MEDICINE AND THE MEDIA

MMR: the scare stories are back

A UK newspaper has once again linked autism with MMR and sparked a spate of media scaremongering. But the original story was wrong on every count, writes **Ben Goldacre**

It was inevitable that the media would re-ignite the MMR (measles, mumps, rubella) autism scare during Andrew Wakefield's General Medical Council hearing (see p 118). In the past two weeks, however, one front page splash in the broadsheet Sunday newspaper the *Observer* (8 July) has drawn widespread attention: the newspaper effectively claimed to know the views of named academics better than those academics themselves, and to know the results of research better than the people who did it. Smelling a rat—as one might—for once, I decided to pursue every detail.

The *Observer's* story made three key points: that new research had found an increase in the prevalence of autism, to 1 in 58; that the lead academic on this study was so concerned he suggested raising the finding with public health officials; and that two "leading researchers" on the team believed that the rise was due to the MMR vaccine. By the time the week was out, this story had been recycled in several other national newspapers, and the 1 in 58 figure had even been faithfully reproduced in a *BMJ* news article (doi:10.1136/bmj.39272.468044.4E).

On every one of these three key points the *Observer* story was simply wrong.

The newspaper claimed that an "unpublished" study from the Autism Research Centre in Cambridge had found a prevalence for autism

of 1 in 58. I contacted the centre: the study that the *Observer* reported is not

finished and is not published. The data have been collected, but they have not been analysed.

Unpublished data is a recurring theme in MMR scares, and it is the antithesis of what science is about: transparency, where anyone can read the methods and results, appraise the study, decide for themselves whether they would draw the same conclusions as the authors, and even replicate the study, if they wish.

The details of this study illustrate just how important this transparency is. The study was specifically designed to look at how different methods of assessing prevalence affected the final figure. One of the results from the early

analyses is "1 in 58." The other figures were less dramatic, and similar to current estimates. In fact the *Observer* now admits it knew of these figures and that these should have been included in the article. It seems it simply cherry picked the single most extreme number—from an incomplete analysis—and made it a front page splash story.

And why was that one figure so high anyway?

The answer is simple. If you cast your net as widely as possible, and use screening tools and many other methods of assessment, and combine them all, then inevitably you will find a higher prevalence than if—for example—you simply trawl through local school records and count your cases of autism from there.

This is not advanced epidemiology, impenetrable to journalists—this is basic common sense. It would not mean that there is a rise in autism over time, compared with previous prevalence estimates, but merely that you had found a way of assessing prevalence that gave a higher figure. More than that, of course, when you start doing a large scale prevalence study, you run into all kinds of interesting new methodological considerations: is my screening tool suitable for use in a mainstream school environment? how does its positive predictive value change in a different population with a different baseline rate? and so on.

These are fascinating questions, and to answer them statisticians and epidemiologists were invented. As Professor Baron-Cohen, lead author on the study, says:

"This paper has been sitting around for a year and a half specifically because we've brought in a new expert on epidemiology and statistics, who needs to get to grips with this new dataset, and the numbers are changing. If we'd thought the figures were final in 2005, then we'd have submitted the paper then."

The *Observer*, however, is unrepentant: it has the "final report." And what is this document? I can't get the paper to show it to me (and what kind of a claim about scientific evidence involves secret data?), but grant giving agencies expect a report every quarter, right through to the end of the grant, and it seems likely that what the

Observer has is simply the last of those: "That might have been titled 'final report'," said Professor Baron-Cohen. "It just means the funding ended, it's the final quarterly report to the funders. But the research is still ongoing. We are still analysing."

But these are just nerdy methodological questions about prevalence (if you skip to the end, there is some quite good swearing). How did the *Observer* manage to crowbar MMR into this story? Firstly, it cranked up the anxiety. According to the *Observer*, Baron-Cohen "was so concerned by the 1 in 58 figure that last year he proposed informing public health officials in the county."

But Professor Baron-Cohen is clear: he did no such thing, and this was simply scaremongering. I put this to the *Observer*, which said it had an email in which Baron-Cohen did as the paper claimed. *Observer* staff gave me the date. I went back to the professor, who went through his emails. We believe that I too now have the email to which the *Observer* refers. It is one sentence long, and it is Professor Baron-Cohen asking if he can share his and the other researchers' progress with a clinical colleague in the next door office. This dramatic smoking gun reads: "can i share this with ayla and with the committee planning services for AS [autism services] in cambridgeshire if they treat it as strictly confidential?"

Professor Baron-Cohen told me, "That's not saying I'm concerned, or that we should notify anybody; these are just the people who run the

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Fiona Scott

them statisticians and epidemiologists were invented. As Professor Baron-Cohen, lead author on the study, says:

local clinic, who I share a corridor with, who said they were interested to hear how it was going so far. They are not public health officials, and it's not alarmist, it's simply voicing concern, it's simply saying: 'Am I allowed to share a paper with a colleague in the next door office?' It seems very important to me that we discuss clinical research with clinical colleagues, and I only stressed confidentiality because the paper was not yet final."

But what about the meat? The *Observer* claims that "two of the academics, leaders in their field, privately believe that the surprisingly high figure [1 in 58] may be linked to the

use of the controversial MMR vaccine." This point is repeatedly reiterated, with a couple of other scientists disagreeing to create that familiar, unnerving, illusory equipoise of scientific opinion that has fuelled the MMR scare in the media for almost a decade now.

But in fact, the two "leading experts" concerned about MMR were not professors, or fellows, or lecturers: they were research associates. I rang both, and both were clear that they wouldn't really describe themselves as leading experts. One is Fiona Scott, a psychologist and very competent researcher at Cambridge. She said to me, very clearly: "I absolutely do not think that the rise in autism is related to MMR." And: "My own daughter is getting vaccinated with the MMR jab on July 17."

She also says, astonishingly, that the *Observer* never even spoke to her, before incorrectly reporting that she has a privately held view that MMR might be partly to blame for autism. I say "reporting," but in some ways, it's more like an accusation. Dr Scott is horrified. She simply does not believe that MMR has caused a rise in autism.

The *Observer's* "readers' editor" column one whole week later (15 July), when the paper half-heartedly addressed some (and I mean some) of the criticisms of its piece, reinforced the idea that Fiona Scott holds this view. The paper says it knows this because she said it in a court report in 2003. She says this is untrue. Even more bizarrely, the paper still has not contacted her: so apparently the *Observer* knows the opinions of this woman better than she knows her own mind,

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despite her public protestations.

The only voice Dr Scott could find (while the *Observer* continued to describe her as a "dissenter") was in the online comments underneath the readers' editor piece, where she posted an impassioned and rather desperate message. I shall reproduce it, almost in full, because she deserves the space in print that the *Observer* has repeatedly denied her: "I feel, given that I was one of the two 'leaders in the field' (flattering, but rather an exaggeration) reported as linking MMR to the rise in autism, that I should quite clearly and firmly point out that I was never contacted by and had no communication whatsoever with the reporter who wrote the infamous *Observer* article. It is somewhat amazing that my 'private beliefs' can be presented without actually asking me what they are. What appeared in the article was a flagrant misrepresentation of my opinions—unsurprising given that they were published without my being spoken to.

"It is outrageous that the article states that I link rising prevalence figures to use of the MMR [vaccine]. I have never held this opinion. I do not think the MMR jab 'might be partly to blame.' As for it being a factor in 'a small number of children,' had the journalist checked with me it would have been clear that my view is in line with Vivienne Parry of the JCVI [Joint Committee on Vaccination and Immunisation]. The 'small number' was misrepresented by being linked inappropriately and inaccurately with 'rise in prevalence,' leading readers to arguably infer that it is in fact NOT a small number!

"I wholeheartedly agree with Prof Baron-Cohen, and many of the posts and responses received to date, that the article was irresponsible and misleading. Furthermore I reiterate that it was inappropriate in including views and comments attributed to me and presented as if I had input into the article when I had not (and still have not) ever been contacted by the journalist in question. I am taking the matter under advisement."

Then the story takes one final, bizarre turn. The last "leading expert" is Carol Stott. She does believe that MMR causes autism (at last!). However, she is no longer even a "research associate" at the Autism Research Centre. Carol Stott works in Dr Andrew Wakefield's private autism clinic in America, and she was also an adviser to the legal team that failed in seeking compensation for parents who believed that MMR caused their child's autism. She was paid £100 000 of public money for her services. She

says her objectivity was not affected by the sum, but to me this is not the issue: it seems an astonishing pair of facts for the *Observer* to leave out of its original article. It is still not satisfactory for this kind of information to appear only one week later in the readers' editor's column. "Conflict of interest" is a situation, not a behaviour.

And were her views private, and unknown? No. Stott is so committed to the cause against MMR that when the investigative journalist Brian Deer exposed the legal payouts in 2004, although she had no prior contact with him, she spontaneously fired off a long series of swear-y emails titled "game on": "Try me, shit head . . . Beleive [sic] me, you will lose . . . so go fuck yourself." And so on.

I rang her with some trepidation, but when I got through I instantly and genuinely warmed to her. She regrets that many people have fallen into entrenched positions over MMR on both sides, including herself. But she's not a leading expert (as she herself agrees); she's hardly a senior Cambridge academic suddenly expressing a fresh and private concern (her views are perfectly public); and even she is very clear that this new research tells us nothing whatsoever about MMR causing autism.

Outside of the details, there is a wider story here. The media have diligently avoided writing anything on the negative findings in autism research. Instead they have chosen repeatedly to concoct huge stories from the "concerns" of "experts" and research that is unpublished and inaccessible, locked away in a box, where they can say what they like about it. They can even refuse—as the *Observer* has with my approaches—to actually show their evidence; and that is the absolute polar opposite of what science and evidence based opinions are about.

On this occasion I was able to go to the source, and debunk the *Observer's* claims: often, though, there is no such luck because these "new unpublished research" stories are concocted with the complicity of researchers from the anti-vaccine movement.

Whatever one might think about Andrew Wakefield, he was just one man: the MMR autism scare has been driven for a decade now by a media that over-emphasises marginal views, misrepresenting and cherry picking research data to suit its cause. As the *Observer* scandal makes clear, there is no sign that this will stop.

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ATLANTIC CROSSING Uwe Reinhardt

Getting America to take the shame

Film maker Michael Moore is to be thanked for holding up mirrors to the US healthcare system

Long before American film maker Michael Moore's *Sicko* opened at cinemas around the nation on 29 June (review *BMJ* 2007;335:47), his oeuvre had triggered a firestorm of protests from the right of the political spectrum. Its inhabitants still unquestioningly regard America's health system as the best in the world and routinely write off all other nations' health systems as "socialised medicine," a derogatory label in these latitudes.

To be sure, Michael Moore's juxtaposition of the government dominated health systems in Canada, Europe, and Cuba with America's more private, market driven health system would hardly pass the requirement of balance and robust evidence demanded by any peer reviewed, scholarly journal. When his camera is on the US health system the lens is relentlessly focused on the system's warts and never on its unblemished parts. Moore does the obverse when illuminating foreign systems. A viewer could be forgiven, for example, for believing that under the British NHS doctors are exquisitely well paid, patients pay nothing for the excellent care they receive promptly, and the only function of the cashier's window in medical facilities is to provide cash to patients on the way out. Much the same impression is conveyed on the other health systems, including Cuba's.

But Moore's series of movies on America's many warts do not seem to be intended as well balanced, scholarly treatises. Instead, like his earlier movies, *Sicko* should be seen as a plank swung squarely into the viewers' faces, to get their attention for one overarching question: "What have we Americans become as a people to allow so much callousness and outright cruelty in a health system that is abundantly endowed with resources—in many instances excessively well endowed—and, as most Americans must know, also is home to much human kindness and excellence?"

Can anyone in Canada, Europe, or Cuba imagine a hospital that calmly quotes a patient showing up with two sawn off fingertips a price of \$60 000 to repair one of the two fingers and a "bargain price" of only \$12 000 to repair the other, and then to ask this hapless, bleeding, and uninsured patient to make on the spot a rational consumer choice between three options: no service, repair of the "low cost" finger only, or repair of both the low cost and high cost fingers? (The "consumer" in the vignette chose the second option.)

To some dyed in the wool libertarian American economists, this scenario may be the ultimate dream of "consumer driven health care," based on the theory that patients can be retrained to act as smart, well informed consumers of health care. Elsewhere in the United States, this vignette is apt to be viewed as a source of national shame. No well balanced scholarly paper and no equally balanced testimony before Congress could ever kindle that sense of shame among Americans as well as Michael Moore does in *Sicko*.

Moore's vignettes should not be seen as rare and isolated instances. Several years ago the *Wall Street Journal* featured on its front pages a series of investigations by staff reporter Lucette Lagnado chronicling the plight of uninsured Americans in need of hospital care. One low income American, whose wife had been treated for cancer at a non-profit academic health centre, had incurred a hospital bill of some \$20 000. In the five years after her death, her husband—an unskilled, low paid worker—was mercilessly hounded by the hospital for payment of that bill. Although over the years he did pay installments adding up to nearly the original \$20 000, interest charges and legal costs had puffed up the amount owed to the hospital to over \$50 000. In another vignette, an uninsured

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waitress working at a pizza parlour had incurred a hospital bill of several thousand dollars as the result of a miscarriage. Fearful that a judge might force her to agree to an unaffordable payment schedule, she had failed to show up at a court hearing, whereupon she was arrested and briefly jailed.

To Canadians and Europeans it will be incomprehensible that in for-profit and non-profit hospitals alike, along with community pharmacies, bills for uninsured patients, who typically are from the lower income strata, are routinely twice or three times higher than the prices paid by private insurance companies. Jailing a mother of two over an unpaid hospital bill caused by a miscarriage would be even more incomprehensible. Surely it can fairly be asked, as Moore does, why these harsh edges are necessary in a system that spends almost twice as much per capita on health care as does neighbouring Canada and many times more than comparable European countries. Indeed, it can be asked what Canada's or Europe's health systems could offer their citizens if, like the United States, they chose to allocate 16% of their gross domestic product to health care, rather than the 9% to 10% these countries actually spend.

It remains to be seen what impact Moore's *Sicko* ultimately will have on the forthcoming debate over health reform in the United States, and on the plight of underprivileged people in America on obtaining health care. Meanwhile, Americans should be thankful that Moore uses his talent and his financial resources to hold up mirrors in which they can behold the blemishes in their complexion. It is one necessary step on the way to a better countenance.

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