PILOT SURVEY OF PARENTS’ USE OF THE INTERNET AND MEDIA TO ACCESS INFORMATION ABOUT MEASLES, MUMPS AND RUBELLA IMMUNISATION.

Presented for the degree of Master of Science in Community Paediatrics

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1. Objectives

The objectives of this project are:

- To determine how many parents of children who are due their first Measles, Mumps and Rubella (MMR) immunisation access the Internet to find out information about MMR immunisation.

- To determine which websites they are using.

- To ascertain whether they consider that the material they find on the Internet influences their decision making about MMR immunisation.

- To establish which other sources of information about MMR parents are using and their views about how this influences their decision about MMR immunisation.
2. Introduction

Immunisation programmes have significantly reduced the levels of target diseases in the population worldwide and are an effective public health measure. In industrialised countries immunisation has been so successful at preventing morbidity and mortality due to infectious diseases that many parents and doctors have had no experience of the natural diseases and so fear of their consequences wanes. The greater the success of the immunisation programme at the population level the less health relevance there is at the individual level – the so called ‘prevention paradox’. As a result both the perceived and real risks and side effects of immunisation become more concerning to parents than the actual disease. In the U.K childhood immunisation is not compulsory but the national programme involves large numbers of healthy children. Concerns about vaccine safety are intensified by ready and increasing parental access to information from many sources of varying quality including the mass media and the Internet.

Widespread adverse publicity about putative side effects of a vaccine leads to a decrease in its uptake resulting in subsequent re-emergence of the disease. This occurred with pertussis vaccine in the 1970s and was associated with significant morbidity and mortality. From 1998 to present day (Measles, Mumps and Rubella) MMR vaccine has been the subject of adverse publicity and uptake of MMR has fallen with resultant outbreak of measles in 2002 in London. Britain is currently at high risk of measles re-establishing itself as an endemic disease.

The MMR controversy was accelerated in 1998 when a study was published in a reputable journal (The Lancet) hypothesizing but not proving a link between MMR vaccine, bowel disease and autism. At a subsequent news conference one of the researchers suggested that the combination of three
vaccines in one might overload the immune system and proposed the immunisations should be given separately. In 2001 Wakefield published another paper questioning the safety studies that were carried out before MMR was licensed. Expert groups in the UK and elsewhere have conducted numerous studies into Wakefield's claims but none have found any scientifically robust evidence in support of his hypotheses. In spite of this Wakefield's claims were prominently and consistently publicised by the mass media and have had a major impact on public opinion and knowledge. The controversy was politicised in September 2001 when Tony Blair refused to declare whether his infant son Leo had received MMR and further fuelled by the government's refusal to provide single vaccinations despite much public pressure. In February 2002 BBC television broadcast a documentary (Panorama) which was sympathetic to Dr. Wakefield's views and intensified the controversy. This and the ongoing media coverage has resulted in the uptake of MMR falling from a maximum of 93% in 1993 to 77.9%, (Jan-March 2003) for England, 78% in south-east and 67.9% in London.

Many factors have been established as influencing the uptake of immunisation. These include parental and health professional attitudes and knowledge, parental socio-economic status and service provision. A significant predictor of immunisation uptake is parental attitude. In particular parental beliefs and attitudes about the safety of immunisations are more important in influencing their decision than their perceived seriousness of the disease. In a study exploring the beliefs of non-immunising parents the authors found that the most commonly omitted immunisation was MMR because 'of the fear about long term side effects particularly autism and bowel disease'. These parents perceived mumps and rubella to be mild diseases although two thirds did rate measles as
serious. Parents often feel they do not have enough information about immunisation. In one study 42% of parents wanted to know more about the side effects and long term risks of immunisation, as well as how the immunisation worked and the risks of not having the child immunised. In coming to a decision about immunisation it has been found that many parents undertake a 'risk-benefit' analysis and during this process they search for more information. Parents seek information from a variety of sources including health professionals, friends, family, print and broadcast media and increasingly electronic media. Some parents express dissatisfaction with the immunisation process because of a lack of information. Parents who were dissatisfied with the advice provided by health professionals looked on the Internet for information about MMR.

Health professionals’ positive attitude, behaviour and knowledge are significant factors in determining compliance with immunisation. In studies the majority of parents report turning to and trusting health professionals for information more than any other source. Health visitors are often the first point of contact for parents seeking advice about immunisation at baby 'drop-in clinics' and in post-natal group discussions. However, some parents feel that health professionals give them biased or unsatisfactory information. This is a perception that is strengthened for some by the fact that General Practitioners (G.P.s) receive remuneration for reaching immunisation targets. Other parents receive the wrong advice and are supported in their decision to have single MMR vaccines by health professionals. Some health professional's knowledge about MMR is poor. In one study 33% of practice nurses stated that MMR was likely to be associated with Crohns disease and 27% stated that it was associated with Autism despite expert advice to the contrary. There is wide variation in knowledge and practice regarding MMR immunisation, which is felt to be
influencing the advice given to parents\textsuperscript{17,18}. The Department of Health recognises the crucial role of the health professional in influencing parents decision making and issued a resource pack to all health professionals involved with immunisation in an effort to provide them with the information needed to counteract the adverse publicity in the mass media about MMR.

The media can have a significant effect on mothers' intention to immunise. This was demonstrated by numbers of mothers indicating they would not allow a future child to have MMR, peaking at times when there was high negative media reporting about MMR\textsuperscript{19}. A local paper in Wales mounted a long-running, anti-MMR campaign. This was followed by a significant decline in MMR uptake - 13.6% in the distribution area of the paper and by only 2.4% in the rest of Wales\textsuperscript{20}. Media reporting suggested many mothers had permanently declined MMR whereas actually only a small percentage (6%) of mothers surveyed by 'immunisation information' had done this. One study examined the media (TV, newspapers, radio) coverage of the MMR issue from January to September 2002 in conjunction with exploring the public's knowledge and opinions using a national survey\textsuperscript{8}. They found that the media coverage was very successful in providing the basis of public understanding about MMR and felt that 'the consistency of the coverage, the coherence of the narrative and the connection to the broader public interest made much of it memorable'.

2.1. The Internet

The Internet is an electronic medium that has grown exponentially in its size and popularity. It took five years for 50 million people to use the Internet compared with thirteen years for television and thirty-eight years for radio to establish the same number of users\textsuperscript{21}. It is a channel for both audiovisual communication and access to an extensive amount of current information
for both health professionals and health consumers. For the latter group a major advantage of this medium is its convenience, anonymity and ready access from home twenty-four hours a day. It is important to many health seekers that they can get more information online than they can from other resources. In the U.K 70% Internet users are from more socially affluent groups and nearly half are aged less than 35 years. In the U.S.A 55% of adults with Internet access have used the web to get health or medical information, the majority at least once a month. The longer someone has had access to the Internet the more likely they are to search for medical information.

There has been little published about parental seeking of health information from the Internet on behalf of their children. Some surveys have been conducted on specific parent groups e.g. those attending paediatric outpatients and parents of children with surgical and congenital heart disease problems. These studies showed widely differing rates of parental Internet use (22%-71%) to obtain health information. It is apparent that many parents are using the Internet to obtain information relevant to their children's medical condition or general health. In one survey 69.4% of health professionals reported patients coming to them with information from the Internet.

The volume of health information on the Internet can be overwhelming and time consuming to navigate and filter. The type of websites accessed depends on the method of searching used, e.g. search engines, gateway sites or sites recommended by health professionals. There has been much concern about the accuracy and unregulated nature of health information on the Internet, although variability in content and quality also exists in both print and broadcast media.
A systematic survey of websites advising on a common childhood condition (managing fever at home) found only a few provided complete and accurate information. Another survey also found that the quality of paediatric surgical information on the Internet varied significantly. Websites giving paediatric surgical advice owned by lay people offered information which paediatric surgeons did not concur with. The type of content rather than quality affects popularity of the website and there is no correlation between measures of quality and link popularity.

There have been several suggestions to ensure health consumer access to high quality information on the Internet, which include kite marking of websites and the creation of quality, assured databases of information. In addition some tools have been produced to enable good quality sites to be developed and for consumers to assess the sites. These include codes of conduct, quality labels, user guides, filters and third party certification. However there are problems with this approach as 'quality' depends on the type of information a consumer needs, therefore regulation of websites may not be helpful.

Anti-vaccine groups have negatively influenced the uptake of some vaccines and anti-vaccination material is prominent on the Internet. A study using seven leading search engines and search terms of 'vaccination' and 'immunisation' found 43% of the websites were anti-vaccination - often strongly so. They frequently had the appearance of a scientific site but contained highly emotive content and used conspiracy claims to promote their anti-vaccination argument. Common themes of these sites include, vaccines cause idiopathic illness and erode immunity, vaccine reactions are underreported and vaccination policy is motivated by profit. Anti-vaccination sites material represents 'a return to an idealised, natural
existence. Complementary and alternative medicine is also based on this ethos. Many parents cite a belief in complementary medicine as a reason for not immunising their children and some complementary medicine practitioners advise their patients over the Internet against MMR immunisation.

Patients today are encouraged to be self-helping and actively involved in the management of their health, both illness prevention and treatment. Provision of information to and involvement of patients is crucial for promoting choice, informed consent, and shared decision making. This has implications for health professionals and The National Health Service who need to be able to help patient's access high quality information.

None of the recent studies of specific patient groups have looked at parents' use of the Internet compared to other information sources to find information about MMR. Many parents have obtained the wrong information about MMR particularly from the Internet. It is relevant during the current MMR crisis to identify whether or not there is significant use of the Internet for this purpose. If so, health professionals could direct parents to reputable, reliable sites for immunisation information. It may prompt health professionals to become cognisant of the content of popular anti-vaccination websites so they can discuss and present the counter arguments for this material with their patients.

2.2. The Study

In this study a self-completed postal questionnaire was used to explore which information sources including the Internet, media and health professionals parents perceive to influence their decision making about MMR immunisation.
The survey was conducted in Woking (population 89,840 census 2001) and Walton-on Thames (population 18,834 census 2001)\(^1\) in Surrey. The population structure of the two towns is similar to that of Surrey and England. The under 16's make up approximately 20% of the population in both towns. They are relatively affluent towns with a higher than average percentage of people employed in social-occupation groups one and two and a lower percentage than average of people who have never worked or who are long term unemployed (see Table 1). However there are some wards in both Woking and Walton that have a higher proportion than the UK average of people in lower socio-occupation classes.

**Socio-occupation characteristics of adult population in Woking and Walton-on Thames.\(^2\)**

<table>
<thead>
<tr>
<th></th>
<th>% of people aged 16-74</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Woking</td>
</tr>
<tr>
<td>Never worked</td>
<td>1.8</td>
</tr>
<tr>
<td>Long term unemployed</td>
<td>0.3</td>
</tr>
<tr>
<td>Socio-occupation group 1&amp; 2</td>
<td>15.6</td>
</tr>
</tbody>
</table>

The towns were within the catchment area of Bournewood Community and Mental Health Trust, which was disbanded in April 2002 to become North Surrey Primary Care Trust (PCT), which includes Walton-on Thames and Woking PCT. The immunisation data collection remained unchanged with COVER (cover of vaccines evaluated rapidly) figures being submitted in the same way although this is due to change in the future. The local child health immunisation office (based in a health centre in Woking) uses a computer database to send parents in the two Primary Care Trusts an invitation for immunisation depending on their child's age and based on the national immunisation schedule. The practice nurses complete the immunisations at
local health centres. Information on completed immunisations is returned to
the child health immunisation office and then forwarded on to the Public
Health laboratory service to form part of their COVER data.

3. Methods

The target population was parents of children due to have their primary
MMR immunisation, the study population was parents with the above
characteristics belonging to four G.P practices (two in Woking and two in
Walton) and the study sample was 64 parents whose children were
routinely invited for MMR immunisation during the study period of 8 weeks
(June 12th 2002- August 9th 2002).

3.1. Questionnaire design

There was no pre-existing questionnaire that could be used, however the
format was in part based on a questionnaire that had been used to explore
knowledge, attitude and concerns with respect to childhood immunisation
(Bedford H, unpublished). A recent questionnaire based study \(^{24}\) asked
parents of children attending a paediatric outpatient's clinic about their
Internet use to find information relating to their children's health problems.
This questionnaire was short and used mainly closed questions.

To ascertain whether or not parents were using the Internet and other
media sources to access information about MMR immunisation the
researcher selected questions for inclusion trying to ensure that each item
could be related to at least one of the study objectives. This included, were
parents using the Internet, where from, frequency, how and what for, in
addition to other sources of media information being accessed and how this
information influenced their decision making process.
The individual questions were designed in the knowledge that it would be a self-completed postal survey. Predominantly 'closed' questions were used with some 'open' questions. This was because the issue under study is a new area and the response to some questions was not predictable. In the closed questions an 'other' option was included allowing the respondent to reply in their own words. Closed format questions were used because they are easy and quick to fill in, crucial in a postal questionnaire to try to maximise response. The results are easier to record and analyse, and also enable less literate respondents to complete the questionnaire.

All the responses were tick boxes with the exception of Question 15, which used a Likert scale in an attempt to measure attitude, and question 25 - a rating scale. The questions were brief and unambiguous and a skip was incorporated. A funnel design was used with a brief introduction at the beginning of the questionnaire (in addition to the introductory letter-appendix 5) and the patients demographic details requested at the end. There was an opportunity for the respondent to include any other comments at the end of the survey and they were thanked for completing the form.

The questionnaire (appendix 6) was re-drafted several times before it was piloted. It was pre-piloted in a discussion on questionnaire design on the MSc. Community Paediatrics course. Helpful suggestions for amendments were received from the researcher's colleagues. The number of questions included was reduced in the final form to minimise the time taken to complete the form and to encourage parent co-operation.

Seven local G.P surgeries were approached an invited to participate in the survey by sending them an introductory letter (appendix 4), followed up by telephone calls. Four agreed to participate; two declined and there was no response from one other. Of the two surgeries that declined to participate
one did not give a reason. A G.P partner for the other surgery explained they were concerned that the survey would encourage parents to look on the Internet in particular at anti-vaccination websites, which may have a detrimental effect on their MMR uptake figures with a resultant adverse effect on practice income.

3.2. Administration

It was originally intended to ask parents to complete the questionnaires at the surgery at the time they brought their child for immunisation and non-attendees were to be sent the questionnaire. There were two concerns about this approach. The first was that practice staff felt this may produce unacceptable extra work for them while running the immunisation clinic by prompting parental questions about filling in the form or about its content. In addition the Ethics committee felt that patient confidentiality would be compromised if the researcher were to identify addresses from patient lists in order to post the non-attendees questionnaires. As a result the method was changed to sending out all the questionnaires by second-class post in the same envelope as the invitation to attend the primary MMR immunisation. This was performed by the child health immunisation office staff and was the most simple and resource friendly method of administering the questionnaires. A letter of introduction (appendix 5) was sent with each questionnaire as well as a pre-paid return envelope. The questionnaires were sent out by Child Health immunisation team staff at Goldsworth Park Health Centre and were returned directly to the researcher by post.

3.3. Ethics approval

North West Surrey Local Research Ethics Committee granted approval for the survey. A detailed application form (appendix 1) was presented with the
other submission requirements (appendix 3). The researcher attended the Ethics committee meeting to present the project. The committee wished to ascertain the scientific need for the survey, how the results were to be analysed and used in a functional way to improve patient care.

The main issue however was confidentiality. The committee felt that to protect patient confidentiality the researcher should not have access to patient lists in identifying and/or sending out documentation to potential participants but that it would be acceptable for immunisation administrative staff to. The researcher would have to submit written consent from the staff involved before they could send the questionnaires on her behalf. There was additional concern about the protection of information obtained i.e. names and addresses. Therefore it was requested that questions were removed asking for this information. The ethics committee requested that a summary of results of the study would be circulated to all participating surgeries.

4. Results

Of the 64 questionnaires sent out, 28 completed questionnaires were returned (A response rate of 43.8 %). The data collected were coded and entered onto a computer database. Frequencies and cross-tabulations were calculated.

4.1. Demographics

The child's mother was the respondent in 26/28 (92.8%) of cases. Most respondents 27/28 (96.4%) were either married or living with a partner. The baby's dates of birth ranged from 2/3/01 to 1/8/01.
78.5% of respondents were planning to have their child immunised with MMR1. The majority of respondents had other children 17/28 (60.7%); of these respondents 13/17 (76.4%) were planning to have their child immunised with MMR1, 3/17 (17.6%) were not and 1/17 (5.8%) was undecided. Of the respondents who had only one child 11/28 (39.2%), 9/11 (81.8%) were planning to have their child immunised with MMR1 and 2/11 (18.1%) were undecided.

Occupations of both parents were requested on the questionnaire and the highest earning occupation given was classified into one of the nine major groups of the Standard Occupation Classification 2000 to provide socio-economic information. The majority of respondents were from higher socio-occupation groups (see Table 2).

### Socio-occupation classification of respondents (Table 2)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>No. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managers &amp; senior officials</td>
<td>9</td>
</tr>
<tr>
<td>Professional occupation</td>
<td>8</td>
</tr>
<tr>
<td>Ass. Prof. &amp; technical occupation</td>
<td>3</td>
</tr>
<tr>
<td>Skilled trades occupation</td>
<td>2</td>
</tr>
<tr>
<td>Admin. &amp; secretarial</td>
<td>0</td>
</tr>
<tr>
<td>Personal service occupation</td>
<td>0</td>
</tr>
<tr>
<td>Sales &amp; customer service</td>
<td>0</td>
</tr>
<tr>
<td>Process. plant &amp; machine operators</td>
<td>4</td>
</tr>
<tr>
<td>Elementary occupation</td>
<td>2</td>
</tr>
</tbody>
</table>

Respondents' postcodes were also collected in order to provide additional demographic information but were not used in this pilot survey. Non-responders were identified by postcode and were evenly divided between Walton and Woking areas (18 non-responders each). The only other
available information for this group was the primary MMR status of their children.

4.2. Internet use

The majority of respondents reported using the Internet - mostly from home (see Table 3) and between once a day and once a week in frequency using a search engine. Yahoo and Ask Jeeves were the most frequently used search engines.

Internet use, location and frequency (Table 3)

<table>
<thead>
<tr>
<th></th>
<th>% of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet user</td>
<td>78.5%</td>
</tr>
<tr>
<td>From home</td>
<td>78.5%</td>
</tr>
<tr>
<td>From work</td>
<td>4.5%</td>
</tr>
<tr>
<td>Home and work</td>
<td>31.8%</td>
</tr>
<tr>
<td>Frequency of access 1/day-1/wk</td>
<td>86.3%</td>
</tr>
<tr>
<td>Multiple search engines</td>
<td>42%</td>
</tr>
</tbody>
</table>

The non-Internet users were mainly in socio-occupation class 1(4/6) with two respondents in socio-occupation class 8/9. Of respondents who currently use the Internet 54.5% would not use it from their doctor's surgery (but then these people have access already). The question should have been asked of all respondents and in particular the non-Internet users and was a fault in the design of the questionnaire.

4.3. Internet and Health information access

Some of the respondents using the Internet 10/22 (45.4%), had found information about their children's health, 4/10(40%) in the month previous to the survey. One respondent had searched for information about eczema and glue ear.
4.4. Internet and MMR

Half of mothers (5/10) accessing the Internet for child health information used a search engine to find information about MMR. The websites visited for this purpose included www.imm.org.ok (1/5), www.doh.gov.uk (2/5) www.babyworld.co.uk (1/5) www.jabs.org.uk (1/5) www.news.bbc.co.uk (1/5).

The first parent used the Internet both at home and work, once a day. The search engines she used were Yahoo and Ask Jeeves but she used the latter to search for information on ‘MMR risks and options/risks re. single vaccines’. Various websites were visited, the names of which she was unable to recall. When the local authority was telephoned for advice she reported that they suggested www.jabs.org.uk. The respondent did not know which organisation or person provided the information, but indicated that she ‘mostly’ understood but was ‘not sure’ if she trusted the information, and felt that it did not help her make a decision about MMR. She also discussed this information with her GP as well as receiving an information leaflet on MMR. In addition she had read newspaper articles but not seen or listened to any TV or radio on the subject. Her GP was rated as the single major influence on her decision-making about MMR and ‘in particular the leaflet he gave me about the risks of single vaccines’. Her baby (only child) had been given the MMR and had completed the primary course of immunisations.

The second parent accessed the Internet from home only, once a week using Yahoo, Ask Jeeves, Lycos and Microsoft MSN. She used the Department of Health and the Panorama websites. The respondent felt it was clear which organisations maintained the sites, ‘completely understood’ the information provided by them but was ‘not sure’ whether she trusted the
information provided, adding that she was aware they 'had their own agendas to push'. However she felt that the information did help her to make a decision about MMR, discussing the information with her GP. She had received an information leaflet from her G.P's surgery, had seen and listened to TV and radio and had also read newspaper articles on the subject. Friends were rated as the major influence on her MMR decision making followed by Internet and T.V. Her baby (only child) was to have MMR though 'later than suggested-delayed to ensure mature immune system' and had completed the primary course of immunisations. She added the comment:

'Couldn't remember much detail re Internet sites used'

The third parent accessed the Internet from home only, once a week using Ask Jeeves and had looked for information about glue ear as well as MMR. She couldn't remember which websites had been visited and did not respond to question 13,15,16, was not sure whether the information she found helped her make a decision but did discuss the information she found with her health visitor. The respondent had received an information leaflet from her GP's surgery, had seen and listened to TV and radio programmes and read newspaper articles. Family was rated as the major significant influence on her decision making followed by books and then her health visitor. She intended her baby (only child) to receive MMR and he/she had completed the primary course of immunisations She added the comment: 'I feel that if parents wish to give MMR as separate vaccinations this should be available privately through your GP or you GP should be able to tell you where they are available'.

The fourth parent accessed the Internet from home only, once a week, using Yahoo and Ask Jeeves and found www.immunisation.org.uk and
www.babyworld.co.uk. She 'completely' understood the information on the baby world site, 'mostly' understood the information on the other site. The respondent trusted the information on the baby world site because 'parents chat with other parents, lots of sources'. The information helped her make a decision about MMR, discussing the information with her practice nurse. She had received an information leaflet from the GP surgery and had read newspaper articles but had not seen or listened to any TV or radio programmes on the subject. The health visitor was rated as the major significant factor in her decision making followed by the Internet, then family and friends. She intended her baby (second child) to have MMR and he/she/had completed their primary immunisations.

The fifth parent accessed the Internet from home and work, once a week using Yahoo. She found www.doh.gov.uk. And 'mostly' understood the information it provided but was 'not sure' whether she trusted the information. The information obtained helped her make a decision about MMR but she did also discuss the information with the practice nurse. The respondent had received an information leaflet from her GP’s surgery, had seen T.V programmes and read newspaper articles about the subject. The question about decision-making was not completed. She intended her baby (only child) to have MMR and he/she had completed primary immunisations.

Another parent accessed the Internet from home using Google. The respondent had tried to find information about immunisations (although not MMR specifically) using websites recommended by a magazine and family, but couldn't remember what they were. She did not trust the information she found, did not discuss it with a health professional and it did not help her make a decision about MMR. The respondent had received an information leaflet from her GP surgery, had seen TV programmes and read newspaper
articles about the subject. Family and friends were rated as the major significant influences on her decision making followed by her GP.

This parent indicated that she did not intend to immunise her child with MMR and he/she had not received their primary immunisations. There were seven other children in the family of whom the youngest five had not received any immunisations.

Summary of information from respondents using the Internet to find information about MMR immunisation (Table 4)

<table>
<thead>
<tr>
<th>Location</th>
<th>No of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home only</td>
<td>3</td>
</tr>
<tr>
<td>Home and work</td>
<td>2</td>
</tr>
<tr>
<td>Frequency</td>
<td></td>
</tr>
<tr>
<td>Once a day</td>
<td>1</td>
</tr>
<tr>
<td>Once a week</td>
<td>4</td>
</tr>
<tr>
<td>Search engine used</td>
<td></td>
</tr>
<tr>
<td>Yahoo</td>
<td>4</td>
</tr>
<tr>
<td>Ask Jeeves</td>
<td>4</td>
</tr>
<tr>
<td>MSN</td>
<td>1</td>
</tr>
<tr>
<td>Lycos</td>
<td>1</td>
</tr>
<tr>
<td>Discussed Internet info with health professional</td>
<td>5</td>
</tr>
<tr>
<td>Information leaflet</td>
<td>5</td>
</tr>
<tr>
<td>TV</td>
<td>3</td>
</tr>
<tr>
<td>Radio</td>
<td>2</td>
</tr>
<tr>
<td>Newspaper</td>
<td>5</td>
</tr>
<tr>
<td>Internet helped make decision</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Not sure</td>
<td>1</td>
</tr>
<tr>
<td>MMR given</td>
<td>5</td>
</tr>
<tr>
<td>Primary immunisation given</td>
<td>5</td>
</tr>
</tbody>
</table>
4.5. Non-Internet sources of child health information

**Health professionals**

Parents reported their most popular source of information about children's health (Figure 1) to be Health Visitors (78.5%) followed by family (71.4%) and G.Ps (71.4%).

Number of respondents using each information source (Figure 1)

![Bar chart showing information sources](image)

The number of respondents who indicated that they used the Internet 28.5% contradicted the response obtained from the very first question on the survey asking about Internet use. This discrepancy may reflect the layout of this question (no.19), in which respondents were invited to tick appropriate boxes from a list. The majority of respondents ticked multiple boxes indicating that they used multiple sources of information (Figure 2). It is possible that several respondents ticked the Internet box in error as they ticked down the list, or they may have simply misunderstood the question. This was the first question after the skip from question 1.
Number of respondents using from 1-9 sources of child health information (Figure 2)

While 16/28 (57.1%) respondents had consulted their GP or health visitor for advice about MMR, more respondents 20/28 (71.4%) had received leaflets about MMR from their Health Visitor/GP (MMR information campaign). In one case a health visitor had recommended using the Internet to find information about MMR but had not given the respondent a website address. Four respondents (14%) did not rate at all any health professionals when asked about major significant influence on MMR decision-making. One of these parents subsequently declined MMR.
Complementary practitioners

Only three respondents indicated that they used a complementary practitioner (see Table 5).

Characteristics of complementary therapy users (Table 5)

<table>
<thead>
<tr>
<th></th>
<th>Respondent Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Standard Occupation</td>
<td>2</td>
</tr>
<tr>
<td>Classification</td>
<td>7</td>
</tr>
<tr>
<td>Significance rating of</td>
<td>1</td>
</tr>
<tr>
<td>Compl. Pract. by</td>
<td></td>
</tr>
<tr>
<td>respondent</td>
<td></td>
</tr>
<tr>
<td>1=high</td>
<td>10</td>
</tr>
<tr>
<td>12=low</td>
<td></td>
</tr>
<tr>
<td>MMR?</td>
<td>No</td>
</tr>
<tr>
<td>GP/HV used as source of</td>
<td>No</td>
</tr>
<tr>
<td>child health info?</td>
<td></td>
</tr>
</tbody>
</table>

Media

The majority of respondents had been exposed to print (26/28, 92.8%) and broadcast media (22/28, 78.5%) coverage of the MMR controversy, while fewer (9/28, 32.1%) had heard radio programmes about MMR.
4.6. Parents’ perceptions of MMR decision-making

Most Significant factor in MMR decision making (Figure 3)

The health visitor was rated as the major significant influence on decision-making by 7/28 (25%) respondents, whilst family and GPs were rated as the major significant influence by 6/28 (21.4%) respondents. The Internet was rated by one respondent as being of major influence in decision making each (Figure 3).

The majority of respondents 22/28 (78.5%) intended having their child immunised with MMR, 3/28 (10.7%) were undecided (Table 7) and 3/28 (10.7%) were not intending to have MMR immunisation (Table 6). Immunisation data for the non-respondents revealed an MMR1 immunisation rate of 83.3%. In this group there were three non-immunisers each from both Woking and Walton areas.
### Characteristics of MMR non-immunisers (Table 6)

<table>
<thead>
<tr>
<th>Respondent Number</th>
<th>2</th>
<th>24</th>
<th>28</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child received primary immunisations?</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Respondent has other children?</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Did these child(ren) receive MMR?</strong></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Did these child(ren) receive primary immunisations?</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Significant influences</strong></td>
<td>Books/complementary practitioner</td>
<td>TV/papers</td>
<td>Family/friends</td>
</tr>
<tr>
<td><strong>Internet user?</strong></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Standard occupation classification</strong></td>
<td>3</td>
<td>1</td>
<td>8</td>
</tr>
</tbody>
</table>

None of the above respondents indicated that they used their G.P.s as a source of child health information.

### Characteristics of MMR 'undecided' immunisers (Table 7)

<table>
<thead>
<tr>
<th>Respondent Number</th>
<th>15</th>
<th>17</th>
<th>21</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child received primary immunisations?</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Respondent has other children?</strong></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Did these child(ren) receive MMR?</strong></td>
<td>-</td>
<td>Yes</td>
<td>-</td>
</tr>
<tr>
<td><strong>Did these child(ren) receive primary immunisations?</strong></td>
<td>-</td>
<td>Yes</td>
<td>-</td>
</tr>
<tr>
<td><strong>Significant influences</strong></td>
<td>GP/T.V</td>
<td>GP/friends</td>
<td>GP/health visitor</td>
</tr>
<tr>
<td><strong>Standard occupation classification</strong></td>
<td>3</td>
<td>8</td>
<td>1</td>
</tr>
</tbody>
</table>

All of these respondents indicated that they did use their G.P as a source of child health information.
4.7. Local and National immunisation data

MMR1 coverage at 24 months decreased across the U.K to 83% for the period 1st July to 30th September 2002. Bournewood Community and Mental Health NHS Trust COVER data figure for the same period is 78.8%, much lower than the above national average and the average for the South East (83.1%), but higher than the figure for London (72.9%). The percentage of survey respondents who reported they were planning to take up MMR1 78.5% correlates very closely with the above local figure.

With the exception of Meningitis C immunisation, Bournewood’s COVER data for the primary immunisations completed by 24 months corresponds to the national averages (Table 8).

Local COVER data for primary immunisations (Table 8)

<table>
<thead>
<tr>
<th></th>
<th>DTPol3%</th>
<th>P3%</th>
<th>Hib3%</th>
<th>Men C%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bournewood</td>
<td>93</td>
<td>93.5</td>
<td>93.5</td>
<td>77.8</td>
</tr>
<tr>
<td>UK</td>
<td>93.7</td>
<td>93</td>
<td>93.2</td>
<td>92.2</td>
</tr>
</tbody>
</table>

No. Of children resident in the district reaching their second birthday during the previous quarter=674

The majority of respondents 27/28 (96%) reported that their child had had all the primary immunisations, whilst one child had had none. Some of the respondents 17/28 (61%) had other children and of these 15/17 (88%) had had MMR and their primary immunisations
5. Discussion

5.1. Structure and response rate of the questionnaire

The response rate of the self-coded questionnaires in this pilot survey was low. This critically affects the quality and validity of the study by introducing non-response bias. Methods of increasing response rates to postal questionnaires were examined in a systematic review. This identified effective factors that increased the response rate to postal questionnaires by different odds (Table 9).

Increasing response rates to questionnaires- systematic review
Edwards et al 2002 (Table 9).

<table>
<thead>
<tr>
<th>Method</th>
<th>Odds ratio 95% confidence interval</th>
<th>Method used in this survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monetary incentive</td>
<td>2.02 1.79-2.27</td>
<td>No</td>
</tr>
<tr>
<td>Incentives non-conditional on response</td>
<td>1.71 1.29-2.26</td>
<td>No</td>
</tr>
<tr>
<td>Short questionnaires</td>
<td>1.86 1.55-2.24</td>
<td>Yes</td>
</tr>
<tr>
<td>Personalised questionnaires/letters</td>
<td>1.16 1.06-1.28</td>
<td>No</td>
</tr>
<tr>
<td>Coloured ink</td>
<td>1.39 1.16-1.67</td>
<td>No</td>
</tr>
<tr>
<td>Recorded delivery</td>
<td>2.21 1.51-3.25</td>
<td>No</td>
</tr>
<tr>
<td>Stamped return envelope</td>
<td>1.26 1.13-1.41</td>
<td>Yes</td>
</tr>
<tr>
<td>First class post</td>
<td>1.12 1.02-1.23</td>
<td>No</td>
</tr>
<tr>
<td>Contact pre-questionnaire</td>
<td>1.54 1.24-1.92</td>
<td>No</td>
</tr>
<tr>
<td>Follow-up contact</td>
<td>1.44 1.22-1.70</td>
<td>No</td>
</tr>
<tr>
<td>2nd copy of questionnaire to non-respondents</td>
<td>1.41 1.02-1.94</td>
<td>No</td>
</tr>
<tr>
<td>Interesting questionnaire</td>
<td>2.44 1.99-3.01</td>
<td>Yes</td>
</tr>
<tr>
<td>University generated questionnaire</td>
<td>1.31 1.11-1.54</td>
<td>No</td>
</tr>
</tbody>
</table>

The researcher was unable to incorporate many of the identified effective methods into the survey because of financial constraints due to lack of funding. However offering a financial incentive would not be ethical in a
health questionnaire setting and may introduce bias. In addition pre- and post questionnaire follow-up, and personalising of letters were not permitted by the Ethics committee. Piloting the survey using the postal questionnaire method revealed a significant degree of non-response bias, which must be reduced to obtain valid results. Therefore it would be beneficial to obtain funding in order to incorporate strategies effective at increasing the response rate such as coloured ink on the questionnaires or recorded delivery. Application to the Ethics committee for consent to access to patient name and address details would also be vital in enabling follow-up contact, to send a second or even third questionnaire to non-responders. It would also be useful to be able to have telephone contact with selected respondents in order to conduct face-to-face interviews.

The response rate may have also been affected by the timing of the study, since the questionnaires were mailed during the school holiday period, the respondents are all busy parents and may not have had the time or inclination to complete a questionnaire. In addition, the content of the questionnaire, especially the section on the Internet, may not have been of interest to the majority of parents. The questionnaires were sent to parents before the MMR1 immunisation was due and it is possible that receiving it may have prompted some to search on the Internet when they might not otherwise have done so leading to an over estimate of Internet use in the results.

The size of the bias introduced into the results may depend on the response rate. A low response rate such as that in this study is more likely to give biased results because there is a high chance respondents are not representative of the target population. A low response rate is a particular risk for postal surveys because it is easy for the recipient to discard the
questionnaire or 'not get round' to filling it in. Non-respondents are likely to significantly differ in a number of ways to those who returned the questionnaires and those differences may be directly related to information the survey is trying to measure. It is possible that non-respondents read 'Internet' on the front of the questionnaire and felt that because they didn't use the Internet the survey was not relevant to them. If the majority of non-respondents are non-Internet users, then the level of Internet use recorded in the pilot study will be an overestimate. In this survey MMRI uptake rate was higher among the non-respondents (83.3%) than the projected uptake rate of the immunisation by respondents (78.5%). This may be explained because parents who had concerns about MMR would be more interested in filling in a questionnaire relating to the subject whereas parents who did not have concerns were possibly less interested. It is important to be able to collect as much information as possible about non-respondents, which unfortunately in this survey was not possible because of ethics committee restraints.

In the general population non-respondents to health surveys are more likely to be in semi-skilled or unskilled manual occupations while respondents are better-educated and healthier. The postcodes of the non-respondents in this survey were identified in order to provide a marker of their social class and to enable comparison with the socio-occupation classification of the respondents. The researcher was unable to gain access to the postcode classification data and therefore this comparison could not be completed.

The quality of the returned questionnaires was good. The item responses (with the exception of question 19-already discussed) were appropriate and consistent with no apparent need for new response categories. The skips were followed correctly and the comment section was well used. Piloting the
study however revealed some flaws in the design of the questionnaire. The majority of respondents frequently omitted some questions. This reflects the lower than expected usage of the Internet to find child health and MMR information. Many respondents who used the Internet to find child health information did not fill in the free text item about what it was they were looking for. It is not clear why this was but reasons may include couldn't remember, didn't think it was relevant, couldn't be bothered or didn't wish to disclose this information.

Those respondents that had used the Internet specifically to find out information about MMR found questions 15 and 16 difficult to answer because of lack of recall of websites used. This was also found in another study, which reported that 'very few participants remembered which websites they had retrieved information from' 51. It would have been more useful to use qualitative method observing parents retrieve information from the Internet or alternatively using a prospective method asking parents to keep an Internet diary, recording websites visited.

Question 3 (asking whether respondents would use the Internet if it was in their doctors surgery) was located in the wrong part of the questionnaire and as a result was only asked of respondents who already had access to the Internet-respondents who don't have access at home may have been interested in using it at their doctors surgery. It has been found that while access to the Internet is important there are other factors which influence uptake of the Internet as a health resource-especially motivational factors 66. Question 3 is a 'hypothetical' question, which is not useful in surveys and should be removed as 'people are not good at predicting what they will do in a circumstance they have not yet encountered' 52.
5.2. Demographics

The survey failed to sample a range of parents from different socio-occupation groups; the majority of respondents were in socio-occupation groups one and two with no respondents from groups four to seven. This may reflect the characteristics of people more likely to return postal questionnaires (better educated) however in Elmbridge and Woking there is a relatively higher percentage of people in groups one and two-42 % and 35 % respectively compared with the U.K average of 27%. The uneven sampling reduces the validity of the results.

The majority of the respondents were mothers who were married or living with a partner and already had other children. Only one respondent was a single parent (3.6%) which possibly reflects an under representation of this group in my sample. The percentage of the population in lone parent (including children up to 16) households in Woking and Walton is 4.6% and 5.3% respectively 41.

5.3. Internet use

A high percentage (78.5%) of respondents in this study have access to the Internet compared to the general U.K population (45%) 53. It is possible this is due to the higher than average socio-economic status of the respondents but is much more likely to be an effect of the large non-response bias.

Levels of Internet use and access increases rapidly with income 53 and also with maternal and paternal education levels 54-56. Details of maternal education level achieved were not asked for in this survey to try and keep the questionnaire as short as possible. Internet users amongst breast cancer sufferers were more likely to be significantly younger, better educated and less satisfied with their treatment than non users 57.
In the U.K, the National Statistics Omnibus Survey[^53] found that general Internet use is higher in 16-24 year olds (95% adults) and 25-44 year olds (81% adults) than older adults, with men (66%) using it more than women (58%). The respondent's ages in this pilot study were not ascertained but would be expected to fall within the 16-44 year age range and the majority of Internet users were female. In the USA, the health seeker population is made up of many more women than men and 16% of these women were searching for health information on behalf of a child. Mothers often have very little free time so the convenience of using the Internet to look up information is very attractive to them[^22]. The high percentage (86.3%) of mothers who accessed the Internet once or more a week is likely to be significantly affected by non-response bias resulting in an overestimate of frequency of Internet usage compared with the national figure for women of 47%[^53]. The respondent's own home was the most popular location for Internet access (78.5%), which corresponds with the general UK figure of 80%[^53].

In the U.K, adult Internet use is mostly to find information about goods or services[^53] which was also the experience of one respondent who wrote:

'I use Internet for direct information e.g. entrance fees/opening times of local attractions or for convenience shopping I do not regard it as an authority on specialist subjects e.g. children's health for which I prefer to consult directly with experts e.g. in the medical field or read around subject in question where there has been some degree of responsible editorial control; and some credibility'

Of the six respondents who were not Internet users, four were from socio-occupation group 1 (44% of group 1 respondents) and 2 were from group 8/9 (33% of group 8/9 respondents). They were not asked the reasons for
their non-use of the Internet, as this did not directly relate to this study's objectives. It would be expected that a higher proportion of non-users would be from lower socio-occupation groups due to lack of access or lower levels of education, but as previously noted this group is under-represented in this survey. This may have resulted from a study sample unrepresentative of social class mix or due to non-response bias.

In the National Statistics Omnibus Survey, 42% of people surveyed do not use the Internet because they are not interested, 30% because of no access and 26% because they are not confident or do not have the skills. In a study asking breast cancer sufferers about the Internet 53% of the non-users lacked access whilst 33% were unfamiliar with it, a further 13% distrusted the information on the Internet.

5.4. Internet and Health Information access

In the U.K. there is a paucity of data about the general populations' use of the Internet to access health information. In the U.S.A available estimates of Internet use and impact for this purpose vary widely. Several studies have looked at patient groups and their use of and access to the Internet (Table 10). There are very few studies of parental use of the Internet (Table 10) and the researcher was unable to find any that had explored parental Internet use to find preventative health information for their children such as for immunisation.
Studies exploring patients Internet access and retrieval of health information (Table 10)

<table>
<thead>
<tr>
<th>Study</th>
<th>% of patients with access to Internet</th>
<th>% of patients with Internet access searching for health information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diaz et al 2002</td>
<td>53.3</td>
<td>53.3</td>
</tr>
<tr>
<td>Baker 2003</td>
<td>53.3</td>
<td></td>
</tr>
<tr>
<td>Perreira 2000</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Pennbridge 1999</td>
<td>40</td>
<td>56</td>
</tr>
<tr>
<td>Taylor 2001</td>
<td>47.6</td>
<td>47</td>
</tr>
<tr>
<td>Budtz 2002</td>
<td>48.3</td>
<td>20</td>
</tr>
<tr>
<td>O'Connor 2000</td>
<td>50</td>
<td>51</td>
</tr>
<tr>
<td>Murero 2001</td>
<td>42.7</td>
<td>51.4</td>
</tr>
<tr>
<td>Lai 2000</td>
<td>--</td>
<td>16</td>
</tr>
<tr>
<td>Rokade 2002</td>
<td>45</td>
<td>13</td>
</tr>
<tr>
<td>Gupte 2002</td>
<td>55.3</td>
<td>52</td>
</tr>
<tr>
<td>Ikemba 2002</td>
<td>58</td>
<td>58</td>
</tr>
<tr>
<td>Semere 2003</td>
<td>85</td>
<td>71</td>
</tr>
<tr>
<td>Tuffrey 2002</td>
<td>51</td>
<td>22</td>
</tr>
<tr>
<td>Gordon 2002</td>
<td>43</td>
<td>27</td>
</tr>
<tr>
<td>This Study</td>
<td>78.5</td>
<td>45</td>
</tr>
</tbody>
</table>

Those with home access are over three times more likely to have sought online health information in the past year than those who had access elsewhere. One respondent in this study used the Internet from work only and did not search for child health information, all the other respondents who used the Internet had access from home and half of these sought online health information. Motivational factors were not explored in this study but are also important in predicting Internet use for health information, particularly possessing the belief that using the Internet will convey health benefit. A worldwide survey of Internet e-health consumers found that the
most important issue for them was accuracy of information (26.3%) followed by trustworthiness of the material (11.45%)\textsuperscript{27}.

In the few studies that have been conducted a significant proportion of parents are accessing the Internet to retrieve additional information about their child's medical condition\textsuperscript{24-26} and many find the information helpful\textsuperscript{22,26}. Just under half of Internet users in this study were seeking child health information.

Health care decision-making is influenced for a significant proportion of patients by health information found online\textsuperscript{22,58} provoking many to ask their doctors further questions\textsuperscript{22}. The authors of one study\textsuperscript{25} were concerned about how much trust parents put in the information they had found on line, especially as nearly a third of these parents were unaware of the ownership of the websites visited and source of the information they obtained. They were therefore not in a good position to evaluate its quality. Doctors should be proactive and aware of patients information needs enabling patients to find accurate information by providing Internet references\textsuperscript{26}. The majority of parents felt doctors should suggest websites, \textsuperscript{24,59} others said they would be more likely to trust a website if it was recommended by a doctor or pharmacist\textsuperscript{24}. Health professionals should be prepared to direct patients to quality websites and to discuss information from the Internet with a patient\textsuperscript{55} although currently very few patients receive Internet recommendations from health professionals\textsuperscript{24,59}. One respondent in this study had been advised to look on the Internet for information about MMR by a health visitor but was not given a specific website address.

In the Pew\textsuperscript{22} study 81% of respondents had conducted their own search to find the health websites they visited. General search engines such as Google and Yahoo are often the most popular means for parents to locate
medical information but they offer the least amount of screening because they are not geared towards finding reliable medical information. All the Internet users in the pilot study used at least one general search engine; none used medical directories such as Health on the Net (HON).

5.5. Internet and MMR

One GP practice had declined to participate in this study because they felt that it might encourage parents to access the Internet and anti-vaccination websites resulting in a decline of MMR uptake. The latest findings (March 2003) from the Department of Health's immunisation tracking studies show that 12% of mothers questioned had reported they had used the Internet for information about immunisations. In this study very few respondents used the Internet to find MMR information and of those that did all subsequently had their children immunised with MMR. Only one respondent completely trusted the information found, although they all 'mostly' or 'completely' understood the material. Other studies have shown that Internet users are undecided about the trustworthiness of the medical information they had obtained over the Internet. Very few Internet users check the authors/owners of the website details, read the disclaimers or can remember where they have retrieved information from.

All 5 respondents in this study had discussed their retrieved Internet material with a health professional in contrast to another study when only a minority discussed their findings with a doctor. The small number of respondents and lack of recall of sites visited meant it was difficult to determine whether or not any anti-vaccination material had been encountered.

Most respondents used Ask Jeeves and Yahoo search engines. Using the search term 'MMR', Ask Jeeves found 2,750 and Yahoo 35,900 websites.
Six out of the first ten sites listed were shared in common albeit at different rankings. It has been found that only the first few links on a website are explored by users when searching for health information. The MMR home pages for both search engines differed in their presentation. Yahoo's headlines included 'new measles warning' and 'measles fear as MMR shunned' whilst Ask Jeeves recommended 'Learn about single MMR vaccinations'. Its first listed website www.e-med.co.uk is a fee charging medical advice service that offers single MMR vaccinations. The second is a Department of Health site www.doh.gov.uk and the third is www.jabs.org.uk - a site used by one respondent to find information about MMR. This is the website of a self-help group offering support to parents of vaccine damaged children and campaigning for a legal right to compensation. It states 'we neither recommend or advise against immunisation' however the flavour of the material it presents is generally anti-immunisation. In contrast Yahoo's top listing is www.mmrthefacts.nhs.uk a website launched by the Department of Health in September 2002 in an effort to inform parents and counteract the adverse media publicity. The second site listed is also a Department of Health site and corresponds to the second site listed by Ask Jeeves www.doh.gov.uk. The general medical material on the third site www.medinfo.co.uk, is written by a G.P, is easy to read and presents the facts in an unbiased manner. The reasons for having MMR are clearly stated. One respondent used BBC television Panorama's site on MMR news.bbc.co.uk. The website material is based around the documentary broadcast in February 2002. Dr. Wakefield's work over a period of a year was filmed in addition to three families who were convinced their children developed autism as a result of the MMR immunisation. This programme fuelled the debate further, creating high media interest and over the following months there was an increase in
the percentage of mothers who indicated they would not allow future children to be immunised\(^{19}\). [www.babyworld.co.uk](http://www.babyworld.co.uk) is a site set up in 1996 providing information and support for parents and has a team of resident experts including a doctor, midwife and health visitor and was used by one respondent. A search on the site for ‘MMR’ obtained 133 hits. The first link gives a history of MMR immunisation, discusses the risks of non-vaccination and whether or not single jabs are the answer, concluding that ‘the tiny risk of side effects of MMR are far outweighed by the benefits’.

5.6. Non Internet sources of child health information

Multiple sources are used by the majority of respondents (27/28) to obtain child health information. These include health professionals family, friends broadcast and print media and is a finding that has been noted in other studies \(^{67}\).

Health professionals are more trusted than any other source including the Internet \(^{15,68}\) and in this pilot survey health visitors were the most popular source of child health information. In a cross sectional study of parents attitudes to MMR 74% parents reported seeking advice from health professionals before having their children immunised \(^{68}\).

The majority of respondents (71.4%) had received MMR leaflets as part of the MMR information campaign. This was launched by Health Promotion England in 2001 in an effort to combat the extensive adverse media coverage and consists of a range of resources to promote the safety of the MMR vaccine including leaflets, posters and videos. A resource pack was sent to any health professional concerned with immunisation to help them in discussions about MMR with parents.
Family and friends were also popular sources of information in this study. In another study, this group gave both positive and negative advice about immunisations and when their views differed to the parents it led to emotionally charged discussions. In contrast, another study found peer pressure was not a significant factor in the MMR decision-making process.

A minority of respondents (10%) in this survey use a complementary practitioner compared with an approximate figure of 20% in the general population in the U.K in 1999. Two respondents rated their complementary practitioner as being highly significant influence in their decision about MMR. One of these mothers declined MMR for her child and also for an older child but had completed the full course of primary immunisations for both children. Complementary practitioners often have a negative attitude to immunisation and frequently advise their clients against immunisation.

An analysis of mass media coverage of the MMR controversy from February to September 2002 revealed that several major themes emerged in consistent and regular reporting. These included the postulated link between MMR and autism, the refusal of the government to provide single immunisations, the prime minister's decision about MMR immunisation for his own son and that uptake of MMR was falling. These messages were powerfully transmitted to the public. When a 'knowledge and opinion' survey was carried out in October 2002 by the same team two out of three people surveyed could name autism as the condition linked with MMR. Television was the most favoured source of information and the most common source of information on side effects on MMR. The media coverage left a lasting impression on mothers with peaks in negative publicity followed by a fall in MMR coverage. There was also media reporting of widespread refusal of parents to have MMR implying a dramatic fall in the uptake, which was
not reflected in the MMR coverage figures. The powerful impression left by the media coverage is likely to have been achieved by lengthier than average coverage of the MMR issue and the high level of public engagement in the story. The latter was facilitated by using the public as a source of anecdotal information e.g. parents of autistic children. The presentation of the MMR controversy by the media is predominantly negative and although the body of scientific evidence fully supports MMR-with no evidence linking autism and MMR, this was not so strongly or consistently reported. Consequently in the Cardiff survey - 53% of people believed that there was an equal body of evidence for each side of the MMR debate. The power of the news media to (mis) inform is demonstrated by the extent of public knowledge on this issue. One respondent's comment illustrates the confusion caused by the media adverse publicity:

'I feel the whole debate has been amazingly badly handled with little really helpful information and plenty of spin. Presenters of arguments either for or against appear to have ulterior motives rather than straight facts. I feel both very angry and very vulnerable that as a parent I am in this position almost playing God with my baby's life.'

The majority of respondents in the pilot study had been exposed to print and broadcast media. One respondent outlines the effect media can have on parental attitudes and behaviour with the following comment:

When I had my daughter the doubts of MMR were starting- 8 years later there are still doubts and more information has become available. The TV programmes were broadcast while I was pregnant with my son. Also my neighbour had contact with a little boy who is now autistic following MMR. Having a son who has asthma, allergic to cats and all the media attention
gave me no choice but to opt out. However he is having the single vaccines carried out by Direct Health 2000'

5.7. Parents perceptions of MMR decision making

The MMR decision-making process was intentionally not explored in detail in this survey. This is a complex process and cannot be effectively explored in a postal questionnaire\(^7\). Qualitative research methods are more useful to probe parental attitudes, beliefs and perceptions about immunisations and to explore the risk/benefit analysis undertaken\(^{12,13}\).

A cross-sectional study of factors affecting maternal intention to vaccinate showed that for parents the most trusted source of information on MMR was the GP\(^6\). In this pilot study respondents used multiple information sources but rated the health visitor as most significant influence on their decision-making. The majority of parents in this study and nationwide make the decision to take up MMR for their children\(^{8,19}\) but often they are not happy with the decision or have made it reluctantly. Decline in acceptability of MMR appears to be greater in parents from higher socio economic groups \(^{68}\). This is a possible explanation for a higher MMR immunisation rate for non-responders than responders in this pilot study as responders were mainly from the latter group. In addition parents who already had children were more likely to refuse MMR. All mothers with their first baby were planning to have MMR. Birth order can affect uptake MMR uptake and it tends to be lower in third or later born children and in children of single parent families\(^72\). The presence of older siblings in families of lower socio-economic groups is strongly associated with lower uptake of immunisation in subsequent children \(^{10}\). Parent's re-evaluate immunisation decisions with each child they have\(^{13}\) and this is illustrated by the following parental comment:
‘Do feel strongly that my GP (and possibly my health visitor) would question if I didn’t have my baby immunised. Felt that as the older child has his MMR we have no choice with our 2nd, despite having doubts. However, we know the risks are higher if they don’t. Do feel it would be nice to have the choice of MMR or single vaccines especially when we hear of GPs being offered grants (allowances?) for MMR uptakes-this makes us question GPs’

It also illustrates that reluctance to upset their relationship with their G.P. is an important factor in parent’s immunisation decision\textsuperscript{73}. Some parents feel they accepted MMR because of pressure from health professionals rather than making an informed choice\textsuperscript{16}. In addition GP target payments are widely perceived by parents as a barrier preventing GPs giving balanced information\textsuperscript{13;16}.

All the parents in a focus group study\textsuperscript{16} felt that MMR should be available as single vaccines - a sentiment that was reflected in the above parental comment and the following:

I feel that if parents wish to give MMR as separate vaccinations this should be available privately through your GP or you GP should be able to tell you where they are available.’

The risk/benefit assessment of immunisation is derived from the health belief model\textsuperscript{74} in which the side effects and effectiveness of immunisation are balanced against the perceived seriousness of the disease. This is demonstrated by the following respondent’s comment:

‘I feel the risk of measles is higher than the possible side effects of MMR

Despite professional knowledge of MMR, still fell concerned about MMR but feel???? Possible side effects e.g. autism far less likely than bad side effects occurring if caught measles.’
Some parents initially comply with immunisation but then experience or become concerned about side effects and change their minds\textsuperscript{73}. This was the experience of one respondent who wrote:

'Due to reaction to my 18 year old we stopped all immunisations' This mother had five other younger children who were all completely un-immunised.

Parents who have had experience of diseases tend to be more careful in taking up immunisation than those who haven't\textsuperscript{75} as described by the following parental comment:

'I decided to have my children immunised (including MMR) because of my husband's experience. As a baby his parents decided not to get him immunised for whooping cough because of a similar 'immunisation scare'. I think it was the risk of brain damage. Consequently when he was 12 he suffered a serious attack of whooping cough costing him 4 weeks off school plus severe damage to his lungs. Even today any cold he has immediately turns into a chesty cough and he is very short of breath. I also have a friend at school with polio (she came from Ethiopia) plus I know a foster mother who cared for brain-damaged children from being exposed to measles in the womb. Immunisation is a must for all!'

Whilst checking the local MMR immunisation uptake figures it became apparent that although parents had eventually had their child immunised many parents had
delayed it for at least 6-12 months after it was due. This is reflected in the following comment:

‘As with my son I am waiting until my daughter is a few months older before I consider giving her the MMR jab. Nearer 2 than 1’

5.8. Respondent’s comments

Only two of the comments were directly related to Internet. This may indicate that parents appear to be more engaged with the MMR/autism/single vaccines controversy than they are interested in Internet use.
6. Conclusion

The results obtained are non-conclusive for several reasons:

1) Poor response rate and resulting significant non-response bias is a major limitation.

2) Small sample size.

3) Respondent’s socio-demographic characteristics were not representative of general population of parents.

The survey results did inform some of the study objectives. A number of parents do use the Internet but for the respondents in this survey it did not result in them declining MMR immunisation. The majority of respondents use health professionals and the media for information to help with MMR decision-making. The survey results revealed very few websites used for MMR information because of lack of use of the Internet for this purpose. It was more useful in identifying what other sources of information parents using and whether this influences decision-making. The pilot survey was effective in highlighting problems with the questionnaire design. These included:

a) Questions that needed to be omitted or changed (13,15,16,3,19-already discussed)

b) Additional information that was needed such as mothers/fathers educational status to enable construction of a more detailed socio-demographic profile of respondents.

C) Questions that were not effective in determining which websites were used.
Conducting the study again, it would be essential to increase the response rate by strategies already discussed. Actively following-up non-responders with further questionnaires and telephone calls would help to increase response rate. In addition increasing the sample size would allow meaningful statistical analysis of the results.

A prospective qualitative study would be more useful to try and answer the second objective - to determine in detail which websites are used by parents and whether this influences decision-making. The third objective would require a randomised controlled trial to examine in detail the causes and effects contributing to the parental decision-making process about immunisation. In this pilot study parents use a variety of sources to obtain information about immunisation. The Internet is not widely used for this purpose currently but is likely to become increasingly popular as a channel for patient health information in the future.

Health professionals are the single most important and trusted source of health information and advice. They need to be able to guide parents to credible websites, helping them avoid misinformation and warning them of the variability in quality of information on the Internet.

One recommendation is that General Practitioners develop a home page with links to reputable sources or construct a website for example about MMR immunisation with a compilation of information from various websites. Patients could be referred to sites with the HON code logo (Health On The Net Foundation, www.hon.ch) which produces the oldest and respected website quality label. Safer browsing could also be encouraged by giving parents basic non-medical criteria by which they can assess website
Health care providers are being encouraged to consider provision of Internet access in clinics and surgeries for those who don't have access elsewhere.

The challenge for health professionals is to embrace 'e-health' information and technology, to use it for their own medical education in addition to empowering their patients. The health professional’s role is pivotal in providing evidence-based advice in an unbiased manner and to guide patients towards high quality information from other sources including the Internet so that they can make an informed choice about MMR immunisation.
7. Acknowledgements

I would like to thank the participating G.P surgeries and parents for completing the questionnaires, the immunisation office staff at Goldsworth Park Health Centre and Helen Bedford for her helpful comments and encouragement.
8. References


INSTRUCTIONS: Please complete in typescript. Please select YES/NO options as appropriate. A version of this form is also available on disc in Word for Windows from the Ethics Committee Secretary.

It is essential that this form is completed fully and the relevant enclosures are received if the study is to receive proper scrutiny by the Ethics Committee. Please complete the checklist before sending the form.

CHECKLIST

Please indicate if the following has been enclosed by selecting YES/NO/NOT APPLICABLE option below. For details of the numbers of copies for the form and relevant enclosures required, please contact the relevant LREC secretary

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>NOT APPLICABLE</th>
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...14... copies of application form (double sided if possible)  ...14... copies of protocol  ...14... patient consent form(s)  ...14... patient information sheet(s)  ...14... GP / Consultant information sheet(s)  ...

...3... copies of lead applicants CV on 2 sides A4

(Do not submit if already submitted in last 12 months)

Questionnaire * ☑ Finalised ☐ Not Yet Finalised

Copy of manufacturers data sheet for all drugs (two copies only)
Copy of investigators brochure (3 copies only)
Copy of manufacturers indemnity (3 copies only)
Copy of CTX /CTL/DDX (3 copies only)
Annexe A **
Annexe B ***
Annexe C †

* Please indicate if not yet finalised
** If the study involves the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product license
*** If the study includes the use of ionising or non-ionising radiation, radioactive substances or X-Rays
† For research in general practice

Please indicate which other LREC this application is to be submitted
SECTION 1  Details of Applicant(s)

1. Short title of project
   Internet and MMR information

   Full Title
   Survey of parents' use of the Internet to find information about MMR immunisation.

   Summary of practice benefits/improvements in patient care which are envisaged
   If parents are using the Internet to obtain information about MMR we would consider the possibility of adding immunisation information to the local PCT website in the future.

2. Applicant (all correspondence will be sent to this address unless indicated otherwise)
   Surname: Brockway
   Forename: Claire
   Title: Dr

   Present appointment of applicant: Staff Grade Community Paediatrics

   Qualifications: MB,BS MRCPCH

   Address: 115 Vale Farm Road, Woking, Surrey GU21 1DP

   Tel: 01483 857027
   Fax: E-Mail: claire.Brockway@ntlworld.com

3. Other workers and departments / institutions involved
   Dr. Helen Bedford, Lecturer in Epidemiology, Institute of Child Health, London.

4. Signature of relevant bodies

   I undertake to carry out the work in accordance with the principles of the Declaration of Helsinki (copy available from the LREC secretary) and its amendments.

   Signature of applicant: .............................. Date: 21.3.02

   Signature of Head of Department/Supervisor/Principal in General Practice with overall responsibility for the project: .................... Date: 21.03.02

   NAME AND TITLE IN CAPITALS...DR. HELEN BEDFORD.................................

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5. Aims and objectives of project (ie., what is the intention of the project)

The aim of the project is to determine whether or nor a sample of local parents are using the Internet to find information about MMR immunisation, prior to their child being immunised. I aim to determine which websites they are using and whether what they find on the Internet influences their decision making process. The survey will also look at what other sources of information about MMR that parents are using and how they value its relative usefulness.

6. Scientific background of study

Over the period July to September 2001 an estimated 9.7 million households in the U.K could access the Internet from home. This is approximately 39% of households and is over four times the number three years ago. Levels of access vary according to income and are highest in London and the South East. From my own and my colleagues clinical practice it is apparent that parents are increasingly using the Internet to find health information relevant to their children. The combination of rapid access to a large amount of information is contributing to increasing consumer involvement in decisions about health care.

MMR uptake has been declining since 1995 when the first queries about MMR came to public attention. MMR uptake is consistently behind that of other childhood immunisations and the controversy about MMR continues currently. There has been widespread media coverage and in addition there is a wealth of websites with information about MMR, including those run by anti-MMR organisations.
Brief outline of project (ie., what do you intend to do)
I will ask parents to self-complete a questionnaire when they come to the surgery to have their infant immunised with the first MMR immunization. I would like to use three G.P practices in Woking and the four G.P practices based at Walton Health Centre. The survey will continue for 2-3 months. I will send non-attenders the same questionnaire and ask them to return it by post in an S.A.E.
I will collect and analyse the data in the questionnaires and this will form the basis of a written dissertation for a MSc. in Community Paediatrics.
8. Study design (eg., cohort, case control)
   Survey using a questionnaire

9. i) How was the size of the study determined?
    The size of the study will be determined by numbers of questionnaires returned within the time period available to conduct the survey.

   ii) Was there formal statistical input into the overall study design?
    □ Yes   ☑ No

    If yes, please give name of adviser

   iii) What method of analysis will be used?
    Frequencies, cross-tabulations and statistical analysis as appropriate depending on results

10. Does the study fall into any of the following categories?

    Pilot            □ Yes   ☑ No
    Multi-Centre Study □ Yes   ☑ No
    Student Project          ☑ Yes   □ No

    (part of course requirement)

    If this is a multi-centre study, please complete the details below, otherwise go to Question 11.

    i) Which centres are involved?

    ii) Which ethics committee's have been approached, and what is the outcome to date?

    iii) Who will have overall responsibility for the study?

    iv) Who has control of the data generated?
11. Where will the study take place and in what setting?
In the waiting room for immunisations in GP practice premises and at home for those who do not attend.

12. Is any payment being made, or actively being sought by the investigator or department/unit in respect of this study (include research grants)?

   If Yes, complete the section below; if No, go to Question 13.

   i) Is the payment:
      a) A Block Grant
         If yes, give details, including amount and source of funding
         Name of funding body
         £
      b) Based on the number of subjects recruited
         If a payment is based on number of subjects recruited (per capita/payment),
         State total sum payable for each subject completing the study £
         State number of subjects agreed.
         Will patients have their travel costs paid
         If multi-centre study, state total number of subjects to be recruited.

   ii) Is the payment made in order to:
      a) Pay a salary(ies) £
      b) Fund equipment £
      c) To support further departmental research £
      d) Other (State) £

   iii) Who will have control of the funds? eg. Charitable Trust etc.

   iv) Does the investigator(s) have any direct personal involvement
      (eg., financial, share-holding etc) in the sponsoring organisation?
      (If Yes, give details)

   v) Will all the costs incurred be the institution be covered by the grant?

   iv) If the project is to be carried out in a Trust has the R&D lead in the Trust been notified of the project?
      If No/NA give reasons:

13. Schedule

Proposed starting date: May 2002
Proposed Duration: 2-3 months
SECTION 3 Recruitment of Subjects

14. How will the patients or subjects in the study be selected, approached and recruited; what inclusion and exclusion criteria will be used? STATE IF THEY ARE THE SUBJECT OF THERAPEUTIC OR NON-THERAPEUTIC RESEARCH

Non-therapeutic
Selection- all parents whose children are due to have their first MMR immunisation
Recruited-will be asked by the practice nurse to complete questionnaire in the waiting room. Non-attenders will be posted questionnaire for self completion.

15. How many subjects will be recruited and of what age group?
As many as possible over the study period
Age group- N/A

16. How will the control group (if used) be selected, approached and recruited; what inclusion and exclusion criteria will be used? Type N/A if no controls.
N/A

17. How many controls will be recruited and of what age group?
N/A

18. Are the subjects or controls included in this study involved in any other research investigation at the present time? □ Yes □ No □X Not known
If Yes, please give details

19. Will healthy volunteers be used? □ Yes □X No
If Yes, complete details below. If No, go to Question 20
i) what is their relationship to the investigator

ii) Will they receive any payment, and if so, what is the source of that funding?
If Yes, give details of payment per subject AGE 61 OF 78
Applicants should undertake to explain to volunteers that the researcher will contact their GP to ask about any drug therapy and that they must inform the researcher if they consult another doctor during the study, and that this doctor will be informed of this study.

## SECTION 4 Consent

### 20. Is written consent to be obtained?

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<th>Yes</th>
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If yes, please attach a copy of the consent form to be used.

If no written consent is to be obtained is it because one of the following methods of research is employed?

<table>
<thead>
<tr>
<th>Method</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Questionnaire</td>
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<tr>
<td>Interview</td>
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<tr>
<td>Other</td>
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If Other, please justify.

### 21. Does the study include subjects for whom English is not a first language?

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<tr>
<th>Unknown</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
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If Yes give details of arrangement made; if No please justify

Predominantly English speaking community

### 22. Are the subjects or controls in one of the following vulnerable groups?

<table>
<thead>
<tr>
<th>Group</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Children under 16</td>
<td>[ ]</td>
<td>[x]</td>
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<tr>
<td>People with learning difficulties</td>
<td>[ ]</td>
<td>[x]</td>
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<tr>
<td>Other vulnerable groups eg., mental illness, dementia</td>
<td>[x]</td>
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</table>

If Yes, please complete the details below, otherwise go to Question 23.

i) What special arrangements have been made to deal with the issues of consent and assent, eg., is parental or guardian agreement to be obtained, and if so in what form?

ii) In what way, if any, can the proposed study be expected to benefit the individual patient/subject on whom it is performed?

### 23. Will the patient/subject be given a written information sheet or letter?

<table>
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<th>Yes</th>
<th>No</th>
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<th>Yes</th>
<th>No</th>
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</table>
If Yes, please attach copy to this application form
If No, please justify

### SECTION 5 Details of Interventions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>24. Does the study involve the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence?</td>
<td>☐ Yes</td>
<td>☑ No</td>
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</table>

If Yes, please complete Annex A in the Guidance Notes, otherwise go to Question 25.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>25. Will any ionising or non-ionising radiation, or radioactive substances or X-Rays be administered to the patient or volunteer?</td>
<td>☐ Yes</td>
<td>☑ No</td>
</tr>
</tbody>
</table>

Please ensure information in Q14 includes exclusion criteria with regard to ionising radiation if appropriate.

If Yes, please complete Annex B in the Guidance Notes, otherwise go to Question 26.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>26. What investigations and/or interventions will subjects and/or controls have over and above routine care? (Please complete the table below by selecting YES/NO options as appropriate. If YES, please give details)</td>
<td>☐ Yes</td>
<td>☑ No</td>
</tr>
<tr>
<td>Self completion questionnaires</td>
<td>☑ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>Interviews/interview administered questionnaires</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Video/audio tape recording</td>
<td>☐ Yes</td>
<td>☑ No</td>
</tr>
<tr>
<td>Physical examination</td>
<td>☐ Yes</td>
<td>☑ No</td>
</tr>
<tr>
<td>Internal physical examination</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Venepuncture*</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Arterial puncture*</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Biopsy material*</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Other tissue/body sample</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Imaging investigations (not radiation)</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Other investigations not part of normal care</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<td>Additional outpatient’s attendances</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<td>Longer inpatient stays</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Local anaesthetic</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>General anaesthesia</td>
<td>☐ Yes</td>
<td>☑ No</td>
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<tr>
<td>Other</td>
<td>☐ Yes</td>
<td>☑ No</td>
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Details:

*Please see guidance notes.*

If additional investigations or tests are involved with revenue consequences for the NHS the relevant head(s) of department(s) must be contacted.
<table>
<thead>
<tr>
<th>SECTION 6</th>
<th>Risks and ethical problems</th>
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<tbody>
<tr>
<td>27. Are there any ethical problems or considerations that the investigators consider to be important or difficult with the proposed study?</td>
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<tr>
<td>□ Yes □ No</td>
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<tr>
<td>If Yes, please give details:</td>
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| 27a Is it possible that the trial medication will not be available at the end of the trial? |
| □ Yes □ No □ N/A |

| 27b If yes, is this made clear in the patient information sheet? |
| □ Yes □ No |
| If No, give reasons |

| 28. Are there any potential hazards to subjects or patients? |
| □ Yes □ No |
| If Yes, please give details, and give the likelihood and details of precautions taken to meet them, and arrangements to deal with adverse events and overdoses, including reporting to the relevant authorities. |

| 29. Is this study likely to cause discomfort or distress to subjects/patients? |
| □ Yes □ No |
| If Yes, estimate the degree and likelihood of discomfort or distress entailed |
30. Will information be given to the patient’s General Practitioner (especially if a drug is to be given or an invasive procedure is undertaken)?

☐ Yes ☑ No

If Yes, please enclose an information sheet for the GP.
If No, please justify. N/A

If the study is on hospital patients, has the consent of all consultants whose patients are involved in this research been obtained?

☐ Yes ☐ No N/A

If the study is in general practice, has the consent of all the partners been obtained?

☐ Yes ☑ No

IN PROCESS OF SEEKING CONSENT

Where available, please enclose an information sheet for consultants or GPs.
SECTION 7  
Indemnity and Confidentiality

Product liability and consumer protection legislation make the supplier and producer (manufacturer) or any person changing the nature of a substance eg., by dilution, strictly liable for any harm resulting from a consumer's (subject or patient) use of a product.

31. i) What arrangements have been made to provide indemnification and/or compensation in the event of a claim by, or on behalf of, a subject for negligent harm?

N/A

ii) What arrangements have been made to provide indemnification and/or compensation in the event of a claim by, or on behalf of, a subject for non-negligent harm?

N/A

iii) Will a medical student been involved directly in the project?

☐ Yes  ☑ No

32. In cases of equipment or medical devices, have appropriate arrangements been made with the manufacturer?

(Please indicate NA if not applicable)

☐ Yes  ☐ No  ☑ N/A

If Yes, give details

33. i) Will the study data be held on computer?

☑ Yes  ☐ No

ii) If Yes, has the relevant Data Protection Officer been notified?

☑ Yes  ☐ No

Give name of Data Protection Officer: ...Jenny Church

iv) If No, give reasons
34. Will the patient’s medical records be examined?  
☐ Yes  ☐ No

If Yes, will information relevant to this study only be extracted  
☐ Yes  ☐ No

If extra information is extracted, please justify.

What, if any, additional steps have been taken to safeguard confidentiality of personal records?

35. Will the study include the use of any of the following?  
Audio/video tape recording  ☐ Yes  ☐ No
Observation of patients  ☐ Yes  ☐ No

If Yes to either,
a) how are confidentiality and anonymity to be ensured?

b) What arrangements have been made to obtain consent?

c) What will happen to the tapes at the end of the study?

36. Will medical records be examined by research worker(s) outside the employment of the NHS?  
☐ Yes  ☐ No

If Yes, it is the responsibility of the principal investigator to ensure that research workers understand that they must:
i) *undertake never to divulge information about patients or research subjects, recorded or otherwise, to anyone without the authority of the Consultant/GP under whose care the patient is;*

ii) *also understand that the names, addresses and places of work of patients or research subjects are confidential and must not be divulged.*

Please ensure that you complete the check list on the front cover of the application form and enclose all relevant enclosures.
30 April 2002

Dr Claire Brockway
115 Vale Farm Road
WOKING
Surrey
GU21 1DP

Dear Dr Brockway

PRO/32/02 Please use this reference in all correspondence

Survey of parents' use of the internet to find information about MMR immunisation

Thank you for submitting the above protocol and attending its formal review by the North West Surrey LREC on the 24 April 2002. I am pleased to confirm that the committee have granted your application ethical approval, subject to the following amendments:

- Please submit the Participant Information Sheet, GP letter and questionnaire on Truhead paper;
- In the questionnaire, to ensure confidentiality we request that you remove the questions asking for name (26) and address (27), although you may ask for the post-code if you wish. We also request that you sub-divide "occupation" (28) into mother and father's occupations (which should enable you to remove (31));
- If you ask for more than the first half of the post-code or you are using any other means of identifying the participant, you must remove or alter your statement in the Information Sheet declaring, "Any information you provide is completely confidential."
- If you plan to involve staff with access to the appropriate patient lists in identifying and/or sending out documentation to potential participants (eg non-attenders), please submit letters of consent from all such staff;
- Please clarify the objectives of the study and declare your intention to provide a summary of the results, for example to all participating surgeries.
The committee also made the following suggestions:

- At the end of the Participant Information Sheet, you advise patients to ask their GP for advice. To show sensitivity to the possibility that the patient may not wish to approach their GP for advice, you might offer a leaflet instead;
- It may be beneficial to change the title on the questionnaire so that it does not include the word “Internet” as this might put off potential participants at first glance if they do not use it;
- Q19 in the questionnaire: alter “HV” to “Health Visitor”;
- You may wish to clarify what you mean by “health professional” to gauge more detailed results.

For your information, the following documentation was reviewed:

- LREC application form – dated 21 March 2002
- Protocol
- Patient information letter
- GP information letter
- Questionnaire
- Curriculum Vitae for Claire Marie Brockway

I look forward to receiving one copy of the above requested amendments in the near future.

The NW Surrey Local Research Ethics Committee operates according to ICH-GCP and applicable laws and regulations.

Yours sincerely

Dr Dayantha Fernando
JOINT CHAIR
9.3. Appendix 3 - Study protocol

**Parents use of the internet and media to access information about immunisation**

**Aims:**

To determine whether parents use the Internet and media (TV, radio, papers) to find information about MMR immunisation.

To ascertain which websites and sources of media information they have used.

To explore whether this affects their decision making about the immunisation.

**Background:** Parents' confidence in MMR immunisation has been undermined by the suggestion that there is a link between MMR and Autism and in addition by health professionals' confusion about the whole issue. This is reflected in declining MMR uptake since 1995 when the first queries about MMR came to public attention. There has been and is currently wide media coverage about MMR immunisation.

It is likely that parents are seeking alternative sources of information before making a choice about MMR immunisation. There is a wealth of websites with information about MMR, including those run by anti-MMR organisations. The Internet has a huge resource of health information, which is being accessed globally. Internet access has increased in the UK over the last four years and is highest in London and the South-East. The combination of rapid access to a large amount of information is contributing to increasing consumer involvement in decisions about health care.

**Methods:** A questionnaire survey in 2 Health Centres of parents bringing their infants for the first MMR immunisation.

Parents will be asked to self-complete a questionnaire when they attend clinic with their baby for the first dose of MMR immunisation, non-attendees will be mailed a questionnaire for completion.

**Results:** A qualitative analysis of questionnaires will discuss the shortfalls/strengths of the questionnaire design. Statistical analysis will include frequencies, cross-tabulations and significance testing if appropriate. Websites and media material used by parents will be described and analysed. A discussion about decision-making will be included.
Appendix 4 - G.P information letter

Dear Mrs Vaughan,

I am writing to enquire whether Dr. Lyttons' Practice would be willing to participate in a small study that would form the basis of a student research project. This is a module of the MSc. in Community Paediatrics course for which I am currently studying at the Institute of Child Health, London.

I am interested in whether parents use the Internet to find information about MMR immunisation and would like to conduct a survey using a parental self-administered questionnaire. This would be completed at the time a parent brings their baby for the first MMR at 13-15 months. I intend to mail the non-attenders with the same questionnaire. I have enclosed a copy of the draft questionnaire for your perusal. Completion of the questionnaire by the parent is entirely voluntary and any information obtained as a result would be confidential.

I am also writing to Dr Smith's and Dr Bourke's practices and to the practices based at Walton Health Centre in an effort to maximise numbers of questionnaires returned.

I need to obtain ethical approval for the study and plan to submit it to the Local Research Ethics Committee meeting in April. If the study is approved I would like to start the study in May and anticipate the duration to be three months.

I would be very grateful if your practice would consider participating in this study.

Please do not hesitate to contact me if you require any further details. I look forward to hearing from you.

Yours sincerely,

Dr. Claire Brockway  MRCPCH
Staff Grade Community Paediatrics.
Dear Parent,

I am a Community Paediatrician and am also studying part-time for a MSc at the Institute of Child Health, London. I am undertaking a piece of research work about whether parents use the Internet and other sources of information to find out about MMR immunisation.

I would be very grateful if you would take some time to complete the attached questionnaire. This is voluntary and you do not have to complete the questionnaire if you do not wish to do so.

If you have any questions about MMR immunisation please ask your G.P. or Health Visitor for advice.

Thank you for your help.

Yours sincerely,

Dr. Claire Brockway.

Staff Grade in Community Paediatrics.
Survey of parents’ use of the Internet to find information about MMR immunisation.

This questionnaire is about whether or not you have used the Internet to find information about MMR immunisation for your child. For each question please tick the box that best describes your view and write in more detail when asked. All your answers will be treated in strict confidence.

1) Do you use the Internet?
   Yes □  No □  If no go straight to question 19.

2) Where do you use it from?
   Home □  Work □  Friends house □  Relatives house □
   Library □  Internet cafe □  Other □

3) Would you use the Internet if it was available in your GP’s surgery?
   Yes □  No □  Don’t know □

4) How frequently do you use the Internet?
   Once a day □  Once a week □  Once a year □
   Other-please describe............................................................

5) Do you use a search engine?
   Yes □  No □  Don’t know □
6) **Which search engine do you use?**

Google □  Yahoo □  Hotbot □  Ask Jeeves □  Lycos □  
Don’t know □  Other –Please describe □ ........................................

7) **Have you ever used the Internet to find information about children\'s health?**

Yes □  No □  If not go straight to question 19.

If yes, have you used in the last month for this purpose?

Yes □  No □  Don’t know □

If yes, please describe

..................................................................................................................

8) **Have you ever tried to find information about immunisation on the Internet?**

Yes □  No □  If not go straight to question 19

9) **Have you ever tried to find information about MMR on the Internet?**

Yes □  No □  If not go straight to question 19.

10). **Did you find any information about MMR on the Internet?**

Yes □  No □  If not go straight to question 19.
11) Did you visit any of the following websites? Please tick those that apply.

- www.immunisation.org.uk ☐
- www.doh.gov.uk ☐
- www.rcgp.org.uk ☐
- www.babyworld.co.uk ☐

other—please describe .................................................................

Can't remember ☐

12) How did you find these websites?

- using a search engine ☐
- from newspaper/magazine ☐
- recommended by friend or family ☐

other—please describe ☐

Can't remember ☐

13) Was it clear by who or what organisation/company provided the information and maintained each website that you looked at? Please tick the box that applies for each website that you visited.

<table>
<thead>
<tr>
<th>website</th>
<th>health professional</th>
<th>member of public</th>
<th>hospital</th>
<th>government</th>
<th>other (please describe)</th>
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</table>
14) Has a health professional e.g GP or health visitor recommended using the Internet to find information about MMR?

Yes □  No □   If not go straight to question 15

If yes, did they give you a website address?

Yes □  No □

If yes please describe ..............................................................

If yes, did you use it?

Yes □  No □

15) Did you understand the information on MMR you found from the Internet? Please tick the box that applies for each website that you visited.

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<th>Not at all</th>
<th>partly</th>
<th>mostly</th>
<th>completely</th>
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<td>website 6 please state</td>
<td>❄️</td>
<td>❄️</td>
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</table>
16) Did you trust the information you obtained about MMR on the Internet? Please tick the box that applies for each website you visited.

<table>
<thead>
<tr>
<th>Website</th>
<th>Yes – please describe why</th>
<th>No</th>
<th>Not sure</th>
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<tr>
<td>Website 6</td>
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</table>

17) Do you think the information you found from the Internet helped you to make a decision whether or not to give your baby the MMR immunisation?

   Yes □  No □  Not sure □

18) Did you discuss the information you found from the Internet about MMR with a health professional?

   GP □  HV □  Practice Nurse □

Other—please describe.............................................................................................................................................
19) Where do you usually get the information you need about your baby/children’s health? Please tick all those that apply.

- TV
- Books
- Radio
- Newspapers
- Magazines
- Internet
- Family
- Friends
- Complementary Practitioner
- GP
- Health visitor
- Other
- None of the above

20) Have you asked a doctor/health visitor for advice about MMR?

Yes □   No □

21) Have you received information leaflets about MMR from your doctor/health visitor?

Yes □   No □

22) Have you seen any TV programmes on MMR?

Yes □   No □

23) Have you read articles in newspapers or magazines about MMR?

Yes □   No □

24) Have you heard any radio programmes about MMR?

Yes □   No □
25) Which was the major significant influence on your decision about MMR?

Please rate in order of importance (1=most important 12=least important)

Family □
Friends □
TV □
Papers □
Magazines □
Radio □
Books □
Internet □
GP □
Health Visitor □
Practice Nurse □
Complementary practitioner □

Please state

26) Postcode..........................................................................................

27) Mothers occupation..........................................................................

28) Fathers occupation ..........................................................................

29) Are you  Living with partner □ Single □ Married □

31) Baby’s date of birth       date/month/year.........//........//........

32) Relationship to baby

   Mother □
   Father □
   Relative □
   Guardian □
   Other □

34) Do you intend to give your baby the MMR?

   Yes □ No □ Don’t know □

Other please describe........................................................................
35) Did your baby receive the full course of primary immunisations? Please tick those that apply.

- Diphtheria 1 2 3
- Tetanus 1 2 3
- Whooping Cough 1 2 3
- Hib 1 2 3
- Polio 1 2 3
- Meningitis C 1 2 3 (please check in red book)

36) Do you have any other children?

- Yes □  No □

If so what are their ages? 1) .......... 2).......... 3).......... 4)..........  

37) Have they had MMR ?

- Yes child 1 □ child 2 □ child 3 □ child 4 □
- No □ □ □ □
38) Have they had primary immunisations?

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39) Please feel free to add any further comments

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Thank you very much for taking the time to complete this questionnaire.