

The University of Sheffield

The Measles, Mumps and Rubella (MMR)  
vaccine scare: the information needs and  
information sources of parents

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VOL I

A study submitted in fulfilment of the requirements  
for the degree of Doctor of Philosophy at the  
University of Sheffield

Department of Information Studies  
September 2005

VOLUME ONE

# Abstract

This thesis presents the findings of a three year AHRB funded PhD examining the role of information in the measles, mumps and rubella (MMR) vaccine scare. The findings of research by Wakefield et al. (1998) regarding alleged side effects of the MMR vaccine and the subsequent media reporting of this research influenced parents' decision making about the MMR vaccine and led to falling MMR vaccine rates and confusion regarding the safety of the MMR vaccine. This study sought to examine parents' information needs, parents' views about information and the information that parents were provided with in relation to the MMR vaccine and the MMR vaccine scare.

The study took the form of three phases of data collection: a semi structured interview study with parents of children aged between one and two years (n=17), a questionnaire study, utilising the Health Belief Model (HBM) with parents of children aged between one and two years (n=112) and a content analysis of newspaper articles and World Wide Web (WWW) news articles (n=227) during an episode of the MMR vaccine scare in January and February 2002. The data collected in the interview and questionnaire studies were triangulated for confirmation and completeness.

The study found that the information needs of parents tended to be based around the potential risk to their child of the MMR vaccine and did not address the risk of measles, mumps and rubella. Parents had unmet information needs relating to the MMR vaccine scare. Some parents sought information to address these needs, while others did not as they did not believe that the information they wanted was available. The extent to which parents used different information sources was related to the extent to which they trusted the information source and the motives that the source had in providing information. This emphasised the importance of interpersonal information sources for parents. Parents received information about the MMR vaccine scare from the mass media, but found it hard to use as the mass media were not providing information to aid decision making and the information that was provided was often conflicting. The content analysis found that while the media attempt to provide balanced articles about the MMR vaccine, the agenda behind media information is not to enable informed decision-making. In conclusion, the MMR vaccine scare generated information needs for parents, but also influenced how they use information sources.

# Acknowledgements

Firstly, I would like to thank the Arts and Humanities Research Board (AHRB) for funding this study. I would also like to thank the John Campbell Trust and the Health Informatics Research Group at the University of Sheffield for providing funding to enable the findings of this study to be disseminated at two conferences (iSHIMR 2003 and ISIC 2004).

Members of the Health Informatics Research Group and members of Room 204 also provided invaluable support. The happy demeanour and prompt assistance of the computing support staff in the form of Andy Stones, Paul Fenn, Pete Holdridge and Alison Evans made my life a lot easier.

The PhD fieldwork would have been impossible without Janet Chaplais and Angela Ford at Sheffield Children's Trust and I am grateful for all the assistance they gave me.

I would also like to thank the parents who participated in the questionnaires and interviews and gave their frank and honest opinions about the MMR vaccine scare.

The support and advice provided by Dr Peter Bath greatly assisted me in undertaking and completing this study. Thanks to Cheryl, Rabiah, Catherine and Briony for advice, friendship and reassurance throughout my three years in the Department of Information Studies.

Finally, thanks to Andy. For everything.

# Contents

<b>Abstract</b>	<b>i</b>
<b>Acknowledgements</b>	<b>ii</b>
<b>Contents</b>	<b>iii</b>
<b>Figures</b>	<b>v</b>
<b>Tables</b>	<b>vii</b>
<b>Chapter One – Introduction</b>	<b>1</b>
1.1 Overview	1
1.2 Background	1
1.3 Rationale	2
1.4 Setting	3
1.5 Structure	3
1.6 Summary	5
<b>Chapter Two - Literature Review</b>	<b>6</b>
2.1 Introduction	6
2.2 Setting	6
2.3 Information, health information and risk information	9
2.4 Health Scares	30
2.5 Vaccination	39
2.6 MMR vaccine scare	54
2.7 Conclusions	64
<b>Chapter Three – Methodology</b>	<b>70</b>
3.1 Introduction	70
3.2 Philosophical frameworks	71
3.3 Assessing research	74
3.4 Interviewing	76
3.5 Questionnaires	78
3.6 Triangulation	85
3.7 Content Analysis	86
3.8 Conclusions	89
<b>Chapter Four - Interview Study</b>	<b>90</b>
4.1 Introduction	90
4.2 Methods	91
4.3 Results	97
4.4 Validity	126
4.5 Limitations	130
4.6 Conclusions	132
<b>Chapter Five - Questionnaire Study</b>	<b>136</b>
5.1 Introduction	136
5.2 Methods	138
5.3 Pilot Study	145
5.4 Quantitative results	157

5.5	Qualitative results	202
5.6	Limitations	207
5.7	Conclusions	212
<b>Chapter Six - Triangulation</b>		<b>217</b>
6.1	Introduction	217
6.2	Aims	217
6.3	Methods	218
6.4	Results	220
6.5	Conclusions	243
<b>Chapter Seven - Content Analysis</b>		<b>244</b>
7.1	Introduction	244
7.2	Methods	246
7.3	Results	254
7.4	Discussion	381
7.5	Limitations	386
7.6	Conclusions	388
<b>Chapter Eight - Conclusion</b>		<b>291</b>
8.1	Introduction	291
8.2	Summary of setting	291
8.3	Findings of the PhD	292
8.4	Limitations of the PhD	298
8.5	Implications of the PhD	300
8.6	Overview and future research	303
<b>References</b>		<b>305</b>
<b>Appendices</b>		<b>324</b>
Appendix One - Interview Study		325
Appendix Two - Questionnaire Study		345
Appendix Three – Content Analysis		375

# Figures

<b>Chapter Four - Interview Study</b>	<b>90</b>
Figure 4.1 - Category diagram – Information and the truth	102
<b>Chapter Five - Questionnaire Study</b>	<b>136</b>
Figure 5.1 - Example of tick box question	149
Figure 5.2 - Example of question that required rating	150
Figure 5.3 - Content of received and sought information	187
<b>Chapter Six – Triangulation</b>	<b>217</b>
Figure 6.1 – Triangulation of data	219
Figure 6.2– Development of triangulation themes	221

# Tables

<b>Chapter Two - Literature Review</b>	<b>6</b>
Table 2.1 – UK vaccination schedule for children	40
<b>Chapter Four - Interview Study</b>	<b>90</b>
Table 4.1 – Response rates by location of recruitment	98
Table 4.2 – Demographic characteristics of participants	99
Table 4.3 – Demographic characteristics of participants children	100
<b>Chapter Five - Questionnaire Study</b>	<b>136</b>
Table 5.1 – Pilot Study - Electoral wards in Sheffield in order of decreasing deprivation in tertiles	146
Table 5.2 – Pilot Study – Response Rate	147
Table 5.3 – Pilot study - Participants by age and gender	148
Table 5.4 – Children of participants by MMR status	148
Table 5.5 – Pilot Study – Comments added to questionnaire	151
Table 5.6 – Pilot Study – Length of time taken to complete questionnaire	151
Table 5.7 – Pilot Study – Comments on questionnaire	152
Table 5.8 – Pilot Study - Changes made to the questionnaire as a result of the pilot study	154
Table 5.9 – Pilot Study - Changes not made to the questionnaire as a result of the pilot study	156
Table 5.10 – Parents according to age and gender	158
Table 5.11 – Parents according to ethnic background	159
Table 5.12 – Families according to NS-SEC	159
Table 5.13 – Families according to number of children in family	160
Table 5.14 – Questionnaire children according to age	161
Table 5.15 – Questionnaire child according to MMR vaccination status	162
Table 5.16 – Comparison of size of groups	162
Table 5.17 – Comparison of groups – Age, gender and MMR vaccination status of children	163
Table 5.18 – Comparison of parents and population of Sheffield in terms of ethnic background	164
Table 5.19 – HBM - Susceptibility to Measles, Mumps and Rubella	167

Table 5.20 – HBM – Greatest susceptibility to measles, mumps and rubella	167
Table 5.21 – HBM – Severity of measles, mumps and rubella	168
Table 5.22 – HBM – Benefits– Protection against measles, mumps and rubella	168
Table 5.23 – HBM – Benefits– Efficacy of the MMR vaccine	169
Table 5.24 – HBM – Benefits – Herd Immunity	169
Table 5.25 – HBM – Barriers– Risk of MMR vaccine to child’s health	170
Table 5.26 – HBM – Barriers– Option of single vaccines	170
Table 5.27 – HBM – Barriers– Other ways to protect children	171
Table 5.28 – HBM – Cues to action (I)	172
Table 5.29 – HBM – Cues to action (II)	173
Table 5.30 – HBM - Likelihood of MMR vaccination – susceptibility, severity and benefits	174
Table 5.31 – HBM – Likelihood of MMR vaccination – Friedman test results	175
Table 5.32 – HBM - Likelihood of MMR vaccination – Barriers	176
Table 5.33 – HBM – Likelihood of MMR vaccination – Internal consistency	177
Table 5.34 – HBM – Likelihood of MMR vaccination – Likelihood by group	177
Table 5.35 – HBM - Construct correlations	178
Table 5.36 – Information – Source of received information	182
Table 5.37 – Information – Other sources of received information	183
Table 5.38 – Information – Content of received information (I)	183
Table 5.39 – Information – Content of received information (II)	183
Table 5.40 – Information – Source of sought information	184
Table 5.41 – Information – Other sources of sought information	185
Table 5.42 – Information – Content of sought information (I)	185
Table 5.43 – Information – Content of sought information (II)	187
Table 5.44 – Information – Useful information sources – All sources (n=36) (1=most-useful, 6=least useful)	188
Table 5.45 – Information – Useful information sources – Some sources (1=most-useful, 6=least useful)	189
Table 5.46 – Information – Trusted information sources – All sources (n=36) (1=most trusted, 6=least trusted)	190
Table 5.47 – Information – Trusted information sources – Some sources (1=most trusted, 6=least trusted)	190
Table 5.48 – Information – Parents’ useful information sources	191
Table 5.49 – Information – Parents’ trusted information sources	192



Table 5.50 – Information – Sources not trusted/useful	192
Table 5.51 – Information – Informed decision	193
Table 5.52 – Information – Parents comments on informed decision	194
Table 5.53 – Information – Impact of MMR vaccine scare	195
Table 5.54 – Information – Final decision about the MMR vaccine	196
Table 5.55 – Information – Received and sought information – cross tabulation	221
<b>Chapter Seven – Content Analysis</b>	<b>244</b>
Table 7.1 –Circulation figures for newspapers	247
Table 7.2 – Location of information sources	248
Table 7.3 – Development of the data collection tool (T= Triangulation, L = Literature Review, R= Research Question)	249
Table 7.4 – Inductive categories	252
Table 7.5 – Variables in the subscales	254
Table 7.6 – Information sources (before and after weeding)	255
Table 7.7 – Information sources by date of publication of articles	256
Table 7.8 – Word counts for articles in information sources	256
Table 7.9 – Focus of the article according to information source	257
Table 7.10 – Format of article	258
Table 7.11 – Themes	259
Table 7.12 – Individuals/groups	260
Table 7.13 – Stance of individuals	261
Table 7.14 – Content	262
Table 7.15 – Associations - Both sides of the MMR debate being mentioned and content/individuals	265
Table 7.16 – Associations – Providing evidence that the MMR vaccine is dangerous and content/individuals	266
Table 7.17 – Associations – Andrew Wakefield and content	268
Table 7.18 – Associations – Tony Blair and content	268
Table 7.19 – Associations – Parent (anti MMR vaccine) and content	269
Table 7.20 – Associations – HCP (pro MMR vaccine) and content	270
Table 7.21 – Associations – HCP (anti MMR vaccine) and content	270
Table 7.22 – Logistic regression – Theme - Both sides of the MMR vaccine debate mentioned	271

Table 7.23 – Logistic regression – Theme - Giving advice	272
Table 7.24 – Logistic regression – Providing evidence that the MMR vaccine is dangerous	272
Table 7.25 – Subjective stance	273
Table 7.26 – Assessment of article stance – positive subscale	274
Table 7.27 – Assessment of article stance – negative subscale	275
Table 7.28 – Assessment of article stance – overall scale	276
Table 7.29 – Association between subjective and objective assessments	276
Table 7.30 – Information source and article stance	277
Table 7.31 – Headlines	279
Table 7.32 – Views on information sources	280

# Chapter One - Introduction

## 1.1 Overview

The study that will be described in this thesis was designed and operationalised in order to fulfil the requirements for the degree of Doctor of Philosophy (PhD) at the University of Sheffield. This thesis presents the rationale for undertaking research in the chosen subject area and presents the methodology, methods and results of the data collection methods that were used to answer the research questions. This chapter presents the background to the PhD study, the rationale behind the PhD study, the setting of the PhD study and finally the structure of the thesis

## 1.2 Background

The PhD study was designed in spring 2001. The idea for the study was collaborative, between the author and the supervisor of the PhD. The initial aim of the research originated from the interests of the author and the supervisor and was to look at the impact of health scares on people in terms of information. As this question was too broad, the focus was narrowed to look at people's use of information as a result of health scares and the impact that these scares had on the need for information and the information sources that people wanted to use. This more specific question was again narrowed down as it was decided that the most effective way of examining health scares would be to use a specific instance of a health scare and the impact of that health scare on a specific group of people.

A discussion of the current issues facing people with regard to health and health scares quickly led to the scare surrounding the safety of the measles, mumps and rubella (MMR) vaccine and the impact that this was having on parents. It was decided that this would be both an interesting and worthwhile subject area and thus the research proposal was designed with the MMR vaccine scare as the focus. An application to undertake the research at the Department of Information Studies (University of Sheffield) was made and an application for funding was made to the Arts and Humanities Research Board (AHRB). Both of these applications were successful. The study commenced in October 2001.

## 1.3 Rationale

Health scares are a new phenomenon. They are not easy to describe, but they are easy to illustrate. For example, the United Kingdom (UK) has been faced with scares about the safety of eating beef, the safety of mobile phone masts and the safety of the MMR vaccine. This is by no means an exhaustive list and while the concept of a health scare is difficult to define, most people can readily name a health scare, especially if it is one that has affected them.

The rationale for this study was to find out more about the types of things people want to know about a particular issue and where they go to find these things out. While anecdotal evidence and statistical data about health scares have been gathered through research, there has been little research on health scares in terms of how they have influenced people and the things that they want to know. More specifically there has been little research in how people react to the specific issue of a health scare and the influence of key stakeholders related to the health scare. Thus it was decided that this aspect of health scares would be interesting to focus upon in the PhD study.

The rationale for undertaking research addressing these issues with reference to the MMR vaccine scare was for a number of reasons. The first reason was the currency of the MMR vaccine scare. At the time of developing the research proposal, the safety of the MMR vaccine was receiving attention in both the print and broadcast media. Despite the fact that the original research surrounding the safety of the MMR vaccine was published in 1998, frequent media coverage has addressed the safety of the MMR vaccine since then and throughout the time that the PhD study was being carried out. This media coverage tended to take the form of ongoing reporting with short intense episodes of reporting. The second reason that motivated the choice of the MMR vaccine scare as the subject of the thesis was a desire to undertake research that could directly involve people. The research proposal emphasised the fact that the experiences of parents were key to understanding the MMR vaccine scare and the research methods adopted would reflect this. The third reason was a desire to undertake research that could potentially have practical benefits in terms of revealing parents' opinions of the MMR vaccine scare and the factors that influenced their decision regarding the MMR vaccine.

The MMR vaccine is a triple vaccine aimed at preventing the diseases of measles, mumps and rubella. It is recommended that children in the UK are given the MMR vaccine at the ages of 13 months and again before they start school (Hey, 1998). The MMR vaccine was introduced in 1988 and its introduction saw a fall in the rates of the diseases of measles, mumps and rubella (Owens, 2002). However, the MMR vaccine received adverse publicity in 1998 with the publication of research by Wakefield et al. (1998) that suggested that the MMR vaccine might be unsafe for children. This research was widely reported in the media and there was an increase in demand for single vaccinations against measles, mumps and rubella. A fall in MMR vaccine rates and subsequent disease outbreaks were blamed on the adverse publicity that the MMR vaccine received and the MMR vaccine assumed greater importance for parents in terms of the perceived risk that it posed to their children. More detail regarding the MMR vaccine scare is given in Chapter Two.

## 1.4 Setting

The setting for the study was Sheffield. Sheffield is a city in the north of England with a population of 513 234 (National Statistics, 2001). The study was restricted to Sheffield for reasons of cost and convenience, but also because there was a sufficiently large population within which to undertake the study. Recruitment for the data collection (interviews and questionnaires) was undertaken through community based childcare organisations and National Health Service (NHS) organisations in Sheffield. Local Research Ethics Committee (LREC) approval was obtained for the sections of the study recruiting through the NHS.

## 1.5 Structure

This section outlines the structure of the thesis. Chapter One presents an overview of the thesis, the rationale behind the research, the setting of the study and the structure of the study.

Chapter Two is a review of key literature related to the topic of the thesis. The literature review contains an examination of four key issues: information, health scares,

vaccination and the MMR vaccine scare. In all of these areas, key literature is reviewed and synthesised. Gaps in the literature are highlighted and related to the research questions for the study, thus strengthening the rationale for the study. In addition, literature relating to the impact of the MMR vaccine scare on parents, which was published after the initial literature review, is also reviewed. Finally, the contribution that the literature made to the overall study is examined.

Chapter Three presents the methodology adopted in the study. The chapter places the study in a philosophical framework of post-positivism and addresses the debate between quantitative and qualitative research before presenting the methods adopted in the data collection and analysis, namely interviewing, questionnaires, triangulation and content analysis.

Chapter Four presents the initial exploratory data collection, the interview study. Semi-structured interviews (n=17) were carried out with parents in Sheffield. This chapter details the methods of the study, the results of the study and the impact of the findings of the study on future data collection.

Chapter Five presents the second phase of data collection, the questionnaire study. Questionnaires were distributed to 400 parents in Sheffield and returned by 112 (28%). This chapter details the background to the study, the procedures that were followed and the methods adopted. Then the results of the questionnaire study are presented, in terms of univariate, bivariate and multivariate analyses.

Chapter Six presents the results of the triangulation carried out on the data. Qualitative and quantitative data from the interview and questionnaire studies were used to triangulate for confirmation and completeness. These data then provided the background for the content analysis study.

Chapter Seven presents the content analysis study. A content analysis was undertaken on a data set consisting of articles from five mass media sources over a two-month period during an episode of the MMR vaccine scare which occurred during the PhD study. The results of the content analysis are presented in terms of the quantitative and qualitative data collected.

Chapter Eight summarises the findings of the data collection and whether the data collected and analysed has filled the gap that was identified in the literature review. The success (or otherwise) of the methods adopted will be addressed, as well as the conclusions that can be drawn from the data collected. Finally this chapter will suggest research questions and areas for further research.

## 1.6 Summary

This chapter has outlined the reasons why the research presented in the thesis was undertaken. It has also outlined the structure and the content of the thesis. The following chapter (Chapter Two) presents and reviews key literature associated with the research area.

# Chapter Two - Literature Review

## 2.1 Introduction

Chapter One introduced the aims of the thesis and the setting and rationale for the PhD study. This second chapter provides a background to the study in terms of literature relating to the study area. A full literature search was undertaken on key concepts relating to the PhD. The literature reviewed is presented in this section. This overall literature review is then followed by a review of key literature that was published after the initial literature review was written. The chapter concludes with a section that addresses the contribution of the literature to the overall study. The literature review will give an overarching introduction to research that has been undertaken in relevant areas, looking at research from a critical perspective by discussing shortcomings of previous research.

This review of the literature then sets the scene for Chapter Three, which looks at the methodology adopted in the study, before the actual study is presented in Chapters Four to Seven. The literature review starts with an initial examination the MMR vaccine scare, to place the study in context. Then, information as a broad concept and subsets of information, such as health information and risk information, are examined. The issue of health scares and the MMR vaccine scare are addressed. Then, following on from this initial literature review is a section that looks at the literature published during the PhD study, in terms of literature relating to the topic of the thesis, parents' views about information and the role of different information sources in the MMR vaccine scare. Finally, the key gaps in the literature reviewed are highlighted and the contribution that this literature makes to the study is examined.

## 2.2 Setting

As the key issue addressed in the study is the MMR vaccine and the health scare that surrounded the safety of the MMR vaccine, this section gives some background information by looking at the conditions of measles, mumps and rubella, the vaccine that is used to prevent them and the scare that has concerned the safety of the MMR vaccine.



### **2.2.1 Measles, mumps and rubella**

Measles is a viral infection, which almost always causes symptoms in those infected. Measles is an infection with serious side effects, secondary infections are common and post-measles encephalitis can be life threatening. The disease is highly infectious and exposure to the disease (and subsequent infection) will normally lead to immunity (Bannister, 2000). Mumps is also a viral infection. It is the commonest cause of viral meningitis in children and other side effects include deafness and inflammation of the testes and ovaries. Mumps can cause serious side effects, e.g., infertility, in male adults if they catch the disease (Rose, 1998). Rubella is also a viral infection. Clinical symptoms of rubella are mild conjunctivitis, a mild sore throat and a rash. Rubella is most dangerous for pregnant women because if they become infected, their foetus will also become infected, which can have serious consequences such as tissue damage and developmental defects. This is congenital rubella syndrome, which can also result in spontaneous termination of pregnancy (Bannister, 2000).

### **2.2.2 The MMR vaccine**

Immunisation against infectious diseases has been an important part of the healthcare and health prevention of children in the latter part of the twentieth century and the early twenty-first century in the UK. Children in the UK undertake a schedule of vaccines that include diseases such as diphtheria, tetanus and tuberculosis. There are 10 diseases that are preventable by vaccination and these require 18 vaccines and 3 oral administrations (Owens, 2002). The MMR vaccine, which was introduced to the UK in 1988, is administered to children at the ages of 13 months and again before they attend school. In the last 30 years, over 500 million doses of the MMR vaccine have been administered in over 90 countries, but, despite this, 890,000 children die of measles worldwide each year (Owens, 2002). Further detail on vaccination is presented in section 2.5.

### **2.2.3 The MMR vaccine scare**

A vaccine scare occurs when the public and/or those who are making a decision about vaccination are presented with information that causes them to believe that the vaccine

is either not safe or not effective. Defining vaccine scares is complicated and there have been few attempts to define them in the literature. Nicoll (2001) provides a definition which is narrow, but relevant to the example of the MMR vaccine scare. Vaccine scares occur when a causal link is claimed between the vaccination in question and a disease or condition (Nicoll, 2001). An association is claimed by one group of investigators, often with media publicity. The findings are not confirmed by subsequent investigations. However, the original research continues to get media coverage and can be attributed to changes in people's behaviour (Nicoll, 2001).

The MMR vaccination scare is one example of a vaccine scare. The Measles Mumps and Rubella (MMR) vaccination scare originated in 1998 with the publication of research (Wakefield et al., 1998) which suggested a link between the measles virus and bowel conditions that were associated with autism (autistic enterocolitis) (Thrower, 2001). It was suggested by one of the researchers (Andrew Wakefield) that this measles virus may have been present in the research subjects as a result of their being given the MMR vaccine.

The research of (Wakefield et al., 1998) was carried out by the Royal Free Hospital Inflammatory Bowel Disease Study Group and published in an internationally renowned, peer-reviewed medical journal, *The Lancet*. The research described 12 children with bowel disorders and developmental disorders and found that in 8 of these children, parents reported the symptoms as having started soon after the MMR vaccine had been given. The authors also questioned the safety of the vaccine and the studies that had been carried out testing the MMR vaccine before it was introduced in 1988. While the sample sizes for this study were low, the fact that the research was published in an international peer reviewed journal meant that the research gained a lot of attention, particularly in the mass media and generated concern in parents which eventually led to falling vaccine rates and reported increases in the incidence of the diseases (Department of Health, 2002).

The MMR vaccine scare has had a serious impact on children (and their parents). Falling MMR vaccine rates have led to outbreaks of the diseases against which the MMR vaccine protects. In Dublin in 2000, the low uptake of the MMR vaccine over a number of years led to measles outbreaks which resulted in two deaths (Owens, 2002). The impact of the MMR vaccine scare on parents is less quantifiable, but the research

that will be discussed in the literature review indicates that parents are finding the MMR vaccine decision increasingly difficult because of the uncertainty that has surrounded the MMR vaccine.

#### **2.2.4 Summary**

This section has introduced the MMR vaccine scare. As the literature has shown, the conditions of measles, mumps and rubella are serious conditions for children, but the alleged side effects that were suggested by Wakefield et al. (1998) are also serious and this combination has led to the emergence of a health scare. Following on from this introduction to the setting of the study, the literature review will now address some of the key issues in the study by giving an overview of the information field, particularly health information and an overview of vaccination, before concentrating on the MMR vaccine scare.

### **2.3 Information, health information and risk information**

This section addresses the concept of information in terms of the difficulties and conflicts in reaching a definition of what is information. Key terms such as information needs and information seeking are also examined. In more practical terms, a subset of information, health information is addressed, emphasising policy and the way in which health information affects different groups. Finally, risk information and the communication of risk are considered, particularly in relation to health and the communication of health issues. This section is important to the thesis as it develops an understanding of the importance of information in health, especially for health care consumers and sets the scene for the rest of the thesis.

#### **2.3.1 Information**

Within academic literature, information is a concept about which there is little consensus. The concept of information is complex and has multiple meanings, and the definition that is adopted depends upon a variety of factors, such as the person who is defining it, the way in which the information is being used and the format of the information. This list of factors is not exhaustive and there are many factors that

influence the definition of information, some of which will be addressed in this literature review.

Definitions of information can be conceptual (i.e. what the information is) or they can be physical definitions of a source of information (i.e. how the information is transmitted). As Meadows (2001) explained, information can be "*something told or the act of telling*" (Meadows, 2001, p.15). Therefore the 'something told' is the conceptual definition of information and the act of telling involves the physical transmission of information and the source through which this transfer occurs.

Because of the difficulties in defining information, Case (2002) suggested that the most useful way to classify information is in terms of what individuals understand to be information, which could be either a physical manifestation or a conceptualisation or both. Krikelas (1983) views information as "*any stimulus that reduces uncertainty*" (Krikelas, 1983, p.5). This highlights two key aspects of information, that its impact is not necessarily active and observable and that (when sought) it is sought to assist individuals.

Information is part of the society that we live in. As Feather (2000) emphasised, we live in society that is reliant on information, in terms of both the actual information that we access on a daily basis and the technology that supplies it. This has both positive and negative aspects. While access to information is quicker than it has ever been and there are a plethora of information sources supplying different information, information can have a divisive role, resulting in individuals in society either being 'information rich' or 'information poor'. This is because information is not free and comes at a cost, which not all people in society can afford. Information will, at some stage in its creation or transmission, generate costs that have to be borne by either the supplier or the consumer of the information. This cost has increased with the advent of computers. Feather (2000) argues that there is an information market place, and that if someone requires information, they have to enter into the market place to try and obtain this information. If, however, they do not have the resources to obtain this information then they cannot access it and are considered to be 'information poor'. It is important to be aware of the difficulties that some individuals have in accessing information, as this determines how they respond to information that they are provided with and whether they are motivated or able to search for information themselves.

In recent years, information has also become a political issue in the UK. With the election of the Labour Government in 1997 came a commitment to the 'Information Age'. This overarching policy views information, and in particular, information technology, as offering opportunities for modernisation in education, health and other important policy areas. In this sense information is viewed as a technology rather than as a concept and what is inferred by information is a method of access rather than the actual content. However, the emphasis on technology could lead to a potential division in society in terms of access.

#### 2.3.1.1 Information needs

As acknowledged above, there is a difficulty in defining information. Therefore there is also a difficulty in defining information needs. There is a large amount of literature on information needs which examines issues such as what motivates individual need for information, how information needs are expressed and how information needs are satisfied.

Case (2002) reviewed the literature which has addressed the subject of information needs and concluded that there are two main issues that have to be considered when looking at information needs, namely the information that is being sought and the characterisation of the need for information. Needs are differentiated from wants in the sense that needs are more central to satisfaction than wants but equally they are not considered to be vital to human existence. It is also important to differentiate between the satisfaction of information needs through information which is actively sought and that which is passively received.

Walter (1994) discusses the two paradigms that surround information needs and the research that has been undertaken on them. The traditional paradigm sees information as objective and examines the behaviour of users and how they use information systems. In contrast the alternative paradigm sees information as being subjective and socially constructed. Information only exists when people need it to deal with specific issues.

Dervin (1992) developed the sense-making model in an attempt to understand information needs. Sense-making proposes that information needs are a result of gaps in

an individual's knowledge that an individual identifies for himself or herself. These gaps need to be filled and as a result the individual seeks information until they have filled the gap and can make sense of a situation. However, Miller et al. (1988) proposed that not all individuals seek information in response to an information need, identifying two distinct information behaviours, monitoring and blunting. A 'monitor', having identified a need for information, will seek all the available information relating to that need whereas a 'blunter' is less likely to seek information, possibly because they do not identify an information need or alternatively because they want to avoid information relating to an identified need for a variety of reasons.

Wilson (1997), in an article which sought to develop a general model of information behaviour, believed that information needs are difficult to define as they are "*a subjective experience that only occurs in the mind of the person in need and is not directly accessible to an observer*" (Wilson, 1997, p.552).

#### 2.3.1.2 Information seeking

A logical consequence of the identification of an information need is information seeking. When an individual becomes aware of a need for information, they also need to develop a strategy to seek out this information. This strategy can be described as information seeking, although as Miller et al. (1988) identified, information seeking is not a necessary consequence of the identification of an information need and may happen spontaneously.

Case (2002) viewed current definitions of information seeking as being narrow as they focused on information seeking as defined above i.e. in the sense that information seeking is active and planned. Case (2002) argued that information needs could be satisfied by active information seeking but also by the passive acquisition of information.

#### 2.3.1.3 Information behaviour

While the concept of information needs and information seeking are problematic but generally accepted, Wilson (1999) argued that these concepts are more usefully grouped together under the concept of information behaviour, which is defined as follows:

*...those activities a person may engage in when identifying his or her own needs for information, searching for such information in any way and using or transferring that information* (Wilson, 1999, p.249). In this sense information behaviour is the entire process from identifying needs through to searching, identifying and using the information found. This concept appears attractive in that it does not seek to impose boundaries on individuals in terms of the stages of their information journey. Case (2002) agrees with this definition as it depicts a sequence of behaviour rather than simply a sequence of related events.

Krikelas (1983) highlighted that information behaviour is highly dependent upon the nature of the problem. He contrasted continuous problems and discrete problems, both of which need to be solved by information but may require different approaches and information behaviour. Continuous problems are those that face individuals on a daily basis such as a chronic health condition, e.g., asthma. In contrast, discrete problems are one-off incidents such as an acute health condition, e.g., a heart attack.

This section has examined the concept of information, information needs, information seeking and information behaviour. As discussed, despite a wealth of academic literature, there is little consensus on the definition of these terms. However, it is always important to be aware of the individual and how information impacts upon them and influences their behaviour. The following section looks at a subset of information, health information.

### **2.3.2 Health information**

In the same way as information, health information can take a variety of forms and can be transmitted through a variety of media. This section looks at health information policy and the health information needs of a number of specific groups.

#### **2.3.2.1 Health information policy**

This section provides a brief review of health information policy in the United Kingdom, where this study is set. The communication of information relating to health has become an increasingly important political priority, especially since the election of the Labour Government in 1997. The Labour Government's election promise was to

modernise Britain and following their election they published a number of white papers concerning modernisation, which included the 'NHS Plan' (National Health Service, 2001), which aimed to modernise the NHS.

One element of improving healthcare was focused on the role of information for the benefit of both the public and professionals. There have been various papers that reflect this increased emphasis on health information, some of which predate 1997. The 'Health of the Nation' (Department of Health, 1992) aimed to increase the responsibility that patients have for their own health and to move it away from health professionals. 'Working for Patients' (Department of Health, 1989) stressed the importance of patients having access to information.

However, the main document that has reflected the rhetoric of modernisation and information in the health service was 'Information for Health' (Burns, 1998). This was followed up with 'Building the Information Core' (Department of Health, 2000). The basic premise of these reports is that "*Better care for patients, and improved health for everyone depend on the availability of good information, accessible, when and where it is needed*" (Burns, 1998, section 1.1). The reports view the availability of and access to information as being central for improved health. The supply of information to the public can be used to support self-care and treatment, improve diagnosis and reduce pressure on the health service: "*people have more autonomy and control ... more choice, more appropriate and effective use of services ... a healthier population better able to look after themselves*" (Burns, 1998, section 5.10-5.11).

The focus of 'Information for Health' (Burns, 1998) and 'Building the Information Core' (Department of Health, 2000) is on the practical issues that surround the improvements to health information specifically relating to sources of information. The advent of new media types is examined, with particular emphasis being placed on the World Wide Web (WWW) and digital television as well as looking at more traditional means of accessing information such as leaflets. However, the report also mentions the importance of ensuring that the use of new media does not lead to the 'information poor' sections of society becoming unable to access this information and therefore isolated from it. A key aspect of 'Information for Health' is better public access to health information through a variety of media.



The most obvious manifestation of the Government's investment in health information has been the NHS Direct information resources, both on the WWW and via the telephone. 'Information for Health' (Burns, 1998) has been the major force behind the growth in services such as nhs.uk (NHS information about healthcare services) and NHS Direct (a telephone and online service designed to alleviate the pressure on the face to face healthcare services and give patients more control over their health). Both these services are based on the premise that giving patients more information about health and healthcare services will be beneficial to all the interested parties.

'The Expert Patient' (Department of Health, 2001a) is a manifestation of the commitment to using information in health. In 1999 the Government established a task force to look at the role of patients in their own care and the findings of this task force led to the white paper of 2001. The crux of 'The Expert Patient' was that patients possessed extensive knowledge about their own conditions and this knowledge could be harnessed to allow more effective management of conditions.

'Information for Health' (Burns, 1998) expanded upon a key concept, that of health information for different groups. Four key groups are focussed upon in the white paper, namely patients, Health Care Professionals (HCPs), managers and the public. Health information can be for patients e.g. information about a condition such as cancer. Health information is also essential for HCPs to treat patients (e.g. x-rays). It can also be information that is used by health managers e.g. mortality statistics. Health information can also be more general information provided to the public about healthy living.

This section has looked at health policy in the UK. The next section looks at health information in terms of the individual. General health information needs are examined, before the health information needs of parents are examined. Finally the section concludes with a look at health information sources and the role of the media in health information dissemination.

#### 2.3.2.2 Health information needs

Health information is increasingly important as the role of the patient changes from being a passive recipient of healthcare to an active participant in healthcare. A major method of empowering patients is through the provision of information to aid their

decision-making. As the supply of information to patients has become more important, the volume of research in this area has grown. As Case (2002) discussed, patients are increasingly viewed as “*health care consumers*” (p.264). Gann (1991) suggested that patients are viewed as consumers because they have increased access to health services. Gann (1991) cited examples such as family doctors, community care, self-help groups and the availability of health benefits as examples of the exchange between provider and consumer.

Consumerism in health care has been an important issue since the early 1990s, which saw the publication of the ‘NHS and Community Care Act’ (National Health Service, 1990). This introduced market forces into health care and therefore gave the patient greater choices about the care they wished to receive. ‘Local Voices’ (NHS Executive, 1992) formalised the role of patients and the public having a more active role in determining their health care. Since the publication of these documents there have been a number of other white papers which have enhanced the role of consumers in health care, including the ‘Patient Partnership: Building a Collaborative Strategy’ (NHS Executive, 1996), ‘Patient and Public Involvement in the New NHS’ (Department of Health, 1999) and ‘Involving Patients and the Public in Healthcare’ (Department of Health, 2001b). All of these white papers have increased the importance of the health care consumer. The health care consumer is an individual who has more choice about their care, improved access to information and the ability to make informed decisions. The link between health care consumers and information is an important one and is examined here.

Huntingdon et al. (2002) undertook a study that attempted to characterise users of health information by the source they used, using a semi-structured questionnaire (n=723). The study found that the most important sources used were all oral sources (Doctor/Practice Nurse 79%, NHS Direct phone line 37% and Family/Friends 26%). Huntingdon et al. (2002) identified four groups of health information users. Active traditional information users used sources such as books and the mass media. They exhibited an interest in medical news. Passive traditional information users relied on HCPs for their information and were more regular visitors to the doctor. Electronic isolated users used the TV and NHS Direct for their health information, in order to isolate themselves from HCPs. Electronic sociable users used similar information sources to the isolated users but also used friends and family for information. The study attempted to show that the sources of

information that people use could be used to classify them but there are numerous different influences on behaviour and the characterisation of health information users simply by the source that they use does not allow for other factors such as the situation about which the health information user is looking for information. It is also the case that individuals may use different sources of information in different situations and may therefore fall into more than one of the groups that Huntingdon et al. (2002) proposed.

Eysenbach & Köhler (2002) examined how people use the WWW to search for and appraise information regarding their health. Using focus groups, interviews and naturalistic observation with 21 participants, the study found that the study participants developed criteria for assessing web sites for quality, primarily focusing on the source of the web site. Despite this, the participants did not look at the "about us" section on the website. When using search engines, they only visited the first few web pages retrieved from search engines. When questioned later about the websites they had visited, participants could not remember where they had retrieved the information. This may suggest that the information retrieved becomes more important than the source. This may have implications in the sense that it does not allow the information to be criticised in terms of the reliability of the source if the sources cannot be recalled.

Buckland (1994) carried out a literature review on health information needs. The review found that the demand for health information was constantly increasing. The greatest demand was for information that dealt with diseases and conditions. In terms of information sources, patients relied on HCPs, although information sources that were perceived as being easier to access were also used, such as help lines and paper-based sources of information. This review reflects the time at which it was carried out, as there is no mention of the Internet or WWW as an information source. Many people now use the Internet and the WWW as a source of health information.

Bolton & Brittain (1994) examined the effect of health information on patients. They detail two conflicting arguments regarding health information. Firstly, that the more information patients are given, the more informed they are and the better able they are to manage their condition which leads to improved outcomes for patients and the health service. The second argument is that the less information that patients are given, the less likely they are to worry about their health. This has two implications, firstly that there is a "correct" and "incorrect" way of giving patients information. The second implication

is that individual patients have different information needs, which need to be ascertained by the health information provider. This also suggests that information needs are unique and creates a dilemma for the health professional about whether to give patients all the information available. However, Bolton & Brittain did not suggest how this conflict could be remedied.

The next section looks at the sources of information both for parents and for the general public.

### 2.3.2.3 Health information sources

All sources of information have the potential to disseminate health related information. Professional sources of health information include HCPs (doctors, nurses, hospital staff, pharmacists etc), general information sources (libraries, citizens advice bureaux, the WWW, interpersonal sources etc), dedicated health information sources (NHS Direct, nhs.uk, NHS Direct online etc.) and the media, who do not have a remit as an information source, but may often supply health information to people through their entertainment remit (television, radio, newspapers magazines etc.).

Byström & Järvelin (1995) contrast three different types of information sources. These are fact-oriented, problem-oriented and general-purpose. While these types were developed within the business field, they can be readily applied to the health information field. Fact-oriented information comprises databases and registers, for example, a patient records system. Problem oriented information concerns people and documents that are concerned with a specific instance or problem, e.g., a consultation with a General Practitioner (GP) about a particular condition and the GP's written and verbal advice on how to deal with the condition. The third type of information is general purpose and concerns readily available information sources, such as books, journals and medical leaflets. Experts are also included as a general-purpose information source (e.g. HCPs).

As well as the source of information, it is also important to look at how it is communicated. Dixon-Woods (2001) contrasted two different ways in which information is communicated to patients. Traditionally information was communicated via very mechanistic methods concentrating on biomedical issues and treating patients

as passive receivers of information. In contrast, more recent information provision to patients has concentrated on communicating all aspects of an illness to patients, with a more patient centred approach, focussing on empowering patients. These two different discourses reflect the difficulty in communicating information to patients and the extent to which the source adopted can influence how the information is communicated.

Shannon & Weaver (1949) developed the mathematical model of communication, which argued that communication is a "*mechanistic and sequential process concerned with the movement of information*" (Dixon-Woods, 2001, p.1423). They argued that information transfer can be measured in amounts and communication relies on the transfer between two individuals, with the "*noise*" (Dixon-Woods, 2001, p.1423), that interferes with communication, minimised.

#### 2.3.2.4 Health information and parents

This section looks at the health information needs of a specific group, namely parents. Parents have specific information requirements relating to their children, both in terms of their general welfare and their health. Both empirical research and theory will be discussed.

Nicholas & Marden (1998) examined the information needs of parents with children under the age of five. They used semi-structured interviews (n=35) and focus groups (n=18) to elicit the information sources used by parents, the information needs of parents, and parents' perceptions of their own information needs. The study found that parents had the greatest need for information about health and childcare. Parents were sceptical about obtaining health information from HCPs and instead wanted access to alternative viewpoints or medical research. Parents mentioned two health scares: "*The need for the very latest information was highlighted by recent media health scares, when parents needed to know about the safety of baby milk. Parents ... wanted current research findings on immunisation*" (Nicholas & Marden, 1998, p.43). Parents used a wide variety of sources for information. Health visitors were regarded as the most important source of information for parents about their child's health. Parents did not consider the opportunistic information that they acquired from the mass media as meeting their information needs. The authors suggest that parents use television for its primary purpose, entertainment and that the secondary information they gained from the

mass media (either through active searching or passive acquisition) was considered to be too general. They were also unwilling to use written sources, with the authors suggesting that the use of written sources is related to both educational attainment and the availability of these sources in parents' language of choice (Nicholas & Marden, 1998). These findings contrast with Kai (1996a and 1996b) who found that parents used the information that they gained from the mass media as a response to their lack of trust in HCPs. Kai (1996a and 1996b) also found that parents had a preference for information in a book format, although this preference was for an illustrated book. The difference in the findings of these two studies highlights the variation between groups of individuals that is a challenge when undertaking research with parents.

Levy (1999) undertook a focused interview and observation study of how pregnant women (n=17) deal with information regarding pregnancy. The study concerned the way in which they make choices and the role that information plays. In terms of information, women actively accessed information in order to maintain equilibrium (i.e., to remain in a balanced condition physically and mentally). The women in the study regulated the information they received through three different courses of behaviour: avoiding information, delaying the pursuit of information and pursuing information. They also attempted to place the information that they received in context, through assessing the validity and trustworthiness of the source providing the information and through personalising the information.

Huws et al. (2001) examined the use of an email group by parents of children with autism through observing messages (n=6142) posted to this email discussion group over a three-month period. Parents with autistic children had problems gaining sufficient information about their child's condition, despite the fact that they interacted with HCPs on a regular basis. The study analysed the messages using a grounded theory approach. The study found that parents used the email group to 'make sense' of autism. Parents also used the email group to provide information and solve problems. They expressed a need for information from other parents due to an inability to gain information from other sources.

Kai (1996a and 1996b) undertook a study that examined acute illness in children, how their parents coped with this illness and the information needs associated with the illness. The study used qualitative methods (semi structured interviews (n=32) and focus

groups (n=63)) to collect and analyse data using a grounded theory methodology. Parents coped with illness by being aware of perceived threat and having personal control. Parents sought information in order to cope with the illnesses that their children faced. They expressed a need for more information about all aspects of acute illness. Information from HCPs led to parents feeling uncertain, as they felt unable to understand methods of diagnosis. Their preference was for information in the form of an illustrated book. Kai (1996a and 1996b) found that the media played a part in determining the concerns that parents held about acute illness, citing the media coverage of and awareness campaigns about meningitis as providing information to parents. Information was seen as having an empowering role for parents, in that education and information had a role in allowing parents to judge more accurately the threat that their children faced.

A study by Pain (1999), which involved the parents of disabled children (n=20), found that parents had specific views on their preferred information source. Parents valued personal communication from key health and social workers most, as these workers were seen as being approachable and supplying information that was practical and tailored to the parents' needs. Written information was valued by parents but was viewed as a back up to personal communication. Pain (1999) found that parents used information in a similar manner to that found by Kai (1996a and 1996b). Information was used as a coping strategy, allowing parents both practical and emotional support. Information was used to: *"enhance management of the child, to help the parents cope emotionally, and to be able to access benefits and services"* (Pain, 1999, p.305). In terms of emotional coping, information allowed the parents to accept their child's condition, from the time of diagnosis and beyond, and allowed them to plan for the future of their child. Information about services and benefits reduced the pressure on parents by allowing others to help them with their child's upbringing. Information allowed parents to manage their children's behaviour better (Pain, 1999).

Brazy et al. (2001) examined the information needs of parents of premature infants through an interview study (n=19) and found that as well having specific information needs, parents were on an information journey. Initially they were passive recipients of information but gradually became more active.

Finlay & Lunts (2000) examined information materials that had been designed for parents and their readability. They examined 59 different sources of information for parents, and found that the majority of information sources were acceptable in terms of readability. Patient Information Leaflets (PILs) were considered easy to read, which reflects the testing that they undergo. The most difficult information sources to read were those provided by self-help groups, which Finlay & Lunts (2000) attribute to the fact that these are often written by educated people for educated people.

Mitchell & Sloper (2002) sought to understand how information needs of parents of disabled children could be met. On the basis that previous research had shown that parental information needs were unmet and the assumption that information led to empowerment, Mitchell & Sloper (2002) undertook focus groups with parents and professionals (n=32) to see how this could be addressed. The study found that simply giving parents information was not enough, as both too little information and too much information led to parents feeling isolated. Instead, parents wanted to receive information that was in a variety of formats and at a variety of levels. They wanted information to be targeted at key periods in their child's development and also to give them coping strategies to deal with their children.

As this body of empirical research shows, parents differ in the ways in which they deal with information and the sources that they choose to use. This variation is evident within groups of parents, e.g., who have children with a specific condition and between groups of parents. Information is important to parents to make sense of the situation in which they find themselves, a situation that is often new. Awareness and coping are themes which run through much of the research discussed here and are enhanced by information. It has also been shown that the information needs of parents may differ according to the health of their child and also that individuals have multifaceted information needs generally and this does not differ with reference to their information requirements as a parent. It is important to again highlight that the different concepts and definitions that different studies/authors take to the term 'information' complicates the understanding of how these different groups use information.



### 2.3.2.5 Health information and the media

An important issue related to the study area is the role of the media in communicating health information to the public. A great deal of research has been carried out on how the mass media cover health stories and convey health information to the public. The mass media are a source from which people receive information, but the provision of accurate information, to inform decision-making is not within the remit of the mass media. Instead the information that the media supply tends to be focused around entertainment. Despite this, the media have an important role in communicating health information to the public, as they can often be the only source through which parents are exposed to health information.

Bartlett et al. (2002) examined how the mass media report research that was originally reported in the medical press. They examined press releases from the BMJ and the Lancet (n=517), which reported original research published in their journals. The subsequent reporting of these press releases in the mass media (n=81) was divided into good news and bad news. Good news was that which was of benefit to patients (e.g. a new intervention or a beneficial side effect to an existing intervention). Bad news was anything that may potentially cause harm to patients (e.g. a previously unrecognised side effect to an intervention). Bartlett et al. (2002) found that the media are more likely to report bad news than good news, despite the fact that press releases from medical journals to the media are equally balanced between good and bad news. The most frequent bad news stories reported concerned women's health, reproduction and cancer.

Entwistle (1995) examined how mass media journalists use medical journals (British Medical Journal and Lancet) when they are reporting medical research. Interviews were carried out with key mass media journalists (n=10) and a content analysis of broadsheet newspapers (n=4) was performed. Journalists wanted to report at least one medical story each week, and looked for topical diseases or key authors when writing articles. The journalists commented that medically worthy research is not necessarily newsworthy research and that their priority is to get their story printed. Areas that they concentrated on included common diseases which lead to fatalities, less common diseases which were considered to be 'interesting', diseases of a sexual nature, controversial diseases and new treatments.

Deary et al. (1998) undertook a study that examined an article published in the *Lancet* and examined how this article was subsequently reported in the popular press. The initial research article reported that submissive people were less likely to have a myocardial infarction (heart attack) than less submissive people. The article pointed out that only in the case of women, was submissiveness more significant than other factors. Following on from the original research, Deary et al. (1998) noted that the reporting of this research was often inaccurate. Journalists reported both the press release and the article incorrectly. Headlines were designed to attract people to the story rather than to inform them of the facts of the research. The media concentrated on the fact that this research was more statistically significant for women than men and focused their attention on creating a link between traditional domestic roles performed by women and longevity.

Entwistle et al. (2000) examined the media coverage of a new medical intervention (the *Norplant* contraceptive device) by analysing 101 national newspaper articles printed between 1992 and 1996. The media coverage varied in its tone and content throughout the six-year existence of the intervention. Initial coverage was positive and contributed to the early success and high uptake of the intervention. However, over time, the tone of the reporting changed to a negative stance, with anecdotal stories from women claiming damage by the device. Despite the lack of clinical evidence, the media reported the device in a very negative manner with an emphasis on the human-interest element of the stories.

Lupton (1994) outlined two different types of health stories that the news media report: general interest health issues and acute or uncommon health risks. Lupton (1994) views the media as having an important role in placing pressure on the Government to respond to health issues and in increasing awareness of medical research. The news media are also central in communicating medical research to the wider public. However, it could be argued that communicating medical research in the most appropriate manner is not necessarily a responsibility of the news media and there may be consequences for the general public in terms of decisions that they make and opinions that they hold, if the media do not report accurately the facts relating to particular medical research/issues. Lupton (1994) also believed that the medium constrains the way in which health stories are presented. Television coverage is constrained by the need for visual image and is constrained by time. The print media are constrained by the need to conform to either

tabloid or broadsheet reporting. These constraints can present problems when communicating health related issues, as the information that needs to be communicated is often complex. Restricting the amount or complexity of information communicated can lead to people having limited information, which may have serious consequences if it is subsequently acted upon by patients or the public.

Brown et al. (2001) examined the influence that the media have in shaping the public perception of illnesses, by looking at the print media coverage of possible environmental causes of breast cancer. The research used popular magazines, science periodicals and newspapers (n=1707) and found that the media had a strong influence on the public in terms of how they frame their coverage. Coverage often focused on the individuals' lack of knowledge of the disease, which led to inappropriate behaviour. The media were more likely to focus blame for the condition on the individual than on society as a whole.

As this section has illustrated, while the media have an important role in communicating health information to the public, two aspects of the media mean that accurate reporting is often compromised. These aspects are firstly that the media's role is to report interesting stories that are often framed in terms of 'bad news'. The second is that the format of the media does not encourage in-depth reporting of any issues and health issues are often complex and require an in-depth approach.

### **2.3.3 Risk information**

This section discusses the issue of risk and the communication of risk related information. How individuals perceive information about health communicated to them is influenced by a number of factors including the individual's perception of risk. This may then influence how the individual behaves as a consequence of the information. Therefore the way that risk is communicated is important in determining health behaviour. This section looks at how risk can be communicated, how the public understand risk and how the media present risk to the public. It is important to define what risk information means. The overall meaning of health information is information that contains advice, facts and opinions about all aspects of health e.g. healthy living and information about diseases and conditions. In contrast, risk information, as

discussed here, is the subset of health information that addresses health where there is some risk involved e.g. alleged risks of vaccination and unsafe practices e.g. smoking.

Lloyd (2001) discussed the way in which risk can be presented. Broadly, risk can be presented qualitatively (in words) or quantitatively (in numbers) or in a combination of the two. Both these methods require the individual to employ specific methods to understand the way in which the risk has been presented. Qualitative presentation of risk may lead to the individual attempting to quantify the risk, for example, trying to compute the extent of risk if a minority are reported to be at risk. Conversely, presenting risk in numerical terms may have the opposite effect, with individuals unable to assess and understand the real probability of risk when faced with numbers, for example, a 0.05% chance of catching a specific virus (Lloyd, 2001).

Calman (1996) discussed health scares within the context of the public understanding of risk. He discussed the paradox that health scares can cause people to change their behaviour, for example the MMR vaccine scare (which has led to some parents rejecting the triple vaccine and substituting it with single vaccines or not vaccinating at all), but other risk behaviours, such as smoking are continued, despite the hazards being well publicised. He argues that there must be a classification of risk: whether the risk is avoidable or unavoidable, whether the risk is justified and the severity of the risk.

The extent to which the public understand risk and the way in which it is communicated to them has been described as risk literacy (Petts & Homan, 2001). This section also looks at how the public understand risk and to what extent their risk literacy affects their perceptions. Petts & Homan (2001) undertook a study of the risk literacy of the public. The study involved questioning both 'at risk' and control groups about specific health risks e.g. air pollution and mobile phones. The study was undertaken with the premise that risk information is not treated as an objective fact by the public but is instead shaped by the individual beliefs. The study found that in order for risk to be communicated effectively, the following two factors must be considered, what is communicated and who is communicating it. The study found that individuals want risk information to be personalised and practical. Information must avoid technical jargon and be as comprehensible as possible. It must be targeted at specific groups and be available through as many mass media sources as possible. In terms of who is

communicating it, the source must be seen to be independent, credible and free from bias (Petts & Homan, 2001).

Lloyd (2001) examined patients' understanding of risk and how this affects their decision-making. Lloyd (2001) reported that decision-making was affected by two main factors: heuristics and perceptions of risk. The availability heuristic states that people will judge an event to be more of a risk if they can easily remember an occurrence of it. This accounts for the perceived risk travelling via rail as opposed to travelling via road. While road accidents are more common than rail accidents, the fact that rail accidents receive heavy media coverage means that people are more readily able to recall the 'risk' of travelling via rail. Other factors that influence perceptions of risk include the immediacy of the risk, whether the risk is controllable, whether the risk is new or established, the possible consequences of the risk, whether the risk is natural or manufactured and the confidence with which experts in the field support or discredit the risk (Lloyd 2001).

Kent (1996) examined the impact that information has on anxiety and how people understand risk. He viewed risk as being affected by a number of factors. Literacy affects the way in which people understand terms such as risk. Anxious people are more likely to perceive risks as being greater than calm people. Kent (1996) also noted the fact that people are unable to judge the risks of everyday behaviours, e.g. smoking or crossing the road, and less frequent events such as health interventions e.g. vaccinations. Less frequent events are perceived of as being more risky, despite the fact that there is no evidence for this.

The media, as with health information, have a key role in communicating risk information. Stallings (1990) argued that risk is a product of the media. Risk is not an objective fact and is shaped by the way in which it is presented. The information that the public receive is, to a certain extent, that which the media have decided that they want the public to see. However, the media is not the only source of risk information.

Kent (1996) also argued that the media play a role in shaping perceptions of risk, in the form of the availability heuristic (Lloyd, 2001). This states that people will perceive something as being of a greater risk if they are constantly exposed to negative information about it. The media repeatedly report negative stories and, as Kent (1996)

remarked, the perception of risk is affected by whether people can remember events that occurred. Perceptions of risk are also influenced by people's personal exposure to the risk and their experiences.

Klaidman (1990) examined how the media report health risks. He argued that the media do not report health risks accurately and are selective in their reporting. The media concentrate on health risks where there is a story that will generate interest, rather than where they have a duty to report information that is in the public interest. He argues that the media should aim for reports that are accurate, understandable, objective and complete.

Risk information is also communicated by HCPs to patients and the public. Alaszewski & Horlick-Jones (2002) argue that effective risk communication is dependent upon the two groups, i.e., professionals and patients, using information effectively: "*Effective communication depends upon the ability of professionals to assess and make available information and patients willingness to trust professionals and use their assessment to manage their health*" (Alaszewski & Horlick-Jones, 2002, p.2).

Alaszewski & Horlick-Jones (2003) examined patient-physician communication about risks and looked at why people make irrational judgements about risk. They believe that the best forum for communicating risk is through the medical interaction between doctors and patients. Providing risk information is not just about giving people information, it is also about ensuring that information providers are aware of how people use information. Key aspects of this are that the information is trusted, that the information is made relevant for everyday life and decision-making, how information about one issue can be related to another and the importance of previous knowledge and experience: "*In judging the trustworthiness of risk information, individuals give particular priority to personal knowledge and experience, and official bodies need to work hard to overcome such barriers through engaging the public*" (Alaszewski & Horlick-Jones, 2003, p.729). Alaszewski & Horlick-Jones (2003) concluded that as individuals are not rational, it is important to be aware of the social context of risk information. To improve risk communication, doctors need to build relationships of trust, be aware of all the risk information that patients access and be sensitive to psychological and social factors which influence responses to risk information.

This section has looked at the importance of effective communication of risk information. In the case of health information, it is not only facts about diseases or conditions that need to be communicated, but factors such as the extent of risk. The communication of risk is complex and the public may view the risk that is being communicated as subjective rather than objective, as it is difficult to frame risk in language which implies that the risk is a fact. This is enhanced by the fact that the source that is communicating the risk information needs to be trusted by the individual, in order for them to trust fully and absorb the information that is being provided. Risk information can be seen as a subset of health information (although clearly risk concerns individuals in other parts of their life). The media are more likely to focus on the subset of health information that is risk information, because these issues better fulfil the medias aim to entertain.

Information and trust are seen as being central to risk communication. Without both of these elements, communication is broken down and people are not aware of risks. The widespread coverage of risk issues by the media means that the public often receive incorrect information and issues such as Bovine Spongiform Encephalopathy (BSE) have reduced the public's trust in medical expertise, leading to a breakdown in trust and incorrect information, which can have serious consequences on behaviour, which can then have serious consequences for health.

#### **2.3.4 Summary**

As this section has highlighted, information is a huge area in which to undertake research. It is also a constantly changing area, as there is little consensus about the definition of information. While there has been a reasonable amount of research on information needs generally, the information needs of parents have not been widely researched, especially within the area of health information. Information is considered to be increasingly important, in terms of how it is provided and how it is communicated and the sections on health information in the media and risk information emphasise the importance of information and how it can influence behaviour. None of the research about parents and health information that has been discussed here used a quantitative methodology, indicating a gap to be filled, as while qualitative research illuminates the area under consideration, it does not allow for any conclusions to be generalised. Research on health information in the media often concentrates on assessing the content

of the media report. Following on from this assessment of the content of the report, the impact that this content may have on individuals is discussed. Rarely is the impact of the media on individuals examined by researching from the individual's perspective. Despite this, research has found that the mass media do impact on individuals in terms of their behaviour, one example being the systematic review by Grilli et al. (2005), which found that publication in the mass media was an effective method of influencing patient behaviour.

The next section sets the research in context in terms of health scares.

## 2.4 Health Scares

This section examines health scares and gives a brief overview of what a health scare is and the major characteristics of a health scare. Four health scares are examined, focussing on the role of information within health scares.

### 2.4.1 Definitions of health scares

Health scares have not been extensively defined in either the academic literature or in popular literature. The term is relatively new and is one that people readily attribute to events such as the concern surrounding the safety of the MMR vaccine, without having a clear definition of what this is. It is difficult to understand why there is no consensus about what a health scare is, apart from the fact that they are a relatively new phenomenon, and, while they do have some common characteristics, no individual health scare is like another. Haynes (2000) defined a health scare as follows: "*A health scare arises when public alarm is generated out of all proportion to the degree of risk that people actually face*" (Haynes, 2000, p.30).

Haynes' (2000) definition highlights the three key aspects of health scares: public alarm, degree of risk and generation of public alarm. Health scares are characterised by public alarm, which is often disproportionate to the risk faced. This can be attributed to the communication of risk, which is often inaccurate, presenting one course of action as being more or less risky than the actual risk faced. A health scare has to be generated. Health scares are not simply reporting of health research. They have to contain some interpretation of the research that intentionally or accidentally causes risk or concern.



Defining health scares can also be related to Showalter's (1997) work on hysteria. She proposed that the mass media has facilitated the rapid spread of hysterical stories about health. Examples used were Gulf war disorder and the Ebola virus as these affect relatively few people but have gained extensive media coverage. Hysteria in this context is described as a modern epidemic which: "*...requires(s) at least three ingredients: physician enthusiasts and theorists, unhappy, vulnerable patients; and supportive cultural environments*" (Showalter, 1997, p.17).

As this literature review will describe, the health scares under examination share some of these features, namely specific individuals who are likely to be affected by the scare and a society which is influenced by the opinions of the media and the opinions of scientists, doctors and the public as presented in the media.

#### **2.4.2 Characteristics of health scares**

The most obvious characteristic of a health scare is its appearance in the mass media. Klaidman (1990), Boss (1997) and Ward (2000) argued that the development of health scares is mostly caused by the mass media, whether this is newspapers, magazines, TV, radio, the Internet or a combination of these.

Klaidman (1990) argued that the nature of the health issue is what changes a health story to a health scare. Health stories that contain the following characteristics are more likely to become health scares: unpleasant consequences of the risk/event, inaccessible information about the risk, complex scientific principles, incomplete scientific data and inaccurate risk estimates. However, it can be argued that these characteristics are more likely to be attributed to health scare stories, as they are also characteristics that the media can capitalise upon when producing a press report.

Ward (2000) claimed the fact that health stories turn into health scares was related to the conflict between the media and public health officials. Journalists do not have a responsibility to judge how the public will use the information they provide and they often have a difficult relationship with public health officials, who do have a responsibility to ensure that the public are given accurate information. The health stories themselves generate scares because of two main reasons, that human-interest stories

(which are often the basis of health scares) do not establish proof of a medical problem and also that the public confuse absolute and relative risk. Scientists deal with probabilities rather than absolutes, which the public find harder to understand.

Boss (1997) in a review of literature argued that the media are the most evident characteristic of health scares, in the sense that they shape people's reactions to the issue: "*Too often it is the media created event to which people respond rather than the objective situation itself*" (Boss, 1997, p.237).

### **2.4.3 Impact of health scares**

This section details a number of health scares, how they developed and their impact, placing particular emphasis on the role of information and the role of the media.

#### **2.4.3.1 Contraceptive pill scares**

The contraceptive pill is an oral intervention given to women to prevent pregnancy through doses of hormones. Various contraceptive pill scares (usually referred to as pill scares) have been generated through the mass media coverage of potential medical side effects of the contraceptive pill that have been discovered through research. Frequent pill scares have led to women stopping taking the pill, which has resulted in an increased number of unwanted pregnancies. Research into pill scares has concentrated on a number of aspects related to the scare, such as the number of unwanted pregnancies. Research has also looked at the role of information in pill scares, focussing on the sources of information for women (both initial sources when finding out about the scare and sources of information used as a response to the scare). It is this research that is examined here.

Wellings (1985) examined the media coverage of the scare that surrounded the pill in 1983. Original research by Pike et al. (1983) was published in the Lancet and found a link between taking the pill and an increased risk of breast cancer and cervical cancer when compared with users of intra uterine devices (Pike et al.1983). The Lancet article by Pike et al. (1983) generated 195 articles in both local and national newspapers. This was compared to an article in the Lancet the previous week that linked the pill to

increased protection against breast cancer, which generated one article in newspapers. This highlights the media's preference for reporting bad news.

In the 1990s there were various scares surrounding the safety of the contraceptive pill, which were reported by the media. The research concentrated on linking the pill to various life threatening conditions, such as blood clots and breast cancer. Different types of contraceptive pill are often described as belonging to a particular 'generation', which is an indicator of when the pill was introduced and the hormone level within the pill, with third generation pills being the ones most recently introduced.

In response to the pill scare of 1995, a family planning clinic in Glasgow set up an information line that was evaluated by Armstrong et al. (1995). Attendances at the clinic and phone calls to the clinic increased three-fold following the emergence of stories relating to the contraceptive pill in the mass media. Women who telephoned the information line were given a questionnaire when they subsequently attended the clinic (n=178). The questionnaire quantitatively measured their response to the scare. In terms of the source from which women found out about the alleged side effects of the contraceptive pill, the mass media were the most common sources with television, radio and newspapers being the source for 83% of women. 77% of the women questioned expressed that they wanted more information as a result of the scare (Armstrong et al., 1995). However, this only reflects the views of women contacting the telephone line and attending the clinic, who are more likely to be those who would actively seek information, not necessarily the views of all women affected by the scare.

A study carried out by Allison et al. (1997), in light of the 1995 pill scare, found that women (n=1334) used multiple sources of information, e.g., HCPs and friends, when making decisions about which contraceptive pill to take. However, the sources used in this 'everyday situation' differed from the sources used in critical situations, such as during pill scares. In these situations, women relied heavily on the mass media, with television, newspaper and radio being named. Interpersonal communication with both HCPs and friends/family were relied on less in urgent situations, both in terms of the frequency of sources used and their perceived helpfulness.

Flett et al. (1998) examined the local impact of the 1995 pill scare on abortion rates. The study also looked at the media role in the scare through the use of a questionnaire with

women who presented at a hospital for an abortion (n=403). The study found that there was no change in the abortion rates for the six-month period following the media coverage, but prescribing of second generation pills rose in this time period, arguably as a response to the scare (which concerned third generation pills). In a questionnaire about the media impact of the scare, 79% of women remembered the publicity, but of these women, 17% did not remember the details. Women expressed a need for information about alternative methods of contraception and the risks of continuing to take a third generation pill.

The research by Armstrong et al. (1995), Allison et al. (1997) and Flett et al. (1998) highlighted that when the media report a health scare story the reports include opinion as well as fact. This is due to the media's primary aim, which is to entertain, rather than to provide information and the fact that the media have no responsibility to provide health information. Because of the use of fact and opinion in media reporting, women had to interpret the risks presented by the media, rather than interpreting the risks themselves.

Hammond (1997) compared the media coverage and the resulting change in behaviour in two different scares concerning the contraceptive pill. The first scare occurred in 1995. It linked third generation contraceptive pills with an increased risk of venous thromboembolism. This scare was widely reported and in language which may have led to panic on the part of women taking the pill. The scare in 1996 linked the pill and breast cancer. This story was reported widely but had a clear 'don't panic' message attached to it. Hammond (1997) sought to differentiate between these scares in terms of the coverage that they received by an analysis of print and television media. The analysis showed that there was less coverage in the 1996 scare. Both the TV and the print media used risk language to a greater extent in 1995 and the health benefits of the pill were not mentioned. In both scares the print media covered risks and benefits in a more balanced manner than the TV media. However, the major difference was in the intrinsic qualities of the stories. In 1995 the emphasis was on the human aspect of the story, particularly deaths associated with the scare. In 1996 there was more of an emphasis on the medical aspects of the story, especially the fact that the research that pointed to an increased risk of breast cancer also pointed to a decreased risk of ovarian cancer (Hammond, 1997).

Weatherall (1996) examined the newspaper reporting of the pill scare in October 1995. The research found that while the content of the stories did contain responsible advice about the best course of action to take, the headlines that were attached to the stories were highly alarmist e.g. 'Danger Pill: 1m women warned'. Weatherall (1996) indicated the conflict between the media and scientists. While scientists and newspaper journalists may both be involved in science journalism, they both have very different agendas. Journalists tend not to be critical of scientific research, especially if it allows them to publish articles that sell newspapers and lead to profit (Weatherall, 1996).

As Calman (1996) pointed out, the reason that the reporting of medical research turned into a health scare was because of the communication of the risks attached to the pill. While the relative risk of venous thromboembolism when using third generation contraceptive pills doubles when compared with the second generation pill, the absolute risk is small, and smaller than that associated with pregnancy. Mortality rates per million women per year were reported as follows: third generation pill 3 women, second generation pill 1.5 women and pregnancy 6 women (Calman, 1996).

There is a large body of research on the role of the media in contraceptive pill scares. It is clear that the media are highly influential in shaping women's responses to the risks that they face. Despite the attempts of other information providers, such as HCPs, the message that the media is presenting is the one which women are most responsive to and therefore the one that determines their behaviour. This can be dangerous if the information that the media are presenting is inaccurate. It is a limitation of the research presented here that it does not examine the opinions of the women influenced by the media-generated contraceptive pill scare and the extent to which their perceptions of both the media and information sources have been affected.

#### 2.4.3.2 Baby milk scare

In 1995, the media reported a study that found phthalates (dangerous industrial chemicals) in some brands of infant formula milk. (Scowen, 1996). The Ministry for Agriculture Fisheries and Food (MAFF) study reported these findings but stated that the levels of phthalates would not be any danger to infants and as a result they would not be naming the brands in which the phthalates were found. Despite this, the media reporting created an alarmist response. With the Government refusing to name the brands

affected, the responsibility fell on HCPs to reassure parents. However, the nature of the scare meant that HCPs could not be briefed in advance about the story and were unable to inform and reassure parents correctly.

#### 2.4.3.3 BSE scare

BSE is a disease that affects cattle. It is caught through the use of animal remains in animal feed. It is fatal to these animals and devastating to the farming industry. In 1996, reports indicated that BSE had been transmitted to humans in the form of a new variant form of Creutzfeldt-Jakob Disease (CJD), which was a previously unrecognised form of CJD, with a “*novel pathology and consistent disease pattern*” (Phillips, 2000). Despite the recognition of a possible threat to humans and a possible link between BSE and variant CJD (vCJD), the Government sought to minimise the alarm to the public. Although the Government sought to minimise alarm about the risks of eating beef infected with BSE, their reassurances that BSE could not be transmitted to humans was misplaced (Phillips, 2000) and as a result the UK Government had to admit that they had given inaccurate information to the public. The BSE scare led to distrust in the Government, in that the Government retracted their initial statement that eating beef was safe and acknowledged the risks of eating beef, a statement which was underlined by the fact that over 80 people are believed to have died as a result of eating beef infected with BSE (Phillips, 2000).

The BSE scare highlighted the role of the Government during a health scare and how the communication of incorrect information can have serious consequences for the public. Klein (2000) examined the BSE Inquiry (Phillips, 2000) on how the UK Government handled the BSE scare and found that the crucial issue was that of the communication of risk. Risk is a complex issue and the Phillips report (2000) raised the question of how to avoid risk, in the context of the BSE scare. The report asked whether all possible potential risk should be eliminated or whether risk should be minimised. In the case of the BSE scare, the UK Government was unwilling to admit that there was any risk for fear that this risk would be taken out of all proportion. This led to distrust of the UK Government, which has influenced parental response to the MMR vaccine scare: “*The examples of oral contraceptives and measles vaccination show how easily – and damagingly – information about risk may be translated into overreactions*” (Klein, 2000, p.1091).

The Economic and Social Research Council Global Environmental Change Programme (ESRC, 1999) examined the UK Government's management of health scares and controversial issues, such as BSE. They argue that while there are scientific answers to questions raised by these issues, there are also ethical issues that are often overlooked. Crises such as BSE have led to public distrust of the Government. The report argued that risk communication is a problem because risk can only be communicated when probabilities and outcomes can be defined. The report also discussed the perception that the individuals or groups of individuals who generated public awareness of the risk are considered to be more trustworthy than those who refute the risk due to the fact that those who refute the risk may be seen as needing to protect themselves.

#### 2.4.3.4 Pertussis vaccine scare

This example of a health scare concerns vaccination. The scare surrounded the Pertussis element of the Diphtheria, Tetanus and Pertussis (DTP) vaccine, which is given to children in the first few months of life and again before they start school. This health scare has particular relevance to the study as it concerns both children and vaccination and was the first major vaccine related health scare in the UK.

Fears about the safety of the vaccine were generated through media reporting of research findings about one uncontrolled case series. (Kulenkampf et al., 1974). Parents rejected the DTP vaccine and switched to a vaccine containing Diphtheria and Tetanus alone. In 1977 vaccine rates of the DTP fell from 77% to 33%. There were three major epidemics and an estimated 36 children died (Baker, 2003). The study was only refuted seven years after publication (Nicoll, 2001).

Gangarosa et al. (1998) examined the impact of anti-vaccine movements, established in different countries worldwide, as a result of the scare surrounding the DTP vaccine. This examination looked at the levels of Pertussis and compared these to whether countries had anti vaccine movements. Gangarosa et al. (1998) found strong evidence of a relationship between active anti-vaccine movements and Pertussis epidemics, with increasing incidence of Pertussis as anti-vaccine movements increased. In terms of the anti-vaccine movements, they identified countries where there is no opposition to vaccines, countries where there is active opposition and countries where there is passive

opposition. Active opposition involved the media and popular press in opposition to vaccination, while passive opposition was characterised by opposition from religious groups and HCPs.

Baker (2003) examined the development of the Pertussis scare, in terms of the role of three key stakeholders: the press, the medical profession and parents in vaccine victim advocacy groups. Baker (2003) found that opposition to the vaccine was characterised by divisions within the medical profession about whether the DTP vaccine was safe (as British doctors were traditionally seen as being sceptical about vaccines), legal battles by parents of vaccine-damaged children, and eventually, an acceptance that DTP was safe. With reference to the similar scare that has surrounded the MMR vaccine, Baker (2003) believed that the only reason that MMR vaccine rates have not dropped even more than they have is because HCPs get incentives in the form of target payments, which makes them more willing to disregard their scepticism and advise parents to proceed with the MMR vaccine.

In a study following on from the scare surrounding the Pertussis vaccine, Calderdale Health Authority undertook a four-year project to increase public and professional confidence in the vaccine (Bruce-Quay, 1981). The study found that parents were influenced by the media and HCPs, and needed more education and guidance. Information was central to this, with new leaflets produced, the consent form rewritten, posters and a local media campaign, with exhibitions and displays. During the project, Pertussis vaccine uptake doubled.

As these four studies have shown, the Pertussis vaccine scare had a lasting impact, both in terms of the health of children and in terms of trust in vaccination. The operation of active anti-vaccine movements influences parents' views about vaccination and the role that the media play enhances this.

#### **2.4.4 Summary**

Health scares are a modern phenomenon and are difficult to characterise. While attempts have been made to research health scares that have occurred, there have been fewer attempts to understand what generates health scares, how they develop and how they are resolved. Because of this it is difficult to characterise health scares, and with



the occurrence of additional health scares, the character of them is likely to be different, which highlights the problems that face both individuals and the Government in dealing with them. A number of important studies have been presented in this section. However, there has been little attempt to look at health scares through empirical research.

Research surrounding health scares has to be, by its nature, retrospective, but research addressing the general impact of health scares on issues such as trust in organisations could be carried out at any time. The research surrounding contraceptive pill scares was widespread, but did not address the long-term impact of the health scare in terms of how it affected behaviour, including information behaviour. The lack of research looking at the impact of health scares on information behaviour needs to be addressed. This PhD concerns a vaccine scare (the MMR vaccine scare) and the following section discusses vaccination in general before the MMR vaccine scare is discussed in section 2.6.

## 2.5 Vaccination

The main subject of this PhD is the role of information for parents and the MMR vaccine scare. Therefore as well as an understanding of information and health scares, it is vital to examine vaccination, as an understanding of the concept of vaccination and the rationale behind it is key when examining the MMR vaccine scare. In this section, the concept and rationale of vaccination are examined, and then two key issues, the ethics of vaccination and vaccination uptake are looked at. Drawing closer to the main subject of the study, vaccine safety, vaccine information and the roles of vaccines in the media are discussed.

### 2.5.1 Background

The Pocket Oxford Dictionary (Thompson, 1992, p.830) defines vaccination as "*inoculating with a vaccine to immunize against a disease*". The rationale behind vaccination is that if a person is exposed to a modified pathogen, (e.g., a virus or bacterium that is not sufficient to cause them serious harm) then they will produce antibodies to combat this pathogen. This means that if they are exposed to the pathogen (in the form of a specific disease) in future then they already have the antibodies to protect themselves against it, which elicits a more rapid response against the disease. The origin of the word comes from the first vaccine, which protected against smallpox through the injection of cowpox (vacca is the Latin for cow). The discoverer of

vaccination was Edward Jenner who, in 1796 in the UK, discovered that people who had been exposed to cowpox could not catch smallpox (The Edward Jenner Institute for Vaccine Research, 2003).

It is important at this stage to differentiate between vaccination and immunisation. Vaccination is the inoculation (i.e. via injection) of the material mentioned in the definition above whereas immunisation can be via different formats, such as oral.

Children (and adults) in the UK are given vaccinations based on advice from the UK Joint Committee for Vaccination and Immunisation (JCVI). This committee decides which vaccines children and adults should be given and when, and issues this advice to HCPs, although ultimately the decision about whether to vaccinate lies with the individual (or in the case of children, the parent or legal guardian). Table 2.1 summarises the UK vaccination schedule for children. It does not include vaccinations/immunisations given to children who are considered to be at risk (National Health Service, 2003).

Table 2.1 - UK vaccination schedule for children

Approximate age	Vaccination/immunisation
2-4 months	Polio
2-4 months	Diphtheria, Tetanus, Pertussis and Hib
2-4 months	Meningitis C
13 months	Measles, Mumps and Rubella
Pre-school	Diphtheria, Tetanus and Accellular Pertussis
Pre-school	Polio
Pre-school	Measles, Mumps and Rubella
10-14 years	BCG (Bacillus Calmette-Guérin)
13-18 years	Tetanus
13-18 years	Polio

Vaccination in the UK is administered through the NHS. Parents are sent reminders that their children are due for vaccination and are asked to present to a GP. The vaccine is administered and GPs receive payments for ensuring that as many children that are eligible are vaccinated (Beecham, 2003).

### 2.5.2 Reasons for vaccination

While, for an individual, protection against a disease is vital, an important aim for vaccination programmes is to achieve herd immunity, which is when a whole population is protected even though not all of the members have been vaccinated (Bedford et al. 2002). This is achieved when a critical percentage of the population have been vaccinated against the disease in question, leading to those who have not been vaccinated being protected as a result of the fact that the disease is no longer present in the population, or if there is an incidence of the disease in the population, the proportion of individuals not vaccinated is so small that the disease is not transmitted to other individuals during the infectious stage and thus the disease cannot establish itself in the population.

Fine & Clarkson (1986) examined the rationale of individuals when choosing a course of action for vaccination and compared it to the rationale of government in promoting vaccination. The government, in theory, is acting to protect society as a whole and will therefore adopt a policy that maximises coverage. However, the rationale for vaccination in individuals differs to that of the government. Fine & Clarkson (1986) reported that parents will aim to minimise risk for their children, however this depends on the parent perceiving the vaccine to be less of a risk than the illness. Minimising risk to their children could also be achieved by relying on herd immunity, as described above. This complicates the motivation for vaccination. The reason that conflict occurs is because the government aims to protect the community as opposed to the individual who seeks only to protect themselves and their family (e.g., in the case of children).

The success (or otherwise) of vaccination is measured in terms of how prevalent the disease that they prevent against is. As the prevalence of diseases falls, there is less incentive to be vaccinated. This is the "*paradox of success*" (Nicoll, 2001, p.22). Individuals forget the negative impact and consequences that the diseases which vaccination prevents against can have on their children. The success of the vaccination schedule is partly responsible for the distrust that individuals have in it because parents only see (what they perceive to be) the negative consequences of the vaccine, as the vaccine has meant that people no longer have to suffer the negative consequences of the disease.

### 2.5.3 Ethics and vaccination

When deciding whether to vaccinate, there are numerous factors that individuals have to take into account. When deciding on a medical treatment, individuals weigh up costs and benefits and make a decision based upon self-interest. However, decisions may also draw upon the best interests of other people, as well as on self-interest. Therefore vaccination generates ethical conflicts and conflicts in personal choice. Vaccination in the UK is not compulsory and as such, parents have free choice about whether to vaccinate their children. This differs to other countries around the world, e.g., the United States of America (USA) and France where vaccination is compulsory (Hobson-West, 2003). However, the choice is not simple, as the individual concerned is not the only person affected by the choice about whether to vaccinate.

The conflict between whether to consider individual needs or the greater needs of society has a basis in two philosophical standpoints: utilitarianism and autonomy. Utilitarianism (which has a foundation in consequentialist ethics) argues that actions should be judged on their outcome and whether they produce the best outcome for the majority of people. The parent acting in a utilitarian manner will maximise advantage for all, therefore allowing their child to be vaccinated to ensure herd immunity. Autonomy, which is based on deontological ethics, states that the individual has sovereignty over their choices. Therefore the parent can decide whether they want their own child to be vaccinated. The decision-making procedure about vaccination is complex and as such it is likely that parents draw upon opinions based on both utilitarianism and autonomy.

Sampson (1998) highlights the conflict between personal choice and a consideration of the good of the community when considering vaccination. Sampson (1998) also considers the ethical duty of information providers to ensure that parents are fully provided with information so that they can make an autonomous choice about vaccination. Sampson (1998) discusses the incomplete provision of information to parents and the possible reasons for this. Although it could be argued that the deliberate non-provision of information is in the best interests of the parent, it can also be viewed as being paternalistic.

Hershey et al. (1994) defined three factors that motivate people's behaviour and that can also be applied to the vaccination decision. These are altruism, free riding and bandwagoning. The decisions that these factors are concerned with tend to be decisions that are made within society and with awareness that the outcome is likely to influence society as well as influencing the individual. Altruistic behaviour is behaviour that considers the best outcome for all affected by the decision and acts upon this. Free riding behaviour occurs when an individual does not carry out an action or make a decision in the hope that someone else will have made the decision and they will benefit from it. Bandwagoning behaviour occurs when individuals copy the behaviour of others on the proviso that other individuals have calculated the risks and benefits and made their decision based upon that. With reference to the vaccination decision, altruistic behaviour occurs when individuals are vaccinated to protect both themselves and society. Free riding behaviour is when individuals refuse vaccination in the hope that sufficient members of society have been vaccinated to ensure herd immunity and eliminate their chances of being infected. Hershey et al. (1994) found that bandwagoning had the greatest effect on people's behaviour, because of a pressure to conform to group behaviour and trust that others have made the best choices. The study by Hershey et al. (1994) has wider implications in the context of health scares in campaigns to increase vaccine uptake. Campaigns must emphasise the acceptance of vaccines and the impact that positive behaviour can have on others (Hershey et al., 1994).

The actions of governments in the case of vaccination also have ethical principles underlying them. A government will act in the collective interest of all individuals in society. Therefore the interests of the individual may appear secondary to those of society. However, the fact that the Government in the UK does not insist upon compulsory vaccination indicates that they are respecting the ethical principle of freedom of choice, i.e., autonomy. However, this may also suggest that the Government does not have the political will to enforce a compulsory vaccination policy, which is likely to be unpopular with the electorate.

#### **2.5.4 Uptake of vaccination**

The nature of vaccination causes problems for maintaining uptake within populations and ensuring people are protected from infectious diseases. The issue of vaccine uptake

and the reasons for vaccination are complicated. Vaccinations are given to people who are not unwell (in contrast to most other medical interventions). The beneficial effects of vaccination are only felt if the individual is exposed to the disease and the nature of vaccination is that its effect should not be felt at all. In contrast, the efficacy of other medical interventions is measured in terms of the immediate (and long term) effects that they have on the individual. Chen (1999) points out that the public's tolerance of adverse reactions to interventions given to healthy people (i.e. vaccinations) is lower than that of interventions given to ill people. Also, vaccinations are normally given to children and the public/media tend to be more intolerant of side effects when they concern children.

A number of factors have been identified that predict vaccine uptake (Bond et al. 1998, Carter 1985, Harrington et al. 2000, Hull 1987, Johnson & Joynes 2001, Miller et al. 1994, New & Senior 1991, Paunio et al. 1991, Roberts et al. 1995, Simpson et al. 1995, Strobino et al. 1996). These include socio economic factors (Hull 1987), service delivery (Carter 1985), parental beliefs and motivations (Miller 1994) and information (Bond et al. 1998, Mason & Donnelly 2000b).

Carter (1985) sought to examine the reasons behind non-immunisation of children against measles. Through examining the role played by HCPs (n=119) in addition to the attitudes of parents (n=91) by interviewing both of these groups, the research found that parents had a wide variety of reasons for refusing immunisation, but viewed unprofessional advice and inertia on the part of HCPs as being a main factor in their refusal of immunisation. In contrast to this, HCPs viewed the parents' choice of non-immunisation as being a result of parental apathy.

Hull (1987) in a review of literature on vaccine uptake looked at the reasons why children were not immunised and found that the blame was shared by parents and health professionals. This study found that socio-economic class was a determinant of vaccine uptake and that families in crisis were less likely to vaccinate their children. Health visitors particularly were seen as having a beneficial impact on vaccine uptake. Hull (1987) found that more information would have a positive impact on vaccine uptake. Parents wanted information about the diseases that the vaccine prevented against, the consequences and rates of infection and the efficacy and safety of the vaccine.

Miller et al. (1994) examined the risk factors for delayed uptake of MMR vaccination in the USA. A telephone questionnaire of parents (n=348) found a number of risk factors. The strongest factor was awareness of the correct age for MMR vaccination, with 70% (n=244) unaware of the age. Other significant factors in low uptake were a greater number of older siblings and younger maternal age. Other, less significant factors were maternal education, number of house moves and parental participation in Government assistance programmes.

Johnson & Joynes (2001) examined uptake in a rural setting through a questionnaire (n=71) that was designed to examine the decision by parents not to have their children vaccinated with the MMR vaccine. The decision came down to two factors, perceived lack of severity of the diseases and fears over the vaccines safety. 21% (n=15) perceived measles, mumps and rubella to not be serious diseases and 68% (n=48) cited concerns over vaccine safety as their reason for not vaccinating.

New & Senior (1991) hypothesised that transport problems and physical constraints were the most likely barriers to parents taking their children for immunisation. Parents (n=273) were interviewed on the basis of their child's immunisation status (full, partial or incomplete immunisers). The interviews found that physical constraints alone were not a predictor of behaviour, but when combined with social factors and parental belief, could be a barrier to immunisation. Issues that were found to influence uptake included the presence of other young children in the family (additional to the child being vaccinated), transport and mobility, illness in the child to be immunised, parental attitudes, health related experiences and gender role constraints.

Simpson et al. (1995) examined the reasons why children were not immunised. Using a list of children that had not been vaccinated in a six-year period (n=86), parents were sent a questionnaire to ascertain the reasons for not vaccinating their children. The major reasons that were given were use of homeopathic medicine (21%) and religious belief (16%) although medical reasons for not vaccinating were also a concern to parents (20%). These medical reasons included residual conditions such as developmental disorders and eczema and a previous family reaction to vaccination.

Strobino et al. (1996) argued that parental attitudes were not the main predictor of under immunisation in children. The interview study carried out with parents (n=557) found

that parental attitudes and beliefs had little effect on children's immunisation levels although parents did hold beliefs that could damage uptake. However, immunisation was strongly associated with socio-demographic variables. The study by Strobino et al. (1996) focused on a relatively poor area of a large city in the USA and found that children born to teenage mothers, children with an absent biological mother and children in large families were less likely to be vaccinated (Strobino et al., 1996).

During a measles outbreak in 1995, Roberts et al. (1995) examined the reasons for non-uptake of the MMR vaccine. The authors targeted children who had not previously been vaccinated and therefore who may be susceptible during the outbreak. The study used a questionnaire with parents (n=2170) and accessed the medical records of their children. The study found the following reasons for non-uptake: previous infection with measles, fear over side effects, inability to have child immunised by the GP, the child's GP having said that the MMR vaccination was unnecessary and parents who did not think that measles was sufficiently serious to vaccinate against. While the targeted campaign did lead to increased uptake, further barriers to uptake that were encountered were refusal of vaccination and non-return of consent forms.

In a study examining mothers' perceptions of severity and the reasons for low uptake, Bond et al. (1998) carried out semi-structured interviews (n=45) with parents in the UK who were complete immunisers (had followed all of the immunisation programme), incomplete immunisers (had followed none of the immunisation programme) and partial immunisers (had followed some, but not all of the vaccination programme). The study found that the main barriers to immunisation for mothers were a "*lack of balanced detailed information*" and "*poor communication between health providers and parents*" (Bond et al., 1998, p.441).

The media can have a positive impact on parental compliance with vaccination and uptake of vaccination. In a study carried out in Finland, Paunio et al. (1991) examined the impact of a mass media campaign on the uptake of the MMR vaccine and compared this with other methods of increasing compliance. The study found that mass media campaigns had a useful impact in increasing awareness, but the most effective method was to contact parents personally through a letter that included detailed information. Other methods that have been used to increase compliance include legislation to make



vaccination compulsory and increasing/decreasing the age at which children are vaccinated.

Harrington et al. (2000) looked at the process of immunisation and whether it had any impact on uptake. They carried out in depth interviews (n=23) with mothers and questioned them on their reasons for non-uptake. The interviews focused upon the mothers' emotional response to and satisfaction with the procedure. The study found that mothers preferred the approach of GPs to other HCPs as they attempted to empathise with mothers concerns. However, adverse immunisation experiences, such as an unsympathetic GP or a very upset child were likely to discourage mothers from attending subsequent immunisation appointments.

Mason & Donnelly (2000b) undertook a randomised controlled trial to see whether targeted information had any influence on uptake of the MMR vaccine. The study (n=511) sent information about MMR vaccine, in the form of a Government produced leaflet, to an intervention group (n=255) and no information was sent to a control group (n=256). The study found that there was no significant difference in the number of children immunised between the control group and the intervention group. They attribute this to the fact that the extensive media coverage that the MMR vaccine has received has led to parents developing attitudes that could not be influenced by additional information. Mason & Donnelly (2000b) recommended that information based interventions need to be more complex, taking into account the attitudes and beliefs of parents and the role that the information which parents acquire from the media has in shaping these attitudes and beliefs.

There are a wide variety of factors that have been attributed to vaccine uptake. In terms of personal factors, awareness of the age of vaccine uptake was important (Miller et al., 1994). Simpson et al. (1995) found personal reasons (i.e., religious beliefs and use of homeopathic medicines) determined vaccine uptake. In terms of healthcare professionals, both GPs and health visitors were found to influence vaccine uptake (Carter, 1985 and Hull, 1987). Paunio et al. (1991) and Mason & Donnelly (2000b) found that the media had a real impact on vaccine uptake.

### 2.5.5 Safety of vaccination

The success of the vaccination programme in the UK has led to individual perceptions of the risk of diseases and the safety of these vaccines being affected. The reduction in the incidence of diseases due to the success of vaccines has led to parents having a reduced awareness of the risk of the disease. This also has the potential to influence the perception of the safety of the vaccine in the sense that if the disease is seen as less of a risk, it is possible that when side effects of the vaccine are reported, these assume a greater importance for parents.

Questions about safety of vaccines tend to take the form of research that derives an association between a particular vaccine and a condition or disease in the person who has received the vaccine. However, as Freed et al. (1996) discussed, the major question that surrounds this research is whether the association is coincidental (happens by chance) or causal (whether the vaccine was a cause of the condition).

Nicoll (2001) examined the characteristics of a vaccine scare and saw them as following a specific course. Initially, a causal link was claimed with a disease by one investigator/group, with extensive media coverage. However, other researchers do not confirm the claimed link and any research that negates the findings is not published. In spite of this, spurious claims are made about the vaccine, which leads to a loss of confidence and falling vaccine rates.

As Chen (1999) pointed out, no vaccine is completely safe or completely effective. Therefore risk communication needs to be tailored to this. Chen (1999) advised a number of strategies to ensure that risk is communicated effectively. Information should be tailored to individuals, as one standard set of information does not take into account the educational, social and experiential differences in people's lives.

Spier (2002) examined why vaccination is considered to have disproportionately more risks than it actually has. Vaccination does not show immediate benefits, like other medical interventions and therefore the benefit of vaccination may never be felt. The risk of vaccination cannot be measured, even in the case of accepted medical side effects. Finally, it is also the case that people want vaccinations to be both 100% effective and 100% safe, which is impossible. The best way to judge vaccine safety is to

judge the relative safety of the vaccine (e.g., as compared to the disease that it is preventing against) rather than judging the absolute safety of the vaccine (Spier, 2002).

Dittmann (2001) discussed public understanding of risk within the context of falling immunisation rates and the impact on public health. Dittmann (2001) regarded the damage that vaccine scares have on the community, as being partly related to the inability of HCPs to communicate risk effectively. Particular aspects of vaccination, which require special emphasis on risk communication, include the fact that immunisation is carried out on people (often children) who are not unwell (which makes the intervention seem less necessary), the fact that the success of vaccines has led to a perception of reduced severity of the diseases and the fact that vaccines are not risk free and when there are problems with vaccines, they are reported extensively and in a sensationalised manner by the media. Dittmann (2001) suggested that future responses to vaccine scares should be rapid and tailored to the specific population that they are affecting. The format of the information is important and printed materials do not always convey risk accurately. The information conveyed must be balanced, looking at risks and benefits and including references for further reading if required (Dittmann, 2001).

Nasir (2000) undertook a review of anti-vaccination websites, i.e., websites that questioned the safety of vaccination. A random sample of websites (n=26) found that anti-vaccination websites were published by a wide variety of different groups (e.g., alternative medicine, civil liberties and conspiracy theorists). All the sites reviewed documented side effects to vaccination and most sites speculated on the reasons that HCPs promoted immunisation. The presentation of information on these sites often appeared unbiased.

### **2.5.6 Information and vaccination**

This section examines the relationship between vaccines and information from a number of different perspectives. These include information provision in acute situations (Brooks & Finlay, 2002; Gellin et al., 2000) and general information provision (Clayton et al. 1994; Gill & Sutton 1998) as well as studies with non-immunisers (Smailbegovic et al., 2003).

In a study carried out during the introduction of the Meningococcal C vaccine (Brooks & Finlay, 2002), it was shown that the introduction of a new vaccine increased the information needs of parents. Three hundred and four calls received by a vaccine hotline in the Bath area, UK, showed that parents felt that they were not given detailed information about the vaccine from their HCP and they wanted information about multiple vaccines, vaccine safety and the eligibility of their child (Brooks & Finlay, 2002).

Clayton et al. (1994) examined the impact that information had on parents' views about immunisations, by assessing their knowledge and opinions about vaccination both before and after the introduction of Vaccine Information Pamphlets (VIPs). Parents (n=333) were given VIPs either before or after their child's vaccination and their knowledge was tested. The study found that VIPs were useful as an information source for parents in that parents who received the VIPs became more pro-vaccination and knew more about vaccination than parents who had not received the VIPs. However, parents still viewed the HCP as the main source of information, with VIPs acting as a form of supplementary information for parents. This may be due to the fact that VIPs are inaccessible for some parents as the language they use is only suitable for parents who have a high reading age. However, Dixon-Woods (2001) argued that reading age is not a barrier to leaflet comprehension.

Gill & Sutton (1998) carried out a study that examined parents' information needs and preferred information sources in relation to immunisation. The study took the form of a cross-sectional interview study with parents (n=759) in London, UK. The study categorised parents in one of four categories. Automatic immunisers were often first time mothers who perceived the vaccine to be less risk than the diseases and preferred information from HCPs. Questioning immunisers went ahead with the vaccination programme but found it a hard decision. Elective immunisers were articulate and well informed but still felt guilty that they may damage their child despite the fact that they decided to make the decision to immunise. Selective immunisers were influenced by the authorities, not necessarily in a positive way and only went ahead with immunisation if they were in the right place at the right time, e.g., if they were approached by the HCP regarding vaccination during a routine appointment.

Gellin et al. (2000) undertook a telephone survey to assess parental understanding of immunisation and parents' information needs and information sources in relation to immunisation. The study was undertaken in the light of the increasing concern about the safety of vaccines. The sample of parents (n=1600) were asked questions which had been developed through focus groups with parents. The study found that parents used the doctor as the main source of information (n=1347). Other professional sources of information were not used as extensively, e.g., nurses (n=131) and health clinics (n=120). Parents also actively sought information from the media (newspapers and magazines (n=290) and books and journals (n=197). Parents expressed satisfaction with the doctor as an information source, although the study found that approximately 300-400 parents harboured misconceptions about immunisation.

Austin (2001) undertook a phenomenographic study of parents' perceptions of information on immunisation. Interviews were carried out with parents (n=15) who were asked about their knowledge of the immunisation programme, communication with health professionals and the consistency of information about immunisations. The study found that parents were anxious about immunisations, especially in light of reported vaccine adverse events. Both trust and communication were important for parents, but communication was often poor with parents noting an inability to remember information that was provided verbally. While information was important, too much information was seen as a deterrent. In terms of what parents wanted, they were keen for professionals to realise that parents have differing information needs. Parents wanted to be able to ask questions of HCPs, especially health visitors and wanted information to be provided approximately one month before their child was due for immunisation.

Fitzgerald & Glotzer (1995) undertook a study of the views of parents and HCPs about VIPs. The study was undertaken in the US where VIPs are compulsory. The short survey (n=223) found that parents were satisfied with the length and amount of VIPs but HCPs were not. HCPs also believed that parents were not satisfied with the VIPs, which indicated that there was a difference in parents' views of VIPs and HCPs' perceptions of parents' views.

Smailbegovic et al. (2003) undertook a questionnaire study in the UK with parents of non-immunised children in order to look at their knowledge about vaccines, their attitudes about vaccination and their sources of information. One hundred and twenty

nine parents who had not completed the vaccination schedule were sent questionnaires and 68 (52.7%) were returned. With reference to decision-making about immunisation, most parents (n=45) used three or more sources of information. Thirty-one parents said HCP advice about immunisation was the most important source of information for them. However, while 37 parents said HCP advice was satisfactory, 19 parents said HCP advice was unsatisfactory, blaming the Government for unduly influencing the information that HCPs were able to give parents.

### **2.5.7 The media and vaccination**

Coverage of vaccines in the media is widespread and can have both positive and negative effects. Leask & Chapman (2000) carried out a survey to characterise the negative media reports surrounding vaccination. They looked at 2440 articles in the Australian newsprint media concerning vaccination. Of these 2440, 244 (10%) referred to anti-immunisation arguments. They found 8 key themes that were being presented in the media. These are as follows: there are facts about immunisation that are being covered up, the media presents the 'true' facts about immunisation, drug companies have an alliance with the establishment for mutual profit, fears of compulsory vaccination, 'us' versus 'them' arguments, vaccines are poisonous, vaccines are responsible for many conditions and vaccination is against nature, which is the best way to protect against diseases.

Leask & Chapman (2002) also undertook a study to determine the nature of pro-vaccination media coverage. The study looked at 3090 reports concerning vaccination in the Australian press. Of these 3090, 24 (0.77%) of the reports were neutral and 8 (0.26%) were opposed to vaccines. The rest (98.9%) were supportive of vaccination. The study also looked at how the pro-vaccination reports were presented. Low vaccine uptake was presented as being a threat to the Australian public. Much of the coverage focused on the diseases that the vaccination presented against. Blame for low uptake was attributed to three groups: anti-vaccination campaigners, the Government and parents. HCPs were least likely to be blamed for low uptake and parents were more likely to be blamed. Vaccination was presented as being of benefit to the community and information was seen as being very important in ensuring increased uptake of vaccination.

### 2.5.8 Summary

This section has looked at vaccination. The principles behind vaccination and the vaccination schedule for children in the UK have been described and the reasons for vaccination and the ethical principles governing the parental decision have been discussed. As highlighted, the vaccination decision is complicated, and the impact of vaccine scares, such as the MMR vaccine scare, is likely to complicate this decision further. Vaccine uptake has been shown to depend upon a variety of reasons, both related to the parent making the decision, the HCP facilitating the decision and intervening variables. The studies looking at vaccination and information showed that parents have a variety of information needs about vaccination and these are not always being met. Parents often express a need for more information following either planned or accidental contact with vaccine information and vaccine information can often cause concern for parents. The brief section on vaccination and the media highlighted that parents are confronted with conflicting information.

There has been a variety of research looking at the impact of information on vaccination uptake. Most frequently, this research has tended to adopt qualitative methods or large-scale intervention methods, although a number of different methods have been used in the studies presented here. Examinations of parents and their use of information in relation to vaccination have tended to be based around VIPs and quantitative examinations of information used. Another emphasis has been upon the influence of other factors (e.g., socio-economic factors) on vaccine uptake and less research has been undertaken on the role of information in determining uptake.

As this section has shown, the decision about whether to vaccinate can be problematic. Despite the clear rationale for vaccination, there are a number of factors that influence vaccine uptake. Information is one of these, and while some information and some sources of information can have a reassuring role for parents, information, especially from some sources, can be a factor that causes parents concern. The next section examines the MMR vaccine scare, referring back to issues covered in this section such as the information needs of parents regarding vaccination and the information sources they use. It is also important to bear in mind the role that information plays in vaccine uptake and how this is affected by the MMR vaccine scare.

## 2.6 MMR vaccine scare

This section focuses on the key issue in the study, the scare that has surrounded the MMR vaccine (henceforth referred to as the MMR vaccine scare). The section looks at the role of information, HCPs and the media in the MMR vaccine scare before looking at the impact of the MMR vaccine scare on parents. It is worth noting that this section addresses literature reviewed when the initial literature review was undertaken and which influenced the design of this study and section 2.6.6 separately reviews the studies published after this initial review.

### 2.6.1 Information and the MMR vaccine scare

Little research published prior to 2001 addressed the MMR vaccine scare in terms of information. The following two studies looked at the role of information within the MMR vaccine scare from the perspective of information sources.

A questionnaire study of 71 parents who lived in rural areas (Johnson & Joynes, 2001) found that 69% (n=49) of parents used the information that they acquired from the mass media as a source of information about the MMR vaccine. The use of this information, which was not always sought, was a result of their distrust of official information from the Government and GPs. This had been fostered by previous health scares in the case of Government information. In the case of GPs, distrust had been fostered by the fact that GPs receive bonus payments if they get a certain number of their patients vaccinated. Therefore, parents viewed HCPs support for vaccination as being influenced by these target payments and chose to use information that they perceived to not be externally influenced to provide a specific viewpoint.

In an attempt to quantify the quality of information about the MMR vaccine, Abbott (2000) reviewed 40 web pages concerning the MMR vaccine and found that when considering content, authorship and aesthetics, 60% of the web pages were considered to be lacking in design and content, with many containing inaccurate information.



## 2.6.2 HCPs and the MMR vaccine scare

Parents frequently mention the importance of the HCP in making their choice about the MMR vaccine (Elliman & Bedford 2001, Harris 2001, Hatton 1990 and Petrovic et al. 2001). HCPs are in a unique position in ensuring sufficient uptake of the vaccine, particularly in light of the scare that has surrounded the safety of the MMR vaccine.

Elliman & Bedford (2001) examined the impact that HCPs can have on parents as a result of the MMR vaccine scare. The provision of information was seen as being integral to professionals as well as parents. This is because the main way that professionals can answer parental concerns is through the provision of information. The media make this more difficult as often research is published in the mass media without prior warning being given to HCPs. Therefore addressing the concerns of parents is more difficult, as HCPs are often unaware or ill-informed about the concerns that they are addressing.

Hatton (1990) examined the knowledge of HCPs about the MMR vaccine before the MMR vaccine scare originated. A postal questionnaire to all HCPs involved with parents in Leeds (n=216) showed that their knowledge was incomplete, with 85% of HCPs not knowing the correct solution to a theoretical situation with which they were presented. GPs and GP trainees had less knowledge than health visitors.

Harris (2001) carried out a similar study of HCPs following the MMR vaccine scare. A questionnaire examined the HCPs' knowledge of contraindications to the vaccine. The study found that GPs had lower knowledge than other HCPs (e.g. health visitors). Harris (2001) also found that GP knowledge and uptake of the vaccine were positively correlated, indicating that information needs to be targeted at HCPs to ensure they can accurately inform parents about the vaccine and provide them with timely and accurate information.

Petrovic et al. (2001) carried out a study which concentrated on opinions about the second dose of the MMR (the booster dose, given to children before they start school). Questionnaires were distributed to and returned from health visitors (n=148), practice nurses (n=239) and GPs (n=206) in a Health Authority in Wales. Almost half of the HCPs had reservations about the second dose of the MMR. HCPs also wanted more

information about the second dose. While health visitors were found to be the main source of information to parents, only 20% would advise the MMR vaccine to parents who were unsure about it.

As these studies have shown (and as section 2.5.1.3 on the uptake of vaccination showed), HCPs have a vital role, both in ensuring uptake of vaccines and providing information about them.

### **2.6.3 The media and the MMR vaccine scare**

Moreton et al. (1998) examined the relationship between the MMR vaccine and the media. Immunisation has a history of being presented unfavourably in the media. At the time of Jenner's discovery of vaccination, the media produced cartoons of people growing cow-like features. The media's questioning of the safety of vaccines in current times has the potential to create even more damage for the following reasons: an increase in media sources, the media's propensity to distort stories (to make them more newsworthy) and the fact that the public increasingly obtain health related news and comment/opinion from the media. This can be actively sought from the media, but is often gained opportunistically i.e. when using the media for other purposes such as entertainment. The use of the media to actively seek health information reflects the mistrust in traditional health information sources and also reflects the widespread availability of the media and the nature of the media. The media can be an information source for parents, but it is primarily used for other purposes.

Mason & Donnelly (2000a) found that the media has a real impact on parental behaviour. In light of the negative coverage that surrounded the MMR vaccine, Mason & Donnelly (2000a) compared uptake in an area of South Wales that had a local paper (South Wales Evening Post) that ran a campaign against the MMR vaccine to uptake in the rest of Wales. Prior to the media campaign the area had a significantly higher ( $p=0.05$ ) uptake of the vaccine (91%) than the rest of Wales (89.2%). Following the South Wales Evening Post campaign, vaccine rates in the area fell by 13.6% as compared to the rest of Wales, which fell by 2.4%. Although this showed an association between local media coverage and falling vaccine rates, a causal relationship between the media coverage and falling vaccine rates could not be proven.

#### 2.6.4 Parents and the MMR vaccine scare

The safety concerns that have surrounded the MMR vaccine have led to some parents choosing to vaccinate their children with single vaccines, separating the measles, mumps and rubella components. Single vaccines are not available on the NHS in the UK; therefore parents must pay to have these vaccinations given privately. Bedford et al. (2002) found that some parents were choosing to vaccinate their children with single vaccines on the basis of the media reports. Despite the fact that neither the Department of Health (DOH) nor the General Medical Council (GMC) has endorsed single vaccines, a study by Harris (2001) (n=265) found that 7% of GPs (n=19), 11% of health visitors (n=29) and 45% of practice nurses (n=119) were recommending single vaccines for some children.

In the light of the MMR vaccine scare, and the consequent impact on uptake, Pareek & Pattinson (2000) sought to investigate the factors that influence mothers' intention to vaccinate their children with the MMR vaccine and the information sources that they used. They undertook a cross sectional survey with 300 mothers in Birmingham, UK. Mothers were highly influenced by the media, with links to autism (29.8%) and Crohn's disease (13.1%) being mentioned as potential side effects to the vaccine. On the whole, mothers had good knowledge about the vaccine and a positive attitude towards it. They were shown to consult a wide variety of information sources, but the most common and most valued sources were HCPs. The HCP was used by the majority of mothers for general information about the vaccine. However, the media was shown to be the main source for parents about side effects. When deciding whether to vaccinate, mothers valued the GP highly as an information source. Thus the authors recommended that the GP is the most effective way of communicating information supporting the MMR vaccine.

Evans et al. (2001) undertook focus groups with parents (n=48) to investigate the reasons that affect whether parents either accept or reject the MMR vaccine and whether this was related to the questions surrounding the safety of the MMR vaccine. The study found that all parents (whether they had immunised their child or not) were anxious about the safety of the MMR vaccine. The vaccine was perceived to have risks and single vaccines were seen to be a safer option. In terms of information, parents recognised that media reporting was sensationalised. However, official information,

both from the Department of Health and the Government was seen as being insufficient and parents were not happy using either these information sources or officially produced leaflets. Parents used HCPs, family and friends, the Internet and books and journals as an information source, although they found that information was either very pro- or very anti-immunisation. HCPs were used as an information source but parents were unhappy with the information that they provided, feeling pressure from them to vaccinate and an unwillingness to discuss other alternatives to the MMR vaccine. This study showed that parents felt that they received insufficient information and that which they did receive was of little use. Parents who were unsure about the vaccine were heavily affected by the media reports on MMR. The key information need that parents detailed was to understand the rationale behind MMR vaccination.

Sporton & Francis (2001) undertook follow up study on previous work on parents and immunisation. They aimed to examine the process of parents' decision not to immunise, with reference to previous studies such as New & Senior (1991), which had suggested reasons for parents not immunising their children. Interviews with parents (n=13) who were either non-immunisers or partial immunisers found that decision-making was an extended process. Initially, in the trigger stage, parents were made aware that they had to make a choice about vaccination. Then they entered a questioning stage, which led to a search for information. Following this, they then had a dilemma in weighing up risks and benefits. Then parents made a decision, once they considered that they had enough information to make it. Finally parents reflected on their decision, which could potentially change with external influences.

### **2.6.5 Summary**

This section has introduced the background to the MMR vaccine scare and the limited research that exists on the impact of the MMR vaccine scare. While the impact of the concerns surrounding the MMR vaccine can be measured in terms of the numbers of children being vaccinated with the MMR vaccine, the impact on parents in terms of how their decision-making about the MMR vaccine has been influenced is less easy to quantify. Research has shown that parents often receive and appreciate the mass media for news and opinions relating to health, as a result of the media being readily available but also as a result of the source being seen as less biased by parents, who view HCPs as being influenced by the Government in terms of the advice and information they give

about the MMR vaccine. Parents are clearly finding it difficult to make a decision about the MMR vaccine and at the current time, the information that parents are being supplied with is not alleviating the fears that they face when making a decision about the MMR vaccine. The lack of research relating to the MMR vaccine scare, which was published when the initial literature review was undertaken, is noteworthy. This clearly reflects the currency of the issue and also the delays that can occur in publication of research.

#### **2.6.6 Literature reviewed following data collection**

Following the initial literature review, subsequent literature searches were undertaken and a relatively large body of literature was uncovered on the subject of the MMR vaccine scare. This reflects the currency of the research and the following section considers this research and what it adds to what was previously known. Research on the MMR vaccine and the MMR vaccine scare since 2001 has more closely examined the issue of information, how information is communicated and the role of specific information sources, such as the media and the government.

Clements & Ratzan (2003) undertook a review of how information was communicated to the public in the case of the MMR vaccine and whether the information that they received was sufficient to allow them to make an informed choice. In terms of sources of information, Clements & Ratzan (2003) identified six sources that had a role in informing parents. These were the Government, HCPs, scientists, the mass media, the medical press and the anti-vaccine lobby. However, information was only communicated through two main sources, the Government and the mass media, both of which were inherently problematic. Information from the Government was seen as being untrustworthy to parents. Clements & Ratzan (2003) argued that the media have less of a vested interest in reporting issues relating to the MMR vaccine to parents. Despite this, there were still problems with the media reporting. This was because the media wanted to present an unbiased slant on the story and therefore gave equal weight to both sides of the argument, in favour and against the MMR vaccine. While this does present a balanced view, it ignores the fact that the weight of medical opinion is in favour of the MMR vaccine and any evidence presented against the MMR vaccine is anecdotal (Clements & Ratzan, 2003).

The British satirical magazine 'Private Eye' has been a critic of the Government's response to the MMR vaccine scare (Mills, 2002). In May 2002, they published a special issue that was highly critical of the MMR vaccine and supportive of the work of Wakefield et al. (1998) whom they saw as challenging the Government's support of the MMR vaccine. Elliman & Bedford (2002) were highly critical of the Private Eye issue, arguing that instead of making issues clearer for parents, it confused them and relied on emotive anecdotal opinion rather than scientific fact. In addition there was an absence of academic references for parents to follow up.

Hargreaves et al. (2003) undertook a survey and examination of media coverage to assess the extent to which the media shape the public's understanding of science. One strand of the research looked at the reporting of the MMR vaccine scare and assessed people's knowledge of the issue. When examining the media coverage, Hargreaves et al. (2003) found that although the story originated as a science story, it quickly moved to being a general story. Coverage was mainly on the television. The main area of concern for Hargreaves et al. (2003) was in the style of reporting. As the research of Wakefield et al. (1998) questioned the safety of the vaccine, the burden of proof fell on those who supported the MMR vaccine to prove categorically the safety of the MMR vaccine. However, as the majority of experts supported the MMR vaccine, arguments against it had to be provided by parents who believed their children had been damaged by the MMR vaccine, which resulted in highly emotive reporting. In terms of parents' views and knowledge, the TV was the most popular source for parents (Hargreaves et al., 2003). Parents compared the issue to that of BSE, as many key scientists went on record to state that they did not accept that there were risks in eating beef. Hargreaves et al. (2003) found that the media felt that they had a responsibility to provide a balanced argument. However, this led to 53% of individuals interviewed (n>1000) believing that there was equal evidence for and against the MMR vaccine.

As well as looking at the MMR vaccine scare from the perspective of information providers, research also looked at the impact of the MMR vaccine scare on parents from their perspective.

Alcock (2002) undertook a study of a particular family on behalf of the British Broadcasting Corporation (BBC). The study examined their decision-making process over the vaccination of their son. The family were: "... *hungry for as much information*

as they could get” (Alcock, 2002, p.492). Despite this the family expressed that their perception of the truthfulness of Government information had been shaped by the BSE crisis and this in turn had made them sceptical of the information supplied by HCPs, as they were unsure of the motivation behind the information that they supplied.

Both Hargreaves et al. (2003) and Hobson-West (2003) argued that the reluctance of the Prime Minister Tony Blair to reveal whether his son had been given the MMR vaccine might have shaped parents’ responses to the MMR vaccine scare. Hargreaves et al. (2003) believed that in not revealing his son’s vaccination status, Tony Blair might have led to believe that he had made an educated decision that the MMR vaccine was unsafe. Hobson-West (2003) argued that by not telling parents that he had vaccinated his child, Tony Blair appeared untrustworthy, in not revealing, “ *whether his behaviour was in line with the public policy he defended*” (Hobson-West, 2003, p.12).

Lunts & Cowper (2002) examined whether HCPs understood parents’ reasons for refusing the MMR. The study they undertook was a questionnaire study with parents (n=93) and if parents agreed, a questionnaire to their HCP. Lunts & Cowper (2002) compared the reasons that parents gave and the reasons that their HCPs thought motivated parents’ decision not to vaccinate. Health visitors were aware of the reasons in 47 of the cases, but GPs were aware in only 14 of the cases. The primary concern of parents was the risk of autism (n=26).

Bellaby (2003) described possible reasons for the fact that parents perceive the MMR vaccine as being a risk to their child, although there is little medical evidence to support this opinion. Bellaby (2003) contrasts this perception with the fact that parents readily use cars to transport their children despite the obvious risk that cars present to their occupants. Bellaby (2003) suggests that parents’ behaviour is instinctive and in the best interests of their child. Therefore the MMR vaccine seems like more of a risk than not vaccinating with the MMR vaccine whereas the use of cars is widespread because this is seen as being less of a risk than walking.

Ramsay et al. (2002) also sought to examine parents’ attitudes to vaccination in light of the adverse publicity received by the MMR vaccine. The survey with a non-random representative sample of parents (n=1013) was carried out in March 2001. The study found that overall awareness of the MMR vaccine was 96%. 74% of mothers had got

information from their HCP prior to vaccination. Of this 74%, 91% had been informed about the benefits and 75% about the risks. In terms of safety, the percentage of parents who believed that the MMR vaccine was safe was 64%, and it was noticeable that mothers from higher socio-economic classes were less likely to agree that MMR vaccine was safe. 92% would allow another child to be immunised and 6% said they would refuse, with 80% of these 6% having previously refused MMR vaccine. This study shows that while there has been a fall in the acceptability of the MMR vaccine, this fall has been small. The decline in the acceptability of the MMR vaccine seems to be related to higher socio-economic class. Following a fall in the acceptability of the MMR vaccine there appeared to be a consequent rise which Ramsey et al. (2002) believed was related to better dissemination of information.

Raithatha et al. (2003) undertook a qualitative study with parents of children who had been given the MMR vaccine (n=18) and examined their perceptions of the risks attached to the vaccine. Side effects of the MMR vaccine were considered rare but provoked feelings of dread, especially as children were considered to be vulnerable. Parents felt under pressure to immunise. They also indicated a lack of accessible information and also expressed that the lack of consensus on the safety of the MMR vaccine made decision-making more difficult. Parents also had difficulty in trusting two key information sources, the UK Government and HCPs. This was as a result of BSE, the target payments that HCPs received for high vaccine uptake, so-called rogue doctors and medical scandals. This study has highlighted that parents who immunise their children have fears about the MMR vaccine and that the decision to vaccinate is not simple. Increased risk perception about the MMR vaccine was due to a dread of side effects, doubt of scientific knowledge and perceived lack of control in the immunisation process. Raithatha et al. (2003) recommend that it is vital to ensure that positive immunisation messages are communicated to parents. Messages should be balanced, HCPs must listen to parents' concerns, GP target payments need to be evaluated and information should be disseminated at a local level not a national level, in order to increase trust in the MMR vaccine.

Health professionals have also been a focus of much of the research undertaken, reflecting the nature of the MMR vaccine scare and the role that health professionals play for parents. Schmidt & Ernst (2003) examined the advice that HCPs were giving to parents about the MMR vaccine over the Internet. They contacted HCPs via email and



presented them with a fictitious situation on regarding a mother who was unsure about whether to vaccinate her child with MMR. The query was emailed to homeopaths (n=144), chiropractors (n=50) and GPs (n=111). Response rates (responses from HCPs who did not withdraw their advice once the nature of the query was exposed) were as follows: homeopaths = 77 (46%), chiropractors = 7 (11%) and GPs = 0 (0%). Schmidt & Ernst (2003) found that the chiropractors and homeopaths were more likely to respond to a request for information via the Internet than GPs. The homeopaths and chiropractors tended to advise against MMR vaccination. While the sample sizes and response rates for the study were small, this shows the extent to which complementary medicine is against the MMR vaccine and the information that complementary medical practitioners are giving to parents regarding the MMR vaccine. It also indicates the fact that GPs are unwilling to respond to queries for advice, in a non face-to-face situation.

Hobson-West (2003) examined the information provided to parents by HCPs and the Government in light of the MMR vaccine scare. This information was designed to restore faith in the MMR vaccine and therefore increase uptake. Hobson-West (2003) found three facts that underpinned the promotional material designed to reassure parents of the safety of the MMR vaccine: that parents make decisions through comparing risk, that concern about the danger of the MMR vaccine is a miscalculation of risk and that providing risk statistics is the best solution to the MMR vaccine scare. Hobson-West (2003) argued that the premise upon which this information is provided means that parents would already have decided that MMR vaccination is not the best course of action. This is because providing risk information implies that parents are willing and able to make a rational decision. However, if parents were to make a rational decision about MMR vaccination then they would choose to free ride on the decision of other parents (as described in section 2.5.3). Hobson-West (2003) also argued that statistics are not the best way in which to present information to parents as parents may not understand statistics and may be unwilling to trust the source from which they originate. Hobson-West (2003) commented that parents trust in GPs is likely to be influenced by target payments, despite the fact that recommending vaccination with the MMR vaccine may be in the best interests of both the GP and the child who is being vaccinated.

## 2.7 Conclusions

This section will firstly provide an overview of the findings of the literature review. It will then highlight emergent issues and themes from the literature review before examining the influence of the literature review on the overall study.

### 2.7.1 Key findings

The literature review has found that in the modern information society, the multitude of sources that individuals are faced with makes the judging of sources and assessment of needs difficult. In addition, information is a term that lacks clarity in definition, both from the point of view of the researcher looking at information and in terms of the individual when using information. Individuals, when faced with the diversity of information, adopt different roles in both how they look for the information and how they use it. The diverse research reviewed suggests that these different roles are also influenced by the situation that the individuals find themselves in and information behaviour when addressing a specific and potentially important information need differs from everyday information behaviour, for example when experiencing situations relating to their own or another persons health. Although attempts have been made to understand information behaviour in a variety of contexts in relation to health, the information behaviour of individuals is often complex, making it difficult to develop a clear understanding of this behaviour.

Health information has become a political issue and there have been changes in the way information is perceived by the public, patients and HCPs. The impact that this has had on patient empowerment and public awareness has yet to be extensively assessed. Clearly individuals have a wide variety of health information needs that are not always fulfilled. Parents are especially likely to have unmet information needs particularly in relation to coping with their children's health and illness, which may not always be met. This is enhanced by a general distrust in information sources which has been fostered by health scares, such as the BSE scare, which led to distrust in the Government, and the reporting of the removal of children's organs without parental consent, which has led to distrust in the medical profession.

Health stories can generate a large amount of media attention and interest. The literature reviewed suggests that the media's motivation is to entertain rather than to inform. This may lead to incorrect and misleading information reaching the general public. As risk information is often communicated through the media, this creates problems in terms of the presentation of risk information and the actual information that is conveyed. Risk information has the real potential to influence and change behaviour and the media, whose reporting often contains risk information, do not have the responsibility to ensure that the information that they supply is accurate.

The limited amount of research that has been undertaken on the impact of information on parents has shown that their information needs are, on the whole, unmet. Information is shown to have both practical and psychological implications for parents, with information playing an important role in caring for children. Despite the fact that there is more research concerning the information sources that parents use, the diversity of sources used and issues of trustworthiness mean that there is a wide variation in the preferred information sources of parents, in both health and general terms. Research on parents' information needs and preferred information sources has, to date, either concentrated on very general subjects (Kai, 1996a and 1996b and Nicholas & Marden, 1998) or very specific subjects such as parents with children with autism (Huws, 2001). The research has not looked extensively at how parents' information needs or preferred information sources change as a result of external influences such as health scares.

Health scares are a relatively recent phenomenon and have not been extensively examined as a concept within the academic literature. Despite this the literature review has highlighted the major characteristics of health scares and how they develop. The impact of health scares on particular groups can be shown by the consequences of the questions surrounding the safety of the contraceptive pill, which have implications for the women concerned and those who supply information to them. The research has shown that women had increased information needs, in the short and long term. The importance of the mass media in disseminating news stories and information was also highlighted. Research has shown that the effective management of the contraceptive pill scare in the media can reduce the impact on behaviour.

The BSE scare highlights the impact that questioning the safety of something which was not considered to present any risk has on the public, not only in terms of behaviour and

information needs, but also in terms of distrust of information providers. This has long-term implications for both information providers and those who need information. Health scares that affect children generate concern for parents, who must act in the best interests of their children. This is because parents have a legal responsibility for their children but also because children are not necessarily able to assess risks and adjust their behaviour accordingly. Vaccine scares are of particular concern to parents in health terms and in information terms.

Vaccination is an area that presents difficult choices and decisions for parents to make. The decision about whether to vaccinate depends on a number of factors, and increased awareness of whether a vaccine is safe increases the difficulty of making this decision. Information plays a substantial part in parental decision to vaccinate. Various studies showed the media to be generally pro vaccination. However, the media have presented anti-vaccination stories, either when presenting research findings that cast doubt on the safety of vaccines and when they are reporting on concerns about vaccination, in a way that has generated health scares.

The impact of the MMR vaccine scare on parents and the public can be considered to be a result of various factors including the power of parents' anecdotal evidence about the scare, the distrust in official information sources and the media coverage that it has received. Despite attempts to refute the original research that was undertaken by the Government and health professionals, vaccination rates have fallen. Studies have shown this to be linked to the issue of the safety of the MMR vaccine, although a causal link is hard to prove. Despite the attempts by the authorities to support the MMR vaccination, demand for the single vaccines of measles, mumps and rubella has increased. Studies that sought to examine the impact of the scare found that the mass media and HCPs were the most used information sources for parents. However, both of these sources had their problems. HCPs were shown to be lacking in the accuracy and quality of the information that they supplied to parents. They were also considered to be untrustworthy by parents who viewed them as being wholly influenced by political motivations. The mass media were also considered untrustworthy as a result of their primary aim not being to inform parents. Politicians were also viewed unfavourably as a result of their handling of the BSE scare.

The importance of information to parents concerning their children's health and the health scare concerning the MMR vaccine scare has highlighted the need to undertake research to identify the information needs and behaviours of parents in relation to the MMR vaccine scare, the following section describes the key issues and themes that emerged from the literature review, before describing how these contributed to the design of the study.

### **2.7.2 Emergent issues from the literature review**

This section examines how the literature, which was summarised in the previous section, contributed to the study design. Firstly, the themes that have emerged from the literature are presented. Then what is known, what is not known and the response to this gap is presented.

The first theme surrounds the complexity of information. Information as a concept is difficult to define. What one person understands by the term "information" may not be what another person understands. As well as the concept of information presenting difficulties in definition, information is something that is specific to situations and specific to individuals. Therefore parents' requirement for information in a situation such as pregnancy may be different to their requirement for information in a situation such as the MMR vaccine scare. In addition, when placed in a specific situation, individuals will differ in their information needs.

The second theme concerns the importance of information for parents in terms of the health of their child. The importance of information can be related to the importance of the child to the parents. It is also related to the difficult decisions that parents have to make for their children e.g. vaccination and the extent to which health and illness are important issues for parents. The difficulty in decision-making may also reflect the unmet information needs which parents have.

The third theme concerns the information needs that are generated by health scares, when the safety of a previously 'safe' medical intervention is called into question. This has been shown by the early research into the MMR vaccine and research into the pill scare. These issues have been characterised by controversy and a requirement for information.

The final theme is the role of information providers in meeting information needs. Concerns have been raised in the literature around the ability of specific sources to meet information needs. This may be related to the mistrust in the information source, the source not having the information that an individual requires, or the source being used for information when its primary aim is not to provide information.

These themes have led to an examination of what is known, what is not known and what the response to this will be.

Although there is some understanding of parents' information needs in relation to general health in their children and in relation to specific conditions, very little research to date has examined the information needs in relation to the MMR vaccine and the health scare surrounding it. The research question emerging from this gap is as follows: What are the information needs of parents relating to the MMR vaccine and the MMR 'scare'?

Research on the impact of the media has tended to look at media reporting and then extrapolate from this to the impact that the media may have on these groups and has not examined the impact of the reporting from parents' perspectives. Parents have been shown to rely heavily on the media during the MMR vaccine scare, with Pareek & Pattinson (2001) indicating that television is the most popular information source for parents. Mason & Donnelly (2000a) showed the quantifiable impact that the media can have on parents. It is also important to look at the role of HCPs, as while they are often cited as a key information source, Johnson & Joynes (2001) amongst others, have indicated the distrust that parents feel in HCPs. The emergent research questions are therefore as follows: What are the information sources that parents use relating to the MMR vaccine and the MMR scare? What are parents' perceptions of the media, HCPs and the Government as related to the MMR vaccine scare?

Although the pill scares of the 1980's and 1990's generated much research on the impact of the scare on women's behaviour, there has been little research on health scares and little is known about the impact of the MMR vaccine scare on parents and the role of information in decision making. The study will examine the MMR vaccine and the decision-making processes which parents go through. It is important that the role of

information in the decision and the role of the health scare in influencing parents' decision-making are explored in depth. The research questions relating to this gap are as follows: What role did information have in parents' decision to/not to vaccinate? What role did the MMR vaccine scare have in parents' decision to/not to vaccinate?

### **2.7.3 Summary**

As previously identified, the main issues that this study seeks to address are the issues that emerged for parents (as a specific group with particular responsibilities) as a result of the MMR vaccine scare. The general aim of the study is to develop an understanding of the importance of information for parents with reference to the MMR vaccine scare and the specific objectives are to identify parents' information needs, the sources that they use and the role of information in decision making in relation to the MMR vaccine scare. This literature review has given an overview of the topic of the thesis with reference to key literature in the area. The contribution to the research design that the literature has made has been discussed, the gaps in the literature that the study is seeking to fill have been described and the research questions that will generate data for the study have been outlined. These questions will be addressed through a mixed methodology, described in Chapter Three.

# Chapter Three - Methodology

## 3.1 Introduction

Methodology can be defined as “*a body of methods, used in a particular activity*” (Thompson, 1992, p.559). Methodology is an overarching term that concerns the methods that are used in research (e.g. interviewing) but also concerns the rules that are applied to research and the assumptions that underpin research. This chapter outlines the methodology and methods that were used in the PhD study.

Determining an appropriate methodology requires a consideration of the most appropriate methods to answer the research questions. In addition, a researcher must decide on the stance they are going to adopt in terms of ontology and epistemology i.e. how the researcher views the reality of the situation that they are researching how the researcher can measure and understand this reality. In addition, the researcher must also decide whether the methods that they are going to adopt are qualitative or quantitative or mixed. Once the researcher has resolved the epistemological and ontological issues concerning their research, they can then decide upon an appropriate research method. The research method chosen will clearly be influenced by the methodological stance that the study is adopting.

The aim of this chapter is to examine both the methodology and the methods that were used to answer the research questions. The chapter is framed within the requirement of the PhD study, which was to answer the research questions that emerged from the literature review.

Section 3.1 addresses issues of methodology and discusses the philosophical framework and epistemological/ontological stance that this study is going to adopt. Section 3.2 examines different approaches that can be taken to research. Section 3.3 looks at how research can be examined and assessed. Then the methods used to answer the research questions are examined, namely interviewing (section 3.4), questionnaires (section 3.5), triangulation (section 3.6) and content analysis (section 3.7). Finally, issues of methodology and method are summarised and concluded in section 3.8.



## 3.2 Approach to research

When determining the methodological approach that a study is going to adopt, it is important for a researcher to decide upon their view of the reality of a situation and how this reality can be measured. Only then can they choose an approach that is appropriate to this reality. While it is important to be clear about the approach that the study is going to take and the philosophical framework in which it is to be situated, Baum (1995) argued that epistemology and methodology should not be prescriptive: "*The epistemological debates are ... crucial and important but should not lead to an adherence to any particular methodology*" (Baum, 1995, p.459). Instead, research should be situated within a paradigm, which helps to guide the researcher. Denzin & Lincoln (1994) viewed a paradigm as "... *a worldview that defines...the nature of the world, the individuals place in it, and the range of possible relationships to that world*" (Denzin & Lincoln, 1994, p. 107).

This study is located within the paradigm of post-positivism. Post-positivism is a paradigm that draws upon both positivism and naturalism but reduces the polarity between these standpoints by making them more applicable to the social sciences (Clark, 1998). Positivism has been the dominant paradigm in scientific research for the last century. It is an approach to research that "*assumes that there is a single objective reality which can be ascertained by the senses, and tested subject to the laws of the scientific method*" (Bowling, 1997, p.110). Naturalism is defined by Bowling (1997) as "*studying people in their real, natural settings, interactive and jointly participative by investigator and respondent*" (Bowling, 1997, p.112). Naturalism views reality as a social construction, rather than an objective reality that is observable.

The main way in which post-positivism differs from positivism and naturalism is in its view of the nature of truth. Truth is not just linked to observable facts, but is extended to incorporate "*unobservables*" (Clark, 1998, p.1243). The notion of unobservables suggests that there may be other influences on observable phenomena than those that can be directly measured e.g. in positivist research. This allows concepts such as personal opinion to be incorporated into research and blurs the divide between positivist research (which views reality as objective) and naturalistic research (which views reality as subjective).

There are still a number of similarities between the positivist and post-positivist approaches. As Denzin & Lincoln (1994) emphasised, the aim of both types of research is explanation and prediction, although, in the case of post positivism, the phenomena under investigation are extended from the physical to include the human. Values and ethical considerations are still considered to be external to research. The standard of the inquiry is still judged by the same benchmarks as positivist research, those of validity and reliability. However, in positivism, research findings can be generalised whereas post-positivism is similar to naturalism in the sense that research findings are context bound (Clark, 1998). In addition, in positivism the aim is to verify hypotheses but in post-positivism, the aim is for falsification.

The debate between qualitative and quantitative research is related both to the methods that the research is going to adopt and the framework within which the research is undertaken. As this research adopts a post-positivist approach, it is also using qualitative and quantitative research methods. Quantitative research has traditionally been allied with positivist approaches whereas qualitative research has been allied with naturalistic approaches and, in examining these differences, this section also seeks to resolve the conflict between the methodologies and suggests that they can be used to complement one another.

Quantitative social research applies a natural science approach to social phenomena (Bryman, 1984). Proponents of quantitative social research view it as being useful “*if the issue is known about, relatively simple and unambiguous and amenable to valid and reliable measurement*” (Bowling, 1997, p.114). Quantitative research is concerned with the numerical or experimental measurement of phenomena and seeks to maintain a distance between the researcher and those being researched. The quantitative researcher is viewed as an “*objective scientist*” (Shih, 1998, p.638) whose purpose is to control the environment that they are investigating. As Bryman (1984) discussed, the questionnaire is an ideal example of a quantitative social research method.

Qualitative social research applies a naturalistic approach to social phenomena (Bryman, 1984). A naturalist epistemology is adopted which views knowledge as consisting of facts and opinions which are observable in the interaction between the researcher and the researched. Key to qualitative research is that the data collected come from the perspective of the individual being researched rather than from the perspective

of the researcher (Bryman, 1984). A useful example of qualitative research is the focus group, where interaction between the researcher and those participating in the group strengthens the data that are being collected.

Both qualitative and quantitative research employ very different methods and these methods are allied to specific epistemologies and ontologies. However, the conflicts between quantitative and qualitative research are often due to questions of procedure. Silverman (1993) makes a distinction between the two forms of research in terms of the fact that qualitative research occurs in natural settings whereas quantitative research often occurs in artificial, contrived situations. This study seeks to use both qualitative and quantitative methods. The approach recommended by Baum (1995) is one which this study adopts. It was decided that a post-positivist approach would allow a constructive and flexible approach to be adopted while incorporating rigour and high research standards to the research. Key to uncovering the reality of parents' reactions to the MMR vaccine scare were research methods which allowed both a broad and deep understanding of the situation. Therefore it was vital that the research methods adopted allowed an examination of the reality of parents' situations in two distinct ways. Firstly, parents' situations needed to be examined in depth and secondly, a wide-ranging number of different situations needed to be examined. This study aimed to use diverse research methods whilst broadly adhering to a post-positivist approach, in order to explore the issue in both an extensive and in depth manner. Reflecting the fact that post-positivism was developed as a response to the weaknesses of a wholly positivist or naturalist approach, this research aimed for a balance in the methods adopted. Therefore initial exploratory work was carried out using a qualitative approach with parents (semi-structured interviews) as qualitative research is best utilised: "*...for exploring new topics and obtaining insightful and rich data on complex issues* (Bowling, 1997, p.114). The second phase of research used a quantitative approach with parents (questionnaires) to examine the issue in more detail and to provide data that is generalisable. The third phase used triangulation, a research method that used the interview and questionnaire data together, to aim for confirmation and completeness. The final stage of research utilised content analysis to both qualitatively and quantitatively analyse data from media sources.

The next section addresses how the quality of research can be assessed.

### 3.3 Assessing research

When designing a study and determining the methodology and methods that it is going to adopt, it is important to look at how this methodology and the methods associated with it can be assessed, in terms of whether the information collected reflects the reality of the situation.

The assessment of research depends on the philosophical and methodological framework in which the research is located. Some approaches advocate the assessment of a study in terms of validity, reliability and generalisability whereas others advocate an alternative approach which takes into account the research approach being used. This section will first address validity, reliability and generalisability, which are the major ways in which research is assessed, and then examine alternative ways of assessing research.

#### 3.3.1 Validity

Validity assesses whether the study measures what it claims to measure. Internal validity assesses the instrument used in the study (e.g. survey) in terms of whether it is able to measure the reality of the situation and external validity assesses whether the results from the study can be generalised from the sample from which data was collected to the population who they represent (Bowling, 1997).

Validity can take a number of forms. The main types are face validity, content validity, construct validity and criterion validity (Bowling, 1997). Face validity assesses whether the instrument is clear and easy to use, content validity measures whether the instrument is able to measure accurately what it intends to measure, construct validity measures whether the instrument measures the hypothesis and constructs that it plans to measure and criterion validity compares the instrument with other instruments that are used successfully in similar research.

#### 3.3.2 Reliability

As Oppenheim (1996) noted, validity and reliability are associated with each other. Reliability is a prerequisite for validity as an instrument that is unreliable cannot be

valid. Reliability assesses whether the instrument in question is able to reliably measure what it intends to measure. It is a measure of consistency of measurements. Reliability is a concept that is better addressed to quantitative research as a number of the terms that it addresses are related to statistical measurement. The major measures of reliability are test-retest reliability, inter-rater reliability and internal consistency (Bowling, 1997; Oppenheim, 1996). Test-retest reliability measures whether the same result would be gained if the instrument were used repeatedly. Inter-rater reliability measures whether results gained from more than one researcher are convergent. Internal consistency assesses the extent to which the instrument in question measures only what it is supposed to measure. This is often measured using Cronbach's Alpha Coefficient (Oppenheim 1996).

### **3.3.3 Generalisability**

Generalisability is closely linked to external validity as it assesses whether research findings can be generalised from a sample to a population. Generalisability is also a construct that is closely allied to quantitative research, as it is not the aim of qualitative research to generalise from the sample studied to a larger population, but rather to represent the reality of a situation for a smaller sample of individuals (Whittemore et al. 2001). Therefore generalisability measures whether the sample is of sufficient size to generalise and whether the sample possesses characteristics that are representative of the population.

### **3.3.4 Alternative measurements**

As discussed in section 3.1, philosophical frameworks influence the entire research process in terms of methods and methodology. The measurements of reliability and generalisability (and to a lesser extent validity) are closely allied with positivist approaches to research, especially quantitative research.

In response to this, Lincoln & Guba (1985) sought to develop a system to assess research that was based upon measures from positivist research but could be applied to social science settings (Whittemore et al., 2001). This led to the development of the concepts of credibility, transferability, dependability and confirmability, which contrast with validity, reliability and generalisability. These measures are based upon a broader

understanding of research. Credibility is most closely allied with internal validity and assesses whether the reality of a situation as presented by a researcher is in line with the reality of the individual participating in the research. Transferability is allied with external validity and is concerned with the applicability of the research findings from one setting to another setting. Dependability is related to reliability and is a measure to ensure that the research process is clear and can be followed by someone who was not involved in the study. Finally, confirmability is related to objectivity and assesses whether two or more researchers would interpret the data similarly (Lincoln and Guba, 1985).

### **3.3.5 Summary**

As this section has shown, there are a number of ways in which research can be assessed. The choice of which method of assessment is adopted depends very much on the philosophical standpoint of the study and the methods that are being utilised.

## **3.4 Interviewing**

### **3.4.1 Theory**

Interviewing is one of the most common and widely used methods of data collection in social science research and can take a number of forms, from structured interviewing which follows a pre determined set of questions to interviewing which is not structured and relies upon the interviewee to determine the interview procedure. Between these two extremes lies semi structured interviewing which is an approach which includes elements of structured and less structured interview methods. This method tends to be more commonly used and is the method adopted in the interview study reported in the thesis. In semi-structured interviewing, the role of the researcher in interacting with interviewees is important because, as Britten (1995) emphasised, it is vital to have an element of interviewer interaction to allow full understanding of the interviewees answers and to have the opportunity to probe them for further answers where appropriate.

Interviews generate textual data. The interpretation of what these data represent will depend upon the philosophical framework within which the researcher is working. As

Silverman (1993) highlights, if interviews are being approached from a positivist position, the interview is a research method designed to elicit facts about the interviewees. Interviews should be carried out using structured, closed questions and interview results should be presented in numerical terms e.g. frequencies of response. In contrast, the interactionist approach (Silverman, 1993) uses the interview situation to elicit data about the experiences and situation of the interviewees through less structured interviews. In the case of this approach, interview data should be presented thematically and aim to represent the interviewees' comments as closely as possible. This is the approach that the interview study is adopting. Data is being analysed using a computer aided qualitative data analysis system (CAQDAS). Computer software facilitates the researcher's use of a 'code and retrieve' method of data analysis. While computer software does not speed up the analysis of data, it gives a more structured and less paper-intensive approach to data analysis. CAQDAS are claimed to provide "*a more complex way of looking at the relationships in the data... and, aid more conceptual and theoretical thinking about the data*" (Barry, 1998, paragraph 2.1). It is argued that CAQDAS do not allow the researcher to become fully immersed in the data that they are working with, as is allowed with manual methods. However, the fact that in this study, full transcription preceded the data analysis and regular reading of the transcripts was also carried out during the data analysis meant that there was familiarity with the data. Barry (1998) argued that any limitations in data analysis are caused by the inadequacy of the researcher rather than the method that they use. As Creswell (1998) describes, CAQDAS should be "*an adjunctive procedure in the analysis process*" (Creswell, 1998, p.156). It is also important when using CAQDAS that the researcher ensures that they are not inclined to treat the analysis and presentation of data in quantitative terms as qualitative data should not be presented numerically (Barry, 1998). Kelle (1997) warned against the use of CAQDAS as a methodology in itself, rather than a means of applying an existing one. He believed that certain prerequisites must be in place for a CAQDAS to be used: "*... the danger of methodological confusion and distortion if basic prerequisites of qualitative theory building are not taken into consideration*" (Kelle, 1997, p.3)

### **3.4.2 Application**

The initial stage of data collection needed to be exploratory, as data were being collected in a previously unresearched area. Carrying out exploratory research allowed

this area to be explored and also informed future research in the area. This was important as little previous work had been undertaken in the research area and the research area was developing.

It was decided that, in the initial stage of this project, individual interviews would be carried out. Interviews were chosen as they allowed an in-depth examination of the views of the participants. Individual interviews were chosen because it was important to understand the diversity of views that the participants held in a situation in which they would not feel threatened by the views of other participants and also that deeper understanding of the reality of the situation would be better understood by the views of an individual rather than a group.

The interviews were semi-structured. As Britten (1995) highlighted, semi structured interviewing can incorporate a greater element of interviewee interaction, with the comments made by interviewees guiding the interviewer to use probes to examine the issue further. The schedule for the interviews in this study was semi- structured, allowing the researcher to explore topics of interest, while allowing the participants the freedom to expand upon areas in which they felt they had a lot to comment. The interview schedule was developed through a process that referred both to the original research questions for the overall PhD study and to the literature review.

The specific CAQDAS that was used in the analysis of the interview data was ATLAS ti (Muhr, 1997). ATLAS.ti differs from other CAQDAS in the sense that the networks and codes are not represented in a hierarchical 'tree structure' but rather in a looser 'network structure' (Kelle 1997). This network structure can then be used to develop structures in whatever format is most useful and appropriate to the researcher. In this case, a hierarchical structure was developed from the network structure as the data collected more appropriately fitted into a hierarchical rather than a network structure.

## 3.5 Questionnaires

### 3.5.1 Theory

Questionnaires are one of the most frequently used qualitative and quantitative forms of data collection in the social sciences. They are a method of researching which is



characterised by a common purpose, to elicit structured information from a large group of people. The data that are collected can be used either to represent the people from whom the data have been collected or to generalise from the people from whom the data is collected (sample) to a larger group whom they represent (population).

Questionnaires can take a number of different forms. These are determined by factors such as question type (closed or open). Closed questions are structured questions, e.g. answered by “Yes” or “No”. They have a limited number of answers and may include a “don’t know” option where appropriate. They are appropriate when an answer is factual or when specific hypotheses need to be tested or specific groups compared (Oppenheim 1996). Open questions are questions that allow the respondent to determine the answer to the question, usually using a free-text response. As well as open and closed questions, there can be scaled questions (Frazer & Lawley 2000) that measure the extent to which the respondent agrees with a single statement. The most common scale used in questionnaires is a Likert scale. Similar to scaled questions are ranked questions, which ask respondents to compare a number of responses and rank them appropriately. In terms of purpose, questionnaires can ask respondents facts, such as their age, sex or marital status, to which there is one correct answer or they can ask people about their feelings or attitudes, to which there is no correct answer. Lydeard (1991) discussed the four types of questions that relate to feelings: attributes (what people perceive they are), behaviour (what people do), attitudes (what people say) and beliefs (what people think is true). She highlighted attitude measurements and belief measurements as being particularly sensitive and in need of careful question development.

When designing a questionnaire, it is important to be aware of the pitfalls that can compromise the ability of the questionnaire to address the subject matter than it is designed to address. The actual questions used in a questionnaire must be designed to avoid ambiguous words, such as *often* or *frequently* (answers will reflect the respondents’ perception of time). Questions that contain two concepts, loaded words and/or double negatives must also be avoided. Questions must also avoid social desirability factors, where respondents feel compelled to answer in a certain manner to appear socially acceptable. Questions must be placed in a logical order and be chronological, e.g. the order of questions about parents’ decision-making and the MMR vaccine. It is also important to consider the length of the questionnaire. If the questionnaire is too long then the participants will not complete the questionnaire and if

the questionnaire is too short then the questionnaire will not generate sufficient data. Questionnaires must be aesthetically pleasing. The design of the questionnaire is important and can influence response rates, as a recent systematic review by Edwards et al. (2002) demonstrated.

In addition to the design of the questionnaire, there are a number of issues to resolve relating to the way in which responses can be maximised. If a questionnaire is aiming to determine a level of statistical significance (when the results gained from a questionnaire can be generalised from a sample to a population as the sample is representative of the population) the sample must be of sufficient size to be representative of the population and secondly, specific characteristics of the population must be reflected in the sample. Therefore it is important to ensure that the sample is sufficiently sized but also that the sample reflects the population in terms of characteristics. Maximising the response rate to the questionnaire can normally ensure this. Factors that increase response rates have been heavily researched and the systematic review (Edwards et al. 2002) that reviewed the results of 292 randomised controlled trials found that there were a number of factors that increased response rate (monetary incentives, short questionnaires, personalised questionnaires and letters, coloured ink and paper, sending the questionnaire by recorded delivery/ first class, including a stamped addressed envelope, contacting participants both before distribution and if they do not return the questionnaire by the deadline, avoiding sensitive questions and making questionnaires of interest to participants).

In the case of this study, it was important to ensure that low response rates do not lead to a sample that is not representative of the population, which can lead to problems with generalisability. Also the lack of control that the researcher has over the participants may limit the questionnaire in terms of the misunderstanding of questionnaire wording. Literacy problems limit the ability of respondents to represent their opinions accurately and respondents cannot be assessed for their honesty and accuracy in responses. The questionnaire used in the PhD study was designed with the above considerations in mind, but was also designed using the Health Belief Model, which is discussed in section 3.5.3.

### 3.5.2 Application

The aim of the questionnaire study was to examine in greater detail and with a larger sample, some of the more interesting emergent issues from the interviews. The questionnaire consisted of factual and attitudinal questions based around three different subjects. These were demographic characteristics (of the person completing the questionnaire and their child), beliefs about the MMR vaccine and the MMR vaccine scare and the role of information in the MMR vaccine scare and parents' views about the role of information in the MMR vaccine scare. More detail about the format of the questionnaire can be found in Chapter Five. The questionnaire was developed using the Health Belief Model (HBM), which is discussed in the next section.

### 3.5.3 The HBM

#### 3.5.3.1 Overview

The Health Belief Model (HBM) is concerned with the reasons and motivations behind an individual's choice to undertake behaviour which may be beneficial to their health. Researchers working in the United States of America's Public Health Service (Bates et al. 1994) undertook research to attempt to understand why the public were not taking up preventative health actions, such as immunisations. They developed the HBM to explain and predict preventative health behaviour, i.e., the likelihood that an individual will choose to carry out a preventative action. The model was developed in the 1960s and has undergone a number of revisions since this time. However, the basic concept of the model remains the same: "*Behavior (sic) is predicted from the value of an outcome ... to an individual and from his expectation that a given action will produce that outcome*" (Becker, 1979, p.254)

The likelihood of preventative actions can be determined by measuring a person's view on the susceptibility and severity of the disease/condition (henceforth referred to as disease) that the preventative action is preventing against and their view on the benefits and barriers of the preventative action. The likelihood of a preventative action occurring depends upon susceptibility, severity, benefits and barriers but also on the influence of three modifying factors, namely cues to action, self-efficacy and demographic variables.

The construct of perceived susceptibility concerns the disease. This is the individual's subjective perception that they will catch a disease. It considers how at risk of catching the disease an individual feels. Perceived severity also concerns the disease. This is the individual's perception of the consequences of the disease, if they caught it. It depends upon how serious they perceive the disease to be and how they think that it will impact upon their health and ultimately their life. Perceived benefit deals with the intervention. This is the perceived effectiveness of the intervention in reducing the likelihood of catching the disease. Perceived barriers also deal with the intervention. These barriers are the individual's perception of the consequences of the intervention, which can be physical, psychological or financial. The individual will need to overcome these barriers if they are to proceed with the intervention. As discussed above, the HBM also includes three modifying factors (cues to action, demographic variables and self-efficacy). These are factors that are considered to be influential, but not causal, in motivating health behaviours. Cues to action are stimuli that motivate people to take action. These can take a variety of forms including advice, information from a variety of sources and personal experience. Demographic variables are factors that may intervene with the likelihood of action through individual health motivations and perceptions. The final modifying factor is self-efficacy, which is an individual's belief that they can and will be able to successfully execute the action.

#### 3.5.3.2 Application

The HBM has been used in a number of studies addressing different health behaviours, although as this section will highlight, it has not been used to examine the health behaviour of individuals making health decisions for people other than themselves. This section presents some of the major research carried out using the HBM that was used to inform the questionnaire study.

Gore et al. (1999) aimed to identify barriers to immunisation and factors that were important in completing the vaccination schedule. A telephone survey carried out in West Virginia (n=316) found that there were a number of barriers to immunisation. These included negative beliefs about immunisation as well as socio-demographic and self-efficacy factors. They concluded that improving beliefs and attitudes alongside an easier process of immunisation (to improve self-efficacy) would increase immunisation rates. This study suggests that socio-demographic factors are important, which is an

issue that the questionnaire study is seeking to examine. In addition, negative beliefs about immunisation are considered to be a barrier to immunisation. The questionnaire study will seek to examine whether negative beliefs about immunisation or negative beliefs about behaviour are more likely to influence immunisation. Bates et al. (1994) undertook research relating to maternal health beliefs by examining non-compliance in inner city paediatric clinics through a 48-item HBM questionnaire (n=500). They found that each of the four constructs of susceptibility, severity, benefits and barriers were independently predictive of health behaviour. Tuma et al. (2002) undertook research with caregivers in Cameroon (n=550) and looked at whether the beliefs and attitudes of the caregivers were associated with the immunisation status of their child. Beliefs and attitudes were found to have a positive impact on compliance with immunisation. In particular, demographic factors such as level of education were also associated with immunisation levels but increased perception of the severity and susceptibility of diseases was associated with a decreased likelihood of immunisation. The authors did not suggest any reasons for these results. In a study published during the period of the research, Smailbegovic et al. (2003) examined the attitudes towards immunisation of parents (n=76) whose children had not been immunised with the MMR vaccine. They also looked at the extent to which HCP's influenced parents' attitudes. Non-immunisation was based upon a number of variables, including vaccine safety and lack of information. Time constraints (which are not included in the HBM) were also an issue for some parents. Vaccine safety and lack of information are key issues in the questionnaire study. It is intended that these two key issues will be examined in depth. Norman (1995) undertook a study of the role of the HBM in predicting attendance at a health check up and found that a cue to action (in this case a reminder card) had a major influence in modifying behaviour. Hawe et al. (1998) compared measles vaccination rates between parents sent a vaccination reminder card that was written in language related to the HBM and parents sent the usual vaccination reminder card and found that there was a small, but significant, improvement using the HBM card. Cues to action will be examined in the questionnaire. They provide an interesting issue to examine as they are related to the HBM but also to parents' use of information.

There have been three systematic reviews related to the HBM (Carter & Kulbok 2002, Harrison et al. 1992 and Janz & Becker 1984). Carter & Kulbok (2002) examined research about the motivation for health behaviours in nursing literature by examining quantitative and psychometric research studies (n=41) which were not all related to the

HBM but were all related to motivation. The review found that the HBM was the most commonly used model to examine motivation. While motivation is extensively researched within nursing literature, studies examining the impact of motivation on health behaviours were often unsuccessful. The authors recommend an improvement in the measurement of motivation and a more diverse examination of the subject. Harrison et al. (1992) undertook a systematic review of the Health Belief Model (n=16) and the research that had been undertaken using the model and found that the individual HBM constructs were useful as predictors of behaviour independently but were not as effective in predicting behaviour when combined. The authors warned that the predictive validity of the HBM might be lacking, especially as there is no validated instrument with which to measure health beliefs. The systematic review by Janz & Becker (1984) covered research utilising the HBM in the previous ten years. The critical review of published research (n=29) supported the use of the HBM in research and found that perceived barriers were the most powerful predictive construct.

#### 3.5.3.3 Analysis using the HBM

Various statistical tests have been carried out as part of research undertaken using the HBM. These can be divided into tests that examine the validity of the results and tests that analyse the results and present them numerically. In the study by Matsuda (2002) the analysis was carried out using Cronbach's Alpha for susceptibility, severity, benefits and barriers to check to what extent different terms measure the same characteristics and also correlation co-efficients to ensure that there was no relationship between susceptibility, severity, benefits and barriers. Regression analysis was also undertaken. The reliability and validity of HBM variables has been tested in other studies using Cronbach's Alpha and test-retest reliability co-efficients. Effect sizes have been tested using Pearson's product moment correlation.  $\chi^2$  tests have been extensively used. Logistic regression has also been extensively used to analyse the effects of the four constructs (and other factors) on the health action in question. However, Strecher & Rosenstock (1997) argue that the four individual constructs should be treated as such, rather than being entered into multivariate analyses. Therefore analyses should be undertaken on the individual constructs and their role in determining health behaviour. These findings will be taken into account when analysing the data.

A number of criticisms and limitations have been levelled at the HBM. Central to these criticisms is the fact that there is no specific measurement tool that is attached to the HBM. Other models of health behaviour have specific tools, such as questionnaires, which are used to measure or predict the likelihood of action. In the case of the HBM, different studies have utilised different research methods, although the research methods used have been limited to questionnaires and interviews. A common method when using the HBM is a Likert scale (Matsuda 1998; Norman & Brain 2001). This format of scale will therefore be used in the questionnaire study. Another criticism is that factors other than health beliefs are not incorporated into the HBM but are believed to affect health behaviours. These include cultural factors, socio-economic status and previous experiences. However, in the case of this research, these were incorporated into the questionnaire. The importance of the constructs (severity, susceptibility, benefits and barriers) could then be assessed by comparing them with other factors in determining whether the parent chose to have their child vaccinated with the MMR vaccine. Matsuda (1998) also argued that the lack of inclusion of demographic variables weakens the model, but these can be added to the questionnaire. He also argued that research into past actions could be subject to recall bias although with this research, the sample was restricted to parents who had made the decision about MMR vaccine recently.

The next section examines the third method used in the PhD study, triangulation.

### 3.6 Triangulation

Triangulation is a research method that allows researchers to use two or more sets of data collected using different methods or in different studies to gain another perspective on the data. The original meaning of triangulation was developed in surveying and navigation. It suggested that with two known points, a third position could be found. This is the approach that triangulation in research also adopts in that it allows researchers to strengthen a specific position through the use of supporting data. Fontana and Frey (1994) define triangulation as “*multimethod approaches to achieve broader and often better results*” (Fontana & Frey, 1994, p.373).

The two main aims of triangulation are confirmation and completeness. Triangulation for confirmation is used to discover commonalities in the data, which lead to a single truth. As Bradley (1995) comments, this is a less important use of triangulation in social

research, as social research does not aim to discover on a single truth. Instead it may be more useful to consider confirmation as a way to reinforce conclusions that are being made. Triangulation for completeness allows a more holistic view of the research area, giving different perspectives on the data collected. Triangulation can be undertaken through a number of methods: investigator triangulation, data triangulation and methodological triangulation are the three main methods (Shih, 1998), although as Bradley (1995) emphasises, the most frequent use of triangulation is methodological. This study uses both methodological and data triangulation. Data triangulation maximises the range of data collected. It allows the collection of multiple sources of data and is often used for completeness (Dootson 1995) while methodological triangulation uses more than one method to collect data. This allows complementary findings to compensate for the insufficiency of a single methods study (Bradley 1995). Triangulation can be 'between methods' or 'within methods'. Between methods triangulation combines different methods (usually qualitative and quantitative) to examine one concept. In contrast, within methods triangulation uses similar methods to examine one concept. In this study, between methods triangulation is being used. Within this study, qualitative and quantitative data were collected separately. With these two sets of data, the themes for the questionnaire study and interview study were compared and a framework was established which incorporated the themes from both the interview and questionnaire study. This framework was then used to organise the data that was used for confirmation and completeness. The application of triangulation is described in Chapter Six.

## 3.7 Content Analysis

### 3.7.1 Theory

Content analysis is a form of document analysis which is described as "...*various procedures involved in analyzing (sic) and interpreting data generated from the examination of documents and records relevant to a particular study*" (Schwandt, 1997, p.21). In the case of content analysis, documents (e.g., newspaper articles) are analysed either in terms of numerical occurrences of themes, or in terms of the content and context of the document. While content analysis was developed in the 1950s as a purely quantitative data collection method, used mainly within social science (Berelson 1952



and Krippendorff 1980), it has evolved to include qualitative methods and is used in a number of different fields.

Graneheim & Lundman (2004) differentiate between quantitative content analysis, which is used predominantly in media research, and qualitative interview analysis, which is used predominantly as a method for analysing interview type data. However, qualitative content analysis can be used in the analysis of media messages. There are many different methods of analysing documents, for example, semiotic analysis examines documents in terms of key themes and focuses on coding texts in order to build up themes that run through the documents being analysed. It does not view the document in terms of social context but in terms of the intrinsic nature of the document (Bowling 1995).

For the aims of this study it was considered that content analysis which incorporated qualitative and quantitative elements was the most appropriate method of data collection, as it allows a structured approach to be adopted, while not omitting any data that is more suited to qualitative analysis (Cavanagh, 1997). Content analysis concentrates on “*the systematic and objective identification, linking and counting of special characteristics*” (Bowling, 1995, p.377). Data are categorised and coded into structures that must be both systematic and predetermined. Content analysis can either be qualitative (coding and categorising data to develop themes) or it can be quantitative (developing codes and categories and counting instances of the occurrence of certain codes within text). Weber (1990) emphasised that “*There is no simple right way to do content analysis*” (Weber, 1990, p.13). While content analysis can adopt a variety of methods, the key procedure that runs through all these methods is to reduce words or phrases into categories. After this has been done, there are a variety of different methods that can be carried out, including measuring the frequency of words or classifying codes into categories and then developing themes.

In order to undertake an effective content analysis, the following procedures should be adopted. A unit of analysis (e.g., a newspaper article) is condensed into a meaning unit (e.g., a word or phrase), which is abstracted into codes (which are labels for meaning units) and placed into categories to create a theme that runs across the categories (Graneheim & Lundman, 2004). It is important to decide what the unit of analysis is. In this study meaning units were interpreted in different ways, depending upon the data

collection that was being undertaken i.e. a meaning unit ranged from being a word or phrase to the entire article that was being analysed. It is also important to determine what the categories are. The categories in this study were determined according to the literature review, research questions and findings from the triangulation of interview and questionnaire data. As Berelson (1952) stated: “*Content analysis stands or falls by its categories*” (Berelson, 1952, p.147). Categories must be mutually exclusive and exhaustive and no content should appear in more than one category. Silverman (1993) argued that the categories used in content analysis are: “*not determined by an arbitrary or common sense version of what may be interesting to count in a text*” (Silverman, 1993, p.128). The selection of the sample is also vital to content analysis. There is often a large amount of data that can be analysed and a decision needs to be made about how much is going to be analysed and how to select the sample. Riffe et al. (1998) recommend purposive samples, despite the fact that the use of a purposive sample is not seen as being ‘good science’ in the majority of quantitative research. However, the justification for using a purposive sample must be made clear.

As with all research, it is vital that the research is legitimate in terms of reproducibility, reliability and validity. In a study which adopts an approach that uses quantitative and qualitative methods, one of the most important tests of the reliability and validity of the study will be its reproducibility. As Weber (1990) highlighted, it is important that the inferences from content analysis to text are reproducible and therefore reliable. Reliability is assured by consistency in methods and analysis. There are three key aspects to validity in content analysis, namely stability, reproducibility and accuracy (Weber 1990, Krippendorff 1980). Stability is assured by the results from the content analysis being stable over time, i.e. reproducible. As Bowling (1995) also argued, two different researchers must be able to make the same inferences from the text to the codes, i.e., the results of the data analysis are reproducible. Finally, accuracy measures the extent to which coding is being carried out to a specific predetermined norm, i.e., whether a specific method has been chosen and is being used in the collection of data. As Weber (1990) commented, it is vital that these issues are dealt with before the content analysis starts. Validity is assured by making sure that the variable in question (a code or category) measures what it purports to measure. Weber (1990) views the most important aspect of validity as being construct validity, which allows the variable to be generalised “*across measures or methods*” (p.19).

### 3.7.2 Application

The key to content analysis is addressing the tension between qualitative and quantitative methods, while ensuring that rigorous research is being undertaken. The key elements of the approach that were incorporated into the content analysis were an awareness that the key aim of content analysis was to reduce words/phrases into categories. These categories were then be used in two distinct ways. The occurrence of categories were counted and frequencies of categories measured, but also the occurrence of categories alongside other categories were examined and possible reasons for these occurrences suggested, which gave a more qualitative aspect to the data collected and allow a more rich interpretation of the data collected. In addition, a subjective and objective assessment of the content of the article was undertaken.

## 3.8 Conclusions

This chapter has outlined and emphasised a number of key issues in research in the social sciences and has sought to outline the position that the study is taking. The study is positioned within a post-positivist framework, using both qualitative and quantitative methods and triangulating qualitative and quantitative data from parents. While the key concerns of validity and reliability are central to the study, issues of confirmability, dependability, credibility and transferability (Lincoln & Guba, 1985) will also be considered.

The next chapter reports the methods and findings of the interview study, followed by the questionnaire study in the next chapter. Then the triangulation chapter is presented. Finally the content analysis chapter is presented. Within all of these chapters, the specific methods that were adopted are outlined and their application described in relation to the methodological considerations described in this chapter.

# Chapter Four - Interview Study

## 4.1 Introduction

The findings of the literature review (Chapter Two) highlighted that there had been little research on the health information needs of parents in relation to the MMR vaccine scare or on the impact of the MMR vaccine scare on parents. As a result of this it was decided that an initial qualitative exploratory study would be undertaken in order to explore the gaps highlighted in the literature review, in light of the developing nature of the MMR vaccine scare.

This exploratory (qualitative) study, which was undertaken using semi-structured interviews is presented as follows: Section 4.1 presents the background and rationale to the interview study. Section 4.2 presents the methods used in the study, in particular the recruitment, materials, piloting, data analysis and validity. Section 4.3 presents the demographic and interview results). The interview results are then discussed with reference to the literature examined in Chapter Two. Section 4.4 discusses the participant evaluation of the study and Section 4.5 discusses the limitations of the study. Section 4.6 summarises and concludes the findings of the interview study and suggests emergent research questions and areas for future exploration.

### 4.1.1 Background

As the literature review in Chapter Two has shown, the MMR vaccine scare has had an impact on parents, both in terms of falling vaccine rates and in terms of the decision-making process that has surrounded the MMR vaccine. In January and February 2002, the MMR vaccine was widely reported in the media as a result of suspected measles outbreaks in London and Newcastle, which were attributed to a fall in MMR vaccine rates. The reporting of these outbreaks led to a re-emergence of the debate about the safety of the MMR vaccine, as demonstrated by the increase in media coverage in Table 7.7. It was at this point (January and February 2002) that the study was carried out.

### **4.1.2 Research questions**

In designing the research questions for this exploratory study, the aims of the exploratory study were combined with the gaps highlighted in the literature review (Chapter Two) and the overall research questions for the PhD study. The aims of the interview study were to explore a previously unresearched area and generate data that could be used to inform future data collection. The research questions developed are as follows:

- What are the information needs of parents relating to the MMR vaccine and the MMR vaccine scare?
- What are the information sources that parents use relating to the MMR vaccine and the MMR scare?
- What are parents' perceptions of the media, HCPs and the Government as related to the MMR vaccine scare?
- What role did information have for parents when making their decision about the MMR vaccine?
- What role did the MMR vaccine scare have in parents' decision to/not to vaccinate?

## **4.2 Methods**

### **4.2.1 Study design**

The study used a qualitative methodology, employing semi-structured interviewing (as described in Chapter Three). It was planned to interview approximately 20 parents in order to gain a variety of viewpoints, within the financial and time constraints imposed.

### **4.2.2 Sampling and recruitment**

The participants were drawn from a sampling frame with the following criteria. Participants needed to be parents of young children (under the age of five) in order that they had recent experience of the decision-making process surrounding the MMR vaccine.

The study was undertaken in the Sheffield area, concentrating on one postal code area of the city, for reasons of convenience. Concentrating on one area meant that costs could be reduced and that a larger number of parents could be interviewed in a shorter amount of time, to ensure the currency of the most recent MMR vaccine scare in parents' decision-making process.

It was decided that the most appropriate way to contact parents would be through childcare organisations i.e. nursery schools and toddler groups. This would allow the parents to be contacted directly by the researcher, as opposed to requiring an intermediary (e.g., a HCP) to recruit participants on behalf of the researcher. Using an intermediary to recruit would have introduced biases into the study and could also have made the recruitment process slower, thus not taking advantage of the currency of the MMR vaccine scare. Details of childcare organisations in Sheffield were obtained from the Sheffield Children's Information Service. This service provides information to parents on childcare issues and information from organisations concerned with child rearing and childcare. The Sheffield Children's Information Service provided a list of nursery schools and toddler groups in the S10 postal code area, which was used for the study recruitment.

#### 4.2.2.1 Nursery schools

The initial phase of the study recruitment was through two nursery schools in Sheffield. Both nursery schools were contacted by telephone and the nursery leaders contacted agreed to assist with the study. The nursery school leaders were then contacted by letter (appendix 1.1) and were given an envelope containing a letter and an information sheet to distribute to parents (appendix 1.2 and 1.4). They were asked to return all envelopes that had not been distributed in order to measure the response rate.

In the letter that was distributed to parents, the study aims were outlined and the requirements for participation were detailed. Parents were then invited to contact the researcher if they were interested in participating in the study. They were also asked to suggest an appropriate time and location for the interview. The information sheet (appendix 1.4) contained further information about the study and study procedure.

#### 4.2.2.2 Toddler groups

The initial phase of the recruitment did not generate sufficient participants. There are various reasons that can be suggested for this including the sensitive subject matter, lack of time for participation on the part of parents and lack of understanding about the study. Therefore, it was decided that toddler groups would be used to recruit participants, in addition to nursery schools. Three toddler groups were contacted. Two were identified through information supplied by the Sheffield Children's Information Service and one was identified through a participant who had been recruited through a nursery school. The leaders of the toddler groups were contacted and their agreement was obtained for the researcher to attend the toddler group and speak to all the parents in a group, and as individuals if they desired, and to distribute envelopes containing a letter and information sheet to them. The letters that were distributed to parents at toddler groups (appendix 1.3) were similar to those distributed at nursery schools. They were also given an information sheet (appendix 1.5) that had been slightly altered to reflect comments made by participants who had been interviewed as part of the nursery school recruitment. Arrangements for interviews were made either at the time of the toddler group or at a later time through telephone contact.

#### 4.2.3 Materials

The materials given to parents and nursery leaders prior to the interviews are detailed above. Directly before the interview started, participants were asked to complete a consent form (appendix 1.7) and following the interview they were asked to complete a demographic questionnaire (appendix 1.8). The interviews were recorded using an Olympus Micro cassette recorder (Pearlcorder S701). The interviews were carried out using a interview schedule (appendix 1.6), which was designed using the findings from the literature review and the research questions. The interview schedule comprised a list of questions that were both factual and attitudinal. The interview schedule indicates how the initial questions that parents were asked related to parenting and the role of information in parenting. These questions were asked to gain insight into the way that parents used information on a typical day-to-day basis, as well as familiarising parents with the concept of information and the wide-ranging definition of information that this study was adopting. Following on from the questions about information, parents were then asked about the MMR vaccine and finally the MMR vaccine scare. While the

interview schedule presented in appendix 1.6 appears structured, it was designed to alert the researcher to the key areas to be addressed and prompt the researcher when required. The interview schedule was not rigidly adhered to and a more flexible attitude to the collection of the interview data was adopted. The issues to be addressed were often addressed in a different order to the order of the interview schedule. This was related to increased familiarity with the skills required for interviewing and increased confidence of the researcher as well as a need to adapt the interview schedule to the parents' interests and time constraints.

#### **4.2.4 Piloting**

Two pilot interviews were carried out in order to test the interview schedule, consent form and demographic questionnaire. They were also used to practice interviewing techniques. The first pilot interview consisted of interviewing a female colleague (who was a parent of a young child) and gaining her feedback on the interview schedule and interviewing techniques. Changes were made following this pilot interview. The second pilot interview consisted of interviewing a female parent with the revised interview questions and asking her to complete the consent form and demographic questionnaire. The second interview was tape-recorded. The second interviewee also gave feedback on the interview schedule and interviewing technique as well as on the demographic questionnaire and consent form. The interview schedule was also changed following this second interview. There were no changes to the consent form or the demographic questionnaire as a result of the second pilot interview.

#### **4.2.5 Data collection**

The interviews took place in a variety of situations and these may have influenced how the data were collected. Two participants chose to be interviewed outside of their home, but the majority chose to be interviewed in their own home. In all of the interviews in participants' homes, children were present and this provided challenges in undertaking the interviews. Interviews often had to be started and stopped e.g. if a child needed to be fed and this sometimes led to parents needing to be reminded of what they were talking about. However, these interactions among the participants, the researcher and the participant's children led to a more relaxed atmosphere. For example, the participants in asking the researcher to assist with the care of the children indicated a relaxed



atmosphere. Often conversation moved away from the topic of the interview and therefore the interview schedule had to be used in a flexible manner e.g. when one interview was interrupted by a telephone call and the conversation that the participant had been having on the telephone alerted them to a specific incident when they were getting their child vaccinated with the MMR vaccine that they had not previously mentioned. Again, this flexibility served to make a more relaxed atmosphere. The demographic questionnaires were often completed by the researcher at the parents' request, due to the presence of their children. A discussion of how the interview procedure influenced the data collected is presented in section 4.5.

#### **4.2.6 Demographic data analysis**

The data collected from participants using the demographic questionnaires were entered into the Statistical Package for the Social Sciences (SPSS) 11.5. The data were entered following a coding framework. The appendix contains the data collected from the demographic questionnaires (appendix 1.9).

The socio-economic status of the participants was determined according to Standard Occupational Classification (SOC) 2000 (Office for National Statistics, 2000). Where the occupation of both the participant and their partner was given, the occupation of the person in full time work was used to determine the socio-economic status. Where the participant gave the occupation of either themselves or their partner, this was used to determine the socio-economic status. In the case of one of the participants, data were only available for one person, who was on maternity leave from full time work. For the purpose of this study, the occupation of this person was used to determine socio-economic status.

#### **4.2.7 Interview data analysis**

The interviews were tape recorded, transcribed and then analysed. Firstly the tape-recorded interview data was transcribed into Microsoft Word 2000. One participant refused to be tape-recorded. In this case, extensive notes were taken during the interview and transcribed immediately after the interview. A false name was attached to each of the 17 transcripts and where names appeared in the text (e.g. names of children), these names were changed to false names. All of the transcripts were imported into

ATLAS.ti (Muhr, 1997) and then read. The reading of the transcripts continued throughout the data analysis, in order to encourage familiarity with the data. ATLAS.ti allowed the coding of textual data in a systematic and structured method. The coding of data consisted of: “... *labelling passages of the data according to what they are about or other content of interest in them*” (Richards & Richards 1994 p.446).

The second stage took the form of an analytical and intellectual process involving the coding of the data. The transcripts were read and a coding structure was developed with reference to the literature review and the research questions, as well as ideas generated during the process of carrying out the interviews and during the reading of the transcripts. The transcripts were then coded by applying these codes to sentences or longer units of text. If further codes, to those initially identified emerged during the coding process then these were added to the list of codes and the transcripts were re-read and re-analysed in light of the new codes. Throughout the coding process, the constant comparative method was employed. This required that: “... *each item of data is compared with every other item of data*” (Cutcliffe, 2000, p.1477). Using the constant comparative method ensured that the codes were rich and in-depth and also that they covered the ideas, themes and incidents that they represented.

For example, when parents were interviewed, it became clear that as well as information regarding the potential side effects of the MMR vaccine, parents were also interested in information regarding the MMR vaccine itself, to help their decision making. Therefore the code: MMR vaccine: ingredients was attached to both of the following data e.g.

I would like to know the ingredients of the MMR jab (Susan)

I know that it is grown in egg culture, which I know can cause problems if the children are allergic to egg (Jane)

The list of codes developed was then examined with the data that they were attached to, and categories developed from these codes. For example, as well as finding out or having information about the MMR vaccine scare and the information needs that this generated for parents, parents were also interested and knowledgeable about the MMR vaccine and it was decided that two distinct categories were to be developed which addressed parents' knowledge and information needs surrounding the MMR vaccine and parents knowledge and information needs surrounding the MMR vaccine scare. The

examples above were therefore categorised with information needs regarding the MMR vaccine, as opposed to information needs regarding the MMR vaccine scare.

Another example that can be given relates to the category 'Being a parent'. Parents were initially asked about general issues relating to their children's health and welfare. Quotes such as the following indicate that becoming a parent generated information needs for parents:

From the moment that I was pregnant with my oldest child, I think you want to find out as much information as you can (Kate)

I think that there is an expectation that everybody knows how to be a parent (Mike)

This category was further developed when it became clear that there were specific issues that parents required information about. These were related to welfare e.g. schooling and health e.g. allergies, but in both cases, these were directly related to the information that parents needed to know in order to make decisions for their child.

The results were then written up as a narrative, structured around the categories developed, with the codes being used to support them.

#### **4.2.8 Validity**

In order for validity to be established, a summary of the results was distributed to the participants, with a covering letter. The participants were also given a brief evaluation sheet and asked to complete this and return it to the researcher. The letter, summary and evaluation sheet are contained in the appendix (1.10-1.12). The participant evaluation of the results can be found in section 4.4.

### **4.3 Results**

Section 4.3.1 shows the study response rate. Section 4.3.2 presents the demographics of the participants and their children and section 4.3.3 presents the interview study results. This section includes a diagram (Figure 4.1) that illustrates the categories and sub categories, a description of these categories and codes and finally, supporting data in the

form of quotations from the interviews. Section 4.3.4 relates the interview results to the literature as reviewed in Chapter Two.

### 4.3.1 Response rate

Seventeen parents participated in the interview study. Table 4.1 shows response rates for nursery schools and toddler groups. Detailed breakdown of the results by individual nursery school and toddler group can be found in appendix 1.9.

Table 4.1 - Response rates by location of recruitment

Location	Letters distributed	Responses
	n	n (%)
Nursery schools	64	4 (6.3)
Toddler groups	61	13 (21.3)
Total	125	17(13.6)

Table 4.1 shows that, overall, there was a 14% response rate to the recruitment. (Nursery Schools = 6%, Toddler Groups = 21%). Recruitment at toddler groups was significantly higher than at nursery schools (Fishers Exact test,  $\chi^2 = 0.13$ , degrees of freedom (d.f.) = 1,  $p=0.05$ ).

### 4.3.2 Demographic characteristics

This section will firstly look at the demographic characteristics of the study participants and the demographic and MMR vaccine related characteristics of their children.

#### 4.3.2.1 Participant characteristics

The demographic characteristics of the 17 participants are presented in Table 4.2.

Table 4.2 - Demographic characteristics of participants

Variable	Category	n (%)
Gender	Female	16 (94.1)
	Male	1 (5.9)
Age range (years)	18-24	1 (5.9)
	25-34	9 (52.9)
	35-44	7 (41.2)
Marital Status	Married/Living with partner	17 (100)
Ethnic Background	White	16 (94.1)
	Mixed Race	1 (5.9)
Employment Status	Full Time	2 (11.8)
	Part Time	3 (17.6)
	Maternity Leave	2 (11.8)
	Not currently employed	9 (58.8)
Socio Economic Class	Modern professional occupations	3 (17.6)
	Clerical and Intermediate occupations	9 (52.9)
	Senior managers or administrators	4 (23.5)
	Not classified	1 (5.9)

As Table 4.2 indicates, the majority of the participants were female, aged between 25 and 34 years, white, married or living with their partner and had a higher socio economic status.

#### 4.3.2.2 Children's characteristics

The 17 participants had a total of 29 children. Demographic characteristics of these children are presented in Table 4.3:

Table 4.3 - Demographic characteristics of participants children

Variable	Category	n (%)
Age range (months)	0-12	5 (17.2)
	13-24	7 (24.1)
	25-36	9 (31)
	37-48	3 (10.3)
	49-60	2 (6.9)
	61-156	3 (10.3)
MMR vaccination status	Vaccinated/ Intending to vaccinate	19 (65.5)
	Not vaccinated/ Not intending to vaccinate	10 (34.5)

#### 4.3.2.3 Interview characteristics

Seventeen interviews were carried out with participants, of which 16 were recorded. Of these 16 interviews, the range of word counts was 2200-6782 words. The mean word count was 3222 words and the median was 2891 words. For the participant who wished not to be recorded, notes were taken during the interview that totalled 600 words.

### 4.3.3 Interview results

#### 4.3.3.1 Overview of categories and sub categories

The analysis of the interview data generated one core category 'Information and the truth' as well as four main categories, 'Being a parent', 'Information and the MMR vaccine', 'Information and the MMR vaccine scare' and 'Information and the system'. These categories are related to further sub categories, which are presented diagrammatically in Figure 4.1

#### 4.3.3.2 Categories

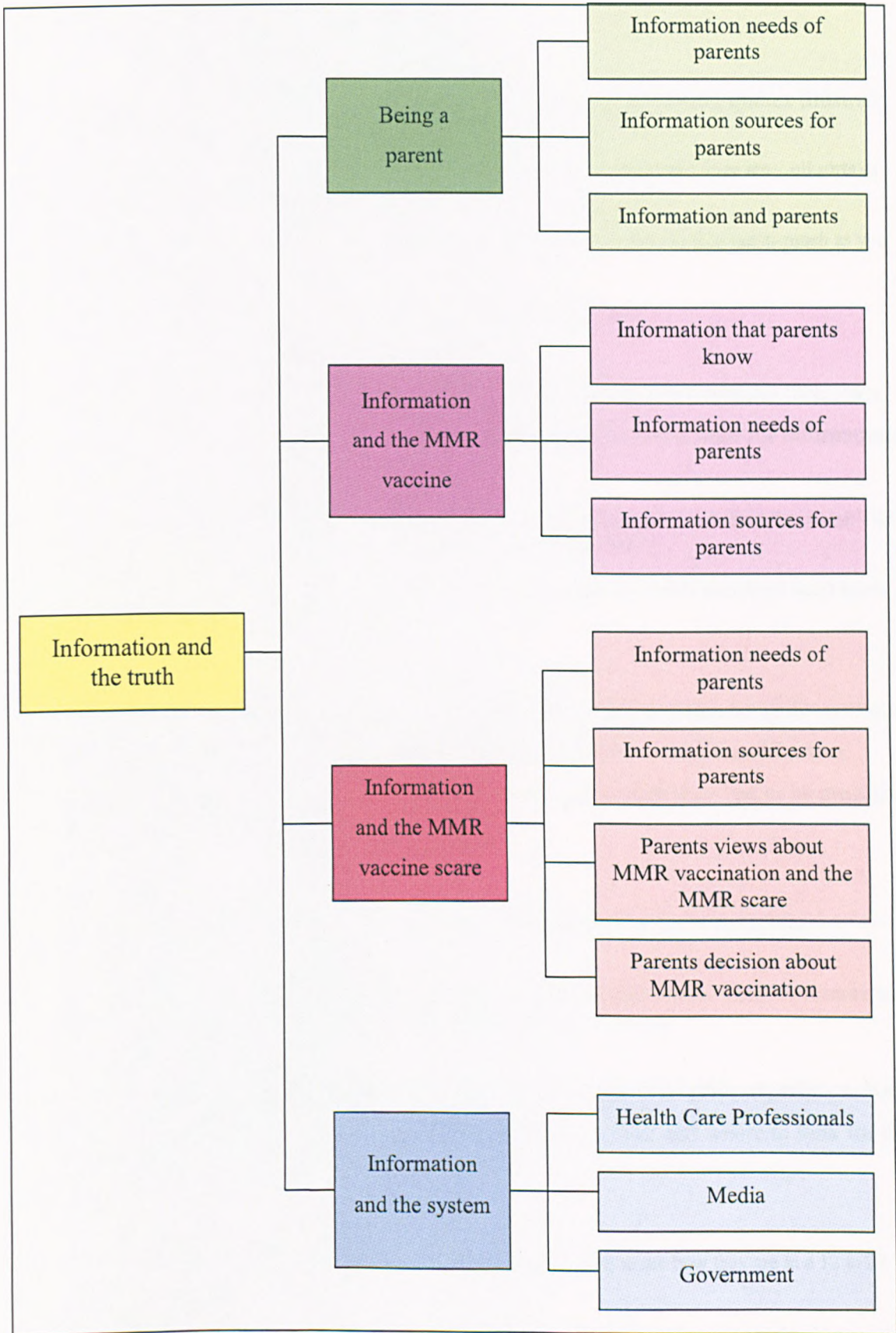
The core category in the results is 'Information and the truth'. The parents in the study were constantly trying to address the difficulty in accessing the information that they wanted, but also in trusting information that they received. Clearly, addressing information needs was key to parents, but supplying them with information that they felt unable to trust created additional difficulties for them:

So do I want more information? Not necessarily. I just want the truth (Mike)

It just comes down to people trusting the information that they are given (Carol)

Four categories were developed. The aim of the interview study was to address parents' information needs, preferred information sources and the role of information in decision making. The first category, 'being a parent', was developed to categorise parents' comments about information as they related it to general parenting. The category developed as a result of the questions which parents were asked about parenting. As previously explained, these questions gave an insight into how parents viewed information and therefore relate to the other categories in terms of how parents use information and the extent to which how they use information in day to day situations may shape their use of information in the context of the MMR vaccine scare. The second category is 'information and the MMR vaccine'. This category addresses parents' information needs and their knowledge about the MMR vaccine. This category is separate from 'information and the MMR vaccine scare'. These categories were separated in order to distinguish between the information that parents knew or that parents wanted about the MMR vaccine and the information that parents knew or the information that parents wanted as a result of the confusion that surrounded the MMR vaccine as a result of the MMR vaccine scare. Although it is impossible to say that information needs and knowledge regarding the MMR vaccine (as in the category 'information and the MMR vaccine') are not related to the confusion generated by the MMR vaccine scare, the categories seek to define the difference between the confusion generated by the MMR vaccine scare and information needs and knowledge related to issues which were not confused for parents as a result of the MMR vaccine scare. The difference in the categories also lies in other issues such as the different sources used when looking for information. The final category sought to examine some of the key information sources in more depth. The analysis of the data suggested that parents' views about the information they were provided with as a result of the MMR vaccine scare were heavily influenced by the source from which this information originated. Therefore it was considered important to analyse parents' views about these information sources in greater depth to try and get a better understanding of how information sources may influence how parents deal with the information that they seek and receive.

Figure 4.1 - Category diagram – information and the truth





### 4.3.3.3 Being a parent

#### Being a parent: information needs of parents

Becoming a parent generated a need for information, as the following quotes illustrate:

I think that there is an expectation that everybody knows how to be a parent and there are...all sorts of things that you just don't know about (Mike)

From the moment that I was pregnant with my oldest child, I think you want to find out as much as you can (Kate)

As a parent I think that you have certain information requirements (Kate)

In terms of both their child's health and (in the case of female participants) their own health, parents viewed pregnancy as being a state that generated a need for information:

... they give you lots of information about pregnancy ... but I think in reality what that often doesn't do is help you with some of the immediate issues that you are addressing (Kate)

... they tend to assume that I know what is going on because it is my third child but often I don't know what the systems are, maternity wise (Sally)

Allergies are an example of a health issue that generated information needs for parents. This may be related to the fact that parents felt that the available information was lacking and did not address their information needs. As a result they had to be proactive in seeking that information from other sources:

I feel really informed about Ricky's allergies but we have had to go out and find that information ourselves (Annie)

I telephoned the Children's Hospital and the allergy clinic had been suspended ... I phoned Manchester and went there. Most parents wouldn't have found the information. (Naomi)

Information needs relating to health were influenced by parents' prior experience, both in terms of determining whether parents required information and where to look for the information:

I have got a good idea about what is serious and what isn't, so I tend to see how they are in a 12 to 24 hour period (Becky)

I am a children's nurse so I think in some respects, gathering information, I know the right places to go (Sharon)

I would go to a book. In fact the child books that we have got ... would be my first port of call (Carol)  
... the help line, the national health thing, I have rung that a couple of times (Mary)

Parents had information needs relating to their child's development:

I need to know things like if he is doing things at a certain age is that about the right time (Rosie)

I think what is quite difficult is knowing what is normal for children; you have got no benchmark (Kate)

Parents also expressed information needs about the schooling of their children:

The one major thing, you don't get any information about when you need to put your child's name down for playgroup, nursery's or schools (Susan)

You don't really know anything about schooling, which is quite scary (Heather)

#### Being a parent: information sources for parents

Parents received information from the health visitor; especially regarding their child's health and health visitors were an information source which some parents found useful:

I quite like asking the health visitor because it is instant because you ring and if they are not there then you leave a message and they ring you back straight away (Jean)

We have only just moved to Sheffield and she came round yesterday to see us and she said that we can phone anytime so that is good (Mike)

I ... got much more information on the different issues by talking to the health visitor (Jean)

... you get most of the information from the health visitor (Sally)

However, not all parents viewed health visitors favourably as an information provider, as they felt that the information that the health visitor provided was either not of use for them or did not supplement their own knowledge.

I am not very keen on health visitors. I think ... that they don't really know what they are talking about (Heather)

I realised as I went through my children that she didn't know any more than I knew (Sally)

Other parents were an important source of information, especially in the case of their child's development and schooling:

I got it from other parents and through the toddler group (Sally)

That tends to be other mums because I think although you can read things in books they are all, I wouldn't say vague, but they say 'around about this sort of time' (Helen)

I think it is much more based on informal information, I knew other people who have had children in Sheffield (Kate)

A lot of the information is actually gleaned from talking to other mums at playgroup (Lisa)

Information in a written format was important for parents regarding health, development and schooling. The Sheffield Children's Information Service was a source that was used by a number of parents in this study.

... it was the first place that I went when I got to Sheffield, for a list of things, schools and playgroups from them (Lisa)

The Children's Information service is excellent and I got a good amount of information from that (Naomi)

I accessed the Sheffield Early Years information for information about what was available locally and then went to see them myself and got my own view (Alison)

In terms of other information sources, parents mentioned NHS Direct, a nurse-led information service delivered over the telephone and Internet as a useful information source, emphasising the fact that it is always available:

I have rung NHS Direct a couple of times and they have been quite helpful (Rosie)

I got an instant call back from the midwife ... I think that is quite good because when you need information you need it there and then with children (Jean)

Parents appreciated the accessibility and availability of information over the Internet:

I quite like the Internet because you get up-to-date information (Jean)

However, parents were cautious about information accessed over the Internet:

You have to be careful about what you get on the web (Lisa)

I am still quite sceptical about the quality of some information on the Internet (Carol)

## Being a parent: information and parents

This sub-category describes parents' general views about information. As well as giving an insight into how parents use information, it sets the scene for the next three categories, which are looking at how parents use information.

The following quotes illustrate the role that information played for parents, indicating that information could have a positive and empowering influence:

... to make decisions (Mike)

... to make an informed choice (Susan)

...to gain knowledge (Naomi)

The following quotes illustrate how information could have a negative influence on parents, although, as these quotes suggest, the positive and negative attributes of information are often related to the context in which the parents receive the information:

I know that these things are in the world and you can't avoid them, but you don't need it repeatedly telling to you (Sally)

... the thing about information is how much information do you need about these sorts of things? Because otherwise the world can look a very depressing place (Kate)

In addition, parents did not believe that information could meet all their needs and, in the case of parenting, some parents valued prior experience ahead of 'formal' information:

... they think all this theory is the same as having your own kid and at the end of the day, it isn't (Rosie)

I think parents do have a lot more insight because you are with your children 24 hours a day (Annie)

The parents in this study recognised the growth in information sources and the impact that this may have on their relationship with information:

I think we have got these masses of sources of information and I do think that has exploded with IT, particularly interactive IT and things like the Internet (Kate)

Nowadays you have got a big choice about information, you have got the internet, you have got radio, all sorts of media, television, you have got exchange with other people, books, anything really (Jean)

As the data in these categories has shown, parents viewed information as useful, but the context in which the information was accessed and the source from which the information originated influenced parents' response to it.

#### 4.3.3.4 Information and the MMR vaccine

This category addresses parents' knowledge about the MMR vaccine, which is distinguished from their knowledge about the MMR vaccine scare i.e. knowledge relating to the safety of the MMR vaccine. As well as looking at parents' knowledge about the MMR vaccine and the conditions of measles, mumps and rubella, the category examines parents' information needs and how these information needs were addressed.

##### Information and the MMR vaccine: information that parents know

The majority of parents were well informed about the MMR vaccine and expressed knowledge about the format of the MMR vaccine, the UK vaccination schedule and the administration of the MMR vaccine, as the following quotes illustrate:

I know its three vaccines together, a triple vaccine (Becky)

I know that there are three live viruses (Jean)

I know that they have one when they are fifteen months and one when they are about five and you can expect a reaction within about ten days (Annie)

... that it is two doses, one at a year, one at pre-school (Heather)

While parents expressed knowledge about the MMR vaccine, it is not possible to say whether this knowledge was as a result of the increased coverage that the MMR vaccine received or whether parents would have been aware of this information about the MMR vaccine without the increased awareness generated by the MMR vaccine scare.

Parents had differing opinions about the conditions of measles, mumps and rubella. Some parents viewed the conditions as being serious:

I know that in years gone by children died from them and they are potentially very serious (Carol)

I know that they are life threatening (Sally)

Measles was considered to be the most serious of the conditions:

I know that measles is a killer (Susan)

I think that people underestimate just how serious measles is (Jane)

... the more I read the more I thought measles was a dangerous disease and I didn't know that before (Jean)

However, the perceived severity of mumps depended upon the gender of the child:

I know that mumps can make boys infertile (Helen)

... as far as I am aware mumps is only dangerous for boys not girls (Mary)

Rubella was not perceived as being a serious condition for the children themselves:

Rubella, they don't really need that do they? It's just added in, it isn't vital that they have it, it's just in case they come across any pregnant women (Susan)

I don't think that German measles is as bad when you are suffering from it, I don't remember being that ill when I had it (Jane)

I know that rubella can be dangerous for pregnant women but I think that they are illnesses rather than serious and life threatening (Mary)

These views are reflected in the opinions of parents who did not consider any of the diseases to be a risk. These opinions appeared to be influenced by personal experience:

Listening to my parents' generation ... that was a normal thing for them (Sally)

When you say disease you think of cancer, meningitis or polio. These three [Measles, Mumps and Rubella] just seem like things kids have (Mary)

In our family it was never perceived of as a big illness. It was just something that you got (Lisa)

The belief of parents that the conditions of measles, mumps and rubella were not serious had an impact on their view of the MMR vaccine:

I don't know what all this hoo-haa is about because I had measles, mumps and rubella. I am absolutely fine so why vaccinate in the first place (Jean)

... we all had measles and we are all ok and I think that had contributed to the difficulty that 'well why do you need this fairly harsh vaccine...when we all had it [Measles] and we are all ok' (Kate)

It would appear that in these cases, personal experience was the greatest influence on opinions about measles, mumps and rubella. While parents expressed that they felt they

were relatively well informed about the conditions of measles, mumps and rubella, the wide variety of differing views expressed by the parents would suggest that this is not the case. Indeed it could be argued that the attitude of parents towards the diseases is related to their choice about whether to proceed with MMR vaccination. However, this hypothesis would require further examination. Parents' perceptions of the severity of diseases and the MMR vaccine are also related to their understanding of risk, which will be further examined in the category 'Information and the MMR vaccine scare'.

#### Information and the MMR vaccine: information needs of parents

Parents had information needs related to the format and function of the MMR vaccine:

I would like to know the ingredients of the MMR jab (Susan)

... what we don't know is how the MMR given to a young baby impacts on the later requirements for immunisation (Kate)

... why do you have to have it in a triple form ... I think that is the information that I require (Kate)

Whilst parents expressed a need for information about the MMR vaccine, the majority of parents did not express the same need for information about the conditions that the MMR vaccine protects against, possibly because they had allowed their children to have the MMR vaccine:

I've not looked for any specific information on the diseases (Becky)

I don't have a desperate need for information about those three [measles, mumps and rubella] because I am assuming that my children are all protected (Kate)

The availability of information on the conditions of measles, mumps and rubella was considered to be good:

The information on the actual illnesses I thought was really good, there was lots of stuff out there and [they] gave you the basic information (Mary)

#### Information and the MMR vaccine: information sources for parents

Information about the MMR vaccine and measles, mumps and rubella appeared to be gained mostly from two information sources; leaflets and HCPs.

Leaflets were considered to be an insufficient source of information for the parents in this study:

... they gave us a leaflet, the gen that the Heath Education Authority wants you to know which doesn't really tell you a great deal (Carol)

I asked for some information and she gave me ... a little leaflet and it didn't tell me anything that I needed to know (Sally)

Parents also received information and advice about the vaccine from HCPs:

Like they inform you when it is due (Mike)

What the doctor has said... that seems to have covered most of what I need to know (Susan)

I have been to see the immunisation woman ... the immunology expert for Sheffield ... I got some advice from her and some papers (Annie)

However, HCPs sometimes provided parents with conflicting advice about the MMR vaccine:

... all the doctors we saw said we should and all of the health visitors and pharmacists and nurses said that we shouldn't (Annie)

I got different answers from my health visitor and my midwife (Sharon)

You'll ask the health visitor and they'll say the current medical advice is that the MMR is safe and that is all that they will say to you (Becky)

Overall, parents did express knowledge about the MMR vaccine and measles, mumps and rubella. However, this does not mean that this is a result of the information provision to them. Parents cited personal experience as the main contribution to their knowledge about the conditions of measles, mumps and rubella. With regard to the MMR vaccine, it is unclear to what extent parents' knowledge can be attributed to information seeking about the MMR vaccine and the information that was provided to them about the MMR vaccine and how much can be attributed to the wider availability of information about the MMR vaccine as a result of the MMR vaccine scare, especially in the media. The following category examines the MMR vaccine scare and the extent to which information played a role in shaping parents' reactions to it.



#### 4.3.3.5 Information and the MMR vaccine scare

This category examines the impact of the MMR vaccine scare on parents' use of information. It is distinguished from the previous category as it addresses parents' information needs as a result of the questions that surrounded the safety of the MMR vaccine especially in the mass media. In addition, the category looks at parents' views about the MMR vaccine scare and the decisions that they made about whether to allow their children to receive the MMR vaccine.

##### Information and the MMR vaccine scare: information needs of parents

Parents expressed the opinion that they lacked information on a wide range of issues in relation to the MMR vaccine scare. This lack of information was often expressed as an information need:

... there is an information requirement to look at whether or not it will be severe, whether or not they think thirteen month olds can cope with the severity of the triple (Kate)

We would like to see ... a medical study into the kind of children more likely to develop bowel problems and autism as a result of the MMR triple vaccine (Annie)

The conflicting nature of the information that parents were accessing was often problematic for them:

It would be nice to see a straightforward report on it rather than all this arguing (Jane)

It is confusing and conflicting. In order for it to be informative you have to sift through the information (Naomi)

Parents felt that the information they were receiving about the MMR vaccine was insufficient and was influenced by other bodies that had a vested interest in promoting the MMR vaccine:

I don't think that we had as much information as we should have had or were as informed as we could have been (Susan)

It [leaflet] just said here is the government propaganda on it and it didn't say here is some real information from real people (Sally)

As a result of the lack of readily available information, parents believed that they had to be more proactive in their information seeking:

... the only way that you can get more of a balanced argument is to go and look at it yourself (Becky)

If I need to know about something then I will go out and find out about it (Helen)

A number of parents expressed a desire for information in the form of medical research. This may be due to the belief of the parents that the evidence against the MMR vaccine was insufficient and the original research that cast doubt on the safety of the MMR vaccine (Wakefield et al. 1998) was flawed.

A parent who did not get their children vaccinated with the MMR vaccine expressed a need for information in a specific format and from a specific source. This emphasis on using non-governmental researchers suggests the relationship between information and the truth can be as a result of specific sources that are not seen as providing true information:

... employ a non-government body to research it and look into every single avenue and not be influenced by the government in any way (Helen)

Arguably, the method (and information source) through which parents found out about the MMR vaccine scare was one determinant in shaping their response to it. Most of the parents found out that the safety of the MMR vaccine was being questioned through the media and this may have influenced parents' information needs and the source from which they sought it.

#### Information and the MMR vaccine scare: information sources for parents

Parents gained information about the MMR vaccine scare from a variety of sources. Contact with information sources occurred in two main episodes, when initial information was gained and when/if parents chose to follow this information up.

Initial information about tended to be gained via the media. This is unsurprising, as it has been argued that the media were in part responsible for generating questions about the safety of the MMR vaccine through reporting of the research of Wakefield et al. (1998).

Parents had a complex relationship with the media as an information source. They saw them as being important as an information provider but were sceptical about the quality of the information they provided.

I think that they have got a very important role in exposing these issues (Kate)

I felt that it was great for the initial information (Jean)

I just use it as a background. I don't take it as a consensus view on anything (Becky)

The media wants to make money and therefore the stories are sensationalised (Naomi)

Another source of information for parents about the MMR vaccine was the leaflet although parents viewed leaflets regarding the MMR vaccine in an unsatisfactory light.

... they gave us a leaflet, the gen that the Health Education Authority wants you to know which doesn't really tell you a great deal (Carol)

... it was a little leaflet and it didn't tell me anything that I needed to know (Sally)

Within the context of the MMR vaccine scare, parents' experiences of the HCP as information provider varied. Some parents used their HCP heavily as an information source, whereas others rejected the information supplied by HCPs as a result of their lack of trust in them. The reasons for this lack of trust are further examined in 'Information and the system'.

Health visitors were heavily criticised by parents as sources of information about the MMR vaccine. Parents viewed the information that they provided as being insufficient, as this quote illustrates:

I think that my health visitor ... need (s)... some real expert sources of information (Kate)

Overall, parents' views on information sources were determined by two factors, the format that the information was in and whether the source from which the information originated could be trusted. For the parents in this study trustworthiness was more of an issue and this can be seen in category four ('Information and the system'). Parents mentioned less often the importance of the format of the information in shaping their views on the source.

#### Information and the MMR vaccine scare: parents' views about MMR vaccination and the MMR vaccine scare

This category addresses parents' views about the MMR vaccine, in light of the MMR vaccine scare. While the majority of parents interviewed supported the MMR vaccine,

this support was not based on one factor and encompassed a complex set of views about their children and about vaccination in general. These factors will be addressed, along with parents' views about the issues that influenced their views about the MMR vaccine.

Support from some parents for MMR vaccination was based upon their scepticism about the study that cast doubt on the MMR vaccine, as the following quotes illustrate:

... there were one or two reported studies, one team I think which reported a potential link with autism and Crohn's disease, that wasn't substantiated by any other studies. (Becky)

I have read that research paper. I don't think that it was a particularly good piece of research, tiny sample, relatively low incidence... (Kate)

...it came from one study that wasn't a statistically good study because it was looking after the event and it wasn't a controlled study (Heather)

Parents also believed that the length of time that the MMR vaccine had been in use and the fact that it was used in many countries across the world supported the claims that it was safe:

I know it's used worldwide with very few problems (Becky)

... it is used in many many countries and it has been for many many years (Alison)

The majority of parents who supported the MMR vaccine agreed with the Government's suggestion that the alleged link between the MMR vaccine and autism/bowel disease was a co-incidental link, not a causal link:

I can't help thinking that some of it is because of the fact that autism develops at the time that they have the vaccine (Jane)

... autism becomes evident at the time you get the MMR so to say that it is causal is pretty poor (Lisa)

Some parents are associating it with autism, but autism coincides with the timing of the MMR (Naomi)

In contrast, a number of the parents interviewed were very strongly opposed to the MMR vaccine for a variety of reasons. A few parents expressed that they believed that the anecdotal evidence that parents (who believed their children had been damaged by the MMR vaccine) gave against the MMR vaccine was sufficient:

I think that they talk about there not being any medical evidence and they don't talk about the fact that there are thousands more autistic children than there ever were (Annie)

I know that people say that there is no link between autism and the MMR but when you know someone who says they are so sure you sort of stop and think... (Jean)

Parents also believed that its relatively short existence provided another reason to be cautious about the MMR vaccine:

I just don't think that it is long enough and withstanding enough for everyone to say that it is safe (Annie)

... while with whooping cough, diphtheria and tetanus they have been time tested, it doesn't seem like the MMR has been time tested (Sally)

Some of the parents interviewed who had decided not to vaccinate their children with the MMR vaccine, supported the research that had been carried out by Wakefield et al. (1998):

... everyone was just writing stuff that discredited Dr Wakefield rather than investigating what he said (Annie)

I know that the research that Andrew Wakefield has done and his findings. I know that it is not categorically proven but to me there is enough evidence to be questioned (Helen)

While the MMR vaccine scare caused confusion and concern for parents, the following quotes suggest that, for some parents, a general scepticism about vaccination may have influenced their views on the MMR vaccine:

... you are putting something foreign into a child's immune system and it is a risk whenever you do it (Annie)

A perfectly well child who you are going to stick something into and make them a bit unwell for a few days afterwards. Its not very nice at all, really horrible (Susan)

Parents exhibited concern about the MMR vaccine in terms of the format and administration of the vaccine. Parents' main concern about the MMR vaccine centred on the finding that the vaccine had been linked to autism and bowel disease.

You read all these things in the paper about people who think that their children have autism and it is directly because of this [MMR] (Susan)

As a result of this alleged link, parents expressed information needs about the possible link between the MMR vaccine and autism/bowel disorders:

... no-one has been able to give me a definitive answer on two things which is whether egg allergy should be any contradiction to the mumps part of the vaccine and whether or not children with milk allergy ... are more likely to suffer from the autism effects (Annie)

Parents were concerned about the fact that the MMR vaccine contained three components (measles, mumps and rubella vaccines) in one vaccine and this led to them expressing information needs about the format of the MMR vaccine:

... it is a triple vaccine so its quite powerful and quite a lot for a child to deal with (Susan)

... why should you have them all together, what is the benefit of having them all together? (Kate)

These quotations have indicated that the MMR vaccine scare caused confusion for some parents but that this confusion led to specific information needs that parents sought to address. This then leads to the final sub-category, which examines parents' decision making about the MMR vaccine.

#### Information and the MMR vaccine scare: parents' decision about the MMR vaccine

Most of the parents interviewed made the decision that their children would have the MMR vaccine:

I was quite happy for her to have it...unless they come up with a lot more about it, more substantial evidence then he will be having it (Jane)

I'd rather know that my boys are safe and vaccinated (Sharon)

Although these parents decided to have their children vaccinated with the MMR vaccine, the impact of the MMR vaccine scare meant that they were still concerned about the MMR vaccine. This suggests that, in proceeding with the MMR vaccine, parents were not endorsing it as being safe, but rather that they felt it was the best course of action to take.

...although I am doing MMR I am not 100% convinced because the scare has affected you (Lisa)

I think I probably went along with slightly more head than heart thinking I suppose that is ok (Kate)

The parents who decided not to proceed with MMR vaccination had strong reasons for this decision, as the following quotes illustrate:

... we decided that we wouldn't give it to our son ... because of his allergies (Annie)

It was a programme ... saying that the research that they have done so far said that the links to the MMR and bowel disease and autism were higher in children that had a family history of arthritis diabetes, children who are on long term antibiotics and there was one other thing (Helen)

I decided that I didn't want to take the risk... I think that the other part of the decision-making process was ... sometimes children are over vaccinated and they don't get a chance to build up their immune systems when they are young (Sally)

We swung back and forth but in the end we decided that it was too big a risk... we thought that the benefits of the vaccine didn't outweigh the risks (Mary)

Other parents interviewed decided to delay giving their children the MMR vaccine. It is unclear whether this decision was influenced by the confusion surrounding the MMR vaccine:

...because of the idea of the cocktail of drugs, so I thought well her immune system would be better when she was eighteen months, so I thought we were going to wait (Lisa)

...my son wasn't well enough, because you have to be in good health to receive that vaccine and he wasn't well enough to get it (Alison)

The decision about MMR vaccination was problematic and two of the parents interviewed mentioned relief that they did not have to make the decision about whether to vaccinate with the MMR vaccine:

I am actually glad that I am in this position, that I have got my youngest daughter done, that I haven't got to think about it for her at this point, because I think that I would be more cautious now (Kate)

We are moving to Germany... you get a choice between the MMR and the single vaccines and we are going to go for the single vaccines, I am glad that we are moving and I don't have to make the decision here (Jean)

The process of vaccination was seen as risk laden. Parents weighed up the risk from the MMR vaccine and the risk from the conditions. Parents presented conflicting views, depending upon their attitude towards the MMR vaccine. In the following cases the MMR vaccine was perceived as being more of a risk than the diseases of measles, mumps and rubella:

...what would you rather risk, having measles or autism (Helen)

Although there is a risk from not having the inoculation, you don't really want to put them in any possible danger (Sally)

Had this controversy been about the meningitis vaccine or the polio vaccine then I would have had it done ... but because of the diseases that it vaccinated against, I didn't think that it was worth the risk (Mary)

In contrast, one parent believed that the risk of the MMR vaccine was less than the risk of the conditions of measles, mumps and rubella.

... there is going to be some sort of risk, but if the risk was too great then they wouldn't insist that every child has it would they? (Rosie)

Although parents who had made the decision to vaccinate their children with the MMR vaccine felt secure in their belief that their children were protected from the conditions of measles, mumps and rubella, they were sympathetic to other parents who had not had their children vaccinated:

I wouldn't know what to say to people who didn't and then their children got measles. I mean you couldn't blame them...it just wouldn't be right (Susan)

The decision about the MMR vaccine depended on the nature of the child and the environment in which the child was brought up as well as the parents' belief about the vaccination:

...we would be totally prepared to vaccinate one and not the other (Annie)

people have complications but I am quite convinced that that is because of bad healthcare to start and bad diet (Mary)

The parents' views show that the decision about whether to proceed with the MMR vaccine is based upon two main factors, parents' perceptions of the risk of the MMR vaccine (as opposed to the risks of the diseases of measles, mumps and rubella) and parents' views about the nature of their child. Some parents viewed the MMR vaccine as being a risk regardless of the nature of the child, whereas others had less strong overall views about the MMR vaccine, but an overall perception that it would be risky for their child. However, when looking at the reasons parents gave for having the MMR vaccine, they gave altruistic reasons as well as personal reasons for vaccinating their children:

Given that there has to be a certain percentage of take up in a particular area for it to be effective, that was the influencing factor knowing that not only was she at risk but other people in the community (Carol)

I'd rather know that my boys are safe and vaccinated and that I am not then putting them and other people at risk as well which is a big issue, rather than just being concerned totally with my child (Sharon)

I think that the only thing that would change my mind would be that I didn't want to put children at risk by him not being vaccinated (Sally)

The attitude of parents towards the role of information in making their decision is interesting. There were a variety of views about how information influenced parents'



decision-making. For some parents, information played an important role in the decision-making procedure:

You can make informed decisions about the MMR (Mike)

I went on the Internet... it was an educated decision rather than off the top of our head (Sharon)

My daughter had it later because it took me two months to decide you know, two months to read and make a decision (Becky)

...when I read that research I thought 'fine'. There is no causal link between autism and Crohn's disease (Lisa)

For other parents (both immunisers and non-immunisers), information was less important, as the following quotes illustrate:

I didn't do a lot to seek out information although it is something terribly important (Carol)

I think that before we started it we were on the side of not having it really. So I suppose information didn't make us change our mind (Mary)

I had decided before they gave me the information about it (Sally)

... once we decided to go ahead with it, we never pushed for any more information (Mike)

While parents varied in the extent to which they believed information had influenced their decision about whether to proceed with MMR vaccination, parents' awareness of the MMR vaccine scare suggests that they have been in some way affected by information, even if it was not cited as being an influence on their decision.

Many parents' decision about MMR vaccination was influenced by pressure and information from their family and friends:

...the other influential thing was talking to friends and family who have also made the decision (Carol)

I was influenced by other mums saying that there was a problem (Naomi)

My mum is a doctor; I have things like the BMJ from her (Annie)

My mum is one that tends to send me everything that she sees, articles and that (Helen)

#### 4.3.3.6 Information and the system

As the previous categories have shown, parents' relationship with information is shaped by a number of factors, but most importantly is the source of the information. The parents in the study mentioned the role of a number of key information sources in their

perceptions of the MMR vaccine scare. These sources had both positive and negative influences on parents.

### Information and the system: HCPs

For some parents the HCP was a positive influence on their decision. This influence took the form of providing information, in both formal and informal forms:

The doctor gave it to her and she has got her own children and she was quite adamant that it was quite important (Susan)

... we went and said that we had our doubts, that my husband had his doubts, they didn't dismiss them, they provided us with further information, to enable us to make the choice (Alison)

The health visitor and the people in the hospital either gave me leaflets or [I] talked about particular issues with the doctor (Carol)

In addition, the GP was a positive influence on parents because of the support that the GP gave the parents:

I think we could have made the decision either way and it wouldn't have affected the relationship (Alison)

The doctor is fantastic; I am really lucky that we have got a good doctor (Mary)

Despite the examples provided above, parents were on the whole critical of HCPs. This criticism appeared to be based upon parents' belief that the information that HCPs supplied was biased (it is worth noting that these comments were from parents who had decided not to vaccinate their child with the MMR vaccine):

All the information that you get from the surgery and from the health visitors is quite biased because they support the MMR (Jean)

... they weren't even willing to discuss an alternative point of view and they just said 'no it is perfectly safe' (Mary)

Parents had a number of suggestions for this biased information that was provided to them:

I just feel like their hands are tied and they can't say anything to you because they are supposed to give the standard line so they can't really tell you what they feel if they've got doubts (Becky)

I think that they should be able to make their own decision and not be paid bonuses for getting an uptake of over 90% (Helen)

Health care professionals do what they are told to. They spew out the standard line and are not free thinking (Naomi)

I find it hard to put a lot of trust in what they say because they go on the government recommendations so you'll ask the health visitor and they'll say that the current medical advice is that the MMR vaccine is safe and that is all that they will say to you (Becky)

### Information and the system: media

Parents appreciated the information that they received from the mass media:

I think that they have got a very important role in exposing those issues (Kate)

I felt that it was great for the initial information (Jean)

However, although the information that parents passively acquired from the media was considered to be useful, when following up information, the media were appreciated less. Some of the parents interviewed had only been aware that there were concerns surrounding the safety of the MMR vaccine since they had had their children vaccinated. As a result they viewed the media coverage as threatening as well as being informative:

It concerns me a little bit more because ... since she has had it there has been a lot more in the news about it (Jane)

Parents expressed generally negative views about the media:

I think that the media disable you (Mike)

I think that it has been all blown out of all proportion, sensationalised. The media has got hold of it and it has been blown up (Rosie)

I don't think that the media have helped an awful lot with the scare. I think that they have inflamed it (Lisa)

I tend to take all media information with a pinch of salt (Sally)

Despite this, parents believed that they were able to select the media information which was useful to them and which they considered to be reliable and reject that which they believed to be unreliable:

I just take it as a background; I don't take it as a consensus view on anything (Becky)

... to be perfectly honest, the scare-mongering in the press, I don't take any notice, or far less than the statistics (Heather)

I will assess the source before I would incorporate any information that I am given into my body of information (Lisa)

I think that I would probably judge it on whether it is sensational or a publicised scientific article (Heather)

The variety of media sources available to parents led to particular sources being considered more highly than others. Television was considered highly by some parents, although sometimes this depended upon the programme they watched. Television was seen as being balanced by parents. This is due to the fact that programmes of this nature often attempt to provide an unbiased view of the issue that they are addressing.

I remember seeing the news. It scared me as I think it was supposed to, but then I watched a couple of programmes which were one hour exposé's and they were a lot more helpful (Lisa)

TV is always good; I thought that debate on Trevor McDonald was really useful (Annie)

I found the Panorama programme quite good because it wasn't biased (Jean)

It depends what programme it is. If it is something like the news then it is ok, but if it is something like Watchdog then I take it with a pinch of salt (Heather)

The visual format of television had an impact on parents:

I know the television source is not great for scientific reporting; yet I seem to be more affected seeing the stuff on the telly (Lisa)

I think when its visual it is more lasting and shocking. (Alison)

However, many parents viewed the television negatively, as the following quotes illustrate:

... you can get information from some news programmes but it is sensational (Carol)

I have watched a few things on the news but not a lot because I tend to think that the little bite size potted things on the main news don't give you the full science (Lisa)

I think that by its nature you are watching a programme that someone else has designed to give you that side (Helen)

In terms of newspapers, parents appreciated their format:

If I really want to start off getting a bit of background, I'd probably get a paper, a good paper and read the newspaper and get a good idea of where to go from there (Becky)

I think newspapers have quite a high influence because with newspapers I will cut the article out, read it and go back again in a couple of days and read it again (Helen)

I can take in the statistics a bit more rather than just hearing them on the TV and not being able to remember them half an hour later (Helen)

However, parents were reluctant to trust newspapers, especially the tabloid press, who were seen as being less balanced than the broadsheets:

I think that the broadsheets would be better in that they would give a more balanced view (Rosie)

The tabloids tend to hype things up a little bit (Jane)

There is a difference between the broadsheets and the tabloids because the tabloids sensationalise the story and seem to lose the truth in it (Alison)

The radio was not mentioned as frequently as other types of media such as television and newspapers, but those parents that did mention it viewed it positively:

I feel that I get a lot of information from the radio. I listen to Radio Four a lot (Carol)

I enjoy Radio Five because it debates the news stories (Alison)

### Information and the system: Government

The parents interviewed for this study had very strong feelings about the Government and politicians. Confidence in the Government was low and this affected parents' reaction to the Government's role in the MMR vaccine scare. This refers directly to the core category of 'Information and the truth' and suggests the role that trust in an information source can play in determining an individual's use of that information source:

I haven't seen any government programme saying this is what we have actually done, which to me means that they have got something to hide if they are not willing to tell everybody what they have done (Helen)

Parents objected to various aspects of the Government's response. The Government were seen as incapable of addressing parents' concerns:

I am very sceptical about what the government say, mainly because they talk about why it is good but I haven't heard any of them talk in depth about the sincerely held concerns that these people really do believe that their children have been harmed by it (Carol)

The main issue of concern for parents was that the Government were seen to be supporting the MMR vaccine on the grounds of cost:

I think that it is because it is cheaper and you only have to give it to individuals once (Kate)

Because it saves them money. They are just economic reasons and are related to drugs companies (Naomi)

I think because in the long run it costs them less money (Mary)

I always think that there's an agenda behind what's said and there are cost implications to what they say (Becky)

Interestingly, two parents were sympathetic to the fact that the Government had to consider the financial implications of offering single vaccines:

... if MMR is cheaper than I can see their point. I can see why they have to, with the NHS being in such a state (Jean)

You can't blame the government at all for trying a vaccine that they generally think is fine and is cheaper than doing singly (Alison)

Some parents thought that the Government's support of the MMR vaccine was not influenced by negative factors:

One assumes that it is because the doctors advising the Department of Health say that it is an ok thing and because you can give it in one shot so there is no danger of not finishing the course (Carol)

I think also that they are going on with what they have been told to say by the BMA and the medics (Alison)

Parents did not view the Government as being sufficiently in depth in their opinions about the MMR vaccine and the research that had been undertaken on the MMR vaccine:

... you only hear sound bytes, I haven't heard any politician talk in depth or at length about it (Carol)

... the government just say we have found no link and doesn't go into detail about the experiments that they have carried out (Helen)

I think that the problem is where you tend to see them on television you only get thirty seconds, a minute to talk about it ... if I listened to them talking for half an hour then I might have a little bit more belief in what they say (Heather)

One reason for the scepticism shown by parents towards the Government can be attributed to the Government's handling of the BSE issue and other health issues of concern to the public:

It been similar for things like BSE, they've said a particular thing and you know over a five to ten year period its come out that there are problems and perhaps their advice hasn't been the best thing so that's made me sceptical (Becky)

... you would have though that mad cow disease , railway disasters would teach us better (Mike)

The parallel drawn by parents between the scare surrounding the safety of the MMR vaccine and that surrounding the safety of beef highlights issues that may be of real importance to parents. In these cases, the belief that the Government were perceived as hiding the truth from the public was a major factor in distrust of the Government. Once initial damage had been done to the reputation of the Government, they could not be trusted again to be truthful about health issues.

The refusal of the Prime Minister, Tony Blair to reveal whether his son, Leo had been vaccinated with the MMR was an issue of concern for some parents:

I think that Tony Blair should have come out and said whether or not his little boy had had the jab. I think that it is important because what the public needed was a show of confidence (Rosie)

... people really do need to know, if he is telling us that it is safe, he means that it is safe for his children as well (Alison)

If he is going to stand up there and say that 'this is what I think' then I think that he should back it up with proper evidence and he should say yes or no (Mary)

As these quotes illustrate, the reason that parents wanted Tony Blair to disclose whether Leo had been vaccinated was because of their need to be reassured. However, other parents were not concerned about the vaccination status of Leo Blair:

I thought that it was a bit ridiculous to be honest; I mean you are hardly likely to decide whether your child has it depending upon whether the Prime Ministers' child had it (Jane)

With Blair I am very pleased that I don't know whether his children have had MMR or not because I think that, I don't want to (Lisa)

... his son is not the Prime Minister and therefore his choice about what he does with his son shouldn't be public knowledge (Alison)

Overall, parents did think the Government had an important role to play but could not always fulfil this role:

I think they could potentially have quite a lot of influence but I don't think that they do (Helen)

... annoyed as they aren't doing more research. They aren't willing to replicate the research that Dr Wakefield did (Naomi)

Parents were keen for the Government to be seen to make a positive stand to reassure parents:

I think the government have a real responsibility to address the problem as well, rather than trying to sweep it under the carpet (Annie)

I am pleased that the government has stood by it and said 'this is our decision and we are not influenced by the media (Lisa)

One parent summed up the overall view that parents had about the role of the Government in the MMR vaccine scare:

I think that confidence will have to be restored in the government, not in the vaccine; parents should be able to trust (Jean)

This comment illustrates the problem at the crux of information, and the core category of 'Information and the truth'. If parents are to trust information that they receive, there are two key factors in this, belief that the information is correct and trust in the source that is providing the information. As this section has shown, trust in key sources is lacking, and this has led to detrimental effects on information provision to parents.

#### **4.3.4 Validity**

Of the 17 participants in the study, nine returned the evaluation sheet distributed to them, giving a response rate of 53%. All nine of the respondents thought that the results contained elements of the interview that they had participated in and that the results were an accurate representation of the interview. Of these nine, five provided written comments on the results of the study. These tended to focus on parents' views about the issue of the MMR vaccine, rather than on the summary of the results of the interview study. One parent commented that they enjoyed participating in the study.

Participants' comments regarding the summary of the results are as follows:

... it makes for interesting reading, notably that parents felt influenced by the BSE scare.

This issue seems to have fallen off the agenda at the moment. However, I don't feel that any attempt to provide more and better information has or is being made. I hope your research will help to change this.

However, one parent felt that their GPs offer to provide them with research papers about the MMR vaccine should have been mentioned. During the interview this parent mentioned that this was a major influence on their decision to proceed with the MMR vaccine, however while the role of this GP in providing information to this parent was mentioned in the results of the study, it was not mentioned in the summary, as this comment was specific to this parent:



*No reference to helpful information provided by GP – which informed our decision. Perhaps could be less general...*

## 4.4 Discussion

This section relates the findings of the interview study to literature previously reviewed.

The finding that becoming a parent increased information needs was also found in the studies by Nicholas & Marden (1998) and Kai (1996a and 1996b) who looked at parents' general information needs and Pain (1999) and Huws et al. (2001) who looked at parents' information needs in a specific context. Information sources for parents with reference to general health tended to be professional sources and prior experience. This finding was consistent with that of Nicholas & Marden (1998) who found that: "*health visitors were the most important source of professional information on children's health*" (p.44).

This qualitative evidence is in line with the quantitative evidence of Huntingdon et al. (2002) who found that 79% of respondents to a national health survey (n=273) quoted oral sources, such as HCPs as their most important source of health information.

Parents varied in the extent to which they were influenced by the information during the health scare that surrounded the MMR vaccine. An overall distrust of authority, as represented by HCP's, scientists and the Government was traced back to previous health scares, particularly surrounding BSE. However, some information sources were seen as being fundamentally flawed. Parents placed an emphasis on gaining information that was trustworthy and honest. They prioritised this above any particular source or format. Written information was, however, popular with parents in this study. This is in contrast to Nicholas & Marden (1998), who found that parents were unwilling to use written sources. Finlay & Lunts (2000) also found that, when testing the readability of health information, books were inaccessible to a large number of parents because of the high reading level required to understand them. This discrepancy may be due to socio-economic class of the parents in the study. It is possible that socio-economic class is related to educational attainment and therefore to how parents use information and their preferred information sources. However, Pyke-Grimm et al. (1999) found that in a

group of parents of children with cancer, socio-demographic variables, such as socio-economic class, were not predictors of information needs.

In terms of information sources, parents found that most of the available information sources did have the potential to supply them with the information that they wanted, but that parents had to be selective about the extent to which they trusted the source and the extent to which it was useful for them. This view of leaflets/pamphlets as being an insufficient information source was also discovered in a study of VIPs (Clayton et al. 1994) who also found that parents used pamphlets as an additional source to the HCP, who was the main information provider. Sporton & Francis (2001) found that parents believed that leaflets supplied by the Health Education Authority exaggerated the efficacy of vaccines. The lack of impact of leaflets on parents was confirmed by a study by Mason & Donnelly (2000b) who found that sending a Government produced leaflet to parents in an attempt to improve uptake actually had no impact on the parents, and uptake was similar in a control group who had not received the leaflet. Evans et al. (2001) also found that parents thought leaflets were an inadequate source of information about the MMR vaccine. This may be specific to the case of the MMR vaccine, as Clayton et al. (1994) found that VIPs had a beneficial impact on parents, leading them to express pro-immunisation views. This may indicate the impact that a vaccine scare has on people's perception of information sources.

It is important that HCPs are consistent in the information that they supply, as numerous studies have found that GP knowledge and information provision are important factors in vaccine uptake (Hatton 1990, Hull 1987 and McGuire 1997). It is also important that HCP's maintain a support role with parents and encourage them to give their children the MMR vaccine. Duffell (2001) found that confidence in vaccines and uptake of vaccines were positively associated. The media were an important source for parents. Pareek and Pattison (2000) found the media to be the main source for mothers about the MMR vaccine. However, the information gained from the media tended to be about the alleged side effects of the MMR vaccine, not factual information about the MMR vaccine.

Evans et al. (2001) found similar views in the parents surveyed for their study. The media were viewed as being sensationalised and either very pro or very anti the MMR vaccine. The lack of a balanced argument about the MMR vaccine often led to

scepticism about the source. This lack of a balanced argument has been found in numerous studies, most notably Alaszewski & Horlick-Jones (2002) who argue that the media are more likely to amplify risk (by removing balance from the argument) where there is a low probability of the risk occurring, but serious side effects if it does. In contrast, Clements & Ratzan (2003) argued that presenting the arguments surrounding the safety of the MMR vaccine in a balanced way was actually a misrepresentation of the truth as it suggested that there was a balance of medical opinion that the MMR vaccine was safe and unsafe, whereas in reality, the weight of evidence was that the MMR vaccine was safe (Clements & Ratzan 2003).

In terms of decision-making about the MMR vaccine, personal experience and information were important factors in parental perceptions of risk, which in turn influenced their choice about whether to have the MMR vaccine. Measles was seen as being a serious disease, but mumps and rubella were not seen to be as much of a threat to children. Arguably this judgement that the conditions of measles, mumps and rubella are low risk can be attributed to the success of the MMR vaccine. As a result of high vaccination rates and consequently low incidence of the conditions, the vaccine becomes a greater perceived threat to the children than the diseases: "*Individual parents may fail to see its (the vaccine) current relevance for the children in that the parents do not perceive the children to be at risk*" (Poland & Jacobson, 2000, p.136). In addition, Evans et al. (2001) found that once parents had made the decision to vaccinate their children, the perceived risk of the diseases diminished. Therefore this may suggest that as perceived risk diminishes so does parents' need for information. This is an issue that would merit further examination.

Parents viewed the risk from diseases in relative terms. In contrast, parents who viewed the vaccine as being a risk expressed it in absolute terms. This may be due to the finding that risk is not communicated effectively to them, either by the mass media or by HCPs (Dittman 2001).

With falling MMR vaccine rates and a Government-established target of 95% vaccination, the Government have a responsibility to increase the vaccination rates of the MMR vaccine. It is interesting to note that at least two of the non-immunisers claimed that if they could access information about a credible study, which showed that there was no link between the MMR vaccine and autism/bowel conditions, then they

may reconsider their decision. This may, however be a reflection on the parents that took part in the study and not be the case with the general population.

The extent to which information influences parents appears not to be related to the immunisation status of their children, but to whether they had made a decision or not. Both immunisers and non-immunisers admitted avoiding information once they had made a decision about whether to proceed with the MMR vaccine.

There are a multitude of factors in the literature that predict uptake of vaccination in addition to information including maternal characteristics, views about the diseases of measles, mumps and rubella, professional inertia, HCPs knowledge, views about vaccination on the whole and interest in alternative health (McGuire, 1997, Bond et al., 1998, Carter, 1985, Harrington et al., 2000, Hull, 1987, New & Senior, 1991 and Strobino et al., 1996). However, this research was carried out on parents when they were not faced with the confusion of the MMR vaccine scare, and the unusual situation that parents faced, arguably increased the extent to which parents used information. Allison et al. (1997) differentiated between sources of information that are used in everyday situations and sources of information that are used in urgent situations and found that the mass media were relied on much more in the urgent situations, arguably because the information that people require needs to be timely and in response to a specific event (e.g. measles outbreaks).

## 4.5 Limitations and considerations

The majority of participants that took part in the interview study demonstrated prior knowledge about the research surrounding the MMR vaccine. Some of the participants interviewed supported the MMR vaccine on the basis that the research carried out by Wakefield et al. (1998) was flawed. This high level of understanding about the issue of the MMR vaccine and the MMR vaccine scare may have influenced the results collected. It is important to understand the reasons for this high level of understanding and whether it can be related to use of information. It could be argued that this understanding can be related to the (high) socio-economic class of the participants in this study. It may also have been related to the currency of the issue and the reporting in the mass media. However, the results from the interview study must be interpreted with caution, as they may not be representative of the population.

In addition to the high levels of understanding, in this study, the group of participants interviewed initially appeared relatively homogeneous. All but one of the participants was female and all but one of the participants was white. This inevitably introduces a bias into the data collected. The majority of the participants lived in relatively affluent areas of Sheffield (S10 and S11). However, this does not necessarily indicate homogeneity and the experience of the researcher was that the participants were diverse in terms of their affluence. While demographic data was not collected on factors such as home ownership, some of the participants made it known that they were renting their accommodation due to financial constraints. While information such as this cannot be used to categorise the participants, it can be used to develop a picture of the sample which indicates that the homogeneity in terms of gender and race was not extended to other characteristics of the sample and information about their situation that was not collected from participants revealed that the sample was more diverse than it initially appears.

Another factor that may influence the results was the response rate to the recruitment. The overall response rates for the study were low (nursery schools 6.3% and toddler groups 21.3%). This may suggest that the parents who volunteered to participate in the study were those who felt very strongly about the MMR vaccine, or those who were interested in the issue. This also may have introduced bias into the results, but the use of triangulation in the overall study should allow an understanding of whether the views expressed by the participants in this study are reflected in a wider sample.

It is also important to be aware of the researchers' influence on the participants and the data collection (Silverman, 1993). It is impossible for the researcher to be totally separated from the participant when interviewing them. Indeed it is undesirable that there is no rapport between the researcher and the participant. However, it is important for the researcher to remain neutral. In the case of this study, participants frequently asked for the opinion of the researcher about whether the MMR vaccine was safe. It was important to ensure that the participants did not feel ignored, whilst ensuring that any comments made by the researcher did not adversely influence the participants. When questioned, the researcher suggested that parents ask their HCP and other sources of information that they trusted for information and advice about the MMR vaccine. A strong rapport was built up between the participants and the researcher in a number of

cases. Indeed one of the participants recruited through the nursery schools suggested a toddler group for the researcher to attend in order to recruit participants. This strong rapport was beneficial in encouraging the participants to be open in their views and created an enjoyable atmosphere for the interview. As discussed in section 4.2.5, a reflexive attitude was taken to the interviews, with frequent interruptions being an unavoidable aspect of interviewing while children were present. While these interruptions were not always a problem, and contributed to a relaxed atmosphere, parents often forgot what they were saying or had a point to make, when they were interrupted.

## 4.6 Conclusions

### 4.6.1 Findings

This exploratory study yielded extensive results in an area where little previous research had been undertaken. The analytic method adopted allowed the interview transcripts to be coded, analysed and reported in a systematic matter. These findings were then compared with previous literature, from both before, during and after the study was carried out.

Parents were shown to have highly individualistic information needs and varied in the extent to which they were influenced by the media during the health scare that surrounded the MMR vaccine. An overall distrust of authority, as represented by HCPs, scientists and the Government was traced back to previous health scares, particularly the BSE scare. Parents placed an emphasis on gaining information that was trustworthy and honest. They prioritised this above any particular source or format. This can be seen by the finding that Department of Health leaflets about general health issues were rated highly by parents, but leaflets on the MMR vaccine were thought to be inadequate and inaccurate.

In terms of decision-making about the MMR vaccine, personal experience and information were important factors in parental perceptions of risk, which in turn influenced their choice about whether to have the MMR vaccine. Measles was seen as being a serious disease, but mumps and rubella were not seen to be as much of a threat to children. Parents viewed the risk from diseases in relative terms. In contrast, parents

who viewed the vaccine as being a risk expressed it in absolute terms. This may be due to the finding that risk is not communicated effectively to them, either by the mass media or by HCPs (Dittman 2001).

With falling MMR vaccine rates and a Government-established target of 95% vaccination, the Government have a responsibility to increase the vaccination rates of the MMR vaccine. It is interesting to note that at least two of the non-immunisers claimed that if they could access information about a credible study, which showed that there was no link between the MMR vaccine and autism/bowel conditions, then they may reconsider their decision. This may, however be a reflection on the parents that took part in the study and not be the case with the general population.

The extent to which information influences parents appears not to be related to the immunisation status of their children. Both immunisers and non-immunisers admitted avoiding information once they had made a decision about whether to proceed with the MMR vaccine.

The study achieved its aims. Parents' information needs and information seeking behaviour in the context of general information, health information and MMR vaccine information were examined. Their preferred information sources were also looked at. Information in the context of decision-making was also looked at, by looking at the impact of different information sources and formats on parents' decision to immunise.

Individual parents had different needs in different situations, and the response of parents, in information terms and in general terms could not be generalised because the study did not use a sufficiently large, representative sample. Parents had unique methods for accessing information and using it to make decisions.

#### **4.6.2 Future research**

The next phase of the research will be a questionnaire study of parents. The reasons for this are two-fold, to test the results of the interview study and to undertake research with a larger sample of parents. While the interview study uncovered a number of interesting issues, these were only highlighted and it would be useful to explore these on a larger scale.

Future work will also concentrate on generating additional data to triangulate, both for confirmation and completeness. The implications of researching with a homogeneous sample from a high socio-economic class will be examined by researching with a wider, more socio-economically diverse sample.

Results from the interview study that are worthy of further explanation are as follows. Firstly, the key issue of how risk informed parents' decision-making. The MMR vaccine scare appeared to influence parents' perceptions of the risks of the MMR vaccine and contrast these with the risks of the diseases of measles, mumps and rubella. Therefore, it would be interesting in future work to look at the balance that parents make between the benefits of the MMR vaccine (in preventing against measles, mumps and rubella) and the risks of the MMR vaccine (in causing the alleged side effects proposed by Wakefield et al, 1998). The interview study also suggested that parents' relationship with information is based on not only how useful an information source is in meeting parents information needs, but also how trustworthy that source is perceived to be. Therefore it was decided that these two issues would form the basis of the questionnaire and, if possible, be tested against a validated tool to measure these factors. In addition, it would be interesting to examine whether parents use information differently when they passively receive it, as compared to when they actively seek it. The role of information in decision making is also worthy of further consideration, in terms of whether information is considered a determining factor in decision making.

The emergent research questions, as outlined below, that have been generated from the interview study will be operationalised and used in additional research.

- Is there any difference between parents who have decided not to get their children vaccinated with the MMR vaccine and those who have in terms of their information behaviour?
- What extra information do parents want about the MMR vaccine, over and above what they have acquired or have been given?
- Which sources of information do parents trust and which sources do parents think are biased and which do they think are neutral?



- Is there a relationship between parents' attitudes and opinions about the conditions of measles, mumps and rubella and whether they have/intend to vaccinate their children?
- Is there a relationship between perceived risks of the MMR vaccine and need for information (i.e. does the need for information diminish as perceived risk of the conditions of measles, mumps and rubella diminishes)?
- What impact did information have on the decision to vaccinate? What other factors were involved in the decision-making process?

These questions will be addressed in Chapters Five and Six, which describe the questionnaire study and the subsequent triangulation of results from both studies.

# Chapter Five - Questionnaire Study

## 5.1 Introduction

The interview study, which formed the exploratory section of the PhD research (detailed in Chapter Four), generated rich results. Some of the parents interviewed were heavily influenced by previous health scares, which generated distrust of official information sources. This manifested itself in parents' unwillingness to trust information from HCPs and the Government. Although parents used the media for information, they also felt this information was untrustworthy but that they were able to judge better whether the information they received was accurate. In terms of parents' views about the conditions of measles, mumps and rubella, views on the risks from the conditions were relative (i.e., compared with other situations, such as crossing the road) whereas the MMR vaccine itself was viewed as being a risk in absolute terms. The results from the interview study suggested that MMR vaccination status of their children was not related to how the parents used information. Instead the parents had unique, individual ways of accessing information.

However, as the interview study was qualitative and had a small sample size, the findings could not be generalised to the population. Therefore, the next stage in the PhD was to see whether the findings of the interview study were generalisable through using a questionnaire with a larger, random sample (the inclusion criterion being that parents needed to have either recently made the decision about MMR vaccination or be currently making the decision about MMR vaccination) and to explore further some of the key findings from the interview study using statistical methods.

Incorporating the findings of the literature review with those of the interview study, it was decided to utilise a quantitative methodology to look at the role of demographic and socio demographic characteristics of parents/children in parents' decision-making about the MMR vaccine, the role of the HBM in decision making and information and the role of information in decision-making. This can be expressed in the form of the following research question:

- Which demographic, HBM and information factors predict uptake of the MMR vaccine and how are these factors related to the MMR vaccine score?

The main research question can be broken down into the following subsidiary research questions:

Demographic factors:

- Is there any relationship between the MMR vaccination status of children and demographic variables relating to their parents or their family?

HBM factors

- What role does the HBM have in parental decision-making about the MMR vaccine?
- Is there a relationship between parents' attitudes and opinions about the conditions of measles, mumps and rubella and whether they have/or intend to vaccinate their children?
- Is there a relationship between perceived risks of the MMR vaccine and need for information (i.e., is there a lesser need for information associated with a lower perceived risk of the conditions of measles, mumps and rubella)?

Information factors

- What are the information needs of parents relating to the MMR vaccine and the information needs generated by the MMR vaccine score?
- What information were parents given about the MMR vaccine and what extra information do parents want about the MMR vaccine, over and above what is given to them?
- Which information sources do parents use the most, which do they trust and what are the sources that parents would like to use?
- Which sources of information do parents trust and which sources do parents think are biased and which do they think are neutral?
- Is there an association between the information that parents received and the information that they sought?
- Is there an association between the source and content of information about the MMR vaccine?

- What impact did information have on the decision to vaccinate? What other factors were involved in the decision-making process?

The questionnaire study chapter is structured as follows. Section 5.1 introduces the study background and aims. Section 5.2 details the study methods, including ethical approval, research governance and study indemnity. Section 5.3 details the methods and results of the pilot study and the consequent alterations to the study materials. . Section 5.4 presents the results of the study, in sections addressing demographic characteristics of the study participants and their children, the HBM and information factors and their role in the decision about MMR vaccine. Section 5.5 presents the qualitative data collected in the questionnaire study. Section 5.6 discusses the validity and limitations of the study and the data collection instruments and Section 5.7 summarises and concludes the findings of the study.

## 5.2 Methods

### 5.2.1 Study design

The questionnaire study was designed to elicit quantitative factual data and structured opinions from the parents of young children. This section details the methods that were adopted in designing the questionnaire, the process of gaining approval to carry out the study, the sampling and recruitment strategy, the materials that were used in the study and the analysis and presentation of the data collected.

### 5.2.2 Questionnaire design

The questionnaire was designed with three issues in mind: good questionnaire design (Bowling 1997), the main and subsidiary research questions and the need to design questions that would allow meaningful data to be collected and analysed. When designing the questionnaire, principles of good questionnaire design were considered. The questionnaire was designed so that the questions were valid in terms of measuring what they intended to measure. It was also essential that the questionnaire was legible. Guidelines from the National Literacy Trust were followed (National Literacy Trust, 2004). A Sans Serif font, with a minimum font size 12 was used to ensure legibility. The Flesch Reading Ease Score for the questionnaire was 74.6, which is classified as

“fairly easy” (maximum score is 100, and the higher the score, the more readable the document). The questionnaire consisted of three double-sided pages and one single sided page comprising a variety of open and closed questions. A copy of the questionnaire can be found in appendix 2.8. The research questions that were operationalised in the design of this questionnaire are presented in section 5.1.3. The questionnaire was designed in spring 2003 and underwent a number of revisions as a result of comments from individuals, the Local Research Ethics Committee (LREC), the research governance committee and as a result of the pilot study (section 5.3).

### **5.2.3 Questionnaire design**

In terms of demographic characteristics, the questionnaire asked about parents’ age, gender, ethnic background and occupational status. This allowed a demographic profile of the participants to be developed. Information about the children of the participants was collected on their age, gender, MMR vaccine status, the size of the family and which (if they had more than one child) they had to make the decision about the MMR vaccine for most recently.

The health belief model incorporates the constructs of susceptibility, severity, benefits and barriers. The questions relating to susceptibility asked parents to rate the likelihood of their child catching the diseases of measles, mumps and rubella. These questions were designed to assess the likelihood of MMR vaccination in terms of whether parents thought their children were susceptible to these diseases. In addition to susceptibility, the HBM also suggests that perceptions of the severity of the diseases will predict the likelihood of MMR vaccination and therefore parents were asked whether they believed the diseases of measles, mumps and rubella would be serious for their child. The HBM hypothesises that if parents believe that their child is susceptible to measles, mumps and rubella and that the disease has serious implications for their child then they will proceed with MMR vaccination. In addition to susceptibility and severity, which relate to the conditions of measles, mumps and rubella, the benefits construct also examines the likelihood of MMR vaccination, but relates to the MMR vaccine itself. In the questionnaire, the questions that related to the benefits construct asked parents whether they believed that it was important that their child was protected against measles, mumps and rubella. It also asked whether they believed that it was likely that the

MMR vaccine would protect their child and whether MMR vaccine was important because it conferred herd immunity on other people. However, the likelihood does not depend just upon the factors that motivate parents to proceed with MMR vaccination, but also the factors that may provide a barrier to it. The questions that related to barriers to MMR vaccination asked whether parents would choose single vaccines as an alternative to the MMR vaccine, whether parents believed that the MMR vaccine would be a risk to the health of their child and whether parents believed that there were alternative ways to protect their child against the diseases of measles, mumps and rubella. All of these questions originated from parents' comments in the interview study about the MMR vaccine. Parents were also asked about their cues to action to MMR vaccination. This question was related to the HBM but also introduced the concept of information into the questionnaire.

In terms of information, parents were asked whether they received information at the time of this decision and the source and contents of this information. They were also asked whether they sought any additional information about the MMR vaccine and the source and contents of the information. They were asked whether they were able to make an informed choice and, if they were not able to make an informed choice, the reasons for this. They were also asked to rank key information sources (as identified by parents in the interview study) in terms of their usefulness and trustworthiness, as these were issues that emerged relating to parents' use of information sources in the interview study. Finally, parents were questioned about the role of the MMR vaccine scare and information relating to the MMR vaccine scare in their decision-making.

#### **5.2.4 Ethical approval**

NHS LREC approval was required for this research. Any research within the NHS (that involves patients of the NHS, their staff or their premises) requires ethical approval from an ethics committee local to the research. This study required approval as NHS staff assisted with the recruitment of parents whose children were registered as NHS patients. An application was made to the South Sheffield Research Ethics Committee (SSREC). A system of reciprocal approval exists between the two committees in Sheffield, so reciprocal approval was granted by the North Sheffield Research Ethics Committee (NSREC) once SSREC approval had been granted. The application for ethical approval consisted of submitting an application form, a study protocol, the

documentation used in the study, evidence of departmental peer review and curriculum vitae. Reciprocal approval was granted based on a review of the documents submitted to SSREC and the approval granted by SSREC. The first application to the SSREC was made in June 2003 and the study was not granted approval. The second application was made in October 2003 and approval was granted subject to a number of minor revisions made to the protocol, which related to ensuring response rate was maximised. The approval letters can be found in appendix 2.1 (SSREC) and 2.2 (NSREC).

#### **5.2.5 Research governance approval**

Research governance approval ensures that research which is undertaken within the NHS adheres to specific ethical and scientific standards and aims to protect the people involved in research as subjects while also increasing public confidence in medical and health related research. The research governance process involved applying to the research department of the Sheffield Children's NHS Trust. The application procedure consisted of submitting an application form, a study protocol and evidence of approval by the SSREC. Approval was granted in November 2003 (appendix 2.3).

#### **5.2.6 Study indemnity**

The questionnaire study also required indemnity from the University of Sheffield. This is to ensure that the research and the researcher are insured against any problems that may occur. A Certificate of Insurance for a Non Clinical Trial was issued in June 2003 (appendix 2.4)

#### **5.2.7 Sampling**

The population for this study was all parents in the UK with at least one child between the ages of one and two years. The sampling frame limited the potential study participants to those who fulfil the above characteristics and whose child was registered on the Sheffield Child Health Computer System. (CHCS) The CHCS is a record of all children who have received health services in Sheffield. The CHCS was introduced in 1984 and the number of children on the CHCS is 130,000. Children born in Sheffield (approximately 6,500 per year) are entered onto the CHCS. Children who move to the area are entered onto the system when they are registered with a GP. Children who have

links with Sheffield (such as living outside Sheffield but having a GP within Sheffield) are also on the system. All the above groups were included in the sampling frame. Children who have received health services in Sheffield, e.g., whilst on holiday, are also included on the system but were not included in the sampling frame for the study.

In order to gain information on the MMR vaccination status of children in the sample, the inclusion criteria were narrowed to children aged 15-24 months. This differed to the original plan of the study in which the inclusion criteria were that children were aged 13-24 months. This change was made on the recommendation of the administrator of the CHCS and was to ensure that parents had recently made a decision about the MMR vaccine and that this decision had been entered on the CHCS. The birth dates of these children (16<sup>th</sup> January 2002-16<sup>th</sup> October 2002) were used as a query to search the CHCS and a sampling frame was generated, which numbered 4079 children.

When determining the size of the sample, three elements were considered; effect size,  $\alpha$  (alpha) and  $\beta$  (beta). As Cohen (1992) outlined, the effect size measures the size of the effect,  $\alpha$  measures the probability of committing a Type I error (i.e. incorrectly rejecting a true null hypothesis) and  $\beta$  measures the probability of committing a Type II error (i.e., incorrectly accepting a false null hypothesis). It was determined that a sample size of 147 would be required in order to detect a medium effect size, with  $\alpha = 5\%$  and  $\beta = 80\%$  (Cohen, 1992). If 147 responses were required to achieve this level of statistical power, then it was estimated that questionnaires would have to be distributed to 400 parents (assuming an estimated minimum response rate of 35%).

From the CHCS, a sample of 400 parents was generated and invited by a letter from Dr Janet Chaplais, District Immunisation Co-ordinator to take part in the study. Dr Chaplais wrote the letter to parents, as direct contact by the researcher was not permitted under the Data Protection Act of 1998. The administrator of the CHCS and the researcher undertook the sampling for the study. The CHCS was unable to generate a random list of children within the sampling frame. Instead, an alphabetical list of all children who fulfilled the sample criteria was generated, and every 10<sup>th</sup> child was selected for the sample. Therefore the sample for this study was a systematic, random sample. The sample was random in that any parent on the database who fulfilled the population characteristics had the same chance of being selected before the sampling started. The sample was systematic in the sense that the sampling frame was ordered



systematically, i.e., alphabetically. The starting point of the sampling determines the rest of the sample to be selected. In this case, the list of all children was printed out, and a random page was selected upon which to start the sampling.

### **5.2.8 Materials**

The data collection instrument of the study was the questionnaire. This was sent to parents along with a letter, written and signed by the District Immunisation Coordinator, asking them if they would be prepared to participate (appendix 2.5). Also included with the questionnaire and the letter was an information sheet (appendix 2.6) and a consent form (appendix 2.7). Parents were supplied with all of this in an envelope, which was posted to them and also contained a stamped addressed envelope to return the questionnaire and consent form.

### **5.2.9 Data analysis**

This section outlines the analyses that were carried out on the data collected from the questionnaire. The coding of the data is described and then the analyses undertaken on the data are described.

#### **5.2.9.1 Coding**

Once the questionnaire had been returned from participants, the data were coded and entered into SPSS 11.5.

In terms of the demographic characteristics, the socio-economic status of the participants was determined according to National Statistics – Socio Economic Class (NS-SEC) (Office for National Statistics, 2000). When there were two parents, both working full time, the occupation of the participant completing the questionnaire was used. Where only one parent was working (either full time or part time), their occupation was used. Participants were also given the option to describe themselves as being long-term unemployed.

### 5.2.9.2 Statistical analysis

Once data had been entered into SPSS 11.5, a variety of tests were carried out. A variety of descriptive (univariate) analyses and analytical (bivariate) tests were carried out. Basic frequency analyses of relevant variables were undertaken to provide descriptive statistics and  $\chi^2$  tests were carried out to test for the null hypothesis that there was no association between the variables. A number of additional tests were carried out when appropriate.

### 5.2.9.3 HBM analysis

A variety of tests were undertaken on the HBM data. The key aim of the HBM was to see whether HBM scores regarding susceptibility, severity, benefits and barriers were predictive of MMR vaccination. The likelihood of MMR vaccination occurring depended upon four constructs: susceptibility, severity, benefits and barriers. The likelihood of action was calculated using the following procedure. The question numbers related to the revised questionnaire in the appendix.

- Responses to questions D4 and D8 were reversed so that they represented barriers.
- Questions C1, C2, C3, C5, C6, C7, D1, D2, D3, D4, D5 and D8 were coded so that strongly agree = 1, agree = 2, disagree = 3 and strongly disagree = 4.
- Subscales were developed for susceptibility (C1, C2, C3) severity (C5, C6, C7) benefits (D1, D2, D3) and barriers (D4, D5, D8).
- The individual scores for susceptibility, severity, benefits and barriers were totalled (range 3-12 for each construct).
- The final HBM score was created by adding up the susceptibility, severity and benefits scores and subtracting the barriers score from that total.

### 5.2.9.4 Analysis of qualitative data

Written comments were initially entered into Microsoft WORD. The comments were printed out and read and these comments were used to develop codes. These codes were then developed into categories and these are presented in the results section.

## 5.3 Pilot Study

### 5.3.1 Aims

It is important when designing a questionnaire to pilot it (Bowling, 1997). This involves recruiting participants to complete the questionnaire and then comment on it, in terms of the ease of completion of the questionnaire and any difficulties they may have had in completing it. Piloting the questionnaire helps to ensure that the questionnaire is easy to understand, that the questions are answerable and that it is possible to carry out meaningful analyses on the data collected. Piloting also checks for systematic errors or questions that are repeatedly missed or answered incorrectly, which can be a result of not including appropriate responses (Bowling, 1997). It was important in this questionnaire study to ensure that the reading age was not too high for the sample and also that the questionnaire was comprehensible for speakers of other languages.

### 5.3.2 Methods

The pilot study aimed to recruit approximately 10 parents of young children, via nursery schools in Sheffield. The sample in the pilot study aimed to reflect the potential characteristics of the participants in the questionnaire study by being stratified according to the level of deprivation of the area in which the nursery was located. Three different areas were selected according to their level of deprivation and the leaders of three nursery schools in the selected areas were contacted and invited to participate (letter can be found in appendix 2.9). The nursery schools were contacted by letter and asked if they would be prepared to assist in the pilot study by distributing letters to parents (with at least one child between the ages of one and two) who have children attending their nursery school. If the nursery schools agreed to assist they were sent 10 envelopes and asked to distribute them to parents who met the above inclusion criteria. The envelopes contained a letter to parents (appendix 2.10), an information sheet (appendix 2.6), a copy of the questionnaire (appendix 2.8) and a pilot study comments sheet (appendix 2.11). The envelope also contained a stamped addressed envelope to return the questionnaire and comments sheet to the researcher. The pilot study aimed for a response rate of at least 30%, in order to generate 10 parents.

### 5.3.3 Sampling

In order to gain a sample of parents from different backgrounds, sampling took account of the geographical spread of deprivation in the city of Sheffield. Therefore a sampling strategy based on geographical areas and their associated levels of deprivation was adopted. The most appropriate method through which to do this was using the Townsend Score (a measure of deprivation which is based upon census data), which is available for the electoral wards in Sheffield. The wards were ranked in order of decreasing deprivation. Three electoral wards were selected from the list of 29 (one from the most deprived tertile, one from the middle deprived tertile and one from the least deprived tertile).

The 29 electoral wards in Sheffield, in order of deprivation (with the most deprived ward first) are shown in Table 5.1. The wards that were selected for the pilot study were Sharrow, Heeley and Dore.

Table 5.1 - Pilot study - Electoral wards in Sheffield in order of decreasing deprivation arranged in tertiles

Tertile 1 (most deprived)	Tertile 2	Tertile 3 (least deprived)
1. Manor	11. Darnall	21. Hillsborough
2. Park	12. Owlerton	22. Stocksbridge
3. Southey Green	13. Handsworth	23. Broomhill
4. Castle	14. Brightside	24. Chapel Green
<b>5. Sharrow</b>	<b>15. Heeley</b>	<b>25. Dore</b>
6. Burngreave	16. Birley	26. South Wortley
7. Firth Park	17. Intake	27. Beauchief
8. Netherthorpe	18. Nether Edge	28. Hallam
9. Nethershire	19. Walkley	29. Ecclesall
10. Norton	20. Mosborough	

### 5.3.4 Results

The pilot study was carried out in November and December 2003. The nursery schools that were contacted have been anonymised. Firstly, a summary of the data gathered

from the questionnaires is presented and, secondly, the data from the pilot study comments sheet are presented.

#### 5.3.4.1 Questionnaire

##### Response rate

Of the four nursery schools that were contacted, two agreed to participate giving a nursery school response rate of 50%. Twenty questionnaires were distributed to parents and six were returned, giving a response rate of 30%.

In the case of the two nursery schools in Sharrow, nursery leaders did not respond to the written approach from the researcher and when contacted via telephone by the researcher reported that they were unable to assist. The response rate for each nursery school is shown in Table 5.2. It was unclear which of the nursery schools the questionnaires were returned from as an identifier was omitted from the questionnaire.

Table 5.2 - Pilot study – Response rate

Nursery School	Questionnaires distributed n	Questionnaires returned n	Response rate %
1. Sharrow	Unable to assist		
2. Sharrow	Unable to assist		
3. Heeley	10	6	30
4. Dore	10		

##### Demographic results

Six parents participated in the pilot study. The demographic characteristics of the six participants are shown in Table 5.3. It can be seen from Table 5.3 that half of the respondents were aged 26-35 years old and nearly all (n=5) were female.

Table 5.3 - Pilot study - Participants by age and gender

Age	Gender		Total (n)
	Female (n)	Male (n)	
26-35	3	0	3
36-45	2	1	3
Total	5	1	6

The NS-SEC of the six participants was as follows. Half of the participants (n=3) were in the highest socio economic class (modern professional occupations) and all of the participants occupied the highest four (of eight) socio economic classes (clerical and intermediate occupations n=1, senior managers and administrators n=1 and semi-routine manual and service occupations n=1).

The six participants in the pilot study had 15 children. The mean age of all children of the pilot study participants was 3 years and 9 months. The median age was 4 years. Nine (60%) of the children were female and six (40%) were male. The MMR vaccine status of the children in the study is presented in Table 5.4. All of the children had either been, or were going to be vaccinated with the MMR vaccine.

Table 5.4 - Pilot study – Children of participants by MMR status

MMR Status	n (%)
Vaccinated	13 (86.6)
Will be vaccinated	2 (13.4)
Total	15 (100)

### Other results

While the purpose of a pilot study is to test the questionnaire, rather than make meaningful analyses of the data collected, there are some aspects of the data/results that are worth summarising. Parents tended to have similar views on the susceptibility of the conditions of measles, mumps and rubella, but there was a wide variation in the views of different parents about susceptibility. In contrast, differences in the views on severity depended more on the disease in question than on the differences between parents. All of the parents who answered the pilot questionnaire believed that the MMR vaccine protected their child and all but one parent (n=5) disagreed with the claim that

the MMR vaccine could damage their child's health. Despite this support for the MMR vaccine, three of the six parents (50%) said that they would opt for single vaccines if they were available which may suggest that they do not have total confidence in the MMR vaccine. The questions surrounding the safety of the MMR vaccine led to an increased need for information for four of the six parents (66.6%), but all six parents went ahead with MMR vaccination once their child was old enough to be vaccinated.

#### 5.3.4.2 Pilot study

This section examines the questions that were answered incorrectly by the pilot participants and those which were frequently missed or not answered. It also examines the data gathered from the comments sheets. Firstly, it is important to look at the questions that were answered incorrectly by the participants. These tended to be the questions that required either one or another box to be ticked or questions that required rating. Figure 5.1 shows a question which required one or another box to be ticked (in this instance whether an information source had been used).

Figure 5.1 - Example of tick box question

Where did you try and find this information from? Please tick all that apply.		
	Yes	No
GP/Health Visitor	<input type="checkbox"/>	<input type="checkbox"/>
Leaflet	<input type="checkbox"/>	<input type="checkbox"/>
Television/radio	<input type="checkbox"/>	<input type="checkbox"/>
Newspaper	<input type="checkbox"/>	<input type="checkbox"/>
Magazines	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>
Friends/Family	<input type="checkbox"/>	<input type="checkbox"/>
Other, please detail here .....		

Figure 5.2 gives an example of a question where respondents are asked to rank sources numerically.

Figure 5.2 - Example of question that required rating

What were your most and least- <b>useful</b> sources of information about the MMR vaccine?	
Please rate the following sources with <b>1 being the most useful and 6 being the least useful</b> . Use each number once only. Please put a X if you did not use the information source	
GP	.....
Health Visitor	.....
Leaflets/other information from the NHS	.....
Friends/Family	.....
Television/Newspaper/radio	.....
Internet	.....

In the case of the questions that had two or more options, participants tended to tick only the 'Yes' box but did not tick the 'No' box, possibly viewing it as being superfluous to the answers they were giving. This is a problem, because if the respondent does not tick any box, the researcher has to assume that they meant 'No'. In addition, a similar problem to this is the ceiling effect (Becker et al., 2003), when participants tick all of the boxes that are available, because this is an easier way to complete the questionnaire or because they have briefly used one of the information sources listed.

In the case of the questions that required the participants to rank an information source in comparison to a number of others, these questions were often answered incorrectly. Participants either did not complete the question as they had not ranked some of the sources (but not using an X if they did not use the information source), or they ranked two or more sources with the same number. In the pilot study, the majority of participants answered these questions incorrectly.

It is also important to examine the questionnaire in terms of the additional comments that participants made to see if these comments should be incorporated into questions in the questionnaire. These are shown in Table 5.5:



Table 5.5 - Pilot study – Comments added to questionnaire

Question	Comment
26	Live in remote areas away from civilisation
33	I talked to the Health Authority Vaccination coordinator
37	I was sent some of the research papers on MMR. It was fairly useful but still biased towards the “party line” Internet (mostly negative)
39	Info from vaccination coordinator – quite trustworthy. About 3 Media (quite useful)
41	I went ahead with vaccination, however I felt anxious
42	My second child developed measles immediately following her MMR vaccine I went ahead with vaccination because I know the risk of complications with measles is high, and likely to be higher than any risk from the vaccine. This does not mean that I think the vaccine is 100% safe; just it is a less risky option. The questionnaire is written very negatively towards MMR. There is no <u>medical knowledge</u> to support this

### Pilot comments

The first section on the comments sheet dealt with participants’ views about the information sheet. All six of the participants understood the information sheet and did not believe that there was any information that they wanted to know that was not on the information sheet

The second section of the comments sheet dealt with participant’s views about the questionnaire. Table 5.6 indicates the length of time that parents took to complete the questionnaire:

Table 5.6 - Pilot Study – Length of time taken to complete questionnaire

Number of responses	6
Mean time in minutes (median)	9.67 (10)
Range in minutes	3-15

The majority of parents (5, 83.3%) found the questionnaire easy to complete, although one parent made the following comment

From 32 onwards was a little confusing. Not sure I conveyed the true picture (Pilot 5)

Participants were also asked to comment upon any specific questions that they found unclear or difficult to answer. Their comments, by question are shown in Table 5.7.

Table 5.7 - Pilot Study – Comments on questionnaire

Question	Comment
10	Should have if “yes” go to question 12, if no go to question 11 (Pilot 2)
11	No vaccination is too near single vaccine box – confusing (Pilot 2)
13,14,15	I had to indicate “disagree” – what I actually felt was my child could possibly catch the diseases (Pilot 5)
17,18,19	More accurate to say the diseases are potentially dangerous – many children contract them and they are not serious (Pilot 5)
25	Maybe it would be interesting to ask for reasons for the answers to this question (Pilot 5)
28	Not sure what the question means (Pilot 2)
37	You ask for details but they were already given in question 33 (Pilot 2)
37 and 39	Seem to be the same question (Pilot 5)
34 and 37	The next question didn’t make sense in light of previous answers (Pilot 5)
38	Maybe you should include question 39 as an option in question 38 – refer back to question 33/37 (Pilot 5)
41	“No, I changed my mind” What does this mean? (Pilot 2)
41	“Negative media coverage?” in whose opinion? The press reported peoples concerns and stated that no risk has been medically proven. Indeed, they reported not to vaccinate could create and epidemic. The media were just reporting, not negatively (Pilot 6)

As Table 5.7 shows, there were a wide variety of comments made regarding the questionnaire, which varied from comments about the progression of questions to

comments about the wording of questions and the extent to which the answers that had been provided for the closed questions matched the answers that the participants wanted to give.

One participant made the following comment, which highlights the importance of researchers being aware of the impact that the study may have on parents, i.e., the Hawthorne effect (Becker et al., 2003):

It made me realise that I hadn't received much information prior to the vaccine. Risks of the vaccine were certainly never mentioned. When my child became very unwell – requiring emergency doctor intervention – I was told it was definitely not due to the vaccine when it clearly was as she had measles. This poses the question as to whether GP's are fully aware of all potential risks, however small. (Pilot 1)

### **5.3.5 Limitations**

The pilot study had a number of shortcomings that limited the extent to which the study results could shape the future design of the questionnaire. Two nursery schools were unable to assist, but as this was only discovered when a follow-up telephone call was made two weeks after the letter was sent. Additional nursery schools could not be contacted due to time restrictions, meaning that only two nursery schools participated and these were in the mid and upper tertiles, and it was not possible to recruit nurseries from the most deprived areas. As anticipated, the response rate to the pilot study was small. Of the 20 questionnaires distributed, only 6 were returned. This does not however, diminish the quality of the responses gained, all of which helped to assist in the redesign of the questionnaire. The pilot study was also limited by the fact that the 6 participants had all had their children vaccinated with the MMR vaccine. Also, the majority of the participants expressed favourable views about the MMR vaccine. This means that the views of non-vaccinators and/or people who do not support the MMR vaccine were not gained. However, this may be indicative of the people to whom the questionnaire was distributed by the nursery leaders or of a non-response bias, such that non-vaccinators felt less inclined to respond. The extent to which responses to the questionnaire are shaped by MMR vaccination status will be examined in the main study. The study was also limited by the homogeneity of the respondents in terms of demographic and socio demographic characteristics, which was compounded by the fact that the questionnaire was not distributed to parents in the lowest tertile of deprived electoral wards.

### 5.3.6 Outcome

This section examines the changes that were made to the study in light of the pilot study. No changes were made to the information sheet as the pilot study participants made no comments about the information sheet and all six pilot participants found the information sheet easy to understand. In the case of the questionnaire, the pilot study highlighted a number of areas for improvement, as a result of three factors - comments made by the pilot participants, frequently-missed or incorrectly-answered questions and the actual answers that participants gave. The findings of the pilot study led to several changes being made to the questionnaire, which are described in 5.3.6.1.

#### 5.3.6.1 Overall changes

The questionnaire was reduced to seven pages from eight pages. Page numbers were aligned on the outside of the page.

#### 5.3.6.2 Changes to individual questions

A number of changes were made to questions as a result of the pilot study. The changes made to individual questions are described in Table 5.8.

Table 5.8 - Pilot Study - Changes made to the questionnaire as a result of the pilot study

Question	Change
(4 and 5)	An option was entered to indicate whether the participant/spouse is in full or part time employment
(6)	In the question, "currently works" was changed to "in employment"
(12)	The question was presented horizontally rather than vertically
(28)	Question wording was changed on the advice of Pilot 2 from "had to make the choice about whether" to "decide whether"
(29)	The question "did you receive any information" was changed to "did you get any information"

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Table 5.8 - Pilot Study - Changes made to the questionnaire as a result of the pilot study (continued)

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(30 and 33)	The option to tick either “yes” or “no” was removed as pilot participants tended to tick the “yes” box and/or leave the “no” box blank. Therefore the only option was “yes”.
(30)	Wording was changed, from “What format did you get this information in” to “Where did you get this information from?”
(32)	Wording was changed, from “Did you try to find any extra information about the MMR?” to “Did you try to find any information about the MMR vaccine yourself?”
(33)	Wording was changed from “What source did you try and find the information” to “where did you get the information”
(34)	Wording was changed from “Information available” changed to “information you used” and “informed choice” changed to “informed decision”
(40 and 41)	The concept of a media generated scare was removed, as it generated a negative response. Instead parents were questioned about how their awareness that the safety of the MMR vaccine was being questioned made them feel and whether this awareness influenced their decision
(42)	Additional lines were added for comments as one of the pilot participants did not have enough space for comments

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### 5.3.6.3 Other suggestions

Some of the comments made and changes suggested by the pilot participants could not be made. These are presented in Table 5.9:

Table 5.9 - Pilot Study - Changes not made to the questionnaire as a result of the pilot study

Question	Suggested change
36-39	Although some pilot participants answered these questions incorrectly, it was hoped that clearer instructions would make them easier to answer on the revised questionnaire. To help “use each number once only” has been put in capital letters and “rate” has been changed to “rank”. The questions relating to additional sources of information and their trustworthiness (37) and usefulness (39) have been incorporated into the rankings questions.
10	Pilot 2 suggested that this question needed “if yes go to question 12, if no go to question 11”. However, questions 10 and 11 have been merged into question B4.
11	Pilot 2 commented that the “No vaccination” box was too close to the “Single vaccines” box. However, this question has been removed.
13 –15	Pilot 5 suggested that the wording be changed from “likely to catch...” to “could possibly catch”. However, the question is framed in terms of the HBM, which concentrates on perceived likelihood of diseases occurring.
17-19	Pilot 5 suggested that the wording be changed from “serious” to “potentially dangerous”. Again the question is framed in terms of the HBM and therefore the wording needs to concentrate on what parents believe will happen rather than what they think could happen.
25	Pilot 2 suggested that it might be interesting to ask for reasons for the answer to the question. While this is true, it is outside the remit of the study and therefore could not be included.
33	Pilot 2 mentioned that they had used the district immunisation coordinator for information. This option will not be included on the questionnaire as the district immunisation coordinator is sending the letter that accompanies the questionnaire
36 and 33	Pilot 2 commented that these questions duplicated the information required. However, question 33 asks which sources were used in the

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Table 5.9 - Pilot Study - Changes not made to the questionnaire as a result of the pilot study (continued)

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	MMR decision, whereas question 36 asks about the usefulness of this information.
37 and 39	Pilot 5 believed that these questions were too similar. However, question 37 asks about the usefulness of information sources and question 39 about the trustworthiness. For many parents this may mean the same, but for others it may not and it is important that all these views are reflected
41	Pilot 1 noted that this question did not allow for comments about feelings e.g. I went ahead with vaccination although I felt nervous. However, this is not the purpose of the question. The primary purpose is to find out the impact of the MMR vaccine scare on the parents' eventual decision.

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The final version of the questionnaire can be found in appendix 2.8.

## 5.4 Quantitative results

### 5.4.1 Introduction

This section presents the results of the questionnaire study. There are three main sections to the results. Firstly, the response rates to the questionnaire and results relating to the characteristics of the sample and their children are presented. It is worth noting here that all of the participants who completed the questionnaire were parents of the children about whom they completed the questionnaire, which is why they are referred to in the results as parents, not as participants. Secondly, the results relating to the HBM are presented and thirdly, the results relating to information are presented. Statistical tests where appropriate are reported and the results are summarised. Where individuals or GP practices have been named, these names have been anonymised.

### 5.4.2 Response rates

From the original sample of 400 parents, a total of 112 questionnaires were returned (response rate = 28%). Two questionnaires (0.6%) were returned without being completed and 286 (71.4%) were not returned.

### 5.4.3 Characteristics of the sample

This section presents the demographic characteristics of the 112 parents who completed the questionnaire, the characteristics of their family and the characteristics of their children.

#### 5.4.3.1 Parents

One hundred and twelve parents completed the questionnaire. Table 5.10 presents the distribution of parents according to age and gender. The majority of parents were in the 26-35 years category; the mean age was 32 years and the median age was 33 years. The majority of the parents (93%) were female.

Table 5.10 - Parents according to age and gender

Age	Gender		Total n
	Female n (%)	Male n (%)	
18-25	12 (11.5)	1 (12.5)	13
26-35	57 (54.8)	4 (50)	61
36-45	35 (33.7)	3 (37.5)	38
Total	104 (100)	8 (100)	112

Table 5.11 presents the distribution of the 112 parents according to ethnic background. The majority of parents (93.8%) were White British and White Other.



Table 5.11 - Parents according to ethnic background

Background	n (%)
White British and White Other	105 (93.8)
Black British and Black Other	3 (2.6)
Asian British and Asian Other	2 (1.8)
Mixed Race	2 (1.8)
<b>Total</b>	<b>112 (100)</b>

#### 5.4.3.2 Families

Table 5.12 presents the participants in terms of NS-SEC. The modal class was the modern professional occupations class, which contained 22 (19.7%) parents.

Table 5.12 - Families according to NS-SEC

Occupation	n (%)
Modern professional occupations	22 (19.7)
Clerical and intermediate occupations	5 (4.5)
Senior managers or administrators	9 (8)
Technical and craft occupations	12 (10.7)
Semi-routine manual and service occupations	7 (6.3)
Routine manual and service occupations	8 (7.1)
Middle or junior managers	12 (10.7)
Traditional professional occupations	11 (9.8)
Part time employment	9 (8)
Student	1 (0.9)
Never worked or long-term unemployed	10 (8.9)
Occupations not stated	6 (5.4)
<b>Total</b>	<b>112 (100)</b>

Table 5.13 presents details of the number of children in the 112 families. While the mean number of children per family was 1.84 and the median was 2, the modal number of children was 1, with 50 parents (44.6%) having only one child.

Table 5.13 - Families according to number of children in family

Number of children	n (%)
1	50 (44.6)
2	38 (33.9)
3	17 (15.2)
4+	7 (6.3)
Total	112 (100)

#### 5.4.3.3 Children

The 112 parents who participated in the questionnaire study had a total of 206 children, (mean = 1.84 children per family; median = 2 children per family). These children ranged in age from 1 month to 300 months. In terms of the MMR vaccination status of all children, this information was given for 204 children and 187 (91.9%) of the children either had been, or were going to be, vaccinated with the MMR vaccine.

There were 112 children about whom the questionnaires were completed. These children are henceforth referred to as the questionnaire child. All parents gave details about the age of the questionnaire child. 109 parents gave information about the gender of the questionnaire child. Of these 109 children, 56 (51.3%) were female and 53 (48.7%) were male. Table 5.14 shows the distribution of the questionnaire children according to age. The mean age of the questionnaire children was 19 months (SD=0.27) and the median age was 19 months.

Table 5.14 - Questionnaire children according to age

Age	n (%)
12 months	3 (2.6)
15 months	4 (3.6)
16 months	14 (12.5)
17 months	13 (11.6)
18 months	14 (12.5)
19 months	13 (11.6)
20 months	10 (8.9)
21 months	13 (11.6)
22 months	11 (9.9)
23 months	6 (5.4)
24 months	10 (8.9)
35 months	1 (0.9)
Total	112 (100)

With reference to these data, four responses appear to be incorrect, as the sampling strategy meant that parents should only have been contacted if the questionnaire child was between 15 and 24 months. A possible reason for children aged 12 months could be that parents who had a child aged 24 months may have subsequently had a child who could be aged 13 months or over and may have been offered the MMR vaccine. Therefore, parents would have made the decision about this second child most recently. The reason for a child of 35 months being the questionnaire child cannot be explained, but may be due to parental error or an error on the CHCS.

Table 5.15 presents the distribution of the 102 questionnaire children according to their MMR vaccination status. The majority of questionnaire children (93.6%) had been, or were going to be vaccinated with the MMR vaccine:

Table 5.15 - Questionnaire child according to MMR vaccination status

Vaccination Status		n (%)
MMR vaccine	Triple MMR vaccine	102 (91)
	Intending to vaccinate (MMR)	3 (2.6)
	Sub total	105 (93.6)
Not MMR vaccine	Single vaccines	2 (1.8)
	Intending to vaccinate (single vaccines)	1 (0.9)
	No vaccination	4 (3.7)
	Sub total	7 (6.4)
Total		112 (100%)

#### 5.4.3.4 Representativeness of sample

To measure the representativeness of the study (i.e. the extent to which the parents in the study are representative of the random sample taken, and the extent to which this sample is representative of the sampling frame and the population), a number of comparisons were carried out, which compared two or more groups including the sample of children to whose parents questionnaires were sent, the children whose parents returned the questionnaire and the children in the sampling frame. The size of these groups is detailed in Table 5.16. The questionnaire child represented 2.7% of all children in Sheffield between the ages of 15 and 24 months.

Table 5.16 - Comparison of size of groups

Group	n
Questionnaire child	112
Children in sample	400
Children in sampling frame	4079

Table 5.17 compares the groups in terms of a number of key characteristics. Firstly the age of the children is compared. It is worth noting that the sampling frame was characterised by the fact that participants had to have at least one child between the ages of 15 months and 24 months. The gender of the children and the MMR status of the children are also compared:

Table 5.17 - Comparison of groups – Age, gender and MMR vaccination status of children

	Questionnaire children n (%)	Sample children n (%)
<b>Age</b>		
12-18 months	45 (41.7)	158 (39.7)
19-24 months	63 (58.3)	242 (60.3)
Mean	19.38 months	19.44 months
Mode	16 and 18 months	17 months
Median	19 months	19 months
<b>Gender</b>		
Female	56 (51.3)	206 (51.5)
Male	53 (48.7)	194 (48.5)
Subtotal	109 (100)	400 (100)
<b>MMR status</b>		
Vaccinated	102 (91)	306 (76.5)
Not vaccinated	10 (9)	94 (23.5)
Subtotal	112 (100)	400 (100)

A number of tests were carried out on the data to compare children in the sample and the questionnaire children. These tests were carried out in order to test the null hypotheses that there was no difference between the sample and the questionnaire children in terms of age, gender and MMR status. The tests carried out revealed the following. In terms of age, there was no significant difference between the ages of the questionnaire children and the ages of the children in the sample (Mann Whitney U Test = 21808,  $Z = -0.430$ ,  $p = 0.667$ ). In terms of gender, there was no significant association between gender whether the children were questionnaire or sample children ( $\chi^2 = 0.00$ , d.f. = 1,  $p = 1$ ). There was also no significant association between gender and whether the children were of responders or non responders ( $\chi^2 = 0.00$ , d.f. = 1,  $p = 1$ ). In terms of vaccination status, there was a significant difference between the questionnaire children and the sample children in terms of their vaccination status ( $\chi^2 = 11.477$ , d.f. = 1,  $p = 0.001$ ). Of the 400 children in the sample, 94 (23.5%), had not been vaccinated with the MMR vaccine compared with the 112 children of respondents, of whom 10 (9%) had not been vaccinated with the MMR vaccine.

The results in Table 5.18 show the percentages for parents in this study and people in Sheffield (Virdee & Causer, 2003) in terms of their ethnic group. There was no significant difference in the proportions of White and Non White people in the parents and the Sheffield population categories ( $\chi^2 = 0.09$ , d.f. = 4,  $p=1$ ).

Table 5.18 - Comparison of parents and population of Sheffield in terms of ethnic background

Ethnic Group	Parents n (%)	Sheffield population n (%)
White British and White Other	105 (93.8)	468069 (91.2)
Black British and Black Other	3 (2.6)	17963 (3.5)
Asian British and Asian Other	2 (1.8)	14884 (2.9)
Mixed Race	2 (1.8)	8212 (1.6)
Other	0 (0)	4106 (0.8)
Total	112 (100)	513234 (100)

#### 5.4.4 Hypothesis testing – characteristics of the sample

Data for the sample characteristics were analysed using  $\chi^2$  tests to answer the following research question:

- Is there any relationship between the MMR vaccination status of children and demographic/socio demographic variables relating to parents/children?

No significant associations were found between parents' gender and questionnaire child's MMR vaccination status ( $\chi^2 = 3.024$ , d.f. = 1,  $p=0.082$ ), parents' employment status and questionnaire child's MMR vaccination status ( $\chi^2 = 4.675$ , d.f. = 2,  $p=0.097$ ) and ethnic background and questionnaire child's MMR vaccination status ( $\chi^2 = 0.290$ , d.f. = 1,  $p=0.591$ ). Although the association was not significant, all of the questionnaire children who were not vaccinated with the MMR vaccine were an only child.

Additionally, although the association was not significant, it is worth noting that all of the questionnaire children who were not vaccinated with the MMR were male ( $n=3$ ) ( $\chi^2$

= 3.569, d.f. = 1, p=0.06). The finding that this association was not significant may be due to the small cell sizes and may constitute a Type II error.

To examine whether there was an association between MMR vaccination status and gender, the MMR vaccination status and gender were compared for two additional groups (all the children of parents and sample children). These tests for association found that there was a significant association between gender and MMR vaccination status in the case of all of the children of parents who participated in the study but not in terms of the sample children. Of the 189 children of parents who participated in the study for whom data were available, 92 were female, of whom 3 (3.3%) were not vaccinated with the MMR vaccine and 105 were male, of whom 14 (13.3%) were not vaccinated with the MMR vaccine ( $\chi^2 = 6.309$ , d.f. = 1, p=0.012).

#### **5.4.5 Discussion – characteristics of the sample**

The questionnaire had a response rate of 28% (n=112). The majority of parents were in the 26-35 years age category (n=61, 54.5%). The parents that responded to this study were mostly female (n=104, 93%). This represents the primary caregiver role that the majority of mothers occupy. While some fathers (n=8, 7%) did respond to the study, it would be interesting to look at why the majority of parents who completed the questionnaire were mothers. Table 5.18 shows that the participants were relatively homogenous in terms of ethnic background, but this is representative of Sheffield, where the majority of inhabitants are White British and White Other (study participants = 93.8%, Sheffield inhabitants = 91.2%) (Virdee & Caser, 2003).

In terms of NS-SEC, there were a diverse number of participants, with all of the socio-economic classes being represented. However, the greatest proportion of parents was in the modern professional occupations as shown in Table 5.12, therefore the extent to which the results can be generalised to the population was limited. In terms of all of the children of parents who completed the questionnaire, there was a high percentage of MMR take-up (91.9%) which is higher than in the sample (76.5%) or in the UK population in 2002/2003 (82% of children vaccinated with MMR before their second birthday) (National Statistics 2004). There was an even higher uptake of MMR amongst the questionnaire child, i.e., the most recent child for whom the decision was made. Of the 112 questionnaire children, 105 had been vaccinated (93.6%). This could reflect an

increasing uptake of MMR vaccination or that the parents who were willing to complete the questionnaire were those who had most recently had their child vaccinated with MMR, or that there was a non-response bias amongst parents who had not vaccinated their child with MMR. There were no real differences between the sample and the children of parents who responded to the questionnaire, except in terms of MMR vaccination, where there was a significant difference between the vaccination status of children in the sample and questionnaire children ( $p=0.0001$ ). It is unclear from the results why this is the case. It could be suggested that parents who have not had their child vaccinated with MMR are unlikely to respond because of social desirability bias, or that the characteristics of parents who have not had their child vaccinated with the MMR vaccine have specific characteristics which reduced their likelihood of completing the questionnaire. These issues are addressed further in section 5.6.

In terms of the characteristics of vaccinators/non vaccinators, statistical testing was problematic due to the small cell size for non-immunisers. However, it is worth noting that all of the questionnaire children who had not been given the MMR vaccine were an only child and were male. Upon further testing it became clear that there was a significant association between gender and MMR vaccination status with girls being more likely to be vaccinated with the MMR vaccine.

The following section presents the results of the questionnaire study that are related to the HBM.

#### **5.4.6 HBM results**

##### **5.4.6.1 Introduction**

As discussed in Chapter Three, the HBM is based upon four main constructs: susceptibility, severity, benefits and barriers (Janz and Becker, 1984). It is argued that these constructs are the main factors in determining a course of action such as MMR vaccination. The constructs of susceptibility and severity are related to the disease(s) that the action prevents against (in this case measles, mumps and rubella) and the constructs of benefits and barriers are related to the action itself (in this case the MMR vaccine).



#### 5.4.6.2 Susceptibility and severity - measles, mumps and rubella

Table 5.19 presents the results for susceptibility, i.e., whether parents believe that, without the MMR vaccine, their child is likely to catch measles, mumps or rubella.

Table 5.19 - HBM - Susceptibility to measles, mumps and rubella

Susceptibility - Without being vaccinated, my child is likely to catch			
Response	Measles n (%)	Mumps n (%)	Rubella n (%)
Agree	90 (80.4)	91 (81.2)	83 (74.1)
Disagree	13 (11.6)	13 (11.6)	15 (13.4)
Don't know	9 (8)	8 (7.1)	14 (12.5)
Total	112 (100)	112 (100)	112 (100)

As Table 5.19 indicates, the majority of parents agreed that without vaccination their child would be susceptible to the conditions of measles (80.4%), mumps (81.2%) and rubella (74.1%). The level of agreement was similar for measles and mumps but the level of agreement for rubella was slightly higher for people who disagreed or did not know about susceptibility.

The frequency with which parents chose which condition (measles, mumps and rubella) they believed their child was most susceptible to is shown in Table 5.20.

Table 5.20 - HBM - Greatest susceptibility to measles, mumps or rubella

Susceptibility - Without being vaccinated, my child is most likely to catch...	
Response	n (%)
Measles	50 (47.6)
Mumps	4 (3.8)
Rubella	8 (7.6)
Equally likely	43 (41)
Total	105 (100)

It can be seen from Table 5.20 that measles was considered by parents to be the condition to which children were most susceptible; with the largest percentage of

parents (n=50, 47.6%) choosing measles as the disease their child was most likely to catch. The second largest response was for 'Equally likely' (n=43, 41%). Fewer than 11% of parents believed that the disease to which their child was most susceptible was either mumps or rubella.

Table 5.21 shows the frequency of responses from parents about the perceived severity of the diseases of measles, mumps and rubella. Table 5.23 shows that measles (91.9%) was the disease that parents most frequently considered to be severe, followed by mumps (87.9%) then rubella (78.6%).

Table 5.21 - HBM - Severity of measles, mumps and rubella

Severity – The disease would be serious for my child			
Response	Measles n (%)	Mumps n (%)	Rubella n (%)
Agree	103 (91.9)	98 (87.9)	88 (78.6)
Disagree	6 (5.4)	11 (9.8)	15 (13.4)
Don't know	3 (2.7)	3 (2.7)	9 (8)
Total	112 (100)	112 (100)	112 (100)

#### 5.4.6.3 Benefits and barriers - The MMR vaccine

Parents were asked whether it was important that their child was protected against measles, mumps and rubella. Their answers are presented in Table 5.22.

Table 5.22 - HBM - Benefits - Protection against measles, mumps and rubella

It is important that my child is protected against			
Response	Measles n (%)	Mumps n (%)	Rubella n (%)
Agree	110 (98.2)	105 (93.8)	105 (93.8)
Disagree	2 (1.8)	6 (5.3)	3 (2.7)
Don't know	0 (0)	1 (0.9)	4 (3.5)
Total	112 (100)	112 (100)	112 (100)

Table 5.22 shows that while for all the conditions of measles, mumps and rubella, parents were most likely to strongly agree that it is important that their child is protected against measles (98.2%), mumps (93.8%) and rubella (93.8%), it is worth noting that a few parents did not perceive that it was important that their child was protected, most notably in the case of mumps, where 6 parents (5.3%) disagreed that it was important that their child was protected against mumps.

Table 5.23 presents parents' views about whether they believe that the MMR vaccine is effective in protecting against measles, mumps and rubella:

Table 5.23 - HBM - Benefits– Efficacy of the MMR vaccine

It is likely that the MMR vaccine will protect my child	n (%)
Agree	105 (93.8)
Disagree	2 (1.8)
Don't know	5 (4.5)
Total	112 (100)

It can be seen from Table 5.23 that two parents (1.8%) did not believe that the MMR vaccine could protect against the diseases of measles, mumps and rubella and that five parents (4.5%) were unsure about whether the MMR vaccine could protect against measles, mumps and rubella. However, it is also worth recognising that parents' answers to this question may reflect their general belief that the MMR vaccine will protect those who are vaccinated with it, but that they may not believe that this statement refers to their children personally. Table 5.24 presents parents' views about the MMR vaccine in terms of herd immunity:

Table 5.24 - HBM - Benefits - Herd Immunity

The MMR is important because it protects other people against measles, mumps and rubella	n (%)
Agree	98 (87.5)
Disagree	6 (5.4%)
Don't know	7 (6.3%)
Total	111 (100%)

It can be seen from Table 5.24 that parents, while generally agreeing that MMR vaccination was important for reasons other than just the protection of their own child (n=98, 87.5%), some parents did express that they either disagreed with the importance of the MMR vaccine for herd immunity (n=6, 5.4%) or did not know whether the MMR vaccine was important because it protected other children and adults against measles, mumps and rubella (n=7, 6.3%).

Table 5.25 presents the important results regarding parents' opinions about the potential risks of the MMR vaccine.

Table 5.25 - HBM - Barriers - Risk of MMR vaccine to child's health

The MMR vaccine poses a risk to my child's health	n (%)
Agree	12 (10.7)
Disagree	72 (64.3)
Don't know	27 (24.1)
Total	111 (100)

The responses detailed in Table 5.26 are critical in examining parents' responses to the MMR vaccine scare. There were a relatively high proportion of parents (24.1%) who were unsure about whether the MMR vaccine posed a risk to their child's health.

Table 5.26 presents the results for whether parents would choose an alternative means of protecting their child against the diseases of measles, mumps and rubella.

Table 5.26 - HBM - Barriers - Option of single vaccines

If single vaccines were available on the NHS, I would choose...	n (%)
MMR vaccine	71 (63.4)
Single vaccines (for all or some conditions)	39 (36.6)
Total	110 (100)

There was no significant association between the MMR vaccine status of questionnaire children and whether their parents would choose single vaccines if they were available on the NHS ( $\chi^2=2.421$ , d.f. = 2, p=1).

The responses to the question asking for parents' views on alternative ways to protect their child against the diseases of measles, mumps and rubella found that the majority (n=95, 88%) believed that there were no other ways to protect their child against measles, mumps and rubella. Parents who did believe their child could be protected in other ways to the MMR vaccine were asked to detail their responses. Twelve parents suggested alternatives to MMR vaccination, which are presented in Table 5.27:

Table 5.27 - HBM - Barriers - Other ways to protect children

Theme	Comment
Single vaccines	Single Vaccinations (Unlicensed) 60% effective (Parent 5)
	Single Vaccinations (Parent 9)
	Three single vaccines (Parent 24)
	Single Vaccines (Parent 61, Parent 79, Parent 86, Parent 97)
	Single vaccine if produced in Britain (Parent 111)
Contact	Try to stay away from measles carriers. Try to get mumps and rubella before adult (Parent 51)
	Only by avoiding contact with persons already infected (Parent 91)
	Try to avoid friends/family with MMR (Parent 95)
	Before MMR, parents actively encouraged the catching of childhood diseases at measles parties (Parent 90)

As the results in Table 5.27 show, parents' perceptions of other ways to protect their children against measles, mumps and rubella were based around two courses of action, either single vaccinations or avoiding/encouraging contact with others.

#### 5.4.6.4 Cues to action

Cues to action are an intervening variable in the HBM. Table 5.28 presents parents' cues to action. Parents could choose as many cues to action as had influenced their behaviour. The mean number of cues to action per parent was 2.05, the mode was 2 and the median was 2.

Table 5.28 - HBM - Cues to action (I)

What made you realise that you had to decide about MMR vaccination?		
Response	Yes	No
	n (%)	n (%)
Experience with other children	41 (36.6)	71 (63.4)
Reminder card from the NHS	47 (42)	65 (58)
Conversation with GP/Health Visitor	51 (45.5)	61 (54.5)
Conversation with friends/family	52 (46.4)	50 (53.6)
Media	39 (34.8)	73 (65.2)
Other	18 (16)	94 (84)

As Table 5.28 shows, parents were prompted to action by a variety of different information sources. The most popular cue to action was conversation with friends and family (n=52, 46.4%), but over 40% of parents were also prompted by conversation with their GP or health visitor (n=51, 45.5%) and a reminder card from the NHS (n=47, 42%).

Eighteen parents gave their own cue to action, which was both in addition to and instead of, the cues to action listed in Table 5.28. These cues to action were placed into different categories and are presented in Table 5.29. As can be seen from Table 5.29, cues to action tended to be related to parents' previous experience/own knowledge and through interactions with HCPs. In a number of cases it is not clear how parents' comments are related to their decision-making process.

Table 5.29 - HBM - Cues to action (II)

Theme	Comment
Personal experience	My nephew contacted measles (Parent 29)
	As a teacher, outbreaks of Mumps had occurred in school. I felt I needed to vaccinate my child (Parent 48)
	My cousen (sic) had a cast in her eye through caching (sic) measles (Parent 62)
	My second child is autistic wich (sic) the MMR could not be ruled out of being a factor to this (Parent 78)
Personal knowledge	Common sence (sic) (Parent 102)
	The principle of vaccination (Parent 67)
	General knowledge (Parent 74)
	Just knew (Parent 99)
	GP: know it has to be done (Parent 107)
Advice from HCPs	Neonatal follow up clinic at Jessop Wing (Parent 2)
	Dr Smith advised me (Parent 18)
	Talk by GP at Breastfeeding clinic (Parent 22)
	Red Book (Parent 88, Parent 111)
	Own knowledge/talk from GP at antenatal class (Parent 101)
Other comments	Took the personal decision that MMR was lesser of two evils (Parent 61)
	Could not afford to pay single vaccine (Parent 73)
	I have always felt it important that children are vaccinated, however, I had no confidence in the MMR vaccine and felt due to the withdrawal of single vacines (sic) I was left with no choice (Parent 109)

#### 5.4.6.5 Likelihood of MMR vaccination

The purpose of the HBM is to predict the likelihood of preventative health behaviours, such as MMR vaccination. This section examines the likelihood of MMR vaccination by examining the previously discussed results on susceptibility, severity, benefits and barriers. The method through which the HBM likelihood scale was developed is described in section 5.2.8. It is worth noting that the results in Table 5.30 to Table 5.34 refer to the data for the HBM, which can be found in appendix 2.12.

### Individual constructs

Table 5.30 presents the results for the individual constructs of susceptibility and severity. These constructs are presented together as they directly relate to the conditions of measles, mumps and rubella:

Table 5.30 - HBM - Likelihood of MMR vaccination - susceptibility and severity (1=strongly agree, 2=agree, 3=disagree, 4=strongly disagree)

	Measles	Mumps	Rubella	Overall
<b>Susceptibility</b>				
n	97	97	97	97
Range	1-4	1-4	1-4	3-12
Mean	1.85	1.89	1.94	5.67
Mode	2	2	2	6
Median	2	2	2	6
S.D.	0.682	0.627	0.674	1.86
<b>Severity</b>				
n	102	102	102	102
Range	1-4	1-4	1-4	3-12
Mean	1.48	1.76	1.73	4.95
Mode	1	2	1	6
Median	1	2	2	5
S.D.	0.64	0.66	0.73	1.64

As the results for the constructs were not normally distributed, the non-parametric alternative to the one-way repeated measures analysis of variance (ANOVA), the Friedman test, was carried out to test the null hypothesis that there was no difference in parents' scoring for the individual constructs of susceptibility and severity for measles, mumps and rubella. There was a significant difference in the constructs of susceptibility and severity for the three conditions. The results of the Friedman tests for susceptibility and severity are shown in Table 5.31. The results in Table 5.30 refer to all the data collected where parents rated susceptibility and severity as individual constructs whereas the data in Table 5.31 refer only to cases where parents ranked susceptibility



and severity for measles, mumps and rubella. Therefore the mean scores and n values in Table 5.31 differ from those in Table 5.30.

Table 5.31 - HBM - Likelihood of MMR vaccination - Friedman test results

Construct	n	Measles (mean)	Mumps (mean)	Rubella (mean)	p value	$\chi^2$ (d.f.)
Susceptibility	97	1.92	2.07	2.01	0.01	9.17 (2)
Severity	101	1.77	2.16	2.07	0.00	15.4 (2)

As Table 5.31 shows, there were significant differences between the mean susceptibility scores for measles (1.92), mumps (2.07) and rubella (2.01) and the mean severity scores for measles (1.77), mumps (2.16) and rubella (2.07).

Table 5.32 shows the figures for the benefits and barriers constructs, which relate to the MMR vaccine, rather than the conditions of measles, mumps and rubella.

Table 5.32 - HBM - Likelihood of MMR vaccination – Benefits and Barriers

Benefits	MMR vaccine is likely to protect child against measles	MMR vaccine is likely to protect child against mumps	MMR vaccine is likely to protect child against rubella	Overall
n	107	107	107	107
Range	1-4	1-4	1-4	1-4
Mean	1.32	1.47	1.4	4.19
Mode	1	1	1	3
Median	1	1	1	3
S.D.	0.54	0.63	0.6	1.6
Barriers	MMR vaccine is unlikely to protect child	Herd immunity is not important	MMR vaccine is a risk to child's health	Overall
n	79	79	79	79
Range	1-4	2-4	1-4	5-12
Mean	3.44	3.43	2.92	9.84
Mode	4	4	3	9
Median	3	3	4	10
SD	0.55	0.59	0.75	1.26

Likelihood of MMR vaccination scale

For the calculation of the HBM likelihood scale, the responses of 67 parents were included (parents who had completed all the questions relating to the four HBM constructs). The internal consistency of the HBM likelihood scale was measured using Cronbach's Alpha coefficient. A scale has internal consistency if the figure for Cronbach's Alpha is above 0.7 (Pallant, 2001). The figures are shown in Table 5.33.

Table 5.33 - HBM - Likelihood of MMR vaccination - internal consistency

Construct	Cronbach's Alpha
Susceptibility	0.9295
Severity	0.7348
Benefits	0.8763
Barriers	0.4646
Overall HBM likelihood scale	0.4718

As the figures in Table 5.33 show, the internal consistency of the susceptibility, severity and benefits constructs are high (i.e., above 0.7) whereas the barriers construct has low internal consistency (0.4646) which leads to a Cronbach's Alpha coefficient of 0.4718 for the overall likelihood scale, which demonstrates a low level of internal consistency.

In response to this, a revised likelihood scale was constructed which included only susceptibility, severity and benefits and omitted barriers. This revised scale had a Cronbach's Alpha coefficient of 0.7887, which indicates that the scale has a good level of internal consistency. The figures for this revised HBM likelihood scale (without the barriers construct) are as follows. Parents' scores on the HBM likelihood scale ranged from 9-36 (median = 14, mean = 14.63, SD= 4.44, inter-quartile range = 12.0-17.0). It was hypothesised that the lower the score on the likelihood scale, the more likely the parent is to have their child vaccinated with the MMR vaccine. Parents were rated as being either "likely" or "unlikely" to vaccinate with the MMR vaccine (as compared to other parents in the study) by allocating them to groups based on the median score for likelihood:

Table 5.34 - HBM - Likelihood of MMR vaccination - Likelihood by group

Group	Calculation	Score	n (%)
Likely	Lowest-median	9-14	36 (53.7%)
Unlikely	Above median	15-36	31 (46.3%)

As the scores for the barriers subscale were unable to be used in the HBM likelihood scale, a  $\chi^2$  test was undertaken to whether there was an association between likelihood of MMR vaccination according to the HBM and perceived barriers to MMR vaccination. Parents were either placed in the "high" barriers or "low" barriers group depending upon whether they were above or below the median score for the barriers

construct. There were no significant associations between the categorical variables of likelihood score (likely and unlikely) and “high” or “low” barriers score ( $\chi^2=1.859$ , d.f. = 1,  $p=0.173$ ). This reinforces the findings of the Cronbach’s Alpha test, which found that the barriers construct was not internally consistent and therefore could not be included in the overall likelihood scale.

#### 5.4.7 Hypothesis testing – HBM results

Data for HBM constructs (susceptibility, severity, benefits and barriers) and overall likelihood scores were analysed using a variety of statistical tests to answer the following research questions.

- Are the HBM constructs of severity, susceptibility, benefits and barriers predictive of MMR vaccination?
- Do any of the HBM constructs determine parental decision making about the MMR vaccine?

The null hypotheses stated that there would be no correlation between susceptibility, severity and benefits and no association between these three constructs and barriers. The constructs of susceptibility, severity, benefits and barriers were tested for correlation using Spearman’s rank order correlation test (rho). The significance of correlations was determined according to Cohen (1992). The correlations and p values are shown in Table 5.35:

Table 5.35 - HBM - Construct correlations

Construct 1	Construct 2	Direction	Size (rho)	p
Susceptibility	Severity	Positive	Small (0.272)	0.03
Susceptibility	Benefits	Positive	Medium (0.394)	0.01
Susceptibility	Barriers	Negative	Small (-0.285)	0.02
Severity	Benefits	Positive	Large (0.583)	0.00
Severity	Barriers	n/a	n/a	0.09
Benefits	Barriers	n/a	n/a	0.12

Table 5.35 shows that the strongest correlation was between the severity and benefits constructs, but that there were also significant correlations between susceptibility and severity, susceptibility and benefits and susceptibility and barriers.

$\chi^2$  tests were then used to test the null hypothesis that there was no association between whether parents chose to vaccinate their child with the MMR vaccine (and whether they would choose to vaccinate with single vaccines if they were available on the NHS) and the HBM likelihood scale (including the overall scale and the individual constructs of susceptibility, severity, benefits and barriers).

There was no significant association between overall likelihood score and parents' decision about whether to have their child vaccinated with the MMR vaccine ( $p=0.851$ ). There was also no significant association between overall likelihood score and parents' choice about whether they would choose single vaccines if they were available on the NHS ( $p=0.523$ ). However, there was a significant association between the likelihood of MMR vaccination as determined by the HBM and the gender of the questionnaire child ( $p=0.04$ ). Parents with a male child were less likely to get their child vaccinated with the MMR vaccine than parents with a female child. Of the 32 female children, 23 (71.9%) were likely to be given MMR vaccine compared with the 33 male children, of whom 12 (36.4%) were likely to be given the MMR vaccine ( $\chi^2=8.244$ , d.f. = 1,  $p=0.004$ ).

Mann Whitney tests were carried out to see if there were any differences in the scores of parents on the four HBM constructs (susceptibility, severity, benefits and barriers) in terms of their cue to action. This construct may have a bearing on their decision-making process. The test used the categorical variable of whether the cue to action was used (yes or no) and the score on each of the HBM constructs. The only significant results ( $p<0.05$ ) were found between parents who did and did not use the media as a cue to action. Parents who used the media as a cue to action were less likely to view their child as susceptible to measles, mumps and rubella ( $Z=-2.754$ ,  $p=0.006$ ), less likely to view measles, mumps and rubella as severe diseases ( $Z=-2.04$ ,  $p=0.04$ ), less likely to view the MMR vaccine as being a benefit to their child ( $Z=-2.61$ ,  $p=0.008$ ) and less likely to vaccinate their child with the MMR vaccine ( $Z=-1.98$ ,  $p=0.04$ ).

#### 5.4.8 Discussion - HBM results

Most parents agreed that the diseases of measles, mumps and rubella were a threat to their children. Of the three diseases, measles was considered to be the one which children were most likely to catch and was also considered to be the most serious of the three diseases, with mumps considered to be more serious than rubella. This may be due to prior experience of measles. The finding that parents of questionnaire children were more likely to agree that rubella could be a serious disease for their child if the child was female is interesting because rubella presents an extra risk to pregnant females only, in terms of Congenital Rubella Syndrome and suggests that parents are not fully informed of the consequences of rubella. This is supported by the finding that in the cases of susceptibility and severity, the greatest number of “don’t know” responses related to rubella. This may indicate a lack of knowledge about this particular disease.

Although the majority of parents viewed the MMR vaccine as being effective, seven parents thought that the MMR vaccine was ineffective, or did not know whether it was effective. This suggests that while the parents were questioning the safety of the MMR vaccine, some were also questioning its efficacy. Herd immunity was not considered to be an important reason for MMR vaccination to the same extent as other constructs although only a small number believed that it was unimportant. It is not possible to know whether these parents believed that the principle of herd immunity was unimportant or whether they did not understand the principle of herd immunity. Therefore providing information on herd immunity may help to increase MMR vaccination rates. Although the majority of parents disagreed that the MMR vaccine posed a risk to their children approximately a quarter of parents did not know whether the MMR vaccine was a risk to health. This may indicate that parents are not receiving the message from HCPs and the Government that the MMR vaccine is safe. This may be because parents are not being given this information or that parents are receiving conflicting information and they are unsure of what information to believe. This is a problem as by virtue of the inclusion criterion parents were currently making or recently made a decision about the MMR vaccine. However, despite this fear/lack of knowledge about safety, a large majority of parents proceeded with the MMR vaccination.

Almost a third of respondents in the sample indicated that they would opt for the single vaccines for measles, mumps and rubella if they were available, in contrast to the

finding that the majority of parents in this study chose to vaccinate their children with the MMR vaccine. This could be due to the fact that (at the current time) the single vaccines are not viewed as being an alternative to the triple MMR vaccine (either due to their cost or due to the fact that they are unlicensed for use in the UK and are not available on the NHS) or that the parents viewed the MMR vaccine as being a safer alternative to the diseases of measles, mumps and rubella (although some parents view the single vaccines as being a safer option than the triple MMR vaccine).

Parents were most frequently made aware that they had to make a decision about the MMR vaccine through conversations, either with the GP/health visitor or with friends/family. Parents also mentioned the importance of prior experience with previous children. Both of these sources of information indicate parents' use of informal and interpersonal information sources. In light of the high vaccination rates of parents in this study, this may suggest an appropriate way in which to prompt parents that they are required to make a choice about the MMR vaccine.

The aim of the HBM is to predict the likelihood of preventative health behaviour. The calculation of the likelihood of MMR vaccination revealed some interesting findings, despite the fact that the barriers construct had to be removed from the calculation. The constructs of susceptibility and severity in the model indicated that parents' views about the conditions of measles, mumps and rubella were relatively consistent. In terms of the overall likelihood of MMR vaccination, the internal consistency of the barriers construct meant that this had to be removed from the HBM, which meant that parents' views on the MMR vaccine became less important in the model than their views on the conditions, which limited the extent to which the role of the MMR vaccine scare in shaping likelihood could be generalised. As has already been suggested, parents' views on the susceptibility and severity of conditions may indicate that they consider the risks of measles, mumps and rubella to be greater than the risks of the MMR vaccine and this is the determining factor in their decision, thus emphasising the importance of the susceptibility and severity constructs. As hypothesised, there were significant relationships between most of the constructs, indicating that parents' views about the MMR vaccine and the diseases of measles, mumps and rubella were related, even though the final likelihood model could not include the barriers construct. The HBM findings were supported by the finding that a lower percentage of male questionnaire children than female questionnaire children were vaccinated with the MMR vaccine and

the HBM found that parents with a male child are less likely to proceed with the MMR vaccine than those with a female child.

The next section presents the results of the questions relating to the role of information in parents' decision-making.

#### 5.4.9 Information results

This section looks at the information sources parents used and their information needs in the form of both qualitative and quantitative data. The section refers to received information and sought information, which is further discussed in section 5.7.

##### 5.4.9.1 Received information

This section examines the information that parents received. The majority of parents (n=96, 85.7%) received information at the time of the decision.

Table 5.36 presents the sources from which information was received. Parents could indicate as many sources as they received information from. From a choice of five information sources, the source from which parents most frequently received information was the GP/health visitor in the form of a leaflet. The mean number of sources from which parents were given information was 2.48, the median was two and the mode was one.

Table 5.36 - Information - Source of received information

From which source did you receive information?	n (%)
Leaflet from GP/Health Visitor	77 (80.2)
Conversation with GP/Health Visitor	58 (60.4)
Media	40 (41.7)
Other written information	24 (52)
Other communication	41 (42.7)

Ten parents (10.4%) added additional sources from which they had received information. These were divided into electronic sources and HCP sources and are presented in Table 5.37.



Table 5.37 - Information - Other sources of received information

Source	Comment
HCP sources	Video from Health Visitor (Parent 11)
	Dr Smith advised me (Parent 18)
	Pharmacist (Parent 98)
	BMJ, other journal articles (Parent 90)
Electronic sources	Internet (Parent 29, 47, 73)
	Website (Parent 103)

In terms of the content of the information that parents received, the most commonly received content was about reasons for the vaccine (n=85, 88.5%). This may indicate the sort of information that the NHS and the Department of Health are providing parents with. Table 5.38 presents the content that parents received:

Table 5.38 - Information - Content of received information (I)

What was this information about?	n (%)
Reasons for the vaccine	85 (88.5)
Safety of the vaccine	26 (27)
Ingredients of the vaccine	76 (79.2)

Parents also commented that they received information about other issues, which are presented in Table 5.39.

Table 5.39 - Information - Content of received information (II)

Side effects immediately afterwards (Parent 2)
Reasons against vaccine (Parent 86)
Case Studies, Research (Parent 112)

#### 5.4.9.2 Sought information

As well as the information that they received, parents sought information about the MMR vaccine. Sought information implies that parents actively looked for information. The proportion of parents who sought information was almost identical to the proportion of parents who did not seek information. Fifty-six parents reported that they

(50.4%) sought information and 55 parents (49.6%) reported that they did not seek information.

$\chi^2$  tests for association were carried out to see if there was an association between socio-demographic variables and information seeking. There was a significant association between seeking information and whether the child was the parents' first/second child or not ( $\chi^2=8.295$ , d.f. = 2,  $p=0.01$ ). Of the 91 parents for whom the questionnaire child was their first or second child, 53 (58.2%) sought information; compared with the 19 parents for whom this was their third, fourth or fifth child of whom 4 (21.1%) sought information. There was also a significant association between seeking information and the number of children that parents had ( $\chi^2=8.245$ , d.f. = 1,  $p=0.04$ ). Of the 86 parents who had one or two children, 50 (58.1%) sought information; compared with the 24 parents who had more than two children of whom 6 (25%) sought information. However, there was no association between seeking information and ethnic background ( $p=0.222$ ), the age of questionnaire child ( $p=0.228$ ), the gender of the questionnaire child ( $p=0.771$ ), the gender of the parent ( $p=0.06$ ) and the MMR status of the questionnaire child ( $p=0.592$ ).

Parents sought information from a wide range of sources. Of the 56 parents who sought extra information, the modal number of sources accessed was two ( $n=15$ , 26.7%). The range was 1-7 sources (mean= 3.02,  $SD=1.9$ , median= 3). The sources from which information was sought are presented in Table 5.40. The single most frequently used source was Friends and Family ( $n=33$ , 58.9%).

Table 5.40 - Information - Source of sought information

From which source did you seek information?	n (%)
GP/Health Visitor	29 (51.8)
Leaflet	18 (32.1)
Television/Radio	16 (28.6)
Newspaper	17 (30.4)
Magazines	13 (23.2)
Internet	31 (55.3)
Friends and Family	33 (58.9)

Parents also sought information from additional sources not listed on the questionnaire. All of the sources mentioned were connected to the medical community, whether formally or informally. These are presented in Table 5.41:

Table 5.41 - Information - Other sources of sought information

Source	Comment
Interpersonal	Nurse at local clinic (Parent 2)
	I spoke to my H.V. about it but can not remember what she said (Parent 26)
	Work (Parent 98, who was a General Practitioner)
	My father is a doctor so I got a lot of info (sic) from him (Parent 85)
Other	Medline, via BMA website (Parent 54)
	Medical Magazines etc. (Parent 107)
	Internet- Looked it up. Mother obtained info (sic) for me, she is a district nurse and obtained some recent research (Parent 92)

In terms of the content of the information that parents sought, the most commonly sought content was about ingredients of the vaccine (n=51, 91.1%). Table 5.42 presents the content that parents sought:

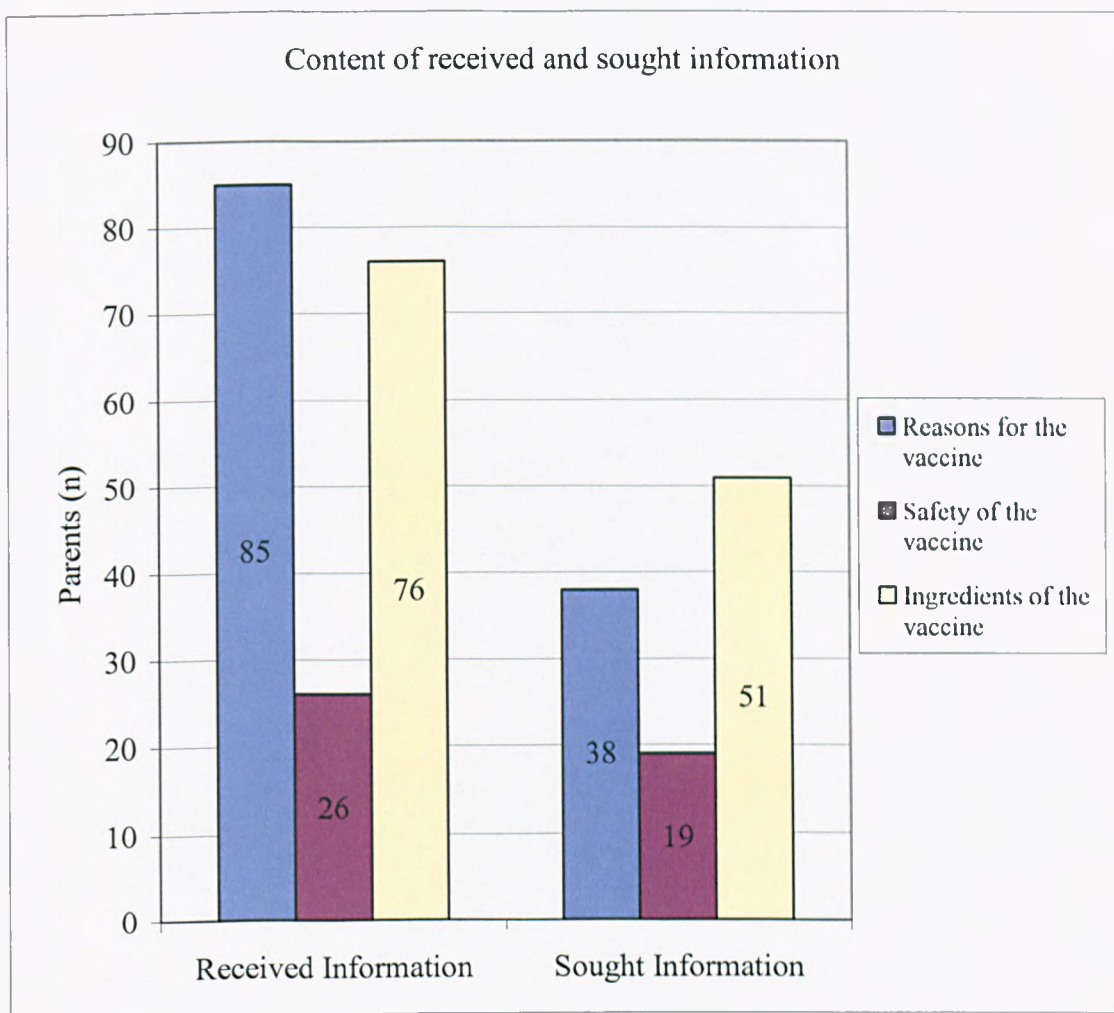
Table 5.42 - Information - Content of sought information (I)

What was this information about?	n (%)
Reasons for the vaccine	38 (67.9)
Safety of the vaccine	19 (33.9)
Ingredients of the vaccine	51 (91.1)

There was no significant association between whether parents received information about reasons for the MMR vaccine and sought information about reasons for the MMR vaccine ( $p=0.06$ ), whether parents received information about ingredients of the MMR vaccine and sought information about ingredients of the MMR vaccine ( $p=0.47$ ) and whether parents received information about the safety of the MMR vaccine and whether they sought information about the safety of the MMR vaccine ( $p=0.211$ )

Figure 5.3 compares the information that parents received and the information that parents sought in terms of the content of this information. The figure shows that the most frequently received content was regarding reasons for the MMR vaccine (n=85). This contrasts with sought information, where the most frequently sought content is about the ingredients of the MMR vaccine (n=51). In terms of both sought and received information, information regarding the safety of the MMR vaccine is the least frequently sought/received information, possibly indicating that parents prefer information about reasons for the MMR vaccine and safety of the MMR vaccine in order to make their own decision about safety of the MMR vaccine. It is also possible that parents interpreted the questions relating to the information that they received about the MMR vaccine as relating to 'positive' information about the benefits of the MMR vaccine as opposed to 'negative' information regarding the suggested side effects of the MMR vaccine.

Figure 5.3 - Information - content of received and sought information



Parents also sought information about a number of other aspects of the MMR vaccine. These are summarised in Table 5.43:

Table 5.43 - Information - Content of sought information (II)

Content	Comment
Reasons for MMR vaccine	Possibility of single vaccinations (Parent 5) Daughter being ill through not having vaccine. Terminal illness (measle (sic) virus) (Parent 24)
Safety of MMR vaccine	Side effects (Parent 2, Parent 26) Safety and autism (Parent 29)
Ingredients of MMR vaccine	NB. I am vegan. Concerned egg in vaccine (Parent 98)
Other	Case Studies, Research (Parent 112)

#### 5.4.9.3 Parents' views about information sources

Parents' views about six information sources were measured through asking parents to rank each of these six information sources in comparison to the other sources in terms of their usefulness to them when making the decision about the MMR vaccine and in terms of their perceived trustworthiness for parents.

##### Useful information sources

This section is divided further into two subsections, parents who ranked all of the information sources and parents who ranked some, but not all of the information sources, depending upon which information sources they had used.

##### All sources ranked

Table 5.44 shows the information sources and their mean, mode and median rankings. As Table 5.44 indicates, information from HCP's was broadly considered to be more useful than information from more informal sources or from the media.

Table 5.44 - Information - Useful information sources - All sources (n=36) (1=most-useful, 6=least-useful)

	Mean	Mode	Median	Range
GP	2.65	1	2	1-6
Health Visitor	2.97	2	3	1-6
Leaflet/Information from NHS	2.69	1	2.5	1-6
Friends/Family	3.67	4	4	1-6
Television/Newspaper	4.56	5	5	1-6
Internet	4.44	6	5	1-6

Tests for Kendall's coefficient of concordance were carried out to test the null hypothesis that there was no agreement among the parents in their ranking of the information sources. The results of the test indicated that there was partial agreement between the parents in their rankings (Kendall's  $W=0.209$ ,  $\chi^2=37.603$ , d.f. =5,  $p=0.00$ ). From this it can be inferred that GPs and leaflets were regarded as the most-useful information sources and the Internet was the least useful.

### Some sources ranked

Table 5.45 indicates the information sources and their mean, mode and median rankings where not all information sources were ranked. As Table 5.45 indicates, there is less differentiation between the information sources in terms of their rankings. This is unsurprising as parents could rank as few or as many sources as they used, but were asked to rank sources with the most-useful source being 1 (i.e., no source could have been ranked 6).

Table 5.45 - Information - Useful information sources — Some sources (1=most-useful, 6=least-useful)

	n	Mean	Mode	Median	Range
GP	16	2.94	3	3	1-5
Health Visitor	21	2.62	2	3	1-4
Leaflet/Information from NHS	26	2.42	1	2	1-5
Friends/Family	25	2.52	1	2	1-5
Television/Newspaper	20	3.25	2	3	1-5
Internet	7	2.00	2	2	1-4

Tests for Kendall's coefficient of concordance could not be carried out as there was a maximum of seven parents for whom all sources were ranked and therefore there were too few data to carry out the tests.

### Trusted information sources

This section examines parents who ranked all of the information sources in terms of their trustworthiness and parents who ranked some, but not all of the information sources, depending upon which information sources they had used.

### All sources ranked

Table 5.46 presents the data for the information sources in terms of how parents ranked them based on their trustworthiness. Again, official sources of information such as the

GP and the health visitor were ranked more highly than more informal sources of information such as friends and family or the Internet.

Table 5.46 - Information - Trusted information sources - All sources (n=36) (1=most-trusted, 6=least-trusted)

	Mean	Mode	Median	Range
GP	2.31	1	2	1-6
Health Visitor	2.72	2	2	1-6
Leaflet/Information from NHS	2.81	3	3	1-6
Friends/Family	3.67	4	4	1-6
Television/Newspaper	5.03	5	5	1-6
Internet	4.44	6	5	1-6

Kendall's coefficient of concordance was again used to determine whether there was any agreement in the ranks given to the information sources by parents. There was an agreement among parents when ranking information sources in terms of their trustworthiness (Kendall's  $W=0.586$ ,  $\chi^2=126.483$ , d.f. =6,  $p=0.00$ ). GPs were the most-trusted source and the Internet was the least-trusted source.

#### Some sources ranked

Again, parents who did not use all of the information sources were asked to rank the sources that they did use in terms of their trustworthiness. These results are presented in Table 5.47 and again the results are very different to those where all sources were ranked. This may be explained by the small sample sizes, e.g., Internet (n=6).

Table 5.47 - Information - Trusted information sources - Some sources

	n	Mean	Mode	Median	Range
GP	17	2.29	1	2	1-5
Health Visitor	22	2.05	2	2	1-4
Information from NHS	27	2.56	3	3	1-5
Friends/Family	24	2.54	4	2.5	1-4
Television/Newspaper	20	3.60	5	4.	1-5
Internet	6	2.5	2	2.5	2-3



Again, tests for Kendall's coefficient of concordance could not be carried out as there was a maximum of six parents for whom all sources were ranked and therefore there were too few data to carry out the tests.

Written comments on information sources

Table 5.48 presents the information sources that parents mentioned that they had used, but were not included in the questionnaire. Some parents also ranked these information sources on the scale of 1-6 (where they had not ranked all of the information sources).

Table 5.48 - Information - Parents' useful information sources

Theme	Rank	Comment
HCP/medical sources	1	Neonatal follow-up (Parent 2)
	1	Talk by doctor at breastfeeding clinic (Parent 22)
	2	Friends and Family as sister is a general practice nurse (Parent 22)
	1	Medical Journals (Parent 90)
	n/a	Pharmacist (Parent 98)
	2	Advisor at work (Parent 98)
Personal experience	1	Experience with my other children (Parent 80)
	n/a	My eldest (sic) child had it and there was no reason to worrie (sic) about her helth (sic) through having it so my othere (sic) children natruly (sic) as + is having the MMR vaccine (Parent 104)
Others	4	Magazines (Parent 76)

As Table 5.48 indicates, a few parents tended to receive information about the MMR from HCPs at various different times and in various different formats. Parents also indicated the role that personal experience plays for them in decision-making. Both these information sources were useful for parents in their decision-making process.

In terms of trusted information sources, Table 5.49 presents these sources. The sources that parents mention as being trusted information sources were often similar to those which they had mentioned as their useful information sources.

Table 5.49 - Information – Parents’ trusted information sources

Theme	Rank	Comment
HCP/medical sources	n/a	Neonatal follow-up (Parent 2)
	2	Friends and Family - "Because they're doctors and nurses" (Parent 22)
	1	Doctor at talk (Parent 22)
Personal experience	1	My own (Parent 78)
	1	Experience with my other children (Parent 80)
	1	Own judgement (Parent 90)
Others	4	Magazines (Parent 76)

Many of the comments that parents made were about how information sources did not meet their expectations. These comments are summarised in Table 5.50. As Table 5.50 indicates, the sources that were not considered to be useful or trusted were HCP/medical sources and media sources:

Table 5.50 - Information - Sources not trusted/useful

HCP/medical sources (Useful)	Watched a video at baby group but didn't really tell me much (Parent 1)
	GP and Health Visitor - None given - should have been for more discussion, at perhaps 7 month check (Parent 92)
HCP/medical sources (Trusted)	GP and Health Visitor - would be 1 if info given (Parent 92)
Others (Useful)	Media ranked 6 - who do you believe? (Parent 22)
Others (Trusted)	Media. 5. Too conflicting (Parent 77)
Others (Trusted)	I did not take any notice of the TV extra. My mind was made up (Parent 104)

#### 5.4.9.4 Information and decision-making

With reference to the final decision that parents made about whether or not to proceed with the MMR vaccine, the majority of parents who answered the questionnaire felt that they had made an informed decision (n=86, 80.4%).

Twenty-one parents (19.6%) were unable to make an informed decision. The reasons that these parents gave for being unable to make an informed decision are presented in Table 5.51. Some parents selected more than one of the reasons for being unable to make an informed decision.

Table 5.51 - Information - Informed decision

Why couldn't you make an informed decision?	n
Not enough information available	5
Information was available but not the information I wanted	3
Information was available but I did not believe it	3
Other reasons/No reasons	12

Parents who stated that they were unable to make an informed decision also added comments, which are summarised in Table 5.52.

Table 5.52 - Information – Parents’ comments on informed decision

Contradictory information	Because there seemed conflicting views as to whether it was safe or not (Parent 1)
	Much conflicting information (Parent 12)
	Mixed information that left one doubting (Parent 73)
	Conflicting Info, media etc (Parent 98)
	It was hard to know who or what to believe as there is so much conflicting information on the subject. It is hard to know whether the scares are media hype or if the government is ignoring possible risks in favour of economic gain (Parent 108)
Insufficient information	...it seemed that insufficient studies have been conducted (Parent 12)
Quality of information	TV reports were obviously sensationalist and relied on anecdotal evidence (Parent 12)
	NHS leaflets were obviously towing the government line with no room for doubts (Parent 12)
	Got lots of negative info from t.v. but still felt I should <u>risk</u> it, as hopefully would be ok and better in the long run (Parent 79)
Other comments	I don't think anyone knows for sure so there is an element of trust and using your instinct (Parent 99)
	I don't know what to think (Parent 40)
	Would have had vaccine even without information (Parent 52)
	Have no other intention than to get my son vaccinated (Parent 95)

$\chi^2$  tests for association were carried out to see if the ability to make an informed decision could be related to any demographic or socio demographic variables. There was a significant association was between whether parents said that they would choose single vaccines if they were available and whether parents said that they were unable to make an informed decision. Of the 21 parents who were not able to make an informed

choice, 15 (71.4%) would choose single vaccines, compared to the 84 parents who were able to make an informed choice of whom 22 (26.2%) would choose single vaccines ( $\chi^2=15.06$ , d.f. =1,  $p=0.000$ ).

#### 5.4.9.5 Information and the impact of MMR vaccine scare

In terms of the impact of the MMR vaccine scare on parents' information needs, the majority of parents wanted more information ( $n=82$ , 75.5%), as is shown in Table 5.53.

Table 5.53 - Information - Impact of MMR vaccine scare

How did the MMR vaccine scare make you feel in terms of information?	n (%)
More information needed	82 (75.5)
Less information needed	2 (2.1)
No change in information needs	24 (22.4)
Total	108 (100)

$\chi^2$  tests for association were carried out to see whether the impact of the MMR vaccine scare on parents in terms of whether they wanted information could be related to any socio-demographic variables. There was an association between the number of children that parents had and whether they wanted more information or less/no change in information. Of the 83 parents who had one child, 67 (80.7%) wanted more information, compared to the 24 parents who had two or more children, of whom 14 (58.3%) wanted more information ( $\chi^2=5.073$ , d.f. =1,  $p=0.024$ ). There was an association between whether parents would choose single vaccines if they were available and whether parents wanted more information. Of the 68 parents who stated that even if single vaccines were available on the NHS, they would still choose the MMR vaccine, 45 (66.2%) wanted more information, compared with the 38 parents who would choose single vaccines if they were available of whom 35 (92.1%) wanted less/no change in information ( $\chi^2=8.853$ , d.f. =1,  $p=0.003$ ). There were no significant associations between impact of the MMR vaccine scare in terms of information and MMR vaccination status of questionnaire children ( $p=0.323$ ) and age of questionnaire child ( $p=0.756$ ).

Table 5.54 indicates whether parents delayed their decision about the MMR vaccine as a result of the MMR vaccine scare and the outcome of this delay. Table 5.56 shows that 19 parents (17.9%) delayed the decision about whether to proceed with MMR vaccination, although the majority of these parents (n=18, 85.7%) decided to proceed with MMR vaccination.

Table 5.54 - Information - Final decision about the MMR vaccine

What was your final decision about the MMR vaccine?		n (%)
No delay	MMR vaccine	85 (80.2)
	Single vaccines	2 (1.9)
Delayed decision	MMR vaccine	18 (17)
	Single vaccines	1 (0.9)
Total		106(100)

#### 5.4.10 Hypothesis testing – information results

Data for information variables were analysed using  $\chi^2$  tests to answer the following research questions:

- Is there an association between information sought and information received?
- Is there an association between the source of information and the content of information?
- What role did information have in parental decision-making about the MMR vaccine?

The null hypothesis stated that there was no association between each of the variables listed above, i.e., information (source and content, sought and received), socio demographic variables and the MMR vaccination decision.

##### 5.4.10.1 Information sought and information received – source and content

Initially, the relationship between information received and information sought was examined. No significant association was found, but for clarity, the figures are presented in Table 5.55:

Table 5.55 - Information - Received and sought information - cross tabulation

Did you receive any information?	Did you try and find any information?		Total n
	Yes n (%)	No n (%)	
Yes	47 (83.9)	48 (87.3)	95
No	9 (16.1)	7 (12.7)	16
Total	56 (100)	55 (100)	111

There was no significant association between the source of received information and whether parents sought extra information.

Although there was no overall significant association between whether parents received information and whether they sought information, associations between the source and content of received and sought information were tested using  $\chi^2$  tests for association. Significant associations relating to sought and received information are presented in appendix 2.12.

A number of significant associations were found and these are presented in appendix 2.12. All of the associations where  $p < 0.05$  are presented here.

There was a significant association between parents receiving information in the form of a leaflet and parents receiving information about reasons for the MMR vaccine ( $\chi^2 = 5.154$ , d.f. = 1,  $p = 0.023$ ). Of the 77 parents who received information in the form of a leaflet, 71 (92.2%) received information regarding reasons for the MMR vaccine, whereas of the 19 parents who did not receive information in the form of a leaflet, 14 (73.7%) received information regarding the reasons for the MMR vaccine.

There was also a significant association between parents receiving information in the form of oral information from the GP/health visitor and parents seeking information from a leaflet ( $\chi^2 = 4.086$ , d.f. = 1,  $p = 0.028$ ). Of the 30 parents who received oral information from the GP/health visitor, 15 (50%) sought information from a leaflet, whereas of the 17 parents who did not receive information from the GP/health visitor, only 3 (6.5%) sought information from a leaflet.

There was a significant association between parents receiving information from the media and parents seeking information from the TV/radio ( $\chi^2=9.266$ , d.f. = 1,  $p=0.002$ ). Of the 21 parents who received information from the media, 11 (52.4%) sought information from the TV/radio and of the 26 parents who did not seek information from the media, 3 (11.5%) sought information from the TV/radio. There was also a significant association between parents receiving information from the media and seeking information from newspapers. Of the 21 parents who received information from the media, 11 (52.4%) sought information from newspapers and of the 26 parents who did not seek information from the media, 4 (15.4%) sought information from the TV/radio.

In terms of the content of information, parents who sought information about the ingredients of the MMR vaccine were more likely to have received information about the ingredients of the MMR vaccine ( $\chi^2=5.4199$ , d.f. = 1,  $p=0.02$ ). Of the 15 parents who received information about the ingredients of the MMR vaccine, 9 (60%) sought information about ingredients of the MMR vaccine, compared with the 32 parents who did not receive information about the ingredients of the MMR vaccine of whom 8 (25%) sought information about ingredients of the MMR vaccine. In addition, parents who sought information about the safety of the MMR vaccine were more likely to have received information about the safety of the MMR vaccine ( $\chi^2=5.44$ , d.f. = 1,  $p=0.02$ ). Of the 40 parents who received information about the safety of the MMR vaccine, 38 (95%) sought information about the safety of the MMR vaccine, compared with the 7 parents who did not receive information about the safety of the MMR vaccine, of whom 4 (57.1%) sought information about the safety of the MMR vaccine. Interestingly there was no association between seeking information about reasons for the MMR vaccine and receiving information about reasons for the MMR vaccine. This may indicate that parents are aware of the reasons for the MMR vaccine and that the information they received met their needs, but their information needs about the safety of and reasons for the MMR vaccine were not being met.

There were no significant associations between the source of sought information and the content of sought information.



#### 5.4.10.2 Information and parental decision-making

There was no significant association between whether parents had received information at the time of the decision about the MMR vaccine and whether the MMR vaccine scare had made them want information ( $\chi^2=0.252$ , d.f. = 1,  $p=0.6$ ).

However, unsurprisingly, there was a significant association between whether parents sought extra information and whether the MMR vaccine scare had made them want information ( $\chi^2 = 12.659$ , d.f. = 1,  $p=0.00$ ). Of the 81 parents who required more information as a result of the MMR vaccine scare, 50 (61.7%) tried to find extra information about the MMR vaccine compared with the 27 parents who required less information or had no change in their information needs as a result of the MMR vaccine scare, of whom 6 (22.2%) tried to find extra information about the MMR vaccine.

There was no significant association between whether parents sought extra information about the MMR vaccine scare and whether they felt they had made an informed choice ( $p=0.221$ ). However, there was a significant relationship between whether parents had received information about the MMR vaccine scare and whether they felt they had made an informed choice ( $\chi^2 = 5.511$ , d.f. = 1,  $p=0.19$ ). Of the 86 parents who felt they had made an informed choice, 78 received information about the MMR vaccine (90.7%) compared with the 21 parents who felt they had not made an informed choice, of whom 15 (71.4%) had received information about the MMR vaccine.

#### 5.4.11 Discussion – information results

Most parents received information about the MMR vaccine ( $n=96$ , 87%) with the most frequently received source being a leaflet ( $n=77$ , 80.2%). It is worth noting that the NHS leaflet: '*MMR: The Facts*' should be received by all parents. Parents received information from a wide variety of sources. Even the source from which they least frequently received information (media,  $n=40$ ) was a source of information to 41.7% of parents. It is also worth noting that the media are not an information source in the same way as the other information sources mentioned in that parents are likely to have accessed the media for a purpose other than receiving information about the MMR vaccine, but this information may have been passively received. Parents also added a number of information sources that they received information from. These tended to be

HCPs e.g. pharmacist. The content of the information that was most frequently received concerned positive aspects of the MMR vaccine (the importance of the MMR vaccine) as opposed to negative aspects.

The finding that the majority of parents stated that the MMR vaccine scare had made them want more information but only half of the parents actually sought any extra information is interesting. It is unclear whether parents are making a decision about the MMR vaccine despite having unmet information needs or whether parents believe that the information available is unable to meet their information needs (therefore additional information seeking will not assist them in making a decision). The relationship between personal experience and the MMR decision is again highlighted by the fact that parents are more likely to seek information if they have one or two children and they are more likely to seek information if they are making the decision about their first child. This indicates that parents who have made the decision about the MMR vaccine for one or two previous children do not require any further information to make this decision for subsequent children.

Among the most frequently used sources of information about the MMR vaccine were interpersonal sources (friends and family n=33, 58.9% and GP/health visitor n=29, 51.8%). However, parents' unwillingness to rate information from friends and family as trustworthy, when they are a source which is used frequently could be related to parents' belief that they are not an information source; rather a source of support. Thus rating them as an information source may not seem appropriate to parents. The Internet was also a popular source (n=31, 55.3%), but was not ranked highly in terms of trustworthiness and usefulness. These responses perhaps reflect the fact that parents prefer information sources that they can interact with. Traditional written sources of information such as newspapers and magazines were also used by parents in this study (n=25, 44.6%) but overall the media (n=21, 37.5%) were not used as much as interpersonal sources (n=30, 53.6%) by parents. However, the finding that around one third of parents were using media information emphasises that this information needs to be accurate if parents are using it as an information source which informs their decision-making. Additional sources that parents added to the questionnaire tended to be HCPs and friends/family (in a number of cases, HCPs were friends/family).

In terms of content, the highest number of parents sought information regarding the ingredients of the MMR vaccine. Parents did not appear to search for information about the safety of the MMR vaccine and reasons for the MMR vaccine to the same extent. The reason that parents did not seek information regarding the reasons for the MMR vaccine may be due to the finding that they held strong beliefs about the potential risk of measles, mumps and rubella and therefore were confident in the reasons for the MMR vaccine. The finding that parents did not seek information about the safety of the MMR vaccine may be due to the finding that the majority of parents had their child vaccinated with the MMR vaccine and therefore did not have any safety concerns. The non-seeking of information about the safety of the MMR vaccine could also be attributed to the finding that parents received all the information regarding safety that they wanted and did not have any additional information needs.

The majority of parents believed that they had made an informed decision about the MMR vaccine (n=86, 80.4%). Parents who felt that they had been unable to make an informed decision most frequently cited an insufficient amount of information (n=5). In written comments relating to the difficulty of making an informed decision, four out of the 10 parents who had added comments mentioned the word 'conflicting' with reference to information that they had received. This suggests that parents are receiving different information from different sources or that parents are receiving different information at different times from the same source. Therefore parents may make their choice of which information they are going to use based upon the source of information that they trust the most.

The source of received information was not associated with whether extra information was sought. However, if parents received information about the safety of the MMR vaccine, they were more likely to seek additional information. In terms of the information that parents received in terms of source and content and the information that parents sought in terms of source and content, a number of interesting associations were found and have been discussed in section 5.4.5.6.

In terms of parents' ability to make an informed decision, having received information was associated with making an informed decision, but seeking information was not. This may indicate that the information parents received was sufficient to allow them to

make an informed decision and that the information they sought was superfluous to the actual decision-making process. Interestingly the only socio-demographic decision that was associated with informed decision-making was parents choice to opt for single vaccines, if available. Parents who said they were unable to make an informed decision about the MMR vaccine were more likely to say that they would opt for single vaccines if they were available, perhaps reflecting scepticism about the MMR vaccine. Nineteen parents delayed their decision about the MMR vaccine. This may be as a result of the MMR vaccine scare, but could also be attributed to other reasons, such as the child to be given the MMR vaccine being unwell at the time that they are due to be vaccinated.

The next section presents the qualitative results from the questionnaire.

## 5.5 Qualitative results

### 5.5.1 Overview

The questionnaire contained questions designed to collect both qualitative and quantitative data. Whilst the majority of the data was collected was numerical data, parents were also offered the opportunity to add written comments to the questionnaire. Forty-two parents made comments regarding the subject of the questionnaire and these qualitative results are presented below.

### 5.5.2 Results

As in the interview study, parents appeared to make their decision based on a comparison of the risks and benefits of the MMR vaccine and the risks of measles, mumps and rubella. This weighing up process for parents was complex, as the following quotes illustrate. All of the parents quoted here did believe that there was a risk from the MMR vaccine, but that it was outweighed by the risks from measles, mumps and rubella:

...I feel that weighing up the pros and cons it [The MMR vaccine] was the best decision. (Parent 112)

In the end we had to weigh up the biggest risk to her and went ahead with the MMR (Parent 1)

We felt anxious at the time of giving her MMR but the alternative of leaving her with no protection seemed worse, particularly the risk of measles linked to brain damage. (Parent 76)

We decided to go ahead with vaccine as we felt the risks posed by measles and mumps (and rubella to others) were greater and more life threatening than any possible effect of vaccine (Parent 101)

MMR - unproven link to autism v. measles which can kill, result in blindness and/or deafness etc! (Parent 19)

... it [MMR] seemed the best option available anyway despite the risks, we went for the MMR when it was due (Parent 45)

Parents mentioned the lack of choice about MMR vaccination. Lack of choice tended to be related to the fact that single vaccines were unavailable on the NHS i.e. without cost and/or unlicensed. This lack of choice made parents' decision harder, as they felt there was no alternative to MMR vaccination. However, despite the apparent problems that parents had with the lack of availability of single vaccines, parents who did not try to get their children vaccinated with single vaccines made the following comments regarding single vaccines.

... we should be able to choose how we want our kids vaccinated freely (Parent 71)

I felt I had no choice but to give my child the MMR (Parent 1)

I feel that parents should have the right to choose single vaccine (Parent 109)

We went ahead with MMR because the alternative single vaccines are not licensed for use in this way (Parent 12)

In the end, the only reason I opted for the MMR was that I couldn't afford single vaccinations (Parent 77)

...it [single vaccine] should be on the NHS for those parents who cannot afford to go private (Parent 71)

Parents felt that it was important that single vaccines were offered, in terms of both increasing choice and increasing confidence in the Government and reducing the potential for disease outbreaks:

Any parent should be allowed the single vaccine. I feel this would stop an outbreak of measles etc spreading. (Parent 62)

...by giving parents a choice it is likely that parents will feel less bullied into a decision which may result in more trust in the government's advice (Parent 109)

A parent also mentioned a need for information about the single vaccines:

...decided to go for the single vaccines. There is not enough information on how to arrange the single vaccines (Parent 93)

Herd immunity was a key issue in parents' decision to proceed with MMR vaccination and motivated some parents in this study:

The single most important reason I went ahead with the vaccine was the growing number of children not being vaccinated and the associated increase in risk of a serious measles epidemic (Parent 19)

Believe that without children being vaccinated likely to be an increase in measles, mumps and rubella which means could be epidemic (Parent 20)

I felt that long term and for the good of my own and other children having the vaccine + taking a risk (if any existed) was better than risking huge numbers seriously ill as a result of not having the vaccine (Parent 42)

The timing of information was important for parents. In these cases information was seen as something that was able to help parents make decisions, if available at an appropriate time:

When the reminder card comes, send the appropriate information with it (Parent 26)

I will wait till this huge debate between the for and against MMR vaccine is dealt with once and for all (Parent 18)

... given information about all before having to make a decision. Good solid reliable informative information (Parent 73)

Personal experience with other children supported parents in their belief that the MMR vaccine was safe and helped with making the decision:

If the MMR was safe enough for my older 3 children and it had no bad effects on them, then I decided that it was good enough for my youngest child, and that it was also safe enough (Parent 80)

Having a child who had the vaccine without any problems 9 yrs ago influenced my decision more than anything else (Parent 32)

Both my older children had the vaccine and they were fine so I had no reason to think my youngest child should be in danger from the vaccine (Parent 36)

I went ahead [with first child]. This made me worry less when it came to the time for no.2 to have his vaccine. (Parent 79)

However, personal experience was also a factor in not getting children vaccinated with the MMR vaccine:

Our eldest daughter, the only one vaccinated with the MMR, was diagnosed at four years with autism (aspergers syndrome). (Parent 40)

The personal experience of friends and family also influenced parents:

It was only because I had a friend who was a GP who advised me that I decided to go with it (Parent 98)

But my friends said their kids were fine so I went ahead. (Parent 79)

... my mother stated that my sister and I had MMR and my other two elder children had it and all were fine after the vaccine (Parent 77)

Some parents viewed the media as providing a balanced, but sensationalised view:

Newspapers covered the debate well if you took the trouble to read behind the basic sensational headlines (Parent 86)

The media can confuse you, but they were fair by giving both sides of the argument (Parent 4)

However, other parents were less positive about the media:

The media, I think, has certainly given rise to the negative impact of the MMR ... I wouldn't trust the media, especially newspapers (Parent 64)

The views and opinions that parents gained from the media led to serious concerns:

My husband and I disagreed about the MMR vaccine - he was more influenced by the scare tactics in the press than I was (Parent 45)

The media debate was very disturbing. The lack of proper validated research supporting the use of MMR fuelled the sense of panic whipped up by the media. (Parent 49)

The availability and quality of leaflets was criticised by parents:

I found leaflets informative but there could have been more leaflets available (Parent 2)

NHS Authorised information limited, not readily available in leaflet form (Parent 5)

Information leaflets to parents don't include risk assessment of your child being affected (Parent 107)

Parents viewed HCPs positively as an information source. This supported the quantitative findings of the questionnaire study that ranked GPs highest of the available information sources in terms of trustworthiness and usefulness:

Having a talk by a GP at antenatal class was very good-felt able to ask any questions (Parent 101)

I trust the NHS to give me the correct information (Parent 112)

However, the qualitative data also indicated that parents felt under pressure to proceed with MMR vaccination and also mentioned GPs' receipt of target payments as being a

factor in not trusting the information they supplied. HCPs were also viewed as not being able to address parents' concerns:

Whilst ever (sic) GPs receive a payment for administering the MMR injection, faith will never be restored (Parent 109)

My GP's nurse tried to insist on my child having the MMR vaccination and I felt under pressure to do so (Parent 93)

I think health visitors and doctors need to do more training on the subject because at the Smithfield surgery, they haven't got a clue (Parent 13)

I was concerned that the nurse at my GP's practice did not give any credit at all to the reports that MMR is linked to autism. There must be some link and would have preferred a more open approach. (Parent 61)

The Government were looked upon unfavourably by a number of parents in this study:

I know many people who have refused to vaccinate through a lack of trust in the governments motives (Parent 109)

...the media/government cloud the issue (Parent 112)

The government did not do enough to allay people's fears (Parent 49)

I do not believe that the general populus (sic) is able to make an informed decision when the government reports are unclear (Parent 15)

Parents mentioned the difficulty of making a decision about the MMR vaccine.

The decision to have the MMR Jab was one of the hardest ever made (Parent 70)

The decision on whether to give my child the MMR was the hardest I have ever had to make (Parent 112)

It was very difficult to make a decision. It was scary. (Parent 98)

The lack of evidence against the MMR vaccine did reassure some parents:

My view is MMR wouldn't be used if it wasn't safe. There seems to be no actual evidence it's harmful. (Parent 66)

The anti-MMR campaign seemed to get all the hype, but had no real evidence (Parent 49)



## 5.6 Limitations

Whilst the questionnaire study provided interesting results which have been discussed in sections 5.4 and 5.5, there were a number of limitations to the study which are presented in this section.

### 5.6.1 Sampling

In terms of the sampling of the study, the study was limited by the sampling method. Sampling was undertaken on an alphabetical list and the sampling was systematic, with every  $n$ th parent being selected for inclusion in the study. Random sampling (which was the intended sampling method) proved to be unfeasible as the CHCS was unable to generate a random list. Therefore the sampling was non random and may have led to sampling bias in that some names may have been over represented in the sample. In specific ethnic groups specific surnames are more common and/or specific surnames are held by a large proportion of the group and this may lead to overrepresentation of this group.

### 5.6.2 Response rate

In terms of the number of responses to the questionnaire, 147 responses were required to detect a medium effect size with  $\alpha = 5\%$  and  $\beta = 80\%$ . The number of responses to the questionnaire was lower than this and this may have limited the study in terms of the generalisability of the results as well as in terms of possible Type II errors. While the demographic characteristics of children of participants were not significantly different to those of the sample, the proportion of MMR vaccinators and non-MMR vaccinators was significantly different. Therefore there are two issues that need to be addressed, the lack of representativeness related to the low response rate and the lack of representativeness related to the significantly different proportion of MMR vaccinators to non-MMR vaccinators. There are a number of possible causes of low response to this study. The source of the questionnaire may have influenced the response rate as the letter came from the custodian of the CHCS. This may have led to scepticism that the questionnaire was being sent to parents in order to collect data on their child's MMR vaccination status and that the data collected may be used in a negative manner. This method of distribution was not the initial method of distribution but was recommended

by the SSREC who did not give ethical approval for the proposed method of distribution. Other reasons for the low response rate are that parents were not given any incentive to complete the questionnaire and parents may have felt that the questionnaire would take too long to complete. An important issue to consider is that parents may have found the questionnaire difficult to complete because of language or literacy constraints. This should have been tested for in the pilot study but there was a non-response bias from parents with language or literacy difficulties. The readability of the questionnaire was considered, but this may not have been sufficient to allow for parents whose first language is not English or parents with literacy/numeracy problems to complete the questionnaire.

### **5.6.3 Respondents**

In terms of the characteristics of the parents who responded to the questionnaire, the majority of respondents were parents who had chosen to vaccinate their child with the MMR vaccine. This indicates a non-response bias from parents who had not given their child the MMR vaccine. This presented a problem for this study as specific research questions and tests could not be answered as they relied on testing to see whether there were any differences between immunisers and non-immunisers in terms of their demographic, HBM and information characteristics.

There are a number of reasons why there were so few non-immunisers who responded to the questionnaire. One of the reasons is that parents who did not vaccinate their children with the MMR may have feared responding to the questionnaire as they may have felt that their responses may have been accessed by HCPs or other interested parties who may have contacted them regarding this decision, as discussed in section 5.6.2. It may also be the case that parents who decided not to get their children vaccinated with the MMR vaccine had specific issues, which meant that they found the questionnaire harder to complete than other parents, such as language barriers. It is important to note that non-response bias may be out of the control of the researcher and all feasible factors were controlled for when the study was designed.

The parents in this study were relatively diverse in terms of ethnic background. The figures for the ethnic background of parents in this study demonstrated that there were a greater percentage of non-white parents in this study than in the population of Sheffield.

However the parents in this study were more likely to be from a higher socio economic class, which means that the results of the study cannot be generalised to the wider population of parents.

#### 5.6.4 Questionnaire design

In terms of the design of the questionnaire, parents (both in the pilot study and in the main study) mentioned that they found some of the questions difficult to answer. Parents commented that the questions relating to susceptibility were unclear. The questions asked whether parents thought that without vaccination their children were likely to catch the diseases of measles, mumps and rubella. Parents added the following two comments to the questionnaire: "Could but unlikely". "Don't know how likely but would be very vulnerable if germs were about". Parents also had similar comments regarding the questions relating to severity. The questions asked the extent to which parents felt the diseases of measles, mumps and rubella were serious. Parents added the following comments: "What do you mean by serious?" "Could be" "I feel that some choices in the questionnaire are impossible to answer, in most cases measles would not be a serious disease but in a small minority of cases it would be". These comments highlight the conflict between ensuring that the questions relate to the HBM and ensuring that the questions are understandable for parents. It is a limitation of the study that parents found the questions difficult to answer and it may have been possible to word the questions differently so that they were understood by parents. What is key in using the HBM is that the constructs of susceptibility, severity, benefits and barriers are measured accurately. With no validated model to assess these constructs, a decision was made to construct the questions in a similar manner to previous research that used the HBM. However, it may have been more useful to construct these questions to make them as understandable to parents as feasible within the constraints of measuring the four constructs.

The additive approach, as outlined in section 5.2.8.2, was used to test the predictive value of the HBM. However, the predictive capabilities of this additive approach are compromised when the perceived susceptibility and severity of a condition tend to score lower on the scale i.e. when the condition is not perceived to be serious and the child is not considered to be susceptible. This lower perceived threat can then compromise the likelihood scores calculated. This is because this low perceived threat, when combined

with the barriers to the action may not be outweighed by the perceived benefits of the action. The mean scores for susceptibility to the conditions ranged from 1.85-1.94 and the mean scores for severity ranged from 1.48-1.76, which may have led to this being an issue in the calculation of overall likelihood scores.

The operationalisation of the HBM was complex. With no validated instrument to predict the likelihood of a preventative action being undertaken, the design of the questionnaire needed to operationalise the constructs of susceptibility, severity, benefits and barriers, which provide some challenges in the questionnaire design. Examining the diseases of measles, mumps and rubella was less complex. It was believed that the MMR vaccine scare had less of an impact on the parents in terms of their perceptions of the conditions of measles, mumps and rubella than it did on their perceptions of the benefits and barriers of the MMR vaccine. However, the questions relating to measles, mumps and rubella were easier to operationalise. In terms of the questions relating to the MMR vaccine, it was important to incorporate the issues relating to the MMR vaccine scare whilst also being aware of parents' views about the MMR vaccine if they had not been influenced by the MMR vaccine scare. However, a number of the questions that were included in the benefits and barriers constructs may not have accurately reflected these constructs. The question relating to the importance of their child being protected against measles, mumps and rubella does not lead to the automatic assumption that parents believe that the MMR vaccine is the best and only way to confer this protection to their child. This question only measures the extent to which parents believed that their child should be protected against measles, mumps and rubella rather than the role of the MMR vaccine in conferring this importance. Again, this may be the case with the question that relates to the importance of conferring herd immunity to the wider population. While the MMR vaccine can confer herd immunity, so can single vaccines against measles, mumps and rubella. Therefore a belief that herd immunity is important does not automatically mean that the MMR vaccine is considered to be a benefit. The operationalisation of the barriers construct was the most complex. The aim of the barriers construct was to look at the factors that made parents less likely to proceed with the MMR vaccine within the context of the MMR vaccine scare. However, the responses to two of the constructs were reversed and this construct was not able to contribute to the likelihood score. While a likelihood score was calculated which incorporated constructs addressing both the MMR vaccine and the MMR vaccine scare, the existence of a validated instrument may have allowed the barriers construct to

be included. The reasons cited above contributed to the finding that the HBM as operationalised in this study was not predictive of the likelihood of MMR vaccination. However, the constructs that contributed to the likelihood score did have internal consistency, suggesting that the operationalisation of the HBM had some strengths as well as weaknesses

The number of parents who incorrectly completed the ranking of sources also limited the study. Quite a high proportion of parents used each of the numbers more than once. As can be seen from the questionnaire in appendix 2.8, parents were asked to indicate only one ranking per source and each ranking only once, but unfortunately did not follow this guidance.

Threats to validity in this study may have come from acquiescence, particularly in the case of the questions which required a Yes/No answer. Validity can also be compromised by random error. There are two main types of error when carrying out statistical analysis. Type I errors occur when a true null hypothesis is rejected, i.e., in reality there is no association between two variables but statistical testing (especially when multiple tests are being undertaken) suggests that there is an association. Type I errors are generated when carrying out multiple statistical tests (i.e., when  $p=0.05$ , 1 in 20 associations will happen by chance by definition) and results must be interpreted in light of these potential problems. Type II errors occur when a false null hypothesis is not rejected, i.e., there is an association between two variables but the null hypothesis that rejects this association is not proved to be wrong. This is often the case when there are small cell sizes and this was a problem in this study, especially when comparing immunisers and non-immunisers.

### **5.6.5 Pilot study**

The main measure taken to optimise the quality of the study was the pilot study. This aimed to improve the usability and accessibility of the questionnaire. However, the homogenous nature of the pilot participants in socio demographic terms and the fact that the pilot study did not include any parents who had chosen not to immunise their children meant that there might have been specific issues relating to the questionnaire which these groups may have had which were not addressed. This was compounded by

the fact that a nursery in the most deprived tertile could not be recruited to assist in the study.

### **5.6.6 Conclusion**

This study had a number of limitations which have been addressed in this section. Despite these limitations, the questionnaire generated a large amount of interesting data, which has given greater insights into the role that information plays in decision-making and has allowed the HBM to be tested in the scenario of parents and the MMR vaccine scare. However, the results generated cannot be generalised beyond the sample from which the data were collected.

## **5.7 Conclusions**

Firstly the use of the HBM is assessed in comparison to other studies that have used it. Then the findings of the questionnaire study are summarised.

### **5.7.1 Comparison to previous studies**

The questionnaire study sought to find out more about parents' use of information, their information needs and preferred information sources. In addition, it used the HBM to examine whether parents' views about the conditions of measles, mumps and rubella and their views about the MMR vaccine were predicative of the likelihood of MMR vaccination. In light of the complexity of using the HBM, it is interesting to look at whether the findings from this operationalisation of the HBM can be related to previous research that has used and critiqued the HBM

In terms of how the HBM was measured, this study used a Likert scale to question parents about susceptibility, severity, benefits and barriers. While previous research has used a Likert scale to assess the concepts of susceptibility, severity, benefits and barriers, it has often measured self-efficacy or cues to action using similar methods to those of susceptibility, severity, benefits and barriers (Gore et al., 1999). In this study the Likert scale was used to measure susceptibility, severity, benefits and barriers, but was not used to measure the other constructs. Using a Likert scale for these may have strengthened the findings of the study.

Most of the previous research using the HBM has found that the concepts of susceptibility, severity, benefits and barriers are predictive of a health action. This was not the case in this study. In terms of the results of this study, the concepts of susceptibility, severity, benefits and barriers were not predictive of MMR vaccination when combined. In particular, the barriers construct was complex to operationalise and was not internally consistent. This is unfortunate as Janz and Becker (1992) found that the barriers construct is the construct most predictive of action. While this is a weakness of the study and does not compare well to other studies, Harrison et al. (1992) do caution that combining the constructs of susceptibility, severity, benefits and barriers may often reduce the predictive validity of the HBM. The difficulty in operationalising the HBM was confirmed by the systematic review of Harrison et al. (1992), which found that of the 22 significant studies, 15 were rejected on the grounds that the same underlying construct was not being measured by the studies.

More specifically relating to previous studies, Gore et al (1999) and Tuma et al. (2002) found that socio-demographic factors were important in determining immunisation uptake. As has previously been discussed, the homogenous nature of the participants made a measurement of socio-demographic status on MMR vaccine uptake unworkable. Although Norman (1995) did not examine the issue of immunisation, he found that a reminder card acted as a cue to action and encouraged uptake of a preventative health action. In this study 77 parents (80.2%) received information in the form of a leaflet from the GP, which may have acted as a cue to action and encouraged MMR vaccine uptake.

To summarise, the HBM was a complex model to adopt in this study, but it was felt that it was the most appropriate model to attempt to understand further the decision making surrounding the risk of the MMR vaccine and the risks of measles, mumps and rubella that parents had mentioned in the interview study. While the operationalisation of this was complex, the comparison with previous studies has indicated that other research has found the process of operationalisation to be complex. Also, some of the major findings of previous research were not measured by this study due to problems with the study sample (i.e. socio-demographic status).

However, the HBM is used here as part of a larger study and while the findings may have not had the predictive power that other models may have potentially provided, the

findings have contributed to the understanding of the numerous factors that are involved in the decision regarding MMR vaccination and, with the exception of the barriers construct, contributed to an understanding of the factors likely to encourage MMR vaccination.

### **5.7.2 Findings**

The questionnaire study yielded interesting data relating to demographic, HBM and information factors in the MMR decision-making process. The limitations with the sample and respondents as outlined above did limit the generalisability of the results but despite this the aims of the questionnaire study were achieved and more is known about the impact of the three independent variables (demographics, information and the HBM on the MMR decision). The following section summarises the HBM and information findings.

In terms of the HBM findings, parents have an evident awareness of the dangers of the diseases of measles, mumps and rubella. While the majority of parents viewed the MMR vaccine as being effective, it is worth noting that 24% did not know whether the MMR vaccine was safe and 32% would opt for single vaccines for measles, mumps and rubella if they were available. However, the finding that despite the concern of parents, the majority proceeded with the MMR vaccine perhaps indicates that parents were more influenced by their opinions about the diseases of measles, mumps and rubella rather than their opinions about the MMR vaccine. The calculation of the likelihood of MMR vaccination score allowed parents to be divided into those likely and unlikely to vaccinate. Removing the barriers construct meant the likelihood of MMR vaccine scale was internally consistent and the success of this likelihood of MMR vaccination score can be seen by the finding that male children were less likely to have had MMR vaccination and parents of male children were considered to be less likely to vaccinate with the MMR vaccine.

In terms of information, 76% of parents indicated that the MMR vaccine scare increased their information needs. Despite this, only 50% of the parents in the sample indicated that they had sought additional information to that which they had received. This suggests that either parents' information needs were being met by the information they received, or that parents were making a decision with their information needs unmet or



that the parents did not believe that the information they wanted was available. The parents in this study emphasised the importance of interpersonal information, either from HCP or friends and family. This indicates a need for two-way communications between parents and other people and the high MMR vaccination rates would indicate that parents' information needs were met by this communication.

When asked to rank information sources, official information was ranked relatively highly. However, when asked to provide written comments, parents were generally negative about information from official sources and questioned the motivation of the information provided by HCPs and the Government. Many of the parents in the study suggested that they had no need for information about the MMR vaccine as they were convinced that there were no problems with it, whereas other parents delayed their decision about the MMR vaccine, possibly indicating that they required more information and time in which to gather this information. The repeated use of the word 'conflicting' in comments relating to the information sources that parents felt were useful or could be trusted is interesting as it indicates how parents felt about information and the influence that information may have had on their decision. This conflicting information appeared to make parents' decisions harder. Again, the influence of personal experience was important in parents' decision-making process:

While the intention of the questionnaire was to differentiate between the information that parents were given and the information that they actively sought, parents' relationship with information was more complex than this suggests. Received information was not necessarily passively received and unsolicited, but may have formed part of the information that parents sought. In addition, sought information could take one of a number of forms. Sought information could be information that parents sought and received, information that was sought because parents hadn't received information or information sought as a response to received information. The complexity of parents' relationship with information is suggested in this section but merits further examination on the extent to which parents are active in their search for information influences how they use that information.

Despite the fact that this study had a number of limitations, a wide range of interesting data relating to demographic, HBM and information factors was generated. The questionnaire study has given a greater insight into parents' information needs and the

information sources that they prefer to use as well as testing the HBM in the context of the MMR vaccine scare. Although the modifications of the HBM meant that the conditions of measles, mumps and rubella occupied a more prominent role in the calculation of likelihood scale, answers to other questions and written comments emphasised that the decision to vaccinate was mostly determined by parents' opinions about these conditions. The qualitative data enhanced the quantitative data and confirmed the findings.

The next chapter (Chapter Six) brings together the qualitative data from the interview study and the quantitative and qualitative data from the questionnaire study in order to triangulate for confirmation and completeness. This is especially important in light of the limitations of the questionnaire study. The emergent issues from the triangulation will then be used to inform the design of the content analysis study (Chapter Seven).

# Chapter Six - Triangulation

## 6.1 Introduction

This chapter presents the triangulation of the data collected in the interview study (Chapter Three) and the questionnaire study (Chapter Four). The purpose and methods of triangulation have already been discussed in Chapter Three. The purpose of triangulating the data in this study is both for confirmation and completeness and in order to provide data for the final stage of data collection, which was a content analysis of media information concerning the MMR vaccine scare (Chapter Seven). The results of the triangulation are presented in three key themes, relating to the MMR vaccine scare;

- The information needs of parents
- The preferred information sources of parents
- The role of information for parents in the MMR vaccination decision

The development of these themes is discussed before the data are presented. The limitations and the validity of triangulating the interview and questionnaire study data and qualitative and quantitative data are addressed, before the role of the data generated by triangulation for the content analysis is presented and conclusions are made.

## 6.2 Aims

The aim of triangulating the interview study data (which consisted of qualitative data) and the questionnaire study data (which consisted of quantitative and qualitative data) was *“to examine a single social phenomenon from more than one vantage point”* (Schwandt, 1997, p.257).

This aim can be further broken down into the following objectives:

- To triangulate data relating to parents' information needs in order to examine and identify:
  - What parents say their information needs are
  - What the data suggest that parents' information needs are

- The information that parents are receiving
- The information that parents are seeking
- To triangulate data relating to parents information sources in relation to the following questions:
  - What information sources do parents receive information from?
  - What information sources do parents seek information from?
  - What are parents preferred information sources
- To build up a picture of parents' information needs and their key information sources

## 6.3 Methods

### 6.3.1 Overview

As Roberts et al. (2002) discussed, there have been extensive debates about the worth of combining qualitative and quantitative data. Methods designed for data analysis in health research have tended to emphasise the importance of quantitative data over qualitative data. However, as Roberts et al. (2002) (and many other researchers) have found, combining qualitative and quantitative data is worthwhile and provides meaningful secondary data, which enhance the initial data collected.

### 6.3.2 Development of themes

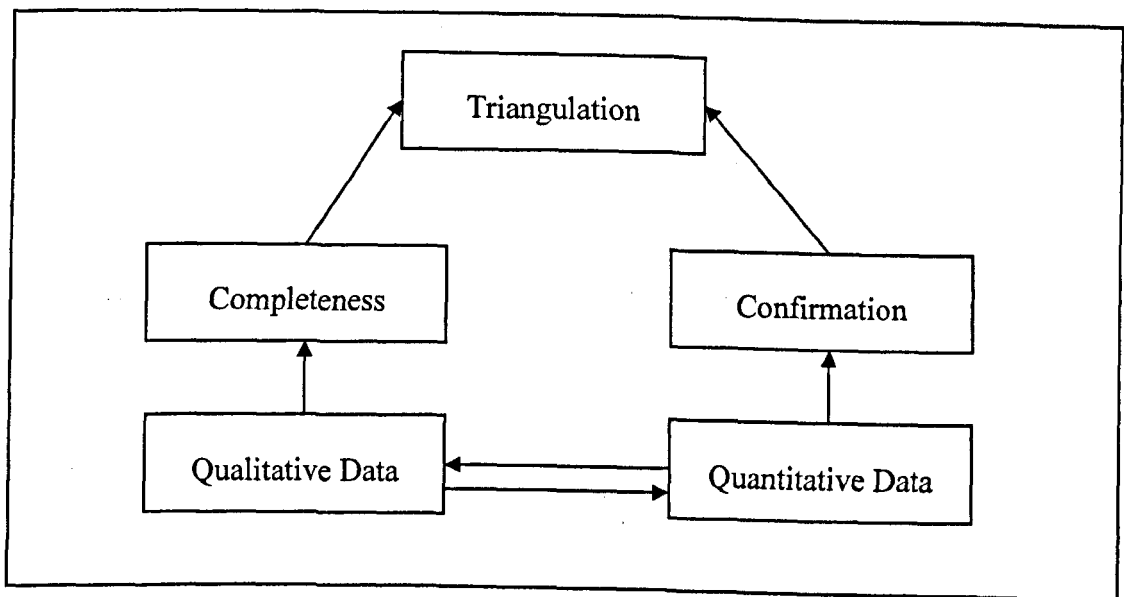
The development of the themes used in the triangulation was informed by the research questions and aims of the overall study, as well as the themes generated in the interview study and the results from the questionnaire study. The data from the interview and questionnaire studies were read and key themes were noted. Commonalities between themes were noted and used as the basis for the themes used in the triangulation.

### 6.3.3 Triangulation of data

Data were triangulated using a manual approach. Initially the interview study themes were examined and key themes addressing information needs and information sources were noted. These key themes were then compared with the results from the questionnaire study. This led to the creation of a number of themes, which were used as

the basis of the triangulated data. Data were compared in order to triangulate for confirmation (when the same or similar point had been made in the interview and questionnaire studies) and completeness (where the interview data can provide a fuller picture when compared to the questionnaire data). It is important to note that parents in the questionnaire study also made qualitative comments. The quality and extent of these comments meant that the triangulation actually took the form of triangulating qualitative (from both the interview and questionnaire study) and quantitative data (from the questionnaire study), as opposed to triangulating the interview (purely qualitative) and questionnaire (purely quantitative) studies as originally intended. Figure 6.1 summarises this process. The focus of the triangulation was two-fold. Firstly, triangulation for confirmation used the quantitative (statistical) results from the questionnaire study to confirm the qualitative results of the questionnaire and interview studies and secondly, triangulation for completeness revisited the qualitative data from the questionnaire and interview studies in light of the findings of the quantitative data from the questionnaire study.

Figure 6.1 - Triangulation of data



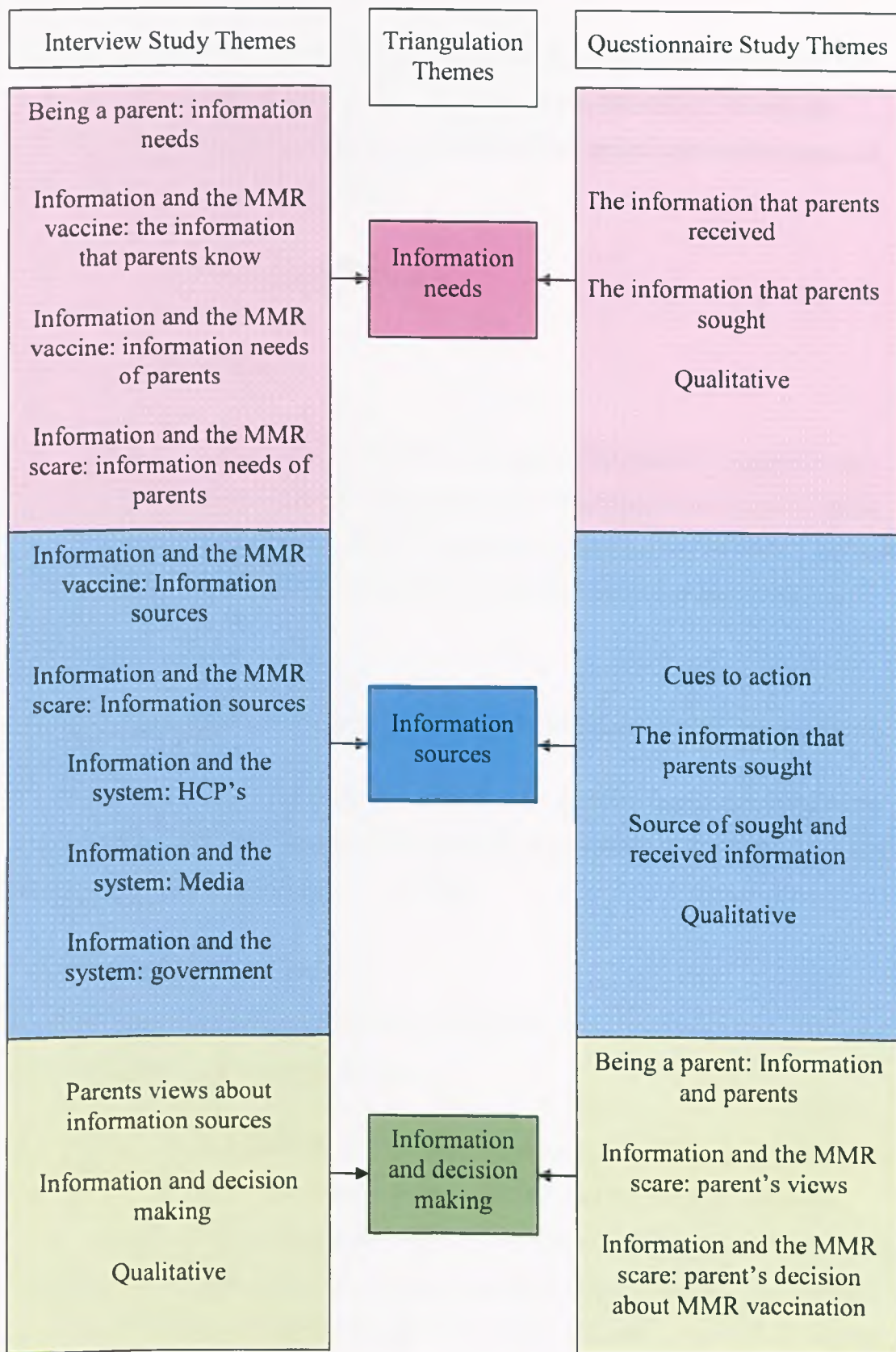
In terms of the presentation of the data, parents from the interview study can be identified by the fact that they were allocated anonymised names, whereas parents from the questionnaire study were allocated numbers.

## 6.4 Results

### 6.4.1 Overview

The findings of the triangulation are presented in terms of the themes in Figure 6.2. The triangulation was based around three key themes, the information needs of parents, the preferred information sources of parents and the role of information for parents in the MMR decision. These themes were derived from the two sets of data: the qualitative data from interviews with 17 parents and the quantitative data from questionnaires with 112 parents, as well as from the research questions.

Figure 6.2 - Development of triangulation themes



## 6.4.2 Information needs

This section examines parents' information needs about the MMR vaccine and the MMR vaccine scare. Parents' information needs were understood to be both the information that parents said that they wanted and the implicit information needs of parents that emerged from the data.

### 6.4.2.1 Triangulation for confirmation

#### Measles, mumps and rubella

The qualitative findings from the interview and questionnaire study, suggested that parents did not have any specific information needs relating to reasons for the MMR vaccine. This may be due to the fact that they believed that as they had proceeded with the MMR vaccine, they would not require information about measles, mumps and rubella.

don't have a desperate need for information ... because I am assuming that my children are protected  
(Kate)

The general lack of information needs relating to the measles, mumps and rubella may also be related to the fact that most of the parents suggested that they were aware of the implications of measles, mumps and rubella:

I know that measles is a killer (Susan)

I know that rubella can be dangerous for pregnant women (Mary)

I know that mumps can make boys infertile (Helen)

Fifty-six out of 117 parents (50.4%) within the questionnaire study sought information about the MMR vaccine and of these 56 parents, 38 sought information about the reasons for the MMR vaccine, which will have concerned measles, mumps and rubella. This information seeking may have not been directly related to measles, mumps and rubella but more related to information seeking about the safety of the MMR vaccine.

It is important to distinguish between the information that parents say they want and the information which parents require, although this requirement is not expressed as an information need. Some parents in the interview study may have had information needs



in the sense that personal experience may have led to a perception that protecting against measles, mumps and rubella was not important:

... I had measles, mumps and rubella. I am absolutely fine so why vaccinate in the first place (Jean)

In our family it was never perceived of as a big illness. It was just something that you got (Lisa)

... we all had measles and we are all ok and I think that had contributed to the difficulty that 'well why do you need this fairly harsh vaccine...when we all had it [Measles] and we are all ok' (Kate)

This contrasts with the findings of the questionnaire study which indicated that a large majority of parents in the questionnaire study believed that the diseases of measles (91.9%), mumps (87.9%) and rubella (78.6%) were severe. Additionally, over 90% of parents in the questionnaire study believed that it was important that their child was protected against measles, mumps and rubella. These views indicate the importance with which parents viewed the MMR vaccine in protecting against measles, mumps and rubella. This may have led to parents not needing information to reinforce these opinions. However, in the questionnaire study, there was a significant association between the gender of the child about whom the questionnaire was completed and the perceived severity of rubella, with parents more likely to believe that rubella would be a serious disease for their child if the child were female. This may indicate that parents have unmet information needs (or that they do not have this knowledge) as the perception that rubella is more serious for female children is incorrect.

There is an apparent discrepancy between the parents in the interview study and the questionnaire study. Parents in the questionnaire study believed that the diseases of measles, mumps and rubella were very serious and related to this, they did not have information needs that needed satisfying, as MMR vaccination was the method through which they protected their children. In contrast, parents in the interview study did not suggest that the diseases of measles, mumps and rubella were serious, citing personal experience as the reason for this belief. Therefore parents in the interview study satisfied their information needs through personal experience and as a result had a perception of measles, mumps and rubella which was not influenced by information. Therefore the results from the questionnaire study do not confirm those of the interview study as the two studies generated very different results, although the commonalities have been highlighted.

## The MMR vaccine

Parents in the interview study claimed to be knowledgeable about the MMR vaccine, as the following examples show:

I know it's three vaccines together, a triple vaccine (Becky)

I know that there are three live viruses (Jean)

I know that they have one when they are fifteen months and one when they are about five and you can expect a reaction within about ten days (Annie)

... that it is two doses, one at a year, one at pre-school (Heather)

However, parents also had information needs about the MMR vaccine:

I would like to know the ingredients of the MMR jab (Susan)

... what we don't know is how the MMR given to a young baby impacts on the later requirements for immunisation (Kate)

... the one thing I am conscious that I don't know is that my children have had the MMR is whether that means they are 100% protected (Susan)

... why do you have to have it in a triple form ... I think that is the information that I require (Kate)

Over half of parents in the questionnaire study indicated that they sought information about the MMR vaccine (n=56, 50.4%). This suggests that parents had unmet information needs about the MMR vaccine from the information that they received. In terms of the information that parents sought, 91.1% of parents (n=51) sought information about the ingredients of the MMR vaccine, indicating that this is an area in which their information needs relating to the MMR vaccine are not being satisfied by received information and an area in which parents would appreciate more information.

Parents' information needs relating to the MMR vaccine can also be examined through the number of "don't know" responses in the questionnaire. Five parents (4.5%) did not know whether the MMR vaccine would protect their child against measles, mumps and rubella. A relatively large proportion of parents did not know whether the MMR vaccine posed a risk to their child's health (n=27, 24.1%). The "don't know" responses may indicate either a lack of knowledge or knowledgeable uncertainty i.e. where parents believe that there are risks attached to the MMR vaccine but are uncertain about

whether they believe these risks to be of concern to them. In the case of a lack of knowledge, the “don’t know” respondents may have unmet information needs, which need to be addressed. However, it is possible that parents may not require more information, in that they have accessed the information that they want, but believe that it is impossible to make a decision based on the information provided.

The results from the questionnaire study confirm the findings from the interview study which suggested that parents have unmet information needs relating to the MMR vaccine. In both studies these information needs were evident in the information that parents said they wanted but also in the information about which they were unsure about. This misunderstanding and lack of information may be generated by the MMR vaccine scare, which is discussed in the next section.

### The MMR vaccine scare

The increased awareness of parents about the alleged side effects of the MMR vaccine led to parents expressing increased information needs:

... why do you have to have it in a triple form... I think that is the information that I require (Kate)

No one has been able to give me a definite answer on ... whether egg allergy should be any contraindication to the mumps part of the vaccine (Annie)

They also wanted information about single vaccines, which had been promoted as an alternative to the MMR vaccine, especially in the mass media:

... there is not enough information on how to arrange the single vaccines (Parent 93)

... possibility of single vaccinations (Parent 5)

I cant understand why they wont go down to three single jabs (Sally)

The finding that 50.4% of parents sought information about the MMR vaccine indicates that parents may have unmet information needs, although that these are as a result of the MMR vaccine scare is more difficult to prove. Interestingly, the least frequently sought content of information about the MMR vaccine by parents in the questionnaire study was about the safety of the MMR vaccine which is surprising in light of the MMR vaccine scare. However, this may be as a result of the manner in which the question relating to information about the MMR vaccine was phrased. Asking parents whether

they sought information about the risks of the MMR vaccine may have generated different answers to asking parents whether they sought information about the safety of the MMR vaccine. However, the phrasing of the question was designed to try and make the question seem as neutral as possible and to avoid suggesting that there were risks attached to the MMR vaccine.

As well as expressing needs for information about specific issues, parents also wanted information from specific sources and that had specific characteristics:

We would like to see ... a medical study into the kind of children more likely to develop bowel problems and autism as a result of the MMR triple vaccine (Annie)

I would rather have specific research ... (Lisa)

It would be nice to see a straightforward report on it rather than all this arguing (Jane)

It is confusing and conflicting. In order for it to be informative you have to sift through the information (Naomi)

Good solid reliable informative information (Parent 73)

Information was not only needed for practical issues and decision-making, it was also needed for reassurance, which explains the desire for information about the vaccine status of Leo Blair (as described in Chapter Four):

I think that Tony Blair should have come out and said whether or not his little boy had had the jab. I think that it is important because what the public needed was a show of confidence (Rosie)

... people really do need to know, if he is telling us that it is safe, he means that it is safe for his children as well (Alison)

Twenty one parents were unable to make an informed decision about the MMR vaccine which suggests that they had information needs that were unmet, although again it cannot be proved that these are linked to the MMR vaccine scare. Of these 21 parents, 12 gave reasons for being unable to make an informed decision, with the most frequent response ( $n=5$ ) being that there was not enough information available. Clearly, the MMR vaccine scare generated information needs for parents as 82 parents (75.9%) responded that they wanted more information as a result of the MMR vaccine scare with 26 parents (24.1%) responding that they wanted less or the same information.

#### 6.4.2.2 Triangulation for completeness

##### The MMR vaccine

The questionnaire study found that information needs relating to the MMR vaccine are influenced by whether parents already have children. The results from the questionnaire study showed that parents who wanted more information were significantly more likely to have only one or two children ( $\chi^2 = 5.073$ , d.f. = 1,  $p=0.02$ ). An explanation for this finding can be uncovered by a re-examination of the interview data:

Having a child who had the vaccine without any problems 9 yrs ago influenced my decision more than anything else (Parent 32)

Both my older children had the vaccine and they were fine so I had no reason to think my youngest child should be in danger from the vaccine (Parent 36)

I went ahead [with first child]. This made me worry less when it came to the time for no.2 to have his vaccine. (Parent 79)

It can be seen that having had children who had been previously vaccinated with the MMR vaccine meant that parents felt adequately informed and did not require further information.

#### 6.4.3 Information sources

This section addresses parents' use of information and their views of information. The results are presented in terms of the different information sources that parents used.

##### 6.4.3.1 Triangulation for confirmation

##### HCPs

Parents used HCPs for information about the MMR vaccine and the MMR vaccine scare:

What the doctor has said...that seems to have covered most of what I need to know (Susan)

I have been to see...the immunology expert for Sheffield (Annie)

Conversation with the GP/health visitor was the second most frequently received type of information for parents, with 52% of the parents in the questionnaire study receiving information relating to MMR from the GP or health visitor.

Some parents were positive about the information that they were provided with:

The doctor is fantastic. I am really lucky that we have got a good doctor (Mary)

... we went and said that we had our doubts, that my husband had his doubts, they didn't dismiss them, they provided us with further information, to enable us to make the choice (Alison)

Of the 56 parents in the questionnaire study who sought information, over half (n=29) sought this information from a HCP, which may suggest that information from GPs was the most easily accessible information or that GPs were an information source which parents wanted to use. This was confirmed by the finding that GPs and health visitors were the mean highest ranked information sources in terms of usefulness and the first and third mean highest ranked information source in terms of trustworthiness in the questionnaire study.

Information from HCPs was supplied in a variety of formats:

I have been to see the immunisation woman ... the immunology expert for Sheffield ... I got some advice from her and some papers (Annie)

... the GP made available ... a file of recent publications and medical journals that he allowed us to take away and read to bring back (Alison)

The health visitor and the people in the hospital either gave me leaflets or [I] talked about particular issues with the doctor (Carol)

Having a talk by a GP at antenatal class was very good (Parent 101)

However, not all parents believed that HCPs could supply them with information:

... a lot of health professionals don't have any information (Becky)

I think health visitors and doctors need to do more training on the subject because at the Smithfield surgery, they haven't got a clue (Parent 13)

It would be very nice if the health visitors were up to speed because I don't think that a lot of them are (Heather)

Parents expressed mistrust in the information from HCPs for a variety of reasons. These included the conflicting information they received:

... all the doctors we saw said we should and all of the health visitors and pharmacists and nurses said that we shouldn't (Annie)

I got different answers from my health visitor and my midwife (Sharon)

Parents were also unwilling to use information from HCPs because they were seen to be dogmatic in their approach to the MMR vaccine:

... they weren't even willing to discuss an alternative point of view and they just said 'no it is perfectly safe' (Mary)

I was concerned that the nurse at my GP's practice did not give any credit at all to the reports that MMR is linked to autism. There must be some link and would have preferred a more open approach. (Parent 61)

Information was also mistrusted because HCPs were seen as being unduly influenced by the Government, whose main concern was herd immunity:

Health care professionals do what they are told to. They spew out the standard line and are not free thinking (Naomi)

I find it hard to put a lot of trust in what they say because they go on the government recommendations (Becky)

NHS concerned with epidemic prevention (Parent 12)

Parents in both the questionnaire and interview studies used HCPs extensively. However, the conflicting approach of different HCPs and parents' perceptions of the Government's influence on HCPs led to mistrust of HCPs by parents in the interview study. In contrast the quantitative evidence from the questionnaire study found that HCPs were viewed as being trustworthy and useful (highest ranked sources for usefulness and trustworthiness). This can be in part explained by the qualitative results from the questionnaire which showed that parents in the questionnaire study had negative feelings regarding HCPs. This indicates that while HCPs were considered to be the preferred information source for parents, this does not mean that they were an information source which was not criticised.

## Leaflets

Some parents in both studies were positive about leaflets as an information source:

I think that leaflets are a good idea ... I think they are the best thing because you tend to keep hold of them (Jane)

... you do get some good leaflets at the doctors surgery (Mike)

I found leaflets informative (Parent 2)

In the questionnaire study, the leaflet was the most frequently received source of information with 77 parents (80.2%) receiving initial information about the MMR vaccine from leaflets. However, a relatively low proportion of parents sought information in the format of a leaflet (n=18, 32.1%). This may be due to parents' unwillingness to choose the leaflet as an information source, or that parents believed that they had received all the information that was available in leaflet form. Information from the NHS was parents' second most-useful and third most-trusted source of information. This information was likely to be in the format of a leaflet.

Parents in the interview study found leaflets to be insufficient in terms of the amount of content that they contained:

Information leaflets to parents don't include risk assessment of your child being affected (Parent 107)

... she gave me ... a little leaflet and it didn't tell me anything that I needed to know (Sally)

Leaflets were also criticised as they were seen as being influenced by other authorities:

... they gave us a leaflet, the gen that the Heath Education Authority wants you to know which doesn't really tell you a great deal (Carol)

NHS leaflets were obviously towing the government line with no room for doubts (Parent 12)

Parents' opinions on leaflets in the questionnaire study confirmed the findings of the interview study. Parents had mixed opinions about leaflets regarding the MMR vaccine and this was reflected across both studies. The majority of parents were aware of, and used leaflets but were sceptical of the quality and motives behind them. Scepticism about leaflets, especially by parents in the interview study needs to be addressed, as they were the second most frequent source of information to cue parents to action.



### Interpersonal information sources

In terms of the decision about the MMR vaccine, information from friends and family generally played a positive role for parents. This role could simply be the provision of information:

My mum is a doctor; I have things like the BMJ from her (Annie)

My mum is one that tends to send me everything that she sees, articles and that (Helen)

However, interpersonal information sources also occupied a support role for parents:

It was very difficult to make a decision ... It was only because I had a friend who was a GP who advised me that I decided to go with it (Parent 98)

... my friends said their kids were fine so I went ahead (Parent 79)

... my mother stated that my sister and I had MMR and my other two elder children had it and all were fine after the vaccine (Parent 77)

...the other influential thing was talking to friends and family who have also made the decision (Carol)

Friends and family were the most popular source from which parents sought information about the MMR vaccine with 58.9% of parents who sought information using friends and family. A small number of parents mentioned that this was because they had friends and/or family who were HCPs. It is not clear whether this information was negative or positive with regard to the MMR vaccine, but in light of the levels of MMR vaccination among respondents in the questionnaire study, it is probable that this information was positive.

### General mass media sources

Thirty-nine parents in the questionnaire study (34.8%) were made aware of the MMR vaccine by the media, as were parents in the interview study. However, although the media were considered important in the initial stages when parents found out about the MMR vaccine scare, parents were less positive about the media in the long term:

It concerns me a little bit more because ... since she has had it there has been a lot more in the news about it (Jane)

The media debate was very disturbing. The anti-MMR campaign seemed to get all the hype, but had no real evidence (Parent 49)

My husband and I disagreed about the MMR vaccine - he was more influenced by the scare tactics in the press than I was. (Parent 45)

Parents mentioned the fact that they believed that the media reporting was inaccurate and that the media had manipulated the evidence about whether the MMR vaccine was safe or not:

The media has got hold of it and it has been blown up (Rosie)

I don't think that the media have helped an awful lot with the scare. I think that they have inflamed it (Lisa)

The media wants to make money and therefore the stories are sensationalised (Naomi)

The media were the source from which parents were least likely to seek information. The media also scored the lowest mean score for usefulness and trustworthiness of information sources. The questionnaire study confirmed that a large number of parents are exposed to the media, as the media was mentioned by all of the parents in the interview study. The finding that the media were ranked lowest in terms of trustworthiness and usefulness and were the least sought sources indicates an unwillingness to use this source but also indicates that the media are perhaps not considered to be an information source in the same way as other sources. However, although parents viewed the media in a generally negative light, this did not mean that what they provided was of no use to parents. When parents received media information, they selectively used the information which they believed would be of use to them:

I just take it as a background; I don't take it as a consensus view on anything (Becky)

... to be perfectly honest, the scare mongering in the press, I don't take any notice, or far less than the statistics (Heather)

I will assess the source before I would incorporate any information that I am given into my body of information (Lisa)

I tend to take all media information with a pinch of salt (Sally)

I think that I would probably judge it on whether it is sensational or a publicised scientific article (Heather)

The media can confuse you, but they were fair by giving both sides of the argument (Parent 4)

These findings relating to the media indicate the importance of the media as an information source for parents and this is explored further in Chapter Seven.

### Newspaper

Some parents were positive about the information that they gained from newspapers:

If I really want to start off getting a bit of background, I'd probably get a paper, a good paper and read the newspaper and get a good idea of where to go from there (Becky)

Newspapers covered the debate well (Parent 86)

The fact that newspapers could be accessed 'as and when' meant that parents appreciated them:

... with newspapers I will cut the article out, read it and go back again in a couple of days and read it again (Helen)

I can take in the statistics a bit more rather than just hearing them on the TV (Helen)

Parents in the interview study indicated that they made a distinction between the tabloid press and the broadsheet press. This distinction affected the way in which parents used the newspaper:

I think that the broadsheets would be better in that they would give a more balanced view (Rosie)

The tabloids tend to hype things up a little bit (Jane)

There is a difference between the broadsheets and the tabloids because the tabloids sensationalise the story and seem to lose the truth in it (Alison)

However, some parents were widely critical of all newspapers:

The media, I think, has certainly given rise to the negative impact of the MMR ... I wouldn't trust the media, especially newspapers (Parent 64)

Newspapers were the second least source of sought information by parents in the questionnaire study but were still a sizeable proportion (30.4%). They were also the equal lowest mean ranked information source in terms of usefulness and trustworthiness, which supports the qualitative findings of the interview study. These discrepant findings are worthy of further investigation.

## The Government

Parents were not explicit about the Government as an information source, although parents in both studies had strong views on the Government's role in the MMR vaccine scare. Parents felt that the Government could have a role in providing them with information:

I think they could potentially have quite a lot of influence but I don't think that they do (Helen)

... annoyed as they aren't doing more research. They aren't willing to replicate the research that Dr Wakefield did (Naomi)

However, they were critical of the information which the Government provided:

I do not believe that the general population (sic) is able to make an informed decision when the Government reports are unclear (Parent 15)

... you only hear sound bytes, I haven't heard any politician talk in depth or at length about it (Carol)

I think that the problem is where you tend to see them on television you only get thirty seconds, a minute to talk about it ... if I listened to them talking for half an hour then I might have a little bit more belief in what they say (Heather)

I always think that there's an agenda behind what's said and there are cost implications to what they say (Becky)

... the ... government cloud the issue (Parent 112)

The Government were also criticised for not giving detail about their reasons for supporting the MMR vaccine:

I haven't seen any government programme saying this is what we have actually done, which to me means that they have got something to hide if they are not willing to tell everybody what they have done (Helen)

... we are very concerned and confused by the government's policy on MMR (Parent 40)

I am very sceptical about what the government say, mainly because they talk about why it is good but I haven't heard any of them talk in depth about the sincerely held concerns that these people really do believe that their children have been harmed by it (Carol)

As a result, this lack of information influenced parents' decision about the MMR vaccine:

I know many people who have refused to vaccinate through a lack of trust in the government's motives (Parent 109)

The government did not do enough to allay people's fears (Parent 49)

Parents were also influenced by the fact that the Government were seen as preventing them from having the choice of single vaccines:

... by giving parents a choice it is likely that parents will feel less bullied into a decision which may result in more trust in the Governments advice (Parent 109)

The quantitative findings from the questionnaire study did not include findings regarding parents' use of the Government as an information source and therefore the qualitative findings from the questionnaire and interview studies are not confirmed by the quantitative findings from the questionnaire study.

### Personal experience

Personal experience was arguably an information source upon which parents frequently drew. Parents in the interview study mentioned this in relation to illness, as the following examples show, but did not mention it in relation to the MMR vaccine scare:

I have got a good idea about what is serious and what isn't, so I tend to see how they are in a 12 to 24 hour period (Becky)

I am a children's nurse so I think in some respects, gathering information, I know the right places to go (Sharon)

In contrast to parents in the interview study, parents in the questionnaire study mentioned personal experience as an aid to decision-making. Prior experience with other children was a cue to action for 41 parents out of the 62 who had more than one child:

If the MMR was safe enough for my older 3 children and it had no bad effects on them, then I decided that it was good enough for my youngest child, and that it was also safe enough (Parent 80)

Having a child who had the vaccine without any problems 9 yrs ago influenced my decision more than anything else (Parent 32)

I don't think they know if the MMR is safe or not all three of mine have had it and they are fine and I had it and I'm fine to (sic) (Parent 65)

Both my older children had the vaccine and they were fine so I had no reason to think my youngest child should be in danger from the vaccine (Parent 36)

Parents were more likely to seek information if they had one or two children than three or more ( $\chi^2 = 8.245$ , d.f. = 1,  $p=0.04$ ). This indicates the role of personal experience as a source of information but also indicates that in some cases personal experience is a substitute for information.

Personal experience of measles, mumps and rubella was also a cue to action for the MMR vaccine:

My cousin (sic) had a cast in her eye through catching (sic) measles (Parent 62)

My nephew contacted measles (Parent 29)

As a teacher, outbreaks of Mumps had occurred in school. I felt I needed to vaccinate my child (Parent 48)

The qualitative and quantitative findings from the questionnaire supported each other and gave a fuller picture of the role of personal experience. It was not, however, possible to complete these findings with those of the interview study, as personal experience did not appear to play a role for these parents. It might be that this is due to the timing of the data collection, as at the time of the interview study parents may not have had any experience of decision-making in light of the MMR vaccine scare whereas the more recent data collected as part of the questionnaire study may have included parents who made a decision about the MMR vaccine during the MMR vaccine scare.

#### 6.4.3.2 Triangulation for completeness

##### Interpersonal information sources

The most frequently stated cue to action for parents in the questionnaire study was conversation with friends and family ( $n=52$ ). This indicates the importance of this source in the MMR vaccine decision-making process. In the interview study, other parents were shown to be a useful information source for parents when making decisions (however these tended to be related to parenting information):

A lot of the information is actually gleaned from talking to other mums at playgroup (Lisa)

I found that the best source of information is a friend with slightly older kids because they have sort of been there (Rosie)

Despite the widespread use of friends and family as an information source, parents ranked them relatively low in terms of their trustworthiness and usefulness, with friends and family being the fourth highest mean ranked source. Friends and family were ranked lower than 'official' sources of information such as HCPs but higher than the media. This may suggest that the information they supplied was useful for parents, but that this information played more of a support role, reinforcing information from the more useful and trustworthy official information sources. It may have also indicated that the information received was negative, as was the experience of a parent in the interview study:

I was influenced by other mums saying that there was a problem (Naomi)

#### **6.4.4 Information and decision-making**

The decision about the MMR vaccine was problematic and complex for parents:

The decision to have the MMR jab was one of the hardest ever made (Parent 70)

The decision on whether to give my child the MMR was the hardest I have ever had to make (Parent 112)

It was very difficult to make a decision. It was scary. (Parent 98)

...although I am doing MMR I am not 100% convinced because the scare has affected you (Lisa)

I think I probably went along with slightly more head than heart thinking I suppose that is ok (Kate)

##### **6.4.4.1 Triangulation for confirmation**

#### **Did information influence decision-making?**

Information was evidently a factor in decision-making:

... we wanted every last piece of information that they could give to us (Annie)

I felt the information confirmed what I was feeling (Alison)

It was an educated decision rather than off the top of our head (Sharon)

However, 86% of parents received information about the MMR vaccine, but only 50% of parents sought extra information about the MMR vaccine. Therefore the 36% who did not seek any extra information may have had their information needs met or

alternatively they may not have sought any extra information, as they believed that the information they wanted was not available. Either way this indicates that information was important to parents and may have influenced their decision-making.

Parents also delayed their decision about the MMR vaccine to access information:

My daughter had it later because it took me two months to decide you know, two months to read and make a decision (Becky)

It can also be argued that the 19 parents (17%) in the questionnaire study who delayed their decision about the MMR vaccine may have done so as a result of wanting to become more informed about their decision.

Some parents commented that information had not influenced their decision from the outset:

... basically I didn't read any information. I believe that my children should be vaccinated. It never did my first daughter any harm. And my main thing in life is to protect my children. (Parent 37)

Would have had vaccine even without information (Parent 52)

Have no other intention than to get my son vaccinated (Parent 95)

Others stated that the information that they had received had not aided them in their decision-making:

I think that before we started it we were on the side of not having it really. So I suppose information didn't make us change our mind (Mary)

I had decided before they gave me the information about it (Sally)

... once we decided to go ahead with it, we never pushed for any more information (Mike)

Other parents did not seek information to aid them in decision-making:

I didn't do a lot to seek out information although it is something terribly important (Carol)

For many parents, personal experience was the main factor in their decision-making about the MMR vaccine:



Having a child who had the vaccine without any problems 9 yrs ago influenced my decision more than anything else (Parent 32)

Both my older children had the vaccine and they were fine so I had no reason to think my youngest child should be in danger from the vaccine (Parent 36)

I went ahead [with first child]. This made me worry less when it came to the time for no.2 to have his vaccine. (Parent 79)

### Information as an influence on decision-making

In general terms, parents had a positive view of information as something that aided their decision-making process:

You can make informed decisions about the MMR (Mike)

The finding that 50% of parents in the questionnaire study sought extra information indicates that they believed that information had the possibility to help them in their decision-making. The modal number of sources that these parents referred to was two and the mean was three, indicating that parents did not want to restrict themselves when seeking information and referred to a variety of sources, which may suggest the importance with which information is viewed.

For some parents, information played a positive role in promoting the MMR vaccine. A number of parents supported the MMR vaccine as they were unconvinced by the evidence which questioned the safety of the MMR vaccine:

I have read that research paper. I don't think that it was a particularly good piece of research, tiny sample, relatively low incidence... (Kate)

...it came from one study that wasn't a statistically good study because it was looking after the event and it wasn't a controlled study (Heather)

...when I read that research I thought 'fine'. There is no causal link between autism and Crohn's disease (Lisa)

My view is MMR wouldn't be used if it wasn't safe. There seems to be no actual evidence it's harmful. (Parent 66)

The anti-MMR campaign seemed to get all the hype, but had no real evidence (Parent 49)

The extent to which information played a positive role for parents can be seen in the finding that 86 parents (80.4%) believed that they had made an informed decision. This is a large majority of parents but 21 parents did state that they were unable to make an

informed decision, with six parents being unwilling or unable to believe the information that they were provided with.

Parents may have been reluctant to use information if it was not tailored to their perceived level of intelligence and need for information:

I don't want to have my intelligence insulted (Carol)

You can't just tell people not to do this, not in today's climate; people want to know why (Sharon)

Another reason that information had a negative influence on decision-making was because it was seen as being conflicting as the following quotes illustrate:

It was hard to know who or what to believe as there is so much conflicting information on the subject (Parent 108)

Much conflicting information (Parent 12)

Because there seemed conflicting views as to whether it was safe or not (Parent 1)

Having insufficient information may also have had an effect on decision-making:

I don't think that we had as much information as we should have had or were as informed as we could have been (Susan)

It is noteworthy that 76% of parents (n=82) stated that they wanted extra information as a result of the MMR vaccine scare but only 50% (n=56) sought it. However the finding that 76% of parents wanted extra information indicates that they believe that information can help them in their decision-making.

Parents in the interview study did not always believe that their information needs were being met and as a result, they felt that they needed to be active in their information seeking:

... the only way that you can get more of a balanced argument is to go and look at it yourself (Becky)

If I need to know about something then I will go out and find out about it (Helen)

#### 6.4.4.2 Summary

The findings of the interview study suggested that parents had differing views on the information that was supplied to them by their HCP. In general terms, parents appeared to be critical of the information that they were supplied with for a number of reasons, including insufficient information, contradictory information from different HCPs and the perceived influence that the Government had on the advice that HCPs were giving parents. However, when speaking about specific HCPs, parents tended to be more approving of the information that they supplied. The parents that trusted the information from their GP tended to do so because they had a personal relationship with the GP. As well as that, parents felt reassured by the fact that they were given other information by GPs to supplement the information that they had received from them. These factors together led to parents trusting GPs. In contrast, parents' opinions about health visitors were less complimentary with health visitors being criticised with reference to the fact that the information that they supplied did not meet parents' information needs. These findings appear to be in contrast with the findings of the questionnaire study that found that HCPs were the most-trusted and useful information sources for parents. While these findings may appear to be contradictory, it is worth noting the finding that parents in the questionnaire study had a limited number of information sources from which to rank their most useful and most-trusted. It is also worth pointing out that just because some parents were critical of the information that was supplied by HCPs, this does not mean that they did not trust this information source or find it useful, just that no information source is ideal when meeting parents' information needs.

Parents' qualitative comments in the questionnaire study confirmed those of parents in the interview study who found that leaflets were a source of information which did not include all of the information that parents wanted to know and were not always available for parents. The finding that leaflets are the most widely received source of information and were ranked relatively highly in terms of usefulness and trustworthiness indicates that these qualitative comments may not reflect the general consensus on leaflets and their role in the MMR decision.

Interpersonal sources of information were of importance for parents in both the questionnaire and interview study. The findings of the questionnaire confirmed that parents use friends and family for information and for reassurance. Friends and family

were the most popular source for sought information which underlines the importance of trustworthiness in information sources. These findings may also suggest why a small minority of parents placed such an emphasis on the advice from their HCP as the HCP may have been occupying the support and information role for these parents that friends and family did for other parents.

The findings of the interview and questionnaire study relating to the mass media were relatively confirmatory. While the media were considered to be useful in making parents aware of the questions surrounding the safety of the MMR vaccine (as expressed in qualitative and quantitative data) they were considered to be less useful in the long term. Parents expressed that they felt that media (especially the tabloid media) sensationalised the MMR vaccine scare and therefore any information that was used by parents was assessed for quality. This mixed attitude towards the media can be seen in the finding that about 30% of parents actively acquired additional information about the MMR vaccine from the mass media but the media were seen as being the least-useful and least-trusted source. These somewhat conflicting figures would appear to suggest that when parents acquired information from the media, either actively or passively, they used the information to develop their views or opinions or to support the views or opinions that they held. The information that was not useful to parents was rejected, thus leading to a perception that the information the media supplied was not useful. With reference to parents' opinions about the television, the usefulness of this source depended upon the way in which the information was being presented, e.g., in a news programme or as a debate. The more in-depth the information was, the more parents appreciated it.

The final key information source for parents was not a traditional information source. Personal experience was a source of information for parents in terms of the finding that it acted as reassurance for them when making their decision about the MMR vaccine. This use of personal experience was seen mainly in terms of the parents in the questionnaire study

Parents' opinions regarding the role of information in the MMR decision were diverse but commonalities can be seen in parents' opinions of how information was used and what influence it had on their decision.

Parents in both the interview study and the questionnaire study showed evidence of having delayed their decision about the MMR vaccine. Whether this can be attributed to concerns about the safety of the MMR vaccine is not evident in all cases, but it did influence some parents. Lack of evidence was a factor in parents' decision-making as parents in both the interview and the questionnaire study made a decision in favour of the MMR vaccine as a result of insufficient evidence against it.

The key issue that influenced parents' decision-making was the finding that information was conflicting and this was an issue that was reflected in the comments of parents in both the interview and the questionnaire study. As a result, parents sought to avoid information, either if they had made a decision to proceed with the MMR vaccine or if they had made a decision not to proceed with the MMR vaccine. This avoidance of information presents problems for information providers, especially in light of the finding that a substantial minority of parents in the questionnaire study had been unable to make an informed decision.

## 6.5 Conclusions

The triangulation of the interview and questionnaire study data has provided confirmation about a number of key issues in the interview and questionnaire studies. It has allowed further examination of the ways in which parents use information, parents' information needs and the information that they know and parents' views on *information sources*.

The results from the triangulation were used to aid the design of the content analysis study (which also refers to the research questions for the study and the emergent themes generated by the literature review). Chapter Seven presents the content analysis study.