

Evidence from the Science Media Centre to the Select Committee on Clinical Trials

May 2013

1. Introduction

The Science Media Centre (SMC) was set up in 2002, in the aftermath of public controversies on BSE, GM crops and MMR, and in response to recommendations in the House of Lords Science and Technology Select Committee's 2000 report on science and society. Its aim is to support and encourage more experts to engage with the media more effectively in times of crisis and controversy, in order to ensure that the public get access to accurate and evidence-based information through the news. In over 10 years of responding to stories such as the Northwick Park clinical trial disaster, claims of cloned human beings, the HPV vaccine scare, swine flu, antibiotic resistance, hybrid embryos, and the recent horsemeat scandal, we have built up a huge body of expertise.

As an organisation we support openness and transparency in science generally, but we do not have a view on how clinical trials could be made more open to scrutiny or who should be responsible for making that decision; we have limited our comments to the aspects of the inquiry where we have experience, namely the portrayal of information and results from clinical trials in the media, and the opportunities and challenges this brings.

2. Reporting Science in the Media

Science is at the heart of almost all the major challenges we face as a society: how to treat incurable diseases, how to feed the growing population, how to tackle climate change. Despite the rapid rise of social and new media, surveys continue to show that the public get most of their information about science from the mass media, including television and newspapers¹. This likely includes information about clinical trials, and many of the news stories the SMC deals with include reporting of clinical trials; from research into cutting edge new treatments to trial safety and regulation.

The MMR scare of the late 1990s is one of the most well-known examples of how media reporting can influence the public on science and health issues. Vaccination rates dropped from 92% to 80% after the scare, and cases of measles in England and Wales rose from 56 in 1998 to 1,370 in 2008²; the recent measles epidemic in Wales highlights the lasting effects of the story. While the media was not solely responsible for the scare, and lessons have been learned by all concerned, some of the underlying values still remain in parts of our newsrooms: the appetite for a scare story, the desire to overstate claims made by one individual, the reluctance to put one alarming story into its wider context, 'journalistic balance' that conveys a divide among experts where there is none, and so on. The recent Leveson Inquiry provided a chance to reflect on the impact of the culture and practice of the press, and underlined the huge potential the media still have to influence public opinion on a wide range of issues.

3. Clinical Trials in the Media

Despite the large number of clinical trials carried out all over the world, the vast majority only hit the headlines when they become controversial or produce surprising, counterintuitive or unexpected results. There are obvious examples such as the trial at Northwick Park Hospital of the experimental drug TGN1412 in 2006 that ended after several participants developed severe immune reactions; or trials on the use of new cutting edge technologies such as embryonic stem cell treatments for spinal cord injury. For obvious reasons, and in reflection of a similar bias seen elsewhere in clinical trial reporting in academic journals, the media also tend not to report those clinical trials that replicate previous results, nor those that produce negative findings, despite their possible scientific importance.

¹BIS Public Attitudes to Science 2011: <http://www.bis.gov.uk/policies/science/science-and-society/public-attitudes-to-science-2011>

² Figures from the Health Protection Agency - <http://tinyurl.com/5uylxdc>

The way in which many parts of the news media cover clinical trials illustrates several of the newsroom values mentioned above: the appetite for controversy and the focus on individual cases without placing them within their wider context. Media articles can overestimate the importance of results, suggesting that early stage safety trials imply a treatment is much more successful or near to fruition than it might actually be. For example, an early stage safety – not efficacy – trial of stem cells for treating blindness was reported in the Independent last year under the following headline: “Once they were blind, now they see. Patients cured by stem cell miracle.”³ Former science reporter Gary Schwitzer has come up with seven words that should never appear in medical news reporting: Cure, Miracle, Breakthrough, Promising, Dramatic, Hope, Victim. This is probably overly idealistic, as many of these words are what draw readers to medical stories in the first place, but Schwitzer's article is worth reading as a summary of where science stories can mislead readers.⁴

Last year the SMC submitted evidence to the Leveson Inquiry on the issue of science reporting in the media⁵. Following this, the Centre worked with journalists, subeditors and scientists to produce a set of guidelines for good health and science reporting. These include putting a study into its proper context (for example, stating whether something is a Phase I or Phase IV trial), and the need to make clear its size and nature. Central to our guidelines is that extraordinary claims require extraordinary evidence. These guidelines are included at the end of this document and have been welcomed by many.

The need for accurate and fair reporting of clinical trials applies as much to science communicators and press officers as to journalists. Many misleading stories about clinical trials and related studies can be traced back to a misleading press release. It is important that those publicising clinical trials to the media and the public do not oversell the importance and potential impact of a trial; there is a responsibility to not press release early stage trials without very good reason.

However, the SMC also see issues in the headlines as an opportunity to inform the public and policymakers about key issues, and encourages experts to engage, irrespective of how complex or controversial a story becomes. The UK is lucky to have a huge number of excellent specialist science and health journalists, across news outlets from tabloids to major broadcast organisations, and much of the coverage of clinical trials, whilst sometimes subject to a degree of hype or unwelcome headlines, is also full of accurate, evidence-based information as a result. These specialists are a dedicated and skilful group of journalists who, despite the pressures of the newsroom and editorial lines, take pride and responsibility in getting science stories right. The previously mentioned article in the Independent may have carried a very strong headline that over-claimed for the impact of the trial, but it was full of lots of detailed information about the trial in question. The current science media environment is a very different one to that which saw the confusion and media frenzy over MMR at the end of the 1990s.

Dr Helen Jamison, Deputy Director, Science Media Centre

Science Media Centre

215 Euston Road

London NW1 2BE

www.sciencemediacentre.org

The Science Media Centre is an independent venture working to promote the voices, stories and views from the scientific community to the news media when science is in the headlines. Over 80 supporters including scientific institutions, media groups, charities, universities, corporate organisations and individuals fund the Centre, with donations capped at 5% of the running costs to preserve its independence. Science Media Centre is a registered charity (no. 1140827) and a company limited by guarantee (no. 7560997). Registered in England and Wales.

³ <http://www.independent.co.uk/news/science/once-they-were-blind-now-they-see-patients-treated-with-cells-from-human-embryo-6293706.html>

⁴ <http://www.healthnewsreview.org/toolkit/tips-for-understanding-studies/7-words-and-more-you-shouldnt-use-in-medical-news/>

⁵ Science Media Centre Evidence to the Leveson Inquiry: <http://www.levesoninquiry.org.uk/wp-content/uploads/2012/01/Witness-Statement-of-Fiona-Fox.pdf>



10 best practice guidelines for reporting science & health stories

The following guidelines, drawn up in consultation with scientists, science reporters, editors and sub editors, are intended for use by newsrooms to ensure that the reporting of science and health stories is balanced and accurate. They are not intended as a prescriptive checklist and of course shorter articles or NIBs will not be able to cover every point. Above and beyond specific guidelines, familiarity with the technicalities and common pitfalls in science and health reporting is invaluable and every newsroom should aim to employ specialist science and health correspondents. Wherever possible the advice and skills of these specialists should be sought and respected on major, relevant stories; the guidelines below will be especially useful for editors and general reporters who are less familiar with how science works.

- State the source of the story – e.g. interview, conference, journal article, a survey from a charity or trade body, etc. – ideally with enough information for readers to look it up or a web link.
- Specify the size and nature of the study – e.g. who/what were the subjects, how long did it last, what was tested or was it an observation? If space, mention the major limitations.
- When reporting a link between two things, indicate whether or not there is evidence that one causes the other.
- Give a sense of the stage of the research – e.g. cells in a laboratory or trials in humans – and a realistic time-frame for any new treatment or technology.
- On health risks, include the absolute risk whenever it is available in the press release or the research paper – i.e. if ‘cupcakes double cancer risk’ state the outright risk of that cancer, with and without cupcakes.
- Especially on a story with public health implications, try to frame a new finding in the context of other evidence – e.g. does it reinforce or conflict with previous studies? If it attracts serious scientific concerns, they should not be ignored.
- If space, quote both the researchers themselves and external sources with appropriate expertise. Be wary of scientists and press releases over-claiming for studies.
- Distinguish between findings and interpretation or extrapolation; don’t suggest health advice if none has been offered.
- Remember patients: don’t call something a ‘cure’ that is not a cure.
- Headlines should not mislead the reader about a story’s contents and quotation marks should not be used to dress up overstatement.