

Health risk communication and amplification: learning from the MMR vaccination controversy

JUDITH PETTS & SIMON NIEMEYER

Abstract *Immunisation is the cornerstone of childhood disease prevention. In this context the combined measles, mumps and rubella vaccination (MMR) has proved a world-wide success, although in the UK it has been at the centre of public controversy since 1998. Through the media, the public domain has witnessed contestation among expert views about the relative risks associated with the diseases vs. the potential side-effects of the vaccination. Attainment of health protection targets has been compromised. The UK Department of Health sought to redress this through a major communication exercise. This paper reports the findings of a study of information strategies that parents use to make sense of health risk issues, particularly MMR. The findings identify the importance of social networks in reinforcing parental understanding and beliefs. While the media are identified as important sources of information, there is no evidence to suggest that parents passively receive and act upon such risk messages. Official information has been able to capitalise on the strong social normalisation of vaccination, but has not responded fully to the evolving social interpretation of risks. The study reveals a preference for personal and face-to-face engagement with health professionals, stressing the importance of user-centred health risk communication.*

Key words: risk communication, social amplification, vaccination, MMR, trust

Introduction

Immunisation is both a public and private good. It provides for protection of the individual child as well as 'herd immunity' with the eventual elimination of major childhood diseases. The public good element has been a driver of mass immunisation since the 1950s with immunisation schedules becoming increasingly complex.

However, these have not been without controversy, most recently with respect to the application of the combined measles, mumps, and rubella vaccination (MMR). MMR has been in use for more than 30 years with over 500 million doses having been administered in more than 90 countries. National successes have been reported in terms of 'elimination' of the indigenous diseases, for example in Finland (Peltola *et al.* 1994). However, despite evidence of

Centre for Environmental Research and Training, The University of Birmingham, Birmingham, UK.

Address correspondence to: Professor Judith Petts, Centre for Environmental Research and Training, School of Geography, Earth and Environmental Sciences, The University of Birmingham, Birmingham, B15 2TT, UK. Tel: + (44) 121 414 8143; Fax: + (44) 121 414 5538; E-mail: j.i.petts@bham.ac.uk

parental belief in the importance of immunisation (e.g. Gellin *et al.* 2000), MMR in the UK has proved a significant area of risk controversy, strong minority opposition threatening achievement of health protection targets (95% up-take rate).

The controversy stems from divergent views about the relative risks of the diseases vs. the side-effects of the vaccination. Such vaccine risk controversies are not new,¹ but there is something particular about the UK MMR controversy, which does not accord with experience in other countries. Paradoxically, the success of immunisation programmes may also set the scene for their failure. Public support for immunisation may decline alongside memory of the effects of the diseases, in turn producing greater reluctance to accept any adverse effects of vaccines either experienced or suggested (Ball *et al.* 1998; Gellin *et al.* 2000). Changes in take-up may sweep across 'local vaccination cultures' (e.g. Streefland *et al.* 1999; Van de Geest and Reynolds-Whyte 1989;) as users are influenced by the decisions of other parents, giving rise to 'bandwagoning' (Hershey *et al.* 1994). These trends are mediated by more specific factors affecting take-up, such as attitudes, health-related experiences and gender role constraints (New and Senior 1991).

Mass shifts in public confidence in immunisation have been attributed to media generated controversy (e.g. Clements and Ratzan 2003l; Gangarosa *et al.* 1998; Leask 2002; Mason and Donnelly 2000). Questions are raised about the relative power and importance of the media. Streefland (2001) describes a trajectory of vaccination resistance triggered by scientific disagreements, which are then spread by the media, giving rise to a kind of bandwagon effect. Echoing the social amplification of risk framework (Kasperson *et al.* 1988) this trajectory describes how risk signals are received, interpreted and passed on by a variety of social agents. A substantial body of research stresses the active and social nature of people's interpretation of media materials (e.g. Morley 1993; Moores 1993; Petts *et al.* 2001).

The UK MMR controversy is temporally associated with publication of preliminary research findings by scientists at the Royal Free Hospital and School of Medicine, London. Wakefield *et al.* (1998) reported an investigation of a self-referred group of twelve children aged 3–11 with a history of normal development followed by loss of acquired skills (including language) together with diarrhoea and abdominal pain. They did not definitely link MMR and autism, but referred to virological studies then underway that 'may help to resolve this issue'. Furthermore, while identifying the onset of symptoms related to chronic enterocolitis (potentially related to neuropsychiatric dysfunction) in children following MMR, they stressed 'further investigations are needed to examine this syndrome and its possible relation to this vaccine'. The uncertainty inherent in understanding cause–effect relationships was reinforced with the potential for inference that a link may be proven.

The UK media responded immediately, focusing on autism and capitalising upon a general awareness of a significant rise in autistic spectrum disorders.² In one month, average MMR uptake dropped from about 91% to 88%, remaining static until March 2000 and falling to below 86% following further adverse reporting, with some areas below 80%. A second paper (Wakefield and Montgomery 2000) fuelled the issue by suggesting that MMR had been introduced without adequate safety trials, a strong rebuttal following from experts from the UK Medicines Control Agency (Arlett *et al.* 2001). The BBC's documentary series *Panorama* tackled MMR on February 3rd 2002, including an online discussion forum

1. For example, widespread resistance against whole-cell pertussis vaccination had damaging consequences for the incidence of whooping cough, leading to an epidemic in Britain in the 1970s (Gangarosa *et al.* 1998). In France, claims of links between the hepatitis B vaccination and multiple sclerosis led to court cases for damages for alleged victims, criminal cases against senior officials, and suspension of routine vaccination of adolescents in 1998.

2. In 2001, the Medical Research Council reported that autistic spectrum disorders affected 1 in 166 children compared to 1 in 2200 in 1988.

(www.news.bbc.co.uk). As well as scientific, some of the controversy was also symbolic, including a media campaign for the Prime Minister to say whether his own young son had had MMR. This he refused to do, defending the rights of privacy and of a parent to decide how to protect their child (New and Senior 1991).

The latter example reflects a public issue of trust. Although groups resisting vaccination have been categorised in libertarian terms of engaging in a struggle between individual choice and state control (Dew 1999; Streefland *et al.* 1999), resistance may reflect a general (e.g. MORI 1999) but widely recognised decline in trust in authority and experts. It has been argued that distrust heightens public responses to risk messages and leads to questioning of the work and decisions of risk regulators and authorities and anyone not perceived to be independent (e.g. Flynn *et al.* 1993; Kasperson *et al.* 1992; Petts 1998). Various studies have sought to unravel the attributes of trust, and a wide range of components including perceived competence, predictability of arguments, objectivity, accountability; fairness, and caring have been identified (e.g. Kasperson *et al.* 1992; Petts 1998; Renn and Levine 1991). The dimensions have proven difficult to measure, although recent work (Pidgeon *et al.* 2003; Poortinga and Pidgeon 2003) suggests that they are not independent. Thus, people can arrive at a state whereby they rely on a person or institution for knowledge and information but combine this with a healthy scepticism—what has been termed *critical* trust (Poortinga and Pidgeon 2003).

Compulsory immunization of an individual may be regarded as unethical. However, given the public good component of vaccination, so too may a decision not to immunize. Informed consent may be the only ethical policy (Bostrom 1999). The Department of Health has increasingly disseminated information into the public domain, supporting recognition that the medical profession is best placed to improve risk communication to parents (e.g. Ball *et al.* 1998; Dittman 2001; Gellin *et al.* 2000; Schmitt *et al.* 2003).

In response to reports suggesting links between MMR, Crohn's disease and autism, the then Health Education Authority produced a public leaflet, *MMR – The Facts* describing the side effects of the vaccine. When reissued by Health Promotion England (part of the Department of Health) in 2001, it included a table of the comparative risks arising from the natural diseases and from MMR (Table 1). A further revision was produced in 2002 responding to questions about having the single vaccines. Two 30-minute videos were also produced—*MMR: the Big Questions* (designed for health professionals but available to parents) and *MMR: What Parents Want to Know*.

Is this kind of information on MMR adequate for communicating risks and benefits?, and what is its role relative to other information sources? These questions were investigated as part

Table 1. *Comparison of the serious effects of the disease and reactions to MMR*

Condition	Children affected after the natural disease	Children affected after the first dose of MMR
Convulsions	1 in 200	1 in 1000
Meningitis or encephalitis	1 in 200 to 1 in 5000	Less than 1 in a million
Conditions affecting blood clotting	1 in 3000 (rubella) 1 in 6000 (measles)	1 in 22 300
SSPE (a delayed complication of measles that causes brain damage and death)	1 in 8000 (children under 2)	0
Deaths	1 in 2500 to 1 in 5000 (depending on age)	0

Source: *MMR: The Facts*. (2002) Health Promotion England

of research conducted for the UK Department of Health as one of three case studies.³ Specifically, the research sought to identify and understand individuals' risk 'literacy' and its impact upon information requirements (Petts *et al.* 2003). Literacy was defined in terms of the nature and breadth of people's underpinning knowledge about, and how they make sense of, health risk issues. The following discussion explores particularly the relative impacts of experience, mediated knowledge and social context upon information needs and understanding. The study did not attempt to map decision outcomes (i.e. take-up of MMR) against information strategies.

Research method

The method utilised two-phase interactive discussion groups⁴ conducted between February and July 2002 amidst intense media debate about MMR. The research was based in the West Midlands area, centred on Birmingham and Nuneaton, which was experiencing take-up rates consistent with the national average. Eight groups (64 participants) were convened. Recruitment was conducted 'on street', with strategies defined by ethnicity, family size and age, and socio-economic criteria⁵—with focus on parents, and particularly mothers (89% of the total) as key decision makers about children's health. Particular effort was made to recruit from the Asian Muslim community (30% of those recruited), being a significant minority population in the area.

The major stratification criterion used was MMR status. Groups 1–4 comprised those intending to take, or who had already taken, their child for MMR (55% of all participants) and with children up to 5 years of age. Groups 5, 6 and 8 comprised those still to take the decision (primarily as their child was younger than 13 months). Group 7 (fathers) was recruited without specification as to decisions about MMR.

The intention was not to recruit a representative sample of participants but to proactively engage with a diversity of MMR experience; of access to information (e.g. higher socio-economic groups potentially having greater access to a larger range of information sources); of knowledge and educational backgrounds; and of parental experience (e.g. young first-time mothers compared to older women with several children). Unfortunately, on-street recruitment of a group of parents who had already refused MMR proved difficult and was abandoned.⁶ Therefore, it is not possible to draw specific conclusions about the impact of information on decisions not to vaccinate (discussed later).

During the first meeting (lasting approximately one hour) each group explored general risk issues of concern, coming to focus on preferred sources of health information. At the end of the meeting, each participant took copies of the MMR leaflet, some also taking either or both of the videos. During the intervening two-week period before the second

3. The other case studies were (i) mobile phones and mobile phone base stations and (ii) air pollution, each also the subject of new and official information campaigns.

4. Interactive discussion groups have the advantage over methods such as questionnaires in that they allow for elicitation and observation of lay talk. They act as a device for staging 'social microcosms' to produce talk about risk issues which draws on patterns of everyday understanding. They do not produce 'representative' views like quantitative survey research, but have increasingly been used to explore group norms and shared ways of conceptualizing and talking about things (e.g. Horlick-Jones *et al.* 1998; Petts *et al.* 2001; Walker *et al.* 1998).

5. A professional agency used random on-street recruitment methods. Groups 1 and 2: Asian mothers with children 2–5 years (socio-economic groups ABC1 and C2-E respectively); Groups 3 and 4 White British mothers with children 2–5 years (socio-economic groups ABC1 and C2-E respectively); Groups 5 and 6 mothers who were expecting or just had their first child (Asian and White British respectively—all mid-range socio-economic groups C1–C2); Group 7: fathers with children 2–5 years, mid-range socio-economic groups C1–C2; and Group 8: mothers with a child 9–13 months who would have to make a decision about MMR soon—mid range socio-economic groups—C1–C2.

6. The only alternative recruitment option possible in the time available raised ethical and patient confidentiality issues as individual data would have been required from GPs.

meeting, participants were encouraged to assimilate information, access the Internet site (www.immunisation.org.uk) and discuss the information with families and friends. At the second meeting (1.5–2 hr) groups explored perceptions of the information and had the opportunity to question an immunisation specialist from the Department of Health.

The discussions were taped and fully transcribed and the resulting textual data analysed using a standard method for qualitative data, namely analytic deduction⁷ (e.g. Silverman 1993). At the end of the first meeting participants completed a questionnaire relating to their children's immunisation history. A questionnaire was administered at the second meeting pertaining to MMR information requirements, preferred modes of provision and trusted sources.

Understanding knowledge and concerns

Not all participants fully understood the purpose of MMR—for example, in the two lower socio-economic Groups (2 and 4) two mothers asked what the initials meant, although both had already had one child vaccinated. Fifteen of the 64 participants did not know that a booster at 5 years is required and this included parents whose children had had the first MMR. However, every participant was familiar with MMR. As indicated by the group questionnaires, approximately 40% had previously seen official immunisation information, while over 60% claimed to have discussed the issue with family and/or friends. Only 25% had spoken to their GPs about MMR, with first-time young white British mothers (under 20 years old—group 5) most likely to have done so. This may have reflected the immediacy and newness of the vaccination issue to them and perhaps greater opportunity through attendance at ante- and post-natal clinics (the experience of which they spoke about), although it is important to note that the corresponding Group (no. 5) of young Asian mothers reported low access to their GPs. The Internet proved a more important source of information in the higher socio-economic groups (1 and 3) and amongst the fathers but overall had low reported usage (12% only). Every group noted newspaper sources, but less than half reported proactively using them for information.

At the beginning of the group discussions it was common to hear assertions that there is '*no information out there*' on MMR, particularly in the Asian and also the lower socio-economic groups. Resourcing was an important issue—both personal and within the health service. Parents expressed a lack of control in accessing information and lack of time to find it. There was reported frustration that professionals in the health service did not have time to relay information, which accords with evidence from the USA.⁸ This was a concern, as most preferred opportunities for direct discussion and information provision from health providers. Sarah (Group 3 – son of 2 years) spoke of how '*the MMR really worried me. He [GP] spent an hour and a quarter with me going through the statistics and just generally putting my mind at rest*'. Notably, this rarely reported experience came from within the Group of British mothers in the highest socio-economic group. This in contrast to the Asian mothers (Groups 1 and 2—all socio-economic groups), who particularly expressed a lack of such opportunities, often portraying distant, sometimes unhelpful and passive relationships with their GPs—their doctors '*having no time for them*' or women concerned they would be accused of time wasting—'*you can't just ask for information, you only go to see your GP when you are ill*'.

7. A systematic exploration of the data for patterns which reflected people's shared ways of talking about, and understanding of health risk issues and MMR. The procedure entailed a partly inductive process of searching and progressive fine-tuning of definitions in light of items which appeared to contradict the emerging concepts.

8. Despite requirements in the National Childhood Vaccine Injury Act that doctors distribute the appropriate Vaccine Information Statements before every dose of vaccine, one third of doctors fall short of this requirement, the most common barrier to their compliance being lack of time (Davis *et al.* 2002).

Despite the low exposure to official information all the participants were aware of the problems with MMR being suggested in the media—every group made direct, unprompted reference to autism, with bowel disease being mentioned unprompted in seven of the eight groups. There was no evidence that participants believed that there was strong scientific proof of a link between autism and the vaccination, but MMR was still a worry. This was equally true for parents who were sure that they must give their child the vaccine as for those who had experienced more uncertainty, and the remainder who still had to make a decision (28%).

The following discussion took place amongst five mothers with children under 1 year old during the first meeting of Group 8. All bar one was still to make a decision about MMR. The discussion illustrates the nature and significance of the issue, the Group collectively exploring the arguments for and against having the vaccination and the alternatives. They reflected on their own experience of the diseases and of evidence from friends; applied ‘lay epidemiology’ (Brown 1992) as they interrogated their experience in relation to causes of adverse health (e.g. ‘autism is already in some children’), but also displayed evident tensions in their arguments and worry about making the right decision:

Emma—My friend has let hers have it and she kept asking the doctors if she could have it separately and they just said they didn’t do it.

Maggie—The thing is how much is it (*single vaccinations*) and where can you get it done, and what are the risks of having them separately?

Jean—I would be very worried about giving them the jab, all three in one, because a bloke I work with, his brother had it and his brother has got autism. He swears it was something to do with it.

Emma—They can’t prove it though.

Jean—They can’t prove it, but he swears. They say it’s the time that autism is going to show up in any case. So why don’t they leave the jab until they are two years of age, so that any signs of autism would already show.

Lazeta—But if you don’t have the jab then they are open to catching whatever they have not been vaccinated against, even if they have it singly.

Maggie—Well we didn’t have mumps did we, and we didn’t have the jab.

For many mothers in Groups 1–4, the concern about MMR emerged following vaccination of their older children. Several recounted how the norm at the time was to ‘turn up and get it done’, or ‘it was just another one on the list’. Two women who had lived abroad (India and the USA) when their older child was immunised noted MMR had not been a public issue. The new, heightened concern about MMR seemed to challenge (but not necessarily overthrow) parental convictions about the benefits of immunisation and previous decisions.

But common to all groups was the fact that expressed concerns extended beyond MMR itself to the level of scientific/expert knowledge about the risks, with understanding that not even ‘the experts’ are certain. Some were suspicious that the knowledge of scientists and doctors did not extend to all possible diseases. A countervailing position held that certain diseases have always been around, but have been undetected. Participants appreciated the importance of the need to prove a cause, e.g.:

Theresa—I think that there are diseases out there and people have them but because nobody knows what they are they are told to go away, there is nothing wrong with you, but when one doctor says ‘This is a disease and I have found out what it is’, then more people come to him and say, ‘well I have got this’ and that’s when they recognise it as a disease . . .

Jenny . . . yes. But it’s like the link with autism and the MMR. I mean autistic children have always been around. It is only now that it is coming to light how many there actually are and some doctor has found that there is a link that there is a problem (Group 4)

Participants in three groups considered the limited opportunity for experts to understand the side effects associated with the vaccination, given it had only been in use in the UK since 1988. However, despite understanding scientific limitations, most parents still wanted an expert (for most, their GP) to proffer definitive, but also personal, advice on the MMR issue.

The media, personal salience and parental instinct

Although most of the parents held childhood immunisation to be a good thing, exposure to media evidence about MMR had clearly shaken beliefs. The media reporting was frequently portrayed as a catalyst of concern and worry not only about whether to have MMR but whether previous decisions had been wise, e.g.: ‘If you had not seen anything or heard anything in the press you would just have gone and done it like all the other jabs’ (Debbie, Group 3—three year old daughter). Media challenges to pre-existing beliefs disconcerted many participants. Their language was often accusatory, characterising reporting as ‘hype’ or ‘sensationalism’. As one commented ‘it is scary that reading newspapers can cause this much harm’. In Group 1, Farhana complained that the media reported the views of ‘one professor as though they were fact’. In Group 4, Jenny who was thinking of not taking her son for MMR explained ‘because there is so much in the media about it being bad and they get autism and all these things and you think “am I doing the right thing?”’. Only in the fathers’ group was it pointed out that media reporting had been beneficial in raising important questions.

Yet media reporting had clearly resonated with direct experience of health difficulties. Eight parents across five groups spoke in detail about friends whose children had experienced onset of speech or behavioural problems after receiving MMR. Yet it was not evident that this direct experience had automatically swayed people against the vaccination, albeit clearly troubling to parents and affecting their information needs. For example a mother in Group 4 recounted how a friend’s daughter who was the same age as her own had stopped talking after having MMR which had prompted her to visit her GP to ask questions and she had been reassured. In Group 8, Emma (16-week-old daughter) talked about a friend who was ‘going through the courts at the moment’ as both her sons have autism. She was convinced that if she was allowed to go to court there must be some connection. She was clearly having difficulty making up her own mind in the face of this apparent ‘evidence’. In contrast Debbie (9-month-old son, in Group 8) recounted how two of her friends had young sons who had had MMR and were ‘fine’ and how their mothers had made the decision taking advice from their mothers, from GPs and from the information. The evidence of the two boys’ health was clearly compelling for her, but she admitted that she was ‘still in two minds’.

In group discussions about MMR versus having the single vaccinations there was much talk of ‘hearing from friends’ where this could be done or of friends who had had it done. Given the refusal of government to support the individual vaccinations the social environment became a primary source of information. As Lucy (Group 3, two daughters) succinctly summarised the

parental learning environment: ‘certainly people do talk to health professionals. . .but I think most people talk to other mums’.

Maternity appears a significant factor forming views on MMR. In all of the Mothers’ Groups women expressed a belief that they have heightened concerns about their children’s health. They used phrases such as ‘you can’t take the risk’; ‘they’re too young and helpless’; ‘they come first’, ‘we want to protect them’ suggesting that mothers have a burden of responsibility to make the right decision for their children. Although women spoke of their partners taking a strong interest in the issue, it was evident that many mothers take the final decision. Indeed in the fathers’ group there was agreement that ‘this is women’s work’.

A feeling of responsibility linked to the uncertainty that had been created by the MMR media reporting heightened maternal responses. Many participants noted the decision pressures created by the tensions between ‘nothing being safe’ and ‘there always being a risk’: e.g.

There’s only a very, very, very minor chance and then there’s the fact that I go abroad quite often and I think what if she catches something there, then what would I do?’’ (Farida, Group 1, one daughter).

You don’t want your child to develop autism or you don’t want your child to be autistic. But similarly you wouldn’t want you child to be badly or severely brain damaged as a result of measles, or death. So it is a balancing act (Hazra, Group 1, two daughters).

I suppose if anything does happen to them and you had a choice to immunise them and you didn’t you could only blame yourself really. Do I really want to immunise them, knowing that there is this issue now? (Sofia, Group 6, daughter 3 months)

I think that the risks that he gets ill without having it are worse than the ones if he doesn’t and as far as I am concerned I want to protect my son as much as I can (Lazeta, Group 8, son 9 months)

The balancing of risk was not confused with demands for zero risk. Indeed throughout the group discussions of child health there seemed to be acceptance that immunisation is not risk free.

In one group of Asian women the impact of religious beliefs was discussed suggesting a lack of personal control over their child’s health—‘if it is meant to happen it will’. However, this did not detract from worries about making the right decision ‘for your child’ and of the need to balance risks.

Linked to responsibility was the importance of parental choice: ‘I think you should be able to have the choice—at the end of the day it’s your kids isn’t it’ (Steve, group 7, 3-year-old son); ‘choices as well to have the single vaccinations even if we have to pay for it’ (Munzra, Group 1, one son 3 weeks, one daughter 2 years) The concept of choice was sometimes discussed in the context of feeling pressurised by government to have MMR as no alternatives were readily available.

Trust

Trust was an important factor, affecting both relationships with GPs and propensity to seek and listen to their advice. Participants talked about the MMR information they looked at being ‘trustworthy’, but had difficulty articulating exactly what this meant without prompting. Some suggested that they trusted it because it had supported their own decision to go ahead with the vaccination.

Trust in political leadership was an important issue. All the Groups expressed concern that the Prime Minister refused to say whether his son had had MMR—the fact that he had not raised suspicion that there is something wrong. As the leader of the Government requiring MMR many held strongly that ‘he is supposed to inspire...[if] it’s good enough for Leo Blair, it’s good enough for our kids...’ (Mandy, Group 3, daughter 3 years). The tension between individual choice and state control was a recurring issue.

Reflecting the discussion of political responsibility, trust was heightened when participants felt that those giving information had had direct experience of the MMR—‘we see they have had their children vaccinated and maybe that could promote more confidence’ (Shanaz, Group 6, four children). Experience in this context was also conceptualised in terms of empathy with parents’ concerns and sense of responsibility. However, trust in GPs was also discussed in terms of ‘trusting their knowledge’. As Steve concluded ‘they know about the science not me’. Interestingly, although throughout the Asian women’s groups there was discussion of difficulties in relationships with doctors there was also evidence of an embedded culture of trust in health experts linked to reverence of expertise.

A rating question about degrees of trust in different institutions and individuals was used during meeting two with discussion of individuals’ ratings helping to tease out some of the dimensions of trust. The Department of Health emerged as the most trustworthy source of information on MMR (Figure 1). This seems to contradict a view that promoters of vaccination and providers of information should be independent (Bostrom 1999). However, it was not evident from the discussions that the Department was necessarily equated with the Government—the latter being particularly characterised as ‘the Prime Minister’.

A similar degree of trust was placed in GPs. However, this was often mitigated by issues of access and concerns that surgeries had financial incentives to promote MMR to the extent that some participants held GPs to be untrustworthy (see Figure 1). Some mothers drew a distinction between GPs and health visitors, regarding the latter as a particularly good source of information as they are more accessible.

Friends and family ranked relatively poorly in terms of trust, compared to the fact that over 60% referred to them as important information sources. The scoring was explained

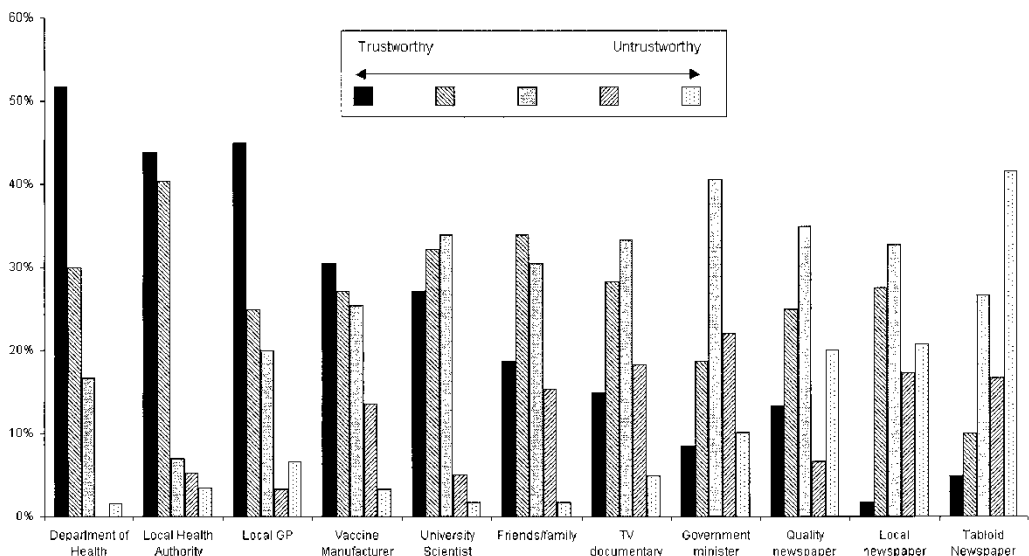


Figure 1. Trustworthiness of sources of information on MMR.

consistently as a combination of 'high' in terms of empathy but 'low' in terms of scientific knowledge:

It sounds a bit disloyal ranking them untrustworthy but they're not experts, they've got your interests at heart and they are caring (Theresa, Group 4, 4-year-old daughter).

I'd trust a doctor rather than my mum because he's in the medical profession whereas my mum is not (Wendy, Group 5, 11-week-old son).

Newspapers generally attracted low trust, as did government ministers, both being viewed as 'in it for themselves'. TV documentaries attracted a degree of support, but some were regarded as more trustworthy than others (in general for example people spoke favourably of the *Panorama* programme on MMR).

Information processing

The study examined how parents responded to the official information provided to them and how the opportunity for engagement with an immunisation expert impacted on information processing. At the beginning of the second meeting participants completed a personal reactions sheet in relation to the leaflets and videos. Most found the information helpful (56%) easy to follow (52%) and informative (62%), presenting factual information that 'helps to put your mind at rest', although 20% referred to the information as 'worrying'.

None had been offered the opportunity to see the videos previously, but considerable interest was generated among those who had watched them. Their use seemed to reinforce the importance of social networks. For example, ten women (16%) had watched with their mothers and one organised a coffee morning with friends to show the video. However, only 40% identified a health video as a preferred information mode—'not the sort of thing you would bother to watch unless you had to' (Rehana, Group 2, 5-year-old son)—and most of these were in the higher socio-economic groups.

The most commonly cited pieces of 'new' learning were in relation to the side effects of the three diseases. Information about the full implications of the effects of measles, mumps and rubella was generally considered compelling, as Sarah (Group 3, 2-year-old child) said 'I think that really needs to be rammed home a little bit, because it sort of puts everything into perspective'. Another said that all of the statistics on measles, mumps and rubella affecting people 'sold it for me' as the reporting of outbreaks in the media had not really stressed the serious effects of the illnesses. Several Groups discussed the need to 'shock people' by showing children seriously ill from measles etc., if government wanted to encourage uptake of MMR, correlating with reports of successful immunisation campaigns in other countries with have used appeals to fear to address complacency (e.g. Leask and Chapman 2002).

During the discussions with the Department of Health experts there was considerable evidence of information processing and learning across all of the Groups. However, the fathers' group generated the fewest direct questions about autism and the three diseases, possibly reflecting the fathers' view that they took a less direct role in immunisation decisions.

Table 2 summarises the most frequent questions asked. What was noticeable was that the questions were often prompted by media reporting and were largely issues not addressed directly by the leaflet. They suggest a heightened interest in trying to understand the effects of MMR, the state of scientific knowledge and the robustness of experience. The higher socio-economic Groups (1 and 3) generated the more detailed exploration of these issues and a larger number of individual questions for the specialists.

Table 2. *Most frequently asked questions related to MMR*

General issue	Specific questions
Autism	What is autism? What causes autism? Are children born with autism? How come there is more autism now? How do they diagnose autism? Has autism increased since MMR has been given? Can you test for autism before giving a child MMR? Can parents be tested for the autism gene? Does autism mainly occur in boys? Why is there no concern about autism and MMR in other countries?
Single vaccines	Why are the single vaccines not recommended? Could having the vaccines singularly cause autism? Has any research been done on the single vaccines and autism? Do other countries use the separate vaccines? If the uptake dropped to a dangerous level would the Government introduce single vaccines?
UK experience	When was MMR first used? Would I have had MMR when I was young? Are there different vaccines? Or does every country use the same one? Why did it take so long for us to use MMR, compared with other countries? How many companies produce the vaccine? Who tests that the vaccines are safe?
The alternative science	How did Wakefield arrive at his conclusions?
Understanding the diseases	Is there a relationship between measles, mumps and rubella? How do you catch measles? Is it air borne? Does breastfeeding give extra protection against? Can adults have MMR? Can it be given before 13 months to give better protection? Why do you wait until 5 to give the booster?

Parents explored whether basic behavioural problems often get labelled autism; whether if children were actually born with autism (generally this was new information) a blood test could be taken to see if they had it; and whether there is a link between autism and bowel disease. Four women in Group 5 articulated how they now understood (having watched the video) that if you ‘have got autism in you it will come out eventually’, and a fifth hearing this promptly joined in the discussion saying that she felt it was important for her to watch the video to put her mind at rest.

Most groups, readily and unprompted considered issues of immunity, of having immunity through the parent and of protection as being related to the age at which the vaccination is given. Sue (Group 4, one son) summarised what she had learnt in terms of ‘so really we are saying if you do not have the MMR around the 13 months you are leaving your child open, they are at risk, aren’t they? They also could readily appreciate the need for mass vaccination in order to achieve protection of the population. Group 3 (higher-socio-economic ‘white British’) discussed at length the ‘irresponsibility’ of parents who do not have their child vaccinated and who are putting other children at risk, with one participant admitting that that was the information that ‘impacted most on her’.

All groups knew something about the ‘alternative’ views of Andrew Wakefield (although did not necessarily know his name). Most wanted to hear about the science behind his research. When hearing a detailed explanation of this from the Department specialists, there was general concern that the leaflets did not provide this type of detail. Parents interpreted the fact that the original study had used a small group of self-referred children as ‘bad science’. Even those who

evidently had little science in their education could articulate concepts relating to sample size and representativeness. For example, one new, young mother (Group 5) said that she did not 'do much science' at school but drew an astute analogy about the issue of representativeness with a television advert that shows clothes washed in one soap powder compared to clothes washed in another, with the former depicted as being whiter. She concluded 'it's like that isn't it?' she enquired, 'that doctor needed another group'. In Group 3, one mother complained that 'we're just getting the headlines...MMR causes this, MMR causes that and you don't hear the background'. Three others in the group concluded that the background to the research by Wakefield *et al.* was 'a crucial bit of information' that parents 'want to know' and 'need to know'.

All of the groups were asked about their views of the small table of comparative risk data in the leaflet (Table 1). Most parents reported that it was interesting and useful, and they appeared to have no difficulty conceiving what the data were portraying. Lisa (group 3, 2 children) talked about how she conceptualised numbers like 1000 and 5000 in terms of the sizes of her local schools. '1 in 5000 is an awful lot because it's a lot of schools put together. The average school is 500, so that's ten schools' worth of children. So just one child in ten schools would die'. However, she also noted that if it was in the school that her child attended that would be very worrying.

In the lower socio-economic and also younger age groups (groups 2, 4, 5) there were a few more dissenting voices—'it's a bit mind boggling', 'quite difficult to understand'—although no-one suggested that the figures should be removed as the comparisons were important. Several in these groups suggested that percentages might be more meaningful. Analysing the questionnaires relating to information provision preferences, the majority (more than 80%) wanted information about the risks to health, and 75% wanted information on the certainty of scientific knowledge and how the risks compare with not having the vaccination.

Discussion and conclusions

This research focused on exploring lay talk about MMR as a means of identifying knowledge, how information is processed and what is needed. The group discussions were facilitated but not directed. Therefore it is not appropriate to draw either strong or statistical comparisons across the groups. There were some key differences between socio-economic groups, i.e. in the higher groups greater access to multiple information sources, a more direct and proactive engagement with their GPs and a broader set of questions raised. However, the rich discussion readily generated by all of the parents provides strong evidence of the immediacy and salience of the issue and the multiple and proactive means by which parents attempt to comprehend child health issues and to take decisions in the face of conflicting 'evidence'.

The attribution of blame on the media for 'blowing risks out of proportion' is common to a wide range of environmental, technological, as well as medical controversies, despite the fact that numerous studies of both newspapers and television have failed to identify any strong link between media consumption and public perceptions of risk (e.g. Freudenburg *et al.* 1996; Gunter and Wober 1983; Petts *et al.* 2001; Wahlberg and Sjöberg 2000). A focus on the media is to over-simplify the complex interactions between direct and mediated experiences that underpin public perceptions of, and responses to, risks. The media are an integral part of collective processes of 'making sense' of the world in different social contexts and localities (Burgess 1990). As dynamic mediators (Petts *et al.* 2001), the media are active interpreters who seek to resonate with social preferences and concerns.

In relation to MMR this resonance has been powerful, because it is a tangible risk issue, displaying key criteria that influence risk perception (Slovic 1992), e.g. the sensitivity of the potentially affected group (i.e. children), the perceived severity of the effects (i.e. the suggested

link to autism, a feared condition) and the ethical considerations involved in state control vs. individual choice. No risk issue emerges in a vacuum, but against a background of multiple issues with which it has to compete for attention. Health and family-related issues usually dominate in studies that identify embedded social concerns (e.g. Petts *et al.* 2001; Poortinga and Pidgeon 2003) so the responses of our parents were to be expected, heightened by maternal concerns and responsibilities. Media discussion of MMR has served to worry and has challenged embedded understandings of the value of immunisation, but for our participants it does not seem to have irreparably damaged a positive culture. It is interesting, for example, that throughout the discussions there was never negative reference to the other childhood vaccinations. However, it is important to note that we did not recruit non-vaccinators that might have been expected to display concerns about vaccinations in general. Also the participants who had already taken their child for MMR or were intending to do so (55%) could have been expected to display beliefs that supported their decision.

This research did not provide evidence that parents had passively received media information without questioning nor that despite support for MMR parents had not still been concerned about making the 'right' decision and worried about the accuracy and veracity of information available to them. The concerns were universal although it was the higher socio-economic groups and particularly the 'white British' mothers who had identified the most extensive use of different information sources to proactively inform themselves. The primary problem seems to have been that other information had not always been available to parents, particularly directly and verbally from their own GPs. This situation represents a fundamental compromise of the 'decision-making partnership' (Ball *et al.* 1998) between parent and doctor, and seemed to be a particular issue amongst the Asian mothers, regardless of socio-economic group (which warrants further research), and also amongst the lower socio-economic groups. Only in the white, British higher socio-economic groups did mothers report proactive engagement suggesting a different fundamental relationship between doctor and patient.

Psychological approaches focused on individual cognition have been combined with network theories of contagion to test whether individuals adopt the attitudes or behaviour of others in their social network (Scherer and Cho 2003). Although this study did not set out to identify parental decisions, it was evident that concerns, understanding and beliefs had been reinforced by the communities in which people live. Maternal responsibilities and knowledge are maintained, supported and developed through a close social network, which in urban areas seems to be amplified by spatial polarisation. The knowledge environment comprises family and social networks through which experience of child health and development is continually cascaded and reinforced. Personal experiences of children who showed signs of autism made it difficult for parents (even those supportive of MMR) to ignore the links being made in the media. The continual comparison of child development, achievements and illnesses amongst parents means that there is always direct evidence to counter 'official' information. However, there is also evidence that people do not automatically follow the advice or experience of families and friends. For example although many of our parents talked about others who were non-vaccinators they themselves had not necessarily been swayed against MMR. The social normalisation of immunisation had been challenged if not broken, but in the process parental fears and concerns had been heightened. Many of our parents were evidently trying to confirm their personal faith in immunisation through a proactive information-gathering strategy.

One hypothesis suggests that in the face of the increasing amount of health information, people either follow habits or making explicit choices (Lindbladth and Lyttkens 2003). While we did not study behaviour (i.e. take-up of MMR) this study suggests that habit and making choices may not be alternatives. Our parents wanted the freedom to choose (e.g. between MMR or the single vaccines) but this may not translate into making the choice.

While the official information had capitalised on the strong majority parental support for vaccination it did not respond fully to the continually developing social interpretation of risks. The revision of the leaflet in 2001 had effectively tapped into people's concerns about the relative risks of the diseases vs. the side-effects of the vaccine. However, the leaflet was perceived to only address the dominant rather than 'alternative' expert views. The leaflet focuses on the weight of world-wide expert evidence and experience which supports government policy. However, in so doing it follows a traditional, 'educational' mode of communication designed to deal with public 'misunderstandings' (Hobson-West 2003). Although the leaflet had been updated to respond to parental questions this research suggests that it had not fully engaged with the depth and breadth of concerns prompted by the media reporting. Most importantly it made no attempt to explain the 'alternative science' and yet this lay at the heart of parental concerns.

Our participants displayed grounded and experiential 'lay' knowledge about the science of health, of childhood diseases and also of the conduct of medical science that provided support to their ability to interpret and understand information, particularly when given verbally, in lay language and with the opportunity for direct questioning. Lay science developed from experience, through analogy and narrative and through engagement with health professionals and within social networks. However, it was evident that the seriousness of the three diseases was learnt not experienced. As experience declines learning in this context needs to be continually reinforced through official information.

Participants understood that medical knowledge is continually developing and that the causes of diseases such as autism are uncertain with evidence taking time to be generated. However, uncertainty did not result in demands for zero risk. Participants readily identified and accepted concepts of precaution and the need to balance risks, costs and benefits. The comparative risk data although not universally understood nevertheless did seem to support the information that was being provided, contributing to a rich tapestry of knowledge that was interpreted against background understanding and experience.

Unfortunately the research was not able to focus on MMR 'refusers' to identify what led them to different decisions to the majority and this would be a valuable follow-up study, perhaps as part of a comparison with take-up of other vaccinations. No attempt was made to formally identify whether people changed their minds about MMR as a result of the process and particularly access to the information. In Groups 4, 5 and 7 there were two mothers and a father who thought that they were 'still not likely to have MMR' but in the same three groups others said that they were now convinced of the importance of MMR having seen the information and listened to the specialists. Studying the link between expressed preferences and actual behaviour is notoriously difficult. Nevertheless a follow-up study particularly of the parents yet to make a decision (Groups 5, 6 and 8), to identify their take-up of MMR might assist in understanding how information strategies translate into decisions.

Distrust in information sources emerges as an important generator of questioning of authorities (particularly the government). However, our evidence would seem to support Poortinga and Pidgeon's (2003) definition of 'critical trust'. While our parents relied on institutions for knowledge they combined this trust with healthy scepticism as to whether they were being given impartial, unbiased advice and hence were continuing to (constructively) question the correctness of the information. Trust was not simply an issue of competence but a combination of competence and care and a vested interest dimension. Most interesting was the response to the Department of Health. It appeared that as long as it is not equated with 'the Government', i.e. in this case the body that curtailed choices, it might be viewed as trustworthy. Much trust research has tended to refer to 'government' with no distinction between different modes and agencies of government. This research suggests a need for finer definition in this regard.

The study supports many others in identifying ‘doctors’ and ‘GPs as trusted information sources. It was evident that the health expert had a twin role in participants’ minds, (i) to be an up-to-date expert, and (ii) to help people to translate science in their personal context. GPs were perceived to largely fill the function of the independent and knowledgeable expert, but they were failing to meet people’s preferences in terms of mode of communication (i.e. face-to-face).

Fundamentally this research supports the role of user-centred risk communication. This implies communication that is informed by an understanding of information needs. In part the official information studied here had responded to this as it had been designed following earlier focus groups with parents. However, what it had more difficulty doing was maintaining a response that moved with people’s rapidly changing information needs not least as media reporting served to cascade new information that both challenged but also sometimes supported (in the case of direct experience of autism) grounded and experiential knowledge. Arguably official, printed material will always face difficulties in being immediately relevant as resources for up-dating and revising information regularly are ultimately limited. This limitation supports multi-modal communication with the direct mode of face-to-face communication ultimately playing the most important role.

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