

# The distorting lens

How does it feel when your vital research is misrepresented or distorted? Is it worse if the culprit is a "serious" newspaper? After a recent encounter, autism researcher **Simon Baron-Cohen** wonders if the media (yes, including *New Scientist*) is trapped in sensationalism – and if something needs to be done about it

WHEN media reports state that scientist X of Y university has discovered that A is linked to B, we ought to be able to trust them. Sadly, as many researchers know, we can't.

This has three serious consequences. For starters, every time the media misreports science, it chips away at the credibility of both enterprises. Misreporting can also engender panic, as people start to fear the adverse consequences of the supposed new link between A and B. Lastly, there can be a damaging effect on researchers' behaviour. Funding agencies and science institutions rightly encourage scientists to communicate with the media, to keep the public informed about their research and so foster trust. If their work is misrepresented, they may withdraw into the lab rather than risk having to spend hours setting the record straight.

I work in one of those sensitive areas of research, autism, in which the facts are liable to be misrepresented or – sometimes worse – misinterpreted. Our problems go back to 1998 with a report in *The Lancet* by Andrew Wakefield and his colleagues of what appeared to them to be a link between autism and the MMR vaccine. Subsequent research failed to support this association, so given the huge potential risk to public health in raising parents' anxieties about the safety of the MMR vaccine – plus the fact that with hindsight most people thought the media had got it very wrong – I had expected responsible journalists would be reluctant to give the MMR/autism story much further coverage. I was wrong. The media kept the story alive, despite the fact that evidence supporting it was tenuous at best, or even downright contradictory.

The MMR/autism story is perhaps not an example of misreporting per se, more one of amplification or exaggeration of the risks, but

even so its effect has been serious. Parental fears about the reported dangers of MMR led to a fall in the number of British toddlers being vaccinated to below the level needed for "herd immunity", with a consequent dangerous increase in the number of cases of measles.

What seems clear is that for some parents of children with autism, this story provides a convenient explanation for why their child developed the condition. A minority of such parents refuse to let go of the theory, not least because it is difficult if not impossible to falsify conclusively. Such parents ignore counter-evidence and see the doctors like Wakefield who still defend the link as lone heroes fighting the establishment, while researchers who are not conducting studies into the MMR/autism link are seen as part of a conspiracy to hide the truth. This drama is perfect for newspapers wanting compelling stories that will run and run.

My personal experience of the misreporting of autism research occurred on 12 January this year, when one of the UK's serious newspapers, *The Guardian*, used its front page to report our new study, published in the *British Journal of Psychology*. This showed a positive correlation between levels of fetal testosterone (measured via amniocentesis) and the number of "autistic

## PROFILE

Simon Baron-Cohen is director of the Autism Research Centre at the University of Cambridge. For his PhD, he worked with psychologist Uta Frith on the theory that autism entails difficulties in understanding other minds. He went on to argue that autism is an extreme form of the "male brain" (*The Essential Difference*, Penguin, 2003). His latest book is *Autism and Asperger Syndrome: The facts* (OUP).







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### Simon Baron-Cohen felt forced to complain about how his team's work was represented

traits" the child shows post-natally. These are not necessarily indicative of autism: children with autism have a high number of them, but our children were all developing "typically" – that is, they did not have autism.

The study followed 235 children whose fetal testosterone levels are known because they were measured in the amniotic fluid. It is important to stress that these children did not have autism, and that what was being measured was how sociable and communicative they were, as well as how easily they could switch attention, recall small details and enjoy fiction.

While the reporters who wrote the article understood the design of the study, it didn't stop the subeditors devising a headline which announced, wrongly, "New research brings autism screening closer to reality", while the strapline read, "Call for ethics debate as tests in the womb could allow termination of pregnancies". The front page also featured a photo of a fetus – an emotive image bound to trigger interest in everyone from campaigners against abortion, parents (especially those expecting babies), and readers curious about what scientists are doing to babies at such a vulnerable stage. What did the caption say? "The discovery of a high level of testosterone in prenatal tests is an indicator of autism."

As the senior author of this study, which had nothing to do with autism screening, let alone prenatal autism screening, I was saddened to see how the report was headlined. Sadness turned to shock at the statement that high prenatal testosterone predicts that the fetus will develop autism. The study had not looked at diagnosed cases of autism, only at children developing typically. It had not found that a high level of fetal testosterone predicts autism: it had simply found a correlation between individual differences in the hormone levels (we all have testosterone, some more than others) and individual differences in sociability, communication skills, attention to detail, attention-switching and interest in fiction. Inside the paper it got worse. There I found an article elaborating on the study and on autism, this time with the headline: "Disorder linked to high levels of testosterone in the womb".

The blatant distortions in headlines and picture captions forced me to write to the newspaper – which quickly agreed to publish a response from me. I say "forced" for two reasons. At the research centre we received distressed emails from readers. Some were offended because the report implied that our

research had a sinister eugenics agenda; it does not. Others came from anxious pregnant women who wanted to get hold of this prenatal test to find out if their fetus would develop autism; there is no such test.

I felt it important to set the record straight, not least because our team had spent 10 years on this unique study, with consent from the women whose amniotic fluid had been analysed and whose children were assessed. We had patiently designed the study to comply with the stringent requirements of hospital ethics committees. After the care that four PhD students had taken addressing the delicate question of whether fetal hormones affect the mind and brain, it seemed like a slap in the face for their work to be treated in such a heavy-handed and irresponsible manner.

So how did *The Guardian* get it so wrong? First, because the headline writers went beyond the data to create a simple, bite-size but inaccurate message. Second, because they fused two issues that should have been kept separate: the study itself, on prenatal hormonal effects in children developing typically; and the issue of autism screening.

### "Should the media be as regulated as scientists since it, too, can do harm?"

While the journalist concerned made it clear in her article that these were separable issues, the headline and caption writers ignored such niceties and went for bold sensationalism.

Later that week I got a call from the British Psychological Society's press office, worried their press release about our study may have led to this misrepresentation. I reassured them they had done nothing wrong. The press officer was alarmed at how other newspapers, magazines and websites had repeated the headlines from *The Guardian*. They were also worried scientists might be put off from talking to journalists, and held a discussion of the issues in their magazine, *The Psychologist*.

It has left me wondering: who are the headline writers? Articles and columns in newspapers are bylined so there is some accountability when they get things wrong. In this case, it was a nameless headline writer who seems to be to blame. Did he or she actually read the journalist's article?

Scientists are rightly regulated by ethics committees because they can do harm to the public. The media too has the potential to do harm. Should there be some similar before-the-event regulation here too? ■