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MMR mobilisation: citizens and science in a British vaccine controversy

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Summary

This paper examines the controversy over measles, mumps and rubella (MMR) vaccine in Britain through the lenses of social movement theory and social studies of science. Since the early 1990s, networks of parents have raised, and mobilised around, concerns that MMR has triggered a particular disease in their children linked to autism and bowel problems, and have been supported in this by certain scientists. In the high-profile and highly-public debate which has ensued, they have challenged established perspectives and institutions in both biomedical science, and public health policy. While much policy and public debate has dismissed their concerns as based on emotion, misinformation or "junk science", this paper locates them as part of a citizen science grounded in parental experience. It tracks how the framing and strategies of parental mobilisation around MMR have developed, in relation to a growing counter-mobilisation from scientists, policy-makers, health professionals and journalists questioning their claims. It argues that the controversy involves differently-framed sciences (clinical vs epidemiological) linked to different political commitments (parents' personal concerns and rights as citizen-consumers vs notions of public health). Each side has nevertheless used similar strategies in deploying science, in exposing the political economy of the other's science, and in working through the media. Both these differences of framing, and similarities of strategy, are important to comprehending why the debate has become so heated and polarised, and why it has failed to reach closure.

Keywords: citizens, science, mobilisation, vaccination, MMR

Contents

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Preface: DRC Working Paper series on Citizens, Science and Mobilisation

Rapid advances in science and technology are accompanied by changing forms of public engagement, with implications for citizenship. There is evidence both of apparent crises of public confidence in science, linked to the emergence of new risks, uncertainties and threats thrown up by science, technology and its application. At the same time, certain local knowledges are being re-worked as citizen sciences, in which publics conduct research and engage critically with expert perspectives on scientific and technological issues.

The Citizens and Science Programme of the Citizenship DRC has been exploring emergent engagements between citizens and public issues involving science, and the processes of rights-claiming and participation involved. This inquiry has moved beyond institutionally-orchestrated attempts at public participation in science to look at more spontaneous forms of citizen mobilisation and activism around scientific and technological issues. Across a diversity of issues and contexts, and drawing together perspectives from social movement theory and science studies, the Programme has asked:

- Who mobilises and who does not, and why?
- What are the patterns of experience, profiles and identities of activists?
- Within what spaces do debates about science and policy take place, and what processes of inclusion and exclusion exist?
- What forms of knowledge – including values, perceptions and experiences - frame these public engagements and movements?
- How are activist networks constituted, and what diverse forms do they take?
- How do science and scientists become enrolled in these networks?

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'MMR mobilisation: citizens and science in a British vaccine controversy', by Melissa Leach.

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1 Introduction and approach

Childhood vaccination is widely regarded as an exemplar of "successful" public health intervention, whether on a national or international scale. Done to everybody (every child), it carries large financial and policy investment linked to past claims and future aspirations for disease eradication, and powerful images of the healthy citizen. "Vaccinology" is also an area of massive scientific advance and investment which is leading to a proliferation of new vaccines, technologies, combinations and applications, many focused on eradicating childhood diseases.

Yet this optimistic picture sits alongside much evidence of public anxieties and forms of mobilisation which are questioning, critiquing or resisting vaccines. While public resistance is itself nothing new, having a history as long as that of mass-vaccination itself (e.g. Durbach 2000), recent controversies in which particular vaccines and combinations are accused of doing harm question the established image of vaccine science and mass-vaccination as unproblematically promoting healthy citizens. Moreover, vaccines, as a point where technology and its implicit policy and politics quite literally enter the body, and the highly personalised and socially sensitive worlds of child-rearing, appear easily to become foci for people to reflect on science, technology and their social and political implications. Thus contemporary citizen mobilisation around vaccines offers important windows onto contemporary science-society relations, and indeed social processes more generally.

The controversy which has raged over measles, mumps and rubella (MMR) vaccine in Britain since the early 1990s exemplifies a case where citizens have raised, and mobilised around, vaccine concerns: in this case, that MMR has triggered a particular disease in their children, linked to autism and bowel problems. In the high-profile and highly-public debate which has ensued, parents – in alliance with certain scientists – have challenged established perspectives and institutions in both biomedical science, and public health policy. They have faced an increasingly vociferous counter-mobilisation from scientists, policy-makers, health professionals and journalists questioning their claims. The complex, heated and polarised debate which has ensued illuminates broader questions about the nature of science, expertise and health-related citizenship rights in the contemporary British setting. To date the debate has not reached closure, and this paper explores why.

To do so, I consider these MMR mobilisations in relation to social movement theory and social studies of science – theoretical lenses which, as I show, help explain why the controversy has defied resolution. This approach also fills several gaps. It locates parental mobilisation as part of scientific process and politics, in contrast with analyses of the MMR controversy which dismiss their critiques from consideration, and portray them simply as them as emotive stories (e.g. Fitzpatrick 2004). It adds missing elements to the growing literature on public engagement with MMR in the UK, which to-date focuses on the perspectives and decision-processes of "ordinary" parents rather than on parental groups voicing claims of vaccine damage (e.g. Petts and Niemeyer 2004, Poltorak *et al.* 2005). It also contributes to the small but significant social science literature on collective public resistance to vaccination, or "anti-vaccinationism" whether in the UK (e.g. Rogers and Pilgrim [1995?]; Hobson-West 2003, forthcoming) or internationally (e.g. Streefland *et al.* 1999; Greenough 1995). While most of this work focuses on discourses questioning vaccination, this account analyses mobilisation in terms of both discourse and the socio-political processes of citizen action.

To do this, the paper draws together several strands of social movement theory. First, theories of political process (Tilly 1978) locate the emergence of collective mobilisations, and their success or failure, in relation to their political and institutional contexts. Incorporating some of the emphases of earlier Resource Mobilisation Theory (e.g. McCarthy and Zald 1977), they draw attention to how forms of organisation, access to professionals, finance, media and legal resources and so on are drawn upon in mobilisation. They focus attention on how actors and organisations taking different positions in a controversy interpret and react to each other's actions, adjusting position accordingly.

Second, theories of framing (Benford and Snow 2000) emphasise how mobilisation takes shape around and actively involves the construction of, particular ideas, meanings and cognitive and moral constructions of a "problem". This may involve selecting from an available repertoire of concepts, explanatory schemes, or arguments in ways that fit the moment, perhaps reframing or redefining these. Mobilisation thus involves struggles not just to promote a given social or political agenda, but to establish and promote certain meanings and problem-definitions as legitimate as against those who would dispute them.[1]

Third, the identity-related aspects of social movements have been emphasised, especially as interest in "old" social movements assumed to be class-based has given way to interest in "new" social movements constituted around symbolic, informational and cultural struggles, and rights to specificity *vis-a vis* dominant state and market forms (Melucci 1989; see also Habermas 1996). Rather than assume shared identities amongst movement participants, recent approaches examine the sources and processes through which common identities are formed, and perhaps dissolved and reformed, through movement processes (Castells 1997). Included here is attention to micro-contexts of common experience and to everyday movement practices in holding movement participants together, even if temporarily (e.g. Laclau and Mouffe 1985).

A fourth dimension in the study of social movements is acknowledgement that contemporary mobilisation frequently involves diffuse, multi-layered forms of networking and alliance (Edelman 2001; Appadurai 2002) and "discourse coalitions" between differently-framed agendas (Hajer 1995). This contrasts with the more conventional focus of social movement theory on single organisations with a single, shared agenda. Indeed some theorists discount such forms of mobilisation as "movements" at all, preferring to label them coalitions or networks (Fox 2000). In this paper I use "mobilisation" in a broader sense to cover all of these, appreciating how new information technologies and media networks are now central to mobilisation forms and processes (Castells 1997).

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[1] Tarrow (1998) and McAdam, Tarrow and Tilly (2001) usefully integrate framing with resource mobilisation and political process approaches in analysing social mobilisation.

As will be seen, these four dimensions of contemporary social movement theory help understand how the MMR controversy has unfolded. However, this case also implicates science, and it is also helpful to link social movement theory with insights from social studies of science which focus on the production of scientific knowledge and the role of science in society. Some strands in this wide-ranging literature draw attention to how "science" is drawn on to advance positions in political and social controversies in what Epstein (1996: 6) terms a 'scientisation of politics'. Yet at the same time, science is politicised, as apparently technical arguments and interpretations incorporate – even if implicitly – the social and institutional interests and lifeworlds of their proponents (e.g. Latour 1999), including their assumptions about citizenship (Leach *et al.* 2005).

In one of the few explicit attempts to engage these two bodies of work, Epstein (1996) proposes four possible ways in which social movements might engage with science: (a) disputing scientific claims; (b) seeking to acquire a cachet of scientific authority for a political claim by finding a scientific expert to validate their political stance; (c) rejecting the scientific way of knowing and advancing their claims to expertise from some wholly different epistemological standpoint, and (d) attempting to 'stake out some ground on the scientists' own terrain' by questioning 'not just the uses of science, not just the control over science, but sometimes even the very contents of science and the processes by which it is produced' (Epstein 1996: 12–13). Parental mobilisation around MMR, as we shall see, in many respects exemplifies this last category, as well as a case of "citizen science" (Irwin 1995; Fischer 2000) where "lay" people are actively producing new knowledge which accords with their own experiences.[2]

In considering the MMR controversy this paper develops these arguments in several ways. First, it relates "science" and movement framing, examining how different "sciences" and forms of knowledge with different methods, foci of inquiry, underlying assumptions and social meanings become part of the framing of both parental and counter-mobilisation. Seen through this analytical lens, the categories of 'citizen/lay knowledge' and 'expert science' – and indeed of citizen and scientist – dissolve, giving way to others that are more significant – such as between individual vs population-focused studies, and clinical vs epidemiological methods.

Second, it shows how these sciences and claims about them are deployed in the strategies and political process of mobilisation. Here, insights from work on science in action and actor-network theory (e.g. Latour 1987, 1999) help illuminate the practices of science-related mobilisation; how both movement actors and their opponents create, consolidate and extend their claims by enrolling other actors and institutions into knowledge/power networks, and how particular events and fora shape the co-production of scientific and social, political or policy positions (Jasanoff and Wynne 1997). In MMR mobilisation, the relevant actor-networks have extended from parents' groups, particular scientific experts and certain health professionals to include a variety of journalists, politicians and lawyers. They have confronted

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[2] In this respect, there are strong similarities with Epstein's (1996) account of AIDS activism in the United States, as well as with cases of popular epidemiology and patient/victim mobilisation around issues of environmental and health risk (e.g. Brown 1992; Petryna 2002).

opposed actor-networks of scientists, policy-makers, government officials, journalists, corporations and lawyers in a political process in which each side has frequently deployed remarkably similar strategies, although for very different ends.

This paper is based on participant-observation of several national events around MMR; a range of interviews and informal discussions with spokespeople and members of a parents' support group in Brighton, Sussex; a review of the web-based publicity materials of key organisations, and a close following of media and internet debate about MMR during 2001–2004. While backed by detailed ethnographic work on "ordinary" Brighton parents' perspectives and concerns around MMR (Poltorak *et al.* 2005), it should be emphasised that detailed ethnographic work on the parental movement *per se* has not been conducted.

The paper proceeds through three sections. Initially I outline key aspects of the political and institutional context for the MMR controversy, raising themes which would surface repeatedly as it unfolded. I then discuss the emergence of parental mobilisation around MMR, focusing on its identity-related aspects, its multi-layered, network-like form, and the framing of the movement. Lastly I examine the political process of mobilisation in greater detail, exploring the interactions between framing and strategies of both the parental mobilisation and its growing counter-mobilisation, and the roles of sciences in these processes.

2 MMR in political and institutional context

The triple vaccine against measles, mumps and rubella was introduced into routine childhood vaccination schedules in Britain in 1988, becoming part of an established vaccination programme credited with bringing about massive reductions in morbidity and mortality. Mass childhood vaccination has a long history in Britain, extending back to immunisation against smallpox in the nineteenth century which eventually succeeded in eradicating the disease. Vaccination programmes and their claimed success and cost-effectiveness as a public health measure have co-evolved with the institutions devising and administering public health policy, and are in many respects a cornerstone of their credibility and reputation.

The appropriate responsibilities of the state, and the relationship between a state and its citizens, constitute a second important contextual theme. The administration of childhood vaccination policies through the National Health Service is linked to a notion of state responsibility for maintaining public health, for the benefit of society as a whole. Citizens of a democracy might expect rights to such basic health protection. Indeed where infectious diseases are concerned, vaccination of an individual child is held to benefit not just the individual's health but community health, by reducing disease levels in the population and thus providing social or "herd" immunity. In this respect, in having their children vaccinated, individuals contribute to a social as well as a private "good". While in some countries these arguments have justified coercive approaches to vaccination (e.g. the US, where it is compulsory for school entry), in the British political context arguments for coercion have not found a foothold.

Vaccination in principle remains voluntary, and public education and trust[3] is relied upon as the main means to maintain high uptake levels, and high levels of surveillance and uniformity in vaccine administration.

However, this emphasis on vaccination to maintain health at the population level exists in tension with a second basic principle in a liberal democracy such as the UK: of the citizen's individual right to pursue their own health (or that of their child). As long as vaccination is deemed by a parent to be in their child's best individual interest, then there is little conflict between these perspectives, but should a vaccine become associated with potential harm to the individual, then these principles diverge. As we shall see, the MMR issue brought this fundamental tension between individual and public health objectives into sharp focus, and became a recurring theme in the controversy.

In Britain in the 1990s, this tension was heightened by further, related aspects of the political and institutional context. First, reforms in the health sector were advocating greater individual decision-making and patient choice, as part of the wider consumer-choice agenda promoted by Tony Blair's so-called New Labour government. Second, notions of individual responsibility and risk awareness, values central to the "risk society" (Beck 1992), were being actively promoted as part of the moral framework for New Labour's "Third Way" politics. The government has sought to promote these values at the expense of more "traditional" sources of authority – notably in the professions and civil service – drawing in sociologists such as Anthony Giddens and Ulrich Beck as part of their advisory networks. Third, Fitzpatrick (2004) argues that the scope of politics in Britain at this time was focusing more on personal issues, encouraging the politicisation of issues such as health, lifestyle, family relationships and childrearing practices. Around these issues, the state was increasingly encouraging "responsible" citizens who self-govern their health, behaviour and lifestyles (Barry *et al.* 1996); notions of individual responsibility embodied in citizens' organisations such as Weight Watchers and self-help therapy groups (see Bauman 1999). In this context, a series of emergent health and environmental scares – over HIV/AIDS, BSE, GM foods, and so on – seemed to many to be evidence of risk society values come true, and of the government's inability to protect its citizens from the risks and uncertainties of late industrial society. All this provided a welcoming public context for mobilisation around MMR concern, and for some of the specific claims which pressure groups were to advance. However, these (neo) liberal, individualised, self-responsibilising, risk-aware values ran entirely contrary to the values still guiding other policy areas – such as public health and vaccination – which relied on public respect for public institutions in promoting a social good, and to the interests of institutions supporting these. The MMR controversy has thus been playing into fundamental schisms in British governance. This is important for understanding both the intensity of the controversy, and the framings and strategies deployed by actors in it.

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[3] For a useful critical discussion of the diverse roles and concepts of trust in UK vaccine policy and resistance to it, see Hobson-West, forthcoming.

3 The emergence of parental mobilisation around MMR

3.1 Parental experience, scientific alliances

Parents who mobilised around MMR locate the origins of concern in their own experiences with their children, dating from the early 1990s. In contrast, much scientific, policy and media commentary has portrayed the controversy as instigated by the publication of a key scientific paper (Wakefield *et al.* 1998) which led to suggestions in the media of a link between MMR and autism.

According to parental narratives, as revealed in my interviews in Brighton and as publicised through the internet and media, from the early 1990s a number of parents noticed what they describe as dramatic changes in their children. From a developmentally-normal infancy, they regressed suddenly from around the middle of their second (in some cases their fourth) year. They became withdrawn, with symptoms later diagnosed as part of the autistic spectrum, along with severe and painful bowel problems. As time went by, such children developed other symptoms such as excessive thirst, loss of language, allergies, respiratory problems and food intolerances. Reflecting on the timing, a number of parents came to link the symptoms to MMR vaccination. Some describe how it had been obvious to them that a serious reaction had occurred just a few hours after vaccination. For others the link emerged when they searched back through family photographs and child health records. The stories of several mothers who became prominent in the emergent movement, as told in the media, are by no means a-typical: contributions to email discussion boards and my own discussions in Brighton reveal many similar narratives. One mother described, for instance, how after the MMR jab her son:

> . . . went pale. I took him home and he slept for an hour, but when he woke, he started screaming. He was clearly in terrible pain. The look on his face terrified me . . . All the next week, he was very sleepy and I couldn't establish eye contact with him . . . He never recovered. I'd watched the life go out of him. Afterwards, he started having horrendous temperatures. He became aggressive, hyperactive and out of control, but the doctors insisted there was nothing wrong.
>
> ('Suing the drug companies', *Daily Mail,* 17 October 2000)

She described how as health professionals refused to listen seriously to her, she 'began to do her homework', and to suspect vaccines. Her account echoes that of the mother on whom the lead character in a December 2003 Channel Five documentary 'Hear the Silence' was based:

> Watching her son walk through the school gates, Kathleen Yazbak is haunted by a moment in her past . . . when, six years ago, Kathleen let her four-year-old son have his MMR booster. Kathleen, 37, was one of the first parents to raise concerns about their children's sudden change in behaviour. She gave up her career in executive recruitment and spent all her waking hours trying to find out what had happened to him. She was one of the first to make what appears to be the link between the MMR vaccine and late-onset autism.
>
> ('Why did my son suffer?', Bonnie Estridge, *The Scotsman*, 9 December 2003)

These parents began to come into contact with each other through chance encounters, existing networks such as autism support societies, and a snowballing of email and telephone communication. As such communication developed, finding others with remarkably similar experiences seems to have supported parents' individual interpretations of a link with MMR. This set of shared experiences and understandings, and the technologies to link them, became important in forging a common identity – a key dimension of new social movements according to Melucci (1989).

These parents also describe how through such communication, they came to learn about medical specialists who might take their experiences seriously. Key among these was Dr Andrew Wakefield of London's Royal Free hospital, whose work was already suggesting possible links between measles virus and the development of inflammatory bowel disease (Wakefield *et al.* 1993; see also Ekbom *et al.* 1994). One mother described how an internet contact gave her Wakefield's telephone number. She called him, and claims that he listened for an hour, before saying that he had heard a few other cases and was interested. She then managed to track down an unusually sympathetic GP in Brighton with a personal interest in autism, who also listened and referred her children formally to Wakefield, who carried out a full series of tests. 'For the first time, we were being listened to.' On finding a set of unusual bowel problems in her son, she claims that Wakefield said to her: 'on behalf of the medical profession, I want to apologise for the way you were treated'. Such encounters marked the start of an important alliance between Wakefield and certain other similarly-disposed medical scientists, and concerned parents, in a movement that came to transcend simple divides between "citizen" and "expert".

Wakefield's interest led to clinical studies of a small number of such children. In 1998 Wakefield and his colleagues published a paper in *The Lancet* (Wakefield *et al.* 1998), reporting how 12 children of previously normal development had suddenly lost their language and social skills, and had developed – along with these autistic symptoms – a new type of bowel disease (ileocolonic lymphoid nodular hyperplasia). They conceded that this combination could have occurred by chance, but suggested that they had identified a unique disease, which they called autistic enterocolitis. The paper did not make any claims that this disease was caused by MMR, although anecdotally, it mentioned that a majority of the children's parents believed that MMR had been a trigger. At a press conference, Wakefield recommended further research, and that single vaccines should be offered instead, on a precautionary principle, until this had been done. This and then a subsequent paper reviewing the literature on the MMR vaccine and suggesting that its original safety studies had been inadequate were reported dramatically in the media, sparking what became a high-profile controversy.

3.2 A multi-layered movement

Social mobilisation developing concern about a possible link between MMR and autistic enterocolitis took multi-layered forms, involving: (a) localised parental support groups; (b) national organisations and networks both focused on the MMR issue, and building on and drawing in strengths and inclinations from pre-existing movements, and (c) a wider field of supportive networking and discussion amongst sympathetic publics.

3.2.1 Local support groups

In some localities, parents who believed their children were damaged by MMR established support groups. Their common experiences and everyday movement practices forged and maintained common identity amongst movement participants (cf. Laclau and Mouffe 1985). One such group in Brighton, for example, included about 20 members who met once a month in a neutral venue such as a community centre. Participants describe equality and common experience as the factors binding them, across differences of class and gender: 'we were all equal and together'; 'we were discovering similar symptoms – it was an amazing insight into not going mad'. Through conversation, affirmation of common experience and identity was combined with emotional support: 'We laughed, cried, and became very close'; 'it was like a family', and the sharing of practical information about diet, treatment options, entitlements to support and so on contributed to this. Conversations would often dwell on experiences with health professionals, in a style which simultaneously served to construct solidarity amongst an "us" versus an unsympathetic "them". Thus several members spoke of health professionals' disbelief when they described their children's symptoms and their view that they were caused by MMR. They speak of being dismissed, and told that their children 'just had toddler diarrhoea', for instance; of 'being made to feel tiny' and of being called a 'bad parent' for questioning vaccination. Several also report being accused by health professionals of having either caused their children's autistic symptoms, or having invented them in a version of Munchhausen's syndrome by proxy.

At least in the account of its founder, the Brighton group and its various activities also became a means through which mothers empowered themselves, acquiring the vocal skills, knowledge of organisations and networks, and familiarity with scientific vocabularies that some would employ elsewhere as part of the wider MMR activist movement. In this way, local support groups did not just forge common identity but also spawned activist strategies of the kind explored later in the paper.

3.2.2 National networks and organisations

Co-existing and interacting with such local support groups emerged a variety of national organisations and networks. These have overlapping aims and involve an overlapping set of actor-networks, although there are also significant differences in their precise agendas and framings. Most came to use the internet as their major means of publicity and coordination, as well as contributing to the media and public events.

A few such organisations originated in parental concern over MMR and campaigned around this as their major issue. They illustrate, in some respects, what Brown (1995) identifies as a politics of injury, where shared experiences of injury and victimhood provide a powerful mobilising force (see also Petryna 2002) – a force perhaps strengthened by the fact that the victims are children. Key among these is JABS (Justice, Awareness and Basic Support), founded by Jackie Fletcher, one of the first mothers to voice public concern over what she saw as MMR-damage to her child. In the account of one of its co-founders, the organisation's original concern was to provide a helpful support network for parents of vaccine damaged children, and to search together for ways to help them. As time went by, however, JABS found other parents looking to the organisation as a source of information and advice on vaccines, as an alternative to both the pro-vaccination stance of official government advice fora and more extreme anti-vaccination websites. JABS explicitly frames its agenda as occupying an independent, middle ground: 'JABS, as a self-help group, neither recommends nor advises against vaccinations but we aim to promote awareness and understanding about immunisations and offer basic support to any parent whose child has a health problem after vaccination' (www.jabs.org.uk/pages/jabsinformation.htm). Its specific demands are for comprehensive information to enable parents to make informed decisions about vaccination; for more research into the long-term effects of vaccination, and for more effective systems for reporting and compensating vaccine damage. MMR is nevertheless the major focus of JABS' work and efforts, largely because of the number of parents reporting adverse reactions to it.[4] JABS has in turn become prominent in the wider debate as the main organisation presenting the perspectives of parents who believe their children damaged by MMR, and has forged specific links with medical scientists researching the possible links between MMR and autistic enterocolitis. In this respect, its opponents identify it as part of – indeed the core of – an anti-MMR movement. Notably, JABS' founders resent and deny this identity, claiming that they are not anti-MMR – let alone anti-vaccination. Rather, they claim they are anti- the giving of MMR to vulnerable children who might be damaged by it, and anti- the secrecy and lack of dialogue which, as later sections will show, have come to pervade the debate and deter investigation of causes of vulnerability. Further, while frequently described in popular and media debate as "activists", JABS' founders also reject this identity, defining themselves first and foremost as parents who have taken on a campaigning role only out of circumstance and necessity, to search for justice and treatment for their children.

A second specific campaigning group is the Autism Research Campaign for Health (ARCH). Like JABS, the core of this organisation is a group of parents and grandparents of children believed to have developed autistic-like symptoms from MMR, again several of whom have been treated at the Royal Free and publicly prominent in the media. However ARCH frames its concern not with vaccines but with "acquired autism",[5] campaigning for more clinical research into its causes, treatment and relationship with specific bowel problems. MMR is not mentioned in its front webpage, although it has been the subject of several of its press releases, and is the focus of the major 100 page "briefing note" that is a centrepiece of its site (www.autism-arch.org/thrower.htm).

Both JABS and ARCH pursue what has become a major sub-agenda in mobilisation around MMR: a campaign for access to single vaccines for measles, mumps and rubella as an alternative to MMR. This fits with their broader framing agendas of avoiding perceived problems with the triple vaccine, and promoting

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[4] JABS registered 2,000 children whose parents believed them vaccine-damaged between January 1994 and 2002. Of these cases, 1,800 concerned MMR, 170 concerned the DTP triple and Hib vaccination, and a handful concerned Hib alone or the flu jab.

[5] As distinct from autism present at birth; the specific syndrome which parents link to MMR can be treated as a sub-category within the broader category of acquired autism.

parental choice.[6] Thus amongst ARCH's demands for appropriate action is 'the provision of single vaccines until all the issues surrounding the triple vaccine MMR are resolved'. JABS has strongly taken up the campaign for single vaccines to be made freely available on the NHS. Its website has a section carrying information about how to obtain single vaccines, either from private clinics or (under particular circumstances) from the NHS. Its discussion board has become a major forum for parents sharing advice and information about this issue. An alliance has also developed between these organisations, and the private GPs and clinics providing single vaccines.

Concern with a steep rise in autism in recent years – and the need to find reasons for it – has been part of the framing agenda of parental mobilisation around MMR. The suggestion within the parental movement is that MMR is contributing to this rise, although notably this concern with "autism in general" somewhat contradicts their own emphasis on the "novel" syndrome they are seeing in their children. The suggestion is that this novel syndrome – a form of acquired autism – is part of the rise, though not all of it. In addressing the rise in autism cases, organisations such as JABS and ARCH share concerns with groups campaigning around autism in general. The emergent alliances can be seen as a discourse coalition in Hajer's sense, where 'a common discourse is created in which several practices get meaning in a common political project' (Hajer 1995: 65). Actor-networks link these, with several parents and scientists active supporters of both organisations such as JABS and ARCH, and those campaigning around autism more generally. Websites have mutually-connecting links, while autism-focused organisations have at times participated directly in MMR-focused campaign activities. Thus for example the National Autistic Society (www.nas.org.uk) which 'exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs' has explicitly supported parents' rights to be listened to over their perceptions of MMR damage, both in the media and at public meetings. Allergy Induced Autism (AIA) describes itself as a 'UK based charity dedicated to identifying the underlying causes and biochemical effects of autistic spectrum disorders' (www.AutismMedical.com). It focuses on providing information about dietary and medical intervention in autism, and raises money for autism research through membership fees. Like JABS, AIA's origins and current activities link parents with a network of supportive scientists, but in this case a network of biochemists and medical practitioners researching the relationship between autism and food and environmentally-induced allergies. While again, the mission statement makes no mention of MMR, the CEO is Rosemary Kessick, mother of one of Wakefield's first research subjects and also an active campaigner on MMR. AIA makes specific mention of Wakefield amongst its supportive scientists, and is pushing for more work on vaccines and viruses as a possible trigger for autism, amongst other causes. The many parents who contact them about this issue are directed to the JABS website.

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[6] The suggestion that giving measles, mumps and rubella as separate injections would avoid the problems claimed to be associated with the triple vaccine can be traced back to a remark by Dr Andrew Wakefield at the press conference around his 1998 paper. Despite the prominence this has assumed as a mobilisation theme, arguably neither his nor subsequent work has properly distinguished between the supposed effects of measles vaccine when given as part of MMR, or when given singly.

A similar broad autism-related framing, yet clearly overlapping sub-agenda and actor-networks with MMR-specific mobilisation, characterises ActionAgainst Autism www.actagainstautism.org.uk/. It aims to counter the claims that autism is a purely inherited (genetic) condition, and to campaign for better screening and treatment for children with autistic symptoms. Amongst the petitions it has organised or publicised have been several focused on MMR. Its directors and advisors, from the USA, Australia and New Zealand as well as the UK, include several who speak out openly on the possibility of an MMR-autism link, including parent of autistic child Bill Welsh; David Thrower of ARCH; and indeed Andrew Wakefield.

At the same time, a number of organisations and networks have taken up concerns about MMR as part of – and framed within – wider opposition to vaccination. A recent review (Nasir 2000) identified 51 "anti-vaccination" websites based in Europe or the US which variously frame their rejection of vaccination in terms of its threat to civil liberties, advocacy of alternative medicine, and as a conspiracy of government and drugs companies, often combining these. 'The Informed Parent', 'Vaccine Awareness Network', 'Whale', and 'What Doctors Don't Tell You' are prominent examples. Several of these websites are platforms for authors promoting similar agendas as part of what might be glossed as a broader anti-vaccination literature (e.g. Coulter and Fisher 1991; Miller 1996; Cave and Mitchell 2001; Coulter 1990; Scheibner 1993, McTaggart 2000). The anti-vaccination movement in itself has many strands, linking with a variety of "alternative" health and lifestyle movements (Hobson-West, forthcoming). While JABS and similar organisations often seek to distance themselves from broader anti-vaccinationism, there are common concerns with vaccine adverse events and the science of vaccination.

3.2.3 Networks of supportive parents

While social mobilisation around MMR inter-animates with the common identities of parents forged through experience, and a core set of actor-networks linking these parent-activists with scientific experts, this "complex" extends further. Many further parents who think about whether to have their own children vaccinated with MMR, and who draw on MMR-activist internet and media materials to inform their own reflections and discussions with each other, find themselves in sympathy and support. Older social movement theory, with its focus on campaign organisations themselves, might cast such parents as social movement "subjects" – those whom a movement seeks to influence. However more recent approaches, would see them as more agentive; integral to mobilisation in which movement organisations constantly connect with wider, supportive social fields (Edelman 2001).

This supportive social field for MMR activism is created and sustained in several ways. Many parents of babies and young children are drawn in to some extent simply through their positions as parents, although they may vary in the extent to which they "read" movement materials sympathetically (see Poltorak *et al.* 2005). "MMR talk" amongst mothers, with its tendency to provoke sympathetic listening to stories of vaccine damage, creates a wider network of affiliation and concern around the issue. It is also sustained through sympathetic readings of pro-movement articles in the media, and through the internet. The electronic discussion boards of campaign organisations such as JABS and AIA are central means for the forging of such broader social fields of support. Contributions to these tend to draw together, and thus expose to each other's perspectives, at least three sorts of movement participant: "core" mobilisers engaging in ongoing discussion over vaccine science and policy; parents sharing stories of what they suspect might be vaccine damage to their children, and other one-off contributions asking for information, for example about single vaccines, or where they might obtain advice. These dedicated discussion boards are joined by a range of other online fora, including both websites for general baby chat and care tips – which have become sites for "MMR talk" among other topics (e.g. www.babycentre.co.uk/tips/542970.html), and temporary electronic fora set up to coincide with, or follow-up, specific media events. MMR mobilisation is thus linking people in virtual networks which link localities both within and outside the UK, forging aspects of common identity in the process in the ways that Melucci (1996) and Castells (1997) see as typical of contemporary social movements.

In the centrality of the internet both to the practices of its core movement organisations, and in sustaining wider supportive social fields, MMR mobilisation illustrates a kind of "cyber-politics" that Bauman (1999) and others see as becoming a dominant mobilisation form in late modern societies with high internet access. But while Bauman considers cyber-politics as too disembodied to produce effective political solidarities, instead both relying on and creating further fragmentation, I do not see this as the case for MMR. Strong solidarity amongst parents has been generated, partly because of the strong sense of shared experience as parents uniting those who communicate through cyberspace, and partly because cyber-networks have been reinforced through other practices – of face-to-face encounter in support groups and campaign events, and through shared work in other movement practices and strategies. It is to these strategies that I now turn.

4 Framing and strategies in the political process around MMR

As parental mobilisation around MMR has proceeded, parents, through these various organisations and networks, have pursued a range of strategies to consolidate, give credibility to and promote their framing agendas and specific claims. These created and drew on sciences, and arguments about science, in a variety of ways. The framing and strategies of mobilisation were also shaped by their engagement with the opposed counter-movement which rapidly emerged to dispute parents' and scientists' concerns about MMR, and to uphold the established tenets of UK vaccination policy in the charged political context of UK health and governance debates.

I divide this account into key themes, even though this inevitably creates artificial divisions, dealing in turn with: producing science and knowledge; exposing the political economy of science; representing science and knowledge through the media, and pursuing claims through the legal process. As we shall see, underlying political tensions – in particular, those between individual and population/public focused perspectives – surface repeatedly.

4.1 Producing science and knowledge

Parents' initial concerns with the MMR vaccine arose from their own knowledge of their individual children's health, or what Fischer (2000) terms "experiential expertise". As parents shared, compared and made causative associations between their children's symptoms and MMR through informal networks, so a form of popular epidemiology emerged, constituting an example of citizen science (Irwin 1995). From the early 1990s, this acquired a greater degree of formality as JABS organised an ongoing web-based survey, from which patterns came to emerge (Fletcher 1995). The JABS website contains a survey questionnaire for parents of 'Vaccinated children with disabilities', designed to probe the course of a child's disabilities acquired since birth, the vaccinations they have received, and specific effects and their timing noted by the parent. This is sponsored by JABS and now managed independently by the company Datasmith.

The survey and informal collation of experiences together generated further lines of inquiry which have become foci for parental reflection and research, and for advancing claims supported by their science. These include, first, confirmation of the various symptoms, to the effect that parents came to interpret them as a "novel syndrome" linked to MMR vaccination. Second, parental research has focused on the timing of onset of these symptoms. This has enabled them to argue against Department of Health arguments that the timing of MMR vaccination and the onset of autistic symptoms is mere coincidence, as autism is usually noticed anyway at around the age of 18 months to 2, when MMR vaccination is given. The parental movement has used its citizen science to counter that 'much older children have also degenerated into autism after MMR. If degeneration in affected children always follows immunisation with MMR or measles-containing vaccine, regardless of the age of the child, then it implies that the link is not coincidental' (Thrower 2002).

Third, acknowledging that it is only a small proportion of a wider population of children affected in this way, parental research is asking about the "co-factors" which might make particular children vulnerable. Here, an emergent set of questions turns on family history: For instance the JABS survey claims to have 'highlighted a number of common allergies in the families: asthma, eczema, hay fever, antibiotics or a history of febrile convulsions, fits or epilepsy. Is it possible the child has some allergy element and has an allergic response when presented with several viruses at once?' (Fletcher 1995).

Fourth, JABS research and collated experiences are tracking the relationship between vaccine reactions, and specific vaccine strains, manufacturers, batches and additives. For instance:

> . . . many children showing adverse reactions received the vaccine from the same MMR batch numbers, and in some cases share the same medical problem: for example, four children sharing one batch number all have varying degrees of autism; another batch was shared by three youngsters all suffering from epilepsy. How much of this can be "coincidence"?
>
> (Fletcher 1995)

In a similar vein, they are asking questions around the effects of adding mercury-containing thimerosal to vaccines, although in this case there is only an indirect relationship with the effects of MMR, since MMR vaccine has never contained mercury. In asking about whether early exposure to mercury (e.g. in DPT vaccinations) could be a co-factor in certain children's later reactions to MMR, the UK movement finds common ground with parents' movements in the US, which have coalesced around the possible effects of mercury in vaccines as their major issue.

Crucially, this "citizen science" has developed in active engagement with the research surrounding MMR and their children's symptoms which was being conducted by certain medical experts. Through what Latour (1987) terms enrolment, aspects of the work and orientation of the accredited experts whose sciences complement parents' experiential expertise became part of mobilisation networks. Enrolment and alliance-building took place through a number of processes. These included directly through clinical consultations, through scientists' advisory roles within parental campaign groups, and through personal discussions between scientists and spokespeople in the parental mobilisation. More broadly, parents exchange and discuss on the internet the latest studies both in support of their experiences, and against them, along with their critiques. Some parent-activists have published their own reviews of studies, such as the major 100-page review by parent David Thrower placed on the ARCH website in 2002.[7] While it may be only a few parents doing this, their contributions to internet discussion boards are there for others to read. Parental groups have drawn attention to the emerging research which supports and complements their concerns. This active engagement with scientific research, and the acquisition of skills in using its concepts and vocabularies, contributes to what Epstein (1996) has termed the scientific "expertification" of lay activists.

At the same time, however, it is possible to identify what might be termed a "layification" of scientific experts. The most active parental engagement has been with the network of scientists and research groups in the UK, Ireland and the US who are pursuing research on different elements of the biological processes that might be implicated in their children's syndrome, and its possible links to MMR. Several of these scientists explicitly present themselves as exploring questions raised by parents. Indeed, that Wakefield's 1998 paper presented no evidence for an MMR link except the experience of the parents attracted furious criticism from government agencies and other medical scientists, yet Wakefield justifies this as an important and legitimate stance:

> It wasn't my hypothesis; it was what the parents said. We acknowledged this did not prove a causal association . . . It's not my job to censor the parents' story. If we censored that history, how would we enable people to test it? The parents said to us: my child has bowel disease. Unequivocally they

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[7] www.autism-arch.org/thrower/thrower-1july2002.doc, substantially updated in 2004.

> had bowel disease which the medical profession had played no part in diagnosing . . . So when the parents say they believe this happened after vaccination, we are not in any position to say, you are wrong. We must say instead we will investigate your history to the best of our ability.
>
> (Melanie Philips, *Daily Mail*, March 2003).

When accused of 'constantly moving the goalposts' by drawing new factors and hypotheses into their investigations, Wakefield countered that the research is constantly evolving, and that new hypotheses arose from the crucial principle that 'You go with the story the parents give you' (Melanie Philips, *Daily Mail*, March 2003). In a similar vein, Bradstreet (2004) argued in a presentation to the Vaccine Safety Committee of the US Institute of Medicine that 'Clearly, meaningful epidemiological studies should test *a priori* hypotheses that derive from all clues evident in the clinical histories of affected children . . .'

This emphasis on hypothesis-building from clinical case histories, and on the scientific analysis of data gathered from detailed individual medical examination, is a uniting feature of research that by early 2004 involved diverse medical specialists – paediatricians, gastroenterologists, pathologists – in at least 11 institutions. Many, although not all, of their studies were coordinated through financial and administrative support from Visceral, the charity set up by Wakefield in 2001 to further research on the issues parents were raising (www.visceral.org.uk), and which is advertised on websites such as JABS.

This is not the place for a comprehensive review or commentary on the scientific content of these studies. Suffice to say they include apparently supportive research from the US on the bowel syndrome and its association with regressive autism that Andrew Wakefield and his colleagues at the Royal Free identified (Horvath *et al.* 1999; Ashwood *et al.* forthcoming; Krigsman 2002), and recording its absence in developmentally-normal control groups (Wakefield *et al.* 2000, Furlano *et al.* 2001). Research examining the blood, intestinal and dietary response conditions of affected children suggests that their intestinal disease may be a source of toxic damage to the developing brain (Sandler *et al.* 2000; Wakefield *et al.* 2002). Further research suggests that affected childrens' bowel disease is consistent with a viral cause (Wakefield 2002), has identified measles virus in the intestines of a significant proportion (Uhlmann *et al.* 2002), and shown this to be of MMR vaccine strain (Shiels *et al.* 2002). Subsequent studies claim to have found measles virus in the cerebro-spinal fluid of children with regressive autism; in a small group and then in a group of 28 children with controls (Bradstreet 2004). Whereas Wakefield's group had originally speculated that the route from bowel disease to brain disorder might be through toxins (opioid peptides) leaking through the gut, other research, especially by Vijendra Singh and his colleagues at Utah State University, began to suggest a possible connection between measles virus and auto-immunity, finding affected children to produce abnormal antibodies to measles virus, which are associated with the production of auto-antibodies that attack the brain's myelin sheath (Singh *et al.* 2002).

By 2003, the science page of the Visceral website carried an 'Emerging picture of persistent measles vaccine virus in autism' which summarised, updated and referenced these studies in scientific, yet clear and accessible, terms – a summary which parental mobilisers subsequently circulated and referred to. This review clarified what had become the emergent core question, at least for the scientists coordinated through Visceral: 'what factors might make a particular subset of children susceptible to an adverse reaction to MMR, when for the majority it appears safe?' (Wakefield 2003), and the emergent hypothesis, that susceptibility to an adverse reaction might be determined by the immune status of the child at the time of MMR administration. Led in part by parents' stories, these scientists were by now turning investigatory attention to a variety of possible risk factors, ranging from a current or recent infection, effects of antibiotics, family histories of autoimmune disease and maternal MMR or rubella vaccination just before pregnancy, or over-exposure to mercury through the preservative thimerosal used in early infancy vaccines such as DTP (Wakefield 2003; Bradstreet 2004).

In this evolving research, the constant interplay between parents and medical experts, their shared concerns, and the mutual processes of "expertification" and "layification" at work, break down established boundaries between lay and expert knowledge, or between citizen science and expert science. Instead, it can be argued that more relevant boundaries in the MMR controversy are between the knowledge production of these MMR-concerned parent-scientific networks, and that of the networks which emerged to oppose them. In particular, there are major distinctions between their framings.

The claims of the parental-Wakefield alliance, and their media reportage, were of serious concern to scientists and policy-makers concerned with public health and vaccination in the UK, who saw questions about MMR safety as risking a decline in vaccine uptake, a drop in social immunity to measles and the return of epidemics, and an undermining of public confidence in the UK vaccination programme as a whole. In response, they engaged in several strategies which directly involved science. The first was to engage critically with the content and methods of the parental mobilisation's science – for instance arguing that Wakefield's 1998 work drew on a very small-self-selected sample – thus discrediting its relevance to a wider understanding of any relationship between MMR and autism. The second was to commission expert scientific reviews ostensibly to settle the issue – the Medical Research Council's (MRC's) *Review of Autism Research: Epidemiology and Causes* (2001), for instance, was commissioned after a key meeting when Wakefield and colleagues presented their findings to the health minister Tessa Jowell, and represented one of the government's main responses. The third was to produce new scientific research. From the late 1990s, numerous studies considered the incidence of autism (and in some cases, bowel disease) in relation to MMR among larger populations, and claimed not to show an association (e.g. Taylor *et al.* 1999, DeWilde *et al.* 2001; Fombonne 2001; see Miller 2002 and Jefferson *et al.* 2003 for reviews). The volume of such studies soon enabled government, scientific and professional organisations to claim that the weight of scientific evidence was strongly against an MMR-autism link.

Parents' organisations responded to these studies, in part, by critiquing them on their own terms, engaging in detailed criticism of their data sources, methods and reasoning, publicising such critiques on their websites. The most systematic of these critiques, on the ARCH website (www.autism-arch.org/thrower/thrower-1july2002.doc) reviewed about 70 of the most pivotal, or most frequently-quoted studies and papers, arguing that that 'there has not been a single credible study that can robustly refute the claims of the parents that their children's acquired autism has been caused by MMR or related vaccines', arguing that each was flawed in design or ambiguous in results. In this respect, parental strategies paralleled the strategies used by pro-MMR science-policy networks to critique Wakefield's work, producing a storm of critique and counter-critique at the level of scientific methods, data and reasoning.

However, major differences in the framing of each side's science became apparent. Fundamentally, whereas the science supporting parents' concerns was grounded in clinical case histories and the medical and biological processes in individual children, the opposed science-policy networks largely drew on statistical analyses of the medical records of the wider population. This contrast between individual/clinical and epidemiological/population work was, parental groups argued, fundamental, with these population studies being wrongly framed to pick up on their concerns. As one Brighton mother put it:

> If I drop a ring on the floor and I see it rolling in one direction and I tell you it is in the other direction, you won't see it. They are not looking in the right place, so they won't find it. They are not looking at our children.

This was echoed in David Thrower's review for ARCH:

> The medical establishment has repeatedly asked itself the wrong question. It has asked itself 'Is MMR safe?', hoping for an affirmative answer. In contrast, researchers and parents have asked two very different questions: 'What is wrong with this child?', and 'Why did this child change from being healthy to being autistic?'. *It is answering these latter two questions that should be the key issue.*

More specifically, parents argue that population-level studies are "too broad brush" to pick up rare adverse events from MMR that may affect only a tiny proportion of children. For instance the National Autism Society – taking a lead from parents' views – is calling for new clinical, physiological research, on the grounds that it is only these that will pick up very rare occurrences.

In some respects, these contrasting individual vs population framings can be seen to reflect each side's social and political concerns, within this politicised scientific field. Whereas parents were primarily concerned about what they saw as the vaccine-damaged health of their individual children, government policy-makers and their supportive scientific networks had institutional commitments to the continued integrity of the UK vaccination programme with its public, population-level imperatives. Tensions between scientific framings thus spoke directly to fundamental tensions in public health policy, and in citizen-state relations. In the controversy, those adopting these different framings tend to speak past each other. Little explicit attention is therefore given to the moral question of whether it is justifiable for the health of a few children to be sacrificed in the interests of maintaining population-level herd immunity. Nor have pro-MMR science-policy networks paid much heed to the parental mobilisation's attempts to resolve this particular dilemma, by claiming that their aim was to determine scientifically which children were vulnerable to the MMR vaccine, so they could be screened out of population-level vaccine programming.

Further, related contrasts in framing are also evident. First, whereas the parental mobilisation claims to investigate a "novel syndrome" in affected children, with a particular set of symptoms, the opposed science-policy networks largely frame their concern as with "autism in general". Second is a contrast between framing in terms of risk, vs uncertainty. Pro-MMR science-policy networks have tended to treat the issue as one of risk. Population studies are designed to determine the risk of developing autism from MMR (and claim this is negligible). Risk has also been the key theme of government communications to the public on the MMR issue, using quantitative comparisons of the relative risks of developing autism from MMR, developing serious complications from measles, and other health risks in an attempt to shore up public confidence that MMR is safe (e.g. Health Promotion England 2001).[8] Whereas the concept of risk presupposes that there are calculable probabilities between known outcomes, those involved in the parental mobilisation tend instead to frame the issue as one of uncertainty or even ignorance, given the many unknowns about the effects of MMR, and to advocate a precautionary principle in holding back on MMR use.

Despite these distinctions, there are also some commonalities in the ways each side has sought to bring "closure" to scientific debate in their favour. Pro-MMR science-policy networks have successively framed reportage of their studies as "settling the issue", claiming to show that MMR is safe in a way that suggests closure to scientific debate. Several practices have been important in this creation of closure and black-boxing of uncertainties (Latour 1987). These include failing, when scientific studies are reported in policy and media contexts, to acknowledge caveats made by the scientists themselves; and omitting from the final reports of advisory reviews the incertitudes and demands for further investigation noted in earlier drafts – something that, it is argued, applies to both the government-commissioned MRC (2001) review and to a review by the Committee on the Safety of Medicines (CSM 1999) (Melanie Philips, *Daily Mail*, March 2003). Further, claims that MMR is safe have relied on recasting absence of evidence as evidence of absence: as Dr Peter Fletcher, a former assessor to the CSM, protested in a letter to a clinical periodical: 'The readers of this journal may ponder the curious turn of events which has now led to the Department of Health, the Medicines Control Agency, the Committee on Safety of Medicines and other eminent bodies citing negative studies as absolute evidence of safety.'

Mobilising parents have equally sought closure in "proving" the link between MMR and their children's disease. Despite the multiple pathways of investigation being pursued by the different scientists supporting them, sometimes following quite different hypotheses, and despite their frequent claims that more research is needed, activist communications in the media and through website reviews have tended to portray the building of an increasingly large and coherent body of evidence which is gradually filling in the pieces of a jigsaw puzzle, telling a coherent and plausible story. Like the governmental movement, the

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[8] For a critique of this approach to risk communication in terms of the assumptions it makes about public perceptions, see Hobson-West (2003).

parental movement can thus be seen to construct a strategic "rhetorical science" which is coherent. That the overall debate has not reached closure reflects, at least in part, the incompatible framings of each side's scientific stories, despite their similar strategies.

4.2 Exposing the political economy of science

Each side in the MMR controversy has sought to critique the science and knowledge of the other by exposing flaws in its content and methods, and in its framing. However mobilisation strategies have also gone further, attempting to expose the political-economic interests underlying the opposition's position, and thus to delegitimise their claims. As both sides engaged in such strategies, so each appeared to construct its own science as "objective", discrediting the other's as conflicted and biased.

Thus evident in MMR-concerned discussions amongst parents, on the internet and in media coverage is much reflection, and critique, concerning the personal, institutional and political-economic biases to statements about the safety of MMR. These portray a perceived alliance between the government and its Department of Health, a range of medical scientists and official advisory bodies, and interested pharmaceutical companies in promoting a message that "MMR is safe", and silencing detractors. This alliance, parents argue, is intended to avert any challenge to childhood vaccination policy, as a revered cornerstone of public health policy, and to protect the political-economic interests claimed to be entwined with vaccine manufacture and sales. As exemplified below, a strong theme in movement communications concerns the various "biases" of individuals and institutions, in many cases revealed in quite detailed exposés of the "real" interests or events behind-the-scenes of public pronouncements of MMR safety. In contrast, parental groups frequently present their own position as non-biased; as simply parents personally pursuing a commitment to their own children's health.

These specific concerns over biases in MMR science echo a strong theme in the broader anti-vaccination literature. Several prominent writers (e.g. Cave and Mitchell 2001; Coulter 1990; Scheibner 1993) adopt an explicit strategy of "exposing" the biases in what they term the "orthodox" medical science which supports large-scale childhood vaccination. They do this both by drawing on other bodies of evidence (e.g. parents' experiences), and by arguing that evidence in published scientific works which apparently support vaccination can and should be reinterpreted, read between-the-lines and against-the-grain, as confirming the ineffectiveness and adverse effects of childhood vaccines. It is such reframing of established scientific evidence that enables Scheibner, for instance, to sub-title her book '100 years of orthodox medical research shows that vaccines represent a medical assault on the immune system'. She suggests that doctors, medical scientists, and policy-makers have been blinkered from seeing this by working within a medical system which is "totalitarian", "highly politicised" and dominated by "big business" interests (1993: 262).

Parental groups' specific accusations include exposés of the personally-biased positions of particular scientists. For example, they claim that Brent Taylor, who produced a frequently-cited study claiming to show no association between MMR and autism, was already in personal confrontation with Wakefield within the Royal Free before the MMR issue became public, and that this biased the orientation of his research. They also turn on the funding sources for the epidemiological research supporting government policy interests. When the government funded the National Institute for Biological Standards and Control to try to replicate Wakefield's research, they claimed that the Institute's director was in the pay of GlaxoSmithKline, one of the firms making MMR vaccine, so the research was biased from the outset (Melanie Philips, *Daily Mail*, 11 March 2003). In November 2003, when Dr Simon Murch, one of Wakefield's co-authors in the original 1998 paper wrote a letter to *The Lancet* disassociating himself from Wakefield and the parental campaign, by proclaiming that 'There is now unequivocal evidence that MMR is not a risk factor for autism', Wakefield counter-attacked by suggesting that Murch's letter had been written in response to intimidation by the hierarchy of the Royal Free.[9] The parental mobilisation's accusations also turn on the "shady practices" of official committees and governmental advisory bodies, both in playing down uncertainties, and in their "stacking" with biased members. For instance, they have publicised claims that a number of expert members on the MRC review panel were advisors to the pharmaceutical companies producing MMR vaccine, and that 19 members of the Joint Committee for Vaccination and Immunisation and the Committee on the Safety of Medicines have declared financial or other interests in these companies.

These suggestions of conspiracy linking pharmaceutical companies and pro-MMR scientists and spokespeople, and the stories about these that circulate, feed back to shape movement identity, by helping to unite parent-activists into a community of trust. Stories of threats and telephone tapping of key movement spokespeople and sympathetic scientists; of pharmaceutical companies' efforts to stop a legal hearing of the issue, and of "huge cover-ups" of evidence in support of their case (e.g. "loss" of samples in hospitals) feed into a construction of a world in which as one member of the Brighton local support group put it: 'you need to trust others to talk; otherwise whatever you say gets back to the drug companies'. In building a mood of hype and solidarity against an "other", such everyday movement practices become integral to movement dynamics in the way Laclau and Mouffe (1985) emphasise.

However, pro-MMR science-policy networks are quick to counter these accusations by pointing to the commercial interests and biases amongst the parents' advisors and publicists. Thus Mike Fitzpatrick, a GP who has become a key media spokesperson for the pro-MMR lobby and who dismisses Wakefield's and related work as "junk science", argues that:

> Anti-MMR campaigners have frequently disparaged doctors and scientists who refute the MMR-autism link for their links with the drug companies that manufacture vaccines . . . Yet there are substantial commercial interests involved in the promotion of junk science to which these same journalists remain oblivious.
>
> (Fitzpatrick 2002)

Among these political-economic interests, he claims, are lavish trips and hospitality offered to journalists by pharmaceutical companies; profits to be made from selling expensive laboratory tests, medicines and

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[9] www.iol.co.za/index.php?click_id=117&art_id=iol1068551426988E216&set_id=1, September 2003.

dietary products to the parents of claimed MMR-damaged children; profits made by private GPs and clinics from selling single vaccines, and legal aid fees collected by lawyers supporting parents to pursue their MMR-damage claims through litigation. In February 2004, the pro-MMR lobby made claims that Wakefield's original scientific work was mired in a "fatal" conflict of interest. An exposé in the *Sunday Times* claimed that at least four of the children in his 1997 study were part of a legal class action against the manufacturers of MMR vaccine, and that Wakefield had received funding from the Legal Aid Board 'to assist their case by finding scientific evidence of the link' (Brian Deer, *Sunday Times*, 22 February 2004). This disclosure was subsequently used by journalists, government spokespeople and top politicians as a basis to discredit Wakefield's work, style of operation and the parental campaign more broadly.

The parental campaign and supportive journalists were quick to respond. As *The Independent* commented, it became evident that a witch-hunt was on; an orchestrated campaign which sought to 'discredit the man, rather than dispute his views' and which exemplified the government's broader use of its "spin machine" to undermine those who held politically-awkward opinions (*The Independent*, 'This orchestrated campaign must not be allowed to stifle real debate on MMR', 24 February 2004). Wakefield denied in the *Sunday Times* and then in a statement which was widely circulated amongst parents' groups and others that there was a conflict of interest, claiming that the legal aid funding did not contribute to his main study, and that he merely reported the findings in good faith. In subsequent press coverage (James Meikle, *The Guardian*, 24 February 2004) he was defended by Jackie Fletcher of JABS, who said that 'Mr Wakefield's original data is not in question at all and the conclusions from it have not changed'. Other commentators (e.g. George Monbiot, *The Guardian*, 24 February 2004) argue that while Wakefield may indeed have been wrong in failing to disclose a conflict of interest, similar undisclosed conflicts of interest in science pass unnoticed everyday, and are dwarfed by comparison with major, orchestrated cover-ups such as those that have occurred over environmental and medical issues that threaten political or corporate issues, both in the US and UK. He thus asks:

> . . . why is it only Dr Wakefield whose bloody remains are being dragged through the streets? The obvious answer is that his alleged co-option works against the interests of the drugs companies, while almost everyone else's works in their favour.

Indeed, Bill Welsh of Action Against Autism, and Rosemary Kessick of Allergy Induced Autism, spoke out against the hypocrisy and duplicity of the government's accusations against Wakefield, using this as an opportunity to re-state longstanding parental claims that many of the experts on so-called independent advisory panels have funding, consultancy or shareholding interests in companies involved with MMR manufacture ('A conflict of interest over MMR? Now look at how 19 government experts are connected', *Daily Mail*, 25 February 2004).

In November 2004, journalist Brian Deer claimed to expose new evidence of Wakefield's biases in a television programme for British television Channel Four's 'Dispatches'. This accused Wakefield of deliberately concocting the MMR scare, despite counter-evidence from his own laboratory, to support his own commercial interests in developing a new measles vaccine, and cures and treatment supplements for autistic children (http://briandeer.com, 2 December 2004). The parental mobilisation responded both by a counter-attack in the media and on internet discussion boards which, among other things, accused Brian Deer of running a personalised vendetta against Wakefield to advance his own journalistic career, and by launching a new website in which Wakefield claimed to give an authoritative, evidenced version of the real events behind Deer's distorted story (www.mmrthequestions.com).

In this to-ing and fro-ing, then, both sides of the controversy have claimed that theirs represents the "objective" view, whereas the other's is biased by economic, political, personal or commercial pressures. Each side has reacted to the other's claims by further claims, in a remarkably similar set of strategies. This echoing of strategy – and the increasing sophistication of strategy use by each side of the controversy – has arguably helped to drive them further apart, contributing further to non-closure of the debate.

4.3 Representing science through the media

As preceding sections have made clear, much of the MMR controversy unfolded publicly through the British print and broadcast media – even while it also rolled on in academic journals. Indeed I have suggested that the mass-media provided not just a vehicle or resource for mobilisation around MMR, but was integral to this mobilisation, as each side enrolled sympathetic journalists into its actor-networks, and as particular forms of coverage fed the debate, requiring reaction. Nevertheless, it is worth considering some of the particular media-related strategies used by the parental mobilisation and its critics, as these were central to how the political process around MMR unfolded.

From the outset parental mobilisation gained a great deal of media coverage, with stories putting forward their claims of damage from MMR – often misreported as a link between MMR and autism-in-general – significantly outnumbering those denying this (Hargreaves *et al.* 2002). The movement benefited from the fact that personalised stories of alleged vaccine damage were appealing, especially to tabloid newspapers and television. So, too, were "David and Goliath" stories which counterposed the struggles of Wakefield and parents against "the establishment" (Science Media Centre 2002), and which portrayed parents as victimised (Fitzpatrick 2004). The tendency for news-framings to represent debates as having two sides with apparently equal evidence also played into the parental mobilisation's interests, appearing to amplify the weight of "scientific" evidence in their favour (Hargreaves *et al.* 2002). Thus a study by the King's Fund (of health reporting by the BBC, the *Daily Mirror*, the *Daily Mail* and the *Guardian*) treats MMR as a case *par excellence* which has lent itself to the dramatic stories that give good news-value, thus acquiring disproportionate and (they claim) amplified coverage of the risks involved, as compared with other risks that might have a statistically greater impact on health (http://news.bbc.co.uk/1/hi/health/3110490.stm, Media 'distorts risks to health'). The parental mobilisation also enrolled key journalists who wrote major investigative features sympathetic to their perspectives. Major examples were a special issue of *Private Eye* by Heather Mills (28 June–11 July 2002), and a major three-part investigation by Melanie Philips in the *Daily Mail*, 11–13 March 2003.

In seeking to counter public anxiety around MMR, the opposed science-policy networks also used media strategies. The Department of Health publicised its claims that MMR is safe through a major leaflet and television advertising campaign, while journalists wrote supportive news articles. Key strategies involved framings in terms of both science, and of risk. Thus epidemiologically-framed science in academic journals was cited to support claims of MMR safety, while Wakefield was dismissed as a charismatic maverick whose work was "bad", or "junk" science, not to be taken seriously. Regarding risk, the government attempted through the media to counter the MMR scare with another scare: the risk of disease (Fitzpatrick 2004). This strategy deployed both stories about measles outbreaks, as presaging a breakdown of social immunity and a return to epidemics, and personalised stories of children damaged by complications from measles, mumps or congenital rubella. These stories in some respects paralleled the parental movement's personal stories of vaccine damage, and could be expected to have similar popular appeal. Public health spokespeople saw emphasis on the risks from measles as especially important to counter what they saw as public complacency about this as a 'mild disease of childhood', in a population which, due to the very success of the vaccination programme, had hardly seen measles and had thus 'forgotten what it was really like'.

It can thus be argued that in their media strategies both sides of the campaign around MMR, in some senses, drew on and promoted the values of the risk society. Each side also invoked "science" in its media strategies. Yet in the translation of complex, diverse strands of scientific inquiry into media soundbites, nuances were often lost. Thus the media staging of scientific debate tended to reduce it to a battle between either the establishment and the lone maverick, or between science-as-epidemiology vs worried parents – between reason and emotion. With a few notable exceptions, such as the *Daily Mail* features, little media coverage dealt in any detail with the clinical science underlying parents' claims.

This media coverage was not constant over time. Rather, particular events – including media events – in the political process of the MMR controversy would spark anew rounds of media "feeding frenzy". One such round of media frenzy erupted in 2001, sparked by controversy over whether or not the Prime Minister's son Leo Blair, who would have been due for his MMR vaccination around this time, had received it or not. Another was provoked in February 2002 by a Panorama television broadcast on Wakefield's research and a simultaneous outbreak of measles in south London. Another took place in late 2003, provoked by broadcast of Channel Five television's docudrama 'Hear the Silence'. Another emerged in early 2004, coinciding with the claimed exposé of funding conflicts in Wakefield's work. During each of these episodes of heightened media attention, each side would take opportunistic advantage to advance their broader claims.

The parental movement is also argued to have adopted a strategy of "leaking" scientific findings to the media, as a central campaigning tactic (Fitzpatrick 2002). Thus studies have been picked up by journalists and used to publicise extravagant claims about links between MMR and autism before they have been published and subjected to peer review. Many examples of this can be identified. One concerned the research by Dublin pathologist John O'Leary which claimed to find MMR-strain measles virus in the gut of autistic children with bowel problems. Long before publication, in June 2002, the

Sunday Telegraph reported this, claiming that 'scientists have found new evidence to support fears that the MMR vaccine is causing children to develop autism and bowel disease'. O'Leary publicly denied this interpretation, insisting that it 'in no way establishes any link between the MMR vaccine and autism'. Nevertheless the work continued to be widely cited by parental organisations and supportive journalists, giving a major publicity boost to their campaign (Fitzpatrick 2002). As in this example, such media strategies have sometimes presented emergent research as "key" to proving a link in ways that extend well beyond the claims and wishes of the scientists involved. Certain scientists, at least, resented this, exposing contextual schisms in the MMR-concerned mobilisation between certain scientific experts on the one hand, and certain journalists and parents on the other.

These stories aside, it is also the case that parents gained relatively little media coverage of the scientific dimensions of their mobilisation. For instance, a survey over a 7-month period of 2002 (Hargreaves *et al.* 2002) found that less than a quarter of stories about MMR mentioned scientific studies which supported parents' concerns, and these mentions were usually confined to Wakefield's original 1997 work. Instead, a common media strategy was to pit "parents" against "science", or emotion against reason, with that science being the largely epidemiological work being used by government networks to claim that MMR is safe. At one level this served effectively to publicise the campaign, by constructing and playing on appealing dichotomies between human experience and real life stories, vs dry statistics. However, at another level it worked against parental concerns, by downplaying the accumulating scientific work supporting their experiences. It enabled critical media to construct Wakefield as a lone maverick, and the opposed policy network to claim, publicly, the moral high ground of "science".

In certain episodes of media coverage, the themes of consumer choice vs public policy, and of the respective rights and responsibilities of citizens and the state, came to the fore – often submerging explicit consideration of scientific dimensions of the controversy still further. This is the case, for instance, for media episodes which have focused on the question of single vaccines. The Department of Health has used the media to publicise and affirm its refusal to make single vaccines available. It justifies this position through the claim that the triple vaccine is safe; that no scientific evidence differentiates the effects of single measles vaccine from measles in MMR; that single vaccines would leave children vulnerable to infection in the gaps between vaccines or where parents did not complete the course; that damage to population immunity would result, and that that there are significant supply problems with single vaccines. The parental movement has used the media to counter that the government was withholding single vaccines to "coerce" parents into having MMR, reinterpreting supply problems as a conspiratorial ban on imports of single vaccines ('Is there a third way?', *The Independent*, 1 August 2003). It also casts the government stance as going against the "patient choice" agenda that the NHS advocates in other arenas, and representing inappropriate interference by a "nanny state". As Bill Welsh of ActionAgainst Autism argued:

> ‘The present policy of “MMR or nothing” is unsupportable and epitomises the arrogant attitude of “doctor knows best”. Choice is the keynote of the government’s NHS policy, so why can’t we have choice with MMR?’ he asked.
>
> (Murray Ritchie, ‘Bill would allow right to free single jabs for MMR’, 17 December 2003, www.theherald.co.uk/politics/6483-print.shtml)

Parental organisations used the media opportunistically to make similar arguments amidst the media episodes that focused on a particular parental dispute. When in July 2003 two mothers lost their appeals in court against their children’s fathers, now separated, who wanted their children to have MMR, JABS used this as a further example of an overbearing state policy, with a JABS spokesperson arguing a propos of the ruling that ‘Vaccinations are not compulsory and should never be’, and that ‘This is not a nanny state but the big brother bully state’. Liberal Democrat health spokesman Dr Evan Harris MP countered that this case was really a dispute about who should decide the interests of a child when parents are separated, that this should be the state’s responsibility, and that – given government policy – the child’s best interests as well as public health interest dictated MMR (http://news.bbc.co.uk/1/low/health/3106465.stm).

In media debate in 2001, the question of individual choice vs public health policy became politicised along party lines. Conservative party spokespeople advocated individual choice and single vaccines, and critiqued Labour’s insistence on the social good of the MMR regime. This political debate itself was spawned by the high levels of media publicity that had just erupted over whether or not the Prime Minister’s son had received MMR vaccination. The Prime Minister’s refusal to disclose the family’s decision, on the claimed grounds of privacy, was seized by both parental campaigners and by the political opposition as likely evidence that he had not been given the vaccination, and this in turn was taken to undermine the credibility of the government’s claims about MMR safety. At least temporarily, the MMR-concerned mobilisation enrolled right-wing politicians. Nevertheless by late 2003, journalists in both tabloid and broadsheet newspapers across the political spectrum were suggesting that offering single vaccines had become a necessary response to the controversy amongst experts that was now baffling parents. The *Express*, for instance, concluded that the government could no longer expect parents to be reassured by its advice that MMR is the best option, while *The Independent* claimed that Ministers would need “marketing genius” to restore public trust, and that anything – even the apparently irrational choice of separate jabs – should be allowed if it improved confidence in any part of the vaccination programme. (http://news.bbc.co.uk/1/hi/uk/3232805.stm).

Intriguingly, MMR-concerned mobilisation has been able to gain support and media coverage from various parts of the political spectrum, by emphasising variants on its messages. Thus the *Daily Mail*, a tabloid newspaper with a predominantly lower middle-class and female readership and right-wing reputation, has been highly prominent in supporting parents’ perspectives, as has the right-wing *Sunday Telegraph*. This, to some extent, reflects a casting of the MMR issue as a question of the individual against the establishment; of parental choice vs a “nanny state”. This pro-individual framing of the movement sits in some contradiction with its alternative framing in terms of demands for public inclusion, social justice and participatory debate about technological risks and consequences; themes which have emerged more strongly in conventionally left or centre-leaning broadsheet newspapers such as the *Guardian* and *The Independent*.

Pro-MMR science-policy networks have similarly mobilised support from diverse corners of the media-politics nexus. Left-leaning media have, not surprisingly, been supportive in putting across messages in support of government vaccination policy as a public health measure, pursuing wider social benefits at the population level. Yet several of those who have adopted a strongly pro-MMR line in the media, dismissing public anxieties, have been identified as part of a network, said to centre on sociologist Frank Furedi that has, bizarrely, swung 'from the most distant fringes of the left to the extremities of the pro-corporate libertarian right' (George Monbiot, 'Invasion of the entryists', *The Guardian*, 9 December 2003; see also 'Reds under the bed', www.gmwatch.org/profile1.asp?PrId=141). This broader network operates primarily through the magazines *Living Marxism* and *Spiked*, and through acquiring influential positions in the formal infrastructure of public communication used by the scientific and medical establishment, including the Association for Sense About Science, and the Royal Institution-linked Science Media Centre. It has promoted a strongly individualist, pro-technology agenda which has extended to rubbishing consumer and environmental campaigns, and dismissing public anxiety, critique and demands for dialogue, for instance over GM foods; a pattern being repeated in rubbishing of public anxiety over MMR (e.g. Fitzpatrick 2004; Science Media Centre 2002).

4.4 Pursuing claims through the legal process

The framing and strategies of mobilisation around MMR have also engaged with the legal process. Indeed the shadow of litigation over MMR has been part of the controversy since the earliest days of parental concern, well pre-dating Wakefield's *Lancet* paper. It has shaped the movement's identity, framing agendas, and strategies in the use of science and media.

In the early 1990s, Norfolk solicitor Richard Barr began to hear about, and then to collect, cases where parents believed their children had been damaged by MMR. By 1996, he was sufficiently concerned by the cases he was seeing to write to the Committee on the Safety of Medicines, expressing anxiety about the safety of the vaccine, and about the inadequacy of the "Yellow Card" system for doctors to report adverse reactions to vaccines. He began to work concertedly with other solicitors to prepare a class action against the three pharmaceutical companies manufacturing MMR vaccine: GlaxoSmithKline, Aventis Pasteur and Merck and Co. Involved solicitors were thus enrolled in the actor-networks of MMR mobilisation. By the early 2000s, several thousand families had signed up to be part of this, although the case itself would centre on eight test cases, including several children who had been part of Wakefield's 1997 study. The case was scheduled for October 2003, and then delayed until April 2004.

As indicated in my interviews with several of those involved, parents framed their participation in this impending litigation in several ways; framings which in turn became part of broader movement framings, as publicised on websites such as JABS. First, they saw litigation in material terms: as a possible way to gain financial compensation and vital treatment for their MMR-damaged children. Second, and –

several parents say, more important – they saw it as a way to achieve broader political and cognitive justice (Leach *et al.* 2005): to prove the legitimacy of their claims. Third, they saw the court case as a vital opportunity for open, public debate, in which each side could present its evidence, and have it listened to and arbitrated in an open, neutral manner. This dimension became increasingly important as the controversy unfolded and, as parents saw it, the government's defensive counter-campaign denied opportunities for open dialogue in any other domain.

Being part of a legal class action helped, in turn, to shape movement identity. For involved parents, it consolidated and focused their concerns, and gave them a formal context. It also seemed to sharpen their sense of community engaged in struggle; it would often be with reference to the legal aspects of their campaigning that parents in the Brighton support group would talk, for instance, of 'fighting for our children's lives'. Sympathetic media coverage played into this, for instance in portraying the impending litigation as a potentially 'epic confrontation . . . the stakes are enormous. If the parents win, the damage to public confidence in vaccine policy will be incalculable. If they lose, the medical establishment will use the case as final proof that MMR is safe' (Melanie Philips, *Daily Mail*, 11 March 2003).

Being part of the class action also seemed to enhance parents' sense of movement "power within" (Lukes 1974), with consequences for their experiences with health professionals and government spokespeople, both individually and collectively. Thus one mother described how she felt her involvement with the legal case altered the tenor of her interactions with local professionals. When she presented a solicitor's letter about her son at a case conference involving local health professionals and social services, she describes how 'the atmosphere changed' from accusation of invented symptoms, to social services 'backing off', and becoming nervous, shifting the power relations between them. However, while such professional perceptions of movement identity linked to litigation could be felt by parents as empowering in some contexts, in others they worked in negative ways. Thus several parents relate how once "MMR litigation" appeared on their children's medical notes, doctors refused to treat them out of fear of becoming embroiled in legal conflict. This created for such parents a conflict between pursuing movement agendas, and pursuing the day-to-day health of their extremely sick children. Nonetheless, parents also feel a strong commitment to the movement's broader concerns with children more generally. As one JABS spokesperson put it in an email: 'It is too late for our children, but it must not be too late for others'.

Interactions with the legal process shaped the scientific dimensions of MMR mobilisation in several ways. First, it provided funds for scientific research – especially significant given that the scientific experts involved were finding it so difficult to secure other funds for their controversial work. The solicitors and parents involved were awarded £15 million from the Legal Aid Board (now Legal Services Commission) to prepare their case, and a significant proportion of this funding was subsequently used for research by Wakefield and other scientists in the US. Second, the requirements of the legal process meant that new scientific evidence had to be kept under wraps as sub judice until the case came to court in April 2004. This fundamentally shaped parental strategies in the use of science and the media, constraining their ability to use emerging scientific evidence publicly in support of their claims or to "leak" findings directly. Instead, they worked strategically with the power of suggestion: thus in media publicity in 2003 the parental campaign hinted tantalisingly at "damning new evidence" building up from scientists in the US, yet also that they could not disclose details, nor could it be published.[10] This frustrated the campaign's critics, which saw this as yet another example of its underhand strategy of publicising their science to the media in soundbite form without letting it be subject to proper peer review.

Then in October 2003, the Legal Services Commission withdrew legal aid. The Commission claim that it is their constitutional obligation to halt a case that is deemed unlikely to succeed. In this case, QCs suggested likely failure because 'medical research has yet to prove a conclusive link'. In interpreting this withdrawal, which they perceived as devastating to their position in the litigation and therefore to overall movement objectives, the parental movement drew on its established strategies of pointing to conspiracy. JABS, for example, placed a journalistic account from Private Eye on the front of its website to inform parents of the "real story" (www.Jabs.org.uk, 12 Jan 2004) around the legal aid withdrawal, suggesting a conspiratorial alliance between the government and drugs companies for the case not to go ahead. This also claimed that the companies' lawyers had on several occasions intervened to stop tests on the children which the parents needed in preparing their case, either by creating practical obstacles or by declaring them unethical. Thus parents were forced to 'wade through litigation treacle' in which every conceivable obstacle had been placed in their way. Some months later, parental organisation websites carried accounts and copies of threatening letters sent to litigating parents by the drugs companies, urging them to drop their case. When an appeal against this decision failed, the class action was abandoned, at least temporarily, although test-case parents continued to search for new routes of appeal, asserting their plans to take the matter to the High Court and ultimately the European Court of Human Rights.

In the aftermath of the Legal Services Commission decision, the new scientific evidence from the US, Ireland and elsewhere did begin to come to fuller public attention – for instance in the debate following Channel Five's December 2003 docudrama, 'Hear the Silence' – and indeed began to be published. When in early 2004 amidst the media accusations that legal aid funding had caused fatal conflicts in Wakefield's work, the medical establishment and politicians called for a full General Medical Council inquiry around Wakefield's work, Wakefield and parental organisations claimed to feel unthreatened by this; indeed that they would welcome it (Daily Mail, 24 February 2004). With the loss of opportunity for open dialogue through the courts, it seems, they saw such an inquiry as the only opportunity to expose and debate their arguments and emerging supportive science openly.

5 Towards conclusions

The question of debate and dialogue, whether it should take place and what it should be about has been a further recurring theme in the MMR controversy. Mobilising parents frequently claim that they are seeking "open discussion", and "to be listened to". And their discussions, whether in local groups, on national organisations' websites, or in the media, turn frequently on what they see as defensive denial of this by those opposed to their cause. For instance they argue that on the few occasions that "official" government

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[10] www.iol.co.za/index.php?click_id=117&art_id=iol1068551426988E216&set_id=1, September 2004.

bodies have invited their representatives to meetings, they have been ignored or delegitimised – for example in the 1997 MRC review (Melanie Philips, *Daily Mail*, March 2003). They claim that their requests for meetings with senior public health officials and politicians have been shunned, and that the Department of Health has refused to entertain proposals for an independent, off-the-record dialogue and sharing of scientific evidence. They also draw attention to the refusal of pro-MMR government spokespeople and scientists to participate in events that MMR-concerned networks coordinate – such as the televised debate following the Channel 5 docudrama. At the same time, they claim that government spokespeople seek their views covertly, for instance by telephoning JABS pretending to be parents, in order to have inside information with which to undermine them. Those in pro-MMR science-policy networks tend to justify their positions on the grounds that there is nothing to debate; that activists' claims are spurious and that they have already reached scientific closure on the safety of MMR – the task is just to communicate this to the public. In this context, there have, as a senior Department of Health official put it, been "encounters" between each side in the controversy, but little real dialogue. Frequently taking place through the media and at public events, such encounters have tended to contribute to further polarisation of positions, sharpening further the stand-off and non-closure that has come to characterise the controversy.

The MMR controversy thus rolls on. What began as a parental movement pushing for citizen perspectives and supportive science to be heard and acted upon, has evolved over the last decade into a struggle between two, equally orchestrated campaigns. To understand its dynamics, social movement theories have been helpful. Theories of framing have been important to see how each side constructed and presented its concerns and created discourse coalitions by drawing together elements of previously more separate movements (around autism and around anti-vaccinationism, for instance), and to identify some of the fundamental incompatibilities that have hindered closure to the controversy – such as between parents' individual-focused, and government's population-focused, orientations. Theories of social movement identity have been important to see how parents came and remained together, united by common sets of experiences reinforced through everyday movement practices. And political process approaches to social movements, which highlight how framing interacts with movement strategies and the mobilisation of resources (McAdam *et al.* 2001), have been important to see how, in practice, the campaigns have taken shape and pursued their goals. This has been through particular activities and practices involving science, mass-media, and the law, in which the agency of particular people and organisations has come to the fore. This focus on strategy has also brought out the strong similarities between each side of the controversy, as parental mobilisation, but also the counter-mobilisation of opposed science-policy networks, has engaged in remarkably similar practices in the deployment of science, in exposing the political economy of the other's science, and in working through the media. At the same time, integrating perspectives from social studies of science, which emphasise the multiplicity of scientific perspectives and their social constructedness, has shown the importance of science to the framing and practices of both the parental and counter-mobilisation. Rather than "parents versus science", the way the MMR debate has been represented in much media, popular and indeed some social scientific debate (e.g. Collins 2004), I have argued – in short – that this is a controversy between differently-framed sciences (clinical/personal vs epidemiological/population) grounded in different ways-of-being and social commitments (the world of parents, vs the world of public health). To understand the shape that the controversy has taken, and why it has not reached closure, it is necessary to appreciate both these broad differences of (scientific) framing, and the similarity of strategy used by each side which has had the effect of driving them further apart.

While parental networks continue to fight for further investigation of possible links between MMR and the syndrome they have identified, and for the choice of single vaccines until uncertainties are resolved, an increasingly orchestrated campaign linking other medical scientists, policy-makers, politicians and journalists seeks to stifle such concerns. Some commentators suggest that the British government's "peculiar difficulty" in handling the MMR issue reflects the way it strikes into the heart of contemporary governance dilemmas and contradictions (Fitzpatrick 2004). It pits the rights of the individual to choice, against the rights of the citizen to public health; both principles which the government has attempted to espouse, but in different policy areas. Having supported choice in many domains, it is difficult to deny it over MMR, yet this threatens the public good emphasis of vaccine policy. The MMR issue also pits the values of the risk society, and the enhanced public awareness and individual responsibility around health, lifestyle and environmental risks in general which the government has supported, against the principles of state responsibility and surveillance enshrined in public health policy. These are emergent framings which have come to be important in the controversy, and to politicise the science of MMR still further, helping to explain the impasse.

The core debate about a possible MMR-linked syndrome, and the appropriateness of differently-framed "sciences" to resolve it, has remained little changed. But as this paper has documented, the ensuing campaigns and counter-campaigns, and their media representation, have sometimes shifted into rather different framings. At times, the struggle has appeared to be about individuals against a "bully state" vs the demands of public health. At times, it has appeared to be about funding ethics, with each side discrediting the other through the claimed commercial conflicts in their positions. At times, it has appeared as a personalised struggle, with each side forwarding charismatic spokespeople and using media and PR "spin" effectively, while critiquing the other for doing so. At times, the debate has shifted gear into the broader politics of the risk society. While these are all important dimensions of the politics of science in contemporary Britain, it is also the case that one after another they have co-opted public and political debate in ways that have deflected it from serious discussion of the core scientific questions at the heart of the controversy.

Commenting on social movements generally, Jamison (2001: 13628) suggests that 'Out of the alternative public spaces that have been created by social and political movements has emerged a new kind of scientific pluralism, in terms of organization, worldview assumptions, and technical application.' In the case of MMR, it can be argued that such scientific pluralism has emerged, and that it now carries high profile in public discourse – in the media, on the internet, and in the ways that many people think and talk about MMR. In this respect, citizen mobilisation, bringing the experiential worlds of parents who believe their children damaged by MMR together with scientific evidence that they see as supportive, has succeeded in changing the ways that (certain aspects of) public discourse are structured. Viewed in some terms, this would in itself be regarded as success: in Eyerman and Jamison's (1991) terms, creative processes have defined new spaces in conceptual thought, while as Melucci (1996) suggests, in contemporary "information society" new social movements should be judged primarily in terms of their capacity to effect changes in language, concepts, information flows and discourses.

However, MMR-concerned parents would see such opening up of public discourse as profoundly inadequate because while they may have succeeded in influencing parts of a broader public as "movement subjects", they have failed effectively to influence the science-policy networks that have been their prime target. Their practical and material claims for their own children and the children of others, present and future – proper treatment for their children, publicly-funded research into their conditions and hence the vulnerabilities of others; material compensation for vaccine damage; new approaches to vaccine adverse event reportage, and free availability of single vaccinations – have thus not, to date, been met. This is in large part because the shifts in popular discourse which have occurred have not been matched by shifts in the discourse or practice of policy institutions which would have the power to effect such changes. Indeed rather than recognise scientific pluralism, pro-MMR science-policy networks persistently seek to create closure through delegitimising the science of the parental movement. Until such pluralism and its politics are openly recognised and debated, it is hard to see how the current stand-off will be broken.

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