

Evidence from the Science Media Centre to the Review of the Liverpool Care Pathway

April 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.

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 in this area and hope that this evidence will be useful to your review of the Liverpool Care Pathway (LCP). Although the role of the media may not strictly be within the terms of reference, it is important to consider how attitudes to the Pathway have been influenced by the media and the wider context of how the media has affected recent societal debate around end of life care.

Science and evidence are 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. The same is also likely to be true of information specifically about medical and health issues, and a significant proportion of news stories the SMC deals with on a daily basis concern public health issues, such as diet, wellbeing, disease and treatment.

The MMR scare of the late 1990s is one of the most well-known examples of how media reporting can influence public attitudes and behaviour. 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 press³, and underlined the huge potential the media still have to influence public opinion on a wide range of issues.

2. The Liverpool Care Pathway in the Media

Despite having been a standard care pathway within the NHS since its development in the 1990s, the LCP really only hit the headlines as a major controversy in October 2012. Regardless of numerous new research studies into end of life care published by the medical and scientific profession over the years, in addition to other opportunities for discussion, the LCP only hit the headlines because of the development of a 'row', which instantly made it more newsworthy.

¹ BIS 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>

³ Science Media Centre Evidence to the Leveson Inquiry: <http://www.levesoninquiry.org.uk/wp-content/uploads/2012/01/Witness-Statement-of-Fiona-Fox.pdf>

⁴ Cancer and the Media, How does the news report on treatment and outcomes?: <http://www.ncbi.nlm.nih.gov/pubmed/20233800>

This is true for many science and health issues that find their way onto the front pages or topping the television news bulletins. For example, reports about the day to day realities of cancer treatments or end of life discussions rarely appear in the national news⁴, yet stories about the denial of drugs from patients feature regularly.

The row over the LCP was precipitated by a number of stories in the Mail and other newspapers documenting individual cases of patients being wrongly put on the so-called “pathway to death”. The controversy deepened when it was revealed that many NHS Trusts were apparently receiving financial incentives to place patients on the pathway. These revelations placed the LCP firmly on the front pages, and the debate over its use within the NHS was painted firmly as a scandal. A selection of headlines from the Mail include: “I survived the death pathway”, and “Hospitals bribed to put patients on pathway to death”, while several news outlets began referring to the LCP as a form of euthanasia.

The way in which many of the media framed concerns about the LCP 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. Whilst very compelling and undoubtedly important, the focus on a small number of individual stories ignored other cases where patients and their families had benefited from the LCP, thus giving a false impression that all experiences were negative. It also did very little to tease apart whether the problems lay with the LCP itself or the manner in which it was supported and delivered across different hospitals and by differently trained staff.

The influence of such media coverage on public debate is not insubstantial. As previously discussed, many of the public get much of their information about science and health from the mainstream media. More specifically, experts working in palliative medicine whom the SMC spoke to at the time said that the effects of the media coverage were being felt in their daily working lives; patients and families fearful of being put on the LCP, possibly even avoiding treatment because of this anxiety, and doctors reluctant to place patients on the pathway for fear of being drawn into the controversy or scaring their patients. At the SMC we regularly see similar situations where the media coverage has a significant influence on public attitudes. In addition, media coverage often has a significant impact on policymaking, and it was understood by many at the time that the review of the LCP was only announced as a direct response to the media furore, rather than a strategic analysis of a care pathway that was due to be reviewed.

However, at the SMC we also see issues in the headlines as an opportunity as well as, or even rather than, a threat. When a story finds its way onto the front pages, whether experts like it or not, that is when the public and policymakers are paying attention. The SMC therefore encourages experts to engage, irrespective of how messy or controversial a story is becoming; we believe that the media will ‘do’ science better, when scientists ‘do’ the media better, by rolling their sleeves up and getting involved in the debate.

The row about the LCP that played out in the media thus provided an opportunity for experts to engage, and communicate accurate and evidence-based information to the public. In January 2013, the SMC held a press briefing on end of life and palliative care, to which we invited the specialist science and health correspondents from the UK national news outlets. This briefing gave experts and journalists chance to discuss end of life care and the LCP with the space and time to go into detail; and in particular, gave the palliative care experts on the panel a chance to talk about where the evidence around the LCP actually lies and to raise any points that had previously been missing from the media debate. This briefing did not take the issue away from the front pages or play it down – and nor should it have done – but it served to ensure that coverage was better informed and less sensational. The opportunity for discussion was also seized upon by other experts working in the field, leading to better

informed articles in some newspapers and more detailed analyses of the issues on programmes such as Newsnight and Dispatches.

Openness and transparency about difficult issues can feel counter-intuitive in the midst of a media “feeding frenzy”, but the SMC is convinced that the benefits of greater openness outweigh the risks. We now have a decade of examples to show that greater engagement, no matter how difficult, benefits public understanding.

3. Conclusions

The mainstream mass media have a huge capacity to influence public attitudes and behaviour, and this has been as true in the case of the LCP as it has with other complex science and health stories. It is imperative that experts engage the media fully and openly about the LCP and end of life care more widely – particularly because it is such a sensitive issue that affects us all. That means having the best experts available and willing to communicate about the evidence and its wider context, especially when there is uncertainty, and not leaving a vacuum to be filled by others who have different agendas to promote.

Sensitive issues such as the LCP should not be treated as a special case by journalists, but we do believe that for stories of such great public interest the highest standards of journalism need to be applied. For this reason it is crucial that experts continue to work with the excellent science and health reporters across UK national news outlets. The SMC recommends that experts working in palliative care within the NHS and academia have access to media relations support, and that those advising Government have access to independent support to allow them to fulfil their dual role of advising policymakers as well as informing the media.

Public opinion polls reveal a high level of trust for doctors and scientists, and yet people feel ill-informed and are keen to be given more information by those with the best expertise. The current review of the LCP is therefore an opportunity to lead the way in public engagement on a complex issue, and to better inform the societal debate on end of life and dying.

We hope this evidence will be useful to your review and would be happy to give evidence in person if that would be useful.

Dr Helen Jamison
Deputy Director, the Science Media Centre

Science Media Centre
215 Euston Road
London NW1 2BE
Tel: 020 7611 8305
helen@sciencemediacentre.org
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.