

‘Trusting blindly can be the biggest risk of all’: organised resistance to childhood vaccination in the UK

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Abstract Sociological interest in vaccination has recently increased, largely in response to media coverage of concerns over the safety of the MMR (measles, mumps and rubella) vaccine. The resulting body of research highlights the importance of risk and trust in understanding parental and professional engagement with vaccination. To date, only limited attention has been paid to organised parental groups that campaign against aspects of vaccination policy. This paper reports findings from a qualitative study of contemporary groups in the UK, and develops three main lines of argument. First, these actors are best analysed as ‘Vaccine Critical groups’ and include Radical and Reformist types. Second, Vaccine Critical groups discursively resist vaccination through a reframing that constructs risk as unknown and non-random. Third, trust as faith is negatively contrasted with the empowerment that is promised to result from taking personal responsibility for health and decision-making. Whilst representing a challenge to aspects of vaccination policy, this study confirms that the groups are involved in the articulation and promotion of other dominant discourses. These findings have implications for wider sociological debates about risk and trust in relation to health.

Keywords: vaccination, risk, trust, resistance, MMR

Introduction

Vaccination has a long history in the UK dating back to the experiments of Edward Jenner in 1786 (Wolfe and Sharp 2002). The aim of vaccination is disease prevention and, in some cases, like smallpox, eventual eradication. For supporters, vaccination represents ‘one of the greatest public health success stories’ (Poland and Jacobson 2001). Vaccination is closely linked to the germ theory which, according to Tesh, is now ‘virtually synonymous with science’ (Tesh cited in Dew 1999: 383). Mass vaccination, such as the childhood vaccination programme, is also founded on the theory of herd immunity. This creates a rationale for high uptake levels in order to reduce disease circulation in a given population. The desire to maintain herd immunity helps explain why the government and the public health community have expressed significant concern over recent falls in the uptake of the MMR vaccine in the UK and have bemoaned the ‘public loss of confidence in vaccine safety’ (Salisbury *et al.* 2002).

The controversy over MMR is usually blamed on media debate following a 1998 *Lancet* article by Dr Andrew Wakefield and colleagues. The paper raised the possibility of a link between the combined MMR vaccine, a form of bowel disease and a type of autism

(Wakefield *et al.* 1998). At a subsequent press conference, Wakefield suggested that it might be better to give the vaccines singly, until further research had been completed. It is this suggestion that is claimed to have resulted in a sharp decline in MMR uptake. The role of Wakefield, and the media coverage of this controversy, is not the focus of this paper (see Fitzpatrick 2004, Horton 2004). For present purposes, the episode is important in so far as it has encouraged a welcome increase in social scientific interest in the topic of childhood vaccination. The aim of the article is to contribute to this emerging sociological literature by providing an analysis of the discourses of one set of actors that remain under-researched: organised vaccination resisters or what I term, 'Vaccine Critical groups'. These groups are set up by parents to campaign against vaccines or to challenge aspects of vaccination policy.

The following section reviews the recent sociological literature concerned with vaccination attitudes and decision-making, and summarises what has been concluded in relation to risk and trust. The small amount of published reference to organised parental groups is then discussed. Next, the rationale behind the empirical project is explained and the methodological design justified. After introducing the Vaccine Critical groups and explaining the difference between Radical and Reformist approaches, the remainder of the paper concentrates on how the groups construct risk and trust and how this construction challenges the dominant vaccination discourse.

Vaccination debates and decision-making: the role of risk and trust

Recent social-scientific literature on this topic is largely based on qualitative analysis of interview data with parents and health professionals (Poltorak *et al.* 2005, Brownlie and Howson 2005, 2006). These particular papers are also useful in their critical summary of previous literature. In relation to the role of risk, three main points are of central importance. First, following an ethnographic study of MMR narratives in Brighton, UK, Poltorak and colleagues argue that 'parental engagement with MMR is part of a wider social world' (Poltorak *et al.* 2005: 711). What is meant by this is that vaccination decision-making (and engagement with vaccination more broadly) is influenced by factors including the child-birth experience, conversations with friends and family, and previous experience with health services. This immediately alludes to the importance of trust and hence the close relationship between risk and trust. The broader implication is that social context is crucial and that this will be missed, or simplified, through a narrow focus on individual risk perception. This argument is located within an 'interpretivist' (Gabe 2004) or 'constructivist' (Wynne 1995) tradition in risk research.

Second, Poltorak and colleagues found that mothers stress the particularity of their child. Vulnerability to disease or to vaccine adverse reactions is seen as influenced by individual characteristics, including diet and hereditary factors (Poltorak *et al.* 2005: 716). In other words, risk is individualised or personalised. This is in contrast to the standard way that risk is presented in some vaccine promotion literature, which presents tables of risk based on large-scale epidemiological data (Hobson-West 2003). At first sight, this contrast could be seen as evidence for a fundamental difference between lay and expert understandings of risk, the former concerned with risk at an individual level, the latter more concerned with the population level (Bennett 1999: 14). This point will be returned to later. In the case of the Brighton study, the intended aim is explicitly not to lament a public misunderstanding of risk. However, in the context of mass vaccination and the demands of herd immunity, some commentators have pointed to parental expressions of concern about their own child as evidence of individualism and selfishness (Hodge and Gostin 2003, Ashton 2004).

The third point of interest in the sociological literature relates to the anxiety caused by concern over MMR and the role of fear and dread, and parental worries about making 'the right decision'. This results in a situation where 'MMR talk' has become a social phenomenon in itself (Poltorak *et al.* 2005) and parents express 'shame' about their own knowledge gaps (Brownlie and Howson 2005: 227). From a broader theoretical perspective, MMR could be seen as just one of many anxieties that characterise life in a contemporary risk society, where risks are potentially catastrophic and unmanageable (Beck 1992, Wilkinson 2001). This has supposedly resulted in a crisis of trust in professional expertise. So what do the studies on vaccination tell us about trust?

Mirroring the first argument about risk, the recent literature suggests that expressions of trust or suspicion in relation to vaccination are partly influenced by previous medical experiences. Poltorak *et al.* (2005), however, stress that this should not be simplified: choosing to vaccinate does not necessarily imply trust (and vice versa). Rather, the decision to vaccinate is sometimes less a result of 'trust' in messages from the Department of Health and more a lack of confidence in the knowledge needed to justify non-vaccination (Poltorak *et al.* 2005: 716). This suggests that trust is partly about knowledge and uncertainty.

Brownlie and Howson defend the utility of the idea of a 'leap of faith' as one key dimension of the practice of trust. Following Simmel they argue that trust is not just about knowledge but involves a kind of suspension (2005: 224), where uncertainties are bracketed off. This takes place 'through social networks and, in particular, through relations of familiarity' (2005: 228). For example their study found that several parents reported asking health professionals to recount their own decisions *as parents*. The authors also argue that parents describe a more general feeling of mistrust towards the government, but that this is partly about an even broader concern with the speed of technological change. Trust is therefore 'a complex relational practice that operates at a number of levels including the individual, interpersonal, institutional and socio-political' (Brownlie and Howson 2005: 235).

Finally, trust is also relevant for an understanding of the role of health professionals. In general, health professionals are expected to act as 'champions of vaccines' (Poland and Jacobson 2001: 2441). There is, however, evidence of professional concern about vaccination, at least about MMR (NHS Health Scotland 1999, Whyte 2002). In a different context, Jackson *et al.* (2004) unexpectedly found that trust was important for how Canadian physicians evaluated and utilised guidelines on evidence-based medicine. Relational issues, as well as 'hard science' or risk statistics therefore impact on expert (as well as lay) behaviour. The authors of the recent studies on vaccination also take care to distinguish between the different roles occupied by health visitors as opposed to family doctors who are more 'in the background' (Brownlie and Howson 2006: 436). In particular, some health visitors have expressed worries about the potential for vaccine uptake target setting to damage carefully built trust relationships with parents (Poltorak *et al.* 2005: 717, Brownlie and Howson 2005: 231). Furthermore, Brownlie and Howson (2006: 438) have suggested that this type of 'audit' may change the nature of the relationship *between* health professionals. This is part of a broader question about the interplay between target setting in healthcare, models of governance, and trust (Flynn 2002).

In summary, recent sociological literature highlights the importance of ideas of risk and trust (and the interplay between these) for an understanding of vaccination debates and decision-making. Some of these debates will be considered later in the article. The next section shifts focus to examine the existing literature and commentary in relation to 'vaccination resistance'. Following Streefland (2001), the notion of vaccination resistance is used in a specific way to mean organised, collective opposition, as opposed to individual refusal.

Organised resistance to vaccination: historical and contemporary

In 19th-century England smallpox vaccination was enforced through state sanction and the threat of fine or imprisonment. There is a small but fascinating social history literature which looks at the birth of resistance during this period in the form of groups like the Leicester Anti-Vaccination League and critical publications like the *Vaccination Inquirer*. Several of the accounts demonstrate the successes of organised campaigns which inspired marches of up to 100,000 people, riots, public burning of effigies of Edward Jenner, and the celebration of martyrs (Beck 1960, Porter and Porter 1988, Durbach 2000). Wolfe and Sharp (2002) also credit the anti-vaccination movement with changes in the law in 1898 to allow 'conscientious objection', the first time the concept had been used in English law and a precursor to its use in relation to military service (Durbach 2002). Other accounts of this period stress the impressive ability of the anti-vaccinators to harness the power of the press (Howard 2003) and the important role of key individuals in pushing forward the movement (Porter and Porter 1988).

Nineteenth century resistance and falls in uptake have been explained as a reaction against the compulsory nature of smallpox vaccination. Durbach, however, argues that middle class resistance may indeed have been about libertarian principles but that the working class felt they were 'pathologised as filthy and contagious' (Durbach 2000: 49). This was partly to do with the close relationship between vaccination and administration of the Poor Law, seen as a symbol of class oppression (Baker 2003). On this reading of history, vaccine resistance was also about resisting negative class identities and the regulation of the working class body. (For a more detailed review see Hobson-West 2005).

There is a conspicuous lack of published accounts of resistance in the early to mid-20th century. By 1995, however, campaign groups had once again been identified as a potential threat to the hegemony of mass childhood vaccination (Rogers and Pilgrim 1995). Commentaries in medical journals do not go much beyond their portrayal as dangerous, and express concern about the availability of critical websites. For example, Nasir (2000) cites Till's vision of the internet as a 'pandora's box' of misinformation. There is also criticism of the media for engaging with parent groups 'without regard to scientific knowledge, facts or credentials' (Poland and Jacobson 2001: 2442). Such commentary would be of interest for those interested in wider debates about the role of the internet (Nettleton 2004, Ziebland 2004) and the media in healthcare decision-making (Hargreaves *et al.* 2003, Harrabin *et al.* 2003, Kitzing 1999). However, more detailed analysis of contemporary groups is sparse.

One exception that stands out is Johnston's (2004) political history of the National Vaccine Information Centre (NVIC), the largest parental campaign group in the US. According to Johnston's sympathetic description, vaccine activism is 'not about ideology but about thoughtful parenting' (Johnston 2004: 275). Although not primarily focused on new empirical research, a recent review by Blume is also useful in considering the extent to which it makes sense to talk of an anti-vaccination 'social movement'. He concludes that the utility of this categorisation is debatable, and, furthermore, that in practical terms it may result in the attention of the public health profession being diverted away from the serious concerns felt by a wider population of parents. Blume does however highlight the need for further empirical research on these organisations and their 'discursive practices' (Blume 2006: 638).

What follows is based on research motivated by the desire to investigate the discourses of organised vaccination resistance. To clarify, the empirical research was not designed as a short-cut to accessing parental attitudes or the views of 'the public'. Furthermore, the study does not predict or measure how the groups' claims are received or interpreted by a wider

population of parents. Instead, Vaccine Critical groups are treated as interesting in their own right and potentially represent 'symbolic challenges' to dominant cultural codes (Eyerma and Jamison 1991: 48)¹. As will now be explained, the empirical research mainly involved in-depth interviews with the leaders of parental groups in the UK. By definition, this means that the study focuses on those who are critical, highly interested in and personally committed to the topic of vaccination.

Research approach

The first stage of the research involved trying to identify all organised groups in the UK who express critical views towards vaccination or aspects of vaccination policy. Given the lack of existing published research, this was far from straightforward. Multiple sources were used including news reports (where representatives of groups are quoted), websites, CD-Roms, online databases and local library reference guides. These library sources were deliberately included as a way of countering the potential bias towards web-based groups. Nineteen groups were eventually identified and all were contacted by letter. Fifteen interviews were arranged (only one group specifically declined to take part, the other three could not participate within the project timescale). Preliminary analysis demonstrated that some of the groups, although critical of vaccination, did not make vaccination their central concern. For example, the Society of Homeopaths and the Christian Science Church are both associated with alternative approaches to health that challenge the rationale behind vaccination, but nevertheless do not make vaccination their primary target. Once vaccination resistance was more narrowly defined, this left 10 groups on which full analysis was carried out. In order to provide context, eight interviews were also organised with national policy-makers although these data are not discussed here.

Interviews were carried out in 2003 with the leaders or founders of the 10 groups. Two were conducted over the telephone and the remainder in the home of each group leader. With the consent of the participants, all interviews were tape-recorded. Interviews began with the use of a protocol which involved explaining that the recording device could be turned off at any point: this was only requested in a few instances, usually when the names of individuals were mentioned. The average interview length was one hour and 25 minutes. Anonymity was not requested by informants nor offered by the researcher. Those who consented to interview took part as representatives of their organisation.

The interview schedule was carefully devised to allow the interviewee maximum space to pursue several issues. This represents a form of guided interviewing (Murphy and Dingwall 2003: 77). The design of the interview schedule was influenced by the PABE study, a European report on attitudes to Genetically Modified (GM) food (Marris *et al.* 2001). This report is attractive in not assuming '*a priori* what kind of knowledge or information is relevant for the shaping of public perceptions' (Marris *et al.* 2001: 29). Such arguments encouraged a design that specifically did not ask questions about vaccine risk-benefit calculations nor about MMR or trust, but left open the space for themes to be introduced by the interviewees themselves.

As well as interview transcripts, analysis was also carried out on written materials from the groups, including leaflets, magazines, and web-pages². These materials were gathered before, during and after the interview. Instead of using a computer package such as NVivo, a more manual approach was adopted. All materials were read several times and emerging sets of themes were compared. A personal system of signs and symbols was used to indicate potential relationships between empirical examples. All original transcripts and documents

Table 1 *Key features of the Vaccine Critical groups*

<i>Name of group</i>	<i>Date</i>	<i>Location</i>	<i>Website</i>	<i>Approach</i>
Ass. of Parents of Vaccine Damaged Children	1974	Warwickshire	No	Reformist
Justice for all Vaccine Damaged Children	1981	Bristol	No	Reformist
AiA (Allergy induced Autism)	1987	Peterborough	Yes	Reformist
Vaccination Information	1988	Hull	Yes	Radical
Informed Parent	1992	Worthing	Yes	Radical
JABS (Justice Awareness and Basic Support)	1994	Warrington	Yes	Reformist
Vaccination.co.uk	1995	London	Yes	Radical
Vaccine Victims Support Group	1997	Birmingham	No	Reformist
AAA (Action Against Autism)	2000	Glasgow	Yes	Reformist
VAN (Vaccine Awareness Network) (now VIS)	2002	Derby	Yes	Radical

were then reviewed again to check whether the themes and sub-themes sufficiently captured the arguments made by the groups. The themes were then expanded, added to, collapsed or refined. Overall, what is essentially being described is a process of data interrogation and the construction and validation of analytical categories.

All types of data were analysed using a form of discourse analysis (DA). Vigorous debates continue in the methodological literature about the merits of different models of DA, and between those who see DA as a specific method and those who believe it should be understood as part of a wider paradigm. For example, Potter (1996) stresses that DA should not be used for accessing accounts and, according to Hammersley, rejects 'the representational model of language, whereby statements are held to correspond to phenomena that exist independently of them' (Hammersley 2003: 756). In contrast, Michael and Birke claim to use DA to interpret 'shared assumptions and representations' but 'employ a representational approach focusing explicitly on the content of discourse rather than on its interactive deployment' (Michael and Birke 1994: 192–3). Whilst space constraints restrict a full review of this literature, the method in this study bears similarity with this latter approach. Discourses are understood as sets of themes or representations that often rely on stock examples and metaphors. As a final step before these discourses are discussed, the Vaccine Critical groups are introduced.

Vaccine Critical groups: Radicals and Reformists

The analysis suggests that the Vaccine Critical groups differ in important respects. Table 1 lists them chronologically and highlights some of their key features.

The table shows that the groups were set up at different times, some originating as far back as the 1970s when there was particular concern over the pertussis (whooping cough) vaccine (André 2003). Geographically, the groups are quite dispersed, although location is arguably less important, given that the majority of the groups have websites. This also holds true for their size: the groups are all relatively small, and led by one or two parents, but potentially reach a large audience through their campaigning activities. Three of the

groups are registered charities, the others explaining that they prefer to avoid the bureaucracy that this entails. Most of the groups accept members or subscribers, and numbers range from 60 to around 2,000.

In terms of attitudes to vaccination, the groups demonstrate two broad orientations. The *Reformist* groups are led by parents who have personal experience with children believed to have been seriously injured following a recommended vaccine. Not surprisingly, these groups have a keen interest in issues around compensation and treatment, and campaign for better recognition of the dangers of vaccination. They are more likely to be supportive of vaccination in general: This is one reason why the phrase 'Vaccine Critical groups' is preferable to 'anti-vaccination movement'. In contrast to the Reformists, the *Radical* groups do not necessarily have personal experience of vaccine damage and exhibit less direct concern with compensation. During the interviews, these leaders described a pre-existing interest in issues such as alternative health, animal testing and 'big pharma' that was then applied to the vaccination case. This is a good example of 'social movement spillover' (Meyer and Whittier 1994). The latter groups are radical in questioning the rationale and use of all vaccines. In preference to a detailed discussion of their organisational strategies, the remainder of the article concentrates on how the groups use ideas of risk and trust to resist vaccination.

Resisting vaccination by reframing risk

An important finding from the empirical research is that the groups engage in very little direct 'risk talk'. In other words, they do not make their case by arguing that the risks of vaccination outweigh the benefits or by challenging the comparative risk statistics put out by the Department of Health. Risk is relevant to an understanding of vaccination resistance, but only in the sense that the groups are engaged in challenging and reframing it. What is interesting is how this reframing is achieved. The analysis reveals that risk is talked about in several different ways (see Hobson-West 2005). First, risk (or, more accurately, risk information) is constructed as strategy, and is therefore not objective. Second, the benefits of vaccination and the dominant narrative of historical success are questioned. Third, the claim is made that vaccination creates new health risks (such as autism); fourth, risk is constructed as unknowns. And finally, the relationship between individual and community risk is rendered complex. To allow a more in-depth discussion, this paper focuses on the final two.

Risk as unknowns

The Vaccine Critical groups rely heavily on a discourse of unknowns in order to challenge and undermine the rationality of vaccination. For example, a majority of the groups make the argument that we do not know the effects of vaccination because of insufficient safety trials, both pre- and post-licence. The most common way this is expressed is by reference to aspects of the standard model of 'good science'. For example, VAN expresses frustration that:

When they are doing the controls for the vaccine, they ought to have these double blind placebo controlled studies which is basically a vaccine tested against a placebo in X group of people. But it doesn't happen. You have a vaccine tested against another vaccine and if vaccine A has no side effect, more than what vaccine B would have, then they consider it safe. But how can you consider something as safe when you're not testing against a placebo? (VAN).

During the interviews, both JABS (a Reformist group) and VAN (a Radical group) claim that during the trial stage, the effects of MMR were only monitored for three weeks. VAN argues that the short-term nature of the trial ensures that potential links between the vaccine and long-term serious health problems will not be made. The true effects of vaccination therefore remain unknown:

Their tests last for three weeks post-vaccination . . . anything that happens in the fourth week is considered out of the window, it's not in the trials. There has never ever been a follow-up. Say you are 40 and have. . . arthritis or whatever. They don't say 'what vaccines did you have as a child?' . . . They are not taking an approach to it that could possibly expose that as being a risk (VAN).

Whether this group genuinely believe that vaccines 'cause' arthritis is less important than the broader argument that 'they are not taking an approach to it that could possibly expose that as being a risk'. What this suggests is that the risk statistics used in vaccine promotion are considered more than just inaccurate: they are seen as irrelevant.

The Radical groups are more likely to use a wider discourse of ignorance. For example, the Informed Parent group argues that:

And I think the more you read on it, the more you realise what little we know about the body and health. There's so much we still don't understand (Informed Parent).

This collective lack of knowledge or discourse of ignorance is used by the groups to explain their wariness in openly advising against vaccination. As will be discussed later, the discourse adopted is instead about helping the parent to develop personal expertise and take responsibility for health and healthcare decision-making. When pressed during the interview, vaccination.co.uk admit that:

I cannot say it is better not to vaccinate the whole world because I don't know. Have we changed the immune system of a generation by feeding them all the antibiotics, by feeding them all the vaccinations? By what we've been doing to their immune systems, have we damaged them irreparably, so that if we did eliminate the vaccination programme tomorrow, would we have mass epidemics, would children be dying all over the place? I don't know . . . and the truth of the matter is no one really knows (vaccination.co.uk).

This final quote is used to illustrate how the groups express the impossibility of knowing what would have happened if society had taken a different path and not developed mass childhood vaccination. Together with the perceived lack of long-term testing or surveillance, the result is a situation characterised by unknowns, ignorance and uncertainty. This is very different from the way in which tables of risk statistics are usually used to imply certainty (Petersen and Lupton 1996: 38). In other words, by concentrating on unknowns and uncertainties, the Vaccine Critical groups undermine the value and relevance of official risk discourses.

Risk as non-random

As discussed above, recent empirical research with parents could be taken as evidence for the lay/expert dichotomy in relation to the understanding of risk. In the light of the importance of herd immunity and accusations of selfishness, how do Vaccine Critical groups construct

the relationship between individual and community risk? The data on this are complex. In short, mass vaccination is attacked from two sides: for being too concerned with the population level and ignoring individual characteristics, but also for not being 'social' enough.

First, the groups criticise the one-size-fits-all nature of mass childhood vaccination. For example, JABS criticises what they see as the practice of vaccinating premature babies, or those recovering from operations, at the standard recommended times:

We've got to actually make sure that what we're giving is right for the individual child. The Department of Health are not good at determining whether a child shouldn't have something. They treat them all as exactly the same (JABS).

A similar point is made by VAN, a Radical group:

We are all different from each other . . . Standard vaccinations take no account of the genetic diversity of individuals . . . Apart from true twins we are all different. That is the first cause of risk (VAN newsletter).

During the interview with vaccination.co.uk, vaccination and biomedicine in general were contrasted with chiropractic medicine, which demands multiple visits and individualised treatment:

But that [chiropractic medicine] is very different from most medical interventions which are based on a bell curve. If you fit in the middle of that they kind of say oh, this is great. It works on 75 per cent of people, yes, we'll use it . . . But if you are outside and you are one who gets a real adverse effect that ain't a lot of consolation. In healthcare we need to treat people as individuals (vaccination.co.uk).

For the Reformist groups, certain policy implications are seen as flowing from this critique. Three of the groups advocate the development of a test to be administered to babies in order to screen out those with a 'vulnerability' or 'immune fragility' to vaccines and vaccine damage. This sub-set of children would not be given vaccines according to the standard-recommended schedule. This proposed test represents a technical solution to the problem of risk, by breaking down the population into several populations with different treatment needs. Behavioural, as well as technical solutions are also suggested. One of the groups (JABS) was keen to praise the activities of a now retired local doctor who reportedly altered the vaccine schedule (and dose) for each child, depending on their health and family history.

Second, the Radical groups, and vaccination.co.uk in particular, make a very different argument about the relationship between the individual and the community. They admit that, on the surface, mass vaccination and herd immunity appear to be community orientated, or even 'socialist' in their aims. In practice, however, vaccination functions as 'just an elastoplast over social problems' with the GP who is 'basically, you know, putting his fingers in a sieve' (vaccination.co.uk). The Radical groups see problems of health and disease as social and cultural in nature, relating to broader structural inequalities of wealth, housing and education. These inequalities require significant and sustained involvement by the state, in contrast to the quick-fix technical solution to disease provided by mass vaccination. During the interview, the leader of vaccination.co.uk clarified:

I just see vaccination programmes as a very cynical method, if you like, of social cohesion. Because if we didn't have vaccination programmes and children were dying I can tell you

where people would be dying . . . It would be places like Brixton and there would be riots. They would be on the street . . . The children that would be dying would not be from Surrey. And that's the kind of reality of the society we live in (vaccination.co.uk).

The Informed Parent also makes a similar argument, that relates to the risk or likelihood of illness and complications:

Creating and maintaining a reasonably sound, stable and healthy lifestyle is the best way to avoid illness and complications. Diseases do not strike randomly. [T]here would have to be underlying factors and weaknesses (Informed Parent, website).

In summary, the data point to two distinct discourses. The first Reformist discourse places faith in screening as a technical improvement to mass vaccination; the second Radical discourse stresses the structural and social determinants of health. However, in terms of risk what both discourses share is the construction of risk as essentially *non-random*. The data do not support accusations of 'rampant individualism' that have been levied at vaccination critics (see Ashton 2004) and the groups do not present themselves as the defenders of the individual. Rather, their critique is articulated through stressing the complex, multifaceted nature of both risk and health.

Resisting vaccination by reframing trust

As is now well recognised, risk and trust are intimately related (Alaszewski 2003). Misztal's book on defining trust is helpful in reviewing the sociological literature and revealing the multiple definitions including trust as faith, confidence, exchange, expectation, role performance, co-operation and gift-giving. In Misztal (1996: 15), trust as faith is the oldest definition of trust and occurs when confidence is placed in what an individual says or does because of another attribute, for example their professional status. Recent work on vaccination takes up the idea of trust as faith (see Brownlie and Howson 2005). In this approach, trust in practice is based on knowledge and a 'leap of faith'. What is striking from the empirical data is the way that the Vaccine Critical groups construct this leap of faith in a highly negative way.

Uncritical trust and compliance

The following extract from Vaccination Information is used to exemplify one image of the parent:

I mean the majority of the population thinks vaccination is a good idea. To look into it, to question it. Who would? If you are a busy parent. It's so much easier. The doctors are telling you it's the right thing to do, TV adverts, friends and family . . . People are inherently lazy . . . If you don't have to research something then why do it? I feel privileged by the fact that I already had doubts because I'm just as lazy as anybody else (Vaccination Information).

The admission that 'I'm just as lazy as anybody else' and reference to the 'busy parent' makes clear that the main intention is not to criticise parents but to construct vaccination compliance as the easiest option. This image is also adopted by the Informed Parent:

I hear so many times health professionals saying ‘most parents want their children vaccinated’. I said, it’s not. Those parents who have got their children vaccinated haven’t thought about it. They just get their [reminder] card and go. They don’t think to question it, why would they? . . . A lot of people just go ahead with it (Informed Parent).

These extracts demonstrate how vaccination is constructed as the easy or natural choice, rather than the result of weighing up of risks and benefits. On one level, this image of the parent as non-thinking is sympathetic and bears some similarity with Wynne’s discussion of the positive construction of ignorance provided by workers at the Sellafield nuclear site, where ignorance is a legitimate stance, rather than a cognitive vacuum (Wynne 1995: 378)³. In the vaccination case, however, the main rhetorical purpose is to negatively contrast the usual passive acceptance of vaccination with the minority of parents who are ‘free thinkers’. When asked during the interviews to describe those parents who question vaccination advice, some of the respondents found this a difficult task. Overall, both Radical and Reformist groups used related metaphors as exemplified in the following quotes:

They don’t follow the herd and just because you do, it doesn’t mean they are going to do it. They have an individual approach to various things. I don’t really know to be honest . . . (Association of Parents of Vaccine Damaged Children).

From our point of view it’s a good thing because it means that people are actually having to think about the thing rather than just being sheep and going along because they are told to do it (VAN).

Crucially, the Vaccine Critical groups do not present themselves as the alternative actors to be trusted. Whilst indirectly, of course, they depend on some kind of trust from their audience, the point is that discursively the leaders do not make their case by stressing their personal experience of parenting or their ‘embodied knowledge’ (Lam 2000) in order to construct themselves as trustworthy sources of advice. Rather, the groups focus on the need for parents to engage in a process of personal education so that they can trust themselves to make the best decision. As made clear by the following quote, their *raison d’être* as groups, is to ‘encourage them to think’:

A lot of parents have become so worried about this [MMR] issue and they’ll ring people like me. They don’t know me, just a voice on the end of the phone and they ask you, what should I do? And I think, well, I would never put myself in that position because I can’t be there to look after their children and nurse them and feed them and see how they grow or whatever. I can’t be there. You have to encourage them to think (Informed Parent).

According to Petersen and Lupton, ‘ideal “healthy” citizens have their children immunised according to state directives’, as well as complying with other procedures such as cervical screening (Petersen and Lupton 1996: 69). Vaccination.co.uk is most explicit amongst the groups in their deliberate reframing of the good parent or citizen:

Good parents are not necessarily by definition those who vaccinate their children and bad parents those who don’t or vice versa . . . Making informed vaccine/vaccination decisions and taking responsibility for them is not an easy thing to do. It may seem a lot easier to simply go along with whatever the prevailing wind tells us to do. *But remaining*

ignorant and trusting blindly can be the biggest risk of all. Only you really know what is the best decision for your child and hence the importance of learning enough to give you the ability to make that decision (vaccination.co.uk website, emphasis added).

What is implied by this quote is that the process of education and learning is more important than the eventual decision and that trust, (or at least blind faith) is constructed as itself a source of risk. Once again, this extract demonstrates that the Vaccine Critical groups are aware of the difficulty for the parent in questioning vaccination. However, the groups, and the Radical groups in particular, provide a positive image of the educated, highly informed parent. In short, what is on offer for the parent, according to this discourse, is the prize of personal responsibility and empowerment.

The prize of responsibility and empowerment

As well as drawing a distinction between those who behave more like sheep and those who are more 'free thinking', the groups allude to the process of education that the parent is encouraged to undertake. What this process entails is not fully articulated but is expected to involve intensive (and critical) reading of information from a wide variety of sources, including the internet. The overall discourse used is one of personal enlightenment, where the parent moves from darkness into light. In many ways this mirrors the process that the various leaders describe in their gradual realisation that vaccination may not be the best strategy, or, in the case of the Reformist groups, that vaccines may be responsible for their child's disabilities. For example, JABS describes how:

I thought I had asked all the right questions, but, with hindsight we find out we hadn't (JABS).

The leader of the Informed Parent also graphically describes the process that she went through, that starts with a kind of naivety:

So they [her children] initially had the early ones [vaccines]. I think I was just typical. Most parents don't. . . especially before you have children, you don't even think about these things . . . (Informed Parent).

For the Informed Parent, this stage of 'not thinking' was then replaced by a period of intensive reading and contacting other people, as a result of a chance encounter with a critical article in the *Evening Standard* newspaper. What is described is a metaphorical 'awakening':

So I sent off for their suggested reading list and then got a whole list of books and of course I thought oh, where do I start? So I just literally started with one and phoned up book suppliers and just chatted to a few people and asked well which ones do you recommend? And then in the end I ended up with them all because as I started to read I thought, goodness me, I didn't know all this about this. It just led you to open your eyes more and more (Informed Parent).

The data from the Radical groups are most likely to include the language of empowerment. For example, vaccination.co.uk argues that:

In health promotion and in the health of society, there's far more issues than just stopping them getting measles. There's issues of empowerment in healthcare. I would

argue the whole vaccination thing is very disempowering because the concept is hey, do this, and you don't get these diseases and they won't kill you. So you'll be alright then (vaccination.co.uk).

For these groups, the alternative to the disempowerment of vaccination and contemporary 'quick fix' healthcare is personal responsibility that results from taking a more holistic attitude to health. For example, the Informed Parent offers an explanation of why the germ theory of disease is attractive to people but also why if you 'look at it from a different angle' alternative approaches are empowering:

The germ theory is much easier to latch onto and be popular because it means you don't have to take on responsibility because you are blaming the germ always . . . I think what's nice about not being frightened of the germs and all that stuff, when you actually start to look at it from a different angle it's actually empowering . . . Empowering in the sense that you can do something about it, it's your choice how you live your life (Informed Parent).

What these final extracts demonstrate is how discourses of alternative health, and, in particular, a holistic attitude to health and disease are closely associated with the idea of personal education and empowerment. Both share a commitment to the idea of responsibility. One group argues that, ironically, this image of the parent is both encouraged and resisted by the NHS:

The National Health Service gives out mixed messages. Part of the stuff that's put out is that we have to take responsibility for our own health. . . . whenever the general public try to take responsibility for its own health, we are knocked down (AiA).

Conclusions

That there is a long and fascinating history of vaccination resistance in the UK is becoming more widely recognised (Wolfe and Sharp 2002, Poland and Jacobson 2002). However, despite the continued high media and political salience of mass vaccination, largely due to the controversy over MMR, the activities and discourses of contemporary organised parental groups have so far been little studied. I have argued that the groups are best understood as Vaccine Critical groups, united by a critical attitude to vaccination policy. The groups differ on key aspects, however, and were further classified as Radical and Reformist. For vaccine policy-makers, recognising that a variety of groups exists would be a useful first step. This would also help anticipate why any policy changes, in terms of MMR or another vaccine, would still be regarded as tinkering and would not appease the more Radical resisters.

The first manner in which vaccination is resisted is through a reframing of risk. A primary way this is achieved by both the Radical and Reformist groups is to construct risk as unknowns. This finding confirms the value of social scientific attempts to distinguish between risk, uncertainty, ignorance and indeterminacy (Wynne 1992). More theoretically, it also serves as an example of how the realist image of risk as a representation of reality is undermined. In the realist account, uncertainty and unknowns may be recognised but are usually framed as temporary phases that are overcome by more research. For the Radical groups in particular, there is a more fundamental ignorance about the body and health and disease that will not necessarily be overcome by more research. Interestingly, this

ignorance is constructed as a collective – ‘we’ as a society do not know the true impact of mass vaccination or the causes of health and disease. This is different from the data from other studies about parental concern with their own personal knowledge gaps (Brownlie and Howson 2005).

As recognised throughout, caution is needed in making claims for parents in general (or even vaccine-critical parents) on the basis of this research. Other large-scale empirical work, however, confirms that unknowns or uncertainty are crucial for understanding technology concerns. For example, authors of the PABE report conclude that instead of risk perception it may be more accurate to talk about ‘public perception of uncertainty’ (Marris *et al.* 2001: 59). Furthermore, the study found that it was precisely the denial of inherent uncertainties, especially about long-term or chronic impacts of GM, that was directly related to a public mistrust of the technology (Marris *et al.* 2001: 87). The broader implication is that the uncritical framing of contemporary controversies as primarily about risk, or even about different understanding of risk, may be misleading (Gofton and Haimes 1999, Hobson-West 2003).

In light of the importance of herd immunity, I also investigated how the groups discussed the relationship between individual and community risk. The Radical and Reformist groups make their case differently but both strands of discourse construct risk (of getting a disease, of suffering disease complications, or of suffering a vaccine reaction) as non-random but influenced by genetic, environmental, and social variables. This view of the individual, each with their own mix of risk factors, bears similarity with some of the discourses of the ‘new public health’, emerging since the 1970s, as characterised by Lupton (1995). As Rogers and Pilgrim briefly hypothesised in 1995, moves towards personalised medicine, the increasing popularity of alternative models of healthcare, and rhetoric around patient choice create a context in which mass vaccination, rather than vaccination opposition looks like the historical anomaly (Rogers and Pilgrim 1995). A decade later, what this empirical study confirms is that Vaccine Critical groups can be considered as organisational expressions of these emerging ‘cultural codes’ (Eyerman and Jamison 1991). In other words, Vaccine Critical groups may well represent a challenge to vaccination policy but express conformity with, and provide an articulation of, broader cultural attitudes. This line of argument is, I suggest, more fruitful for research than attempting to offer further consideration or clarification of supposed differences between lay and expert understandings of risk.

The data from this study also show how the groups resist vaccination by problematising one kind of trust. The analysis reveals only limited differences between the Reformist and Radical groups in this regard. Clear dichotomies are constructed between blind faith and active resistance and uncritical following and critical thinking. Non-vaccinators or those who question aspects of vaccination policy are not described in terms of class, gender, location or politics, but are ‘free thinkers’ who have escaped from the disempowerment that is seen to characterise vaccination. In terms of trust, the groups do not primarily present themselves as alternative sources of expertise, in competition with established authorities on vaccines but, instead, claim to help parents to educate themselves. One could object that parents still have to place trust or faith in something, if not in their doctor’s advice then in the website of a Vaccine Critical group. However, the point is that discursively they do not go down the path of promoting ‘a sense of familiarity’ (Brownlie and Howson 2005: 228) but are instead important contributors to a strong moral imperative on the parent to become informed. This finding has several wider implications.

First, it creates potential problems for those who find it difficult to become a critically informed parent, for reasons of time or financial resources. To recap, instead of good and bad parent categories being a function of compliance or non-compliance with vaccination

advice (Petersen and Lupton 1996), the Vaccine Critical groups reframe these categories so that the good parent becomes one who spends the time to become informed and educated about vaccination. According to the data from other studies some parents do feel pressure to 'look into it': Poltorak's narrative research points to the conclusion that 'vaccination has become a subset of expected parental research into parenting options of all kinds' (Poltorak *et al.* 2005: 714). Furthermore their study found that parents are implicitly defensive if they have not looked into vaccination in detail. My research adds to these debates by suggesting that Vaccine Critical groups are contributors to this pressure on the individual 'where parents are increasingly made aware of the moral imperative to be knowledgeable in order to protect their children's best interests' (Brownlie and Howson 2005: 227).

Second, the Vaccine Critical groups construct trust in others as passive and the easy option. Rather than trust in experts, the alternative scenario is of a parent who becomes the expert themselves, through a difficult process of personal education and empowerment. Note that this discourse demands a *process* of education. Trust in self is not assumed to be automatic or pre-existing. If future research found that this kind of discourse was widely articulated then reference to a crisis of trust in authority is perhaps more accurately described as a crisis of faith or a crisis of deference. This suggestion has important methodological implications: quantitative attempts (*e.g.* Frewer and Miles 2003, MORI 2002) to rank who the public trust assume that trust is like a commodity or finite resource, that is switched back and forth between competing sources of authority. Such research is extremely limited in its ability to capture discourses of deference, personal responsibility and expertise, or indeed, unknowns. One contribution of this paper is therefore to show the range of discourses which might be missed through an overly prescriptive approach to risk or trust.

Finally, the moral imperative to become informed is part of a broader shift, evident in the new public health, for which some kind of empowerment, personal responsibility and participation are expressed in highly positive terms (Lupton 1995, Petersen and Lupton 1996). It also bears comparison with the vision of the 'expert patient' (Department of Health 2001), and by moves towards consumerism in healthcare (Gabe 2004). My analysis can therefore be used to reveal the inherent tensions involved, when choice or expertise leads to views that are out of line with particular health promotion messages. This results in a contradiction, neatly identified by one of the Reformist groups, where the individual patient receives 'mixed messages'. The broader implication is that more examples of resistance to health services and technologies can be expected, and that these may also reveal underlying contradictions. At the very least they should not automatically be brushed aside as misunderstandings of risk. Furthermore, critical concerns will not necessarily be resolved by strategies aimed at restoring trust in professional experts. Whatever discourse is adopted, health policies that are perceived to be an attempt to 'rebuild trust relations' (Poltorak *et al.* 2005: 718) may jar with other powerful discourses, such as those promoted by vaccine resisters, which construct trust as itself a source of risk.

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Notes

- 1 For an interesting analysis of social movements in health, and how they blur the boundaries between lay and expert knowledge, see Brown *et al.* (2004) or Allsop *et al.* (2004) on the health consumer movement. A full review of the social movement literature and analysis of vaccination resistance in these terms is beyond the scope of this paper.
- 2 Utilising both interview and written texts is not to deny that these data are produced differently. Indeed, it is recognised that there are multiple dimensions to the interview encounter. The interview may represent a key opportunity for expression (Jarzabkowski 2001), especially for marginalised groups, and encourages the demonstration of 'moral adequacy' (Murphy and Dingwall 2003: 98).
- 3 My thanks to an anonymous referee for pointing out this similarity.

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