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'Avoiding harm to others' considerations in relation to parental MMR vaccination

discussions - an analysis of an online chat forum

**Abstract** 

Vaccination against contagious diseases is intended to benefit individuals and

contribute to the eradication of such diseases from the population as a whole. The

Measles, Mumps and Rubella (MMR) vaccine is widely recommended for all

children with the aim of protecting against measles, mumps, and rubella. However,

within the UK, there has been significant controversy surrounding its safety.

This paper presents findings from a UK study of discussions about MMR in an

online chat forum for parents. We observed archived discussions (without posting

any messages) and conducted a thematic analysis to explore in more detail how

participants discussed particular topics. Most participants were female, had young

children, lived in the UK. They had reached a range of decisions regarding MMR

vaccination.

This analysis focuses on discussions about 'avoiding harm to others,' which were

important considerations for many of the participating parents. In the context of

concerns about MMR safety, participants expressed a desire to both (a) protect their

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own child and (b) help protect others by contributing to herd immunity. Parents made a distinction between healthy and vulnerable children which had important implications for their views about who should bear the burden of vaccination. Some parents were quite critical of those who did not vaccinate healthy children, and urged them to do so on grounds of social responsibility.

Our findings suggest that social scientists with an interest in vaccination practice should attend carefully to lay understandings of herd immunity as a public good and views about obligations to others in society. Policy makers, too. might consider giving more emphasis to herd immunity in vaccination promotional material, although attention should be paid to the ways in which parents distinguish between healthy and vulnerable children.

#### Introduction

Vaccination against contagious diseases is intended to benefit individuals and contribute to the eradication of such diseases from the population as a whole. The Measles, Mumps and Rubella (MMR) vaccine is widely recommended internationally for all children with the aim of protecting against measles, mumps, and rubella. In the UK (unlike other countries such as the USA where childhood vaccination is compulsory), childhood vaccination is voluntary but parents are encouraged to accept immunisation for their children. The Government policy objective is to achieve 'herd immunity,' for which high uptake rates are required.

The target of the UK immunisation programme for MMR is for 95% of children to receive it by 24 months of age (<u>www.isdscotland.org</u>).

Controversy surrounding the safety of MMR was precipitated by the publication of a study in 1998 reporting a new syndrome of bowel disease and autism in twelve children (Wakefield, Murch, Linnell, Casson, Malik and Bewrelowitz, 1998). The authors speculated about a link between the MMR vaccine and inflammatory bowel disease and autism, and recommended more research into the possible risks of the vaccine. Their press release made a case for giving separate vaccines against measles, mumps and rubella (Royal Free Hospital School of Medicine. New research links autism and bowel disease, press release, 27 February 1998), although single vaccines were not recommended by the Government and were not freely available.

Although some parents had been noticing potential adverse reactions to MMR previously (Fitzpatrick, 2004), publicity about this study generated significant concern among parents, and vaccination rates declined significantly. In 1995-6, 92% of children in England had been immunised by their 2<sup>nd</sup> birthday. This fell to around 87% in 2000-2001, 84% in 2001-2002, and 79.8% by late 2004. Similar changes occurred in Scotland (HPA 2004; HPS 2004). The study and reactions to it prompted further research to investigate the possible association between the MMR vaccine and autism, but the numerous epidemiological studies conducted subsequently have found no evidence of a link (Medical Research Council, 2001).

The MMR controversy generated much academic interest, and a number of studies used surveys, interviews and focus groups to investigate parents' attitudes to, and decisions about, the vaccine (e.g. Pareek and Pattison 2000; Evans, Stoddart, Condon, Freeman, Grizzell, and Mullen, 2001; Health Education Board for Scotland 2001; Lunts and Cowper 2002; Petts and Niemeyer 2004; Poltorak, Leach, Fairhead and Cassell, 2005; Hilton, Pettigrew and Hunt, 2006; Cassell, Leach, Poltorak, Mercer, Iverson and Fairhead 2006; Casiday 2007). These studies have generated broadly consistent insights. Parental decision-making about MMR has been shown to be influenced by a complex range of factors, especially perceptions of their own child's vulnerability to any risk from MMR, and the perceived trustworthiness of different sources of information.

We report on a study that examined discussions about MMR among parents who participated in an online chat forum. We focus particularly on discussions about 'avoiding harm to others,' which were important considerations for many parents within our sample and apparently influential in their vaccination decisions.

#### Methods

We used an internet discussion forum to investigate public opinion. This is an innovative form of data collection with significant potential. As Rier (2007) argued, "online support groups constitute natural, colossal, floating focus groups, offering an unusual opportunity for researchers to tap into specific segments of public opinion, and to watch how it forms, as it forms."

Our analysis focussed on the web site <a href="www.mumsnet.com">www.mumsnet.com</a>. 'Mumsnet' was launched in July 2000 by two UK parents. It describes itself as a website "offering product reviews and parenting tips by parents for parents." By 2001 it was attracting 10,000 people a month and in July 2007 it had 300,000 monthly users (Lane, 2007). 'Mumsnet' members can start discussions on any subject of interest or add messages to existing conversations. The web site allows 'non-member' visitors to search the discussion forum archives using keywords.

We chose this particular website for two main reasons. First, it had a large archive of discussion 'threads' about MMR. Although other websites were more clearly focused on vaccination issues (see e.g. <a href="www.jabs.org.uk">www.jabs.org.uk</a>) they had not generated such a volume of online discussion and were perhaps less likely to attract parents with a range of opinions about vaccination. Second, the public nature of the site minimised concern about examining talk that people might have wanted to keep private. The archives of discussion threads on 'Mumsnet' are accessible without any request to register or 'log on' to the web site. The venue is thus perceived as a 'public' rather than a 'private' sphere (Eysenbach and Till 2001). Mumsnet members are told that their postings on the discussion forum will be publicly available, and are asked to anonymise their postings by using a 'chat nickname' and adopting codes when referring to members of their family. Participants complied with this request and were not identifiable from their postings. We observed archived discussions without posting any messages so the degree of 'intrusiveness' of our

research was minimal: we were not actively involved in online discussions either as declared researchers or covert participants. For practical and ethical reasons, we judged it inappropriate to solicit additional personal data for the purposes of our research.

We focused on the two largest discussion threads which had numerous participants, continued over extended periods of time, and dealt with many aspects of the MMR debate. The earlier, longer discussion thread ran from August 31st 2000 to February 13th 2002 and the more recent discussion took place between January 18th 2003 and March 5th 2003). Our initial categorisation of message content provided information about the range and frequency of issues discussed, and information sources referred to. We then conducted a thematic analysis using a modified Framework approach (Ritchie and Spencer, 1994) to explore in more detail *how* participants discussed particular topics. Initial separate analyses of the two discussion threads revealed extensive thematic similarity between them. To avoid excessive repetition, the content of both threads are discussed together here.

In this paper we focus on one of the prominent topics, the issue of 'avoiding harm to others'. Other studies exploring parental views about MMR have mentioned this issue but found that considerations of 'avoiding harm' to their own child were paramount (e.g Cassiday 2007; Poltorak et al 2005; Health Education Board for Soctland 2001). We found that the issue of 'avoiding harm to others' was a prominent theme, with message postings on this topic being particularly lengthy and

sometimes hostile and judgemental We discuss how individual considerations about their own and other children's immune status had implications for discussions about social responsibility to be vaccinated.

# **Findings**

Sample size and characteristics

Table 1 indicates the duration and size of the two discussion threads, and the numbers of messages posted by participants. 132 different participants contributed a total of 617 messages to the two discussion threads. Eleven participants took part in both threads and fifteen participants contributed more than 10 messages each.

Thread 1, labeled 'MMR jabs', was triggered by a parent asking about alternatives to the MMR vaccine and whether single vaccines were still available in France (they were not available on the National Health Service in the UK). At the time of data collection, this thread had reached its maximum length and no new postings could be made. Thread 2, labeled 'MMR single vaccines just a little bit of info please,' was initiated by a parent asking for advice about single vaccines after receiving an appointment card from her GP for her child's MMR vaccination. The last posting was made on March 5th 2003. The initial short questions posted by the two parents generated rich discussions on a range of topics relating to MMR which continued over time. Parents argued and negotiated different positions.

Our data source did not include demographic information about participants. However, chat 'nicknames' and references in postings to husbands/boyfriends, sons and daughters, GPs, the UK government, and particular TV programmes and newspapers suggested that most participants in both discussions were female, had young children and lived in the UK.

89 participants (67.4%) discussed decisions they had made (or intentions they had) for a specific child or children with regard to MMR vaccination. A range of choices were reported and diverse reasons given (Table 2 and Box 1).

# *Vaccinating to help protect others*

Considerations of social responsibility and of the importance of children being vaccinated to prevent disease spread were particularly striking within our data. As the following quotes illustrate, although there was a strong emphasis in discussions on the need to protect their own child from potential disease and vaccine risk, parents also expressed a concern to protect others in society, and this was apparently influential in some parents' decision-making:

"I very much wanted my child to be vaccinated against rubella because I could not live with myself if a baby was born catastrophically damaged (can you imagine a worse hell than being

deaf and blind?) Because of me & my child passing on an illness..."

(Aloha - chose single vaccines)

"I had my daughter immunised so I hope she helps not to spread this needless measles outbreak to children whose parents didn't have them vaccinated... Because Lill, I don't have an 'I'm alright Jack' attitude. I do worry about other kids getting measles, mumps, rubella even though dd [daughter] has been vaccinated, just as I worry about lots of things that might not affect me personally" (Enid - chose MMR)

The implications to other people of parents choosing not to vaccinate their children were widely discussed during conversations about the three diseases MMR is designed to prevent. We use the case of rubella to illustrate.

The rubella virus has relatively mild effects in most people, but can be very damaging to unborn babies. Participants considered the potential consequences of rubella vaccination for others, especially pregnant women and their unborn children. In contrast to the non-directive nature of discussion of other issues (e.g. whether to choose single vaccines instead of MMR), discussion about vaccinating for the sake of others included several clear attempts to influence other parents' behaviour. For example:

"...Last week I met a woman my age (30s) who is totally deaf, since birth because her mother had rubella while pregnant. I guess this MMR debate must make her quite angry. It's not her fault or her mother's that she is deaf. You can't expect all mothers to be to plan jabs. Plenty of women get pregnant without planning, many don't know if they have already had rubella (do you?). Its up to us all in society to protect 'the herd!'" (Lil).

Participants recognised that women *could* theoretically take individual responsibility for their own rubella immunity status, but several acknowledged that it was unrealistic to expect all to do so:

"...If vaccination was left up to women to ask for it the end result would be more children born blind and deaf. I'm a pragmatist and I'd rather have a well run rubella vaccination programme to protect those children than leave it up to individual responsibility" (*Elliott*).

Only two participants dissented from this view, arguing that pregnant women should be responsible for ensuring their *own* immunity status and not be reliant on children to protect them. In response to the dominant view in favour of vaccinating to protect others, these two parents argued that people (especially children) should

not be expected to accept the risks of MMR vaccination – particularly when the rubella component would bring them no personal benefit:

"I cannot see why I should expose my child to the risk of a combined vaccine to safeguard mothers and doctors that do not take responsibility for their own health" (SBLB).

"...I really do have an issue with Rubella, which is purely vaccinated against for public health reasons. Why shouldn't women take responsibility for their own rubella-immune status... I understand it's to try and eradicate the disease totally, but it seems to me that rubella is only a danger to pregnant women, and not to every man, woman and child on the planet" (*Frieda*).

However, after reading subsequent postings and checking figures relating to recorded infections of pregnant women since the introduction of MMR, the second of these parents changed her opinion:

"Yes, elliott, I did know that it was the unborn child that was at risk, rather than the mother. But I thought that the pre-MMR rubella campaign (where girls only were vaccinated at about 13) was

pretty successful in preventing the infection (and subsequent very high risk of foetal damage) of unborn babies. I've now checked my facts...And, yes, Aloha, that's a very good point about no vaccination being 100% effective. So I'm prepared to revise my view on this one" (*Frieda*).

(This is a good example of how parents responded interactively to each other, and of how some changed their understandings and opinions over time).

When discussing mumps and measles, the protection of other children was also an issue. The concept of 'herd immunity' featured in a number of postings and there was widespread acceptance that this was important both in terms of preventing epidemics and in terms of protecting the more vulnerable members of society.

Who bears the burden for what benefit?

When discussing issues relating to herd immunity, parents often differentiated between 'healthy' and 'vulnerable' children. Children who were regarded as potentially vulnerable to vaccine damage included those with auto-immune conditions or those susceptible to allergies. These children were contrasted with 'healthy' children who were perceived to possess stronger immune systems and be better able to "cope" with exposure to disease or vaccines. These differentiations were quite striking and related not just to who needed protecting, but also to who should bear the burden of vaccinating.

Participants who did not report having significant concerns about the safety of the MMR vaccine (or its effectiveness in preventing the three infectious diseases) were more likely to claim to believe they had a responsibility to ensure that their child was vaccinated in order to prevent the spread of disease, and to protect children who, for medical reasons, or because of their age, could not be vaccinated. Although a sense of responsibility to protect other women's unborn children helped motivate some to get their own child vaccinated against rubella, the fact that the unborn child could potentially be their *own* was sometimes mentioned.

"It's not just our [son] that I considered but also the welfare of the other children with whom he comes into contact and the expectant mothers that he may encounter when he grows up (not least me should we have another) (Harrysmum - chose MMR)

In their messages, these participants were often critical of parents who had decided not to vaccinate their *healthy* children with MMR. Some of their comments on this issue were quite judgemental when considered in the context of the usual respectful tone of discussions on Mumsnet. Two main criticisms were made: first, they relied on others for protection without contributing to the herd immunity that they benefited from (sometimes called 'free-riding'); and second, they were potentially exposing vulnerable children to disease (by not getting their own children vaccinated and thus making the spread of disease more likely). For example:

"Yes, Lill, Pupuce et al you seem to have forgotten that your unvaccinated child will have far less of a chance of catching Measles/rubella etc because the rest of us have built up a herd immunity. A thank-you would be appreciated!! - but as others have said there's the weaker elements of the herd that do need protecting"(Lil).

"I don't think my son should be put at risk of an epidemic because people haven't had their children immunised. I don't think my unborn child should be put at risk of rubella either (although I believe my immunity is ok)" (*Joe1*).

The participants who made these criticisms urged parents with "no excuse" for not immunising to get their children "done" for the benefit of society as a whole, and for three particular vulnerable groups: children who could not be vaccinated for medical reasons; children who were too young to be vaccinated; and the unborn children of unvaccinated pregnant women. For example:

[Comment addressed directly to a participant with a child who could not be vaccinated for medical reasons]:

"Dear Lizp - it is specifically for reasons such as yours that people should have their children immunised to protect those children who are unable to be vaccinated.... So, all those people with no excuse for not having their kids immunised, lets get them done so children like Lizp's won't contract measles" (*Emmam*).

"...Could I just make the point that the risk of not immunising one's children does not only extend to one's own child. My ds [son] is 6 1/2m - therefore too young for the MMR. Since we live near the current outbreak and he is at nursery, I am concerned that he now has a much greater risk of exposure because of other parents decisions, yet we have no way of protecting him..." (bossykate).

"Emmy - rubella can be passed onto a pregnant women damaging her unborn child... some people can't have vaccines hence the reason why the rest of us shouldn't put them at risk" (*Eulalia*).

In summary, several Mumsnet participants urged parents of children whom they considered 'healthy' to opt for vaccination for the benefit of others in society.

Single vaccines as an alternative to MMR

Single vaccines were much discussed on 'Mumsnet'. Although some participants compared them unfavourably with MMR, most people who discussed them claimed they were unlikely to cause harm and thought the government should make them freely available.

Parents who discussed opting for (or intending to opt for) single vaccines instead of MMR avoided the criticisms levelled against parents who apparently were not intending to vaccinate their healthy children at all. Some presented single vaccines as a means to avoid any potential risk from MMR but still protect their own child from disease and act in a socially responsible way. They accepted there was an argument for opting for vaccination to benefit society, but because of their doubts over the safety of the MMR vaccine, questioned why they could not use the single vaccine alternatives that they thought would be safer. They accepted the *idea* of social responsibility, but made judgements about the level of risk and the necessity for the risk they believed they were being asked to take for the sake of others. For example:

The arguments for "herd immunity" are pressing - examples of why those who can be immunised... have been given here and I too know a very prematurely born toddler who can't have his MMR for the foreseeable future. But if I thought that a vaccine that might not be the safest was being pressed on us in the interests of the pharmaceuticals industry's profits, and

that the Department of Health was being forced into this policy, I'd be very angry... I do think it's possible to be concerned about vaccine safety without compromising "herd immunity" and putting others at risk" (Marina).

"...why should we risk our children unnecessarily, when a single vaccine is a viable alternative? I'm not saying I'm not going to vaccinate at all - I don't want to put anyone's child at risk- I'm not implying that a sick child is less important. But why should we be railroaded into taking a risk we are unhappy with...?(*Emmy*).

Not all the participants who expressed concerns about MMR regarded single vaccines as an appropriate alternative. A few were sceptical about the effectiveness of vaccines and the notion of herd immunity. They saw no reason to risk vaccinating their own children because they were not convinced it would benefit others. For these parents, discussions about social responsibility to be vaccinated were irrelevant:

"Sorry but I don't believe in vaccinating one child for the sake of others. There is no proof that it actually works...outbreaks will always occur no matter how many children are vaccinated" (Lill).

"My fear is that we really have no idea of the long-term impact of mass immunisation programmes and their possible consequences in terms of indestructible 'super-viruses'" (Faith).

"If your health visitor is correct [in her belief that vaccination has resulted in the increase of various childhood diseases] we should be asking exactly what good are we doing the community...there is a body of research out there which throws doubt on the efficacy of routine immunisation programmes for healthy children " (Lill).

In summary, single vaccines were widely discussed, often as a means to avoid any potential risks from MMR but still protect their own children and others from disease.

Society's responsibility to individuals who are harmed by vaccination

Discussion about parents' obligations to accept some kind of responsibility to society and get their healthy children vaccinated for the sake of others led some participants to introduce the issue of society's responsibility to individuals who were harmed by vaccination. One participant contrasted the concern expressed about ensuring that 'vulnerable' children did not contract diseases with the lower priority given to

protecting 'vulnerable' children from potential vaccine damage and to care for autistic children:

"Oh god Gracie- swap places with me then- YOU can have the autistic child- and then carry on about social responsibility-where's the social responsibility to my child? I've been told today that his one-to-one funding at nursery... is about to be halved as there's another little boy with communication difficulties at his nursery and there isn't enough money to fund both...Forgive me if I don't want to expose my normally developing [younger son] to a possible increased risk of autism... the words "social responsibility" from someone who has absolutely no idea what daily life is like with autism is like a red rag to a bull" (Jimjams).

Participants discussed the idea that if wider societal considerations are to be considered, then the Government should ensure that vaccine damage is more consistently recognised and that the people affected are appropriately compensated. Several queried the effectiveness of vaccine safety monitoring or compensation schemes because they believed that health professionals were generally reluctant to acknowledge and report potential vaccine adverse reactions. For example:

"A friend of mine's daughter recently got whooping cough despite being fully vaccinated. She had every symptom of the disease... but her GP refused to accept it could be whooping cough 'because she had been vaccinated.' So I suppose she never appeared on any official statistics...I'm not anti-vaccination, but how can the government assess the efficacy of vaccination if doctors are reluctant to diagnose an illness after vaccination?" (aloha).

Others alluded to more general difficulties:

"[Government] should make it a damn sight easier for the small percentage of people damaged to get compensation – and this applies to all vaccines" (Willow2).

In summary there was a concern to ensure that the concept of social responsibility was extended to support those adversely affected by vaccination as well as used to promote uptake of vaccination.

### **Discussion**

This study provides an example of using an online chat forum to provide insight into public concerns and views about topical health issues. We examined an online discussion about the MMR vaccine and found extensive consideration of social responsibility relating to this. Far from regarding childhood immunisation as a purely private issue, parents were aware and concerned about the implications for

the wider community of choosing not to immunise their own children. Avoiding harm to others and contributing to the 'herd immunity' of the population were important considerations for many parents in their decisions about the MMR vaccine. They did not override considerations of their own children's health and safety, but the postings on Mumsnet suggested that parents were keen to act in socially considerate ways as long as the risk to their own child seemed proportionate.

Parents differentiated between 'healthy' and 'vulnerable' children and many participants with healthy children talked of having a responsibility to get them vaccinated in order to help avoid epidemics that could be particularly dangerous for those who were more vulnerable. Some were very critical of parents who chose not to vaccinate their healthy children. Some participants who had strong concerns about the safety of the MMR vaccine saw single vaccines as an alternative means of both protecting their own children and acting responsibly for the sake of others.

However, support for the concept of 'herd immunity' was not universal. A few parents questioned the notion because they were not convinced about vaccine effectiveness. A further point was made that if parents were expected to act for the benefit of society as a whole, more should be done to acknowledge and compensate the minority who are harmed by vaccines.

Protecting their own children and contributing to the protection of others

In the context of concerns about MMR, Mumsnet participants seemed inclined to act in ways that both (a) protected their own child and (b) contributed to the protection of others. This finding contrasts with the findings of some previous studies (e.g. Cassiday 2007; Poltorak et al 2005; Health Education Board for Soctland 2001; Rogers and Pilgrim 1995) which have reported discussions about herd immunity but suggested that notions of social duty or responsibility were less important to parents' vaccination decisions than appeared to be the case in our own study. Their findings suggested that parental decision-making about whether to vaccinate or not tended to be influenced more by perceptions of the personal risks facing their own children than by any sense of social duty to vaccinate. For example, Poltorak et al (2005) found that parental reflections on, and approaches to, vaccination were guided by highly personalised assessments of a particular child's vulnerabilities to disease and vaccination, and that public health framings that highlight the implications of individual decisions about vaccinations for others "have little resonance" with these (p717). Casiday (2007) reported that parents who expressed concerns about MMR safety "clearly resisted the notion that their children should assume this risk in order to help protect others from infection" (p1066).

However, other authors have also found that wider social considerations, as well as considerations of their own children's health, are highly relevant to parents' decisions about MMR. For example, Hobson-West (2003) discussed the importance of arguments about herd immunity, and in a survey of 452 UK parents, Cassell et al

(2006) found that 60% of both MMR compliers and non-compliers gave positive answers to the question "when deciding about MMR...did you consider possible benefits to other children?".

The fact that the issue of avoiding harm to others was a more prominent theme in our study than in previous studies may be explained in part by the fact that the majority of parents in our sample were generally supportive of childhood vaccination. Some other studies have focussed primarily on parents who were questioning of vaccination more generally. For example, Rogers and Pilgrim (1995) studied parents who had refused all vaccinations for their children. When discussing the implications for others of their decision not to vaccinate their own children with MMR, these parents dismissed arguments about vaccinating to promote herd immunity as irrelevant because they viewed catching diseases in childhood as a means of ensuring natural, life-long immunity. Rogers and Pilgrim concluded that health promoters and dissenting parents expressed "diametrically opposed positions" when it came to the question of whether unvaccinated children were a health risk to themselves and others (Rogers and Pilgrim 1995, p. 85).

Our study findings have shed light on the ways in which parents attempt to integrate considerations about societal good with their primary concern for the welfare of their own children. They do this in part by making a distinction between 'healthy' or potentially 'vulnerable' children and using this as a basis for judgements about who should appropriately bear the burden of vaccination and who can

reasonably and fairly rely on others to contribute to the herd immunity that they might benefit from.

The 'healthy' and the 'vulnerable'

In our study, parents expressed opinions about the strength of their own child's immune system and his or her vulnerability to both disease and potential vaccine damage based on beliefs relating to hereditary 'weaknesses' towards allergies, and/or auto- immune conditions which could render them vulnerable to vaccine damage. These beliefs influenced decisions for and against accepting the MMR vaccination.

The notion of personal vulnerability to illness has been recognised in previous studies exploring parental views about MMR (e.g. Poltorak et al., 2005; Casiday, 2007; Cassell et al., 2006) as well as in the broader literature exploring lay understandings of illness and risk perceptions (e.g. Blaxter, 1983; Pill and Stott 1982; Cunningham-Burley, 1990; Olin Lauritzen, 2004). However, while authors such as Poltorak et al (2005) have argued that parents' personalised assessments of their own child's vulnerabilities guided their decision-making about vaccination to the extent that encouragement to consider the implications of their decisions for other children would not resonate for them, we found that parents' distinctions between 'healthy' and 'vulnerable' children could have important implications for their views about social responsibility to be vaccinated. These distinctions formed the basis for judgements not just about who needed protecting but also about who should bear

the burden of vaccinating. A similar observation has been made in a recent exploration of the activities and discourses of contemporary organised 'vaccine critical groups'. Hobson-West (2007) found that parents who belonged to groups that were generally supportive of vaccination but expressed some concerns about the potential dangers of specific vaccines made distinctions between children they perceived to be 'healthy' and children they perceived to have 'immune fragility' (p.206) Some of these parents advocated the development of a test that could establish which group a child belonged to and thus inform decisions about vaccine uptake. Hobson-West suggests "this represents a technical solution to the problem of risk by breaking down the population into several populations with different treatment needs" (2007, p206). However, it is important to note that the criteria that parents use to assess fitness for vaccination may not correspond with those currently used in official vaccination programmes.

#### Criticisms of others within the discussion forum

In the 'Mumsnet' discussions, people who chose not to immunise their *healthy* child against measles, mumps and rubella (as opposed to those who chose single vaccines over MMR, or those who did not vaccinate a child who was particularly vulnerable to adverse reactions) came in for a fair amount of criticism.

Internet support groups are generally considered friendly, non-judgemental spaces for exchanging support and information. The sociological literature on internet support groups has consistently emphasised their functions of support, information

and empowerment (Sharf 1997; Finn 1999). Overall, the 'Mumsnet' website *was* a friendly non-judgemental space where support and information was exhanged. However, as Rier's 2007 analysis of an HIV/AIDS discussion forum highlighted, these sites can also be significant in terms of debating moral dilemmas and attempting to influence offline conduct (Rier 2007).

On Mumsnet, the question of social responsibility to be vaccinated was hotly debated and parents were very judgemental at times. There was also evidence of attempts to influence the behaviour of others, particularly to persuade group members to get their 'healthy' children vaccinated to avoid harming others.

A few studies that have used focus group discussions have also found that discussion sometimes became hostile when the topic of so-called 'free-riders' was raised (e.g. Petts and Niemeyer, 2004., Richardson 2005). However, others have reported that most parents were uncritical of those who had decided not to immunise their child (Evans et al, 2001). Sampling issues might again go some way to explain these differences in findings. For example, the parents interviewed in the study by Evans et al (2001) included several who had refused all immunisation for their children as well as a significant number of MMR 'refusers'. The studies (including our own) that have reported the significance of discussions around social responsibility have included higher proportions of parents who were generally supportive of vaccination and who have accepted MMR.

Implications for official information about vaccination

Policies of mass childhood immunisation are driven by population concerns. The objective of 'herd immunity' requires high rates of uptake, which in turn requires that parents accept recommended vaccines. This is not easily reconciled with policies, in the UK and elsewhere, that encourage individual patient choice and personal involvement in many health care decisions (Blume 2006; Hobson-West 2003). These policies perhaps explain why promotional information leaflets about MMR tend to avoid discussion of social responsibility and concentrate instead on individual benefits and risks in an attempt to convince parents of MMR effectiveness and safety (Hobson-West 2003; see e.g. http://www.mmrthefacts.nhs.uk/basics/truths.php).

The potential effectiveness and acceptability of including explanations about herd immunity in information leaflets for parents, and of encouraging patients to consider others when deciding about vaccination for their own children, are unclear. Some authors have suggested that appeals to parents' wider societal responsibilities are unlikely to be effective as a means of promoting vaccination because decisions about vaccination are more strongly influenced by perceptions of the risks to their own children than by considerations of others (e.g. Poltorak et al 2005; HEBS, 2001; Casiday, 2007). However, one survey found that 67.3% of those who had and 37.4% of those who had not accepted MMR answered "Yes" when asked "Is it right for health professionals to advise parents to have their child vaccinated for the benefit of other children?" (Cassell, et al 2006).

Parents contributing to Mumsnet got information about various aspects of the MMR debate from a range of sources. They did not discuss in any detail how herd immunity arguments were presented in official literature - perhaps because such presentations were generally absent or minimal. Only one participant mentioned in a somewhat critical way the tendency for the government to put the interests of 'society' before the interests of the individual. Some participants could be said to have been taking on a public health role as their postings tended to 'police' and encourage other parents to choose vaccination for the benefit of others.

Our study suggests that carefully presented information about the implications of individual parents' decisions for other people might help support vaccine uptake in some groups. Appeals to the concept of herd immunity and perhaps moral obligations to consider others are unlikely to persuade parents who strongly believe that MMR is ineffective or harmful, because they are unlikely to agree to take what they perceive to be a risk with their own child if they do not think it will benefit others. However, well balanced messages that explain that vaccination can be beneficial for others as well as their own children could still be appropriate – as long as they do not cross the boundary between ethically acceptable attempts to persuade on the basis of appeals to reason and ethically dubious attempts to manipulate people by playing on their emotions. Such messages would probably need to acknowledge that some vulnerable children cannot be vaccinated for health reasons.

Our findings will be of interest to debates about public health ethics that have focussed on arguments about moral obligations in relation to vaccination programmes (e.g. Dawson, 2006). They also suggest that social scientists with an interest in attitudes and behaviours relating to vaccination should attend carefully to lay understandings of herd immunity as a public good and views about obligations to others in society. Further investigation is needed of the lay distinction between 'healthy' and more 'vulnerable' members of society and the implications of this for vaccination policy and practice. Differences between lay understandings of what renders children susceptible to vaccine damage and conventional medical views about contraindications for vaccination will warrant particular attention.

### Strengths of our study

Our study used a searchable online discussion forum with over one hundred contributors as a primary data source. This allowed us to explore the types of questions and issues about MMR that parents generated in discussions among themselves rather than in response to researchers' questioning strategies. It also allowed us to observe how different positions were argued and negotiated, and how some parents attempted to influence others.

#### *Limitations of our study*

We analysed messages posted to only one website, and participants were probably not demographically representative of the wider population. They all had Internet access, a few referred to themselves as scientists, and several engaged in fairly sophisticated discussions about the scientific evidence for and against an MMR-autism link. Also, a higher proportion of participants had refused MMR than was the case in the general population.

All these factors raise legitimate questions about the ways in which it is and is not appropriate to generalise from our findings to the wider parent population, and about whether and how insights from this study should inform future communications about MMR or vaccination more generally.

We cannot make any claims about the distribution of views across the broader population. However, we were able to identify concerns that at least *some* parents had about the MMR vaccine and we were able to identify ways in which at least *some* parents (particularly among those with concerns about MMR) discussed the social implications of not immunising. Also, because our sample included parents who questioned the safety of MMR, requested single vaccines, and felt that their questions were not being answered adequately by government representatives, it contains important insights for efforts to improve vaccination uptake rates.

Although our data collection ended in 2003 and the climate of opinion about MMR may have shifted to some extent with publicity about the General Medical Council's hearing relating to Andrew Wakefield (BBC news 2006), it seems likely that some public concern remains, and the kinds of insight we have identified in relation to MMR are likely to be relevant as concerns about other vaccines emerge in the future.

When analysing message postings to an online discussion forum, the sample and data are both given. There is no scope to modify either and there are limited opportunities to verify either the characteristics of participants or the intended meanings of what was said. Some sample characteristics can be gleaned from message postings, and in this case, analysis of the two discussion threads that we focussed on and a brief investigation of other threads in which participants had posted messages suggested that participants were consistent in terms of the information they provided about themselves and the views they expressed on particular issues. Furthermore, although we as researchers could not probe what participants were saying, it was not uncommon for participants to check each others' meaning or ask for clarification about other people's opinions. It is, of course, possible that parents sought in their postings to present themselves in a positive light. We accept that although the issue of social responsibility was widely discussed we can only speculate that it was an important consideration for actual vaccine decision-making. In other words, we cannot verify the actions or motivations that Mumsnet participants reported. However, it seems unlikely that social desirability considerations would have an unduly strong influence over what people say in the context of an online forum in which participants use pseudonyms.

#### **Conclusions**

Our investigation of parents' discussions about the MMR vaccine suggests the salience of social responsibility considerations for their decisions about vaccination.

It has also shown how judgements about the appropriate distribution of social responsibility for vaccination are shaped by beliefs about the health status of individual children and their susceptibility to any potential harms from vaccination.

Our findings suggest it might be appropriate for vaccine promotional material to include explanations of herd immunity and ensure parents are aware of the potential public health implications of their individual decisions. However, attention should be paid to the distinction parents make between healthy and vulnerable children and, as other authors have argued, there is a need for immunisation information to acknowledge and address these lay concepts of immunity (e.g. Poltorak, et al 2005; Cassell, et al 2006) even if these concepts are at odds with the views held by the medical profession and Department of Health. Policy makers should also strive to be more explicit about what is being done to provide practical support to those harmed by vaccines.

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Table 1 Key features of the two discussion threads

	Thread 1	Thread 2	
	(Aug 31st 2000-Feb 13th 2002)	(Jan 18th-March 5th 2003)	
Number of people	91	52	
posting messages			
Messages per person:			
Range	1-22	1-83	
Mean	3.6	5.5	
Total no. of messages	325	292	

Table 2 Decisions made about immunisation against measles, mumps and rubella

	Thread 1 N=54	Thread 2 N=26	9 participants who contributed to both discussions and who discussed decisions	Total N=89
MMR as scheduled	26 (48%)	4 (15%)	5	35 (39%)
MMR on modified schedule	4 (7%)	4 (15%)	2	10 (11%)
Single vaccines	14 (26%)	12 (46%)	1	27 (30%)
Other alternatives	1 (1.8%)	0	0	1 (1.1%)
No vaccination	2 (3.7%)	1(3.8%)	1	4 (4.4%)
Decided against MMR, but does not say whether considering single vaccines, or nothing at all	2 (3.7%)	0	0	2 (2.2%)
Undecided	5 (9%)	5 (19%)		10 (11%)
TOTAL	54 (100%)	26 (100%)	9	89 (100%)

NB: For participants who discussed having made different decisions for each of their children, the decision made for their youngest child is reported above. Also, as some participants reporting changing their mind during the course of the discussions, the decisions/intentions reported are the most recently reported ones.

# Box 1 Considerations reported for parental decision-making

- a) Past experiences of potential vaccine adverse events/ experience of autism or other disability in the family;
- b) Past experiences of complications of the three diseases;
- c) Communication with health professionals who were also sometimes "long-standing friends";
- d) Beliefs about the social responsibility of being vaccinated to prevent disease spread;
- e) Beliefs about vaccine effectiveness;
- f) Beliefs/fears about the severity of the three diseases and fear of impending epidemics;
- g) "Instincts" or "gut feelings" relating to their own child's immune system and its ability to cope with a combined vaccine or the natural diseases;
- h) Other reasons: e.g. Preference for children to be vaccinated against three disease at once; desire to exercise choice; concerns from history; not prepared to take *any* risk with MMR; concerns about unlicensed vaccines