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Memorandum

LEVESON INQUIRY: CULTURE, PRACTICE AND ETHICS OF THE PRESS

1. Introduction

1.1 This is a submission on behalf of Sense About Science. Sense About Science is a charitable trust that equips people to make sense of scientific and medical claims in public discussion. With a database of over 5,000 scientists, from Nobel Prize winners to postdocs and PhD students, we work in partnership with scientific bodies, research publishers, policy makers, the public and the media, to promote sound science and evidence in public discussions. We are concerned with the impact that the media, among others, have on public perception of science and health.

1.2 Lord Justice Leveson has stated that "it could be said that reporting which is not evidence-based is inaccurate within the meaning of the editors' code" and we agree. This memo is based on observations from our work and the enquiries we receive from members of the public and many intermediaries, including journalists, patient groups and community groups. Every year we respond to over 500 enquiries, many of which are concerned with media coverage on subjects such as vaccination, nuclear energy, genetics or environmental effects. Some examples of questions we receive are: "Is this a scare story?", "Is this something we should be warning people about?", "Do these people represent the majority of scientific opinion?" and "It says here it's from scientific research – how can I tell whether that's true?" Many of the questions we receive, concern the status of evidence that is being reported or whether there is evidence for a claim. The public want to make sense of the news reports about scientific issues but they are often left confused or cynical about what to take notice of, particularly in relation to environmental and public health matters.

2. Accuracy is vital in science and medical reporting

- 2.1 Print and broadcast media are still a significant source of health and scientific information; however, people regularly use the internet to look further into a specific scientific or health topic¹. In relation to health issues, online information has become very significant: it is now commonplace for people with a medical concern or condition to look up information on the internet. Surveys have shown that 80% of internet users gather health information online². The internet offers a permanent record of media stories, which means unlike some other areas of news and reporting, articles containing mistakes or inaccuracies will continue to be accessed by the public in a proactive search for information.
- 2.2 From our experience we have found that people with chronic conditions are particularly susceptible to coverage of alleged medical breakthroughs. Their struggles with conditions for which there is no cure creates a ready market for those generating false hope, not just for products and therapies that are not founded on sound science and evidence, but for the media promoting them. We have also observed that campaigners and advertisers cite media articles to back up their claims (for example, 'as featured in the *Daily Mail*'), placing further importance on accurate reporting.
- 2.3 Good reporting of science and medicine is in the public interest and the consequences and cost of inaccurate reporting can be significant. The media storm and campaigns which followed the press conference by Andrew Wakefield in February 1998 about a (subsequently retracted) 12 patient case series in *The Lancet*, which put forward a link between the MMR vaccine and autism, led to a significant drop in MMR vaccination rates. Rates fell to a low in 2003-04 and despite increases in recent years "MMR coverage is still lower that in the mid 1990s" and lower than the World Health Organization target of more than 95% coverage³. A review of media coverage of the MMR vaccine dispute argued that "the media's critical scrutiny of those supporting MMR was not matched by a rigorous examination of the case against it, and that the public was, as a consequence, often misinformed about the level of risk involved"².
- 2.4 The issue of 'false balance' around the reporting of the Wakefield paper on MMR was referred to in the BBC Trust review of impartiality and accuracy of the BBC's coverage of

¹Ipsos MORI/Department for Business, Innovation and Skills, Public Attitudes to Science 2011 http://www.ipsos-mori.com/Assets/Docs/Polls/sri-pas-2011-summary-report.pdf [accessed 16th January 2012]; NSF, Science and Engineering Indicators 2008, Chapter 7: Science and Technology: Public Attitudes and Understanding, http://www.nsf.gov/statistics/seind08/c7/c7s1.htm [accessed 16th January 2012]

² PEW Research Centre Report, 2011, Heath Topics

http://www.pewinternet.org/Reports/2011/HealthTopics.aspx [accessed 12th December 2011]

³ NHS Immunisation Statistics England 2010-11, The Health and Social Care Information Centre, Screening and Immunisations team

http://www.ic.nhs.uk/webfiles/publications/003 Health Lifestyles/Immunisation%20Stats%202010-11/Immunisations Bulletin 2010 11 v1 2.pdf

science by Professor Steve Jones⁴. It refers to the "non-contentious" nature of some stories and the need to avoid giving "undue attention to marginal opinion". As well as the coverage of claims about the safety of the MMR vaccine, Jones cites more recent coverage of claims about the safety of GM crops and the existence of man-made climate change as examples on this point. For reporting to be impartial, he argues, there is a need for consideration of "due weight" of different views, not just presenting two sides of an argument. It is important not to resort to 'false balance', by which the relative weight of different opinions, or evidence, is not reflected in the reporting and minority views are given equal weight.

2.5 It is not possible (nor desirable) to prevent people from encountering a wide range of information about science and health on the internet and in the news media. It is not feasible to quality-assure such information and would likely be counter-productive to try. This makes it all the more important that journalists interrogate research findings and scientific claims they are reporting, to ensure that not only the conclusions but also the *status* of the findings is conveyed to the audience. This is because the status of the findings is as important as the findings themselves. Science is constantly changing and self-correcting as scientists critically analyse, attempt to replicate or out-mode methods used in previous studies.

2.6 We have found that discussing the status of evidence and equipping people with the tools to be able to question information helps them to evaluate claims in the media without undue cynicism. Many science and health journalists do now refer to the journals in which research has been published and ask whether a study has undergone peer review (and therefore the methodology and results have been published)⁵. There are other indicators that can help a reader make sense of science and health stories: has a piece of research been replicated by others, does a particular study fit in with what we already know, is it based on three people or five thousand? Is the headline consistent with the story? Are there quotes from experts in the field?

2.7 Many of the misleading science claims we see occur in other parts of reporting than science and health. This is where we often see a failure to look into claims or present them in context of the body of scientific evidence. On 20th November 2011 the *Observer* carried a full-page first-person piece by music writer Luke Bainbridge told to another journalist. In it he described how his 4-year old niece had been found to have an inoperable brain tumour and the family had decided to try treatment, called antineoplaston therapy, offered by Dr Stanislaw Burzynski at his USA clinic. This treatment costs up to £200,000, and the family was raising the money "through the generosity of thousands of people touched by the story of this little girl and the help of celebrities and well-known bands". What the story did not

⁴ BBC Trust, July 2011, BBC Trust review of impartiality and accuracy of the BBC's coverage of science http://www.bbc.co.uk/bbctrust/our_work/other/science_impartiality.shtml [accessed 12th December 2011]

³ Sense About Science, 2006, I Don't Know What to Believe

http://www.senseaboutscience.org/resources.php/16/i-dont-know-what-to-believe [accessed 12th December 2011]

discuss was the lack of evidence for this treatment; antineoplaston therapy is not licensed as a cancer treatment by the US Food and Drug Administration (FDA). The story prompted concerns from scientists and organisations such as Cancer Research UK. A similar story appeared in the *Evening Standard* on 14th December 2011, and again referred to the Burzynski clinic's treatment with no mention that the scientific evidence does not support claims that antineoplaston therapy is effective in treating or preventing cancer. Misleading coverage of a medical treatment can lead to people putting their savings, energy and hope into a treatment that has no basis in evidence.

3. Protecting reporting in the public interest

3.1 For the public to be able to make informed decisions about everything from their health to a proposed new technology, it is essential that there is an open discussion about evidence and the nature of evidence in the media. At the same time as addressing the problems of accuracy, the open discussion itself needs protection. The current libel laws are a barrier to this and this is why we are part of the Libel Reform Campaign, together with English PEN and Index on Censorship. Journalists are central to communicating research findings and scientific issues to the public and we need a strong public interest defence to libel to allow journalists to scrutinize individuals and organizations making claims based on poor evidence or promoting unproven treatments.

4. Corrections and the Press Complaints Commission

- 4.1 There is a tension between a nuanced understanding of what research has found and what makes a good news story, unencumbered by caveats. This creates problems and challenges but many journalists resolve this effectively and good science is communicated daily in the press, from *The Sun* to the *Guardian*; it is quite possible to convey research and scientific matters accurately whilst simplifying.
- 4.2 However, when reporting is not accurate, it should be possible to request a correction. Ensuring that people have access to accurate scientific and medical information means correcting misleading stories. At the moment, it is not possible to make a complaint to the Press Complaints Commission (PCC) unless you are directly affected. We would request the Leveson inquiry to look at broadening the basis upon which the public can request corrections. Whilst we understand that the PCC cannot become embroiled in arbitrating scientific disputes, when there is a clear inaccuracy it should be possible to insist on a correction.
- 4.3 We work with over 5,000 scientists and many scientific bodies and organisations and would be willing to provide advice to the PCC to inform their decisions on science and health matters; we have done this for other bodies such as Clearcast, which monitors television advertising.

5. Case study: a story that turned out to be false

- 5.1 The inquiry requested submissions to address the issue of stories that attract a high degree of press attention but subsequently turn out to be false and we address a specific example.
- 5.2 In September 2009, the media reported that a girl had died shortly after receiving the HPV vaccine. Headlines included "Schoolgirl dies after cervical cancer vaccination" (Guardian), "Schoolgirl, 14, dies after being given cervical cancer jab" (Daily Mail) and "Cancer jab alert after girl dies" (BBC). The stories linking the vaccine to her death subsequently turned out to be false: the post-mortem examination concluded the girl had a pre-existing condition, a tumour in her chest and that the vaccine was not responsible for her death.
- 5.3 Even though later stories explained that she had a fatal underlying condition, the false link between the vaccine and her death had already been made. When reporting her death and linking it to the vaccine, many stories did not reflect the context of what we know about the HPV vaccine and its safety (the vaccine is an effective means to protect women against HPV, which is the leading cause of cervical cancer; the vaccination programme is expected to save around 400 lives per year⁶). The impression given was that the vaccine had led to her death. This again is an example that re-occurs when concerned or curious parents of young girls, or young girls themselves, search the Internet for more information.

6. Conclusions

- 6.1 We agree that reporting which is not evidence-based is inaccurate within the meaning of the editors' code.
- 6.2 We think that the recommendations in Professor Jones' recent BBC Trust review of science reporting are relevant to all media, particularly in relation to false balance and context. We would add that reporting the status of research is as important as reporting findings.
- 6.3 We recommend a public interest defence to libel which would protect journalists, scientists, science writers and communities discussing the merits of claims about research findings, research conduct, medical treatments, product efficacy and so on. We hope that the report of the Leveson Inquiry will support the Government's promise to bring forward libel reform urgently in 2012 and the work that the Ministry of Justice has done to that end. In our publications and contributions to this work we have looked in some detail at questions of responsibility and correction in relation to liability and would be happy to provide a further note on the options under consideration once the Ministry of Justice

⁶ HPV vaccination, NHS choices http://www.nhs.uk/conditions/hpv-vaccination/pages/introduction.aspx [accessed 12th December 2011]

publishes its response to the Scrutiny Committee. In any event, it is only an adjunct to the wider need for recourse on matters of accuracy.

6.4 We recommend that the basis upon which corrections can be required by the PCC should include inaccuracy per se. Whilst we understand that the PCC cannot become embroiled in arbitrating scientific disputes, when there is a clear inaccuracy it should be possible to insist on a correction. There is precedent for this in advertising standards.

Statement of Truth

I believe the facts stated in this witness statement are true.
Signed
Date27 th January 2012
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6