

Education and debate

Communication and miscommunication of risk: understanding UK parents' attitudes to combined MMR vaccination

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In this article on the public perception of risks Paul Bellaby considers three examples of risks to children in the UK—an insignificant risk (autism caused by MMR vaccine), a real but probably small risk (vCJD from BSE), and a real and demonstrably larger risk (injuries from road crashes) and contrasts the perceptions of the risks by parents

Science cannot prove a negative, but, where their children are concerned, parents want to be assured that risk is zero. Would establishing a comprehensive “Richter scale” of risks remove that misunderstanding? If not, then what accounts for miscommunication of risk and how might it be overcome? In this article I try to provide answers by considering public perception of three risks, each of a different order, all involving children:

- Autism linked to the combined measles, mumps, and rubella (MMR) vaccination
- Variant Creutzfeldt-Jakob disease (vCJD) arising from food containing the causative agent for bovine spongiform encephalopathy (BSE)
- Injury and death in road transport crashes.

Background

In 1998 Wakefield was the first to make the claim that autism and the MMR vaccine are linked.¹ It is based on a dozen clinical cases of gastrointestinal disorders with which developmental regression seemed to be linked. They arose in previously normal children. His team found that eight of the 12 parents attributed the onset to the MMR vaccination. On a population level, diagnoses of autism increased rapidly from 1988, when MMR was introduced, and through the 1990s, not only in Britain but also in North America. Yet epidemiological studies have found no link between increasing numbers of diagnoses of autism and the introduction of MMR vaccine.²⁻³ The weight of scientific opinion is that the risk is insignificant.

By contrast, there is both laboratory and epidemiological evidence for the transmission of BSE from cattle to humans. Consumption of mechanically recovered meat, common among children, has been implicated.⁴ The risk is considered real but small. Brown et al estimate 10-15 cases a year from its first appearance in 1994, eight years after BSE was identified in UK cattle,⁵ and Ghani et al suggest that the primary epidemic in the known susceptible genotype began to decline in 2001.⁶ It seems that the outbreak of

BSE that led to vCJD abated long ago, and no further cases are likely to be incubating.

Injuries incurred in road transport crashes by children (ages 0-15 years) are easy to demonstrate, common, and recur year on year. In 2002 there were 34 689 casualties from road crashes in Great Britain, of whom 4596 received serious injuries or were killed.⁷ Children (like elderly people) are relatively vulnerable as pedestrians. They are also prone to cycling injuries. But about 45% of child road casualties are car passengers (more than 70% for those aged under 2 years). Although the overall number of casualties from road crashes continues to decline, children are progressively more likely to travel by car and less likely to walk or cycle, even to get to school.⁸ This is one of the factors implicated in the decline of exercise and increasing obesity in children.

Parents' responses to the risks

Although road transport crashes carry by far the largest risk of the three, they have raised little controversy.



Since their inception, vaccination campaigns have provoked vigorous opposition from sections of the public

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The alleged link between MMR vaccination and autism and the small risk of vCJD both met with widespread concern from parents. There has been conflict between expert and lay opinion about MMR and vCJD. Bartlett suspected collusion between government and industrial interests to cover up the threat from BSE.⁹ Similar suspicions of cover up by government developed after Wakefield's claims about MMR and autism.

Adams dismissed the possibility of a Richter scale of risk, arguing that uncertainty and probability are elusive concepts and that the public quite reasonably finds some risks readily perceptible¹⁰; but others, known to experts, are not acknowledged by the public, and still others are "virtual" rather than real. Unfortunately this classification does not seem to account for how parents perceive the three risks in question. Road transport crashes are perceptible risks, the low risk of vCJD is an expert assessment, and the link between autism and MMR is, if anything, virtual. Parents seem to neglect the easily perceptible risk, to reject the expert assessment, and to amplify the virtual risk.

Does this suggest that parents are irrational? Might they be pawns of mass media that seek not the truth but to support minorities against authority, as Bedford and Elliman imply?¹¹ It is a short step from answering "yes" to arguing that the authorities ought to act in the interests of the child, if need be against the wishes of parents, as the Court of Appeal has ruled against two mothers in recent cases involving MMR vaccination.¹²

Lessons from history

Yet there is a history to compulsory vaccination of infants in Britain that is an object lesson for today. From its introduction in law in 1853, compulsory smallpox vaccination for infants provoked vigorous opposition, not only from middle class radical liberals, but also from working class movements.¹³ It was not until 1898 that conscientious objection was allowed,

but this followed progressive decline in compliance with vaccination law from about 1889. From then on, Britain differed from most countries, including the United States and Germany, in not relying on compulsory vaccination in order to control smallpox.

A comparison of vaccination policy and its effects on population health in England and in Prussia and Imperial Germany from 1835 to 1914 suggests that compulsory vaccination led to an earlier downturn in smallpox in Germany. However, by the end of the period, both countries had controlled the disease.¹⁴ This was partly attributable to disease surveillance and containment in Britain, but was also due to another factor, which contributed to Britain's success with many childhood diseases at the turn of the 20th century. This was active engagement with the public at local level in health improvement.¹⁵ By the late 19th century, the liberal middle classes were encouraging the "deserving poor" to change their lifestyles by face to face engagement in their homes, schools, and neighbourhoods.¹⁶ At the same time, they might provide an example of domestic management and hygiene to the many women servants in middle class homes who would later rear their own children in working class areas.

What went wrong with MMR?

The extent of people's willingness to conform to public health programmes in Britain was and remains considerable. From the introduction of the MMR vaccination in 1988 until the scare broke in 1998, levels of take up had been high, rising to 92% in 1997, sufficient to achieve population immunity. One estimate based on surveys to date is that take up fell by only 8.6% from 1995 to 2001.¹⁷

In 1988, at the start of the MMR campaign, take up was higher in affluent areas—a familiar pattern in Britain and North America.¹⁸ Up to 1997, the affluent pattern of take up spread to less affluent areas.²⁰ All the more remarkable then, that, from 1998, take up decreased first in affluent areas and more so than in deprived areas. Even when parents decided for MMR vaccination, a study based on focus groups among the public indicated widespread misgivings.²¹ A survey of health professionals who provided vaccination for children suggested that parents' unease rubbed off on the professionals.²²

The vicissitudes of the MMR campaign show that "mass communication" is mediated or filtered in different ways, through the diverse groups that comprise society and through hierarchies, including the medical profession. It should be no surprise that the same message conveys different meanings to different people.

The conduct of the media may have contributed to the miscommunication of risk,²³ but it would be a mistake to suppose that the media led the public. Parents were predisposed to act in what seemed to them to be the interests of their children. The response of "the establishment" confirmed for some their suspicions that inconvenient truths would be covered up. The handling of the earlier BSE crisis lent support to this view. In the case of MMR vaccination, the chief medical officer would not meet parents' concerns half way by sanctioning access to single disease vaccinations. The grounds for refusal were reasonable enough: the six



The government's handling of the BSE crisis led to widespread distrust of "the establishment" over other safety issues. Here the minister of agriculture of the time eats a hamburger with his daughter to demonstrate that beef was "perfectly safe"

administrations required in all (measles, mumps, and rubella, each twice) would increase the likelihood that vaccinations would not be completed. In the United States children under 18 months old are now given protection against 11 childhood diseases, which requires some 15-19 doses of vaccine, and this has driven healthcare managers to seek ways of reducing infant distress and so making the process more acceptable to parents.^{24 25} After 1998, many UK parents would probably interpret the chief medical officer's argument as insulting, both to their conviction that they were acting in their children's interests and to their competence as responsible parents to ensure that individual vaccination courses were completed.

In spite of appearances to the contrary, one can argue that parents have behaved rationally, not only with respect to MMR vaccination, but also in relation to vCJD and road transport crashes. The case evokes cultural and social context rather than "economic man." True, as the economic man argument suggests, parents who refuse vaccination may "free ride" on the compliance of the majority in order to secure the benefit of herd immunity for their child. But, taken together, responses to the three risks we have reviewed suggest that parents are acting conscientiously as norms dictate, not selfishly. They act in what they perceive to be the interests of their children. If there seems to be any risk to their child, responsible parents will avoid it. Thus, they avoid beef products, and they question the safety of the MMR vaccination. Even though taking children to school and elsewhere by car may have unintended consequences for their health and safety, it is interpreted as a way of protecting them from greater dangers on the streets from other road users and abduction by strangers.²⁶

Changing parents' perceptions

Vaccination has a heroic history in the control of communicable diseases. However, collective provision that is taken for granted today in Britain—not just vaccination, but also sewerage, clean water supply, and food safety—had to be fought for. In the mass mobilisation wars of the 20th century, several public health plans that had foundered for lack of public support in peace time came to seem necessary for the war effort. But mass mobilisation is not a normal state in healthy democracies. A consequence of peace is that public health measures that have not become part of infrastructure have often been challenged. For example, when rationing of food was lifted in 1954, nutritional standards and their rough equality achieved during the second world war were sacrificed for the sake of choice.²⁷

The case of public reaction to MMR vaccination should be viewed in this broader historical context. Any attempt to restore the compulsion that failed in the late 19th century would almost certainly fail again. Instead, public health professionals and scientists should consider the lessons that experience with MMR offers and apply it in the future. The first is that challenge to authority, including the authority of science, should be expected in a healthy democracy. The second is that the establishment should disseminate evidence to the public in a transparent way that is sensitive to the ways of understanding of diverse

Summary points

The size of a risk does not necessarily relate to the controversy it causes

Parents seem to neglect the most obvious risks to their children (such as road crashes), reject expert assessment (as over BSE), and amplify a virtually non-existent risk (autism from vaccination)

Yet public willingness to conform to public health programmes remains high, and parents' behaviour is not necessarily irrational

Parents' behaviour is understandable if they are seen as acting to protect their children within a particular social context

groups. The third lesson is that communicating risk effectively to the so called masses, and so priming people to act appropriately, is about much more than providing even the best of information: it is a matter of two way communication and obtaining agreement. Concordance has to be the aim if compliance is to fall into place.²⁸

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How can doctors communicate information about risk more effectively?

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Effective communication of risk can improve both individual and national health, and there has been substantial investment in such communication. Has this yielded the anticipated improvements in health?

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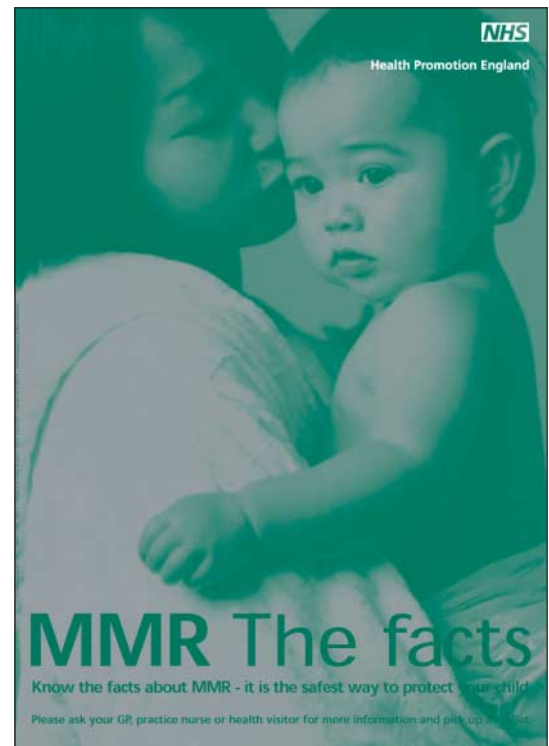
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In recent years risk has become a mature cross disciplinary topic of study, and during this time social science research into risk has experienced a rapid growth. Despite the existence of much relevant social science knowledge about risk, the extent to which such knowledge has been applied in the health field has been perhaps surprisingly limited. In 2001-2, two UK research councils (the Economic and Social Research Council and Medical Research Council) commissioned us to examine the potential for applying social science knowledge about risk to practical medical and health issues. We have used our findings to tackle the thorny issue of physician-patient communication about health risks.

Although there has been a substantial growth in the knowledge about the risk factors associated with ill health, the full benefits of such knowledge can be gained only if the experts such as doctors can communicate this knowledge effectively and patients are willing and able to use it in their decisions about treatment and lifestyles. However, we consistently overestimate the dangers and undervalue the benefits we obtain by living in a complex society. For various reasons, we do not think rationally about risk, and this has reached a level where perverse judgments are damaging to society—for example, issues surrounding risks associated with rail travel and the MMR vaccine.¹

Assumption that patients rationally review evidence

There is little evidence that knowledge of risk as embodied in professional assessments influences the ways in which the general public perceives and responds to risks and dangers.² Epidemiologists have identified a range of risks associated with different patterns of behaviour—such as the harmful consequences of smoking, alcohol consumption, drug misuse, and “unsafe” sex—and the beneficial consequences of changes in behaviour that will reduce preventable disease and premature deaths. The public health response has been to try to reduce risk factors at a population and individual level, especially by communicating



information about risks. This approach is clearly exemplified by current campaigns to persuade parents to choose the MMR vaccine. Hobson-West has examined the nature of the current health promotion and identified three assumptions:

- Parents make decisions through a comparison of individual risk
- Parental concern about vaccination is due to a miscalculation of risk
- A policy of providing more risk statistics is the best response to the controversy.³

This approach to the communication of health risk assumes that the target audience is made up of individuals who rationally review evidence to identify and choose the best course of action—that is, the one