MMR: Learning Lessons

A report on the meeting hosted by the Science Media Centre on 2nd May 2002

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The Science Media Centre

The SMC, which opened for business on April 2nd 2002, is an independent venture working to promote the voices, stories and views of the scientific community to the news media when science is in the headlines. With its roots in the House of Lords Select Committee on Science and Technology Third Report: Science and Society, it will take up the gauntlet thrown down by the Lords to meet the "great challenge" of adapting science to frontline news.

The overall goal of the Centre is to help renew public trust in science by promoting a more balanced, accurate and rational coverage of the controversial science stories that now regularly hit the headlines. For more information about the SMC, go to <u>www.ScienceMediaCentre.org</u>

Background to the Meeting

The MMR: Learning Lessons meeting was hosted by the Science Media Centre at the Royal Institution from 4pm to 6pm on Thursday 2^{nd} May 2002. There were 50 people present at the meeting, which was chaired by Fiona Fox, Head of the SMC.

The MMR vaccine has been a topic of growing controversy for many years. Links with bowel disorders and autism have been suggested by a handful of doctors, while the vast weight of scientific opinion says that the triple vaccine is by far the best way to protect children from measles, mumps and rubella, and that the proposed link with autism is entirely unproven.

Yet despite the overwhelming opinion of the scientific community, the reality is that the public remains unconvinced. One probable cause may be the way that the media covered the issue. That's why the Science Media Centre decided to host a 'Lesson Learning' session on "MMR and the Media".

The session was designed to cover questions like:

- Did the scientific community engage effectively with the surge in media interest in MMR between December 2001 and February 2002? If yes, how, and if not, why not?
- What efforts have been made since 1998, when Andrew Wakefield's research first began to garner serious media attention?
- Are scientists powerless in the face of a news media that loves the minority, anti- establishment view?
- If one reason for the growing disenchantment with science is a general misunderstanding of how science works (i.e. expectations that science can always deliver a single, agreed view and guarantees of 100% safety), how can we use media interest in issues like MMR to communicate the way science works?
- What can we learn from this recent media focus on MMR and how can we now prepare for the next round?

The session brought together key people from science, politics and the media who have first hand experience in trying to put forward scientific arguments about MMR. We hoped that a discussion

based around the experiences of the attendees could shed some light on how science can improve its communication with the public *via* the media. However, one of the key aims of the SMC is to improve relationships between scientists and journalists. We believe that by co-ordinating sessions where the two constituencies can meet to discuss issues like MMR, we can help to generate an improved understanding and respect of each other's specialities. The meeting was designated as strictly off-the-record, to encourage everyone there to be as frank as possible. Notes were taken and an audio recording made to make this report possible.

Meeting Format

We discussed the issue of 'MMR and the Media' in two parts. Firstly, *what* messages were being put out to the media? How effective were they in communicating the opinions of scientists and doctors? How well did the public respond to these messages? Were there other issues that were not tackled? What can we learn from the most recent encounter that will inform more effective communication in the future?

Examples of MMR messages:

"MMR is completely safe"

"The risk from measles is much greater than any risk from the MMR vaccine"

"Trust the experts"

"The triple vaccine is far more effective than the single measles jab - this is why parents are not being given the choice between the vaccines"

"Wakefield's research is suspect, and a minority view within science"

"Immunisation rates are not falling - there is no crisis"

Secondly, *how* were those messages disseminated? What were the media strategies used by doctors, hospital trusts, government agencies and scientists? How effective were they?

Examples of strategy:

Were there any parents' groups who were pro-MMR? Were their voices heard? Were the messages put forward *via* press conferences, statements from individuals, articles placed in the media by doctors, etc?

Was there any coordination between different institutions on their respective messages? Were scientists ready for the level of media interest?

Report Format

This report consists of a summary of views that were aired during the meeting. These are not the opinions or recommendations of the SMC. Individual views are not attributed, and quotes are not used, in order to preserve the 'off the record' nature of the meeting.

What Lessons Have We Learned?

It is naturally very difficult to produce simple answers from an open discussion meeting such as this. The discussion covered many aspects of what is an incredibly complicated communication issue. However, it certainly identified some over-arching themes in communicating risk to the general public. Broadly, two distinct schools of thought emerged, with a great deal of anecdotal evidence aired to support both cases:

- Transparency and openness are now the only reliable routes to winning public trust. Scientists and spokespeople must present the facts of the case in a clear, unvarnished way, offer advice, and then allow the public to decide for themselves. This model is being pursued by the Food Standards Agency, and has been welcomed by most journalists.
- Bombarding the public with information about relative risks, theoretical risks and 'unknown unknowns' just leads to paralysis. In the face of uncertainty, the public will almost always opt for either inactivity or a perceived 'compromise choice', which in the MMR case could result in a serious threat to public health. Parents just want to believe someone who tells them, "This is safe."

Many present thought that the statement 'MMR is safe' is actually very weak, because it can never be proved. Perhaps a better approach would have been to reinforce the distinction between individual and population health concerns. Although the MMR vaccine is not necessarily less likely to produce side effects than single vaccines, it is still the most effective way to protect children's health because of the immunity it confers on the whole population. Attempts to covey this message may have been derailed by references to 'herd immunity', which planted the suspicion in people's minds that they were being treated like cattle.

Others argued that if we adopt the model of openness and transparency, a 'risk vs. benefit' analysis could be presented to the public. Unfortunately, this is very difficult when the risks are unknown, or vanishingly small. It is also much harder to convince someone of the benefits for the whole population, rather than to the individual, because it involves recourse to epidemiology and statistics rather than personal experience. Within the constraints of a media soundbite, these subtle arguments can easily be lost. But that doesn't mean that scientists should stop trying, for as soon as they disengage from the media they automatically lose the battle. Like it or not, scientists may just have to trust the media not to adulterate their messages. Although the broadcast medium is often very constrained by a 'soundbite' culture, there would have been many opportunities for longer, more considered feature articles in the national press. In this forum, the subtleties of risk communication stand a much better chance of being negotiated successfully. According to several 'media monitors' present, those articles were unfortunately few and far between. Similarly, the *Private Eye* special edition on MMR took a very tendentious approach that appeared on every news stand in the country, yet there was no equivalent publication putting forth the case in favour of MMR.

The fact that *all* vaccines carry a risk did not seem to get much coverage either. While the public are aware that medicines do carry risks of adverse side effects, being told that there was no risk at all must have made them suspicious. And as one attendee pointed out, this was a prime opportunity for the media to discuss the issue of vaccination not necessarily being a personal choice, but a public duty.

The Bigger Picture – Vaccination as Public Policy

The MMR scandal has raised wider issues about widespread childhood vaccination as a public health policy. One argument for not allowing parents access to the single vaccines was that it could be seen as an admission of concern about the whole vaccination process, which could undermine one of the greatest achievements in improving public health in the last century. Although it was right for the Government to reassure parents about the relative safety of the vaccine, the constant reassurances may just have made people worry more.

However, most of those present felt that the vehemence of the Government's denial of choice in this matter can only have upset already concerned parents. The fact that single vaccines were not even licensed made matters worse. But is it wishful thinking to suggest that if those few, middle-class parents who demanded the single vaccines were appeased, the whole fuss would have gone away? Was this concern, in fact, just limited to the middle classes?

Measles or autism – you decide

All agreed that it was important to remind the public of the risks posed by measles and mumps. However, many believed that these risks may have been exaggerated in order to make a stronger case. Accusing parents of playing Russian Roulette with their children's lives is tremendously unsympathetic, making parents distrust any further Government statements on the matter. Since the public were already primed to distrust politicians after the BSE debacle, any statements from officialdom were automatically treated as propaganda. It was generally agreed that quelling one panic by creating another is simply not an effective strategy.

People tend to be much more averse to deliberately taking risks, rather than exposing themselves to risk through inactivity. In this case, even though the risk from MMR is undoubtedly smaller than from measles, it is the fact that the MMR vaccination is a positive decision that magnifies the downside in a parent's personal risk assessment. Given that measles was, until recently, quite a common childhood ailment that *most* children recovered from, the public had a lot of anecdotal experience that played down their concerns about the disease.

The controversy was undoubtedly stoked by the fact that there is relatively little known about the causes of autism, a condition which is on the increase in the UK. Many campaigners were looking for a culprit, and MMR fitted the bill. Moreover, the controversy served to highlight a disease that arguably lacked research funding, so as one cynic pointed out, "it was in the best interests of autism campaigners to fuel the debate". Wakefield also appeared to be one of the few scientists who was really listening to the parents of autistic children, and so received a great deal of support from that community.

Attack of the white coats?

There was much debate about the perception of the scientists involved in the MMR controversy. It was argued by some that the most powerful message any 'expert' can give is that they have had their own child vaccinated. Tony Blair's refusal to talk about his son's vaccination became a huge issue because he was expected to lead by example. Since everyone is all too aware of how powerful this argument is, his refusal to exploit it was seen by many as an admission of uncertainty rather than an effort to preserve his family's privacy.

As long as scientists are perceived as cold and unfeeling, an empathetic parent who is concerned about their child's health stands a much better chance of winning the argument against a scientist in a media debate. Scientists tend to stick to fact-based analyses and statistical evidence, while the more powerful

arguments are often emotive and anecdotal. Some of the more media savvy at the meeting thought that employing these rhetorical tools may provide a way out of the classic 'Research shows that ...' trap.

Unfortunately, it is very difficult for the public to judge who the experts are. Several attendees pointed out that although the parents of autistic children are indeed experts on the symptoms and effects of autism, they are not in a position to make balanced judgements on vaccine safety. There were also many scientific pronouncements from politicians involved in the debate, which perhaps diluted the scientists' messages. Could there have been too many 'experts' in the debate? Certainly, if any scientists advocated the use of MMR they were immediately branded a 'Government scientist', and their advice was often discounted for this reason. As several of the medics at the meeting pointed out, much of Wakefield's research (and indeed the media) treated the parents of autistic children as experts on the disease, rather than as experts on the *symptoms* of the disease.

While the motives of the 'authority' scientists were questioned, some people believed that less scrutiny was focussed on those making claims about links between MMR and autism. The media always loves the underdog in a story, and the battle between Wakefield and the establishment was played out in true David vs. Goliath fashion. It highlights the fact that trying to censor a lone voice in science is a disastrous strategy, because it looks like the little guy is being picked on. People argued that it would have been more effective for the scientific establishment to be seen to be listening to Wakefield's concerns and evidence, thereby bringing him 'into the fold'. According to that camp, if the MRC had been more open about how they reviewed Wakefield's research then the public may have been more willing to believe that they were acting in the best interests of the community as a whole. In fact, Andrew Wakefield was asked several times to give evidence to the committee, and each time chose to decline the invitation.

The media 'exposed' several members of the MRC's autism review panel for being in the pay of vaccine manufacturers, and concluded that the whole process was therefore rigged. However, the MRC had declared all the potentially competing interests of the review panel members from the outset. If the MRC were to exclude anyone with commercial or other interests potentially conflicting with the review's objectives, it would be virtually impossible to convene a panel that included any scientists from this relatively small field. Interestingly, the MRC was never asked by Government to make a statement about MMR, and they held no press conferences or briefings on MMR, although they did offer MRC-funded scientists for interviews on autism with the media. Nevertheless, they were apparently widely cited as a source of 'government information' about the subject.

The way that the science and media communities deal with 'mavericks' is crucial to whether their research is lauded, decried or ignored. One attendee argued that if the maverick is right then the scientific world will come round to their way of thinking – thus the proponent quickly loses their maverick status. Maverick scientists who retain that tag for a long time do so because they are almost invariably wrong. Others pointed out that useful ideas can sometimes come way out of left field, and that mainstream science should listen carefully to these voices. However, scientists should remain appropriately sceptical, as should the media. Several people felt that this was essential when the scientist in question has turned away from their peers, and appears to be more interested in convincing the general public *via* the media. Although the maverick may be imbued with anti-establishment cachet by making bold claims, and is often cast in the role of a comic-book hero who 'fights for justice against the tyranny of authority', this does not necessarily mean they are right.

Media Influence

We were told that many health professionals were taking their cues from the media, rather than from local or national health authorities. Although this was alarming in itself, the style of the media's coverage meant that each piece of information about the safety of MMR became a story in its own right, rather than being incorporated into a canon of knowledge that was referred to in each subsequent story. Many key studies were therefore ignored in the bulk of the media coverage, while the same objections from Wakefield and JABS were always present in every single story. "Surely this is not balanced reporting?", accused several of our attendees. Similarly, while criticism was heaped on every aspect of 'Government' research, Wakefield faced a largely uncritical analysis in the media where he was lauded as a 'whistle blower'.

It also seemed to be widely assumed by the media that minority pressure groups like JABS were representing the concerns of every parent in the UK. According to some, this was a gross misrepresentation of public opinion that did a huge disservice to all concerned. Despite the hype, it was generally thought that most parents did *not* believe that MMR automatically caused autism in children. However, there is a widespread public suspicion that there could be a small group of the population that were 'genetically susceptible' to an adverse reaction.

Media stories about dropping immunisation rates may have increased the levels of public fear about MMR by association. According to the PHLS, levels have apparently not declined as much as everyone seems to think. This has been ignored in favour of scares about falling immunisation in London, where coverage is notoriously low anyway.

Of course, there was little that could be done by scientists when the campaigning media decided to use this issue as a stick to beat the government with. This could explain the lack of interest in stories about the dangers of rubella, simply because it did not fit within the media agenda at that time. It was also suggested that the media paid little heed to the very real decisions that faced individual parents. The rhetoric that was used often served to confuse and terrify the public, rather than present the facts in a helpful way. Little wonder that the medical community apparently preferred to deal with parental anxiety through personal dialogue, rather than *via* the national media.

Conclusions

As we had hoped, everyone at the meeting was extremely frank and willing to share their views on the MMR issue. Many attendees commended Fiona's chairing for being tough enough to stop heated debate boiling over into outright warfare. Although most of those at the meeting had dealt with each other professionally during the MMR crisis, many had never had the opportunity to comment on the issue to each other personally, and this was ultimately one of the successes of this gathering. It certainly demonstrated the clear need for a neutral forum where this type of discussion can occur.

Naturally, with so many firmly-held opinions we could never expect an overall consensus. But this makes any common ground all the more precious, as it is more likely to provide a valuable starting point for improving the communication of science in general, and the quality of public debate about MMR in particular.

There was general agreement that when dealing with complex scientific issues, it is imperative that the scientific community is able to deliver its arguments in the right form *at the right time*. In other words, it needs to be more media savvy. Of particular concern is the scientific community's treatment of 'maverick scientists'. Given that scientific advances are often achieved through a process where

disagreement is crucial, science must not be seen to clamp down on dissenting voices simply because they are out of step with the mainstream. If open-mindedness is one of science's great strengths, it is surely important that this is seen to be the case by the general public.

However, the media's treatment of 'mavericks' also deserves scrutiny. While the best research may initially be controversial, other scientists usually confirm it after further investigation. With MMR and autism this has not been the case, yet Wakefield's position was all too often unchallenged by journalists. Although scientists have publicly decried his research, these challenges have frequently been interpreted as personal attacks, rather than as scientific criticisms. It is imperative that scientists negotiate this narrow boundary between personal and professional criticism in all their contact with the media and the public if their credibility is to remain intact. Likewise, the media must clearly distinguish between scientific and personal criticism.

Whatever communication strategies are used, scientists have to retain their integrity. They will almost certainly lose the argument if they are perceived to resort to scare tactics or half-truths. Similarly, if the public believe that the medical profession have an overly paternalistic attitude then the soundest of health messages can fall on deaf ears. However, if the scientific community feels that there is insufficient media scrutiny on bad research, then the fastest way to change that is to engage with the media proactively to point this out. It is also clear that using an emotional approach can be extremely successful, rather than relying on a purely rational argument. If a doctor with children speaks about vaccinating their own child, then the listening public are more likely to believe their scientific arguments because of the overt personal interest.

The media plays a pivotal role in our culture, to the extent that it can influence both parents and health workers far more than government or science are able to. This places a huge duty on reporters and editors to cover stories responsibly, presenting them in a way that will serve the public good. It also means that if scientists want to communicate effectively with the public, they must first communicate effectively with the media.

We intend to facilitate another meeting about MMR communication issues. This time, a smaller group will gather to formulate strategies that will help scientists to put their case more effectively. As one health professional at the meeting said, the public are desperate for someone to tell them if MMR is safe or not. So when MMR hits the headlines again, as it surely will, it is imperative for scientists and journalists to work together in order to inform the public as responsibly as possible.

Attendees

Karen Allen, Health Correspondent, BBC Judith Barnard, Director of policy and public affairs for the National Autistic Society Dr Helen Bedford, Institute of Child Health Neil Bennett, Health Correspondent, BBC Professor Sir Colin Berry, Royal London Hospital Dr David Boak, Director of Communications, The Royal Society Dr Rebecca Bowden, Office of Science and Technology Tracey Brown, Sense about Science Emily Collins, Press Officer, PHLS Carolyn Coote, Assistant Director, Science in Government Dr Natasha Crowcroft, PHLS Carolan Davidge, Chief Press Officer, MRC Dr Bernard Dixon, Science Writer and Consultant Dr Peter Dukes, MRC David Elliman, Institute of Child Health Dr Mike Fitzpatrick, GP Fiona Fox, Head of the Science media Centre and Chair of the meeting Carole Fry, Nursing Officer, Dept of Health Veronique Gibbons, Immunisation Division, PHLS Tony Gilland, Institute of Ideas Pallab Ghosh, Science Correspondent, BBC Simon Gregor, Head of Press and Media Activities, PHLS David Hall, Hazards Forum Adrian van Klaveren, Head of News Gathering, BBC Professor Melissa Leach, Social Anthropologist, University of Sussex Natasha Martineau, COPUS Neil Martinson, Head of Communications, Food Standards Agency Malcolm Matthews, Director of Community Support and Information, SENSE Dr John Maule, Centre for Decision Research, Leeds University Victoria Mayers, Press Officer, SENSE Joff McGill, Head of Voluntary Services Team, SENSE Philip Minor, National Institute for Biological Standards Marjorie Monickendam, Press Officer, PHLS Dr Rachel Moore, Scientist, Lovells Caroline Moore, Barrister, Lovells Becky Morelle, Science Media Centre Vivienne Parry, Journalist and Broadcaster Dr Mark Peplow, Science Media Centre and rapporteur Dr Nick Russell, Imperial College Dr Simon Singh, Science Writer and Broadcaster Tammy Speers, Media Studies, Cardiff Jo Thomas, Internal Communications, Department of Health Eleanor Treharne-Jones, Senior Press Officer, Dept. of Health Dr Tom Wakeford, PEALS Bob Ward, Press and PR, The Royal Society Dr Joanne White, PHLS

Andy Veitch, Science Correspondent, Channel 4 News Jeremy Webb, Editor, New Scientist Professor Simon Wessely, Institute of Psychiatry, King's College, London Ms Joanne Yarwood, Health Promotion England