exclusion Criteria

All children in Somerset aged six to 15 years (birth dates 31/01/2003 to 30/01/1994) and recorded on the Somerset CHIS were included in the Phase 1 study.

4.3.2.3 Data collection

Data in relation to the study population and immunisation uptake was extracted from the Somerset McKesson CarePlus Child Health Information System using Business Objects and imported into a standard excel database for analysis.

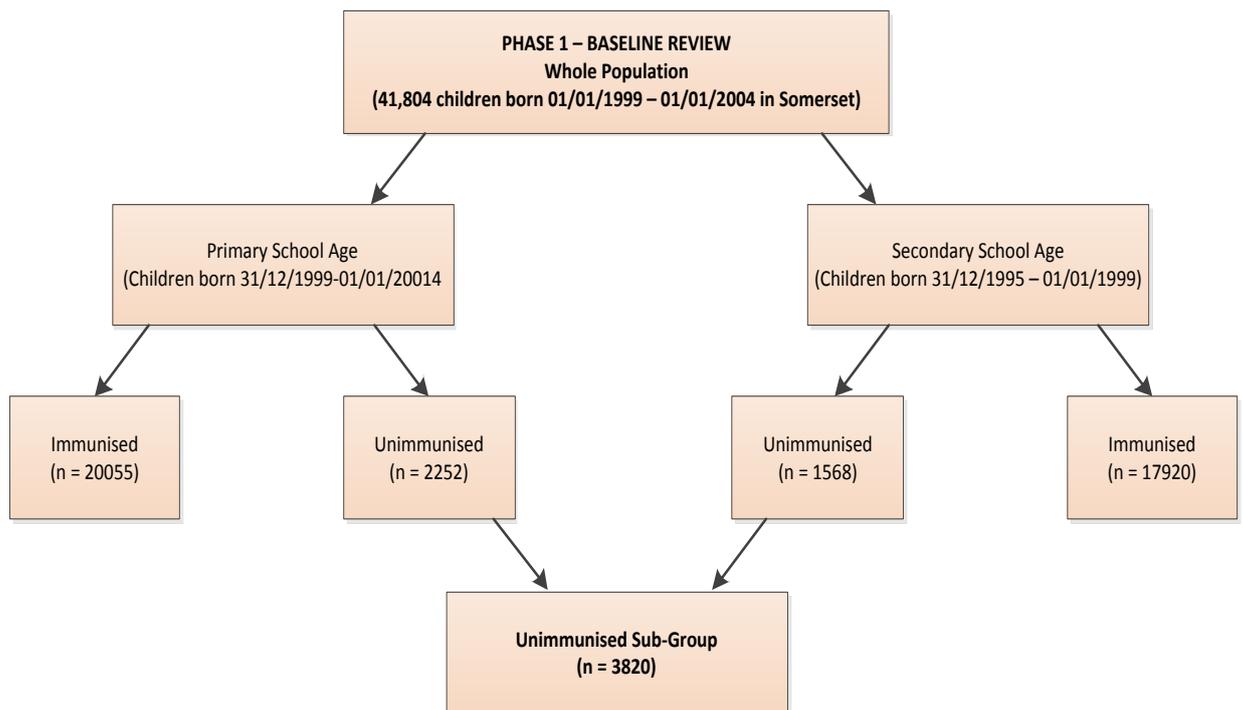
4.3.2.4 Data analysis

MMR status for each child was identified and the children within these two age groups were then labelled either 'immunised' or 'unimmunised'. The demographic characteristics (age, gender, deprivation quintile, MOSAIC group, MSOA, Children's Centre Area, and registered GP Practice) of all unimmunised and immunised children in the two age cohorts were ascertained and any associations between these variables and MMR uptake were investigated using comparisons of proportions. The demographic characteristics of the children in the study population who had had MMR were compared with those whose parents had not consented for them to have MMR (as at 31/03/2009) in order to identify whether there were any associations between demographic characteristics and uptake.

This phase of the study was undertaken by the researcher during July 2011 and the sub-set of 'unimmunised' children identified in this Phase 1 study then formed the study population for the Phase 2 Parent Census Survey.

Findings from the review of the literature (Chapter 3) and this Phase 1 study were used as the basis for developing the content of the Phase 2 ‘MMR Survey’ questionnaire that was distributed as a census to parents of children in this unimmunised population subgroup.

Figure 2 – Summary of Phase 1 study design



4.4 Phase 2 Study – Parent Census Survey (‘MMR Survey 2012’)

4.4.1 Phase 2 Study aims

The aims of this study were to:

Establish the demographic profile of a defined subgroup of parents and children

(persistent decliners) within the Somerset population and to compare this against those described in previously published studies

Provide a sampling frame for Phase 3 of the research study

Phase 1 relied on information available through routine secondary data sources (the Somerset CHIS) and included information in relation to the child that had been eligible for MMR vaccine at the time of the catch-up campaign. Phase 2 aimed to supplement this original dataset by gathering additional data in respect of social and demographic information about the parents of these children and their decision-making in respect of MMR.

The rationale for the use of a cross-sectional design has been provided in section 4.2.1. This rationale applies equally to the design of this Phase 2 study.

4.4.2 Study design

This consisted of a questionnaire, with space for parents to add free text comments and for consent to be given for follow-up for final phase of the research by adding personal contact details on the final page, which was sent as a census to the sub-set of parents of children who continued to remained unimmunised as at 31/03/2009 as identified via the Phase 1 study. Details of the questionnaire design are provided in 4.3.3

4.4.2.1 Population and sample

A breakdown of the children whose details were held on the Somerset CHIS is provided in Table 1.

4.4.2.2 Inclusion and Exclusion criteria (see also Table 1)

a) Child-related exclusion factors:

'Medical' – this refers to children with identified medical reasons for not being given MMR. In these cases the decision not to immunise is usually taken by someone other than the parent, e.g. the supervising consultant or another experienced clinician.

'Refused' – are children for whom parents have actively refused consent for all immunisations (not just MMR). These parents will have also requested not to be contacted by the Patient and Practitioner Services.

'Withdrawn' – this category of children have commenced the primary immunisation programme but have been actively withdrawn prior to completing it. This may have occurred, for example, because of adverse reactions or unrelated medical or other reasons. Again, in these cases the decision may not be made by the parent.

Children whose parents had accepted MMR before 31/03/2009

Children who had moved out of the area were excluded, for practical reasons.

Immunisation Status	Age group of child	Number of children
Unimmunised	Primary school age	2252
Unimmunised	Secondary school age	1540
Immunised	Primary school age	20055
Immunised	Secondary school age	17920
Not allocated	Removed due to no NHS number or missing data	37
Total number of children		41804

Table 1: Breakdown of study population sub-groups

b) Child related inclusion factors

Children within both of the age cohorts whose parents had continued to withhold consent for MMR (persistently declined), a total of approximately 3800 children were included.

c) Parent-related exclusion factors:

Parents who have explicitly requested not to be contacted by the Patient and Practitioner Services

Parents who are not the main carer of the child i.e. who live at a separate address

Parents of children in the five categories detailed in (a) above

d) Parent related inclusion factors

All parents of children in (b) above

All persons who have parental responsibility for these children and who live at the same address, for example, a 'legal guardians' were included

4.4.2.3 Recruitment & consent

The initial survey package was sent to participants from NHS Somerset Public Health. The package contained a letter signed by the researcher (an experienced Consultant in Public Health) introducing the study and inviting the parent(s) to participate. The letter was accompanied by the questionnaire and associated participant information leaflets to ensure participants were fully informed about the purpose of the study and how their data would be used. Participants then self-selected, by completing and returning the form to the Public Health Directorate, where the forms had originated, for collation.

The information letter requested that parents (or guardians) completed the form and returned it in the enclosed envelope provided. Data was collated in an anonymised form unless the participants themselves provided contact details indicated permission for the researcher to contact them to make arrangements for inclusion in Phase 3. Where consent was given, the results from the questionnaire were linked to the information obtained via the subsequent interview.

4.4.2.4 Data collection

4.4.2.4.1 Questionnaire design

The questionnaire was designed to collect data on a number of variables, including:

Age and gender of person completing form

Relationship to child

Child's date of birth / age

Child's gender

Number of siblings

Birth order

Parent's employment status

Marital status

Ethnicity

Knowledge of immunisation

Source(s) of information on immunisation and MMR accessed

Accepted or declined MMR in the period after the 2009 catch-up campaign

Reasons given for continuing to decline

The questionnaires were coded using a unique number and a barcode allocated by FORMIC. FORMIC is a computerised survey package which combines survey design, capture and data management. It enables the collection of data from scanned survey forms into a SQL database using a unique identifier for each form. This enables collation of relevant anonymised data in a form which ensures confidentiality and protects the respondent's anonymity (www.formic.com, accessed 13/5/2015).

The unique number was linked to the child's NHS number within the Patient and Practitioner Services Department, to enable data to be reconciled, responses

monitored and reminders to be sent to non-responders. It also enabled the child's study cohort to be identified for analysis purposes; for self-reported immunisation behaviour to be verified e.g. confirmation of uptake, or not; and any associations between parental or child related social, geographical and demographic factors and uptake to be identified. The NHS number was not known to the researcher.

The questionnaire was developed and refined following discussions with a number of departments and organisations in Somerset who advocate for vulnerable populations. This included: the NHS Somerset and Somerset County Council Patient & Public Participation Departments; the local Patient Advocacy and Liaison Service; Somerset Race Equality Council (SREC); and local organisations supporting new migrant, Gypsy and Traveller populations, and those persons with literacy problems. Access to alternative resources to support participants, (such as alternative media or languages, or an option to complete verbally over the phone) was offered, where necessary, to try to maximise uptake by minority groups. Advice was sought from the organisations listed above regarding the most appropriate resources to use to support these individuals.

The questionnaire was piloted with a subset of parent representatives of children in these age groups, to assess ease of completion and appropriate level of language used, prior to being sent to the wider cohort. The pilot phase confirmed that questionnaires should take no longer than 15 minutes to complete. The questionnaires were administered by post, with a strategy of one follow-up reminder sent to non-responders two weeks after the initial questionnaire. The Invite Letter for Phase 2 can be found at Appendix 6, the Parent Census Survey Questionnaire is included as

Appendix 7 and the Patient Information Leaflet (Q&As) for Phase 2 are included as Appendix 8.

The survey was sent to 3820 participants in March 2012 and was followed up with a reminder postcard to non-responders two weeks later in mid-April 2012.

4.4.2.5 Data analysis

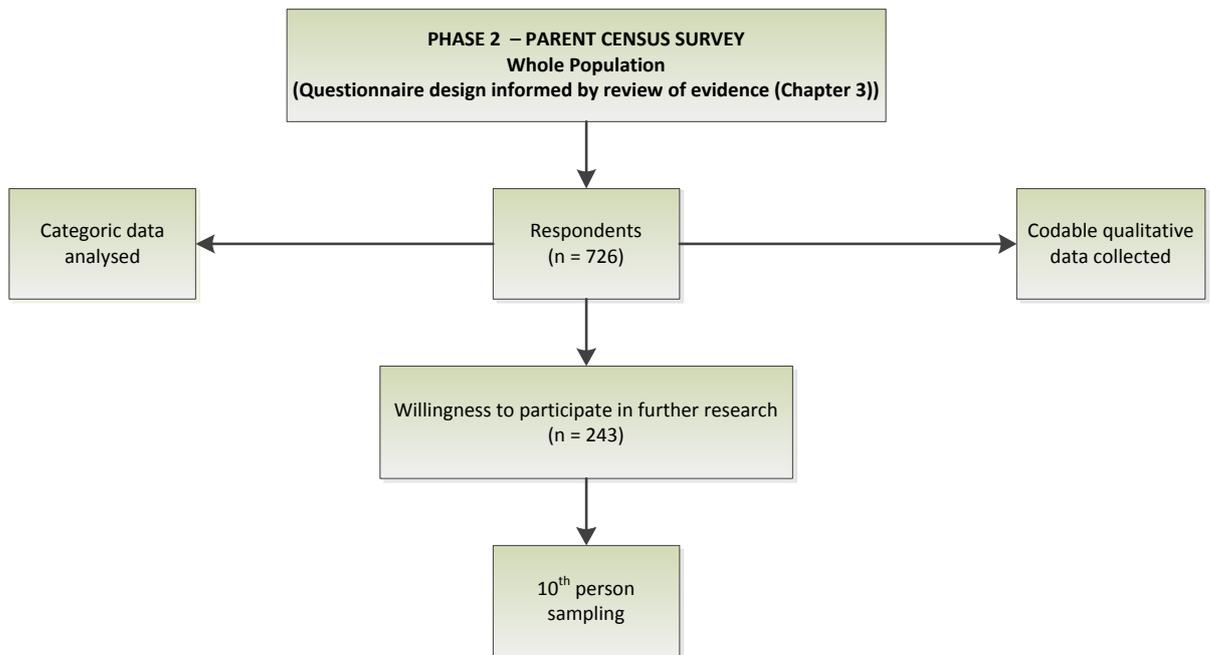
The data obtained via the questionnaires was scanned into a password protected SQL data-base using FORMIC software. The data held in the SQL database was extracted and imported into excel for analysis of the categoric data fields. The categoric data obtained from the survey was analysed using comparison of proportions to explore whether any relationships between personal, geographic, socio-economic, parent- or child-related factors, and uptake could be identified. This analysis also explored whether there were any differences within and between the age cohorts studied and whether any relationships, where identified, were different from the relationships identified in previous studies, such as those undertaken by Bedford et al (2009), or Friederichs et al (2006).

FORMIC software does not, however, automatically collate free text data. All survey forms which included free text were collated after scanning and the free text data was manually entered in to the excel database, using the unique identifier to align the data with the correct child, for later coding and thematic analysis as part of the Phase 3 study.

The coding of the free text data obtained via the questionnaire was used to inform the development of an initial framework for the thematic analysis of the data obtained during the interviews in the final phase (Phase 3) of the study.

The final section of the questionnaire enabled respondents to indicate whether they would be willing to participate in further research. This then also formed the sampling frame for the Phase 3 study.

Figure 3 – Phase 2 Study Design to end of Phase 2



4.5 Phase 3 Study – Qualitative interviews with a sub-set of Parents recruited via the Parent Census Survey

4.5.1 Study Aims and rationale for the use of qualitative interviews and applied thematic analysis

The aim of this third and final phase of the study was to gather a richly descriptive source of qualitative data to answer the following research questions:

Does the ‘Wakefield study’ remain a primary factor influencing parents’ of school-age children to decline in Somerset, or there other factors at play?

How have parent’s early experiences, attitudes and behaviours in respect of MMR and wider immunisation services influenced their longer term decision-making? Have their attitudes and behaviours changed over time or as new experiences occur? Are there

any consistent differences in the experiences of parents who decide to decline MMR vaccination?

Why do some parents persist in declining MMR, despite having information and experiences which appear to counteract the basis on which their initial decision was made?

What factors influence parents who have persistently declined to change their mind and accept MMR for their children?

Qualitative methods were identified as the research approach which offered the most potential for the researcher to build on the previous two phases and explore, in greater depth, these parents' perspectives on MMR and their experiences of both immunisation services and the process of making decisions in respect of accepting MMR for their child where this had occurred (Bowling, 2002). These methods also offered the potential for the development of theoretical frameworks and hypotheses to explain, through the identification and comparison of themes within the data, how and why these decisions were made and the factors influencing these decisions in order to identify more effective strategies for delivering immunisation services, and for communicating with parents about MMR and immunisation, in future (Drummond, 1996).

There are numerous approaches to undertaking qualitative data collection and analysis across a wide range of theoretical and epistemological perspectives (Bowling, 2002). However, the most common methods include interviews, focus groups, field observations and open-ended survey questions (Guest et al, 2012). The data collected then needs to be analysed in a way that is both systematic and which results in 'credible answers to the research questions and objectives embedded within a study' (Guest et al, 2012).

There are two fundamental approaches to analysing qualitative data – deductive and inductive (Bernard, 2005). Deductive approaches utilise a structure, or pre-determined framework to analyse data. In this type of approach, the researcher imposes their own theory or structure on the data and then uses this to analyse the data in the transcripts (Thomas, 2006). Thomas (2006) suggests that this approach is useful where the researchers are already aware of probable participant responses. Advantages of a deductive approach are that it is relatively quick and easy to complete (Guest et al, 2012). Disadvantages are that this approach can be inflexible. In addition there is the potential for the introduction of bias because the lack of flexibility can limit any theme or theory development (Guest et al, 2012).

Within an inductive approach, however, researchers analyse data with little or no pre-determined structure or theory. Instead the data itself is used to derive the structure for the analysis (Strauss & Corbin, 1998). This approach is considered to be the most comprehensive means of analysing the data, but as a result it is very time-consuming (Miles & Huberman, 1994). This approach is most suitable for use where little or no information is known about the phenomena being studied. Inductive analysis is the most common approach used to analyse qualitative data (Guest et al, 2012)

Inductive approaches include 'grounded theory', interpretative phenomenological analysis, and thematic analysis, amongst many others (Braun & Clarke, 2013). These theme-based approaches were each explored as potential options for the design of Phase 3 and a comparative summary of the features, epistemology, strengths, weaknesses and limitations of each approach can be found in Appendix 9.

In the present research, the researcher was already familiar with the relevant literature on MMR and childhood immunisations. Furthermore, the design of the studies was such that each phase was intended to inform the subsequent phase in order to develop

an overall understanding of factors influencing parental acceptance of MMR for this group of children. As a result, the researcher would necessarily have knowledge of potential themes already identified from these earlier phases which then needed further exploration via the interviews and therefore could not approach this data collection with an entirely open mind. The core principles associated with the 'grounded theory' method were therefore not able to be adhered to in a study where the intention is, as here, to employ, even in part, a framework approach to support data analysis.

Adopting a phenomenological approach offered the potential to explore the experience of MMR decliners and their decision-making in rich detail. However, the first two phases of the present research were intended to provide initial information on this subject, which would then necessarily be known to the researcher undertaking the interviews in Phase 3. The researcher could not therefore go into this phase without any preconceived beliefs and opinions and could not apply the 'bracketing' that is central to this approach (Easterby, 1991; Fellows & Lui, 2008), and nor would they want to because these early phases were designed with the explicit purpose of informing the areas for further investigation within the interviews. The final phase interviews had an explanatory as well as exploratory objective, not to ask 'what is it like to experience this situation?', but a more accurately to ask 'what factors impacted on, or influenced the experience?' and therefore required the inclusion of social, cultural contexts surrounding the experience.

Common to both of the approaches considered, so far, is the technique of identifying and categorising themes within the data. Holway and Todres describe this 'thematic analysis' as a 'foundational method, with the "thematizing of meanings" being one of a few shared generic skills across qualitative analysis' (2003, p347). Boyatzis (1998) and Ryan & Bernard (2000) also characterise thematic analysis as 'a tool to use across different methods' or as a 'process within analytic traditions (such as grounded theory),

rather than a specific approach in its own right'. Braun & Clarke (2006), however, argue that thematic analysis should be considered a flexible and useful research tool, which can in itself provide ' a rich an detailed, yet complex account of data' (p.5). This therefore offered another potential option for approaching the analysis of the present research.

Within thematic analysis, the researcher is acknowledged as playing an active role, in that it is they who identifies the patterns and themes and selects which of these is of interest and reports them (Taylor & Usher, 2001). Inductive thematic analysis shares many features with grounded theory and phenomenology, but is not restricted to building theory (as in 'grounded theory') or on focussing on subjective human experience in the way that phenomenology is, and can therefore also include the exploration of broader social and cultural phenomena (Guest et al, 2012).

In both their paper 'Using thematic analysis in psychology' (2006) and in Guest's (2012) publication, a hybrid process is described which combines both inductive and deductive techniques to interpret raw data. In this approach, named 'applied thematic analysis', data driven codes are integrated with theory driven codes within a staged process of data coding and identification of themes. In this process, analysis of the raw data obtained from interview transcripts progresses through coding and recoding towards the identification of overarching themes as described by the participants in the study (an inductive process) but the approach has a pragmatic focus on using whatever tools might be appropriate to complete the analysis 'in a transparent, efficient and ethical manner' (Guest et al, 2012, p.189) and the techniques used may include deductive methods such as quantification, word searches and framework approaches amongst others.

Pope et al (2006) suggest that thematic analysis can be the simplest and is probably the most frequently used technique in healthcare research. Thematic analysis involves

grouping the data into themes and then identifying any relationships between these themes (Tickner, 2008). In their 2004 study, Frith and Gleeson describe how these themes can then be used to develop classifications, or models, or diagrams to try to express the connections between the themes. Thematic analysis can also include themes that are already known to the researcher, for example, from literature reviews or from previous research studies, as well as those that emerge inductively during the current research process (Pope et al, 2006). The addition of a Framework Approach, as developed by the National Centre for Social Research in the UK, enables this prior knowledge to be utilised most effectively (Ibrahim, 2012). The basis for the framework remains the accounts of the people being studied, and it is therefore inductive in nature. The development of the framework is, however, a deductive process, arising directly from the aims, objectives and research questions that form the basis of the present study. This approach is more strongly informed by prior knowledge and prior reasoning than traditional thematic analysis procedures, but is aligned with the method described as 'Applied Thematic Analysis' (Guest et al, 2012).

Having compared the three potential methods, the key element that appeared to be of most relevance, within this comparison, was the potential for applied thematic research to be used 'to build theoretical models or to find solutions to real world problems', since this explanatory process is a desired outcome of the present research.

With acknowledgement of the potential limitations associated with the approach, that is that it may 'miss some of the more nuanced data' (Guest et al, 2012, p.17), and in light of the resources available to complete the research, 'Applied thematic analysis' of semi-structured interviews and open-ended survey questions was therefore adopted as the method for the design of this Phase 3 study within the present research.

4.5.2 Study Design

The Phase 3 design consisted of undertaking semi-structured interviews with a self-selected group of parents who had responded to the Phase 2 Parent Census survey. The interview topic guide provided a general direction for the discussions with parents, but was not restrictive, and this enabled a detailed exploration of the parents understanding of immunisation, disease prevalence and risk; of the ways in which parents engaged with immunisation services; what influenced parental decision-making; and, from this, how parents made decisions in respect of MMR for their children and their experience of doing this in Somerset.

The Interview topic guide for Phase 3 is detailed in Appendix 10.

4.5.2.1 Population and sample

The study population was derived from parents who ticked the 'willing to be interviewed box' on the questionnaires sent to the sample of parents of unimmunised children in both age groups. This ensured a sample with a common characteristic (earlier participation) and with knowledge valuable to the research process i.e. experience of making a decision to decline in respect of MMR immunisation for their child.

The number of interviews conducted was intended to be determined in part by the number of parents who responded and provided details to permit further contact; and also with reference to the work of DePaulo (2000) in respect of sample size required to avoid missing important information. 243 respondents agreed to be contacted were subsequently followed up (see 4.2.2.2 below)

4.5.2.2 Inclusion and Exclusion Criteria

The participants self-selected by completing the additional contact details section of the questionnaire. There were no exclusions.

It was recognised that this method of recruitment (self-selection) might produce a subset that may not be fully representative of the wider group of parents who declined MMR, and the limitations associated with a study of this type are fully acknowledged. However, the mixed methods design ensured the availability and linkage of the demographic and other quantitative data from Phase 1, which meant that any such skewed or unrepresentative population sample could be identified. The study was continued, with the caveat that should any such defined group be found during the analysis, the study would be reported as one which specifically related to that particular demographic sub-group of the 'unimmunised' population. A full examination of the strengths and limitations of the study (including the methodology used) is provided in Chapter 8.

4.5.2.3 Recruitment and Consent

4.5.2.3.1 Semi-structured interviews

Determination of the sampling framework for the interviews was dependent on the number of respondents who ticked the permission box on the postal census. Had the response been poor, it was intended that all of those responding would be interviewed and other techniques, for example, 'snowballing' considered to increase the data source.

It is acknowledged that there is not necessarily a requirement for a qualitative sample to be statistically representative of a study sample as would be expected for a quantitative sample. In fact, authors such as Richie and Lewis (2003) indicate that purposive, or non-probability sampling is the approach most frequently used in qualitative research to seek out participants with particular characteristics and to ensure that a full range of views, including less common ones, are considered within the study. This study population was however already recognised as being skewed following the initial Phase 1 analysis and the number of interviews to be undertaken

within this study was therefore determined with reference to the work of DePaulo (2000) and that of Griffin and Hauser (1993) who propose a different approach in these circumstances. These authors suggest that sample size is as relevant for qualitative as quantitative research, and needs to be considered to avoid 'discovery failure'; that is, missing an important but minority perception or attribute because the sample size is too small. DePaulo's approach is that in order to discover an attribute with an incidence as low as 10 per cent of the population, and to reduce the risk of missing that subgroup to less than five per cent, a sample of $N=30$ should be aimed for, assuming each participant has an equal chance of selection. Griffin and Hauser (1993), using mathematical extrapolations, similarly hypothesised that 20 – 30 in depth interviews would be needed to identify 90 – 95% of factors in their studies.

This ideal situation had to be balanced against available budget and capacity to undertake the study. 243 individuals (30% of all those who responded to the survey) indicated that they would be willing to participate in the Phase 3 study. Interviewing all of these respondents was beyond the capacity of the researcher and two approaches were therefore taken to maximise the potential number of participants engaged.

Each interview was anticipated to last approximately one hour with additional time and resource required to transcribe and encode the interviews and other qualitative data. A decision was therefore made to attempt to complete 24 in depth interviews, within the range suggested by Griffin and Hauser above, and to then supplement this data by running focus groups with the remaining 219 respondents. The use of focus groups was added in order to provide a further source of data to that obtained via the interviews; to maximise the number of participants engaged; and to try to generate a richer and deeper body of data than could be obtained through semi-structured interviews alone. Further information on the Focus Groups is provided in section 4.5.2.2.2.

The process for identifying the 24 individuals to be interviewed was based on a systematic (Nth name selection) sampling method. After the sample size required had been calculated, every Nth (in this case every 10th) person was selected from the list of respondents, starting at a random point in the list. The aim of this sampling process was to obtain a 'representative' and valid sample of the population subset being studied.

The 'population' for this element of the research included all those parents who had returned the survey and indicated that they would be willing to participate in the Phase 3 study. Initial analysis of the Phase 1 Epidemiological study and the Phase 2 survey data had identified that this population sub-set was more representative of the whole 'unimmunised' population than those who had responded to the survey generally. It was therefore considered that this method would be simple to apply and could achieve good coverage. Disadvantages were that this approach is more prone to bias because not all the participants have an equal chance of being selected, and as a result it could lead to over or under-representation of groups within the population. These potential limitations are acknowledged.

In respect of the one to one interviews, the researcher made contact with the participants by telephone and / or email (dependent on the details provided when the questionnaires were returned) to confirm the respondents consent to participate in the study. If given, the researcher then arranged dates, times and venues for interviews to take place, at the convenience of the participants. Further written consent to participate in Phase 3, and for the storage and use of data collected during the research process, was obtained at the time of the interview, before the interview commenced.

4.5.2.3.2 Focus Groups

Focus groups are a form of group interview which, according to Kitzinger (2006), make the most of communication between research participants to generate data. The idea behind this method is that people are helped, through the group process, to explore and clarify their ideas in a way that would be difficult to achieve in a one-to-one interview (Kitzinger, 2006). This method has also been successfully used in previous studies exploring parents' views on childhood immunisations (Evans et al, 2001; Hilton et al, 2006; Leask et al, 2006).

To establish the focus groups, direct contact was made with 80 of the 243 respondents to assess their willingness to attend a focus group (rather than a 1:1 interview) and to ascertain potentially appropriate times, locations and dates for the groups to take place. The responses were reviewed and were found to be consistent and 10 focus group sessions were then planned at various locations and times across Somerset based on this information.

Letters were then sent to all of the 219 respondents who had not been identified for interview, inviting them to take part in a focus group near to their home. The invites were sent two weeks before the dates of the groups, and this was then followed up with both telephone contact and text reminders the day before and then on the day of the focus groups to which they had been allocated. Participants were also given details of all 10 groups and were offered alternative options if they were unable to attend their nearest one. Despite this only one participant arrived to take part in a group and this person was instead interviewed as an individual. Reasons for the failure of these focus groups are unclear since these have been used successfully in other studies, however, the comments of one of the parents who was interviewed may provide some insight:

'I mean it doesn't surprise me that the public meeting wasn't popular. I mean - If I turned up to public meeting I wouldn't have had the chance I've got, you know you can't offload like I have now in a public meeting 'cause that's a nightmare for everybody else I think'. (Interview16: F, 52, S, N).

4.5.2.4 Data collection

The method employed in Phase 3 was in-depth, semi-structured interviews. This method was chosen as it offered the greatest potential for encouraging parents' to recall information freely and to be able to gather a range of perspectives and insights into factors affecting parental uptake of MMR uptake from them.

4.5.2.4.1 The Interview Topic Guide and Structure

The interview topic guide typically defines the areas to be covered in the interview and is based on the research study's aims and objectives (Britten, 2006). Having an interview topic guide, with carefully planned, open-ended questions and probes, can increase the researcher's confidence and also them to concentrate more easily on what is being said by the interviewee (Charmaz, 2007). A flexible interview topic guide was used within Phase 3 of the present research. This was used as both a guide and to determine the nature and direction of questioning depending on the responses that the interviewees gave (See Appendix 10).

Each interview consisted of three phases as described by Keats (2000). These phases involved the opening, the development of themes and the conclusion. In the opening section, Britten (2006) advised using questions that can be answered easily, before proceeding to more difficult or sensitive topics. In the present research, each interview opened with clarification of the demographic information contained within the secondary data source and the survey response, before moving on to questions about

knowledge of MMR and the diseases they protect against and then on to questions about parental decision-making and influences on this.

At the conclusion of the interviews, interviewees were asked if there was anything else they would like to add. This was to ensure that all topics were covered (Keats, 2000). The tape recorder was kept running until the end of the interview, however, on a number of occasions the interviewees started talking again about either issues raised within the interview or new material, after the tape recorder had been turned off. If possible the researcher asked the interviewee if the tape recorder could be turned back on. Where not possible, or where the interviewee declined, notes were taken, either immediately, or as soon as possible after the interviewer had left the interviewee. This situation occurred most frequently when the interviewer was on the doorstep about to leave and the interviewee recommenced the discussion. Notes were then written up in the car before leaving the location.

During the interviews, care was taken to avoid bias and ambiguity when phrasing the questions and to use language that was polite, neutral and not value-laden or leading, and that were appropriate for the interviewee (Keats, 2000; Smith, 1995). Double-barrelled questions, that is questions that ask interviewees to respond to two issues within a single question without specifying which part of the question the interviewee should answer, were avoided (Keats, 2000). Verbal ('Uh huh', 'Mmm', 'Can you tell me more about that?') and non-verbal (nod of the head, silent pauses) type probes were used to encourage the interviewees and to clarify meaning where needed (Smith, 1995).

The researcher was relatively experienced in conducting interviews, having undertaken training in the past; however, feedback on interviewing technique was still sought through piloting and also through discussion of the initial interviews with her supervisor.

Questioning style and the use of probes were noted to improve during Phase 3 as the researcher became more experienced in conducting the interviews.

Several methods were used to record the interviews, these included taking notes (during and after the interview) and audio-taping the interview. Permission was obtained before the start of the interview. Notes were made during the interview to highlight points of interest and issues requiring further clarification. Notes were also made immediately after each interview to record information, such as, location and the researcher's own feelings about the interview. These notes were used to provide context to assist with the later data analysis and to remind the researcher of the nature and of the interview and interviewee (Tickner, 2008). This process is also an important part of developing 'reflexivity' that is the awareness of 'self' within the process of data collection and analysis in qualitative research (Payne, 2004). This is considered further in 4.4.4.1.

All of the interviews were undertaken and transcribed by the researcher. Semi-structured interviews produce rich data, but they are also time-consuming both to conduct and to transcribe (Pope & Mays, 2006a; Britten, 2006). In this study, each hour of recorded interview took approximately seven hours to transcribe (longer where the quality of the recording was not good or where there were multiple voices to transcribe). All 24 semi-structured interviews were transcribed by the researcher in verbatim form to provide a full record of what was said. Payne (2004) argues that it is important to transcribe both the speech of the interviewer and the interviewee, but that it is not necessary to include 'paralinguistic or extra-linguistic elements'. Pope et al (2006), however, suggest that elements such as sighs, laughs and pauses can provide a valuable contribution during the process of analysis. These elements were therefore also included in the transcription of the interviews.

4.5.2.5 Data analysis

An applied approach to thematic analysis was utilised to analyse data collected during Phase 3 of the present research. The use of open questions and the opportunity to add free text narrative comments within the questionnaire design enabled an additional source of qualitative data to be obtained from individuals who responded to the Phase 2 Study survey, even where these respondents did not give consent to be included in the Phase 3 Study and to be interviewed. This data was able to be linked back to the child's records, and therefore to the quantitative data obtained during both Phase 1 and 2 studies, to provide further depth and explanation for the associations identified within these initial phases, to provide an outline framework for the coding of themes in the Phase 3 study, and to ensure that responses to the survey and to interviews were not 'double counted' in the final analysis.

Data from the interviews was transcribed from the tape recordings into written form. It was then systematically analysed by coding, categorising, comparing, refuting and interpreting words and passages in the text (including word frequency analysis), context, internal consistency (were there any shifts in opinion during the interview), frequency and intensity of comments (counting content analysis), trends and themes. The method used followed the six stage process described in a number of publications including Braun & Clarke (2006); Thomas (2006); Burnard et al (2008); Guest et al (2012); and Gale et al (2013). Gale et al (2013) also describe how an analytical framework can be used within the same process, which is of particular relevance, and is included in the design of, the present research.

The approach used within this study was deductive in that it initially made use of the framework of codes established through the initial analysis of the qualitative data from the Phase 2 survey, but also interpretive in that an iterative inductive approach was

then used to develop these codes and themes further as more information emerged from the data. The NVivo 10 software tool was used to code the data and to conduct multiple concept / coded category searches in order to assist in identifying any trends and themes. From this, theories about the process & experience of immunisation decision making were generated and these are presented in Chapter 6.

4.5.3 Reflexivity and maintaining rigour in qualitative research

The involvement of the researcher in all aspects of the data collection and analysis helped to ensure consistency throughout the present research. The nature of the research process was such that it was conducted by a single researcher. This is not uncommon in qualitative research studies, but does have the potential to increase bias (Britten, 1998). The validity of these studies can be improved by the cross-checking of coding strategies and the interpretation of data by other independent researchers (Barbour, 2001). In the present research, coding consistency was tested by initially using two coders (the researcher and a public health colleague) to independently input the codable (free text) comments from Section 5 of the survey. Nodes and coding stripes were then compared and a final node framework agreed before continuing with coding the remainder of the survey data and the interview transcripts. The researcher's academic supervisor also independently coded the first of the interview transcripts and also commented on the subsequent analysis and reviewed drafts of the results and discussion chapters of the study. These processes were useful in that the discussions that took place concerning the emerging coding framework and the resolution of any disagreements in respect of allocated codes and classifications provided additional insights to enable the coding frames to be further refined.

External validity, that is, the 'generalisability' of the findings, can be improved by presenting the final analysis back to interviewees to see whether or not the analysis was consistent with their perceptions and experiences (Kumar & Gantley, 1999). In the

present research, the findings were discussed with two of the interviewees in order to gain, albeit in limited form, further feedback and verification. The findings were also discussed at two workshop sessions outside of the area covered by the research (the South West Scientific Conference and the Bristol Immunisation Group Health Integration partners Team (BIG HIT)).

4.6 Summary of the Research Design

In the preceding sections the rationale for my chosen research approach and subsequent research design have been outlined. The study demanded the explorative opportunities offered by the use of both quantitative (deductive) and qualitative (inductive) approaches. More specifically, the wish to explore specific phenomena related to MMR immunisation; the potential influences on parental decision-making at both a collective and individual level; and therefore on the design and delivery of immunisation services, was best suited to this 'mixed methods' approach.

The design progressed through a preliminary cross-sectional study at whole population level, to specific population sub-group, and then to individual level enabled a substantive level of analysis, which ultimately led to the research findings summarised in Chapter 8. The overall research design from sampling through to data collection to data analysis is illustrated diagrammatically in Figure 4.

4.7 Ethical considerations in conducting the current research

The ethical issues associated with the respective phases of this study are described within this section.

Phase 1 was conducted using routinely available data which did not require consent prior to review. No specific ethical issues were associated with this study.

The main ethical issues for Phase 2 related to maintaining the anonymity of the two groups of children and their parents, and ensuring confidentiality in respect of the responses received via the postal questionnaires. This was achieved by the use of a unique identifier and a barcode allocated by FORMIC, as previously described. Information on how the confidentiality of data and personal information would be maintained was included in the Invite Letter and Patient Information Leaflet for Phase 2 (see Appendix 6 and 8).

In respect of Phase 3, additional ethical considerations included potential risks, informed consent, the researcher's role, funding and sponsorship, sensitive topics / confidentiality and anonymity, data handling and approval by relevant research ethics committees. The management of these ethical issues in the context of this study will now be explained.

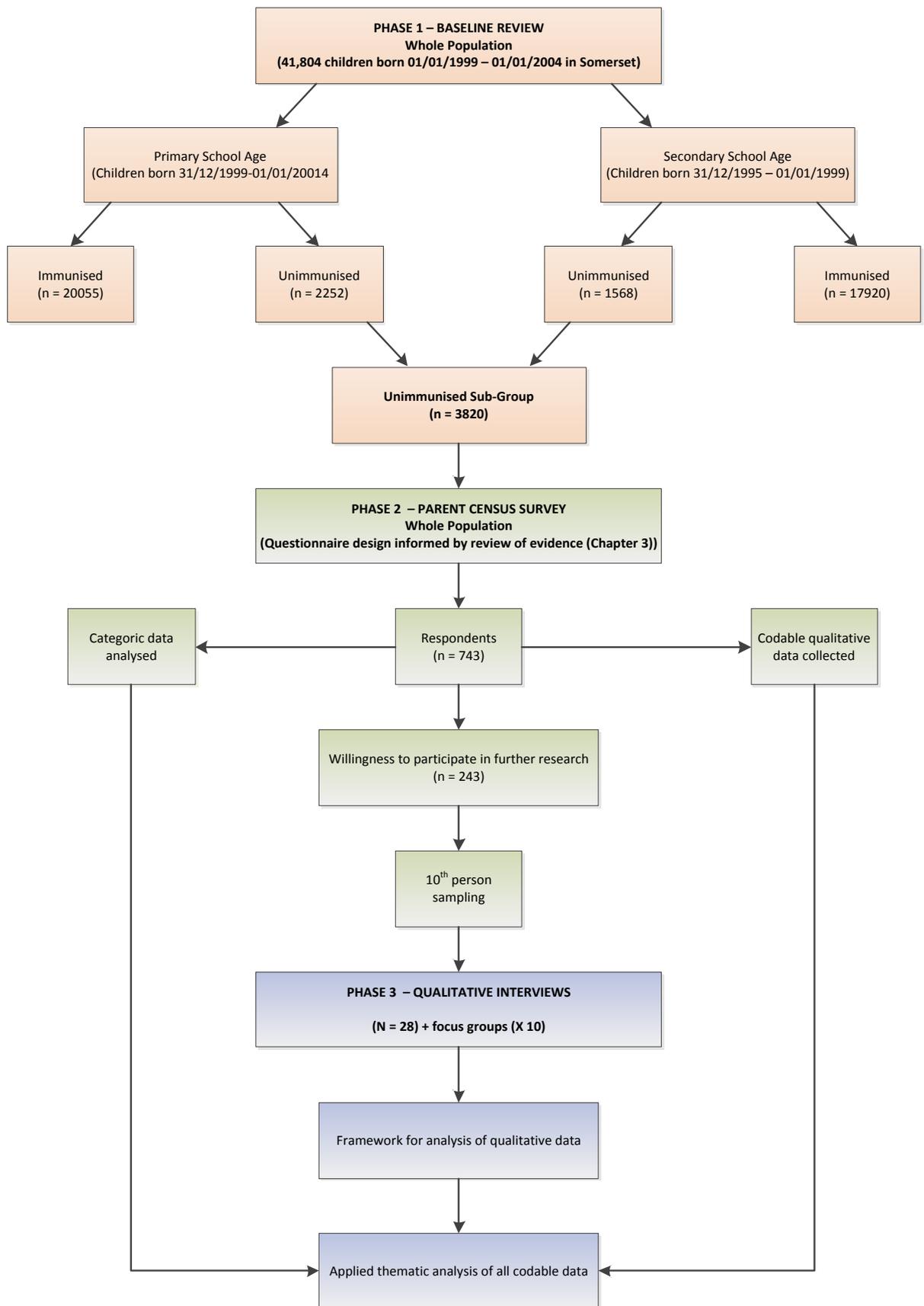


Figure 4: Diagram of Full Research Design

4.7.1 Potential Risks

The following potential risks were identified:

There was considered to be a potential psychological / emotional risk to participants, that is, there was a potential that a minority may have become distressed as a result of exploring their previous decisions in respect of their children's immunisations, particularly if they had had poor experiences, or if they regretted a decision to have, or not to have had these.

During the interview process there was potential that participants might change their mind regarding previous health choices, which may have included a desire to accept previously declined health interventions (e.g. immunisations).

There was a risk that participants may be financially disadvantaged if the interviews were planned to take place at a venue other than the participants home

There was a potential risk to the researcher if the interviews are conducted in a place that was unfamiliar to them and over which they had little control, such as the participants home address

Procedures to safeguard against, or to mitigate, these risks were applied as follows:

All participants were supplied with contact details for the Patient Advocacy and Liaison Service (PALS) who agreed to independently facilitate any access to information or future health services on behalf of the study participants, this included access to counselling or other medical services should these be necessary if distress was suffered as a result of participating in the study. It was recognised that this support should be independent of the NHS, where possible, given the nature of the study, and the availability of alternative provision was explored, and was available throughout the study period, but was not needed.

Participants were assured that access to health care provision would not be affected by any information provided by them during the study and it was agreed that access to health services where these were requested would also be facilitated via the PALS Service. This included advice on how to obtain immunisation should this be requested.

Any expenses incurred by participants were reimbursed in line with NHS Somerset's existing procedures and tariffs for reimbursing patient representatives

The researcher made arrangements and conducted any visits in line with the NHS Somerset's Lone Worker Policy. It was also agreed that if, on arrival, the researcher was not happy to conduct the interview at the location arranged, the interview would be deferred and alternative arrangements would be made.

4.7.2 Informed Consent

This study was undertaken in line with best practice guidance produced by the National Research Ethics Service in respect of information & consent for participants; confidentiality and use of personal data; and data storage (COREC 2006; National Patient Safety Agency, 2007). Participation was entirely voluntary and participants were free to withdraw consent at any point in the process without any consequence to future access to health care.

Advice in respect of provision of information and support to participants who may not adequately understand verbal or written information in English was sought from the following persons / organisations:

Somerset Racial Equality Council (SREC)

NHS Somerset Patient Advice and Liaison Service (PALS)

The Learning Shop

Somerset County Council Gypsy & Traveller Liaison Officer

NHS Somerset Public Involvement and Social Marketing leads

None of the participants selected for interview required translation services or any other support in order to take part in Phase 3 of this study. However, translation services were used to enable a small number of parents to complete the Phase 2 Parent Census Survey and to translate four surveys that were returned by parents with comments written in languages other than English.

4.7.3 The Researcher's role

The principal researcher was an experienced Consultant in Public Health who had worked in with families in the past as a Health Visitor, and more recently as Immunisation Coordinator for Somerset. It was recognised that the role of Immunisation Coordinator was significant and that this could potentially result in allegations of subjective bias within the research process. In order to guard against this, a sample of the transcripts and the free text comments were also reviewed and coded by a second person (the NHS Somerset Head of Health Informatics) and the data analysis was also discussed with the researcher's academic supervisor in order to check that the performance of the interviews was appropriate, and that any coding carried out or analysis undertaken appeared valid and consistent.

In addition, to further avoid conflict of interest, an offer was made to participants for interviews to be facilitated by experienced staff from either the Patient Advocacy and Liaison Service (PALS), or the Patient and Public Participation Service, who have no links with the immunisation service, should they prefer this. None of the participants requested this option.

4.7.4 Funding and sponsorship

The outcomes of the study were used to inform the development of the Somerset Immunisation Strategy and Action Plan 2010 – 2013. The postal census was designed to provide information in respect of the local Somerset population, through patient involvement which had not previously been undertaken. As such the researcher received support from NHS Somerset as follows:

The use of a specific postal address and franking service was negotiated which significantly reduced costs, and an existing Service Level Agreement with Somerset Racial Equality Council enabled formal support to be provided to the researcher to inform the survey design, and for testing to ensure that this was suitable for use with minority populations, including those with difficulties with literacy, as well as those with physical or language barriers. These services were funded by NHS Somerset.

Labels for the envelopes, and lists detailing the individual identifier and the Child / Parents personal information (names and addresses), were prepared by the Child Health Department. The process of reconciling the surveys and the envelopes was overseen by the CHRD Manager and this ensured that no patient identifiable data left the Department. Stationery and other consumables were provided by NHS Somerset.

The postal questionnaires were physically administered (survey forms printed, envelopes filled, franked and posted) by volunteers from the NHS Somerset Public Health Directorate. Follow up reminder postcards were also processed in the same way.

The returned questionnaires were physically scanned into FORMIC as they arrived back in the Public Health Department by a very experienced public health administrator. This administrator also collated the forms into piles relating to:

Not known at the address (these were then rechecked by the researcher against the CHIS database prior to exclusion from the sample)

Completed and scanned

Completed and scanned – free text comments (these forms were then reviewed in full by the researcher who manually transcribed the text into the database for later coding)

Project data, including the completed, returned parent questionnaires, was then received and stored in an anonymised form by the researcher within secure IT systems which met NHS Information Governance standards. These IT systems were managed and backed-up by NHS Somerset.

All parent queries relating to the questionnaire were directed to a single phone number. This phone was answered by the administrator during office hours and by answerphone out of hours. The administrator obtained details of each of the individuals who called the helpline and their query, and inputted this information in to an excel spread sheet. This spread sheet was forwarded to the researcher at the end of each day and the researcher returned the calls personally that evening. 143 calls were received to this helpline during the conduct of Phase 2 of this study and all were responded to by the researcher.

Finally, support was provided by NHS Somerset to facilitate the running of the focus groups. Whilst it was planned that the researcher would lead these groups, members of the Public Health Team volunteered to support the process as second facilitators / scribes on the day. The administrator also made the physical arrangements for the running of the groups (room bookings, crèche facilities, payment of expenses to participants, provision of refreshments) at the direction of the researcher.

This administrative support significantly reduced the time taken to obtain data back from the Phase 2 study in a format that the researcher could then transfer into Excel

for analysis and considerably improved the feasibility of an individual researcher conducting a multi-phased study such as this.

4.7.5 Sensitive topics / Confidentiality and Anonymity / Data Handling

Participants were assured that any information would be handled in confidence and would not be used or passed to other persons without the participants consent.

However, they were advised that should issues related to Child Protection become apparent the researcher would have a responsibility to report these according to local Child Protection Procedures. If any other support was required following discussion of sensitive or embarrassing issues contact was offered with PALS who were able to facilitate appropriate support for the participant. Where this was not acceptable to the participant, the researcher had the option to make direct contact with any appropriate persons or organisations, internal and external to the NHS, as required (depending on the issues raised).

All interview transcripts were anonymised and identified only by a reference number. No personal information was included in, or with, the transcripts. At the end of the study period the transcripts were scanned and stored in a secure electronic database within the Public Health Directorate of NHS Somerset. It was planned that the original transcripts would be destroyed and the scanned electronic copies retained and archived. However, the NHS underwent a major re-organisation in April 2013. As a result NHS Somerset was abolished and the Public Health Department was fragmented. The researcher became employed as Screening and Immunisation Lead for Public Health England (PHE) covering the South West of England, whilst other members of the NHS Somerset Public Health Department transferred to Somerset County Council, in line with the agreed arrangements within the 2010 Health and Social Care Act.

Access to previous software licenses, including FORMIC, was not maintained by any of these organisations and the scanned copies therefore had to be destroyed when the software was decommissioned. The hard copies of all forms and the remaining electronic databases relating to this study were transferred to the PHE Screening and Immunisation Team South West, where they remain in secure storage. Any future access to this data will require written application to the PHE Caldicott guardian (currently the Medical Director) and appropriate ethical approval.

4.7.6 Ethical approval

Ethical approval was sought from and granted by the Ethics Committee of the Department of Nursing at the University of Stirling and the Avon NHS Research Ethics Committee. Approval was also sought from the NHS Somerset Research and Development Consortium. Full approval to undertake the study was received in January 2012 and the study formally commenced in March 2012.

Annual reports on progress have been submitted to Stirling University detailing any changes and progress. Progress reports were also required by the NHS Somerset Research and Development Consortium and have been submitted on a bi-annual basis.

CHAPTER 5 PRESENTATION OF THE RESULTS OF THE ANALYSIS OF PHASE 1 AND PHASE 2 CATEGORIC DATA

5.1 Introduction

Baseline epidemiological investigations relating to MMR uptake had been commenced as part of the NHS Somerset Public Health Department's Health Protection Team Work Plan in 2008/09. However, whilst this initial examination of the published immunisation data had confirmed a variation in the uptake of MMR and other childhood immunisations across Somerset, it had failed to identify any specific geographic or GP practice related correlations which could be used to inform the review and redesign of local services. The present study was designed to build upon these earlier reviews by exploring, in Phase 1, additional local immunisation data available via GP practice and CHIS systems, supplemented by data obtained via the Phase 2 Parent Census Survey. The results of the analysis of this data are presented in this chapter.

Section 5.2 details the results of the analysis of the Phase 1 data. The Somerset CHIS dataset was used to identify the initial Phase 1 population and also the sub-group of 'unimmunised' children corresponding to the two age groups under investigation in Phase 2. Parents of all children within this sub-group were sent the parent census survey and the survey was used to provide a sampling framework for the Phase 3 semi-structured interviews.

Given the relatively low response rates to the parent census survey (20% for primary school age children and 16% for secondary school age children), the demographic and geographic characteristics of the unimmunised children whose parents had responded to the survey, in each age group, were then compared with the characteristics of the unimmunised children in the original dataset to confirm whether the respondents were

representative of the wider group of unimmunised children. The result of this process of analysis is presented in Section 5.3.

The characteristics of the children whose parents agreed to be followed up and those who were interviewed were each then compared with both the original population of unimmunised children and with the responders to the survey, to identify whether these groups were representative of either or of both of these previous groups. The purpose of these latter processes of analysis was to provide an assessment of the relative representativeness of the individuals participating in the survey and the interviews, and therefore the potential limitations of any recommendations for changes in practice arising from this thesis. The results of these analyses are presented in Sections 5.4 and 5.5. The results of the analysis of the Parent Census Survey itself are presented in Section 5.6, and the results are then summarised in Section 5.7

This chapter aims to address the following research question:

What were the social, demographic and geographic characteristics of parents / children who had accepted and declined MMR in Somerset after 2009?

5.2 Results of the analysis of the Phase 1 data

The purpose of this section is to present the findings from the review of the immunisation data relating to the whole population of 41767 children aged six to 15 years in Somerset (as held on the Somerset CHIS database in March 2009) and from this to compare the characteristics of those who had accepted and those who had declined MMR in two defined age groups to see if there were any differences between these population sub-groups. The two age groups investigated were:

Children aged six – 10 years (primary school age)

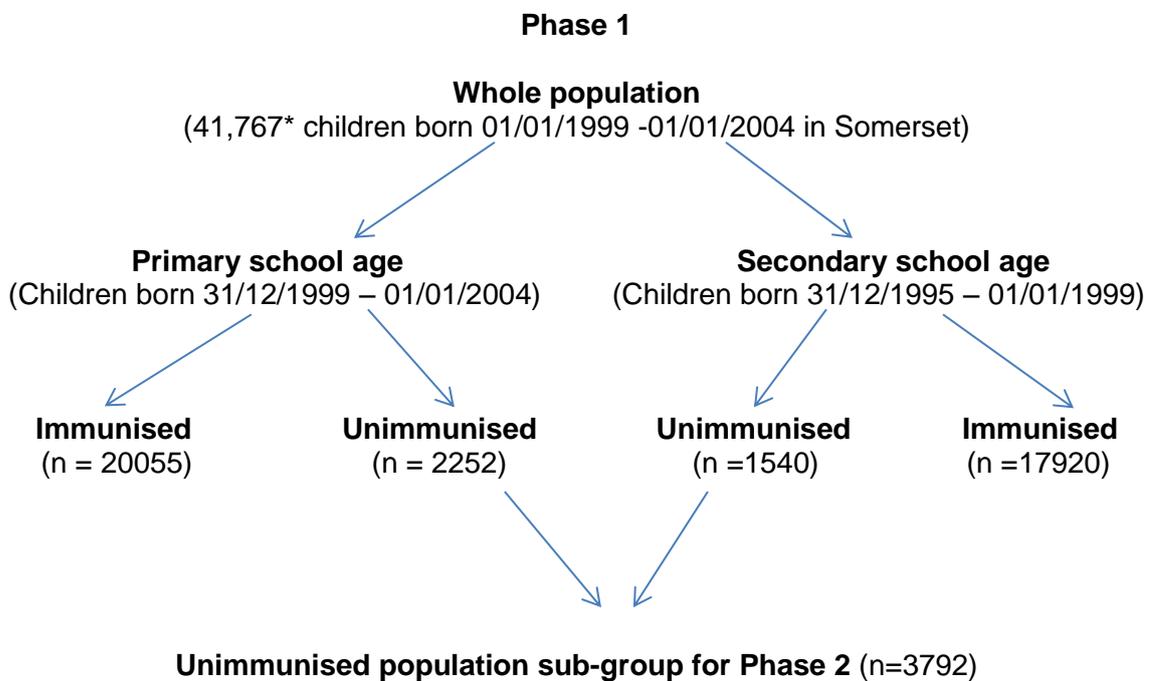
Children aged 11 – 15 years (secondary school age)

The rationale for exploring these age groups has already been described in Chapter 4.

The MMR status for each of these children was ascertained and the children within each of these two age groups were then labelled either 'immunised' or 'unimmunised'.

See Figure 5 below.

Figure 5: Study populations for Phases 1 and 2



(*Note 37 children were not able to be allocated due to no NHS number or other missing data)

The demographic characteristics (sex, MSOA, deprivation (IMD) quintile, MOSAIC group, Child Centre Area, and registered GP Practice) of the immunised and unimmunised children were ascertained. For analysis, children were assigned to MSOAs, IMD quintiles, Mosaic Groups and Children's Centre Areas based on their postcode. These characteristics were then compared to investigate whether there were any differences within and between the two age groups. The results of these comparisons are detailed below:

5.2.1 Gender

Unimmunised children comprised 10% of the children in the primary school age group and 8% of children in the secondary school age group. Using chi-square with Yates' correction, gender was found not to be significant for primary school age ($p = 0.17$) or the secondary school age groups ($p = 0.59$). This is summarised in Table 2 below:

Primary School Age

	Males	Females	Total population
Unimmunised	1186	1066	2252
Immunised	10250	9805	20055
Total	11436	10871	22307
Proportion Unimmunised	10.4%	9.8%	10.1%

$$\chi^2_{1c} \quad 1.90$$

$$p \text{ value} \quad 0.17$$

Secondary School Age

	Males	Females	Total population
Unimmunised	811	729	1540
Immunised	9302	8618	17920
Total	10113	9347	19460
Proportion Unimmunised	8.0%	7.8%	7.9%

$$\chi^2_{1c} \quad 0.29$$

$$p \text{ value} \quad 0.59$$

Table 2: Proportions of Immunised and Unimmunised children by gender and age group

5.2.2 MSOA

Super Output Areas (SOAs) are geographical areas used for the collection and publishing of small area statistics. There are two layers of SOAs; Lower Super Output Areas (LSOAs) and Middle Super Output Areas (MSOAs). Whilst both are used for local area planning, MSOA level data enables the release of data which might be disclosive if published at smaller postcode area level. MSOAs have a minimum size of 5000 residents and 3000 households with an average population size of 7500 (Neighbourhood Statistics, 2014). Figures 6 and 7, and scatter diagram (Figure 8)

below illustrate the geographical distribution of children in each subgroup, based on MSOA.

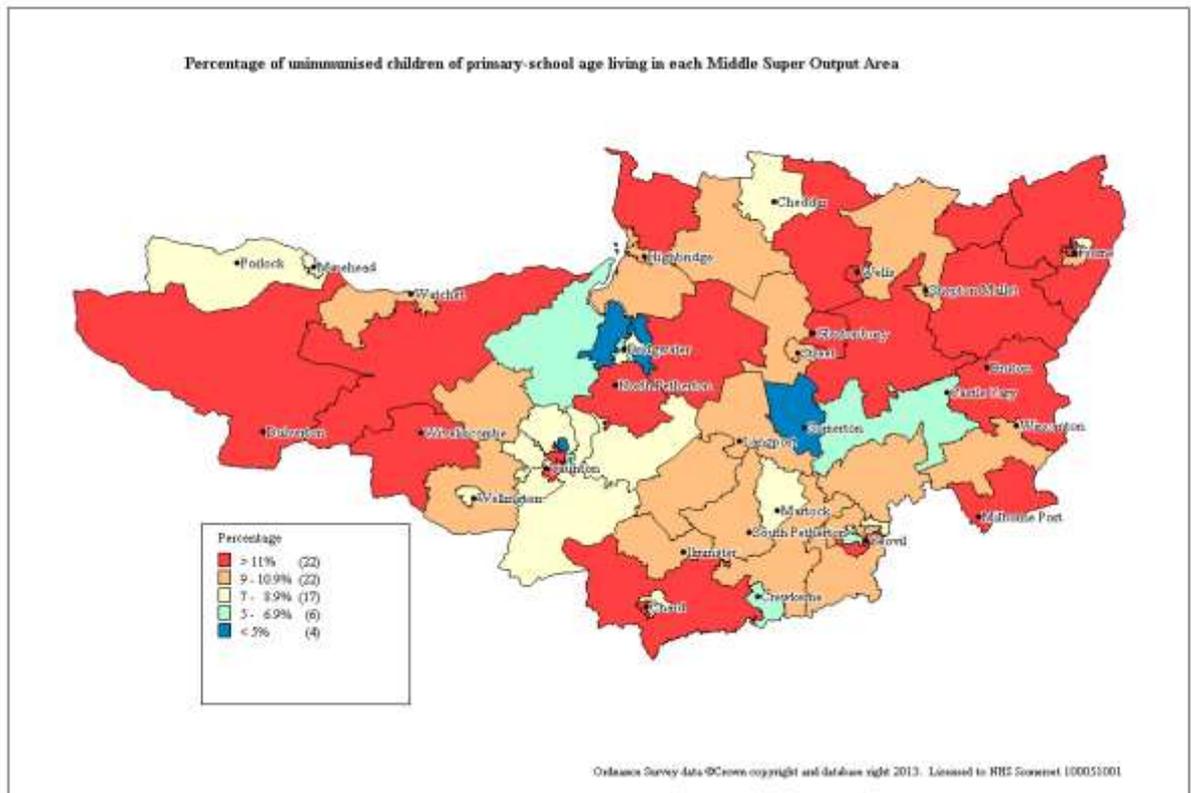


Figure 6: Percentage of unimmunised children of primary school age living in each Middle Super Output Area

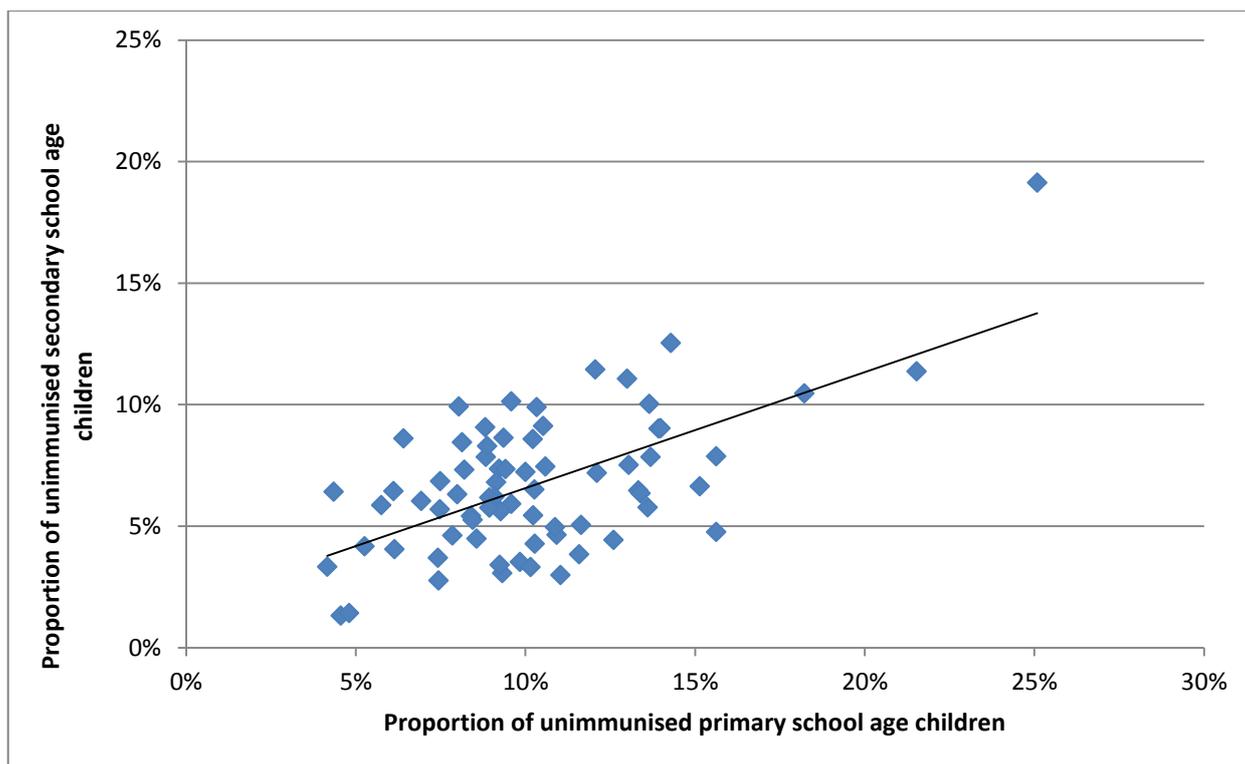


Figure 8: Scatterplot of unimmunised children by MSOA for each age group

Glastonbury and Frome traditionally have higher proportions of their populations who ascribe to alternative lifestyles and holistic health approaches (NHS Somerset, 2012) – Frome also has a large anthroposophic (Steiner) school, which is a characteristic that has also been found to be linked with low immunisation uptake rates in previous studies (Alm et al, 1999). Primary school age children are, however, the age group most likely to have been influenced by the controversy over the now discredited Wakefield paper (Wakefield et al, 1998) which gained media attention in 1999 and on into the early 2000s. This difference in geographical distribution may be relevant.

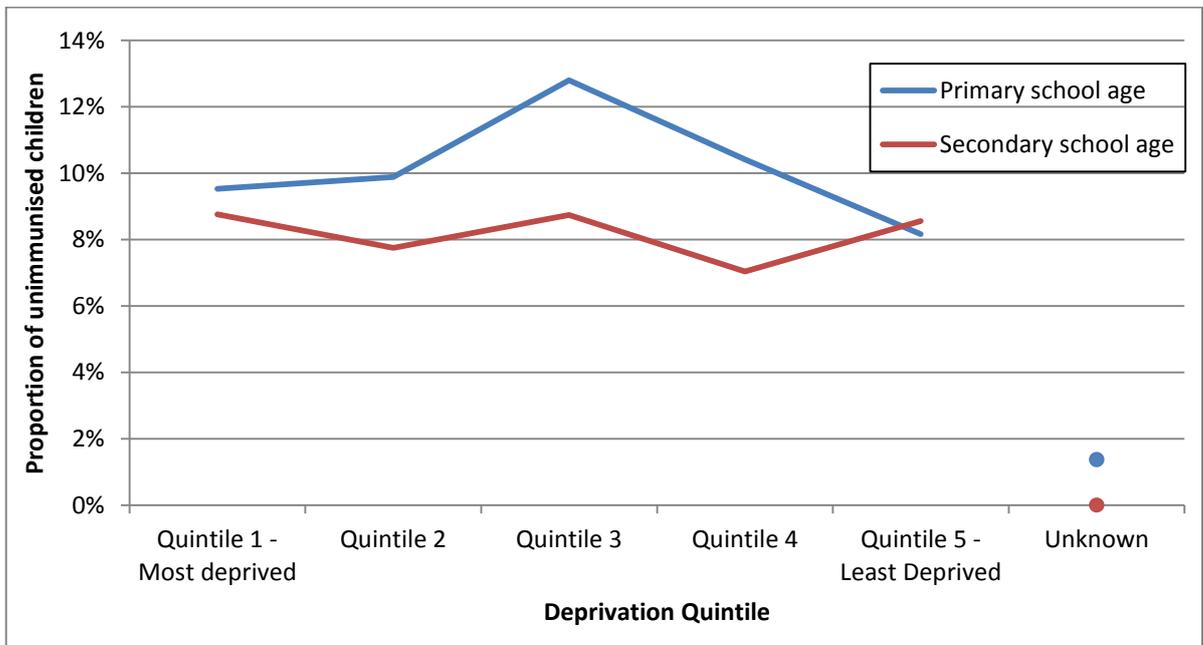
5.2.3 Indices of Multiple Deprivation (IMD)

Figure 9, below shows little difference in adherence to the MMR schedule across deprivation quintiles for the secondary school age children. There is minimal difference between the proportion of unimmunised children in the highest and lowest (least deprived and most deprived) quintiles at 9.5% and 8.5% respectively for primary

school age children and also little difference between the proportion of unimmunised children between the two age groups in these quintiles. However, for primary school age children, it is children in quintile 3 (neither low nor high levels of deprivation) that have the lowest uptake of MMR.

This is not in line with findings from previous studies, where MMR uptake has generally been found to be associated with the most deprived and least deprived groups (Bedford et al, 2009) with poorer uptake in both of these quintiles. However, this finding may be due to limitations in the use of IMD in rural areas where factors such as car ownership (which is essential and not a luxury in these areas due to lack of public transport) or presence of a very small number of very wealthy individuals in an otherwise deprived area can act to distort the integrity of the quintiles. It is unclear whether this did impact and was therefore of relevance in relation to this study.

Figure 9: Comparison of immunised and unimmunised children by deprivation quintile (Index of Multiple Deprivation) and by age group



5.2.4 MOSAIC Group

MOSAIC UK is Experian's system for classification of UK households. It is a commercially available geo-demographic segmentation system, which estimates the most probable characteristics of people based on pooled profiles of all the people living in a small area near a particular address. The current version MOSAIC 2009, classifies the UK population into 15 main socio-economic groups and within 67 different population types (Experian, 2014). Definitions of each MOSAIC group are detailed in Appendix 11.

When reviewing the MOSAIC data some groups were found to contain only a small number of children, there were also a small number of households categorised as groups L and M (elderly people) and this is most likely due to there being a mix of housing in that postcode area. Groups C, G, L, M, and N were therefore combined with Group U, to give a final group called 'Other' for the purpose of analysis. The highest proportions of unimmunised children within this combined MOSAIC group are actually from the 'Unknown' classification. It possible that these are residents of newly built housing estates that were too new to have been allocated a MOSAIC group at the time of the survey.

The proportion of unimmunised children in the remaining MOSAIC groups were then reviewed and the highest proportions of unimmunised populations were found to be in MOSAIC groups A and I for both age groups and also in group D for those of primary school age. Groups A and I represent 'isolated rural communities' and 'lower income workers in urban terraces' respectively. This does appear to reflect the findings of previous studies whereby immunisation uptake has generally been found to be associated with problems with access issues and / or social deprivation (Freidrichs, 2006).

Group D consisted of 'successful professionals in semi-rural areas'. Given that this group consisted of younger children whose parents were likely to have been most influenced by the Wakefield controversy, this is also in line with previous findings. The 'Other' group has the highest proportion of secondary school age and the second highest proportion of primary school age children.

5.2.5 Children's Centre Area

Somerset has 41 Children's Centres, which are physical buildings from which a range of services are delivered for young children and their families and, as such, it was considered that these Centres might have a potential influence on parental decision-making. The county is divided into areas based around each of these centres, and children's services including schools are frequently also co-located or located nearby. The proportions of children in each group were mapped (as for MSOA previously). There was only one Children's Centre Area where less than 5% of primary school age children were found to be unimmunised. However, 10 areas were identified that had less than 5% of unimmunised children in the secondary school age group. Scatterplots were then used to identify the proportion of unimmunised children in each of these age groups by Children's Centre Area. This showed a similar pattern to the MSOA data and the outlier again was Glastonbury Children's Centre. See Figure 10 below:

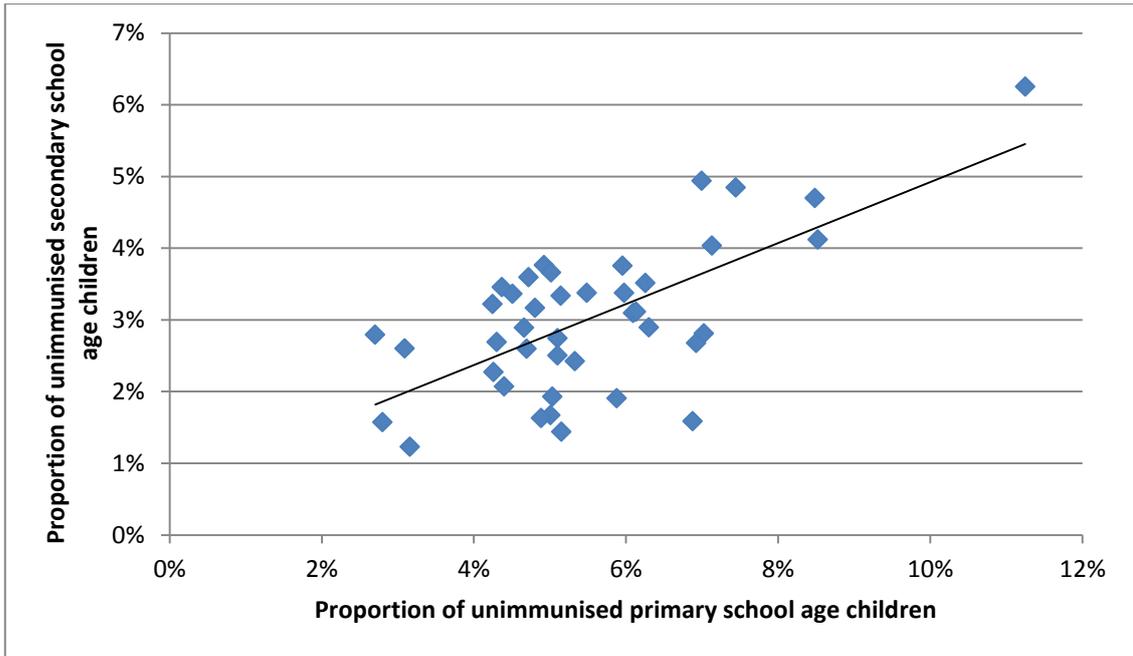


Figure 10: Scatterplot of unimmunised children by Children’s Centre and age group

5.2.6 GP practice

The proportion unimmunised children registered with each surgery also differed, with two surgeries having no children in either of the age groups investigated. Figure 11 and scatter plot (Figure 12) below illustrate the proportions of unimmunised children by GP practice for each of the two age groups:

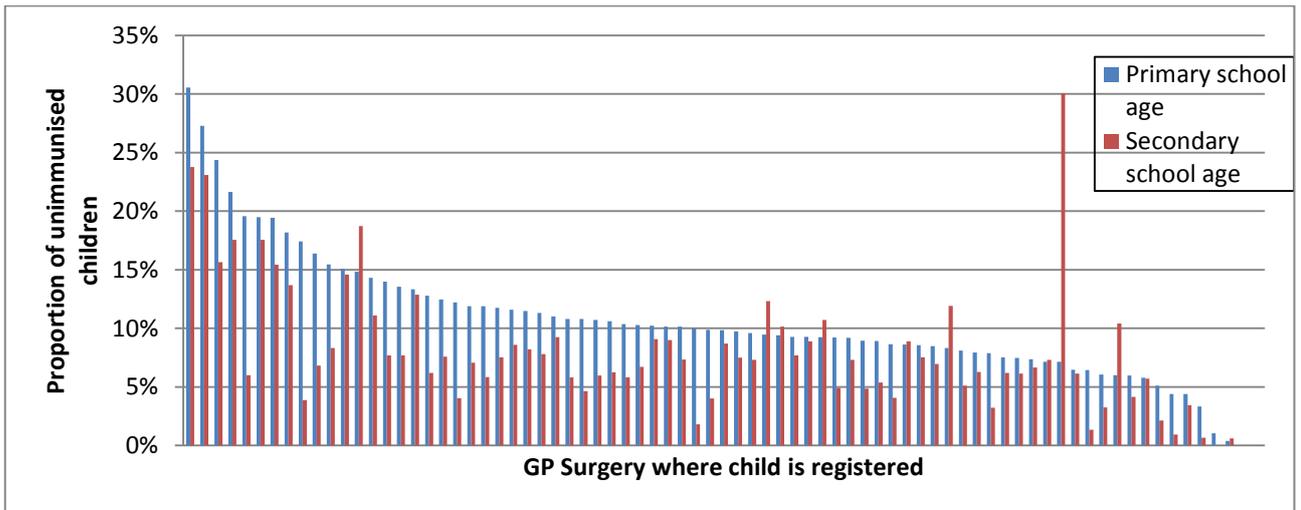


Figure 11: Proportion of unimmunised children by GP practice and by age group

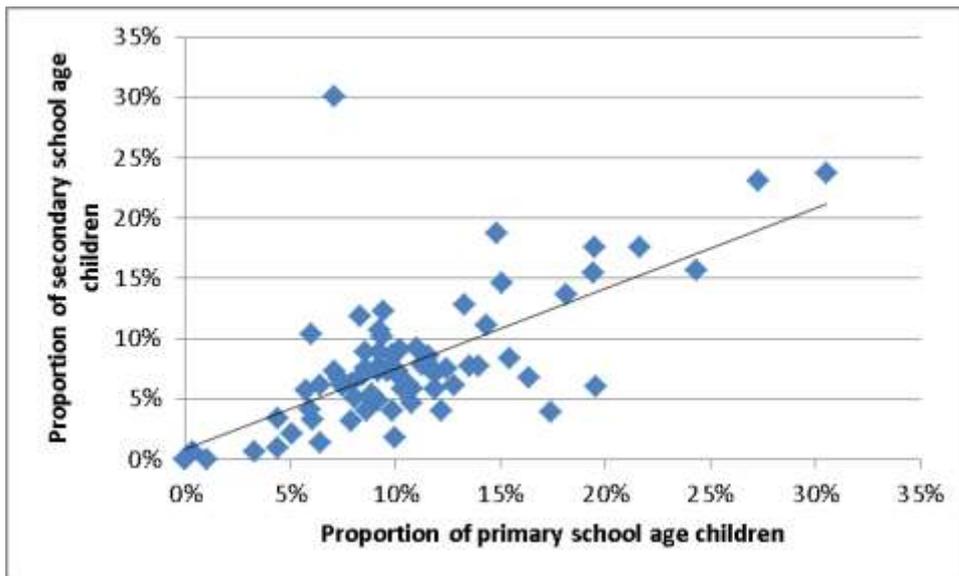


Figure 12: Scatter plot of unimmunised children by GP practice and by age group

This analysis suggests a relationship between registered surgery and parents' decisions whether to have MMR for their child, or not. The data values by GP practice were ranked and analysed using a non-parametric test of monotonic association which confirmed that GP practice was highly significantly associated with decision to decline MMR (p value = 0.00002).

GP practice may be related to people living in a geographical area (MSOA); however, this may not be the reason for this association. Although an exploration of the attitudes and beliefs of HCPs were not specifically included in the scope of this study, there was evidence in Chapter 3 to suggest that health care staff can have a significant influence on parents' decisions to accept immunisation (both as a result of what they do and what they say), as can organisational systems and practices (Penn & Kiddy, 2011; Smallbegovic et al, 2003).

There are several pieces of evidence within this dataset which suggest this may also potentially be a relevant factor here. The outlier in the scatter graph has the highest proportion of unimmunised secondary age children and a relatively low proportion of

unimmunised primary school age children. Further investigation with this practice confirmed that there had been a change in nursing staff between these two time periods. In addition, there are geographical areas which have more than one GP practice. There are two practices in Glastonbury, for example, and whilst for children of secondary school age they are ranked 2/77 and 5/77 respectively (therefore similar), for children of primary school age they are ranked 1/77 and 13/77. There is also evidence of significant differences even between practices that share premises, with one ranking 4/77 (primary school age) and 5/77 (secondary school age) respectively and the other ranking 77/77 for both age groups.

These findings could reflect these GPs having demographically different registered populations, but equally this might also reflect different influences of staff, policies and practices within these surgeries at different points in time. These findings therefore require further investigation.

5.3 Comparison of the data from the Phase 1 unimmunised population and the Phase 2 Parent Census Survey Respondents

There were 726 responses to the parent census survey of which 19 children were subsequently found to have been immunised with MMR as per the national schedule and were reassigned to their respective 'immunised' age groups. A further seven respondents appeared to have completed the questionnaire for a different child from the one detailed on the letter, and a decision was made to categorise these as non-responders. 700 responses were analysed, 453 from parents of primary school age children and 247 from parents of secondary school age children, representing a 20% and 16% response rate respectively. Demographic data for the children whose parents had responded to the survey was compared with data obtained for the unimmunised

children in the original Phase1 dataset to identify if the responders differed from these groups.

5.3.1 Gender

The proportion of survey responses for male children in both age groups was higher than the proportion of responses for female children. This was not however found to be statistically significant and is illustrated in Table 3 below:

Table 3: Proportions of survey responders and non-responders by age group and gender

Primary school age children	Responders	Non responders	Total
Males	253	933	1186
Females	200	866	1066
Total	453	1799	2252
Proportion Male	56%	52%	53%

χ^2 2.15

p value 0.14

Secondary school age children	Responders	Non responders	Total
Males	133	678	811
Females	114	615	729
Total	247	1293	1540
Proportion Male	54%	52%	53%

χ^2 0.11

p value 0.74

5.3.2 MSOA

Response rates varied from 46% to no responders per MSOA for the primary school age group, and from 50% to no responders for the secondary school age group.

Response rates were then plotted on maps to show the geographical distribution of the responders (See Figures 13 and 14):

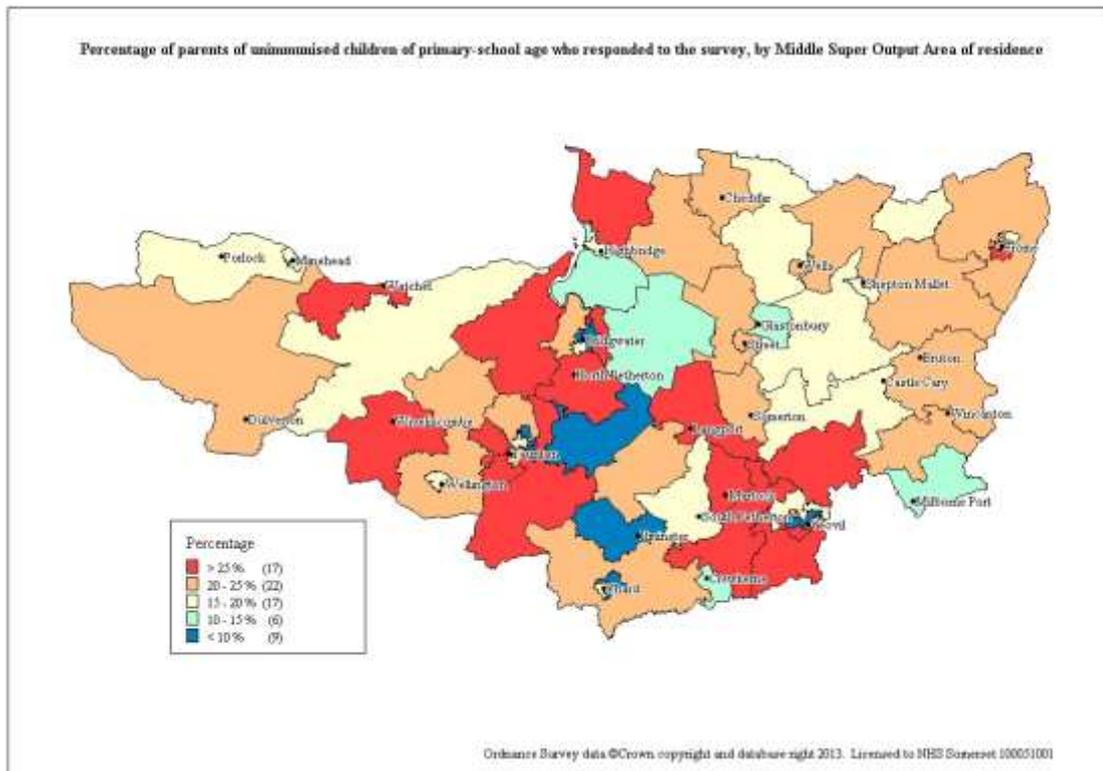


Figure 13: Percentage of responding parents of primary school age children by Middle Super Output Area

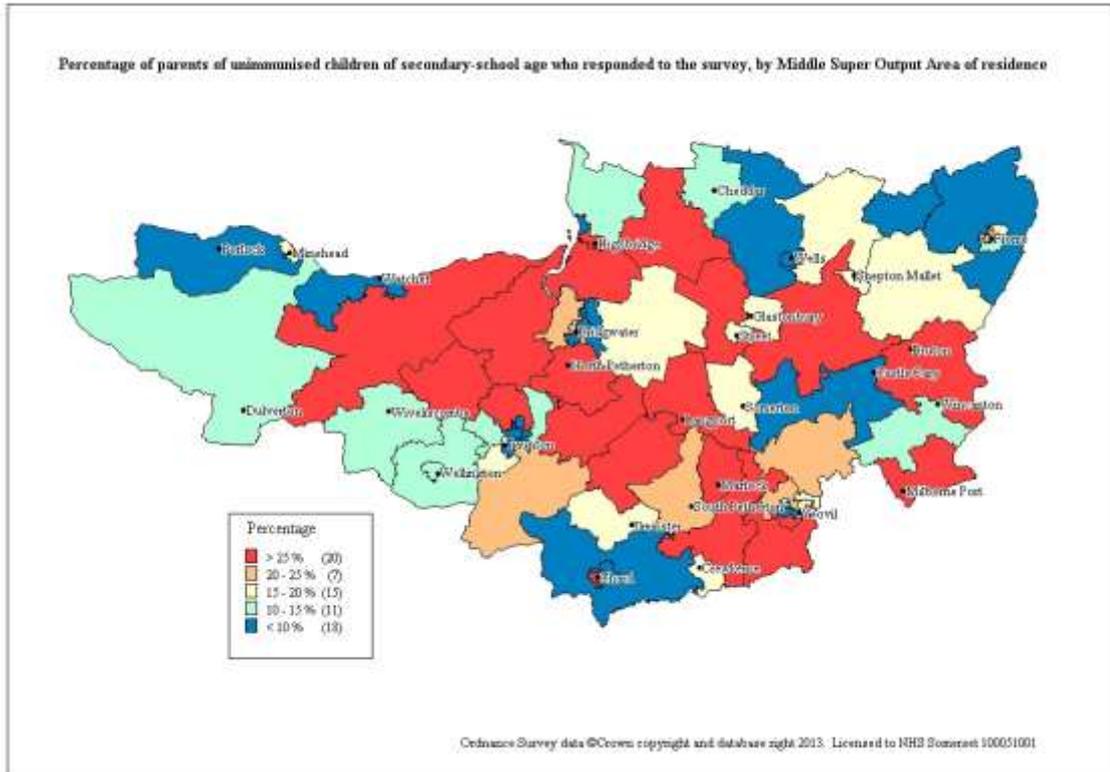


Figure 14: Percentage of responding parents of secondary school age children by Middle Super Output Area

These maps appear to show a smaller proportion of responders from the Mendip (Glastonbury / Frome) area amongst the responding parents of primary school age children, and a more diverse geographic distribution of responses from parents of secondary school age children than seen in for the wider unimmunised Phase 1 population. Analysis of the data found no apparent relationship between the MSOA of residence and the response rates from either of the two age groups. This may indicate a difference between the type of people who responded to the survey and the unimmunised populations as a whole (since the Phase 1 analysis had found an association between MSOA and declining MMR) however, the numbers involved are too small to confirm this.

5.3.3 IMD

There was a greater proportion of survey responses from parents in Quintile 5 (least deprived) than from Quintile 1 (most deprived). This was observed across both age

groups. For responders in the primary school age group, IMD was found to be highly significant ($p < 0.001$). P value for linear trend was also calculated and found to be highly significant ($p < 0.001$) with response rising across the quintile from most to least deprived. The same pattern was found for the secondary school age group, however, for this group IMD was not statistically significant ($p = 0.25$). P value for linear trend (responses increase as deprivation level decreases) was again calculated and this was found to be significant ($p = 0.03$). This is again different from the findings for the analysis of the data from the whole Phase 1 unimmunised group and suggests again that the responders may not be representative of this wider group.

5.3.4 MOSAIC Group

Response rates varied between MOSAIC groups, but as in the Phase 1 dataset, in some cases the number of children in each group was very small, and some of the groups were therefore amalgamated. For primary school age children the response rate varied between 6% (Mosaic Group O Families in low-rise social housing with high levels of benefit need) and 29% (Mosaic Group E Middle income families living in moderate suburban semis). This corresponds with the IMD data shown above. For secondary school age children the response rate varied between no responders in Mosaic Group N (Young people renting flats in high density social housing) and 26% in Mosaic group F (Couples with young children in comfortable modern housing).

Groups D (Successful professionals living in suburban or semi-rural homes), E (middle income families in moderate suburban semis) and F (couples with young children in comfortable modern housing) however, formed a higher proportion of the parents who responded to the survey. These population types are likely to be more literate and articulate and there is evidence that this type of individual is more likely to respond to survey methodology. This may therefore also have acted to skew the response.

5.3.5 Children's Centre Area

As with the MOSAIC groups, response rates varied between Children's Centre areas. This reflected, in some cases, the low numbers of the population in the age groups investigated, with 1 area (Halcon) having less than 5% of unimmunised children in the primary school age group, and 10 areas having less than 5% of unimmunised children in their respective secondary school age groups. The three outliers were identified and on this occasion these were Williton and Nether Stowey, both in Sedgmoor, and Creech in Taunton. This may reflect small numbers, or may again indicate sub-populations of responders, but does not appear to correspond with the response by MSOA as previously described.

5.3.6 GP Surgery

Initial analysis of responses by GP practice suggested an association between GP practice and MMR uptake. However, using a ranking process and non-parametric test as before, this association was not found to be significant for the responder groups (p value = 0.09), and this is therefore different than for the analysis of the previous dataset where the association was found to be highly significant (p value = 0.00002). There were five GP practices where no responses were received from parents of primary school age children and 13 where no responses were received from parents of secondary school age children. North Petherton Surgery was the outlier with a high response for both age groups, whereas Preston Grove had a very high response rate for primary school age and no response for secondary school age children. There is no apparent explanation for these variations.

5.4 Comparison of the survey responders and parents who agreed to follow-up

Of those who responded to the survey, 172 (38%) parents of primary school age children from and 96 (39%) parents of secondary school age children provided contact details and agreed to take part in a follow-up interview. The analysis of the data for this group of parents is presented in the following section.

The “agreed to follow up” group were then compared with their respective Phase 1 unimmunised age groups and χ^2 tests were performed on the distributions across gender, IMD and MOSIAC groups. No significant differences were identified across any of these variables. Comparison of the MSOAs and GPs was not able to be undertaken for the ‘agree to follow-up’ group because of the small numbers involved.

5.4.1 IMD

In terms of IMD, the data did however suggest that the “agreed to follow up” group were less deprived than the wider Phase 1 unimmunised populations and it is possible that the χ^2 test was not significant because there were not enough children in each of the groups to identify this. Previous studies have indicated that those who have refused to accept MMR for their children were more likely to be in the less deprived categories and in addition there is evidence that those in less deprived categories are also more likely to respond to surveys. The quintiles within the dataset were therefore combined to increase the number of individuals in each group. The proportion in Quintile 1+ Quintile 2 were then compared for the “agreed to follow up” and Phase 1 groups and the χ^2 tests performed did identify a significant difference, (p value = 0.03) with those in the ‘agreed to follow up’ group being significantly less deprived than the original unimmunised population (see Figure 15).

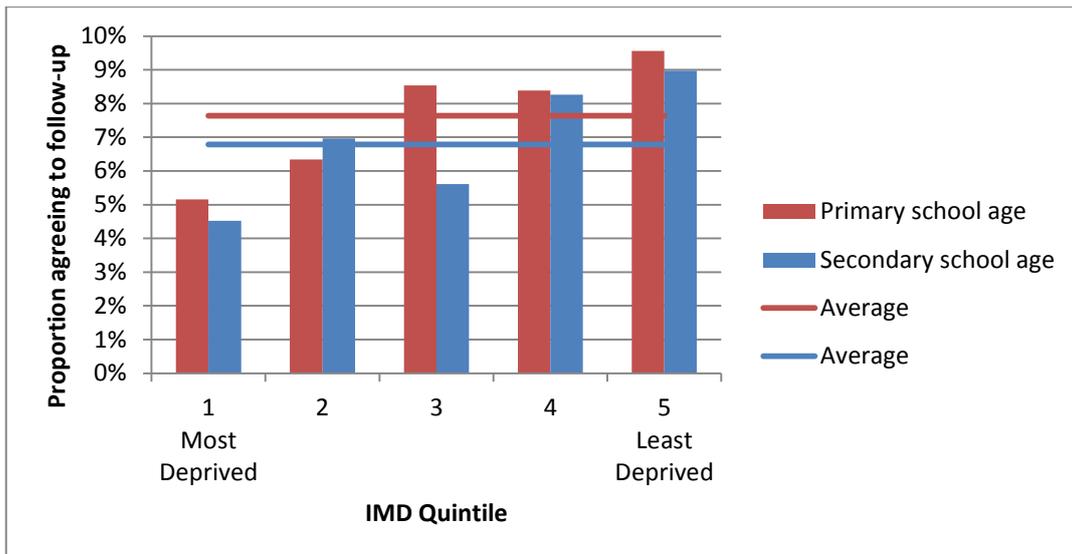


Figure 15: Proportion of parents agreeing to further follow-up

5.4.2 MOSAIC Group

The groups were amalgamated as described as before. Response rates varied between the groups but were not significantly different from the average response rate. The pattern within and between the primary and secondary age groups was similar to that previously identified. However, of those agreeing to follow-up in both groups, a higher proportion were found to be in Group O (families in low rise social housing with high levels of benefit need) than either the unimmunised population as a whole, or the responders to the survey.

5.4.3 Children's Centre Areas

The proportion of those agreeing to follow-up varied between Children's Centre areas. This reflects in some cases the low numbers of the population in the respective age groups, and subsequently low numbers of responders. However there were parents from most areas who were willing to be followed up with the following exceptions. There were no survey responses from parents of primary school age children in Halcon, and none from parents of secondary school age children in Sydenham and

Lyngford. As a result no interviews or further follow-up was able to be undertaken with parents in these areas. These areas have amongst the most deprived populations in Somerset and are therefore a group that is much less likely to respond to a survey approach. There were also no responses from parents of secondary school age children from the Chilcompton and Yeovil Children's Centre Areas who agreed to follow-up. Again these are noted to be areas of relatively high deprivation.

5.5 Comparison of parents who took part in interviews with those who responded and those who agreed to follow-up

There were 268 parents who provided contact details on their survey return and agreed to take part in a follow-up interview, 172 parents of primary school age children and 96 parents of secondary school age children. 20 interviews were carried out.

The breakdown of those invited for interview is shown below:

Of the seven who were not interviewed, two did not provide a contact telephone number, one gave an incorrect telephone number, three were not able to take part in an interview, and one no longer wished to participate. The numbers involved were too small to undertake any meaningful comparisons between this group and the other groups.

Table 4: Outcomes for parents invited for interview

Age group	Invited	Attended a one to one interview	Removed due to administration error*	Focus Group (which became a one to one interview)	Not interviewed
Primary school age	19	15	1*	0	3
Secondary school age	9	4	0	1	4
Total	28	19	1*	1	7

**This participant should have been in the Immunised Group, but this was only realised after the participants for follow-up had been selected.*

The persons invited for interview were selected from the entire responding population who agreed to follow up by a process of Nth (10th) person sampling. As a result, the numbers invited from each cohort are roughly proportionate to numbers agreeing to follow-up. An alternative approach would have been to have adopted a disproportionate strategy that would have meant inviting roughly equal numbers from both cohorts. The strategy adopted is more representative of the total 'agree to follow-up' sample, and was chosen because although there was an interest in understanding the influences on parents of children who were of secondary school age in 2009, primary school age children were the group with the highest levels of non-compliance with the national immunisation programme and therefore the group which would require greatest attention in any future catch-up activity to improve uptake. The interview sample is therefore recognised as being weighted towards parents of children who were of primary school age in 2009 (and therefore of secondary school age or approaching secondary school entry at the time of the interviews with the parents in 2012).

The numbers of parents interviewed was too small for meaningful analysis in relation to MSOA, MOSAIC Group, GP practice or Children's Centre Area. Analysis was therefore limited to a comparison of gender and IMD of the interviewees, survey responders and the wider unimmunised population.

5.5.1 Gender

Parents of male and female children were equally distributed in the Phase 1 primary school age group. There were also similar numbers of parents of male and female children in the responding group and the interviewed group for this age group.

In the secondary school age group, whilst the numbers of immunised and unimmunised children in the total population were not significantly different, more parents of female children responded to the survey and were then identified for interview. This difference was not, however, found to be significant ($p=0.31$).

5.5.2 IMD

IMD was identified for the parents who were interviewed. This was plotted and the pattern was found to be different from that of the parents who responded to the survey and from those who agreed to follow-up. For both of these groups a significant relationship was found between IMD and response.

The IMD for parents who were interviewed was more variable across and more similar to that of the Phase 1 unimmunised population as a whole. P value and P value for linear trend were both calculated and were not found to be significant for either age group ($p = 0.33$ and p value for linear trend = 0.08 for the primary age group and $p = 0.10$ and p value for linear trend = 0.62 for the secondary school age group). These parents therefore appear to be more representative of the wider unimmunised population in this respect than either of the responding and agreed to follow-up groups.

5.6 Results of the analysis of the Phase 2 Parental Census Survey

The analysis undertaken in the previous sections compared the demographic characteristics of the child (gender, age, GP, geographic location and therefore MOSAIC Group, IMD and Children's Centre Area) obtained from routine data sources available within the Somerset CHIS. Additional information in respect of the demographic characteristics of the parents was subsequently collected using the Phase 2 Parent Census Survey. Whilst some of this information is the same as that held on the CHIS (e.g. geographic location / MSOA), other information, such as parents' age, occupation, marital status, and smoking status could only be gathered by asking the parents' for this information directly. This additional information provides valuable additional insights to answer the research question:

'What were the social, demographic and geographic characteristics of parents / children who had declined MMR in Somerset after 2009?'

The results of the analysis of this additional, 'parent derived', data is presented in this section.

5.6.1 Demographic characteristics of parents who responded to the Phase 2 survey

5.6.1.1 Gender

Women formed the largest group of respondents with 88% of respondents in the primary school age group and 85% in the secondary school age group; all of whom defined their relationship with the child as being 'mother'. Fathers completed 11% of responses for primary school age and 12% for children of secondary school age. In the secondary school age group 3% of parents either failed to indicate their gender or preferred not to provide this information.

5.6.1.2 Parental age

Previous studies have identified parental age as one of the most significant characteristics of parents who declined MMR (Friedrichs et al, 2006; Bedford et al, 2009), specifically mothers who were aged over 34 years. Parents were therefore asked to give their age as part of the demographic data collected in this survey. In the primary school age group 90 % of respondents were aged over 34 years and in the secondary age group this rose to 97%. However, this is not surprising given the ages of the children (seven – 16 years). The parents' ages were therefore recalculated to identify age at the time the first MMR immunisation was due by taking (parent age – child age) + one year. The rationale for this was that, as these children would have been due their first MMR at 18 months, parents would have been considering whether to accept it after the child was a year old. The average age of these parents at the time MMR was being considered is detailed in Table 5 below:

Age group	Average age: All parents	Males	Females
Primary school age	33.7	35.8	33.4
Secondary school age	33.3	35.7	32.9

Table 5: Average age of parents who responded to the Phase 2 Survey (recalculated)

Mother aged over 34 was not found to be a significant characteristic for either the primary school age group or the secondary school age group.

5.6.1.3 Highest level of education completed

Education level, that is parents (and specifically mothers) who were more highly educated, has been found to be a significant characteristic of parents who declined MMR in previous studies (Reading, Surridge & Adamson, 2004; Cassidy et al, 2006; Hawker et al, 2007).

Of parents responding to this survey, 45% of those with primary school age children and 48% of those with secondary school age children reported their highest level of education to be University / polytechnic degree level (see Figure 16 below).

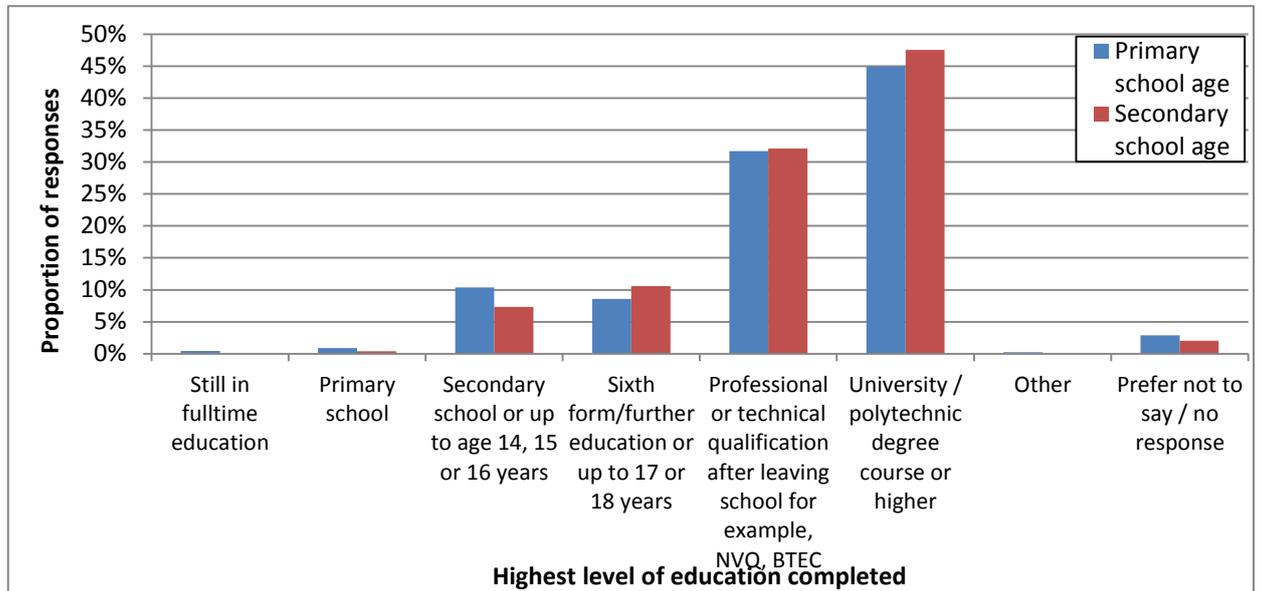


Figure 16: Proportion of survey responders by highest level of education completed and by age group

Data reported from the 2011 Census indicates that 29.7% of people aged 16-34 reported a degree level or above as their highest qualification. However, for the age group 25-34, 40% of people reported having a degree level or above qualification, and under the age of 50 women were more likely to report having a degree or above qualification compared with men (Office for National Statistics, www.ons.gov.uk/ons/rel/census/2011.ce, accessed 28/09/2015). The survey respondents were predominantly women aged 50 years or under, and this therefore needs to be considered when reviewing this data, however, the parents who responded to the survey do therefore appear to be a more highly educated group than the general population.

5.6.1.4 Socio-economic status

The economic status, occupation and National Statistics-Socio Economic Classification (NS-SEC) of the parents responding to the survey were all reviewed. The majority of respondents, 82% of the primary school age group and 77% of the secondary school age group, reported being employed and working as a paid employee, or were self-employed or freelance. Of these, 37% and 38% of the primary and secondary age groups respectively identified their occupation as 'modern professional', with 23 and 17% reporting occupation as 'clerical and intermediate' and seven and 10% as 'senior managers or administrators'. 17% of the parents of the primary school age group and 20% of the secondary school age group reported not being in paid employment, although only 4% of the parents of primary school age children and only 2% of the secondary school age group considered themselves to be unemployed. There was very little variation between the two age groups.

NS-SEC classification is derived from occupation and employment status information and is a nationally and internationally recognised measure of socio-economic status which is used as a predictor of health, educational and many other outcomes (Office of National Statistics, 2015). Occupation is ideally coded to the Standard Occupational Classification (SOC2000) which has 353 unit groups. Coding to this level is very time-consuming and therefore a simpler version of NS-SEC has been developed involving five classifications. This NS-SEC5 version has been shown to be in agreement with the interviewer coded 353 version in 75% of cases and was therefore used here.

Applying this classification, it was confirmed that 56% of parents responding to the survey in both age groups could be classified as 'higher managerial, administrative and professional' – the highest (least deprived) socio-economic category (See Figure 17). In comparison, the percentage of the population in NS-SEC category 1 in England was 10.4% in 2011.

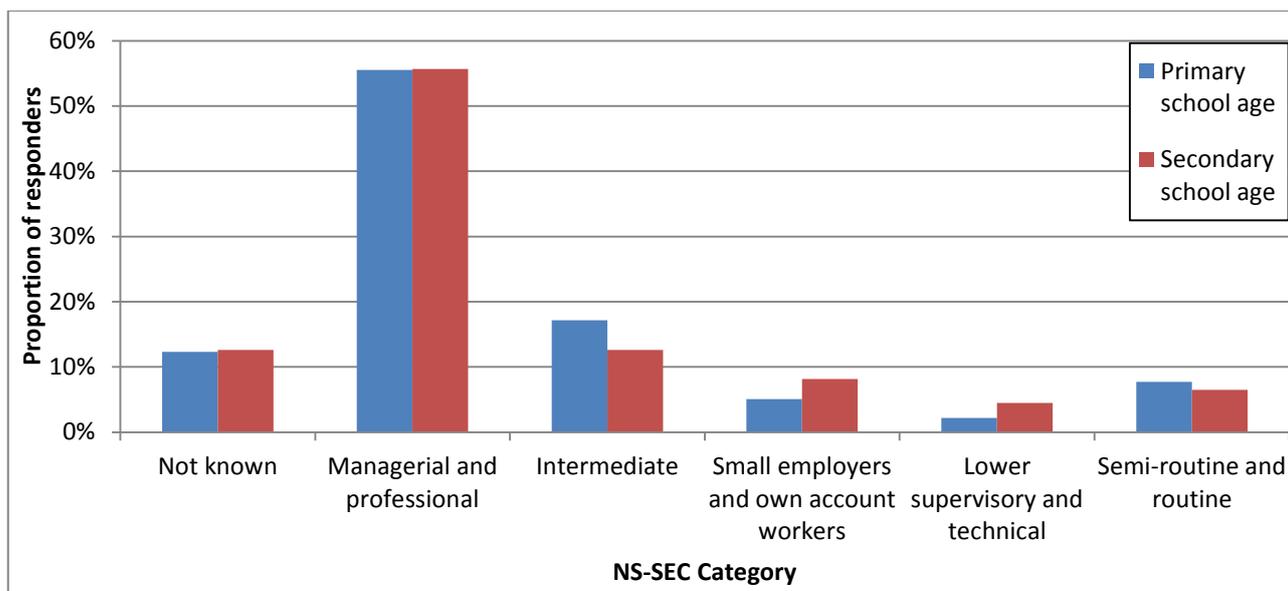


Figure 17: Proportion of responding parents by NS-SEC category and by age group

The South West average was 10.2% and for Somerset 9.3% (ranging from 7.4% in West Somerset to 9.8% in South Somerset and Taunton Deane). The population of survey responders is therefore not representative of either the whole unimmunised or the wider Somerset populations and this must be considered when drawing conclusions from the analysis of the remaining data from this survey.

5.6.1.5 Parents' marital status

Being a single parent has previously been identified as a characteristic of parents who declined MMR (Friedrichs et al, 2006; Bedford et al, 2009). This was not however an observed characteristic of the parents who declined MMR in this study, where 69% of the parents in the primary school age group and 65% in the secondary school age group were found to be married. In comparison, the national archive Census data indicates that the proportion of the UK population who were part of a one family married couple household was 44% and the proportion of the UK population who were part of a one family lone parent household was 11% in 2011, Data for Somerset is in line with this national data, although there are variations by ward.

<http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration>

[13-01-30](#)). See Figure 18 below.

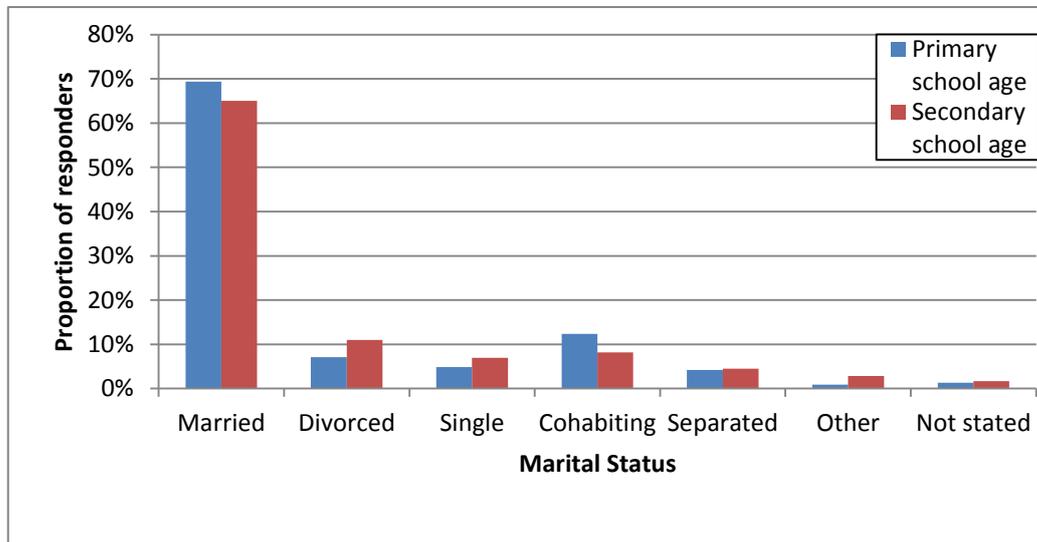


Figure 18: Proportion of responding parents by marital status and by age group

5.6.1.6 Smoking status

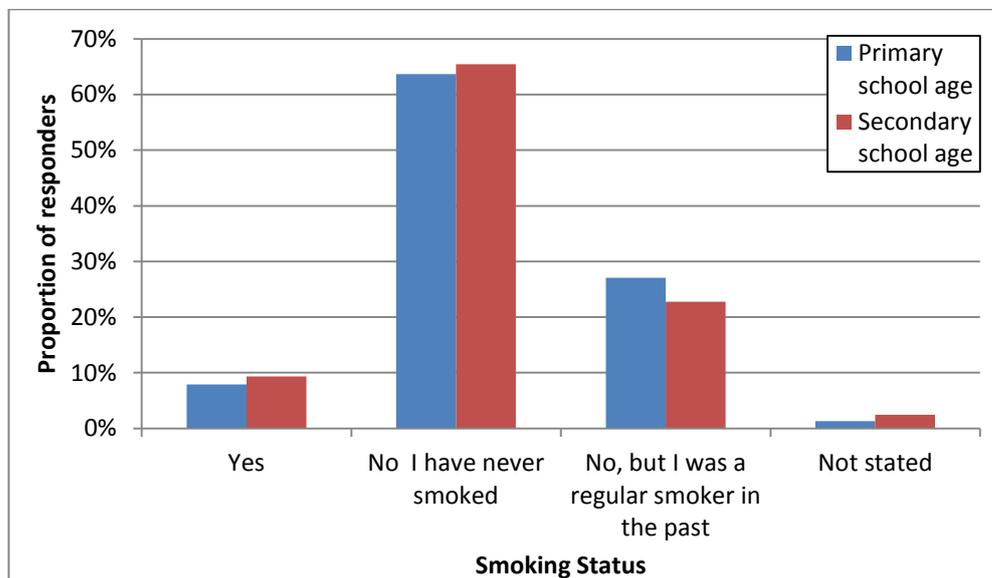


Figure 19: Proportion of parents by smoking status and by age group

Smoking in pregnancy has previously been found to be a characteristic associated with parents who decline immunisations (Bedford et al, 2009). Smoking status of the survey respondents was therefore reviewed (see Figure 19). Whilst smoking did not appear to

be a characteristic of the majority of these parents, it was observed that 27% of parents of the primary school age children and 23% of parents of the secondary school age children reported that they had been regular smokers in the past (and may therefore have been smokers at the time of making the original decisions in respect of MMR). Smoking is also more frequently associated with gender (men) and lower socio-economic status, however, rates of smoking in pregnancy are noted to be higher in Somerset than the England and Wales average (Somerset County Council, 2014). Whilst no associations can be drawn from this data without knowledge of the proportions of parents who smoke in the wider population, the proportion of parents who reported that they are, or were, regular smokers is an unusual observation in a population sub-group comprised of predominantly women of high socio-economic status and may, potentially, be related to higher rates of smoking in pregnancy in this area.

5.6.1.7 Ethnic Group

Somerset is not an ethnically diverse county. 94.6% of the population are 'white British' which is far higher than the England and Wales average (80.5%). The 'white British' population is generally concentrated in and around the principle county towns. 2% of Somerset's residents are from Black Minority Ethnic (BME) groups, which is well below the national average of 14%. There has been a large increase in the number of Polish residents since the accession of the A8 Eastern Europeans to the EU in 2004 and Polish is the most common 'non-UK' ethnicity in Somerset forming 1% of the Somerset population.

The parents who responded to the survey were, however, more ethnically diverse than the Somerset population generally, with only 86% of parents of primary school age responding being 'white British' and 80% of the parents of the secondary school age group being 'white British' (see Figure 20).

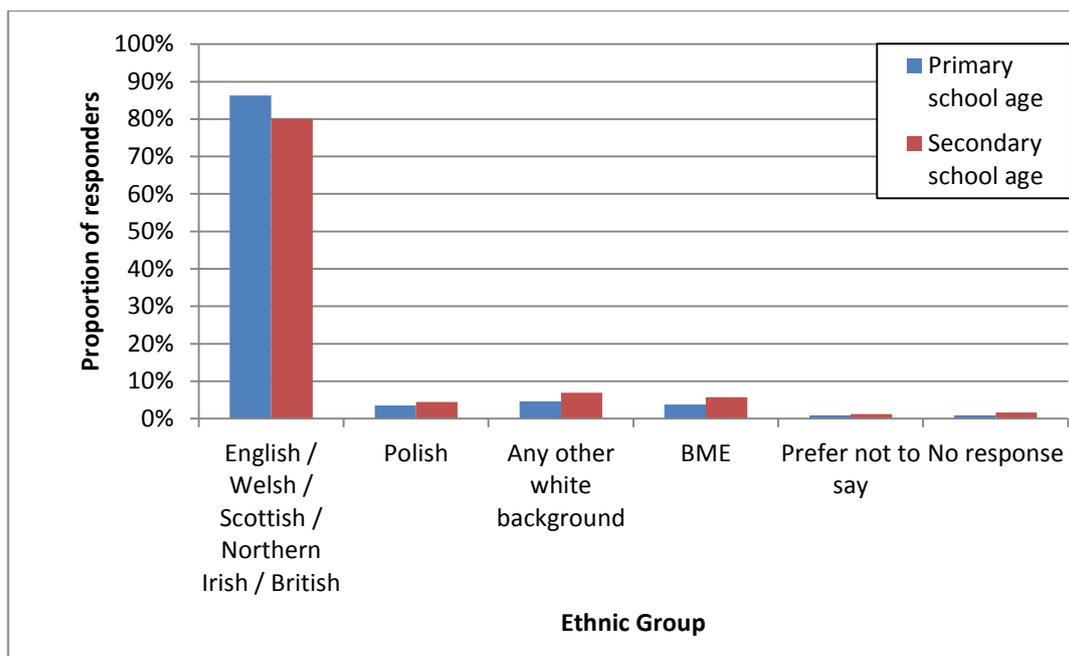


Figure 20: Proportion of Parents responding to the survey by ethnic group and by age group

5.6.2 Investigation of characteristics associated with accepting and declining MMR

The Phase 2 survey also asked parents a number of questions relating to characteristics that had been found to be related to decisions to accept or decline immunisations in previous studies. These included family size, birth order of the child, whether the child had been admitted to hospital before the age of five, and whether other children in the family had been given MMR (Reading, Surrige & Adamson, 2004; Cassiday et al, 2006; Hawker et al, 2007). Parents were also asked about their knowledge of immunisation and MMR and about the sources of information that they accessed, and which they most trusted. These responses are now reviewed and observations in respect of the data described. It should be noted that there is limited potential to draw firm conclusions from some parts of the data, particularly in sections 5.6.2.1 and 5.6.2.2, without access to comparative data to describe the wider

population in Somerset. However, since these characteristics were previously found to be of relevance the descriptions of these observations are included for completeness.

5.6.2.1 Family size

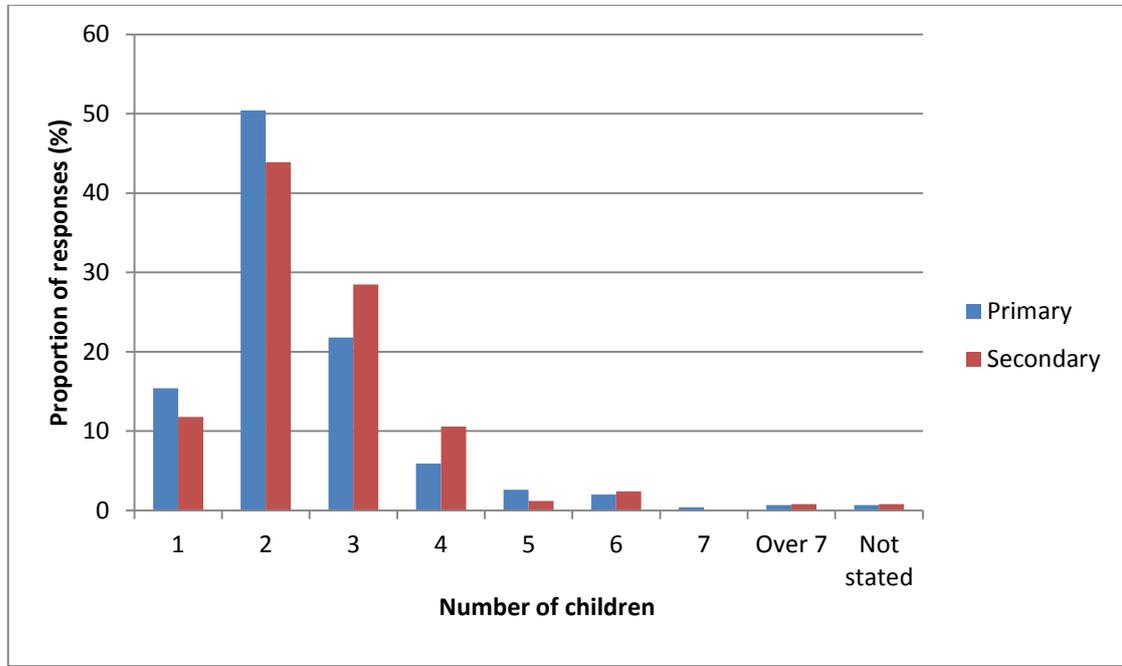


Figure 21: Family size by age group

Both Friedrichs et al (2006) and Bedford et al (2009) identified large family size as a characteristic associated with decline of MMR. In the present study the number of children in the families of parents who responded was similar across both age groups and large family size was not an identified characteristic, with 87.6% of those in the primary school age group and 84.1% in the secondary school age group having 3 children or fewer (see Figure 21).

5.6.2.2 Birth order

There does appear to be a linear relationship between birth order and decline of MMR for this population sub-group, with decline of MMR being more common for first born children in both of the age groups, (49.5% of the unimmunised children being first born

in the primary school age group and 45.9% in the secondary school age group) – see Figure 22.

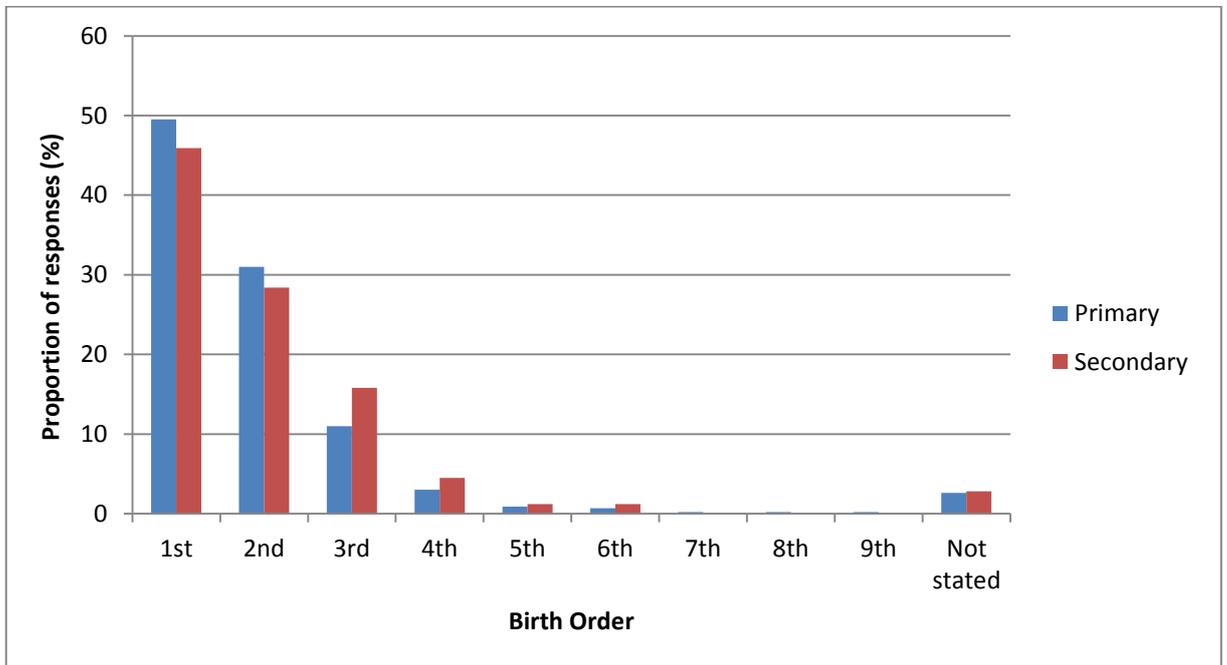


Figure 22: Birth order of the child for which the parent is answering the survey

However, where the parent indicated that they had more than one child it appeared that they did not follow the same decision path for all of their children. 50% of the parents responding in the primary school age group and 58% of the parents of secondary school age children reported that all or some of their other children had had MMR (See Figure 23). This appears to confirm the suggestion that the parents' decision to accept or decline MMR for a child may be a very individual process, related to the specific characteristics and circumstances of that child rather than a generic decision-making process in relation to the vaccine itself, and this requires further investigation.

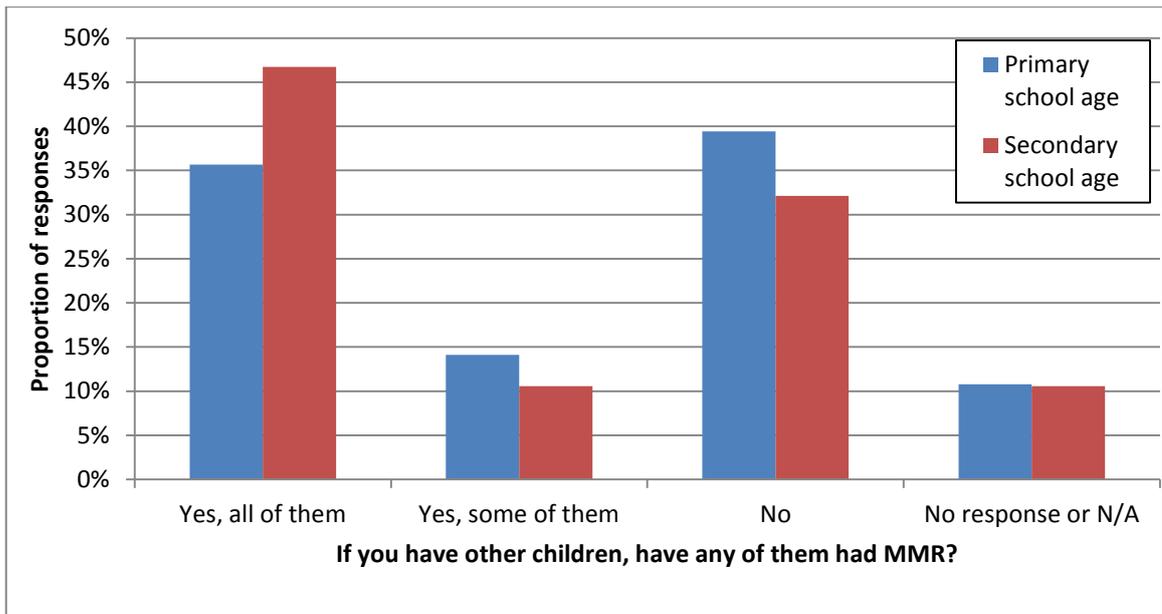


Figure 23: Proportion of parents of unimmunised children accepting MMR for their other children by age group

5.6 2.3 MMR status of the child at the time of the survey in 2012 – reasons given for accepting or continuing to decline the offer

Parents were asked whether the child that they were responding about in the survey had now had MMR. 27% of the parents of primary school age children and 36% of the parents of secondary school age children reported that their child had now had MMR, which suggests that these parents had changed their mind and accepted the offer at some point after the 2009 catch-up campaign.

The parents who had accepted MMR for their children were then asked to provide reasons for now accepting MMR. These reasons are detailed in Figure 24. The most frequent reasons were, firstly, the child being older, second, that they had new information and, thirdly, 'being worried about measles'. The pattern of responses was similar across both age groups.

Parents who reported that their children had still not had MMR were asked to indicate the reasons for continuing to decline the offer of MMR. Whilst a range of options were provided, the most frequent reason given was 'other', followed by 'risk of side effects outweighs the benefits' and 'know of children with problems following vaccination' for both age groups. Where parents ticked 'other' they were asked to add reason in free text. Examination of these responses identified that 35 of the 217 responses for primary school age children (16%) gave 'had MMR in 2009'. In these cases the parents had assumed one dose was a full course, but the CHIS continued to flag as unimmunised as the complete course requires two doses of MMR. 139 of the 217 children (64%) had had single vaccines and the parents considered them fully protected, and 7 (3%) parents reported that their child had had MMR abroad. Of the parents of primary school children who had indicated that they continued to decline MMR for 'other' reasons 83% had therefore declined because they had actually already accepted some form of vaccination for their children.

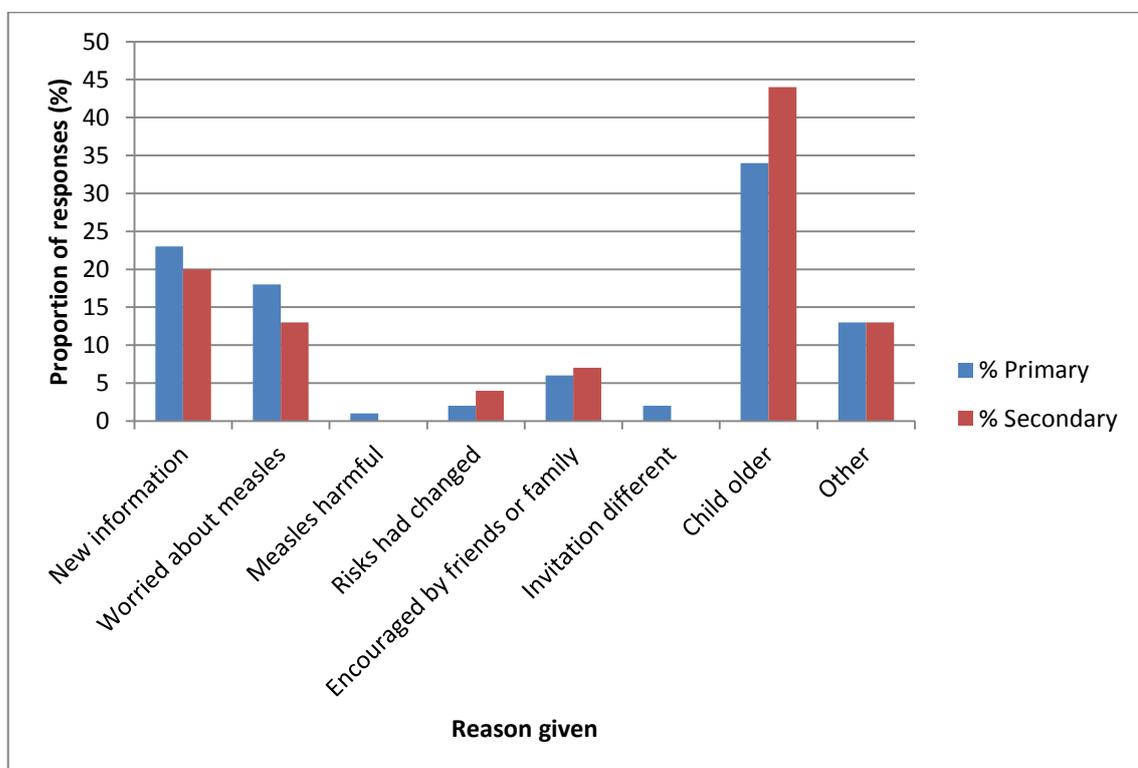


Figure 24: Reasons given by parents for accepting MMR after 2009 by age group

This pattern was similar in the secondary school age group, with 43 of the 95 parents (45.2%) indicating that their child had had MMR1, nine (9.5%) reporting the child had had single vaccines, and 10 (10.5%) that they had had MMR abroad. In this age group 65.2% of those declining for 'other' reasons had done so because they had already accepted some form of vaccination (see Figure 25).

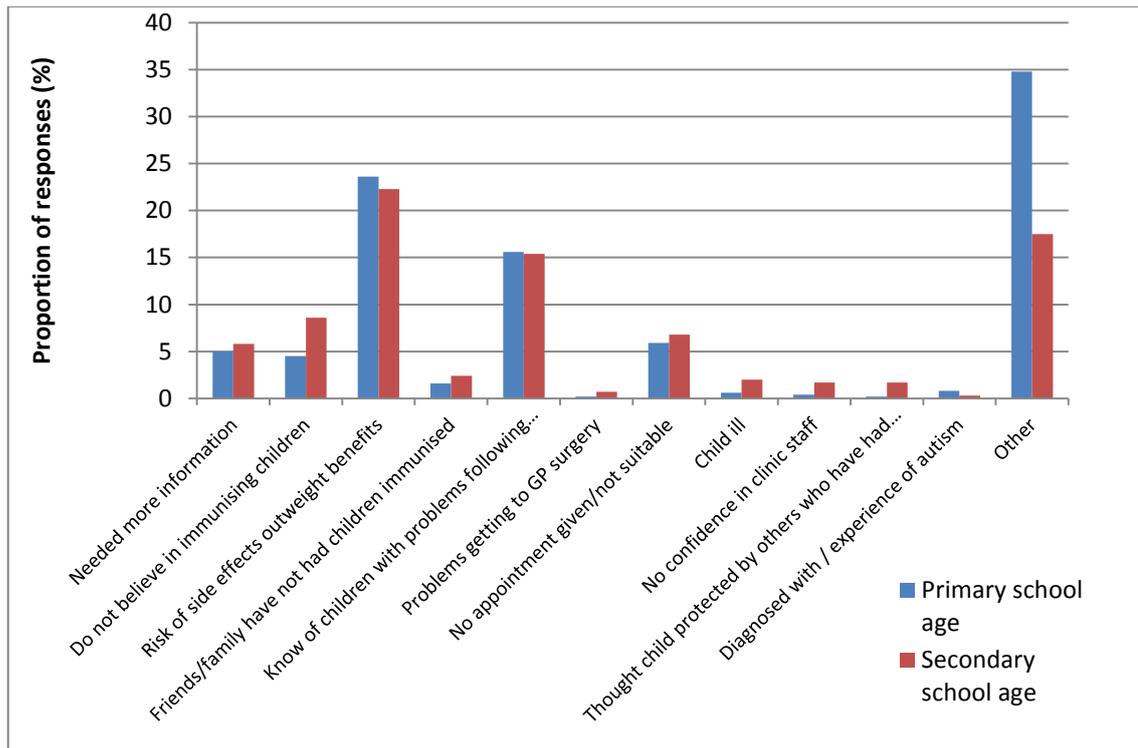


Figure 25: Reasons given by parents for continuing to decline MMR by age group

5.6.2.4 Parents' knowledge of immunisation and MMR

Parents' limited knowledge of immunisation and MMR has been suggested as a potential reason for declining MMR. In this survey, 93% of parents of primary school children and 86% of parents of secondary school children believed that they were fully informed or had some knowledge on which to base their decision to accept or decline the offer of MMR for their child and as such suggests that they believed that they were making an 'informed choice'.

Parents obtained their information about immunisation from a range of sources which followed a similar pattern for both age groups. The most frequently reported sources for both groups were GP and the internet, followed by the media and Health Visitors.

However, when asked which sources of information were trusted by them to be most accurate, parents of children in both age groups reported the most trusted source to be the GP (See Figure 26).

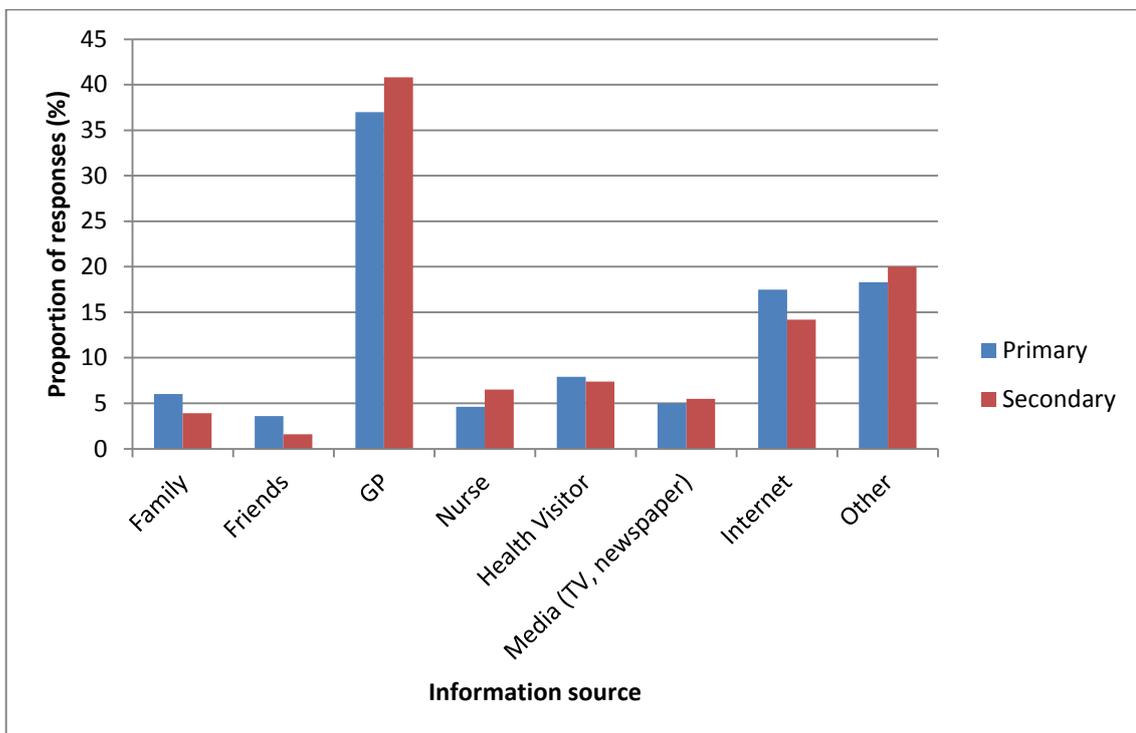


Figure 26: Most trusted sources of information about immunisation / MMR by age group

5.6.3 Relevance and impact of school rather than home address

Somerset has a large number of Independent Day and Boarding Schools and is recognised as a net importer of children into the county (Somerset County Council, 2010). If the parents of children at these schools responded to the questionnaire and provided a home address, the home postcode was used to assign MSOA, deprivation

quintile, Mosaic Group and Child Centre Area. If not, they were categorised as 'Unknown'.

There were 335 children with a school address (Boarding school), of which eight were in the immunised groups (and therefore not sent a questionnaire) and 327 were in the unimmunised groups. Unimmunised children formed 8.6% of the total population of children with no MMR or Partial MMR, but only 26 parents of these children returned a questionnaire, with only two of the responding parents of primary school age children and seven parents of secondary school age children providing a home address and postcode. The high number of parents who were not able to be contacted because of this situation may also have acted to distort the survey respondent population subgroup in addition to reducing the response rate.

The relatively high number of children in this category and low response rate from this group may reflect the fact that many of these children and young people are international students (or children whose parents are in the Armed Services) and therefore are unlikely to have been able to have been easily contacted by the schools to complete the survey. The number who did not have a complete history of MMR immunisation may also reflect either true low uptake, or poor collection of immunisation history by the schools on admission, or poor transfer of information from the schools to the CHIS. This group is significant because there is greater potential for outbreaks of infection where there are susceptible populations living in institutional settings, such as a boarding school. In addition, there is potential for wider spread beyond the school into the wider community because of the combination of Day and Boarding pupils attending these settings. Further detailed investigation of this group of children is therefore required.

5.7 Summary of findings from the analysis of the Phase 1 and Phase 2 data

5.7.1 Demographic and geographic characteristics of immunised and unimmunised parents / children

The analysis of the Phase 1 and Phase 2 demographic and geographic data identified that there was a relationship between parental decisions to decline MMR and MSOA, MOSAIC Group and GP practice and therefore differences in the socio-demographic and geographic characteristics of parents / children who had accepted and declined MMR.

The different patterns observed for each of the two age groups in relation to geography / MSOA, suggests that parents of the unimmunised secondary school age children may be more aligned with traditional persistent decliners of immunisation, whilst those of primary school age are temporally associated with the Wakefield controversy and this may explain the more diverse spread across the geographical populations.

Whilst there are some similarities between the age groups in terms of MOSAIC groups, there were a considerably higher proportion of Group D types (successful professionals in semi-rural areas) in the primary school age group. This is also in line with previous findings that refusal of MMR post-Wakefield was most associated with more highly educated / professional population groups (Friedrichs et al, 2006; Bedford et al, 2009).

The most significant characteristic that was associated with parental decline of MMR in Phase 1 was the GP practice that the child was registered with (p value = 0.00002) and there is evidence to suggest that this may not be entirely related to area of residence.

In terms of the parents who responded to the survey, these differed from the wider unimmunised (Phase 1) population in a number of ways. The MSOA pattern was considerably different for secondary school aged children, being far more dispersed across Somerset, and with relatively low responses from parents in Mendip (Glastonbury, Street and Frome). In relation to Children's Centre Areas and registered GP practice, there were some interesting outliers in the wider Phase 1 unimmunised group, but no apparent corresponding association for those who responded to the survey.

However, whilst tests of statistical significance were not performed, the IMD data indicate that there were a greater number of parents in Quintile 5, least deprived, in the responding group than in the wider unimmunised group, and there were very few survey responses from those in the least deprived groups. This finding is not surprising given that these groups are likely to be more literate and articulate and are therefore far more likely to respond to surveys, but it did suggest that the survey responders may not be fully representative of the unimmunised groups and should therefore be considered as a sub-group of the wider unimmunised population.

Finally, parents who were interviewed appeared to be far more representative of the wider unimmunised population as a whole than the 'Agreed to follow-up' or the 'Survey Responder' group. MOSAIC data also indicated that the 'Agreed to follow-up' group had a far higher proportion of Group O (families in low rise social housing with high levels of benefit need) for both age groups. Given that there were no parents from some of the most economically deprived communities in Somerset (Halcon, Sydenham and Lyngford) in the 'Agreed to follow-up group' and very few in the survey responder group, this potentially suggests dependence on benefits for another reason, which may be related to disability or ill-health. These are factors which have in other studies also been linked to lower adherence to immunisation schedules (Friedrichs et al, 2006).

5.7.2 Summary of findings from the analysis of the Phase 2 Parental Census

Survey

The results of the Parent Census Survey should be viewed with caution for two reasons. Firstly, the response rate for both age groups was low and, secondly, there is evidence to suggest that the survey sample is skewed (with respondents having higher socio-economic status and educational attainment) and may not therefore be representative of the wider population of unimmunised children in Somerset. In addition, tests for statistical significance have not been performed on all of the data and the findings therefore need to be viewed with these caveats in mind.

The characteristics of parents / children who declined MMR were found to be similar to those reported in previous studies in respect of:

Higher parental educational attainment level

Higher socio-economic status

Higher levels / history of maternal smoking (and therefore potentially higher levels of smoking in pregnancy)

Birth order (with first children being more likely to be unimmunised)

History of the child having been admitted to hospital before age five years

The characteristics of this study population differed from those previously reported in respect of:

Parental age (these mothers were not older / aged over 34 years)

Marital status (the majority of parents in both age groups were married with very few single parents)

Family size (most families were not large, the majority in both groups having three or fewer children)

Parents' self-reported knowledge of immunisation / MMR was either 'fully informed' or 'some knowledge' and there was evidence of parents' accessing multiple sources to gain a more balanced range of information. Parents' most frequently accessed source continued to be health professionals and health professionals (particularly GPs) were the source that was most trusted.

A final finding was that almost a quarter of parents in both age groups reported that their child had now had a full course of MMR. In addition, where parents' had reported that their child had not had MMR since 2009, the reason frequently cited was that they had had a vaccine (either MMR or single antigen vaccines) prior to 2009. Although many of these children continued to have incomplete vaccination this mean that far more children have received a measles-containing vaccine and population protection levels are therefore considerably higher than is officially recorded. This finding also implies that many parents who are labelled as 'persistent decliners' are not anti-vaccination per se and this requires further investigation.

5.7.3 Conclusion

In summary, the results of the analysis of the Phase 1 and Phase 2 categoric data suggest that there are differences in the social, demographic and geographic characteristics of children / parents who accept and those who decline the offer of MMR in Somerset. In addition, there also appear to be differences in the characteristics of the parents / children within and between the two age groups studied. The population of parents / children who decline MMR therefore appears not to be a single homogenous group and these differing characteristics have the potential to result in different influences on, and mechanisms for, parental decision-making.

The results of this analysis, and the characteristics identified, were used to inform the development of the semi-structured questionnaire topic guide and the initial coding

framework which underpinned the analysis of the Phase 3 qualitative data. The results of the analysis of this final process of analysis are presented in the next chapter.

CHAPTER 6 PRESENTATION OF THE RESULTS OF THE ANALYSIS OF THE PHASE 2 PARENT CENSUS SURVEY AND PHASE 3 SEMI-STRUCTURED INTERVIEWS

6.1 Introduction

This chapter presents the results of the thematic analysis of the qualitative data gathered during Phases 2 and 3 of the present study. Nine themes emerged from this analysis, which appeared to underpin the thinking of the parents when making decisions about MMR for their unimmunised children. These themes were as follows:

Risk of disease vs vaccination

Vaccine overload

Media

Single vaccines

Other medical comorbidities

More support needed from professionals

Medical models and health

Natural health / holistic approaches

Parents' choice

Further exploration of these themes, and of the commonalities, differences and relationships forming linkages between them, resulted in the identification of three parent sub-groups within the unimmunised population studied:

Parents with a natural / holistic approach to health

Parents of children who had existing medical comorbidities

Parents who had obtained single vaccines

These parents were able to articulate detailed rationales for the decisions they made. However, they differed from each other in the way that these rationales linked to both their personal experiences and to their social, political and cultural perspectives. The parent sub-groups were also found to be linked to different outcomes in relation to the likelihood of accepting MMR and the potential triggers which would encourage them to do so.

The information presented in this chapter is structured as follows: Section 6.2 provides an overview of the development of the nine themes; these themes are then explored in detail in section 6.3. Section 6.4 provides detail on the identification of the three parent sub-groups and the development of a parent sub-group framework. Section 6.5 considers the generalisability of these findings in relation to the sampling strategy and in respect of participant feedback.

The implications of the findings and the development of a theoretical proposition for delivering a pluralist approach to parent engagement within immunisation services to accommodate these differing needs in practice will be explored in Chapter 7.

6.1.1 Demographics of the interview subjects

Throughout this chapter quotes from participants are used as a primary source of evidence to support the author's interpretation of the raw data and to provide specific examples of relevance to illustrate the theme being explored. The characteristics of the 20 interview subjects can be found in Appendix 12. In addition a label has been applied to provide the reader with an outline of key demographic details of the participants for each quote used. The following examples provide detail of how these labels should be interpreted:

(Interview 1, M, 46, P, Y) = Interview Participant no. 1, male, aged 46, child in primary school age group, has had MMR now.

(Interview 2, F, 37, S, N (S)) = Interview Participant no. 2, female, aged 37, child in secondary school age group, had not had MMR (had single vaccines).

6.2 Development of the themes

Exploration of the existing evidence in Chapter 3 and the quantitative data in Chapter 5 provided a number of characteristics of and issues of potential significance to parents of children who had not accepted the offer of MMR. This information resulted in potential answers to the research questions exploring the 'what' (what are the characteristics of parents / children) but not to the remaining research questions that were attempting to answer 'why' these were of relevance and 'how' this then impacted on the decision-making of these parents. Review of the qualitative data in this chapter aims to provide evidence to fill some of these knowledge gaps through the identification and description of major themes within the data, the assessment of the relative importance of these themes, and their linkages to one another. This section describes the process of how the nine themes were identified and developed.

The free text comments derived from Section 5 of the Phase 2 Parent Census Survey were read very carefully and then meaningful units of text relevant to the research topic were coded. The text was read and reread and the codes were reviewed and refined. This process confirmed that the codes were robust and could be used to provide an initial 'scaffold' upon which the coding framework was developed.

The analysis then progressed to a more iterative and descriptive process. The codes were refined again and units of text dealing with the same issue were grouped in

analytic categories and given provisional definitions. A substantive analysis of the entire content of each of the interview transcripts was then completed using these categories or 'codes', to determine the level of literal or theoretical replication across the transcripts and data sources. The data were systematically reviewed to ensure that a name, definition, and exhaustive set of data to support each category were identified.

This process of relooking at and refining the codes was repeated several times in order to look at the overall pattern of discourse and observations to see if the analysis provided evidence to support the my initial perceptions of the importance of these codes. Coding categories were added to, modified, reviewed, grouped and then regrouped into parent and child nodes, reordered and refined as all data sources were reread, and coding checked and revisited.

This inductive thematic analysis resulted in 55 categories, which were grouped in to nine key themes (see Appendix 13 for a full list of categories and themes). The coherence and replicability of the themes was established by a second person (the Somerset PCT Head of Health Intelligence) independently coding the Section 5 survey comments, a process which resulted in a high level of agreement and inter-rater reliability.

Throughout the analysis Nvivo10 software was also used to record personal notes and memos. Previous authors have described this as theorising about ideas from codes and their relationships in order to allow the analysis to build from the conceptual level towards an integrated understanding of the data and the development of propositions (Miles and Huberman, 1994; Docherty, 2010).

Within applied thematic analysis, as described by Guest et al (2012), the emphasis is on empirical investigation of the way in which meaningful elements or codes are

combined to generate thematic or explanatory models. A number of deductive techniques were used to enhance this process, to aid the development of themes, and to generate more detail for each of these. This included the use of word searches, key words in context, coded content, word frequency, frequency of coding references, sources and nodes clustered by word similarity, coding by item, and investigation of the nodes by number of items coded. This information was used to help to explore what I considered the meaning of the data to be, what specific instances of these meanings existed within the text, and whether there were any patterns of relationships amongst these instances of meanings within the text being investigated. In addition, the information obtained from the use of these techniques enabled each of the themes to be reviewed in detail and an assessment of the relative importance of each theme to be completed. Examples of the outputs from these analytical processes are provided in Appendix 14.

The following sections detail the findings, perceptions and selected quotes in relation to this process of analysis. However, it is important to state that the numbers within the study were small and the participants were also self-selecting and this may limit the strength of some of the findings.

6.3 Results of the analysis - the themes in detail

This section provides detailed results of the analysis of the qualitative data by theme. To aid readability, the categories of each theme are presented followed by the number of references relating to each category in brackets.

6.3.1 Risk of disease vs risks of vaccination

The most significant theme that arose in this study related to risk, specifically the parents' assessment of the relative risk of accepting or declining MMR, and how this

assessment differed from those of public health professionals and policy makers. The theme was directly referenced by all of the 20 interviewees and by 105 survey respondents (448 references in total). In addition, the theme generated four memos (autism vs death; perceived risks and guilt; how vaccines work; and health professional as parents and risk).

6.3.1.1 Autism

Risk naturally included references to the potential link that had been made with autism (108), which is to be expected given the media attention at the time many of these children were originally being offered MMR. However, whilst most parents confirmed that they were aware of the Wakefield study (Wakefield et al, 1998) and had seen media coverage at the time, no single, universal parent reaction was identified and this risk was not cited as the key influencing factor, even among those parents who had completely declined vaccination. In fact, several of the references clearly reiterated that the parent did not believe that there was any link with autism. What the parents did suggest was that media interest had raised an element of doubt for them and it was this that had acted as a catalyst for them to investigate risks associated with immunisation in general:

'I did an awful lot of research...I wasn't focussed particularly on this study but it prompted me to think 'So now I'm gonna look into it', and actually it was the other things that worried me more' (Interview 14, F, 36, P, Y)

Whilst it is not cited as a key influencing factor in ultimately deciding to accept or decline MMR, there is evidence that autism does appear to be intimately bound up with parents' value judgements on what constitutes a worthwhile life for their child, and may therefore have had an impact on assessment of risk in ways that many conditions might not have done:

'well, there's different ranges of autism...I saw that as more of a lifelong risk for him and, you know, mumps...you can become sterile, measles you can be blind, you can become deaf...but that...you can overcome those to a certain extent. With autism, whatever part of the scale you are on, that's quite devastating'

(Interview 19, M, 49, P, N).

The stigma associated with social and mental disorders (as referenced in Chapter 3) was also found to be significant:

'Well you shouldn't do, but you feel sorry for somebody...you have more sympathy for people who are blind and deaf rather than those who have behavioural and attention problems, you know?' (Interview 1, F, 38, P, N)

Serious illnesses therefore appear preferable to autism because people with autism are considered by these parents to 'have no quality of life' (Interview 14, F, 36, P, Y) and because autism is considered by them to be 'far worse than death (Interview 1, F, 38, P, N (S)). These observations were not, however, made in abstract. Many of the parents made reference to personal experience of autism and / or to parents' accounts of children changing after they had received MMR:

'And I think probably had we not known somebody personally [who had autism], maybe our decision might have been different. But because we knew somebody personally, that it could have been an effect of MMR; we went the other way really...' (Interview 2, F, 45, S, Y)

Many of the participants interviewed subscribed to the notion described in Chapter 3, that autism may be linked to particular vulnerabilities, whether genetic or associated with the child's immune system response or history. Its development was not

considered inevitable, but a predisposition which could be influenced positively or negatively by biological and environmental factors that the child was exposed to:

'No, and I actually don't have any issues with the MMR causing autism. Because I don't believe that the MMR vaccine causes autism. It might be the last stress for that child – that tripped them into that picture, but it wasn't, you know, the cause of it.'

(Interview 3, F, 42, P, N)

There was considerable evidence therefore that parents reflected on potential factors associated with their own child's vulnerability, or family history, and then factored this in to the decision-making process:

'And [child]...he's always been one that'll run a very fine line and, you know, could that have just swayed him the other way and pushed him the other way to make him autistic, Aspergers or whatever, something like that, who knows? So I think that was the decision really.'

(Interview 8, F, 44, P, N)

Many of the parents interviewed for this study acknowledged that they had had pre-existing doubts about their own child's development, to a sufficient degree that this was what had initially prompted them not to have the MMR. They also provided credible explanations for these doubts, most commonly family history. However, their responses also suggested that, had they accepted the vaccine, any appearance of the disorder would, nevertheless, have been fully attributed to MMR and the contribution of these underlying concerns would have been retrospectively minimised. There was no consideration that this may have been exactly the same for parents in a similar situation who had accepted MMR, and whose retrospective accounts had so influenced their own perceptions of causation.

The evidence reviewed here suggests that the possibility of risks associated with autism whilst reported as not being the only, or most important, factor influencing these parents', did still have a considerable impact on how they behaved in terms of their decision-making. There is, however, evidence that previous decisions made on this basis can be altered over time by the reframing of the respective risks. For example:

'There was all this stuff about measles and people saying about how parents were putting children at risk by not having the MMR...I thought, well ok I'm still not sure it's ok, and I knew I'd feel bad if it goes wrong, but I'll get it done because they're now saying its bad not to have it more than about the autism stuff... so I'll do as they say...'

(Interview 10, F, 49, P, Y)

6.3.1.2 Knowledge of the diseases, the immune system and how vaccines work

A significant body of the professional and policy-based evidence reviewed in Chapter 3 concluded that vaccine refusal is, in large part, the result of poor levels of public understanding of how vaccines and the immune system work (Elliman et al, 2001). This lack of understanding, they argue, subsequently fosters a more irrational and emotionally driven approach to the assessment of risk, which is further compounded by the lack of knowledge of the complications these childhood diseases may cause because parents now rarely experience them. The main issue for professionals and policy makers therefore becomes the rebalancing of these knowledge 'deficits' to enable more effective estimations of risk and benefit to occur. (Bedford and Elliman, 1998).

Survey respondents and interview subjects did provide evidence (26 references) to support these conclusions, or at least the assumptions that some parents do consider that having more information about the diseases would have been of value:

I was aware that there were side effects with vaccinations. I didn't look, so I was, sort of feeling I ought to look into it more...in terms of the risks of the diseases, you know I'd had all these illnesses when I was a child so I don't think I was quite so aware of how dangerous they could be. I didn't understand quite how dangerous measles could be.' (Interview 16, F, 52, S, N)

Parents also highlighted the importance of being supported to be able to digest and explore this information as being equally as important in making their decisions:

'Maybe I could have talked about it and, you know, been more informed myself rather than just having the information sent to me, had time to do a bit of other....looking into it which is what I subsequently did, and then came to the conclusion that actually, you know, I was perhaps jeopardising her by not doing it'. (Interview 2, F, 45, S, Y)

These parents were however in the minority. Most parents in this study emphasised that they believed that they had sufficient knowledge both of the diseases and of how the immune system works when they made their decisions. However, many also acknowledged that their knowledge of the immune system rarely exceeded an understanding of basic principles. For example:

'I know obviously they are injected with a mild dose of whatever it is and it builds up their immune system and therefore hopefully they don't get it at all, or they may have a very mild version that they can deal with themselves.'(Interview 7, F, 41, P, Y)

The human immune system involves highly complex, multifactorial chemical and biological processes. Whilst the basic principles can be readily articulated, as above, understanding of the very complex interactions associated with the various elements of the system requires a highly technical level of knowledge. Whilst the majority of

parents for whom this was a concern reported that they were educated to degree or technical / professional level, this did not mean that they were educated to this level in science. In fact, for most their knowledge of science rarely extended beyond school or GCSE level. This therefore frequently renders much of the information on immunology inaccessible or incomprehensible for most members of the public.

In comparison, groups and individuals who oppose the use of immunisation in general, and / or MMR specifically, often use arguments which are underpinned by simplified scientific arguments which align with the basic principles and educational level that appear to be well understood by parents. These authors frequently use elements of both scientific methodology and language to ground their arguments, turning professional information and advice back on itself. For example, if the vaccine 'kicks the immune system into gear', it does not seem unreasonable to argue that too much might kick it into overdrive, or might allow a disease to run wild, or for it to have unexpected results. Similarly, the science and evidence base surrounding public health suffers from the fact that interventions necessarily relate to populations, rather than individuals. This then results in data which can be interpreted in many different ways and may not always appear to relate to the highly personalised, individual situations that parents find themselves in.

Parents are aware of this, but the fact that they have a level of knowledge that enables them to engage, but not necessarily to challenge the detail of these opposing arguments, results in widespread concern about the validity of any available information source:

'But you know if you look at the research it seems to me that you know you can make, well you can make statistics look however you want them to look I suppose depending on how you present it.' (Interview 5, M, 47, S, N)

Many parents reported extensive, multi-source research when seeking information on immunisation and its potential side-effects. However, their knowledge of the diseases themselves appeared to be gained almost entirely from experiential sources. Parents talked with their families, their neighbours and other members of their communities and drew on these experiences to make sense of these issues. How parents then considered the various issues associated with the vaccination of their children was, to a large extent, shaped by these social interactions, combined with any direct personal experience. This process appeared to strongly influence the parent's current decision-making process:

'I mean I talked about it with my Mum, um, and of course in my Mum's generation they weren't vaccinated for any of those, you know, if she got measles ...they just took a chance and I thought, well that's what I'll do too'. (Interview 9, F, 39, P, N)

Immunisation against many of the most prevalent childhood diseases only became possible in the latter half of the 20th century, and prior to this, deaths and serious illness as a result of these infections were not uncommon. Being commonplace, however, means that many people also recall only suffering mild disease and had subsequently recovered without any long term consequences:

'I know when my parents were younger there was none of this and children got measles you know, and I know horrendous things can happen from it, but it's, I don't know, it's one of those flip things isn't it – you know horrendous things can happen from it but you know children do come through it safely, and if you go back to the 50's then it was a matter of routine. I mean I can remember my mother saying that if someone in her street had measles everybody was in the house to get it to get it over with' (Interview 4, F, 44, P, N)

Grandparents, and older family members or carers, had their own experiences of parenting at a time when there was generally greater acceptance of scientific explanations and also greater deference towards health professionals and childcare experts. It might therefore be expected that they would align themselves more with the authority of the state, and be more willing to accept the positive value of MMR. But this does not seem to be the case.

Whilst older family members will have experienced the first successes that followed the advent of mass immunisation programmes in the UK, such as the eradication of smallpox and the elimination of polio, they will have also experienced first-hand previous medical controversies and adverse medical events (e.g. thalidomide and pertussis). Conversely, the threat of disease, in an age where medicine now offers considerable improvements in treatment and care, alters the recall of the experience of communicable disease, and renders the perception of any consequences mild in comparison. In addition, autism and Asperger's Syndrome were not widely used as diagnostic terms until the 1980's and 90's. This means that grandparents will not have been familiar with the term when they were parenting themselves and will regard it as a new disorder rather than an old one which is now more easily identified, and the apparent rapid increase in diagnosed cases of a supposedly new disease has potential to create fear and concern, especially if linked to previous medical controversies to which parents and grandparents can relate.

Grandparents and older carers were reported by the participants to have had significant influence on parents' decisions to decline, even where there was little day-to-day contact with the child. Examples of these influences included actively voicing their concerns to parents, sending information and articles, and, most significantly offering material payments to fund alternative immunisations or treatments. The latter

was often reported to be the final deciding factor for parents in this study who opted for single vaccines.

Finally, first-hand or shared knowledge of the potentially serious complications of infectious diseases does not necessarily appear to create the same fear, or to result in parents accepting or following the authorised schedule because ironically, there is a belief that, because medical science has progressed since they were children, it will now be able to resolve any problems arising from these infections:

'And I think because medical science has moved on that much and there's so, you know, there's so many things that can be cured, we almost expect it just to be sorted'.

(Interview 4, F, 44, P, N)

6.3.1.3 Adverse events after immunisation

Whilst mention of the issue of autism was common to many parents, a much smaller number of the interviewees (seven) and survey respondents (26) reported that they had made their decisions based on more general experience of adverse events occurring after immunisation. For some these were not recent events, but involved recall of historical events that had occurred many years before or to wider family members:

I can remember (my niece) having her jab and afterwards she was quite ill...and, um, I can remember being actually quite frightened because she had this really sort of glazed look in her eyes...and I thought "Oh my gosh, this is it"...and I mean, you know, she has got better and she was absolutely fine but, you know, I thought, "Crikey, if this is what it does to you..." (Interview 6, F, 50, S, Y)

Experiences such as these were used as evidence to support the notion, that whilst immunisation was considered generally safe, it had to be acknowledged that there could be serious negative consequences and things could sometimes go wrong. There was a strong feeling that health professionals, at pains to promote vaccination, sometimes underplayed these risks and when they occurred, the unexpected nature of the event added to the suspicion that something was being hidden:

'I mean it could have been coincidence, you know, that's what they said happened to them. But on the other hand I know plenty of people who've you know had problems, I mean most people don't. You don't always see any outward signs of, you know, vaccine damage, I guess.' (Interview 5, M, 47, S, N(S))

Concerns relating to family history were frequently translated beyond the individual, to general familial vulnerabilities, and likewise to potential vulnerabilities to all, or other vaccinations. Such a fear, based on some form of personal experience, however distant, is perfectly natural, even if illogical, and does impact on levels of confidence in the somewhat impersonal, population-based presentation of risk that currently predominates within health protection risk communications.

This confidence is further shaken where individuals also recall experience of the fallibility of health professionals or the systems within they work:

'Cause I mean I remember them saying back then, the live vaccine they reckon that's what caused most of the polio, was a child taking the live vaccine. Yeah, and the guy he developed it, he well, apparently it was the same, he made a mistake' (Interview 5, M, 47, S, N(S))

'[Child] had a very strong reaction to the polio vaccination. The doctor's response was that this had not happened because no-one had ever reported it before – so he wasn't going to report it.' (Survey Response Ref 6, F, 37, S, N)

These concerns further reinforce the findings of the previous section – that parents appear to evaluate the perceived dangers of MMR, not in general terms, but in relation to their individual assessment of the child's particular vulnerability to any adverse effects of the vaccine. However, the evidence examined in this study suggests that this view is also influenced by family history and the parent's own experience of being vaccinated, and that these factors are highly relevant in a parent's assessment of the possible risks associated with accepting MMR and other vaccines.

6.3.1.4 Health professional and professionally trained parents and assessment of risk

There is an assumption in much of the existing literature that an individual's social and professional roles can be to some extent compartmentalised (with all health professionals, for example, being expected to be willing and able to be acceptors of and accurate disseminators of national immunisation advice) (Leach & Fairhead, 2007; Leask et al, 2012). Indeed, the recommendations from many studies habitually return to the issue of addressing professional concerns by simply suggesting that the educational knowledge base of these individuals needs to be improved (Smailbegovic et al, 2003; Wood-Harper, 2005; Leask et al, 2006).

However, what became clear in this study was that professionals social roles as parents, grandparents, uncles and aunts are highly significant. They are part of the communities that are debating these controversies and concerns, they are subject to the same social and political interactions as other parents, they have vested interests and they harbour similar doubts. They have access to a wider range and complexity of

information sources and they are expected (as part of both their professional and lay roles) to accept, understand and disseminate this information to others, but they also often experience considerable conflict within and between these multiple social roles and do not always act in the way that is expected of a health professional.

Four of the 20 interview subjects identified themselves as health professionals, and most were in highly influential positions. None of these participants were prepared to accept MMR and two had refused all immunisations for their children. The reasons given either mirrored those of their contemporaries, in relation to risk, or were a further extension of those rationales that had used elements of scientific evidence and professional experience to build apparently evidence based, but factually incomplete or incorrect, arguments. For example:

'I was concerned about the whole idea of vaccination programmes when I read about it, and I've got a nursing background as well, and I looked at the immune system and how it worked and how it developed, and I breastfed them as well. So I had my own immunity when they were babies...So I certainly wasn't at all concerned when they were babies. I was also aware of herd immunity and so the likelihood of them actually getting any of the diseases was quite slim.' (Interview 10, F, 49, P, Y (delayed))

These views appear to be endorsed and reinforced by other colleagues in the workplace both in terms of confirmation, or by the lack of challenge by other colleagues:

'Being from a medical background anyway, I spoke to colleagues who also had children of the same age who also said "well unless we can have it done separately we're not going to risk it.'" (Interview 14, F, 36, P, Y)

Interviewee 14 also recalled a discussion with her GP, and wondered whether he 'would have responded to her in the same way had he not known she was a nurse?' Similarly, Interviewee 10 mentioned that her Midwife and GP also 'knew her professionally, to a degree', and suspected that they did not 'put as much pressure on her to change her mind' as they might otherwise have done.

Healthcare workers when responding to the concerns of friends are equally unlikely to challenge negative ideas about immunisation as robustly as other parents, especially if they are in the minority, for fear of damaging their personal and social relationships. This lack of challenge and tacit endorsement of these rationales then continues to perpetuate feelings of doubt amongst their wider social networks:

'A friend...she's almost in a medical profession and she won't let any of her children be immunised for anything....they've had no jabs, nothing. She's so anti it and I don't actually know why (laughs). I wouldn't mind asking her why, but I won't cos I just know that she's dead against it and it's those sorts of things makes you think, "I wonder what she knows?">' (Interview 12, M, 48, P, Y)

These social factors are significant in that, in policy terms, this potentially impacts on considerations of the reliability and effectiveness of health care workers as a source of advice for other parents, especially given the potential for these individuals to be highly influential, not just as professional advisors, but also as knowledgeable friends and social acquaintances. Whilst accurate information is vital, education and training is as unlikely to address the concerns of these professionals as it is to resolve those of parents in general. Most immunisation sessions for professionals remain primarily didactic, information-giving exchanges. They rarely provide opportunities for an open exchange of ideas or for challenge in a non-judgemental environment. If, as has been evidenced, parents and professionals both formulate their decisions in a similar way

through social talk, then everyday interactions with other health professionals, and with parents, all have a significant part to play in influencing the outcome of parent's immunisation decisions. This evidence therefore suggests that there is a need to reconsider the purpose of professional 'education' forums and to instead provide opportunities for more open discussion in respect of immunisation in a safe environment regardless of their area of work.

6.3.2 Vaccine overload

All of the groups of parents within this study made reference to the concept of 'vaccine overload', and to the fact that they felt that multiple antigen vaccines such as MMR were 'too much in one go'. Specific mention of this was also made by 16 out of the 20 parents who were interviewed. This confirms previous findings widely reported in the literature (Offit et al, 2002), and as discussed in Chapter 3, that the idea of the immune system, its development, and its ability to cope with multiple assaults, appears to be central to how these parents conceptualise their individual child's health.

Evidence that parents make individualised assessments of health has already been established in 6.3.1, as has the principle that parents use these assessments to frame their thinking around child rearing by building on their child's strengths and limiting their vulnerabilities in order to protect them from illness. In light of this, the key concept underpinning concerns about 'vaccine overload', confirmed again here, appears to be a perception that the immune system needs time to mature in order to be able to 'deal with' immunisation. As a result, babies are considered to have 'weak or undeveloped immune systems, but as children get older, and therefore 'stronger', both they and their immune system are better able to cope with the stress of these interventions:

'I think like puppies and babies, all new-borns, um, their immune systems are so vulnerable. Because they're brand new and they suddenly have all this stuff thrown at them, dirt you know and everything that's going...and I just thought "No, this is the last thing that we need to do to an immune system that is still developing, is throw some more stuff at it that it's got to cope with", if it can wait 'til later when they're older and it's developed and settles (Interview 5, M, 47, S, N)

Parents also find immunisation a counterintuitive activity. Parents are told that infants require protection from many common hazards to enable them to survive and thrive and, against this backdrop, it is perhaps not surprising that many parents harbour the belief that the immune system needs to be nurtured and trained to enable it to be slowly built over time, and that they are so concerned about the use of multiple vaccines which they perceive as increasing the risks associated with the vulnerability of the child and the possibility of adverse reactions:

'You think, they're small and you're shoving all this into them, you know it can't be, surely it can't be good for them' (Interview 17, F, 45, P, N)

While this issue is very well reported in the literature, parents reported that these concerns had never really been challenged by peers or by professionals. When asked about this in the interviews, they typically responded that:

'Nobody did. Nobody ever sat me down and said, "Well, why do you think your babies' immune system can't cope with it? Because we think it can and here's why..." Nobody ever said that to me.' (Interview 9, F, 39, P, N(S))

6.3.3 The role of the Media

Many of the respondents to this study were highly influenced by the media, referring to the 'huge coverage' and 'all the furore in the press' (Interview 7, F, 47, P, Y / Interview 14, F, 36, P, Y). They also reported feeling 'bombarded daily' and being 'scared witless' by 'very alarmist' reports (Interviews 1, 4 and 16). A fundamental difficulty for parents in these situations was that, while school teaches you to analyse books and pictures, no one actually tells you how to make sense of the news and parents therefore find making sense of media debates on health issues particularly difficult:

'It's because they take over everything...I know you shouldn't listen or read everything... or believe everything you read, but it's difficult when they've got a way of putting it over to you...and that's what they're trying to do isn't it?' (Interview 8, F, 44, P, N)

Parents who had opted for single vaccines (142 references) appeared to have been the most influenced by popular media coverage, and many made frequent reference to TV programmes such as 'Richard and Judy' which gave considerable air time to parent pressure groups, and to supporters and owners of 'single vaccine clinics'. Much of this was justified by these programmes as being necessary in order to provide information that was unbiased; however, journalists gain their credibility from being viewed as ordinary members of the community and as parents themselves, with their own concerns and doubts. It is difficult to be neutral and still engage parents in an unbiased way in these situations. As a result, many of the parents interviewed for this study confirmed that they did *'get incredibly influenced by stuff like that when it's in the media'* (Interview 9, F, 39, P, N(S)) and some reported that they had actually been so influenced that they had *'phoned the clinic featured on the TV straight away and made an appointment for single vaccines'* (Survey ref 48, F, 41, P N(S)).

Parents who held natural health beliefs, however, had very different ideas in respect of the mass media and reported that it had very little influence on their decision-making, what was of more significance for these parents was the potential link to politics, to the state, and the role of the 'Government press' within that. Parents in this group were found to be far more cynical about any press reporting and about the validity of claims made by either side of the debate:

'Of course then he went public and basically said it was a whole pile of rubbish, which then made you think it's probably one of those conspiracy theory things...Was it something that his hand was forced to make him do that to try and get people to have the MMR because his career was on the line? There was no real explanation as to why it happened, so.....' (Interview 4, F, 44, P, N)

Whilst the media appears to have been highly significant in the decision-making processes, particularly of those parents who opted for single vaccines, the media as a means of bridging these opposing views now appears to have limited relevance, both for parents who have not personally experienced the controversy and for those who did but remain unconvinced. In fact, to continue to fight this out in the media is considered to be counter-productive by most parents, who argue that open dialogue offers a much more acceptable way forward:

And I just think that advertising if you remember that it was on the telly, was really harsh and to scare you...it could've gone a long way to laying down an awful lot of parents fears. And if they'd addressed that instead of saying "oh no, no, no, no, no, no" and, you know, brushing parents' concerns away, and been more open about it then you probably would've found an awful lot more parents would've gone for all the jabs' (Interview 20, F, 41, P, Y).

6.3.4 Single Vaccines and Parental Choice

Access to single vaccines was found to be a common issue for the study participants. Seven of the 20 interviewees had opted for single vaccines and an additional two would have done so, but could not obtain them for their children. There were 551 references to them in the interviews, 678 in the Section 5 survey comments and 1303 additional free text comments within the survey responses. The debate is, however, essentially an extension of the arguments in relation to parental choice and the two, whilst slightly different were found to be inextricably linked within the analysis of the data.

Parents who confirmed that they had opted for single vaccines (259) did not espouse strong alternative beliefs, but instead generally expressed more liberal political views with an emphasis on personal and collective responsibility:

'Yes I mean immunisation, I think it is absolutely the most brilliant thing and not only does it protect your child, but it also protects the population. It's kind of a good full circle – if everybody gets them immunised it really does work' (Interview 7, F, 44, P, Y)

Perceived vulnerability was again cited as a key factor in the assessment of risk for the parents of children who had single vaccines, with many parents (73) also making reference to pre-existing medical conditions as a rationale for their choice. These parents were almost universally traditional acceptors of immunisation, and continued to strongly advocate the benefits of immunisation in their survey and interview responses:

'I think that's why I chose not to not vaccinate [child], even though there was the furore going on I chose to vaccinate them because I genuinely believe that immunisation is a very good thing' (Interview 1, F, 38, P, N(S))

This situation therefore posed a considerable dilemma for them because it challenged their secure beliefs in a service which they had previously strongly supported. They wanted to be compliant, but felt frustrated by the perceived inflexibility of the system, especially when an alternative option existed that had previously been approved for use within the national schedule (Interviews 1, 5, 7, 9, 16, 18 and 20). It is true that single vaccines were available in 1970s and 80s, but the impact on disease incidence was limited (see Appendix 2). Policy makers also had concerns that parents may not complete the full course of immunisations, or that children may be at additional risk of acquiring disease in the gaps that are necessary between doses of immunisations (Ramsay, 2002).

Parents who had chosen single vaccines were all able to produce records of their child's private vaccinations, and had shared these with their GP to ensure that their child's medical records were complete. They had also shown considerable physical and financial commitment in completing the courses, often travelling hundreds of miles and spending hundreds of pounds per child to do so. As a result they were indignant about the official rationale for not providing single vaccines (as evidenced above) and did not agree that this warranted any restriction of their individual personal choice. In fact, many of these parents (commented on the complete irresponsibility, and lack of logic, of a system which extolled the virtues of immunisation, but whose intransigence and unwillingness to compromise potentially left children unprotected:

'If the government is so concerned about these diseases they should make the single jabs available, even if the recipient has to pay a fee or a contribution towards the cost. Providing no alternative verges on the negligent' (Survey Ref 49, M, 52, P, N(S))

This created not just frustration, but significant levels of anger, feelings which have persisted over time, and which have had an enduring impact on relationships between

these parents and professionals long after their concerns about MMR subsided. In the absence of other medical co-morbidities, parents who had opted for single vaccines reported that, if they had not been able to access these, they probably would have accepted MMR (Interviews 1, 5, 16) – but that anger at the attitude of health professionals, and the complete lack of open engagement or dialogue, acted as a block to parental compliance:

'I dragged myself kicking and screaming to that point because I was so resentful of the approach that I felt the Health Service took...I felt patronised and angered, I still do, and that really stopped me from doing anything for a long time – SO THERE!!!!'

(Survey Ref 62, F, 42, P, N(S))

Concerns about pharmaceutical industries do exist for parents who opted for single vaccines. However, they appear to have been evoked simply by frustration at the lack of choice and would not necessarily impact on any future considerations in relation to other immunisations. However, for parents who hold natural health beliefs, the perception of the industry's manipulation of the manufacture, distribution and regulatory frameworks which control the supply of vaccines appeared to form a fundamental socio-political aspect of their immunisation decision-making pathway and this is considered further in section 6.3.8.

In terms of parent choice and decision-making, in most cases (647 / 700), the parent who responded to the study survey and/or was interviewed had been instrumental in making the decision. While some partners had become actively engaged in the decision-making process, for many the process was one of passive acceptance and tacit support of the dominant partner's decision-making. For others, there had been a process of negotiating or rationalising the decision, influenced sometimes by events or

more frequently by research undertaken by one or other of the parents. As a result there was little disagreement between parents of children included in this study:

'I think we were agreed, yeah I mean, I think probably if I'd had the children immunised, I think he probably would've gone along with that as well quite honestly...I don't know it's a bit like I'll let him to sort the car out and he leaves me to sort the kids out' (Interview 10, F, 49, P Y).

Birth order was also found to be of relevance, with levels of anxiety and non-compliance being reported to be highest for parents of first children (14 of the 20 parents interviewed). However, this was slightly more nuanced than first appeared, with some parents (18) justifying their MMR choices by reference to a perception that their male first children had 'weaker immune systems' or were 'less robust' and therefore as having been less able to cope with immunisations such as MMR:

'Um, the girls are OK, but they were very healthy. They were very healthy babies, there was nothing in there whereas he wasn't, he was very sickly, so I just wouldn't have ... I didn't risk it' (Interview 14, F, 36, P, Y)

6.3.5 Other medical comorbidities

In the previous sections the interactions between social perspectives and personal experience has been demonstrated to be a key influence on decisions to accept or decline immunisations, including MMR. A significant proportion (32%) of the survey population and 10 of the 20 interviewees were parents of children with disabilities or pre-existing medical conditions. Whilst this group of parents shared many of the anxieties of other parents as already described, for these parents there were also additional considerations which brought their concerns about immunisation into even

sharper focus. Some of these considerations were the result of more extreme personal experience, but others involved a much more reflective process, and some were quite pragmatic given the circumstances these parents found themselves in. These additional considerations will be explored in this section.

Parents of children with medical conditions or disabilities were often found to have arrived at their decisions through a very different assessment of relative risks, reflecting not only their previous experiences of disability, ill-health or immunisation, but also previous outcomes when they had accepted assessments of an event being considered a low risk medical probability:

'Yeah, I would still have chosen the same decision because...to me it felt like there was a risk...and because we'd already had something go, you know, something happen, I didn't want it to be me taking that chance, whereas I probably would have taken that chance otherwise' (Interview 11, F, 44, P, Y)

For many (164), the act of delaying their child's immunisation was directly associated with the progression of their child's disease, for example, related to waiting for breaks in courses of treatment (Survey ref 26, F, 45, S, Y) or confirmation of diagnoses (Interview 20, F, 41, P, Y). For others (63), there was an acute awareness of the possibility of a developmental disability occurring as a result of prior family history, and therefore a rational desire to avoid falsely attributing the occurrence of such a disability to the vaccine:

'The reason I had the MMR later for my child was because of family circumstances. I have a mentally handicapped brother with a brain age of approx. 2 years, he also has autism. I also have an uncle with similar disabilities...We made the decision to have our child vaccinated when she was older, so that we knew she was completely

healthy...I needed to know that if anything was the matter with my child that the MMR was not to blame'.(Survey ref 11, M, 52, P, N(S))

Parents of this group of children also referenced the contemporaneous impact of other medical interventions on the child, particularly in relation to the timing of immunisations as being a significant influence on their decision-making:

'I mean she wasn't poorly, but I mean she had...you know, two big operations, um, and this stupid great big plaster cast and everything, um, and it was a really difficult time'
(Interview 18, F, 38, P N(S))

These parents also reported declining MMR to be have been directly related to the fear of the possibility of further adverse events occurring at that time:

'I didn't want anything else to happen if you know what I mean. I thought at the time they had had enough and I didn't, you know, I was scared, I was unsure so I just didn't do it' (Interview 11, F, 44, P, Y)

But this fear often had a very practical basis, and the decisions were often pragmatic, balancing a known uncertainty with another that is as yet unknown:

'I did not give my son the MMR jab because I have a handicapped second child, a daughter. She has cerebral palsy – she was damaged at birth through lack of oxygen. We found out later that the midwives went on a tea-break and we weren't looked after properly. So when they said that MMR might be connected with autism I found it very hard to let my son have the MMR. I would have found it very difficult to look after two disabled children.' (Interview 12, M, 48, P, Y)

Parents almost universally reported apparent disconnect between their own needs and concerns and the level of support received from health professionals involved in immunisation. This resulted in a perceived lack of sensitivity by parents of sick or disabled children. One respondent summarised the most important thing that could be done to improve services as: *'to have an understanding of the position of parents who have children with disabilities or special needs'* adding:

'The Health Authority we lived in when my eldest son was born regarded us as statistics and didn't understand why we might have reservations whilst still holding concerns about leaving our child unprotected' (Survey Ref 12, F, 42, S, Y).

Another recalled receiving the standard leaflets and thinking:

'they're sending me really horrible umm leaflets saying 'this is what could happen to your child' and you just think, you know, we've got enough trouble keeping him alive, we don't need to have this hassle as well.' (Interview 20, F, 41, P, N(S))

While such concerns might be expected to result in parents completely declining MMR, the reality is that for the majority immunisation is something which they value, and which they actively desire for their children. As a result, almost all the children who were not truly medically contraindicated had either had MMR at a later age (173) or had opted for single vaccines (68), or had had both. In fact, many of these parents (52 references) were quite indignant at being included in the survey with its implication that they might be bad or non-compliant parents:

'I was slightly annoyed at being labelled a 'non partaker of immunisation' when all my children have had their inoculations. My youngest child had nephrotic syndrome but he has been inoculated when a break in his drug programme had allowed it to be done

safely and with lessened risk. At no point would I have not considered inoculation.'

(Survey Ref 6, F, 41, P, Y)

Within this wider group of medical conditions, children with allergies and/or other atopic conditions seem to require different consideration. The parents of these children shared some of the concerns of those whose children had various disabilities, but they also had other concerns which were much more aligned with parents who adopted natural/holistic approaches to parenting, often as a result of having to try other remedies and dietary approaches when traditional medical treatments offered little improvement in their child's condition. These parents typically had anxieties about the child's immune system being 'already weakened' by allergic conditions, and fear that this might make them more susceptible to any adverse effects:

'At the time he had all these allergies and we didn't know what the allergy was and ...I thought to myself "Well you know, if he's weakened already with eczema and asthma it is putting everything at once into his weakened system, is that going to, um, is it going to work? And what could that trigger"' (Interview 19, M, 49, P, N)

This resonates with the wider public concerns about how the immune system works, and is further complicated by the fact that being 'immune-suppressed' is identified on parent information as a contraindication to immunisation (Department of Health, 2013) but parents and professionals interpret what this means for these children from different knowledge bases and perspectives and come to different outcomes in relation to risks associated with accepting or declining immunisation. This uncertainty and confusion is of particular relevance where conditions, such as coeliac disease, are referred to as having 'autoimmune' components:

'As coeliac disease is an auto-immune disorder, although he is fit and healthy we were not happy with the possibility of compromising our son's health by allowing him to have MMR – it states anyone with immune conditions should not have it. We appreciate that coeliac disease is an auto-immune disorder but it is still to do with the immune system and therefore we are not prepared to take the risk' (Survey Ref 26, F, 39, P, N)

Finally, parents of children with serious illness or disability often have a very different social and parenting experience than other parents. They often find themselves marginalised and stigmatised (Slade et al, 2009) and, as a result of this, their social networks often consist of other parents of children with similar disabilities or conditions, whether through special schools, hospital attendance, or attendance at specialist support groups. By coming together in these potentially skewed populations, parents can get a distorted impression of the incidence of such diseases and disabilities. They are also more likely to be exposed to parents who may have compelling stories about the cause of their problems, for example a link to MMR, and are inclined to reflect on the similarity of their own situation when making their immunisation decisions.

These are significant issues when considering how to apply the findings from this study to improve the impact of immunisation programmes. Transitional periods such as school entry and transfer to secondary school, as well as piggy-backing checks onto other interventions such as those associated with the 5 – 19 Healthy Child Programme, offer opportunities to interact positively with these young people and their parents, and to complete immunisation on a 'never too late' basis. In addition, there is a need for better recording of medical conditions and disabilities by the CHIS systems so that professionals can be aware of the child's condition and adopt a more individualised approach in practice.

6.3.6. More support required from Health Professionals

The previous section has highlighted that parents of children with medical conditions quite clearly feel that they require more support from health professionals, both generally, and specifically in relation to managing decisions in respect of immunisation. Parents who participated in this study, as a more general group, commented that what would help them to make decisions would be 'more information from professionals' (64 references) and this seemed to align neatly with the knowledge 'deficit' models that underpin much of current immunisation policy (Pareek & Pattison, 2000). However, closer unpicking of this with the interviewees revealed that what all of them, with the exception of those who chose alternative lifestyles, wanted was actually more support from professionals in making what they considered to be very difficult decisions (Interviews 5, 8, 9, 11, 13, 14, 15, 16, 19, 20). There are also significant differences between what they want to receive and how they want to receive it, and the 'what' and the 'how' that health professionals currently deliver within local and national immunisation services.

Parents reported that the information they receive from professionals is often inconsistent, confusing and varies between professional sources even within the same GP practice (Survey Ref 1, F, 51, S, N; Survey Ref 2, F, 38, P, Y; Interviews 6, 9 and 16). Parents constantly emphasised that what is needed is for them to have information explained, to have an opportunity to discuss what it means, and then to have time to consider this before making a decision:

'It's a question of having had the information, having the time to talk to other people about it and having time to let it sink in....' (Survey Ref 2, F, 38, P, Y),

This further supports the finding that these parents make their decisions by ‘talking through’ their concerns, and that decision-making is achieved through a process of social interaction. However, the experience of the majority of respondents was that there were few opportunities for this type of interaction with health professionals and instead the process of receiving immunisation was felt to be almost impersonal:

‘You know, I mean you can make an educated decision if you, if you’re sensible about something like this ‘cause it’s very important, but what I found is, I was just not getting an educated answer... a decent adult conversation from any of the health service really, yeah, that would’ve helped definitely’ (Interview 5, M, 47, S, N)

Effective social interaction requires the establishment, on some level, of a personal relationship. Professional / patient relationships featured highly in parents’ responses, with some evidence of a correlation between previous ‘bad’ relationships’, or ‘bad experiences’, with professionals and decisions to decline. Some parents reflected that if they’d had a completely different GP, they *‘may have treated it very different at the time’* (Interview 6, f, 50, S, Y). They were also very frustrated when professionals failed to engage:

‘Well...when you went and asked the health visitor, the um nurses or the, um, doctors, all they did was give you a leaflet’ (Interview 4, F, 45, S, N)

Or,

‘It would’ve been nice to have had some support from the local health authority to say well actually we understand why you can’t have it, instead of having really horrible snotty cards every 6 months’ (Interview 20, F, 41, P, N)

Conversely, where parents had changed their mind and had subsequently accepted MMR, they referred to professionals being ‘very good about it’ and ‘he listened to me’

(Interview 12, M, 48, P, Y) – or reported that they were able ‘to have a different conversation with her so that I did look at it from both angles’ (Interview 2, F, 45, S, Y).

The pragmatics of delivering population-based immunisation programmes plays a significant part in limiting the scope of these patient/professional interactions. However, social talk has been found to be a very salient factor for the parents in this study. If they do not get it from professionals, they will seek it elsewhere – for example, from unregulated internet chat rooms and blogs. At first sight, this kind of interaction with professionals appears too resource-intensive and impractical; but it involves relatively few parents, and should be considered in relation to the costs in time, resources and reputation of outbreaks and of catch-up campaigns.

Parents are no longer passive recipients of healthcare, they expect, and increasingly demand, personalised pathways for both health and child care. They are also being encouraged to be more proactive about their health:

‘The fundamental point is, it’s your body...and the more you understand about the drugs you are taking, or what you might be able to have, the better you are able to work with your doctor...It is essential for the future of the health service and for the future health of the nation, that patients understand their conditions, their treatments, and work with health advisors so that they can have the best care.’ (Haslam, Chair of NICE, 2013)

Current immunisation services seem out of touch with this change, and need to embrace the concept of the patient as consumer. One respondent commented that when you go looking for any other service, or want to buy something, you speak to someone in the shop, you get a chance to look at the product information, and you talk to your friends about what they chose and why. After all, *‘you wouldn’t buy a washing*

machine if you did not know what it did, would you, you'd want someone to tell you and to know it was the best for the job!' (Interview 9, F, 39, P, N(S))

It is clear that parents who decline are a minority; but small numbers matter, and the difference between meeting target uptakes and failing to do so is shown to depend on just a few patients per month for each GP practice in Somerset (Vaccine and Immunisation National Support Team, 2011). Parents do change their mind, and the evidence from this study is that they are more likely to do so when there are opportunities for the small number of parents who have doubts to explore these through active, meaningful, 'adult' conversations:

'I think maybe if you have somebody who is sort of not sure about it or doesn't want to go ahead with it, say "I've got a number of parents like you, can I get you to come along and have an informal group discussion, or just have a talk, um, so that you all are clear why you've decided against it, and to see if we've missed anything" Um, possibly if I'd been offered that I would have gone along, I probably would have gone along and I would've listened' (Interview 8, F, 44, N)

6.3.7 Medical Models, Politics and Health

A specific strand of enquiry, when interviewing parents as part of this study, was to establish what their opinions were in relation to the societal principles of personal freedom versus social responsibility, and how this affected their decisions to accept or decline immunisation.

Parents who advocated alternative therapies strongly articulated the importance of individual responsibility for their personal health and for their childrearing practices, and the importance of maintaining personal resilience through the adoption of healthy

lifestyles and natural remedies. They rarely expressed any concerns about responsibility to the wider society, often referring to the choices made by others as being at the root of those particular individuals' problems. These opinions were framed in the context of alternative lifestyle choices, and this group of parents expressed negative views concerning the role of the state in family and personal life.

Having taken personal responsibility in making a decision to decline MMR, parents in this group felt patronised by NHS health professionals, and felt that their individuality had been overridden, especially when they repeatedly received invitations for their children:

'I was so resentful of the approach that the Health Service took in dealing with people's personas...I felt patronised and angered. They never actually came and said "Why haven't you? We'd be interested to know why you made this decision" and I think they should have been supporting my freedom to make this choice, but instead I just got all these reminders saying "Oh we've made another appointment for you" and just kept getting all these cards through...' (Interview 5, M, 47, S, N)

This approach just served to alienate them further from mainstream policy recommendations and to increase their confidence in their personal convictions:

'It was made very clear that they would prefer me to have my children immunised, yes. Um, but that's what I would have expected from them because that's what they do...it's a bit like you know an evangelical minister is going to preach to people that his way of life is the way to live, um, so somebody who works in the NHS and does immunisations all the time is of course going to be concerned to discover that none of your children have been immunised and try to persuade you otherwise. But yeah, I mean, that's fine I knew what I was doing was right.' (Interview 3, F, 42, P, N)

Some parents, particularly those who had opted for, or who would have preferred the option of, single vaccines, seriously considered the issues of social responsibility, and felt anxious that they were not exercising options which enabled them to have the freedom to choose while protecting their fellow citizens:

'It's really difficult, because you've got your own child and their wellbeing is paramount, but then, you know, if somebody else was to put your child at risk in that situation then you wouldn't be very happy about it...it comes down to the dangers of the disease and if your child is going to be able to catch it from somebody else who hasn't had it, you know, you really ought to vaccinate your own child so that they don't spread the disease too...I mean...we're all part of a bigger society aren't we?'

(Interview 20, F, 41, P, N(S))

Others, often those who had just declined or delayed MMR, openly reported that they depended on the social conscience of others and therefore the principle of 'herd immunity' to enable them to abdicate responsibility for making any decisions. But in doing so, they recognised that there were significant limitations to this approach:

'Oh, taking a very selfish view, most other people were having their children immunised against it, so it seemed there would be little risk of them catching the three diseases that they were being vaccinated for. So I felt fairly safe in leaving it until they were older...then if we all did that, nobody would get their kids immunised would they?'

(Interview 9, F, 39, P, N(S))

All these parents recognised that their decision-making was very subjective, and had sufficient insight into the process to recognise the conflict between their collective responsibility as 'responsible citizens' and their personal responsibility to their child. Invariably, the parents' rationales ensured that consideration of their responsibility to their child took precedence over any sense of collective responsibility.

This suggests that using the concept of 'herd immunity' in order to appeal to the social conscience of MMR decliners (as suggested in Chapter 3) will have little effect, and that maximising the dialogue around potential benefits to the individual child, especially those relating to children with medical co-morbidities, would be a much more productive strategy. In fact, the concept of 'herd immunity' itself implies, by default, that a decision to immunise is not right for some children, and this actually reinforces the decision-making pathways of some groups of parents. As one parent stated:

'If the philosophy behind immunisation is that it is for the greater good, this implies that occasionally some children might be harmed to achieve this. As a parent, your child is the most important child to you. This will always lead to a conflict of interests between parents and medical professionals' (Survey Ref 31, F, 40, S, N)

A frequent complaint articulated by parents who did not follow the accepted national schedule, was that they felt coerced by an inflexible health system and pressurised by the heavy handed tactics of unsympathetic health care workers:

I want not to be treated as if I am ill-informed or irresponsible when not taking the MMR. I have been lectured by a GP and a GPs receptionist looks down her nose...I want not to feel pressurised or bullied into making decisions ...or to be made to feel stupid if they don't agree with my decision' (Survey Ref 8, F. 42, P, N)

Lack of respect by health professionals for alternative points of view was almost invariably found to be counter-productive:

'And he said "Don't read anything about them". He said "They're just terrorists". And I always remembered that (laughs) and I looked at him. He said "They're medical terrorists", and I thought ok, but you know I am quite intelligent, I took it, I took

everything on board...but I think it was the terrorist comment, "Don't believe a word, they don't know what they're talking about" and I'm thinking, these people have done their research. Their children are affected... and I think it turned me off the MMR...having that said by a GP' (Interview 6, F, 50, S, N).

Trust was a concept raised by many parents and intrinsically linked with concerns that health professionals may not always be acting in the best interests of their patients. These concerns were invariably evidenced by reference to financial incentives being paid to doctors for administering vaccines, or for reaching particular uptake targets. Issues of trust also, however, related to more general contexts – lack of trust in government, or in the institutions that decide government policy in respect of immunisation:

'I mean at the end of the day it's a great business isn't it 'cause it's a licence to print money isn't it...it's about you know how you have these drugs that are allowed to be used and then you find out that well actually the people who did the research worked for the bloody pharmaceutical companies, or they paid for the research, they can choose which, you know, the ones that give the results they want, oh we'll let everyone see that but we won't let them see the other results you know, how are you meant to trust these people?' (Interview 5, M, 47, S, N))

Vaccine manufacture involves the application of global technologies and the mobilisation of global assets and resources and the development of new vaccines are therefore high on national and international policy agendas and necessarily involve relationships between pharmaceutical companies and local, national and international governments (Leach and Fairhead, 2007). Parents' concerns about the economy of vaccine production are invariably linked to the power and political influence of the large

multi-national companies that oversee the mass production of vaccines in their societies:

'Yeah well, I mean I can't see me ever trusting politicians or corporations ever, I mean politicians are only there because of the corporations anyway basically 'cause they're the ones that pay to get there and run for, you know all these millions that they, you have to spend to get them voted in I mean the whole lot of them should be locked up shouldn't they really or you know, they should' (Interview 3, F, 42, P, N)

A final element of relevance to this theme was the comparative experience of parents who had accessed immunisation services in other countries, with that experienced in the UK. Key issues highlighted were the impact of societal normalising of immunisation on parents who had previously declined, and as part of this, the role of compulsion, which itself acted in many ways to normalise parental behaviour in many of these other countries:

'and then, you know, you go to a different country and it's just not even an issue. I suppose it made a big difference ... yes, potentially. Yeah. Probably was. It wasn't in the forefront. It wasn't there staring you in the face, you know, wasn't being talked about all the time ...when we went to France I think it did change things because it just ...you just had it done. It wasn't queried and they didn't query it'
(Interview 6, F, 50, S, Y)

It should also be noted that parents living in the UK, but who originated from other countries, often reported that they continued to access immunisation services for their children on visits back to their native country and according to the schedules of these countries. On occasion this had resulted in differences in the reporting and understanding of the child's immunisation status where the parents considered the

child to be up to date according to their home schedule, but UK systems considered them not to have completed the programmes appropriately or at the correct times. This is relevant when considering the impact of small numbers, and of data accuracy, on local uptake rates, especially where there are large ethnic minority populations.

6.3.8 Natural therapies and Holistic Approaches to Health Care

Four out of 20 of the parents interviewed had refused all immunisations; a further two had rejected the majority of immunisations, including MMR, but had accepted some because of specific perceived risks to their children (tetanus from horses for one, and polio from swimming for another). All of these parents articulated very strong alternative health beliefs and refusal of immunisation in these cases was not limited to family members, but also extended to family pets.

In addition, reference was made to natural health or alternative therapies by a further two of the interviewed parents who had declined MMR and by 15 of the survey respondents. None of the parents who had refused all, or the majority of, immunisations had changed their mind at the time of the interview, and all made it very clear that they had no intention of doing so in future. In fact a common feature of this group of parents was their confidence in the decision that they had made when compared with those who had delayed or opted for single vaccines.

Parents who subscribed to alternative health beliefs in both the interviews and the survey responses described a number of consistent views in relation to immunisation. These include the perception that infectious diseases were already declining before the advent of mass immunisation, and therefore the claims made by medicine for the use of this intervention were a myth:

'You know if you look at statistics and things about when immunisation came in in the 50's and 60's, all these illnesses were already going down anyway, a lot of it, I read so much stuff saying it was basically sanitation, better diet and all those sort of things, that's why kids weren't getting ill, not immunisation at all' (Interview 5, M, 47, S, N (S)).

Secondly, that nutrition and maintaining a healthy lifestyle are the most important factors in maintaining a healthy immune system, and that breastfeeding alone would provide adequate protection for children if continued for long periods:

'Yeah, I mean (immunisation is) no substitute for colostrum and good bacteria...I was talking to a microbiologist, he works for a probiotics company, and about how devastating it is for a baby's immune system if it is a) caesarean and b) not breastfed; that your whole gut makeup is completely different and how much more pathogenic it is from then on... so we need to get over the message about breastfeeding the longer the better, you know best milk and the best start in life to grow a strong immune system' (Interview 6, F, 50, S, Y)

Healthy lifestyles are acknowledged as a core component of mainstream public health, and there is actually a sound scientific evidence base for this (Bundle, 2014; Frenk, 2015; WHO, 2015). Similarly, there is evidence to support the benefits of breastfeeding for very young babies. However, the physiological effects of breastfeeding in relation to immunity are limited (and dependent on maternal immunity status) and the benefits are relatively short-lived (NHS Choices, 2015) and this is itself a factor in the timing of primary immunisations in the UK schedule. The interpretations of scientific principles by practitioners of alternative medicine therefore appear not unreasonable at a superficial level; and although these interpretations of scientific fact are in fact misinterpretations, they could offer a potential starting point for engaging in dialogue with these individuals.

Vaccination is also seen by some anti-vaccine protagonists as an 'old model', which 'singles out just one part of the immune system' (antibodies) which they argue causes stress and is thought to *'put toxins in the blood so that the immune system can't carry out its functions as effectively as before'* (Interview 5, M, 47, S, N(S)) In addition, it is believed that vaccination acts in some way to suppress diseases which *'have to come out later often as worse diseases'* (Interview 3, F, 42, P, N), or conversely that not having these diseases naturally means that the immune system *is 'not adequately challenged and so, instead, turns in on itself causing new illnesses such as autoimmune disorders'* (Interview 9, F, 39, P, N(S)) and the rise of other 'modern' diseases, for example, eczema and asthma. The increased incidence of these diseases and the lack of a full medical explanation are considered proof of the causal relationship between these two factors, without any consideration of the possibility of multiple other confounding variables. Concerns about the possibility of long-term unknown effects of vaccination were also referenced:

'I was talking to my daughter yesterday...and she was saying "What if you know, in a few years' time all these people who've had vaccination ...they find there's something wrong with the vaccine and they all just get cancer?"' (Interview 6, F, 50, S, Y)

These concerns are particularly difficult to discount since there is no way of guaranteeing that there will not be such unlikely, but not impossible, effects in future. However, whilst all these parents expressed concerns about the links between 'modern illnesses' and vaccination, interestingly there was little or no reference to any presumed link between MMR and autism. These parents paid little attention to mainstream media reports, preferring to rely on alternative sources of information and personal research.

For all the parents who referenced alternative approaches, adherences to alternative views on immunisation were grounded in a much wider individual lifestyle choice. These parents had similar views on socio-political issues – commerce, the state, personal choice and personal freedom, social responsibility – to a greater extent than any other group. In addition, they appeared to circulate in a distinct social world, often having social relationships exclusively with ‘like-minded people’ (as described in 6.3.7). Their choices were therefore reinforced as a result of these social interactions, and were supported by ‘natural’ therapists who provided an alternative source of information and who employed a personal way of engaging with their clients that those promoting medical models could learn from.

It should be acknowledged, however, that alternative therapy is not a single entity and that there are some inherent dangers in stereotyping. There are many varied ideas and traditions within the spectrum of ‘natural health’ approaches. Some accept immunisation but many do not. Rarely, parents who hold these views will accept certain immunisations because of very specific perceived hazards (for example, tetanus and horses), and some will re-evaluate their choices as a result of changing social circumstances:

‘And, you know, she’s a robust little girl now, and kind of, if someone came to me and said, “Right, this is the age when we need to give the injections” I’d kind of say OK...partly because I’m no longer practising acupuncture and I’ve got a bit more mainstream again now...’ (Interview 18, F, 38, P, N(S))

Finally, some of these parents also do admit that the information they are referencing is potentially biased; and while they are very confident in the approach they have taken for their children, this confidence is often partly grounded in the fact that they feel free to do this because the majority of parents do comply with immunisation:

'part of my training (in acupuncture) was about the body's natural defences and all of those things, but also knowing, and this is the mean bit of it really (laughs) ... knowing that the majority of people would have it done, so there was for [child], there would be a lower risk anyway...'(Interview 18, F, 38, P, N(S))

6.4 Development of the Parent Group Framework

This chapter has, so far provided an in-depth exploration of the nine themes which were found to underpin the thinking of the parents who responded to the Phase 2 Parent Census Survey and those who were subsequently followed up in Phase 3.

The fundamental logic of the organisation of immunisation services is the provision of a 'one size fits all' approach, predicated on the premise of a homogenous population. Detailed exploration of these themes, however, confirmed that the study population was not, in fact, homogenous, and as a result parents were not reaching their decisions to accept or decline MMR for the same reason, or even through the same decision-making process.

Further analysis of these themes using cross referencing within and between data sources and queries within NVivo10 produced a number of observations from which three parent sub-groups were identified within the study population. These general observations were as follows:

Issues of 'risk' and 'parent choice' were found to be salient in all the parent groups, as was the concept of 'vaccine overload'. 'Vaccine overload' was referred to by all parent groups. Parents had remarkably similar rationales and they subscribed to the same

misunderstandings. This has significant implications for all immunisation services, not just MMR.

The issue of parent choice was significant for all parents, but parents in the single vaccine group were more likely to have been influenced by family members, and particularly grandparents, than parents in the other two groups.

Parents in the single vaccine group accepted the general principle of immunisation, but had specific concerns about the risks associated with MMR vaccine. There were some overlaps between this parent group and the medical co-morbidity group, with some parents in the latter also opting for single vaccines.

Parents of children with medical co-morbidities did not necessarily have any specific concerns about MMR, but had made personalised assessments of risk in the context of the current state of health of their child. These parents had a different perspective on the probability of low-risk outcomes occurring because of previous personal experiences of a 'low risk' event actually happening.

The political and economic issues associated with MMR and immunisation were of relevance to both single vaccine and natural health groups; but whilst for the latter these were a subset of their 'alternative' views – which were likely to impact on all decisions about immunisation – for the former, the concerns were limited to MMR as a single issue and were unlikely to influence future immunisation decisions. Each of these groups considered risk from a different social/political reference point.

Parents who subscribed to natural/homeopathic medicine had significant general concerns about the principles, practice and perceived risks associated with all immunisations, not just MMR. This group also had serious concerns about the power

of pharmaceutical companies, and the consequent emphasis on population health initiatives, such as immunisation, at the expense of 'healthy' lifestyles and individual responsibility.

The impact of popular media coverage was most significant for the single vaccine group. For parents of children with medical co-morbidities, the highly personalised nature of their decision-making acted to some extent to divorce them from the wider debate; and for those in the natural health group, inherent distrust of the popular press as a tool of the state meant that they took little interest in the specific debate, except in so far as it reinforced negative perceptions of immunisation in general.

Finally, both single vaccine and medical comorbidity parent groups indicated that they would welcome greater support from health professionals. However, the very clear message was that this should be in the form of a dialogue with parents, rather than in traditional formats such as leaflets or websites. Parents in the natural health group indicated that they would be interested in more data, but implied that it would be highly likely that they would use this information to reinforce, rather than to dispel, preconceived ideas.

A number of key considerations, which differed for each of these parent groups and which potentially impacted on the outcome of the parents' decision-making, were identified from examination of the decision-making pathways for each parent group.

These included:

- how parents considered vaccinations, such as MMR, in the context of what they believe needs to be done to keep their children well
- the role of the parents' social interactions and relationships, and how these became part of the process of accepting or declining immunisations

- the role of parents' political concerns and how these relate to the way they experience and think about immunisation
- how parents frame concepts in respect of immunisation, and especially MMR, and how this interacts with the views of health professionals

Based on these considerations, the following characteristics were identified for each of the parent groups:

Single Vaccines

Not anti-vaccine; agree with principles and have strong beliefs in relation to collective responsibility and medical models of health; feel let down by a system that they believe in. Needs to be acknowledged; continued potential to impact negatively on patient/professional interactions in medium term

Highly influenced by popular media – single issue triggered response

No impact on decisions about other immunisations

Link to socio-political issues relates to power relationships and choice in healthcare, limited wider concerns

Want to engage in social dialogue with health professionals

Will consider changing mind, may accept 'boosters', may allow older children to have an active role in decision-making

Medical Co-morbidities

Not anti-vaccine

Highly personalised decision-making dependent on the parents' assessment of the specific vulnerability of the child

Assessments of relative risk based on negative prior personal experiences - balance of personal freedom versus social responsibility tipped in favour of individual

Very likely to delay all immunisations (not just MMR) until the child is 'stronger', unless specifically advised by paediatrician or other trusted medical source

Want support from health professionals

Some overlap with Single Vaccine group, especially where medical concerns relate to developmental delay, behavioural issues or atopic conditions

Concept of protection via 'herd immunity' is necessary for some children in this group, but knowledge of this can act to reinforce parental concerns for others who are not technically contra-indicated

Will consider changing mind, and often do spontaneously as child's condition stabilises or when treatment allows

Natural Health

Decisions are based on wider 'alternative' convictions and different socio-political rationales

Parents apply different explanations of 'scientific' evidence, and extrapolate different truths and logics from a basic understanding of the scientific method

Very strongly held alternative beliefs on both health and childcare linked to lifestyle choices

Willing to engage with health professionals and accept information, but likely to interpret this in ways that reinforce existing beliefs

Unlikely to accept any immunisations (for children or pets) and very unlikely to change mind

Parent sub-group	Risk	Medical comorbidity	Vaccine Overload	Natural / homeopathic	Media	Medical models, Politics & Health	Parent choice	More support	Single vaccines
Single Vaccines	X	X	X		X	X	X	X	X
Natural / Homeopathic	X		X	X		X	X		
Medical co-morbidity	X	X	X				X	X	X

Table 6: Relationship between parent sub-groups and identified themes

Parent sub-group	No MMR	MMR - Delayed	Single vaccines	Changed decision?	No Immunisations
Single Vaccines		X	X	Yes	
Natural / Homeopathic	X			No	X
Medical co-morbidity		X	X	Yes	

Table 7: Impact of decision making pathway on immunisation outcome by parent sub-group

The relationship between parent sub-groups and the nine themes are summarised in Table 6.

The identification of these parent sub-groups then generated a further hypothesis that each group might not just have different characteristics but might also be associated with different outcomes and therefore require different approaches from immunisation services. The impact of the group specific decision-making pathways on immunisation outcome by parent sub-group is summarised in Table 7 and appeared to further support this hypothesis.

This was further investigated and the outcomes and potential mechanisms for applying these findings to improve immunisation policy and practice are discussed in Chapter 7.

6.5 Summary and generalisability of the findings

The evidence presented in this chapter provides a rich source of information in respect of the characteristics and decision-making processes of specific groups of parents who had declined MMR immunisation. Whilst it is acknowledged that the sub-set of parents who responded to the survey may have been skewed, and the findings may not therefore be fully transferrable, the sub-set who were interviewed were confirmed to be much more representative, in demographic terms, of the whole unimmunised Phase 1 study population.

The data provides many insights into the ways that parents formulate and rationalise their decision-making, and it is clear that this is a dynamic process which is highly influenced by the parents' social interactions and social contexts. This information is valuable because it offers the possibility of using these insights to inform the development of communication frameworks and models to improve engagement with

parents in respect of immunisation, which are tailored to the needs of the groups identified, but also have relevance and application to the wider parent population and to all immunisation discussions, not just those involving MMR.

The key findings arising from this research and the overarching MMR Parent Engagement Strategy which was developed as a result are discussed in Chapter 7. The thesis then concludes with consideration of the potential impact of this study on immunisation policy and practice; with recommendations for further research; and with a discussion on the limitations of this research in Chapter 8

CHAPTER 7 DISCUSSION AND DEVELOPMENT OF THE MMR PARENT

ENGAGEMENT STRATEGY

7.1 Introduction

The primary purpose of this study was to identify whether there were any characteristics, common to parents / children who had refused the offer of MMR, which could be used to help improve the understanding of how parents' make decisions to accept or decline immunisation, and in particular MMR vaccine. It was hypothesised that by improving this understanding it might be possible to recommend changes to practice to improve the delivery of immunisation services and therefore the uptake of MMR in Somerset.

Those who decline and those who promote immunisation often appear to be locked in an almost irreconcilable stand-off in relation to MMR. The finding that those who decline this offer are not a single group, but are more complex and comprised of sub-groups, provides evidence to explain why the current 'one size fits all' approach by health professionals and policy makers to engage these parents in the immunisation decision-making process may not be effective and therefore different approaches, tailored to the needs of these groups, may be needed. A better understanding of the reasons why parents adopt their particular approach should be seen as an essential step in bridging these opposing viewpoints. This understanding then has the potential to be applied to improve the delivery of immunisation services and to ensure more effective targeting of available resources, whilst avoiding alienating those parents who hold different views.

Rather than perpetuating the conventional professional wisdom that parent's decisions in these situations are based on a lack understanding of risks, rooted in distorted social and emotional factors that have been communicated by a misleading media (Leach and Fairhead, 2007), the evidence from this study suggests that parents' decisions

should perhaps be viewed as a rational framing of their understanding of competing uncertainties, related to their own knowledge and understanding of their child's health. This then explains why this process cannot be considered in terms of a single, deliberate and objective calculation of risk, which professionals could readily influence by appropriate provision of better information, but instead should be seen as a much more complex and evolving process of personal engagement and evaluation of many differing experiential sources of evidence.

What this also implies is that, if social interaction and engagement is the key factor, professionals can also potentially influence this process by also engaging in an on-going social dialogue with parents on these matters. However, to do this requires a re-thinking of attitudes towards parents who fail to comply with prescribed immunisation practices and a greater commitment to engage with them, and to engage in different ways.

To be successful, any campaign therefore needs to be targeted, not only to areas of low coverage and at those who have not complied with national schedules, but also within this group at a much more refined level corresponding to the motives identified for specific individuals or population sub-groups, and this requires an understanding of the different reasons that parents have for making these decisions. The MMR Parent Engagement Strategy described in 7.2 has been developed as a mechanism to apply this knowledge and understanding to address these individual needs.

7.2 Development of the MMR Parent Engagement Strategy

The previous chapter explored in detail the nine themes that were found to underpin the thinking of parents' of unimmunised children in relation to MMR decision-making.

Exploration of these themes, their differences and relationships, resulted in the identification of three parent sub-groups:

Parents with a natural / holistic approach to health

Parents of children with medical co-morbidities

Parents who opted for single vaccines

Having identified these common themes and parent sub-groups, the sub-groups were investigated to see whether they were associated with different outcomes in relation to MMR and also whether different strategies and approaches were required to achieve these outcomes. This hypothesis was tested by reviewing the summary data obtained via the Phase 2 survey and the Phase 3 interviews, by using cross-referencing and queries in Nvivo10. Further analysis was then undertaken using data obtained in relation to the 20 interview subjects. Table 8 provides details of the MMR outcomes by interview subject and parent sub-group.

It was identified that 10 of the 20 interview subjects had changed their original decision and had accepted MMR for their child at some time between 2009 and 2012. A further four had documented evidence of a complete course of single vaccines at the appropriate intervals. Of the parents who were interviewed, 70% had therefore made decisions to ensure that their children were fully protected against measles by accepting some form of immunisation.

10 of the parents interviewed were in the Medical co-morbidity group. Of these eight had subsequently accepted MMR and one had accepted single vaccines. The remaining child in this group had on-going medical and behavioural issues and the parent reported that they would be unlikely to change their mind.

Interview Number	Vaccination Category				Parent sub-group	Comments
	Had MMR - Delayed	Had single vaccines	No MMR	No immunisations		
1		x			Single Vaccines	
2	x	x			Single Vaccines	
3			x		Natural Health	
4			X		Single Vaccines	Would have accepted singles, might consider MMR if there was a measles outbreak
5			x	x	Natural Health	
6	X				Medical	Would have accepted singles
7	X				Medical	
8			X		Medical	
9	x	X			Medical	Initially had singles, MMR booster
10		X			Single Vaccines	
11	X				Medical	
12	X				Medical	
13			X		Natural Health / Medical	History of adverse reactions. No pertussis

14	x				Medical	
15	X				Medical	
16	X				Deferred acceptor	Delayed MMR2
17		X			Single Vaccines	
18			X		Natural Health	Accepted oral polio
19		x			Medical	
20	x				Medical	Has considered single vaccines

Table 8: Immunisation outcomes by Interviewee and by parent sub-group

There was a degree of overlap between the Single Vaccine and Medical Co-morbidity groups. One of the parents in the Medical group had eventually accepted MMR, indicating that they would have considered immunising their child earlier had single vaccines been available. Another had accepted MMR booster after initially opting for single vaccines. A third parent who had not accepted MMR reported that they would have accepted single vaccines had they been available.

Of the six parents who had not accepted MMR or single vaccines at the time of the study, four belonged to the Natural Health group and had also refused other vaccines. The fifth had on-going medical co-morbidity, while the sixth had a complicated family history of adverse reactions to vaccines, and had held Natural Health beliefs in the past. This parent reported that they no longer held these beliefs following changes in social circumstances and indicated that they may now consider accepting MMR if there was evidence of a measles outbreak in their area.

The data provided many insights into the ways that parents formulate and rationalise their decision-making, and it is clear that this is a dynamic process which is highly influenced by the parents' social interactions. This information is valuable because it offers the possibility of using these insights to inform the development of frameworks and models to improve communication and engagement with parents in respect of immunisation, which is tailored to the needs of the groups identified, but also has relevance and application to the wider parent population and to all immunisation discussions, not just those involving MMR.

Communication with parents in relation to immunisation is currently usually undertaken in very short consultations, at or around the time the vaccinations are being given. The focus of these discussions has generally been a simple didactic provision of information. Education of professionals has been approached in a similar way –

professionals learn what to say to parents, but not 'how' to say it. Parents want to engage with professionals, but they clearly express that this engagement needs to be based on open, two-way dialogue. Professionals therefore need to focus equally on communication skills that build trust and rapport with parents, that enable them accept questions and rapidly identify parents' specific concerns, to elicit parents' motivations and information needs, and enable parents to make quality decisions in respect of vaccination, without the encounter deteriorating into a prolonged, polarised, adversarial debate.

As a result of reviewing the study findings and of gaining an improved understanding of the motives, decision-making pathways and potential outcomes for each of the three parent sub-groups, I have developed the following over-arching MMR Parent Engagement Strategy as a potential way of improving communication and engagement in respect of immunisation with all parents, but particularly those who decline MMR.

The framework is based on the following premises, derived from the analysis:

Parents who decline MMR are not a homogenous group

Parents in the study population have highly personalised approaches to decision-making

There are groups within the study population which share similar perspectives in relation to the nine themes, and these shared perspectives result in them taking similar courses of action in respect of MMR

Parents' decision-making processes are linked to their social worlds, and are dynamically influenced by social interactions and relationships

That analysis suggests ways of interacting with parents to reduce the current polarisation of parental and professional views

The analysis implies strategies that could be applied in practice to develop a means of engagement with parents in each of the three groups

The strategy is outlined in the following diagram (Figure 27):

Maximise convenient opportunities to receive immunisations (nudge / shove)

NEVER TOO LATE.....

Interactions at Community level: Maximise opportunities for immunisation ‘talk’ via social groups, youth groups, children’s centres, schools and social media. Consider ways to engage grandparents / wider family members, and to challenge beliefs in respect of immunisation (e.g. vaccine overload) – normalise immunisation. NB. Consider the potential impact of different schedules and immunisation practices for ethnic minority populations

Universal services for all families: Use relationships built with professionals from pregnancy onwards to open dialogue at appropriate intervals. View immunisation as an integral part of the Healthy Child 0-5 and 5-19 programmes. Ensure that there is an opportunity for open discussion to identify any specific concerns and for explanation when providing standard information

Additional services that any parent may need some of the time (e.g. concerns about specific vaccines): Ensure that there are individual opportunities for meaningful discussion and open dialogue. Provide, delegate or refer to an appropriate professional to achieve this. Provide opportunities to explore new evidence as it becomes available and to revisit decisions

Additional services for vulnerable families (e.g. children with disabilities or medical comorbidities): Awareness and sensitivity for those with medical contraindications. Acknowledge specific concerns and liaise with medical specialists leading child’s care to ensure consistent messages and to identify appropriate opportunities to immunise. Flag on CHIS and ensure status updated.

Total Refusers (e.g. Parents with ‘natural health’ beliefs): Acknowledge beliefs and concerns, offer information, explanation and constructive challenge where appropriate. Ensure open door policy and opportunities for dialogue. Consider wider impact on child. Consider flagging on CHIS to prevent issuing of further invites. Never too late allows those who change their beliefs to opt back in

Figure 26: MMR Parent Engagement Strategy

This framework is underpinned by an overarching open door, 'never too late' policy to foster effective communication with all parents, and to use key contacts and transition points in the child's life as further triggers to open this dialogue. Whilst the MMR Parent Engagement Strategy has been predicated on the present research in relation to MMR, the approach is equally applicable for all missed immunisations.

Overt 'never too late' policies have been very successfully implemented in other countries. For example, this was the primary approach used by NHS Scotland during the period following the MMR controversy, and MMR uptake rates were maintained at much higher levels than those achieved in England in the same period (Health Protection Agency, 2013). This 'never too late' approach should not just be applied in principle, but will require a fundamental shift in primary and community care to ensure that opportunistic delivery of immunisations, such as MMR, become a practical reality rather than a theoretical consideration. What the MMR Parent Engagement Strategy offers over and above this is a tool to enable practitioners to develop dialogue and to engage with parents in a way that is more likely to be positively received by them, and in doing this to increase the likelihood of a positive outcome when they are ready to make this decision and come through the door.

There has been an increasing amount of published evidence exploring both the characteristics and attitudes associated with uptake of MMR and also more recently a number of published papers which advise health professionals on vaccination communication (Leask et al, 2012). However, there are very few that consider the possibility of a spectrum of different parent sub-groups and perspectives within the unimmunised population, or that look at tailoring strategies to meet the needs of these sub-groups of parents.

The MMR Parent Engagement Strategy that I have developed as an outcome of this thesis therefore offers a new approach to communicating with parents about MMR and immunisation and, as a result, the opportunity to improve service delivery, parent satisfaction with these services, and ultimately the uptake of immunisations such as MMR.

The conclusions, recommendations and a discussion of the limitations of this study are presented in, Chapter 8, the final chapter of this thesis.

CHAPTER 8 CONCLUSIONS, RECOMMENDATIONS AND STUDY

LIMITATIONS

8.1 Introduction

This study was undertaken to explore, in depth, the quantitative data available in respect of MMR in Somerset at the time of the 2009 MMR Catch-up Campaign, and to provide new qualitative data in relation to the attitudes, beliefs and experiences of MMR and immunisation services of a sub-set of parents' who, at the end of March 2009, continued to decline the vaccination. The aim of the study was to identify the characteristics of parents who continued to decline MMR and any factors which influenced parental decision-making within this sub-set of parents; to add to the wider knowledge base in this area of inquiry; and to use this knowledge to improve local immunisation services by answering the following research questions:

What were the social, demographic and geographic characteristics of parents / children who had accepted and declined MMR in Somerset in 2009?

Are parents who persist in declining MMR a single homogenous group?

Does the 'Wakefield study' remain a key factor influencing parents' of school age children to decline MMR in Somerset, or are there additional factors at play?

How have parents' early experiences, attitudes and behaviours in respect of MMR and wider immunisation services influenced their longer term decision-making? Have their attitudes and behaviours changed over time, or as new experiences occur?

Why do some parents persist in declining MMR, despite having information and experiences which appear to counteract the basis on which their initial decision was made?

What factors influence parents who have persistently declined to change their mind and accept MMR for their school-age children?

These questions have all been addressed in the previous chapters and the outcomes will be summarised in this chapter. It should be noted that the study sample was found to be skewed and this needs to be considered when assessing the outcomes, however the findings did appear to add evidence to support the findings of previous studies in relation to the characteristics of parents and children in the unimmunised population (for example, in relation to parents' education and economic status, and birth order of the child) (Dannentun,2005; Friedrichs, 2006).

Key observations arising from the present study are as follows:

Parents who decline MMR for their children are not a single homogenous group. In fact they consisted of a number of identifiable sub-groups, each of which had different motives, decision pathways and predicted outcomes in relation to potential to change their mind and accept MMR. From this it was possible to identify interventions and changes in practice to maximise opportunities to engage with these parents and as a result increase the possibility of achieving a positive outcome (immunisation).

In terms of geographic characteristics, the parents / children in the two age groups studied did have different patterns of distribution across Somerset. The secondary school age children were found to be concentrated in areas that are recognised as having large populations which ascribe to more alternative lifestyles, whilst there was a much more generalised distribution for the primary school age group across all parts of the county.

Whilst many parents were keen to emphasise that the 'Wakefield' controversy was not the primary factor in making their decisions, the very high number of references made to this suggests that this was a very significant factor. For example, the primary school age group were temporally associated with the 'Wakefield' controversy and more

generalised concern about MMR, whilst the older children are more likely to be more traditionally 'anti immunisation'. Even the differences in geographic distribution are therefore also likely to be linked to parent sub-group types as identified in this study and were therefore, at least in part, determined by reactions to the Wakefield study.

However, for most parents, the exploration of the nine themes arising from the data illustrate that this is not the only, or the most important factor in their continuing decisions, and very many had changed their decisions over time and had accepted MMR for their children. The reasons for doing this were multiple and were again intrinsically linked to the particular parent sub-group.

There is good evidence that health professionals have a key role in addressing parental concerns in respect of immunisation. The evidence from this study confirms that GP practice was the most significant factor associated with uptake, and the interviews with parents appear to support the suggestion that interaction between health professional and parent is critical, with evidence of examples of effective interactions addressing concerns and motivating parents towards accepting vaccines, whilst poor communication leads not only to refusal, but can also result in long-term damage to these relationships and dissatisfaction with the care they have received. Assuming that refusal to accept MMR, and other immunisations, arises from a position of ignorance which can be simply addressed by persuading or by providing more information is likely to be counterproductive when interacting with these parents, because it fails to take account of the multiple, complex reasons that underpin these parents decisions.

Parents report a reluctance to change their views because of a perception that this would mean having to admit that their original decision was wrong, or more importantly because their attempts to engage professionals had previously failed, making them so

angry that their views had become entrenched. Providing opportunities for dialogue to be reopened offers the possibility of interaction which could enable parent and professional views to be explored, to shape future experience of immunisations, and to potentially negotiate a way forward together. However, it is recognised that once children reach school age there are currently very few structured or routine opportunities for parents to make contact with health professionals and identifying and capitalising on these in practice may require a more creative approach.

Health professionals, as parents themselves, also have a significant influence (as friends, as family members, and as colleagues) far beyond their professional roles, but in the main these individuals share wider parental concerns and, ironically, lack confidence in medical models. The assumption that simply educating those who have an overt role in administering immunisations will change attitudes, similarly overlooks the impact of their underlying parental concerns on their own interactions with other parents, and also the influence of the wider health care workforce who may have limited professional knowledge of immunisation but who may also be approached as health 'experts' by their roles as friends, neighbours and peers. An approach more in line with the personalised engagement needed with parents, may also be more effective in positively addressing and utilising these professional influencers, rather than just relying on traditional, technical education for immunisation service providers.

The fact that parents in the sub-groups identified within this study appeared to make decisions through engagement, through communicating with and through relating to others, reflects the findings from other recent research (Leach and Fairhead, 2007). The potential to explore the factors that influence these decisions through open engagement, rather than always resulting in division or polarization of views, has the potential to offer a means of effecting change by blurring and bridging parent and professional perspectives. This could have positive outcomes for all involved.

8.2 Recommendations

A very strong message arising from this study was the need, expressed by parents, for more dialogue with health professionals. Parents, in all three groups who had declined MMR, reported that the reasons for them reaching this decision had rarely been explored or challenged by health professionals. Many also felt that professionals were ill-equipped to do this, or had personal doubts themselves. They reported that there were actually few, or no, opportunities for dialogue to take place in the current organisation of immunisation services. If parents' needs are to be effectively met, practice needs to change to facilitate these opportunities and to enable professionals to actively engage in open dialogue with parents on these issues.

This study builds on previous evidence relating to characteristics which influence decisions to accept or decline immunisation, and specifically MMR. Identification of the parent sub-groups; an improved understanding of the factors associated with these groups; and of how these then inform their decision-making pathways, offers an opportunity for health professionals to use new more structured approaches for communication and engagement, which are specifically tailored to the needs of each of these sub-groups of parents. These approaches also align well with the current personalisation agenda in health care (NICE, 2014) and with contemporary 'nudge and shove' theories of public health behaviour change (Thaler and Sunstein, 2008) and have the potential to normalise the experience of accepting immunisation by developing a professional approach based on greater openness, and more opportunities for discussion and challenge, similar to that which has already been highly successful in increasing rates of breastfeeding (<http://www.clahrc-bbc.nihr.ac.uk>). It is an approach that can also be readily integrated with existing professional frameworks, such as, the Healthy Child Programme (0-5 and 5-19), and the Health Visiting 'A Call for Action: Service Model' and can be implemented by

adapting the principles of 'motivational interviewing' which the majority of health professionals involved in the delivery of immunisation services will be familiar with, and already use in other aspects of healthcare where individuals may be resistant to change (for example, smoking cessation).

8.2.1 The Overarching MMR Parent Engagement Strategy and group-specific actions

The MMR Parent Engagement Strategy that has been developed within this thesis offers a framework for engaging with all parents, but particularly those who decline immunisation. It offers strategies to address the concerns of each of the three parent groups identified in this study, based on their different information needs, and requirement for different approaches and levels of engagement.

From a commissioning perspective, embedding frameworks such as this in service specifications and commissioning intentions offers a more cost effective approach to improving immunisation uptake than funding large, poorly targeted and ineffective catch-up campaigns. It is therefore recommended that further research is undertaken to provide evidence of the effectiveness of the approach in practice and to inform future commissioning decisions (for example, by undertaking studies comparing standard approaches in GP practices with the framework approach, and measuring impact on uptake and acceptability for patients and professionals). There is also a wider need to build the evidence base to inform effective communication in relation to immunisation, given the significance of the interaction between professionals and parents on decisions to immunise.

8.2.2 Additional recommendations

Good communication, as described above is only one element of a range of measures that have been identified to improve uptake of immunisation in Somerset. Whilst this is considered to be the most significant of the study recommendations, and is of relevance to all parties who deliver immunisation services, strategies are also required to address other potential barriers identified as a result of undertaking this study, such as difficulties with access to healthcare, or specific factors associated with the providers of immunisation services.

8.2.2.1 GP Practice specific factors

This study identified some very specific findings in relation to immunisation uptake in local GP practices. Whilst the application of the framework may act to improve engagement with parents, regardless of the practice with which they are registered, it is not clear from the evidence obtained as part of this study whether there are other underlying issues in relation to practice-specific factors and uptake in these GP practices. It is therefore recommended that an additional investigation is undertaken with those practices that were identified as significant outliers in Phase 1 of the study.

8.2.2.2 Independent schools

There is a need for a further investigation of the immunisation history of students in independent boarding schools in Somerset to ascertain if low uptake is related to poor record keeping or represents a true incidence of under-immunisation, especially amongst international students.

8.2.2.3 Ethnic Minority Communities

There is a need to consider the use of alternative schedules, and access to immunisation services in country of origin, by parents of children from ethnic minority communities. Parents may not report immunisation abroad to local health systems, and

my not be aware of any need to do this which may result in under-recording of vaccine uptake. Further work is needed with health services in areas with large ethnic minority communities to identify mechanisms and opportunities to identify the true immunisation status for these children.

8.2.2.4 Vaccine overload

All parents identified 'vaccine overload' as a theme, and their rationales and misunderstandings in respect of the capacity and capability of human immune systems were almost universal regardless of sub-group. This has serious implications as new programmes enter the national schedule and combination vaccines containing multiple antigens become ever more common. In line with other parental concerns, the parents in this study reported that there was little attention given to addressing or challenging these misconceptions by health professionals. In fact, there was evidence that many health professionals themselves express similar reservations. There is therefore an urgent need for this to be considered early in any engagement with both professionals and parents as part of any social interaction relating to immunisation and in communication and training strategies at local, regional and national levels.

8.2.2.5 Media

There was a clear message from parents in this study for immunisation services 'not to waste money' on media campaigns, especially those related to MMR, since these appear to do little to reassure parents, or to change their mind. One to one social communication and follow up, in person or by phone, was identified as a more effective approach and this should be the focus of future communication should additional activity be required.

8.2.2.6 Data validation

A key finding when undertaking the study was that the current data held by Child Health Departments, particularly in relation to the immunisation history of school-age children is not accurate. Control over data and the processes which underpin its accurate collection are vital if that is to be achieved. This must include processes for regular updating and cleansing. In order to achieve the required standards for CHRDs and CHIS system information requirements, it is essential that a national service specification is developed not just for the IT systems themselves but also for the Child Health Records Department that manages the whole arrangements around this. This specification should clearly outline the expectations for data sharing and accuracy, define the deliverables and outcomes, and provide mechanisms for joining up teams and systems nationally and locally to minimise inaccuracy and ensure continuity of immunisation history.

However, the NHS Information Centre COVER programme, which obtains data electronically from CHRDs, does not currently monitor school leaver booster, or BCG testing or vaccination. These activities have to be recorded and reported separately on KC50 forms and returned directly to the NHS Information Centre. This complicates the return process, and introduces greater potential for inaccuracy, manual data entry error, and therefore poorer reporting.

Any specification must therefore clearly define the cohort that the system must record as being children aged 0–19 years in order to have national validity. The system should be automatically linked to routine national datasets, with the COVER data collection expanded to capture uptake and coverage of all childhood immunisations including the existing adolescent programmes, the new Meningitis C booster, and childhood flu programmes.

8.2.3 Summary of Recommendations:

Undertake further research to test the framework model in practice and to explore the impact of changing approaches to improving communication with parents in primary care

If effective, align the 'Never too late' framework approach with existing public health nursing service frameworks and service models, and embed the framework into specifications for commissioning immunisation services

Undertake a specific exploration of potential models for improving access to immunisation services for children with pre-existing medical conditions. Link with Paediatric clinicians and specialist children's services.

Investigate fully the immunisation status of, and access to services for, students attending local independent boarding schools, and those in ethnic minority communities

Review current communications and media strategies to include approaches detailed in the framework, and specifically to identify ways of addressing issues related to vaccine overload

Undertake a full data validation exercise for all immunisation programmes in Somerset

8.3 Study Strengths and Limitations

The findings of this study have provided in depth information on the issues which are relevant and important to a group parents in Somerset who decline MMR, and there are many commonalities with previous research findings. The methodology used

enabled the topic to be explored in both depth and breadth, with rich subjective data obtained from individual parents supplementing and enhancing the epidemiological and demographic data obtained via the survey and baseline study. This has provided a much greater understanding of the issues related to the Somerset area than had previously been available and has enabled very effective targeting of approaches to improve local services. Whilst it is acknowledged that there were some significant limitations to elements of this approach, the mixed method study design, and particularly the linking of data by unique identifiers attempted to mitigate against some of these limitations and to provide greater validity and robustness to the study conclusions and recommendations. However, it is recognised that there are a number of limitations which do need to be considered, as follows:

The response rate was relatively low at 16% for the secondary school age group and 20% for primary school age group. The responses may not therefore be representative of the wider unimmunised populations. There may be a number of reasons for the low response rates. Outcomes of the data validation exercise and the national evaluation undertaken in 2013 suggest that it is possible that the original groups that were sent the surveys may have contained children who were actually vaccinated, and therefore should have been in the 'unimmunised' groups, or who had moved away and should therefore have been excluded. These surveys may have been discarded by the recipients rather than returned. Whilst this would not impact on the validity of the survey responders, whose data was cross-referenced to ensure eligibility, it would have potentially impacted on the numbers of children in each age group and therefore on the response rate.

Evidence from the telephone helpline, that was set up to respond to queries from parents who received the surveys, suggested that there were parents in both the 'alternative health beliefs' and the 'single vaccine' group who may also have discarded

the survey as they did not wish to have any further correspondence from immunisation services on this matter, or because they thought that the survey was yet another invite to attend for immunisation. These groups may therefore be underrepresented in the survey response and agreed to follow-up populations.

The data obtained from Phase 1 and Phase 2 also suggests that there may be underrepresentation of parents from lower socio-economic groups, particularly in the survey responder group. The study methodology, that is use of surveys, is likely to have limited the response amongst this group, despite having put in place alternative means of completing the questionnaire (by phone or home visit), alternative versions including 'easy read' and different languages, and piloting the approach with a variety of different parent groups. There is good evidence that parents in lower socio-economic groups fail to immunise because of very practical issues with access to services. These parents' needs would be addressed in part by the implementation of the framework and also through application of the NICE Guidelines 21 compliance framework, and there is already a requirement for NHS immunisation services to implement this. The study intended to look at other factors that may have also impacted on decisions to accept or decline, which had been identified as requiring further investigation in these guidelines and the findings should therefore provide additional information to supplement the actions arising as a result of the implementation of the NICE Guidelines.

The qualitative data for this study was obtained via a number of sources. These included informal telephone conversations with individuals who had accessed the helpline following receipt of the survey questionnaire, respondents to the survey, and people who agreed to take part in one-to-one interviews. Consequently, this is a self-selecting group. Moreover, the study is grounded in a particular context (Somerset),

time (2009 / 2012), and cases (these respondents) and the findings may not therefore be fully applicable in other settings or populations.

The possibility of recall bias is a recognised as a potential risk when using interviews with parents to explore historical events related to decision-making. However, the study included independent checking of immunisation status and timings as a way of identifying and reducing the potential impact of recall errors on the results. Similarly, there was cross referencing of demographic, immunisation uptake and qualitative data between and within the immunised and unimmunised groups to try to improve, as far as possible, the validity of the data.

The factors identified above may have acted to skew the findings of the study, potentially towards those who were in principle more positive and naturally accepting of immunisation, but who had not accepted this immunisation or had not adhered to the national schedule where this was accepted, for example, those with pre-existing medical conditions. The study should therefore be considered as a specific investigation of a sub-group of the under-immunised population, rather than being fully representative of the whole unimmunised population, on this basis.

The numbers of children required to be vaccinated in order to achieve the required levels of uptake and coverage for Somerset are relatively small, and may be achieved by focussing on specific sub-groups of children who are under-immunised. The recommendations within this study therefore do have valid application in practice and have the potential to improve both immunisation uptake and the experience of using immunisation services for the Somerset and wider populations in the South West of England in which this will be applied in future.

8.4 The impact of the study on current practice

This study has already directly influenced practice in the following ways:

The approach to the 2013 MMR Catch up Campaign was completely altered as a result of the findings from this study. The national plan for the campaign recognised that there may be an issue with the accuracy of data for this age group of children. However, this was to be addressed by paying GPs to send letters to patients on their lists that they had recorded as under-immunised. This would have had little or no impact on improving data accuracy at CHR D level. Within the South West an arrangement was therefore negotiated with the local GPs, Primary Care Commissioning, Local Medical Committees and the Clinical Commissioning Groups to instead fund the GPs to validate lists produced by the CHR D, to correct any errors where children had been vaccinated or were no longer registered, add missing children, and then return these validated lists to CHR D. This then enabled the CHR D to update the central CHIS records and to send letters on behalf of the GPs only to the parents of children on the newly validated lists. This reduced the number of letters sent by the NHS England Area Team by more than 8000, and saved over £20,000. More importantly it also reduced the time spent by GP Practices and other staff in responding to calls from parents who were just advising that the letters were wrong, or complaining about receiving a letter when their child had had MMR, reduced parental anxiety, and enabled more effective planning of clinic time to deliver the programme alongside other primary care priorities.

Data validation significantly improved the uptake rates as recorded nationally for the NHS England Area Team. It also enabled better use of resources by more accurately targeting the delivery of services to those areas identified with genuinely poor uptake and coverage. Good practice and lessons learned from the data validation exercise has been shared regionally and nationally via the South West Scientific Conference

February 2014 and the Field Epidemiology National Conference in March 2014. The researcher also contributed to the development of the protocol, and with coordination and data provision for the National Evaluation of the 2013 MMR Catch-up Campaign, including development of the final report for the Department of Health's Oversight Group, which was published in February 2014

Evidence from the study was used as part of the BBC Inside Out investigation into the use of homeopathic 'vaccines' and the researcher's interview was used as part of the subsequent broadcast in January 2012. Following the investigation, the MHRA took action by issuing instructions to two large suppliers of homeopathic remedies (Ainsworths and Helios) to prevent them from advertising their homeopathic products as alternative treatments to proven, conventional vaccines such as those for measles, meningitis or whooping cough.

An independent schools project has been commenced in Somerset. The initial phase involves a collaborative approach with the CHRD staff linking with head teachers and with nursing and GP staff responsible for providing medical services to these schools working together to validate the records of children who attend. This includes developing communication protocols and processes to ensure on-going validation and updating each school year. This has improved the targeting of services to this group of children.

A specific investigation of current practices with the GP surgery which was identified as the most significant outlier in this study identified a number of administrative issues in relation to the provision of immunisation services. These included insufficient and inflexible clinic timings, waiting lists and lack of any proactive follow-up of non-attenders. The Practice had persistently low uptakes of all childhood immunisations, and there was a general perception that this was associated with the alternative

lifestyles of many within the local population. The Screening and Immunisation Team worked with the GP practice to identify the potential issues and to develop an action plan. This plan included introducing additional clinics, improved data recording, strengthening the support provided by CHR D to schedule children into these clinics and telephone follow-up and re-booking of non-attenders. The plan has been fully implemented and the first quarter data is awaited to assess whether the changes have improved uptake. If effective this approach will be used by the Screening and Immunisation Team to investigate and support other poorly performing GP practices

The recommendations for further research – particularly the case-control studies of the MMR Parent framework approach - forms part of the submission, and will be taken forward as part of the research programme, for the Bristol Immunisation Group Health partners Integration Team (BIG HIT) project. This project is a collaborative between NHS and Academic partners (including University of the West of England, Bristol University, the Bristol Vaccine Research Unit and Social Medicine and Behavioural Insights experts from Public Health England) which aims to improve healthcare by developing research to support innovative ways of improving care through whole systems approaches.

The aim of this study was to investigate the distribution of a number of variables relating to factors associated with MMR uptake in Somerset, to compare these factors within and between defined subsets of the Somerset population, to explore the basis on which parents in Somerset made decisions in relation to MMR immunisation, and to compare the findings from this study with those of previous studies described. The evidence presented in this thesis confirms that these aims have been achieved and the research questions have been answered.

In relation to the research questions posed at the outset, the demographic characteristics of the parents and children who accept, decline or fail to attend are clearly described in Chapter 5 and the evidence of the qualitative factors that influenced their original decision not to accept MMR is explored in Chapter 6.

The key findings is that parents who decline or delay MMR are not a single homogenous group, and that there are instead, parent sub-groups within this population who have specific rationales and motivations for the decisions that they make. There is evidence that parents of children with medical conditions, and those who have opted for single vaccines in the past, for example, are more likely to change their mind and accept MMR at a later date than parents who have alternative health beliefs, however, the latter group forms a large proportion of the remaining unvaccinated population and this remains a challenge for immunisers.

There are however some clear similarities between the characteristics of parents in this study and those described previously, particularly within the Millennium Study (Bedford et al, 2007), and this information can be used to inform the development of more effectively targeted and responsive immunisation programmes.

The new information in relation to the identification of specific parent sub-groups offers possible explanations for parental decision-making, and the MMR Parent Engagement Strategy developed as a result of this improved understanding offers new structured ways of interacting and engaging with parents, and with health professionals who provide care and advice to members of the public, to improve the quality and effectiveness of immunisation services and a potential means of improving the uptake of programmes such as the MMR immunisation programme.

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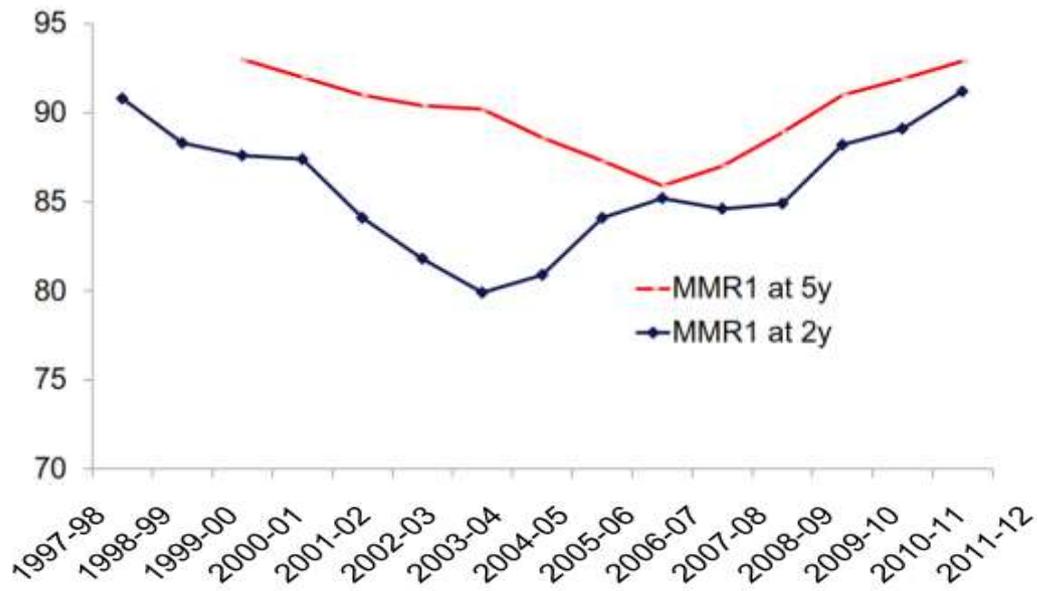
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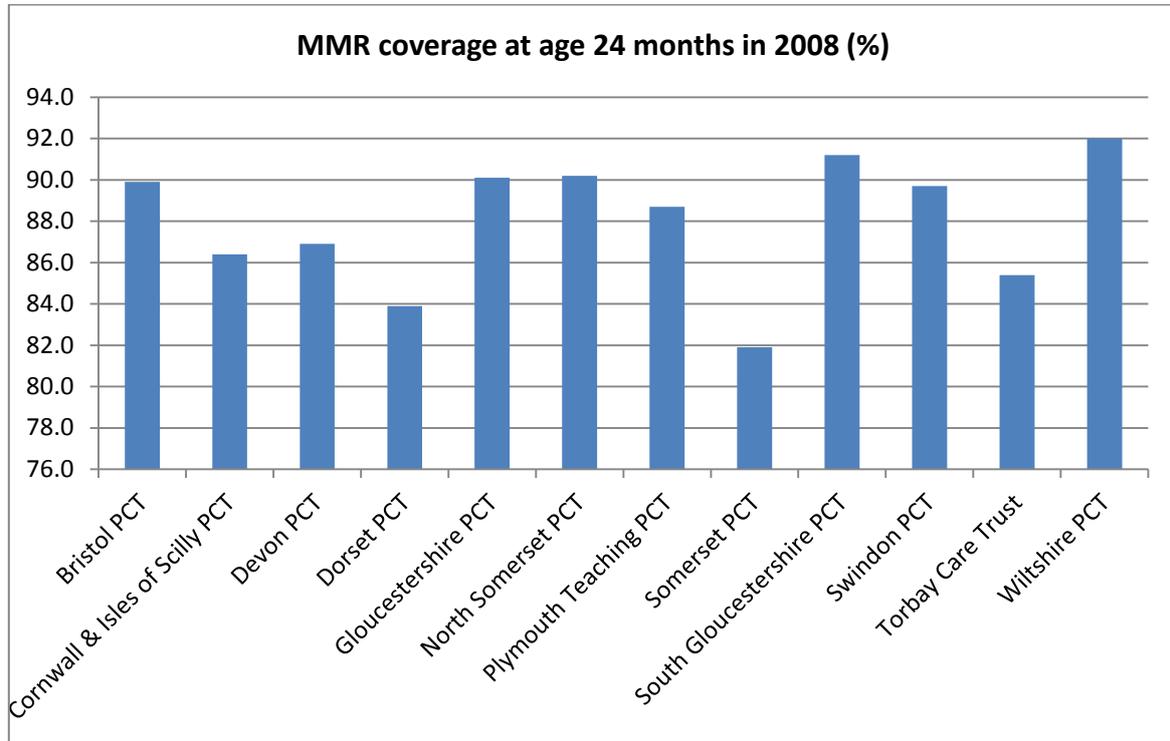
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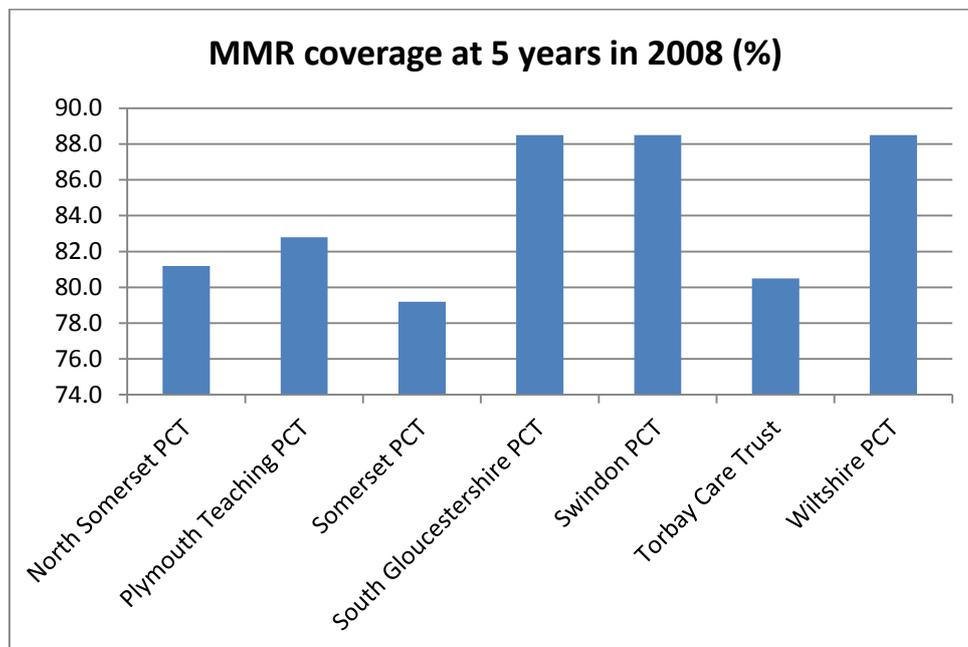
Appendix 1: MMR Coverage at 2 and 5 Years of Age, England, 1997/08 – 2011/12



Appendix 2: MMR Uptake in the South West and Somerset in 2008



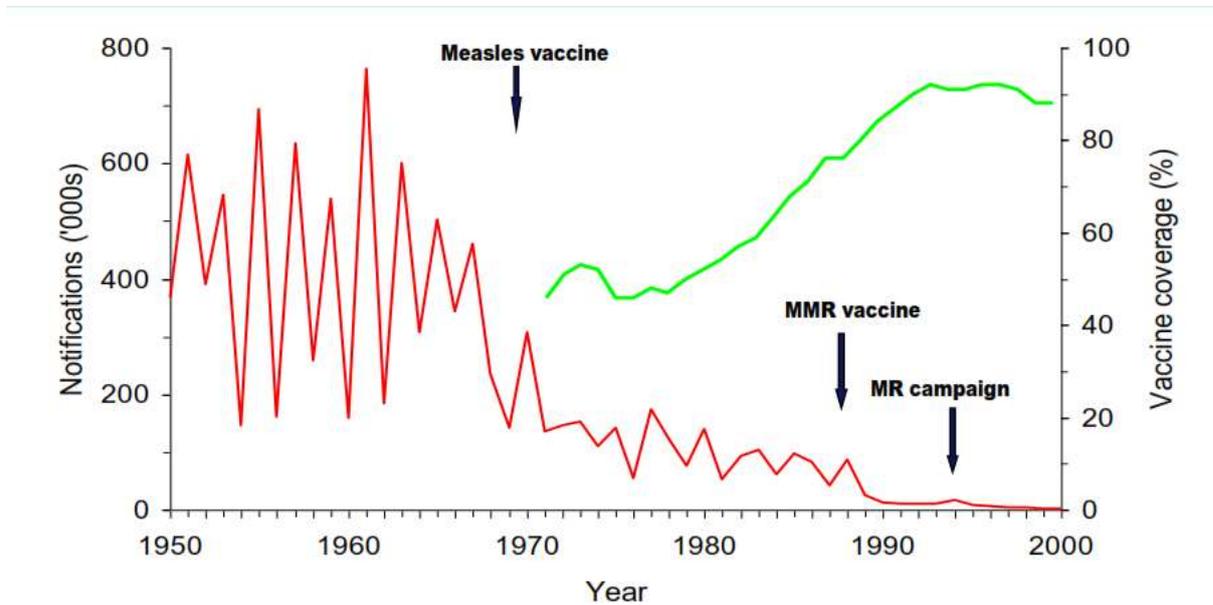
MMR uptake at 24 months of age by PCT in the South West in 2008 (MMR1)



MMR uptake at 5 years of age by PCT in the South West in 2008 (MMR2)

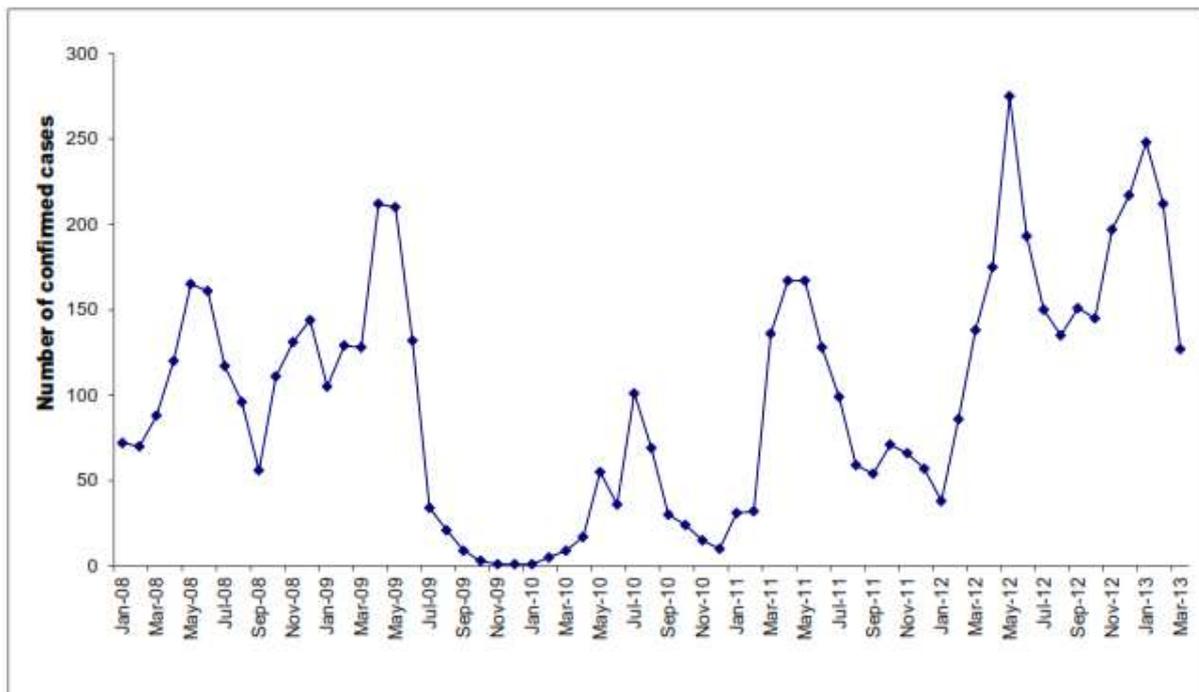
Appendix 3: Measles Notifications & Vaccine Coverage 1950 – 2000

Annual Measles Notifications & Vaccine Coverage, England and Wales, 1950 - 2000



Source: Public Health England

Monthly Cases of Confirmed Measles, 2008 – March 2013, England



Appendix 4: Measles notifications and deaths in England and Wales: 1940 to 2013

Published 10 January 2014

Year	Notifications	Total Deaths
1940	409,521	857
1941	409,715	1,145
1942	286,341	458
1943	376,104	773
1944	158,479	243
1945	446,796	729
1946	160,402	204
1947	393,787	644
1948	399,606	327
1949	385,935	307
1950	367,725	221
1951	616,182	317
1952	389,502	141
1953	545,050	242
1954	146,995	45
1955	693,803	174
1956	160,556	28
1957	633,678	94
1958	259,308	49
1959	539,524	98
1960	159,364	31
1961	763,531	152
1962	184,895	39
1963	601,255	127
1964	306,801	73
1965	502,209	115
1966	343,642	80
1967	460,407	99
1968	236,154	51
1969	142,111	36
1970	307,408	42
1971	135,241	28
1972	145,916	29
1973	152,578	33
1974	109,636	20
1975	143,072	16
1976	55,502	14
1977	173,361	23
1978	124,067	20
1979	77,363	17
1980	139,487	26
1981	52,979	15

Year	Notifications	Total Deaths
1982	94,195	13
1983	103,700	16
1984	62,079	10
1985	97,408	11
1986	82,054	10
1987	42,158	6
1988	86,001	16
1989	26,222	3
1990	13,302	1
1991	9,680	1
1992	10,268	2
1993	9,612	4
1994	16,375	0
1995	7,447	1
1996	5,614	0
1997	3,962	3
1998	3,728	3
1999	2,438	3
2000	2,378	1
2001	2,250	1
2002	3,232	1*
2003	2,488	0
2004	2,356	1
2005	2,089	0
2006	3,705	1
2007	3,670	1
2008	5,088	2
2009	5,191	1
2010	2,235	0
2011	2,355	1
2012	4,210	1
2013**	6,102	1

*Known not to be measles infection

**Provisional data

Source: Office for National Statistics

Appendix 5: Literature Review MeSH Terms and Search Results

Search Strategy Results			
MeSH terms	No. of Articles identified	Articles included (2009)	Additional articles identified (2013 - 14)
'parents' AND 'risk' AND 'immunisation'	112	12	0
'parents' AND 'risk' AND 'MMR'	97	9	5
'parents' AND 'perceptions' AND 'MMR'	21	9	5
'parents' AND 'attitudes' AND 'MMR'	76	19	9
'parents' AND 'decision-making' AND 'MMR'	60	18	10
'parents' AND 'decisions' AND 'MMR'	78	13	3
'factors' AND 'affecting' AND 'MMR' AND 'uptake'	6	3	0
'factors' AND 'affecting' AND 'immunisation' AND 'uptake'	20	4	2
'factors' AND 'influencing' AND 'immunisation' AND 'uptake'	28	3	1
'factors' AND 'influencing' AND 'MMR' AND 'uptake'	28	3	1
'MMR' AND 'Autism'			
Limit to publication year 1990 – 2005	387	86	0
Limit to publication year 2005 – 2013	289	28	23
'MMR' AND 'Bowel Problems'	23	5	0
'MMR' AND 'Crohn's Disease'	50	9	3
Total no. of articles reviewed	1275	229	53
Total no. related to Autism or gastrointestinal problems and MMR	749	128	26
No. of duplicates removed from remaining articles		51	0
Policy documents and academic sources			35
Total no. of articles included relating to specific factors associated with uptake		40	112
'individual' AND 'freedom' AND 'MMR'	2	1	0
'collective' AND 'responsibility' AND 'MMR'	1	1 (duplicate)	0
'Compulsory' AND 'vaccination'	35	9	0
'Herd' AND 'immunity' AND 'MMR'	57	5	5
'Vaccine' AND 'overload'	83	8	2

Appendix 6 – Invite letter Phase 2

Dear Parent / Guardian,

Somerset MMR Immunisation Study

In January 2009, the Chief Medical Officer announced a 'catch-up campaign' for children who had not received Measles, Mumps and Rubella (MMR) as part of their routine childhood immunisations. Your child (whose name appears on the envelope) was one of approximately 13,800 children in Somerset who were invited to attend as part of this campaign.

NHS Somerset wants to find out what parents know about immunisations, particularly MMR, and investigate any reasons why parents have accepted or declined this immunisation for their children. We are inviting the parents of all children in Somerset who were invited to have the immunisation during the 'catch-up campaign', and were between 6 and 15 years old at the time, to take part in this study. Please note that when we refer to parents this also includes 'legal guardians'.

We are really interested in your views and information, and would be grateful if you could take the time to complete the enclosed questionnaire and return it the **FREEPOST** envelope provided.

The information will be used to help us plan and improve services for children and families in the future.

I can assure you that the information you give will be treated in the strictest confidence, and no reference will be made to any individuals in any publications. The results of the survey will be compiled into a report about immunisation in Somerset, which will be posted on our website (www.somerset.nhs.uk). It will also be used to inform a wider research project which will explore this in more depth by interviewing parents.

Completing this survey will not commit you to any further involvement. However, if you would like to take part, and would be prepared to be interviewed, all you need to do is include your contact details in the last section of the questionnaire. We will then contact you with more information and to discuss any future participation in the study with you.

An Information Sheet with the answers to frequently asked questions is attached to this letter, but if you have any other queries regarding this survey please contact us on 01935 384084 and leave your name and a daytime contact number. We will return your call.

Thank you for your time in taking part in this survey.
Yours faithfully

Julie Yates
Consultant in Public Health
NHS Somerset

Appendix 7: Parent Census Survey Questionnaire



MMR Project Survey
JY Size 12 Colour new

Appendix 8 – Parent Information Leaflet (Q & As Phase 2)

What is this study about?

This study is about finding out from parents what they understand about immunisations, particularly MMR, and how they then make decisions to accept or refuse these immunisations for their children.

(For the purposes of this study we are including anyone with parental responsibility for the child when we talk about 'parents', for example if you are a 'legal guardian' then we include you).

Why did you pick me?

The questionnaire is being sent to parents of children who were invited to have the MMR immunisation as part of the 2009 'catch-up campaign', and who were aged between 5 and 15 years old at the time. We are interested in finding any reasons for accepting or refusing the MMR vaccine

How did you get my address?

We have access to the names and addresses of all people registered with a GP in Somerset. We contact patients and the public, from time to time, in order to help the NHS to improve the service that it provides.

How can this be confidential when you have an identification number on the questionnaire?

Each questionnaire has an identification number in order that we can see who has responded to the survey. We use the identification number to send out reminders to those who have not replied. Only a limited number of people are able to access the names and addresses, and as we will not store your personal information (name, address or which GP you are registered with) with your responses your anonymity will be maintained.

Can I give this to someone else to complete? It seems much more relevant to them.

The questionnaire should be answered by the person to whom it is addressed. Please feel free to discuss the questions with other members of your household or friends (and of course, they may fill in the questionnaire on your behalf) – but make sure all the answers relate to you and your child.

Do I have to complete this questionnaire?

It is not compulsory to complete the questionnaire, but it would help us if you would. If you really feel that you don't want to complete it then you do not have to do anything. You will automatically be sent one reminder after about two weeks. If you do not respond to this within one month your identification number will be removed from the database and you will not be contacted again.

Isn't this very expensive to carry out?

A very small part of the overall NHS budget is set aside to look at people's experiences of NHS services. In order to improve and change services, and to make them more effective, we need to consult with patients and the public. As part of this work we often collect information which helps health professionals to plan services appropriately.

If I agree to take part in this study what do I need to do?

Please complete the enclosed questionnaire and post it back in the **FREEPOST** envelope provided. This is all you need to do for this part of the study.

If I complete the questionnaire will I be involved in further research on this subject?

No. You need not be involved in anything else.

However, there will be a second phase of the project which will involve asking parents to tell us about their own experiences of the immunisation processes and services. This will be done by interviewing parents and, if you chose to participate, would be arranged at a time and place convenient to you.

If you would like to be involved in the second project, and would be prepared to be interviewed, you need to include your name and contact details in the section at the end of the questionnaire so that we can contact you with more information.

Providing your personal details will not commit you being involved in this further research and you may withdraw your consent at any time if you change your mind.

I'm having difficulty filling out this questionnaire

If you would like help, we can complete the questionnaire over the telephone. It will take approximately 20 minutes. Please phone us on 01935 384084 and leave your name and daytime contact details.

We will phone you back to save your phone bill and will help you complete it.

Thank you for reading this information leaflet.

If you need more information, contact the researcher:

Julie Yates.
NHS Somerset,
Wynford House,
Lufton Way,
Yeovil,
BA22 8HR

Telephone: 01935 384084
Email: Julie.yates@somerset.nhs.uk

If you would like to speak to an independent advisor who knows about this study you can contact:

Professor William Lauder,
Department of Nursing and Midwifery,
University of Stirling,
Stirling,
FK9 4LA

Telephone: 01786 466345 Email: William.lauder@stir.ac.uk

Appendix 9: Comparative summary of three theme based Approaches to Analysis

(taken from Guest et al, 2012, p.17):

	<i>Phenomenology</i>	<i>Grounded Theory</i>	<i>Applied Thematic Analysis</i>
Defining features	<p>Focusses on subjective human experience</p> <p>Analysis typically thematic in nature</p> <p>Often used in humanist psychology, but approach has been adopted in humanities and social sciences</p>	<p>Uses a systematic comparative technique to find themes and create codes</p> <p>Properly done, requires an exhaustive comparison of all text segments</p> <p>Theoretical models built on themes / codes that are 'grounded' within the data</p>	<p>Identified key themes in text. Themes are transformed into codes and aggregated in a codebook</p> <p>Uses techniques in addition to theme identification, including word searches and data reduction techniques</p> <p>Can be used to build theoretical models to real-world problems</p>
Epistemological Leaning	<p>Interpretive</p> <p>Subjective meaning is interpreted and extrapolated from discourse</p>	<p>Interpretive / positivist</p> <p>Interpretive in that quantification is not included</p> <p>Positivist in that it is systematic and assertions are required to be supported with evidence (text)</p>	<p>Positivist / interpretive</p> <p>Positivist in that assertions are required to be supported by evidence (text)</p> <p>Processes are also systematic and quantification can also be employed</p> <p>Methods and processes (except those of a quantitative nature) can also be used in an interpretive analysis</p>
Strengths	<p>Good for smaller data sets</p> <p>Has latitude to explore data more deeply and extrapolate beyond the text</p> <p>Good for cognitively oriented studies</p>	<p>Good for smaller data sets</p> <p>Exhaustive coverage of the data</p> <p>Interpretation supported by the data</p> <p>Can be used to study topics other than individual experience (e.g. social process, cultural norms etc)</p>	<p>Well suited to large data sets</p> <p>Good for team research</p> <p>Inclusion of non-theme-based and quantitative techniques adds analytic breadth</p> <p>Interpretation supported by the data</p> <p>Can be used to study topics other than individual experience</p>
Limitations	<p>Focuses only on human experience</p> <p>May interpret too far beyond what's in the data</p> <p>Not necessarily systematic</p>	<p>Does not include quantification</p> <p>Time consuming; logistically prohibitive for long data sets</p>	<p>May miss some of the more nuanced data</p>
Key sources	<p>Giorgi (1970, 2009); Moustakas (1994); Smith, Flowers & Larkin (2009)</p>	<p>Glaser & Strauss (1967); Corbin & Strauss (2008); Chamaz (2006)</p>	<p>No one text</p> <p>Elements of inductive thematic analysis can be found in numerous books on qualitative data analysis</p>

SOMERSET MMR STUDY 2012

Interview Topic Guide for Phase 3

Introduction

Obtain consent and confirm understanding of study.

Background

Confirm details from postal questionnaire – ages of children; immunisation history; demographic data, etc (brief)

Knowledge of immunisation and MMR

- General (what does it do / how does it work?)
- Think about the first time MMR was offered. What did they know then about risks of the diseases / of side effects related to immunisation? Relative risk of each?
- Was this knowledge different when they were offered the vaccine during the catch-up campaign?
- What are their beliefs in relation to collective responsibility / individual freedom in relation to immunisation?
- What information did they have to help them make their decision? Did they feel sufficiently informed?
- Where did they get their information on immunisation / MMR from? (friends, family, professionals (GPs, nurses, Health Visitors), the internet, media (TV, radio or newspapers) or somewhere else?).
- If more than one which was most influential?
- How did they use this information?

How did they make the decision to vaccinate or not?

- Was this an active or passive decision? (e.g. refused consent or just didn't attend)
- What previous experience did they have of immunisation services? (Access, appointments, confidence in professionals, attitudes of professionals or other key staff?) Positive / negative.
- Had the child had previous immunisations? Previous children had MMR? If so, why different this time?
- Explain how and why the decision was made and by whom:
 - initially
 - during the catch-up campaign?

Appendix 11: MOSAIC Group Definitions

Mosaic UK Groups and Types

Mosaic classifies households in the United Kingdom by allocating them to one of 61 types and 11 groups.

Group	Group Description	% Households	Type	Type Description	% Households
A	Symbols of Success	9.62	A01	Global Connections	0.72
			A02	Cultural Leadership	0.92
			A03	Corporate Chieftains	1.12
			A04	Golden Empty Nesters	1.33
			A05	Provincial Privilege	1.66
			A06	High Technologists	1.82
			A07	Semi-Rural Seclusion	2.04
B	Happy Families	10.76	B08	Just Moving In	0.91
			B09	Fledgling Nurseries	1.18
			B10	Upscale New Owners	1.35
			B11	Families Making Good	2.32
			B12	Middle Rung Families	2.86
			B13	Burdened Optimists	1.96
			B14	In Military Quarters	0.17
C	Suburban Comfort	15.10	C15	Close to Retirement	2.81
			C16	Conservative Values	2.84
			C17	Small Time Business	2.93
			C18	Sprawling Subtopia	3.08
			C19	Original Suburbs	2.41
			C20	Asian Enterprise	1.02
			D21	Respectable Rows	2.65
D	Ties of Community	16.04	D22	Affluent Blue Collar	3.12
			D23	Industrial Grit	3.82
			D24	Coronation Street	2.81
			D25	Town Centre Refuge	1.13
			D26	South Asian Industry	0.88
			D27	Settled Minorities	1.62
			E28	Counter Cultural Mix	1.36
E	Urban Intelligence	7.19	E29	City Adventurers	1.27
			E30	New Urban Colonists	1.36
			E31	Caring Professionals	1.08
			E32	Dinky Developments	1.10
			E33	Town Gown Transition	0.76
			E34	University Challenge	0.26
			F35	Bedsit Beneficiaries	0.71
F	Welfare Borderline	6.43	F36	Metro Multiculture	1.67
			F37	Upper Floor Families	1.72
			F38	Tower Block Living	0.49
			F39	Dignified Dependency	1.34
			F40	Sharing a Staircase	0.50
G	Municipal Dependency	6.71	G41	Families on Benefits	1.21
			G42	Low Horizons	2.64
			G43	Ex-industrial Legacy	2.86
H	Blue Collar Enterprise	11.01	H44	Rustbelt Resilience	3.00
			H45	Older Right to Buy	2.67
			H46	White Van Culture	3.17
			H47	New Town Materialism	2.17
			I48	Old People in Flats	0.83
I	Twilight Subsistence	3.88	I49	Low Income Elderly	1.63
			I50	Cared for Pensioners	1.43
			J51	Sepia Memories	0.75
J	Grey Perspectives	7.88	J52	Childfree Serenity	1.34
			J53	High Spending Elders	1.53
			J54	Bungalow Retirement	1.26
			J55	Small Town Seniors	2.71
			J56	Tourist Attendants	0.30
			K57	Summer Playgrounds	0.29
K	Rural Isolation	5.39	K58	Greenbelt Guardians	1.74
			K59	Parochial Villagers	1.64
			K60	Pastoral Symphony	1.31
			K61	Upland Hill Farmers	0.41

Appendix 12: Characteristics of interviewees

Interview no.	Area	Child gender	Child age group (age)	Hosp adm / med condit	Had MMR now / single	Rate knowledge	Parent gender	Parent Age (at birth)	Smoked	Marital status	No. of children	Birth order	Ethnic group	Educ level
1	Coleford	F	Primary (8)	No / No	No / Yes	Full	F	38	Past	Sep	2	1 st	White/ British	Prof / tech
2	Yeovil	M	Secondary (12)	Yes / No	Yes	Some	F	45	No	Married	1	1 st	Polish	6 th Form
3	Bishops Lydeard	F	Primary (10)	No / No	No	Full	F	42	No	Married	3	1 st	White/ British	Prof / tech
4	Cheddar	F	Primary (8)	No / No	No	Full	F	44	No	Married	2	2 nd	White/ British	Uni
5	Queen Camel	F	Secondary (14)	Yes / No	No / Yes	Some	M	47	No	Married	3	2 nd	White/ British	Uni
6	Castle Cary	F	Secondary (14)	No / Yes	Yes	Some	F	50	Past	Cohabit	1	1 st	White/ British	Uni
7	Burnham	M	Primary (10)	Yes / Yes	Yes	Some	F	41	Past	Married	2	1 st	White/ British	Prof / tech
8	Cheddar	M	Primary (10)	No / Yes	No / will have	Full	F	44	No	Married	2	1 st	White/ British	Uni
9	Norton Fitzwarren	F	Primary (9)	No / Yes	No / Yes	Limited	F	39	Past	Married	1	1 st	White/ British	Prof / tech
10	Yeovil	M	Primary (10)	No / No	Yes	Some	F	49	Past	Cohabit	3	3 rd	White/ British	Prof / tech
11	Wells	M	Primary (7)	Yes / Yes	Yes	Some	F	44	Past	Married	2	1 st	White/ British	Uni
12	Taunton	F	Primary (10)	No / Yes	Yes	Some	M	48	No	Married	2	1 st	White/ British	Uni
13	Taunton	F	Secondary (13)	No / Yes	No	Full	F	49	No	Married	2	1 st	White/ British	GCSE
14	Coleford	M	Primary (10)	No / Yes	No*	Some	F	36	No	Married	3	1 st	Indian	Prof / tech
15	Crewkerne	F	Primary (10)	Yes / Yes	Yes	Full	F	41	No	Married	3	1 st	White/ British	Uni

16	Shepton Mallet	F	Secondary (14)	No / No	No / Yes	Limited	F	52	No	Married	2	1 st	White/ British	Uni
17	Yeovil	M	Primary (7)	No / Yes	No	Full	F	45	Yes	Sep	4	3 rd	White/ British	GCSE
18	Coleford	M	Primary (9)	No / No	No / Yes	Some	F	38	Past	Married	1	1 st	White/ British	6 th Form
19	Taunton	M	Primary (10)	No / Yes	No / No	Full	M	49	No	Married	3	3 rd	White/ British	Uni
20	North Petherton	M	Primary (8)	No / Yes	No / Yes	Some	F	41	No	Married	2	1 st	White/ British	Prof / tech

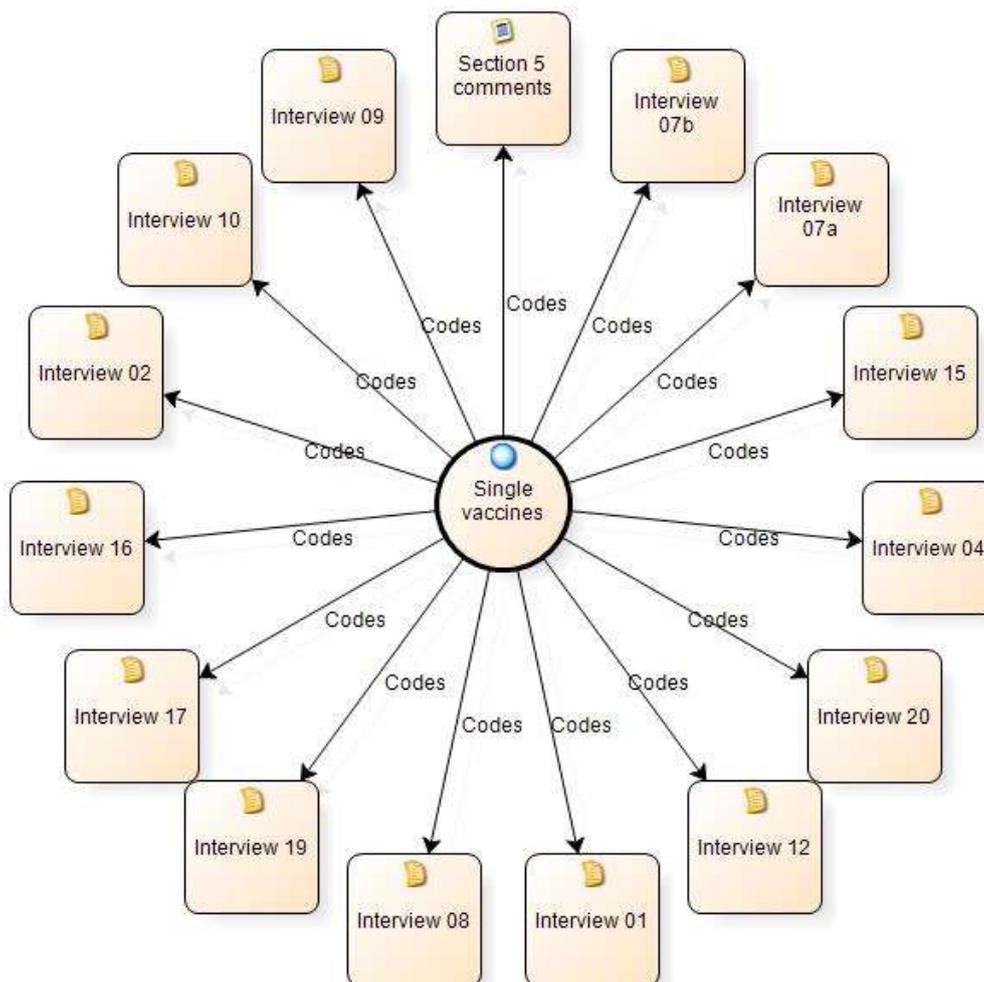
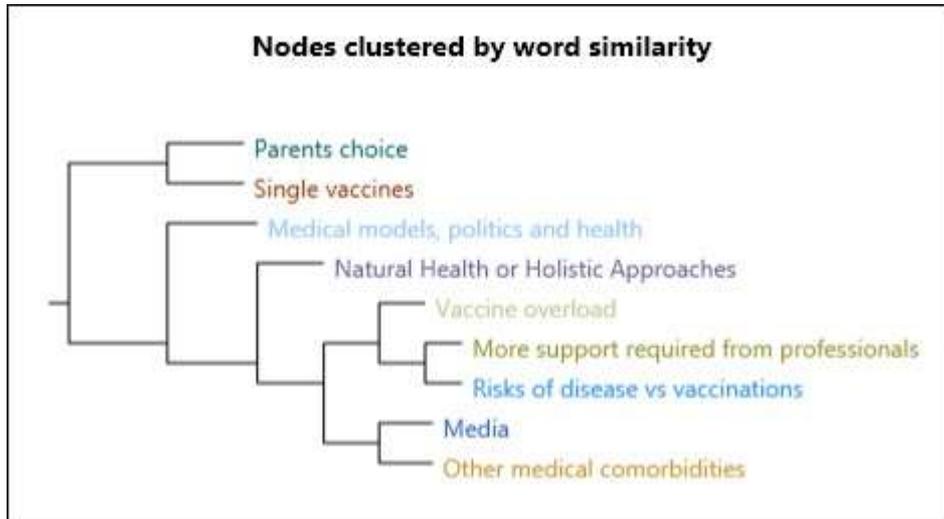
*Not offered

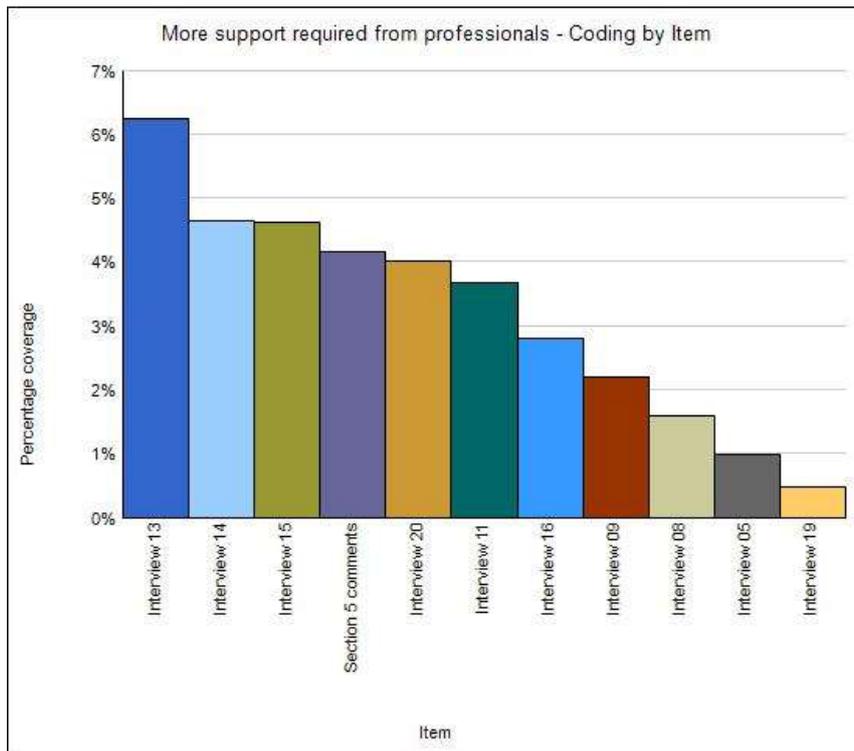
. Appendix 13: Full list of categories (codes) and themes derived from the Phase 3 Thematic Analysis

Category (Code)	Sources	References	Created on	Created by	Modified on	Modified by
Risks of disease vs vaccinations	21	129	13/11/2012 14:31	JFY	21/11/2013 03:50	JFY
Autism	21	108	13/11/2012 14:33	JFY	20/11/2013 23:49	JFY
Advantages and disadvantages	10	111	20/05/2013 16:43	JY	14/11/2013 02:41	JFY
Knowledge of the immune system and how vaccines work	9	26	04/11/2013 07:14	JFY	14/11/2013 04:11	JFY
More information on the diseases	8	20	20/05/2013 16:53	JY	14/11/2013 01:07	JFY
Adverse events after immunisation	7	16	04/11/2013 09:05	JFY	14/11/2013 05:26	JFY
Statistics	5	22	20/05/2013 16:43	JY	14/11/2013 03:23	JFY
No side effects	3	5	21/05/2013 07:35	JY	04/11/2013 09:02	JFY
How the vaccine is made	2	11	20/05/2013 17:47	JY	21/11/2013 03:50	JY
Vaccine overload	17	69	14/11/2012 18:25	JY	14/11/2013 05:01	JFY
Delay	15	38	13/11/2012 14:39	JY	21/11/2013 03:50	JY
Media	16	46	13/11/2012 15:18	JFY	21/11/2013 04:08	JFY
Irresponsible media reporting	7	25	20/05/2013 17:41	JFY	14/11/2013 05:31	JFY
Openness and honesty	3	38	20/05/2013 16:46	JY	14/11/2013 05:16	JFY
Mistrust	9	95	14/11/2012 18:45	JY	14/11/2013 05:10	JFY
Unbiased information	5	41	20/05/2013 16:44	JY	31/10/2013 02:30	JFY
Trusted sources	1	1	31/10/2013 02:30	JFY	31/01/2014 01:23	JY
Independent research	4	20	20/05/2013 16:42	JY	21/11/2013 03:50	JFY
Single Vaccines	15	142	13/11/2012 14:31	JY	21/11/2013 04:19	JFY
More support from Professionals	11	91	20/05/2013 16:49	JY	14/11/2013 04:25	JFY
Information Format	6	10	31/10/2013 01:05	JFY	07/11/2013 09:38	JFY
Written information	3	12	20/05/2013 16:46	JY	21/11/2013 04:15	JY
Information confusing	5	10	13/11/2012 14:33	JY JFY	14/11/2013 05:19	JY
Problems with access	5	11	13/11/2012 14:40	JFY	20/05/2013 19:36	JFY
Antenatal information	1	4	20/05/2013 17:28	JY	21/11/2013 04:15	JFY
Inconsistent professional advice	15	60	20/05/2013 16:48	JY	21/11/2013 03:50	JFY
Other Medical Co-morbidities	11	42	14/11/2012 18:28	JY	14/11/2013 05:20	JFY
Allergy	3	11	13/11/2012 15:10	JY	20/05/2013 16:32	JFY
'needle phobia'	1	2	14/11/2012 18:47	JY	20/05/2013 18:12	JFY
Previous adverse reactions to vaccines	1	21	13/11/2012 14:39	JFY	21/11/2013 04:20	JFY

Natural Health or Holistic Approaches	4	1	20/05/2013 18:04	JY	14/11/2012 04:05	JFY
Non-conformist	5	6	14/11/2012 18:43	JFY	14/11/2013 04:23	JFY
Homeopathy	5	22	13/11/2012 14:30	JY	04/11/2013 09:24	JFY
Wider health of families	3	14	13/11/2012 14:35	JFY	06/11/2013 05:29	JFY
Having symptoms is good	2	4	04/11/2013 08:51	JY	31/10/2013 02:43	JFY
Breastfeeding	1	3	31/10/2013 02:41	JY	04/11/2013 09:08	JFY
Alternative information sources	1	5	04/11/2013 08:44	JFY	21/11/2013 03:50	JFY
Medical models, politics and health	4	16	13/11/2012 14:37	JY	14/11/2013 05:07	JFY
Freedom vs responsibility	16	40	31/10/2013 14:37	JY	21/11/2013 04:09	JFY
Bullying	15	46	31/10/2013 02:21	JY	21/11/2013 04:09	JFY
Financial incentives	10	37	13/11/2012 14:27	JFY	10/11/2013 09:59	JFY
UK vs other countries	4	23	20/05/2013 16:52	JFY	04/11/2013 09:23	JFY
Drug companies	3	18	14/11/2012 19:03	JY	21/11/2013 04:12	JFY
Waste of tax payers' money	1	5	13/11/2012 14:34	JY	21/11/2013 03:50	JFY
Parents' choice	3	23	13/11/2012 14:29	JY	31/10/2014 01:23	JFY
Family influences	17	46	20/05/2013 15:45	JFY	21/11/2013 04:30	JY
Difficult decisions	17	44	31/10/2013 00:50	JFY	21/11/2013 04:32	JFY
No choice	14	65	04/11/2013 06:55	JY	20/05/2013 19:32	JFY
Serology	1	3	20/05/2013 16:51	JY	21/11/2013 04:30	JFY
Differing parental opinions	13	21	20/05/2013 18:39	JFY	14/11/2013 03:35	JFY
Guilt	10	28	14/11/2012 18:48	JFY	13/11/2012 15:17	JFY
Gender	1	3	31/10/2013 00:41	JY	14/11/2013 05:22	JFY
Birth order	5	10	13/11/2012 15:11	JFY	14/11/2013 04:22	JFY
Child's choice	3	4	04/11/2013 07:19	JFY	14/11/2013 18:56	JFY
Flexibility	1	5	20/05/2013 16:50	JY	20/05/2013 18:47	JY

Appendix 14: Examples of Outputs from the Phase 3 Deductive Process





Nodes compared by number of items coded

