

# Parents' perspectives on the MMR immunisation: a focus group study

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## SUMMARY

**Background:** The uptake of the combined measles, mumps and rubella immunisation (MMR) in Britain has fallen since 1998, when a link was hypothesised with the development of bowel disorders and childhood autism. Despite reassurances about the safety of MMR, uptake levels remain lower than optimal. We need to understand what influences parents' decisions on whether to accept MMR or not so that health professionals can provide a service responsive to their needs.

**Aim:** To investigate what influences parents' decisions on whether to accept or refuse the primary MMR immunisation and the impact of the recent controversy over its safety.

**Design:** Qualitative study using focus group discussions.

**Setting:** Forty-eight parents, whose youngest child was between 14 months and three years old, attended groups at community halls in six localities in Avon and Gloucestershire.

**Methods:** Purposive sampling strategy was used to include parents from a variety of socioeconomic backgrounds. Three groups comprised parents who had accepted MMR and three groups comprised parents who had refused MMR. Data analysis used modified grounded theory techniques incorporating the constant comparative method.

**Results:** All parents felt that the decision about MMR was difficult and stressful, and experienced unwelcome pressure from health professionals to comply. Parents were not convinced by Department of Health reassurances that MMR was the safest and best option for their children and many had accepted MMR unwillingly. Four key factors influenced parents' decisions: (a) beliefs about the risks and benefits of MMR compared with contracting the diseases, (b) information from the media and other sources about the safety of MMR, (c) confidence and trust in the advice of health professionals and attitudes towards compliance with this advice, and (d) views on the importance of individual choice within Government policy on immunisation.

**Conclusions:** Parents wanted up-to-date information about the risks and benefits of MMR to be available in advance of their immunisation appointment. Many parents did not have confidence in the recommendations of health professionals because they were aware that GPs needed to reach immunisation targets. Most parents would, however, welcome more open discussion about immunisation with health professionals.

**Keywords:** immunisation; measles, mumps and rubella vaccine; primary health care; attitude to health; decision making.

## Introduction

Childhood immunisation is high on the agenda for parents, policy-makers, and health care practitioners.<sup>1-4</sup> The need to take parental concerns about immunisation seriously has recently been emphasised.<sup>2</sup> Since Wakefield *et al* hypothesised a link between the measles, mumps and rubella (MMR) vaccine and Crohn's disease and autism<sup>5</sup> the uptake of MMR has fallen,<sup>6</sup> despite Department of Health reassurances and recent research emphasising the vaccine's safety.<sup>3,7-10</sup> Several studies have investigated factors affecting the uptake of vaccines; however, these have generally used postal survey techniques which do not allow investigation of the decision-making process.<sup>11</sup> Qualitative research is therefore a useful approach to analysing what factors influence parents' immunisation decisions. Although some studies have looked at the attitudes of non-immunisers,<sup>12</sup> no qualitative studies have explored the perspective of parents who have, and who have not, accepted MMR since the recent concern about its safety.

This study investigated factors that influenced parents' decisions about MMR, with emphasis on the impact of the recent controversy. Understanding the concerns of parents may enable health care professionals to address these and provide an immunisation service that is more responsive to their needs.

## Methods

Six focus groups<sup>13</sup> were held with parents in Avon and Gloucestershire. Three groups comprised parents who had accepted MMR for their youngest child ('immunisers') and three comprised parents who had refused MMR ('non-immunisers'). Their children had a range of histories for immunisations other than MMR. Sampling was purposeful, so that parents were included from a variety of socioeconomic backgrounds who had either accepted or refused MMR immunisation for their youngest child, aged between 14 months and three years at the time of recruitment (Box 1). Ethical approval was obtained from Bristol, Frenchay, Bath, and Gloucestershire local research ethics committees.

Each focus group was facilitated by a moderator and assisted by a different member of the research steering group. The discussions were tape-recorded and fully transcribed. The moderator used a series of open-ended questions about child health, attitudes towards immunisation, the decision-making process, and the effects of the media and other influences on immunisation decisions, but participants were encouraged to explore issues about immunisation that were important to them. The discussions lasted between one and two hours and were held in a convenient location for the parents where a crèche was provided.

Data collection and analysis proceeded simultaneously

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**HOW THIS FITS IN***What do we know?*

Immunisation safety scares provoke anxiety among parents and lead to a reduced uptake. Following the recent media reports of doubts over the safety of MMR, its uptake in the United Kingdom has fallen to a level where epidemics of disease could result, despite Department of Health reassurances about its safety. A recent survey of health professionals identified a need for training and updating about immunisation issues so that they can respond promptly and appropriately to parents' concerns.

*What does this study add?*

Doubts and anxieties about MMR safety are prevalent, both among parents who have accepted and those who have refused MMR for their children. Department of Health statements are insufficient to reassure parents about MMR's safety. Decisions about whether to accept or refuse MMR reflect the degree of parental trust and confidence in medical recommendations and their attitudes towards compliance. Parents want a more informed and open discussion with health professionals about MMR and access to detailed information about its risks and benefits.

until theoretical saturation was reached, according to the constant comparative method.<sup>14</sup> Transcribed data were analysed using modified grounded theory techniques<sup>15</sup> by the research team. The transcripts were scrutinised, emerging themes and sub-themes were agreed, and an initial coding index was developed. Sections of text were coded and these codes were applied to subsequent transcripts. Further codes were added as new themes emerged. Three members of the team coded some transcripts independently and a high level of consensus was achieved. Microsoft Word was used to develop individual files for each theme, allowing the text to be sorted and analysed in detail.

**Results**

Four key factors influenced parents' decisions about whether or not to accept MMR. Despite having made different choices, immunisers and non-immunisers shared many similar views about the MMR vaccination. Similarities and differences between the beliefs of immunisers and non-immunisers will be explored for each of these four key themes.

***Beliefs about the risks and benefits of immunisation compared with the risks associated with contracting measles, mumps or rubella***

All parents perceived that MMR brings potential benefits and potential risks for their children. Although the immunisers tended to stress the benefits of immunisation and the dangers of the diseases to a greater extent than the non-immunisers, they still remained unhappy about MMR and its possible association with childhood autism and bowel disorders. Parents in all the groups talked about their anxiety over this possible association.

Number of participants	48 (43 female, 5 male)
Size of groups (six groups in total)	4 groups had 9 participants 1 group had 8 participants 1 group had 4 participants
Age range	22–48 years (mean = 35 years)
Family size	17 families had 1 child 19 families had 2 children 10 families had 3 children 2 families had 4 children
Marital status	
Married or co-habiting	44
Single	4
Qualifications	
GCSE certificate	12
NVQ or other diploma	10
Degree	26

**Box 1. Study participants.**

*'You have this doubt in your mind, however small I may feel it may be ... autism ... Crohn's disease ... why put parents through the anxiety of thinking, 'Well did I do it by giving them the immunisation or would it have occurred naturally?'' V (Non-immuniser.)*

*'A friend's child was, you know, described as autistic and you think, this was after his MMR, it may not have been as a result of that but it does make, if it's close to home it makes you think.' L (Immuniser.)*

Non-immunisers realised that, by refusing MMR, their children might contract the diseases and did not rely on herd immunity to protect their children. However, they felt that the risk of serious complications from the diseases was small in a country such as the United Kingdom, with generally good standards of health and nutrition. This view was also shared by the majority of immunisers.

*'I mean in the Third World obviously it's a killer, I don't believe that measles is a killer here, I haven't heard of anybody dying.' C (Immuniser.)*

The majority of parents felt they could reduce their children's susceptibility to contracting diseases and developing serious complications by maintaining their general health.

*'We tend to think while they're healthy it's not going to be ... the chances are so small of any serious complication that it's probably better that they catch the things.' I (Non-immuniser.)*

*'The vulnerable children are the ones who don't have good diet or who are from, you know, poorer backgrounds and who obviously are more open to infection in the first place if there are epidemics.' R (Non-immuniser.)*

Most parents had contracted some or all of the diseases in their own childhood, but their personal experiences were not good predictors of their own child's immunisation status. For example, many who had suffered measles severely did

not immunise their children.

*'I had measles at six or something and it allegedly damaged my eyesight very badly but, and I wear lenses now, I'm very blind but, I still would rather run the risk that G catches it sometime now and we catch it quickly enough to put him in bed and so on, than expose his immune system at the age of whatever, a year, to something [vaccination] that may or may not have serious effects on the system itself.'* I (Non-immuniser.)

Parents generally felt that it was important to develop their child's 'natural immunity' through exposure to mild infections. For many non-immunisers, this included early exposure to measles, mumps and rubella. In contrast, they felt the combined immunisation might be harmful to the child's immune system.

*'It's very healthy to have them and it's a positive benefit to the child to actually have those illnesses properly, not a kind of half-hearted thing after the vaccination which does happen.'* W (Non-immuniser.)

Vaccines in general were perceived by some of the non-immunisers as placing stress on a child's immature immune system, with possible short and long-term consequences for their health. For example, an increased susceptibility to allergies, asthma, and eczema was mentioned, and the potential for developing autoimmune diseases, cancer, and AIDS. Non-immunisers also cited the process of vaccine production and the use of animal products as further disincentives to immunise.

A minority of non-immunisers also believed that having the diseases assisted the child's psychological and physical development and enhanced family relationships. Non-immunisers were less fearful of diseases in general, perceiving that they were a necessary part of the spectrum of life and the balance of nature. They reported that they would prefer their children to contract the diseases while they were young to avoid a more severe infection or more serious complications when older, such as male sterility from mumps or congenital rubella syndrome in pregnancy.

Many parents were confused about the role of breastfeeding in promoting immunity, as they were told that this transferred maternal immunity, but that immunisation was also necessary.

*'I've just been told that ... breast feed ... you get immunity so I wonder why the pressure. I feel that the medical profession can't have it both ways, they say breastfeed because the baby gets your immunity therefore well, why have vaccinations then until you stop.'* C (Immuniser.)

All parents felt that immunisation was associated with some risk and very few approached MMR with complete confidence. Although some parents were opposed to all immunisations, many more had concerns specifically about MMR, especially the widely publicised possible association with Crohn's disease and autism.

*'I'm not actually anti-vaccines, I'm quite sort of pro-*

*vaccines, it's MMR in particular that I have a problem with.'* C (Non-immuniser.)

For many parents in all groups, the three separate vaccines for measles, mumps, and rubella were seen as a safer option and one which placed less stress on the immune system.

Vaccine effectiveness was generally accepted by immunisers, despite some knowing immunised people who had developed the diseases. All groups, however, were concerned about the duration of protection from MMR, with the need for an MMR booster raising doubts about its long-term effectiveness.

*'I would prefer to give my child protection against MMR naturally through catching the disease than have to keep boosting him for however long it takes.'* H (Non-immuniser.)

Many non-immunisers felt that the immunisation programme should be targeted at specific 'high risk' groups; for example; rubella immunisation for teenage girls, or mumps for boys.

Data from this study therefore showed that parents went through a process of weighing up the risks and benefits of immunisation, but this process does not fully explain the decisions they made. For example, many who perceived the risks of MMR to be very small still found it unacceptable.

*'They still cannot categorically say the vaccine is safe and until, however small the doubt in my mind is, I feel probably it is safe but I can't live with that and until someone can categorically say that it's going to be all right, it's not going to be acceptable to me.'* V (Non-immuniser.)

The rational analysis of risks and benefits was, however, overlain by other attitudes and psychological processes. Other processes which contributed to parents' decisions about MMR are discussed below.

### *Responses to information from the media and other sources about vaccine safety*

The media publicity about the possible link between MMR, autism, and Crohn's disease had raised doubts in the minds of people who had not previously questioned the safety of immunisation.

*'It was because of the media and the press that I looked into the MMR and decided well whoa, I'm not having that you know, otherwise, before, I didn't just didn't think anything of it.'* C (Non-immuniser.)

Although parents recognised that information in the media can be sensationalised, reassurances about the safety of the vaccine issued by the Department of Health were treated with scepticism as parents felt that their concerns had not been adequately addressed. Many parents believed that the possible link with autism and Crohn's disease was not resolved, so were unwilling to accept MMR.

*'There is a question mark behind the MMR whether that's*

*proven or not there was a question mark, enough for me to sit down and think about it and I think they misjudged that completely ... people do want to know these days, that's the era we're living in ... don't just pat us on the head and say "Oh you'll be OK".*' A (Immuniser.)

Generally parents did not have confidence in statements issued by the government about the safety of MMR and analogies were made with the BSE crisis. Parents had therefore obtained other information from a variety of sources, to investigate the safety of MMR. Although parents were generally well informed about immunisation, they reported that inadequate information had hampered their decision-making process. Apart from consulting health professionals (see below) parents consulted family and friends, the Internet, and a range of 'alternative' books and articles such as 'What the doctors don't tell you'.<sup>16</sup> They felt that much of the available information was biased, either strongly pro-immunisation or anti-immunisation.

*'There doesn't seem to be anything balanced does there, there's either the government sort of, yes, you know it's definitely very safe and every child should have it or there's the other side where, you know, they shouldn't have any etc, and it's very hard to try and work out from those two what to do.'* A (Non-immuniser.)

Parents suggested that more information from independent sources should be easily available at GP surgeries and community clinics. Currently available leaflets were felt to be limited in scope and failed to address their concerns.

*'But that's very confusing isn't it, as a parent because you obviously want the best for your child and when you see all these reports ... and you're trying to look at it and make an educated decision .... I think just basically there's a complete lack of information ... I think there needs to be something a bit sort of totally universal that everyone can sort of get their hands on and that's independent 'cause I think people are just either way polarised.'* H (Immuniser.)

*'It is impossible to get figures that we know are objective and trustable.'* I (Non-immuniser.)

### **Confidence and trust in the advice given by health professionals and attitudes towards compliance with medical recommendations**

Parents often found it difficult to have an open discussion with health professionals about the risks, benefits, and options for immunisation, which they felt would have helped them make an informed decision. In fact, they reported unwelcome pressure from professionals to accept immunisation and many immunisers had accepted MMR because of this pressure rather than making an informed choice, feeling that it was easier to comply than to refuse.

*'Sometimes the doctors and nurses at the surgery can be too much you know, you must have it, you know? And that's what puts a lot of people's backs up doesn't it real-*

*ly, your choice is gone a bit isn't it?'* B (Immuniser.)

*'I, it was really just ... bowed under the pressure that we had the vaccination done, I think.'* A (Immuniser.)

*'We thought long and hard before we had the immunisation done and we're still not happy having had it done.'* K (Immuniser.)

*'You're sort of shoved into it because you think it's the right thing, but you do feel like it's the lesser of the two evils.'* L (Immuniser.)

Many felt afraid to ask questions in case they were labelled as a 'nuisance'.

*'I'm sure they've got it on my file, "neurotic mother".'* N (Immuniser.)

*'They put red all over the notes, red pen, they write REFUSED in big red letters all the way across the child's medical notes so they've sort of got 'difficult parent' in their mind!'* L (Non-immuniser.)

However, for non-immunisers, this pressure to comply made them more resistant to having the immunisation, although some also described how difficult it felt to go against medical advice.

*'But it's hard isn't it if you begin to make an enemy of your doctor by pushing things then you can feel very out on a limb.'* W (Non-immuniser.)

Several examples were given of non-immunised children being offered opportunistic immunisations in accident and emergency departments, or during a hospital admission, which parents felt was both inappropriate and distressing. Parents recognised however, that health professionals are themselves under pressure to reach immunisation targets.

*'All credit to health visitors but they toe the government line, there's no choice about it.'* A (Immuniser.)

Non-immunisers were particularly concerned about GPs receiving payments for achieving immunisation targets. Because of this, parents worried that the recommendations of health professionals may partly be motivated by financial factors and not purely by the child's best interests.

*'Because the GP's funding is based on their quota of immunised children that's something that made me very suspicious about the whole thing. I've got to have immunisation for my child because otherwise they won't get their funding, that's already weighted isn't it.'* L (Non-immuniser.)

However, health visitors and doctors who discussed immunisation issues openly with parents were highly valued. Parents suggested that designated times for discussions about immunisation with health professionals should be



considered, such as meeting in a group during antenatal education or postnatal support. They also wanted to receive information before their scheduled immunisation appointment and suggested this could be sent out with the immunisation appointment card. This would enable further discussion and reflection before their decision was reached.

*'I can't believe that in this day and age they can't get the information across to the parents.'* N (Immuniser.)

*'I might not have had the MMR vaccination, I was given the fact sheet after my son had had it, which I was a bit cross about.'* C (Immuniser.)

Many of the non-immunisers had had their older children immunised, but had changed their views over time as they reported feeling more confident about questioning professional recommendations and exploring alternatives as their experience as parents grew.

### *Views on the importance of individual choice within government policy on immunisation*

The potential conflict between government policy setting immunisation targets and the rights of parents to make their own choice about immunisation was an important issue for the participants.

*'They [the government] are making decisions for what they see as society as a whole and we're making decisions for our individual children so we are polarised to start with.'* R (Non-immuniser.)

As discussed above, there were concerns about the financial incentives offered to GPs for achieving immunisation targets and other vested interests, such as the investment of pharmaceutical companies in the production of MMR.

*'What I wish is that they wouldn't pretend it was value free ... to pretend money isn't a part of it, I find that really irritating.'* W (Non-immuniser.)

Many participants had been parents over a long period of time and had experienced several policy changes about immunisation, which made them believe more strongly that they should follow their own instincts.

*'I resent being told by a GP that I have to have something done because it's better for the population and I want to challenge that somehow.'* H (Non-immuniser.)

All groups emphasised that parents should be able to choose which immunisations, if any, their children received, and they all wanted the single vaccines for measles, mumps, and rubella to be available as an alternative to MMR. Parents felt that the promotion of MMR was partly based on considerations of cost and convenience, such as the potential difficulty in tracking individuals for separate immunisations, factors which are not generally discussed.

*'We were angry that we were not given a choice, that it had to be the combined three together, why they couldn't*

*split it ... We were told no you couldn't ... we were never given that choice, we were just told this is how it is ... why are we not allowed to have it, why is there not the option to have any of those three separate vaccines?'* K (Immuniser.)

*'Just because it's easier and cheaper for the government to deal in those triples, doesn't mean that if you want them as single vaccinations you should be, you know, you should be able to have that.'* J (Non-immuniser.)

Many parents who had refused MMR said they would accept some or all of these single vaccines.

*'I feel quite clear that I would have my children vaccinated against measles as a single vaccine but I'm not happy with the options available ... I only hope that if we do make a stand they will release a single one.'* CC (Non-immuniser.)

In addition, most parents felt that giving MMR at an older age would rule out any coincidental association with autism. Some non-immunisers had delayed having MMR, and were planning to have it just before school entry, but only some GPs had agreed to such arrangements.

While acknowledging the role of immunisation in keeping disease incidence low in the population, parents' overriding concern was for the health of their own children, which was more important to them than any commitment to the societal benefits of immunisation.

*'I think primarily your first thought is, Oh yes, my child and I want to protect them and then as a knock-on effect, as a secondary effect, if you like, the fact that it's going to help everybody is a great — that's good, that's a bonus — but I think the primary thought is — how it will benefit your child.'* H (Immuniser.)

Although a few immunisers felt that non-immunisers were 'irresponsible', the majority respected the opinions and decisions of others. Peer pressure was not a significant factor in their decision; more importance was placed on people making their own choice. However, some non-immunisers felt they had been criticised for not immunising their children and reported feeling unwelcome at playgroups or being removed from GP lists.

## **Discussion**

The majority of participants found that the decision about MMR was both difficult and stressful. Surprisingly perhaps, both immunisers and non-immunisers shared similar anxieties about the MMR, despite having made different decisions. Although some parents were opposed to all immunisations, many more had concerns specifically about MMR, especially the widely publicised association with Crohn's disease and autism.<sup>5</sup> Non-immunisers felt that the potential risks of MMR outweighed the potential risks from contracting the diseases, and did not feel happy about complying with a policy which offered them no choice. In contrast, immunisers generally chose compliance, rather than making an

informed positive decision.

Although parents had assessed the risks and benefits of MMR, most felt that the information available to help them make this decision was insufficient and unreliable and that health professionals were not easily available to support them. Many felt they could not trust their recommendations owing to the pressure professionals are under to reach targets and the financial incentives involved. This potential for conflict has also been recognised by primary health care professionals themselves.<sup>17</sup>

Study parents' immunisation decisions appeared to involve more than a 'rational' risk/benefit analysis, and also reflected their personal attitudes, beliefs and perceptions — a finding previously reported in a study of parents' decisions about pertussis immunisation.<sup>18</sup> The media reports about MMR had affected most parents' immunisation decisions, except for those few who were already committed to their views, being either strongly pro or strongly anti-immunisation. For these people the MMR story had less impact. Although some non-immunisers were worried that their children might contract one of the diseases, the majority found it easier to live with risking the 'natural' process rather than risking a definite action (immunisation), which might cause harm. This reveals a preference for an act of 'omission' rather than an act of 'commission' as previously documented in a study about why pertussis immunisation was not accepted.<sup>18</sup>

Did parents perceive that they had a responsibility to society by immunising their children to reduce disease incidence? Generally, their key concern was for the health of their own children, which overrode any commitment to the societal benefits of immunisations. It has been suggested previously that parents who refuse immunisation are relying on 'herd immunity' to protect their children,<sup>19</sup> but this was not found in this study. Parents accepted that their children might contract the diseases if they were not immunised, but they were optimistic that they would make a good recovery, despite evidence about the dangers of the diseases. The perception, expressed by some non-immunisers, that diseases can be beneficial to a child's development, has also been reported recently in a study of a measles outbreak in an anthroposophical community.<sup>20</sup>

Fears about the combined vaccine placing stress on the immune system, which was of particular concern to non-immunisers, has also been reported in a recent Australian study.<sup>21</sup> Other combined vaccines, in particular the diphtheria, tetanus, and polio combined immunisation, also caused concern for some immunisers and non-immunisers, a finding beyond the scope of the present discussion.

Although the groups were held in locations reflecting the socioeconomic diversity of the region, over half of the participants (54%) were highly educated and their mean age was 35 years, which could limit the generalisability of the results. Since this study was conducted much new scientific evidence has been published, emphasising the safety of MMR:<sup>3,7-10</sup> evidence that was unavailable at the time of the focus groups. It is important that such findings reach the public domain and are presented in a form that can help parents make informed decisions.

This study shows that much can be done by health care professionals to help parents make their immunisation deci-

sions. Professionals may need help and support to develop an open approach with parents. Registrars in general practice have reported not being trained in the skills required to involve patients in shared clinical decision making.<sup>22</sup> GPs and health visitors may also need updating about the risks and benefits of MMR.<sup>23</sup>

A range of information for parents could be available at practices and clinics so they have timely access to this before the immunisation appointment. New booklets and videos are now becoming available, such as those produced by Health Promotion UK.<sup>24,25</sup> Information leaflets could accompany the immunisation appointment card and include fact sheets giving statistics of the risks of diseases, their complications, and the risks of adverse immunisation outcomes, with reference to recent scientific findings.<sup>3,10</sup> The study findings highlight key information items needed by parents, such as why the MMR schedule has changed, the importance of immunising both boys and girls, the duration of protection and the rationale for boosters, the limited transfer of immunity in breast milk, and why immunisation is important at a young age. Only by fully appreciating the concerns of parents will health professionals be able to work with them to restore their confidence in MMR immunisation.

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