Chapter 9

Communication of research and the media

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Chapter 9 - overview

The novel neurotechnologies discussed in this report attract considerable media attention. We consider issues raised by the reporting and representation of scientific research in the popular and non-specialist media. In particular we look at the representation of novel neurotechnologies and the possible impacts of these representations.

The ways in which science and technology are reported and framed in the media may help to shape public understanding and expectations and to influence social norms and the policy and investment landscapes. However, it should not be assumed that media representation determines public attitudes in straightforward or predictable ways.

Some of the ways in which science is reported in the media can be attributed to the pressures upon journalists in an increasingly competitive and accelerated media environment. The demands of this environment can, for example, lead to uncritical reproduction of press releases. Scientists themselves are increasingly engaged in the public communication of science. However, the political and economic pressures on academic researchers to demonstrate the practical and economic impacts of their work can encourage practices that lead to misleading reporting of research evidence through premature emphasis upon commercial applications, or publication bias towards positive or newsworthy findings. These combined factors can contribute to a cumulative spiral of hype.

Some of the hallmarks of poor science reporting practices in general are evident in communication about novel neurotechnologies. These include: headlines that misrepresent research, stories that emphasise the benefits of interventions without mentioning risks or longer-term uncertainties, speculation and extrapolation beyond the evidence and lack of contextual balance in the use of compelling images or personal stories.

Social media might be assumed to provide a more direct connection between scientific researchers and the public and an outlet for personal stories. Indications are, however, that content about novel neurotechnologies on social media platforms is significantly populated by commercial and academic organisations promoting therapeutic services and innovations.

Using the media to promote research into novel neurotechnologies may encourage investment and foster inventiveness, but hype can also be harmful. For example, it may offer false hope to patients and those close to them by failing to alert them to the limits or risks of current technological capabilities. This in turn may undermine their abilities to make informed, autonomous treatment choices. Wider risks include loss of public trust in these technologies and engendering misplaced conceptions that individuals are reducible to their brain functions. Communication practices, therefore, need to exhibit the virtues of humility and responsibility no less than clinical research and care practices do.

Responsible communication of the capabilities of novel neurotechnologies should not only include accurate, evidence-based reporting, but it should also take account of the possible personal and social impacts of the (mis)representations of the capabilities of these technologies. These impacts provide a particular ethical dimension of the ways in which novel neurotechnology research is framed by the media. We recommend that the behaviour of researchers, press officers and journalists involved in the communication of novel neurotechnologies should be informed by humility and responsibility, exercised through reflecting on how their representations of these technologies might contribute to cumulative hype. Points on which to reflect include: vigilance for institutional pressure to hype; the need to contextualise compelling, but potentially misleading, images; attention to use of language that might prematurely imply availability of effective treatments; and recognition that novel neurotechnologies may not be the preferred therapeutic route for every eligible patient (paragraph 9.72).

In addition to research institutions and journalists, we recommend that two further groups of actors should reflect on their role in practices that might drive hype: policy makers and higher education funding councils in framing the value of research in relation to the impact agenda (paragraph 9.73); and commercial enterprises in seeking to attract investment and promote their products (paragraph 9.74).

Introduction

9.1 Novel neurotechnologies attract a great deal of media attention. For example, deep brain stimulation (DBS) has generated claims of patients being "walking miracles";[936] transcranial magnetic stimulation (TMS) has been reported to awaken a "car crash victim from [a] coma";[937] and brain-computer interfaces (BCIs) are the subject of stories such as "BrainGate gives paralysed the power of mind control".[938] It is also reported that neural stem cell research "can rescue the memory from Alzheimer's disease".[939] The majority of media coverage emphasises the potential *therapeutic* benefits of the novel neurotechnologies we consider in this report. However, as we observe in Chapter 8, there are also reports of potentially exciting or sinister applications in non-therapeutic settings, such as the portrayal of the brain as "the next hacking frontier".[940]

9.2 The aim of this chapter is to explore the representation of novel neurotechnologies in the popular, non-specialist media and the possible impacts of this. We locate this discussion in the wider social contexts that influence the nature of these representations, in particular the communications and publications strategies of academic institutions. This chapter concentrates predominantly on traditional print and broadcast media; though we also briefly consider the emerging role of social media in conveying the role and promise of novel neurotechnologies.

9.3 Although we focus our discussion on novel neurotechnologies, the issues addressed can usefully be explored in relation to a wide range of applications of science and technology. Over recent years, many controversies have arisen about how science has been represented by the media in the UK – for example, in debates about 'global warming',[941] 'mad cow disease', GM crops, or the MMR vaccine.[942] The media profile of issues such as these has caused major furore, impacting on stakeholders from politicians to scientists, and supermarkets to consumers. Intellectual and economic productivity have also played a particular role in this debate, by focusing on innovation in science and technology as significant national assets. For example, when the BBC Trust commissioned a review of its own coverage of science, the backdrop to this review was characterised in terms of the UK producing a tenth of the world's scientific research, and deriving a third of its GDP from science, technology, engineering, and mathematics.[943]

9.4 This chapter begins by mapping out why media representations matter at all, before discussing the role of scientists, press officers, and journalists in shaping the representations of science and technology. It then reviews some possible criticisms of the representation of emerging technologies in general, and neurotechnologies in particular. The chapter concludes

[936] Mail Online (7 January 2012) *Standing tall: battery-operated boy who can walk again after doctors 'rewired' his brain to stop his body twisting*, available at: http://www.dailymail.co.uk/news/article-2083523/Battery-operated-boy-walk-doctors-rewired-brain.html.

[937] The Telegraph Online (15 October 2008) *Magnet treatment awakens car crash victim from coma*, available at: http://www.telegraph.co.uk/science/science-news/3353412/Magnet-treatment-awakens-car-crash-victim-from-coma.html.

[938] The Observer (17 April 2011) *BrainGate gives paralysed the power of mind control*, available at: http://www.guardian.co.uk/science/2011/apr/17/brain-implant-paralysis-movement.

[939] The Telegraph Online (20 July 2009) *Stem cells can rescue the memory from Alzheimer's disease, claim scientists*, available at: http://www.telegraph.co.uk/science/science-news/5873215/Stem-cells-can-rescue-the-memory-from-Alzheimers-disease-claim-scientists.html.

[940] Wired (9 July 2009) *The next hacking frontier: your brain?*, available at: http://www.wired.com/wiredscience/2009/07/neurosecurity/.

[941] Boyce T (2009) *Climate change and the media*, *volume 5* (New York: Peter Lang Publishing Inc.); Holliman R (2011) Advocacy in the tail: exploring the implications of 'climategate' for science journalism and public debate in the digital age *Journalism: Theory, Practice and Criticism* **12(7)**: 832-46.

[942] Allan S (2002) *Media, risk and science*, volume 9 (Buckingham: Open University Press); Boyce T (2007) *Health, Risk and News, volume 9* (New York: Peter Lang Publishing Inc.).

[943] BBC Trust (2011) *BBC trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 4.

by proposing recommendations for the responsible representation of novel neurotechnologies in the media.

Why representation matters: the mechanisms of media influence

9.5 The quantity, and indeed prominence, of representations in the mass media have been shown to have an 'agenda setting' function – that is, telling the audience what to think *about*, even if not actually telling us *what* to think. This means that issues given significant media attention often become the focus for public concern and policy interest. In addition, patterns in the way in which the media represents the world can also cultivate particular understandings – for example, conceptions of what is safe or dangerous, desirable or undesirable. Underlying assumptions reiterated across diverse media outlets, such as 'economic growth is good' can come to seem like incontestable common sense.[944] Media influence also occurs through the so-called 'framing' of any representation, for example through tone, emphasis, narrative structure, language and images – often influenced by the key role played by scientists as news sources.[945] This framing can subtly shape how people understand, and respond to, an issue. A number of other quite simple factors have also been shown to be at work. For example:

- a single powerful headline or image can leave the reader or viewer with a strong sense of a threat or hope;[946]
- an emerging issue, described by analogy and linked to previous issues from the past, can create a powerful 'template' framing how people understand an issue as it unfolds;[947]
- a dramatic personal account can be particularly powerful, inviting identification and making people remember these stories disproportionately to more prosaic facts and figures;[948]
- clear provision of key facts can help people understand and assess the technology. However, gaps in information leave readers with a limited tool-kit for developing an informed opinion on an issue;[949] and
- where a narrow range of ethical debates are represented in the media, the ethical debates that fall outside the range are less likely to be discussed by the readers, listeners and viewers.[950]

9.6 As well as influencing understandings of the science itself, communication about a novel technology can also have a number of broader social implications. It may challenge or reinforce particular social norms, for example that a certain state of being is one that should be accepted or conversely, one we should seek to cure. Issues such as these have been brought into focus, for example, by debates about the existence of a 'gay gene'[951] or in the rejection of cochlear implants by parents in the deaf, sign language-using community who objected to imposition of standards of normalcy.[952]

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[944] Lewis J (2013) *Beyond consumer capitalism: media and the limits to imagination* (London: Polity).
[945] See: Allan S, Anderson A and Petersen A (2010) Framing risk: nanotechnologies in the news *Journal of Risk Research* **13(1)**: 29-44.
[946] Corner J, Richardson K and Fenton N (1990) *Nuclear reactions: form and response in "public issue" television* (Luton: University of Luton Press).
[947] Kitzinger J (2000) Media templates: patterns of association and the (re) construction of meaning over time *Media, Culture & Society* **22(1)**: 61-84.
[948] Henderson L and Kitzinger J (2001) The human drama of genetics:'hard'and 'soft'media representations of inherited breast cancer *Sociology of Health & Illness* **21(5)**: 560-78.
[949] Hargreaves I, Lewis J and Speers T (2003) *Towards a better map: science, the public and the media* (Swindon: Economic and Social Research Council).
[950] Haran J (2007) *Human cloning in the media* (London: Routledge).
[951] Kitzinger J (2006) Constructing and deconstructing the "gay gene": media reporting of genetics, sexual diversity, and "deviance", in *The nature of difference: science, society and human biology*, Ellison G, and Goodman AH (Editors) (Boca Raton: FL: CRC Press Taylor and Francis Group).
[952] Tucker BP (1998) Deaf culture, cochlear implants, and elective disability *Hastings Center Report* **28(4)**: 6-14; Lane H (2005) Ethnicity, ethics, and the deaf-world *Journal of Deaf Studies and Deaf Education* **10(3)**: 291-310.

9.7 While recognising the depth and breadth of potential media influence, it is also crucial not to over-simplify this effect. Audiences do not uncritically accept everything they hear and see.[953] The audience is also not a single, uniform entity. Whether it comprises those with general or personal interests, or more particular professional interests, such as policy-makers or investors, the ways in which these groups receive messages will be complex. Audiences will be influenced by their own values and experiences in how they take in and interpret messages. This has been demonstrated specifically with respect to the perception of emerging technologies. For example, in a recent study, a group of Muslim women were the only research participants to have predominantly negative images of nanotechnology. This was attributable to the links made by these participants between nanotechnology and spy-technology and the surveillance of Muslim communities following the events of 11 September 2001.[954]

9.8 Claims about how media representation will influence public attitudes or policy decisions should be treated with caution unless supported by thorough research. Moreover, references to media influence can themselves be used for instrumental ends, such as when media are blamed for creating a climate of opinion, or patterns of behaviour, that the accusers themselves find problematic or illogical. A simplistic accusation of media influence can assume an ignorant lay public who are easily duped (the implication being that the public would agree with the accuser if only they were better informed).[955] It can also confine the cause of the perceived problem to a problem of media misrepresentation. For example, just because people often reference their concerns about emerging science and technology using examples from science fiction, this does not mean that science fiction *causes* public concern about such science and technology.[956] Ascribing blame to media misrepresentation can distract from other influences or present an obstacle to addressing (or responding to) public concerns in other, potentially more effective ways.

9.9 Media representation can have significant impacts, but it is important to recognise that these are subject to complex influences and will not always operate in completely predictable ways. The amount of media attention given to a novel scientific or technological development and the way it is represented can, however, potentially undermine *or* support its development and uptake. Theorists point out that "the future of science and technology is actively created in the present through contested claims and counterclaims over its potential".[957] From this perspective, there is a need to explore "how the future is mobilized in real time to marshal resources, coordinate activities and manage uncertainties".[958] The media can play a crucial role in these processes Sociological studies have highlighted 'the medialisation of science', which:

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[953] For examples related to science, see: Corner J, Richardson K and Fenton N (1990) *Nuclear reactions: form and response in "public issue" television* (Luton: University of Luton Press); Miller D, Kitzinger J, Williams K and Beharrell P (1998) *The circuit of mass communication: media strategies, representation and audience reception in the AIDS crisis* (London: Sage Publications Ltd).

[954] Economic and Social Research Council (2008) *Media discourses and framing of risk*, available at: http://www.cardiff.ac.uk/jomec/resources/KitzingerWkPaper27.pdf, at page 22.

[955] This is highlighted in a discussion of how policy-makers/scientists discussed 'Frankenbunny' headlines and images from a leading tabloid reporting of the creation of hybrid embryos. While this could be seen simply as 'scaremongering' about GM, it could also be read as deploying humour and could be read ironically by readers. See: Haran J, Kitzinger J, McNeil M and O'Riordan K (2007) *Human cloning in the media: from science fiction to science practice* (London: Routledge); Haran J (2007) Managing the boundaries between maverick cloners and mainstream scientists: the life cycle of a news event in a contested field *New Genetics and Society* **26(2)**: 203-19.

[956] For a detailed discussion, see: Kitzinger J (2010) Questioning the sci-fi alibi: a critique of how 'science fiction fears' are used to explain away public concerns about risk *Journal of Risk Research* **13(1)**: 73-86.

[957] Brown N, Rappert B and Webster A (2000) Introducing contested futures: from looking into the future to looking at the future, in *Contested futures: a sociology of prospective techno-science*, Brown N, Rappert B, and Webster A (Editors) (Aldershot Ashgate Press), at page 5.

[958] Brown N and Michael M (2003) A sociology of expectations: retrospecting prospects and prospecting retrospects *Technology Analysis & Strategic Management* **15(1)**: 3-18, at page 4.

> "[I]n so far as it guides the public communication strategies of scientific actors, increases the chances of scientific actors being noticed and taken seriously by the political-administrative system. Effects are seen in a contribution to the legitimization of science by reinforcing the perception of its social relevance and in improving the chances of scientific expertise becoming effective in policy-making".[959]

Representation (or lack thereof) of a technology may help inform the timing and nature of regulation – for example whether it is perhaps premature or belated, permissive or restrictive. This is why, for example, scientists sometimes lobby via the media to try to ensure a supportive debate**.**[960] It can also influence the level of support and cooperation from potential research participants, users or investors. As we observe in Chapter 3, the presentation of the incidence of neurological and mental health disorders in terms of unmet health needs and the opportunities and capacities for technological innovation to address these, can play promissory and performative roles, capturing the interest of potential funders and shaping the direction of research and investment. Efforts to influence media representations are not limited to those with commercial interests. Patient groups may also play a role in seeking to raise the profile of the prospects of particular health technologies in the media.[961] However, unfulfilled promises and hype might equally lead to disinvestment of the kind witnessed in the field of psychopharmaceuticals (see paragraphs 3.32 to 3.33).

9.10 In sum, while there are well-known mechanisms by which media outlets can influence and shape views, opinions and reactions, and even policy in some cases, this does not warrant automatic accusations of undue influence. A balance needs to be struck between awareness of the power of media to shape and frame opinions, and consideration of the many other factors that may add to, change, mitigate or reverse such influence. The NHS initiative *Behind the headlines*, part of the NHS Choices website, is one example of an initiative that seeks to have such a mitigating effect. This online resource provides elucidation and balance by setting representations of health-related research in the popular media in the context of the most robust current scientific evidence.[962]

9.11 In order to understand the constraints and drivers that shape the nature of existing approaches to communication and representation, it is important to examine the role of those producing media messages (including press officers, journalists and scientists) and the impact that their values and judgments, and the structures within which they work, on media representation. The next section of this chapter outlines the role of two sets of key players: the scientists and press officers in research institutions on one hand and the journalists on the other.

The role of researchers and press officers – and the context in which they operate

9.12 Studies of the activities of those who act as sources for journalists – research institutions, businesses and their press offices – suggest that some problems with the representation of science and technology in the media can be traced to these sources rather than journalists.[963]

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[959] Peters H, Heinrichs H, Jung A, Kallfass M and Petersen I (2008) Medialization of Science as a Prerequisite of Its Legitimization and Political Relevance, in *Communicating Science in Social Contexts*, Cheng D, Claessens M, Gascoigne T *et al.* (Editors) (Springer Netherlands).

[960] Williams A and Gajevic S (2012) Selling science: source, struggles, public relations, and the newspaper coverage of hybrid embryos *Journalism Studies*: 1-16, at page 2.

[961] Herxheimer A (2003) Relationships between the pharmaceutical industry and patients' organisations *British Medical Journal* **326(7400)**: 1208-10.

[962] NHS Choices (2012) *Behind the headlines*, available at: http://www.nhs.uk/news/Pages/NewsIndex.aspx.

[963] See: Anderson A, Petersen A, Wilkinson C and Allan S (2009) *Nanotechnology, risk and communication* (Basingstoke: Palgrave Macmillan); Allan S, Anderson A and Petersen A (2010) Framing risk: nanotechnologies in the news *Journal of Risk Research* **13(1)**: 29-44.

9.13 There is an increasing focus on 'communicating science' not only in the UK, but internationally. This focus is profoundly marked in the UK by past debacles such as those surrounding BSE (mad cow disease) and GM crops and food. The emphasis on good science communication has also been shaped by national and international health crises, as well as by financial concerns and fierce debates about the values underpinning research.[964] In the late 20th and early 21st centuries, the 'science community' (including researchers, academic institutions, funding bodies, companies and policy makers) have adopted a more proactive approach to both public relations (PR) and public engagement around science issues. Recent examples may be found in the communications efforts associated with the mapping of the human genome and in the field of stem cell research.[965] If the ratio of professional science communications and PR experts (working in universities, businesses, NGOs and for government) to specialist science journalists follows the patterns seen more generally in the communications sector it is likely that the former now outnumber the latter.[966]

9.14 Professional organisations have been established such as the Science Media Centre (SMC), which describes itself as "an independent press office helping to ensure that the public have access to the best scientific evidence and expertise through the news media when science hits the headlines".[967] Such bodies can be crucial allies for scientists and make strong connections with specialist journalist, providing them with briefings. Scientists are also increasingly being trained in media-communication skills (including use of on-line media) and a wide range of research organisations (including commercial businesses and higher education institutions) have invested in public engagement and PR.[968]

9.15 Such developments can be lauded as evidence of improved communication and an opening up of science to public scrutiny and debate. The expansion in the number of communication/PR specialists and the emphasis on publicising scientific research could be seen as having positive aims and impacts, such as:

- helping to encourage accurate science reporting;
- encouraging scientific literacy;
- providing accountability for publically funded science;
- promoting trust;
- recruiting scientists and technologists of the future; and
- informing the public and hence opening up channels for consultation and upstream public engagement.

9.16 However**,** the increasing emphasis on science PR (or at least some branches of it) can be seen in a less benign light.[969] It can, in particular, be viewed as evidence of efforts to influence public attitudes and the policy-making, regulation and funding environments by emphasising the (imminent) social and economic value of scientific advances.[970] One study examined the

[964] Allan S (2011) Introduction: science journalism in a digital age *Journalism: Theory, Practice and Criticism* **12(7)**: 771-7.
[965] Smart A (2003) Reporting the dawn of the postgenomic era: who wants to live forever? *Sociology of Health & Illness* **25(1)**: 24-49; Haran J, Kitzinger J, McNeil M and O'Riordan K (2007) *Human cloning in the media: from science fiction to science practice* (London: Routledge); Henderson DL and Kitzinger J (2007) Orchestrating a science 'event': the case of the human genome project *New Genetics and Society* **26(1)**: 65-83; Williams A and Gajevic S (2012) Selling science: source, struggles, public relations, and the newspaper coverage of hybrid embryos *Journalism Studies*: 1-16.
[966] In a study by researchers at Cardiff University, cited in Davies N (2009) *Flat earth news: an award-winning reporter exposes falsehood, distortion and propaganda in the global media* (London: Random House), at page 85, it was estimated that the number of people employed in PR in the UK was 47,800 compared with 45,000 journalists.
[967] Science Media Centre (2013) *Science media centre*, available at: http://www.sciencemediacentre.org/.
[968] Illes J, Moser MA, McCormick JB *et al.* (2010) Neurotalk: improving the communication of neuroscience research *Nature Reviews Neuroscience* **11(1)**: 61-9.
[969] Peters HP, Brossard D, De Cheveigné S *et al.* (2008) Science-media interface: it's time to reconsider *Science Communication* **30(2)**: 266-76.
[970] Rödder S (2009) Reassessing the concept of a medialization of science: a story from the "book of life" *Public Understanding of Science* **18(4)**: 452-63, at page 453; Rödder S and Schäfer MS (2010) Repercussion and resistance. an empirical study on the interrelation between science and mass media *Communications* **35(3)**: 249-67; Schäfer MS (2011) Sources,

efforts of a particular research community to influence the regulation of their work by implementing a communications campaign to try to ensure a supportive policy environment for the creation of hybrid embryos for stem cell research. While the strategies were successful in recruiting positive coverage that promoted the value of hybrid embryos, the authors argue that there was a risk of distorting the actual potential of this form of stem cell research over other avenues – and losing sight of broader issues.[971] Some commentators warn of the risks of a shift away from a dialogic and public-centred model of science communication to a one-way, business-influenced, persuasion-oriented model which commentators have termed "PUS [public understanding of science] Inc."[972]

9.17 The pressure on researchers and press officers working to translate their work into the public domain to underline the social usefulness and imminent practical applications of their work is perhaps only to be expected given the economic pressures for 'spin-out' enterprises originating in academic institutions to secure private investment to bridge the 'valley of death' that we noted in Chapter 3.

9.18 The orientation towards expected or hoped-for impact is also driven by the subordination of wider UK research policy to the priority of economic growth. The *Strategy for UK life sciences* places great emphasis on the potential of publicly funded research to contribute to economic growth by delivering innovative products and services.[973] The requirement for universities to demonstrate an extensive record of research published in peer reviewed journals is a long-standing feature of higher education funding. However, the impact agenda is now also part of this landscape. Academic departments are now required to include evaluations of the impact of past research of their members in their submissions to the Research Excellence Framework (REF), which is used to determine future university funding.[974] In addition, research councils require research proposals to show that researchers have considered routes by which their research may have social and economic impact. Reduced funding for higher education from central government also means that universities are increasingly encouraged to seek revenue streams from elsewhere, including the private and voluntary sectors. This increases pressure on those applying for research funding to make strong claims about the potential impact of their work.[975]

9.19 These combined economic, policy and reputational drivers can influence what types of studies are conducted, which are reported, and increase a bias in favour of positive results.[976] The need for prospective demonstration of impact means claims about effective practical applications of novel technologies may be made without sufficient evidence. Results may be reported prematurely, for example prior to peer review. There can also be a failure to caveat uncertainties or the need for further investigations. Another problematic practice in science communication is that of excessive inference, that is, reporting conclusions that go beyond the available evidence and fail to acknowledge the limits of data in a study. The literature reporting

characteristics and effects of mass media communication on science: a review of the literature, current trends and areas for future research *Sociology Compass* **5(6)**: 399-412, at page 402.

971 Williams A and Gajevic S (2012) Selling science: source, struggles, public relations, and the newspaper coverage of hybrid embryos *Journalism Studies*: 1-16, pp. 7-8.

972 Bauer M and Gregory J (2007) From journalism to corporate communication in post-war Britain, in *Journalism, science and society: science communication between news and public relations*, Martin W. Bauer MB (Editor) (New York: Routledge), pp.33-52; Rödder S (2009) Reassessing the concept of a medialization of science: a story from the "book of life" *Public Understanding of Science* **18(4)**: 452-63; Rödder S and Schäfer MS (2010) Repercussion and resistance. an empirical study on the interrelation between science and mass media *Communications* **35(3)**: 249-67.

973 Department for Business Innovation & Skills (2011) *Strategy for UK life sciences*, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/32457/11-1429-strategy-for-uk-life-sciences.pdf.

974 Research Excellence Framework (2014) *Assessment criteria and level definitions*, available at: http://www.ref.ac.uk/panels/assessmentcriteriaandleveldefinitions/.

975 This topic is explored in more detail in Nuffield Council on Bioethics (2012) *Emerging biotechnologies: technology, choice and the public good*, available at: http://www.nuffieldbioethics.org/sites/default/files/Emerging_biotechnologies_full_report_web_0.pdf, pp104-6.

976 Fins JJ (2010) Deep brain stimulation, free markets and the scientific commons: is it time to revisit the Bayh-Dole Act of 1980? *Neuromodulation: Technology at the Neural Interface* **13(3)**: 153-9.

the putative enhancing effects of neural stimulation gleaned from small studies, as discussed in Chapter 8, provides some illustrations of some of these kinds of problems (see paragraphs 8.10 to 8.14). The compound outcome of these various factors is that the findings of research and innovation may be hyped. One scientist who responded to our public consultation stated that hype "is inevitable given the highly competitive nature of science funding and publications (which are linked) and the pressure put on scientists and clinicians (by their employers, grant givers etc.) to be seen to be doing high impact work."[977]

9.20 The pressures upon researchers and their institutions to hype their work coincide with parallel pressures upon academic journals to publish the most 'newsworthy' studies and upon the non-specialist media to attract a greater proportion of an increasingly fragmented and thinly spread audience. It may be seen therefore that there are influences operating on all actors, at every stage of the journey of translating research into the public domain (from seeking funding, to presenting research findings, to publication in a journal, to press release, and to media report). Even if each set of actors only adds a small amount of emphasis on the significance or implications of the findings, this can lead to a spiral of hype spinning into gross exaggeration of, and a disproportionate focus upon, the significance and promises of one area of scientific enquiry.

The role of journalists, and the context in which they operate

9.21 Although the media are traditionally seen as 'mediators' of the promotional and PR activities of sources, or even as 'watchdogs', journalists work in increasingly difficult times and the media industries are under increasing financial pressures. For example, the increasing speed of journalism and the competitive environment in science and in the media, alongside the impact of online media, might mean that journalists are encouraged to sensationalise stories in order to compete for page space or airtime and attention, or that they simply might not have enough time to research stories properly. As a major study of the current situation concluded:

> "news media, and newspapers in particular, are in crisis. With newspaper circulation declining sharply and advertising revenue migrating to online classified sites and search advertising, the newspaper industry is without a workable business model."[978]

9.22 One study found that there has been an increase in the number of specialist science journalists in the UK national news media, and that there is a growing appetite for science news within newsrooms. However, the economic and institutional constraints under which science journalists now operate have led to workload increases and reduced time to seek out stories, check facts, and do basic research. This, in turn, increases reliance on PR material from a very limited pool of news sources, and a growing homogeneity in science coverage.[979] Some researchers suggest that the original craft of journalism is being replaced by a sort of creative "cannibalisation".[980]

9.23 A high proportion of journalistic texts about science are derived directly from press releases. For examples, one content analysis found that 84% of journal articles referred to in newspaper

[977] Robin Lovell-Badge, responding to the Working Party's consultation.
[978] Goldsmiths: University of London (2013) *Goldsmiths Leverhulme media research centre*, available at: http://www.gold.ac.uk/media-research-centre/project1/.
[979] Cardiff University School of Journalism, Media and Cultural Studies (2009) *Mapping the field: specialist science news journalism in the UK national media*, available at: http://cf.ac.uk/jomec/resources/Mapping_Science_Journalism_Final_Report_2003-11-09.pdf, at page 44.
[980] Phillips A, Couldry N, Freedman D and Fenton N (2009) Old sources: new bottles, in *New media, old news: journalism and democracy in the digital age*, Fenton N (Editor) (London: Sage), at page 95.

stories were promoted by the press release.[981] Sophisticated PR strategies can sometimes lead to a high rate of journalists reproducing source material with little change and a low rate of stories generated by journalists themselves. Such practices have been referred to as 'churnalism'.[982] In such cases, journalists enable the distribution of 'newsworthy' science results without playing any gate-keeping or quality controlling role. As former science and health journalist Nigel Hawkes commented:

> "We are 'churning' stories today, not writing them. Almost everything is recycled from another source […]. It wouldn't be possible to write so many stories otherwise. […]. Specialist writing is much easier because the work is done by agencies and/or writers of press releases. [...]. The work has been deskilled, as well as being greatly amplified in volume, if not in quality."[983]

9.24 The acceleration of communication and shift in format to ever more brief and rapid commentary and response (for example the greater use of blogging), while bringing positive benefits, can also have detrimental effects. One freelance science writer, for example, in reflecting on the changes he has witnessed over the course of his career, comments on the pressure to shrink science reporting into ever faster and shorter snippets and argues that the competition for readers and the acceleration of the speed of reporting has led to "fast food" journalism – "only topics that can be presented in a tempting light and easily digested tend to survive, replacing food for thought with a more superficial mental diet."[984]

9.25 For some commentators, one key safeguard lies in championing specialist science journalists and ensuring they get priority in reporting science, and are supported by science communicators and by their editors. Specialists can be assumed to understand the science, and have relevant experience which enables them to report it with accuracy and understand the context.[985] Because of this, they can also engage critically with the developments they are reporting on. There are some outstanding examples of excellent science reporting in the UK and a recent report on BBC science reporting praised "the precision and clarity of most material"[986]. Science journalists are also working together to debate and improve good practice, for example through collaborative initiatives such as the UK Science, Technology, Engineering and Medicine (or Maths) Public Relations Association (STEMPRA) and the Association of British Science Writers (ABSW).[987]

9.26 However, in general, the state of science journalism is hotly contested. For example, at the 2009 World Conference of Science Journalism the UK's Minister for Science and Innovation praised the UK's science reporters as "among best in the world" at "speaking truth to society about science". However, academic analysts commenting on the same conference have noted:

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[981] A study of four quality papers which found that 60 per cent of their home news stories were wholly from wire agencies, mainly the Press Association, or PR material, 20 per cent partially so, eight per cent from unknown sources, and just 12 per cent generated by reporters: Davies N (2009) *Flat earth news: an award-winning reporter exposes falsehood, distortion and propaganda in the global media* (London: Random House), at page 95. de Semir V RCRG (1998) Press releases of science journal articles and subsequent newspaper stories on the same topic *JAMA* **280(3)**: 294-5

[982] The first use of the term 'churnalism' has been attributed to a journalist Waseem Zakir , see: Robbins M Science Churnalism, on *The Lay Scientist hosted by the Guardian* [internet blog] 25 April 2011, available at: http://www.guardian.co.uk/science/the-lay-scientist/2011/apr/25/1 and has achieved prominence through its use in Davies N (2009) *Flat earth news: an award-winning reporter exposes falsehood, distortion and propaganda in the global media* (London: Random House).

[983] Commissioned report for the Joseph Rowntree Charitable Trust (2006) *The quality and independence of British journalism*, available at: http://www.cardiff.ac.uk/jomec/resources/QualityIndependenceofBritishJournalism.pdf, at page 45.

[984] Gross M (2008) Is science reporting turning into fast food? *Ethics in Science and Environmental Politics*, available at: http://www.int-res.com/articles/esep2009/9/journalism/e009pp1.pdf , at page 1.

[985] Weigold MF (2001) Communicating science: a review of the literature *Science Communication* **23(2)**: 164-93.

[986] BBC Trust (2011) *BBC Trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 15.

[987] stempra (2013) *STEMPRA*, available at: http://stempra.org.uk/.

> "[B]arely three hours later, and in the same room, *Guardian* columnist and doctor Ben Goldacre referred to a room full of these journalists as 'murderers with blood on [their] hands'. His argument was that science journalism was now of such a poor standard that it was having a serious detrimental impact on public health at least in part because of the increasingly harsh economic and institutional constraints under which journalists now operate."[988]

9.27 During the recent Leveson Inquiry, which examined the culture, practices and ethics of the press in the UK, evidence was heard relating to the quality of science reporting. Although this topic was not central to the remit of the inquiry, report of the inquiry noted that:

> "Given the important public interest in science journalism, and the potential harm caused by overblown or sensational science reporting, greater care is needed by parts of the press prior to publishing sensational headlines of breakthroughs or scares."[989]

The evidence submitted to the inquiry included the observation that inaccurate or misleading reporting of science issues are not covered by press complaint procedures.[990] The SMC was invited to submit draft guidelines on how to report science and health stories responsibly (cited at paragraph 9.59 to 9.60), which the report of the inquiry suggested should be borne closely in mind by any new media regulator.[991]

9.28 Some factors that threaten to undermine responsible reporting may result not from journalists' poor representation of research findings, but rather the lack of transparency about the commercial interests reflected in the putatively robust sources on which they draw. For example, one commentator suggests that, in many ways, journalists often accurately present the evidence found in peer-reviewed journals, noting that:

> "[A] more subtle problem, and one that may have more long term implications than simply bad reporting, is the faithful portrayal of commercially influenced research results".[992]

Others have highlighted, at its most extreme, the problem of "cheque book science" including the direct involvement of companies in ghost writing articles in prestigious journals.[993]

9.29 It can also be problematic if specialist journalists are, or are regarded as being, too close to their sources, and as uncritical champions of science. In 1987, the sociologist of science Dorothy Nelkin argued that "[m]any journalists are in effect retailing science and technology more than investigating them, identifying with their sources more than challenging them."[994] This problem

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[988] Cardiff University School of Journalism, Media and Cultural Studies (2009) *Mapping the field: specialist science news journalism in the UK national media*, available at: http://cf.ac.uk/jomec/resources/Mapping_Science_Journalism_Final_Report_2003-11-09.pdf, at page 4.

[989] The Right Honourable Lord Justice Leveson (2012) *The Leveson inquiry: an inquiry into the cultures, practices and ethics of the press: volume II*, available at: http://www.official-documents.gov.uk/document/hc1213/hc07/0780/0780_ii.pdf, at paragraph 9.74.

[990] Evidence from Fiona Fox (Science Media Centre) to the Leveson inquiry, The Right Honourable Lord Justice Leveson (2012) *The Leveson inquiry: an inquiry into the cultures, practices and ethics of the press: volume I*, available at: http://www.official-documents.gov.uk/document/hc1213/hc07/0780/0780.pdf, at paragraph 2.6.

[991] The Right Honourable Lord Justice Leveson (2012) *The Leveson inquiry: an inquiry into the cultures, practices and ethics of the press: volume II*, available at: http://www.official-documents.gov.uk/document/hc1213/hc07/0780/0780_ii.pdf, at paragraph 9.75.

[992] Caulfield T (2004) The commercialisation of medical and scientific reporting *PLoS Medicine* **1(3)**: 178-9, at page 178.

[993] Zuckerman D (2003) Hype in health reporting:"checkbook science" buys distortion of medical news *International journal of health services* **33(2)**: 383-9.

[994] Dorthy Nelkin, quoted in Hotz RL (2002) The difficulty of finding impartial sources in science, on at: http://www.nieman.harvard.edu/reports/article/101280/The-Difficulty-of-Finding-Impartial-Sources-in-Science.aspx.

is increasingly discussed, for example one journalist working as science correspondent for the BBC World Service has observed that:

> "My colleagues felt that we reported on published papers without significant analysis, depth or critical comment: we just translated what scientists said. You could say that this is not exactly a description of a journalist – more that of a priest, taking information from a source of authority and communicating it to the congregation. This perception is reinforced when you compare our role with that of other journalists. Political journalists, for example, take an active part in the political debate. They produce expert commentary on the subtleties of the political process, highlighting strengths, weaknesses and potential pitfalls of policy ideas. They interview politicians as equals, challenging them to explain their ideas and, crucially, picking them up on inconsistencies, contradictions and mistakes. These journalists are active participants in the process of knowledge creation [...]. Although science news reporting can influence science funding and research priorities, science journalists are not players in the scientific process. Again this is like a priest, who has little or no effect on the activities of the deity itself and who is not actually needed for the deity to continue."[995]

9.30 Moreover, in view of the wider context of science in society, there could be an ongoing role for columnists, political and economic reporters to cover science and technology topics. Leaving all science reporting to specialist journalists could result in an altogether too narrow picture, and might, in itself, not increase or serve the public interest unless a wide remit is pursued.[996]

Concerns about media coverage of new technologies

9.31 There are two main types of research about the communication of science and technology. The first kind is that conducted by scientists, industry and professional science communicators and is chiefly concerned with whether the science has been represented 'well' and whether the reporting might have mislead the public or undermined trust in science. The second is that conducted by social scientists and media studies academics who are also interested in this question, but, in addition, focus on critical analysis of underlying values – including analysing the claims of science and of science communicators themselves. Those conducting research under the first rubric tend to focus on producing recommendations for journalists, such as how they can be more faithful to the science. Those coming from the second sphere of concern are more likely to critically assess the sources and their strategies (including analysing press releases) and place these in the context of wider debates about the place of science in society. Although very different findings result from these two strands of enquiry , the concerns that between them they have raised include:

- **Inaccuracy, mistakes or lack of detail** in reporting (for example, of figures or statistics), and failing to provide details regarding the methodology of the study, or where it can be followed up.[997]

- **Misuse of 'balance' in reporting**: for example, citing a 'maverick' scientist to balance the views of the majority of mainstream scientist – giving a false impression of the balance of

[995] Murcott T (2009) Science journalism: toppling the priesthood *Nature* **459(7250)**: 1054-5, at page 1054.
[996] Hargreaves I, Lewis J and Speers T (2003) *Towards a better map: science, the public and the media* (Swindon: Economic and Social Research Council).
[997] The Right Honourable Lord Justice Leveson (2012) *The Leveson inquiry: an inquiry into the cultures, practices and ethics of the press: volume II*, available at: http://www.official-documents.gov.uk/document/hc1213/hc07/0780/0780_ii.pdf, at paragraph 3.29 and 9.74.

opinion among scientists about an issue such as the safety of a vaccine or issues such as climate change.[998]

- **Over-reliance on a narrow range of sources**, for example over-dependency on the scientist who made the discovery or breakthrough.[999]

- **Disproportionate focus on some stories over others**. This includes undue attention to a single case study showing spectacular results and an unduly pronounced interest in studies that are newsworthy (regardless of conflicts of interest arising from their sources), and a bias in favour of positive results both in journal publication, and in subsequent media reporting.[1000]

- **Reactive reporting and 'pack journalism'**: journalists can be led by press releases rather than undertaking proactive enquiries of their own.[1001] This can lead to over-dependence on particular sources, which may be academic or commercial organisations. It can also result in celebrity-led reporting (for example, news pieces that focus on the experiences of well-known figures with Parkinson's disease or spinal cord injuries and their views on the potential offered by an emerging technology).[1002]

- **Emotive language which emphasises positive outcomes**, for example referring to the 'promise' of the research (instead of 'possibility') and the strategic use of human interest stories such as those that emphasise 'suffering' or 'need' in such a way as to frame the scientific or technological research being promoting as the *only* answer.

- **Rhetorical techniques which privilege some positions over others**: for example, presenting some views as the voice of reason and others as emotional, or structuring reports around a narrow focus on some ethical issues which sideline other, important ethical aspects from the debate.[1003]

- **Excessive deference for science**: for example, a lack of cautionary comments about scientific claims, perhaps *especially* from science correspondents. Indeed, it has been reported that such comments are least likely to feature in news items by science correspondents.[1004]

- **Lack of information about economic drivers**, for example, failing to mention sources of funding for the research reported,[1005] or profiling an area of research as focused on therapeutic or assistive technologies when a bigger market might be games industry or military.

- **Over-stepping the expertise, or the 'voice of science'**, for example when scientists assume the role of experts when commenting on the social implications of a technology they are working on, even though they have done no research in this area, and have little expertise in

[998] BBC Trust (2011) *BBC Trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 5.
[999] BBC Trust (2011) *BBC trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 5.
[1000] Harrabin R (2003) *Health in the news: risks, reporting and media* (London: King's Fund); Schlaepfer TE and Fins JJ (2010) Deep brain stimulation and the neuroethics of responsible publishing *The Journal of the American Medical Association* **303(8)**: 775-6.
[1001] BBC Trust (2011) *BBC Trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at pages 5 and 41.
[1002] For example, see: BBC News (23 October 2004) *Reeve stem cell appeal airs in US*, available at: http://news.bbc.co.uk/1/hi/entertainment/3947029.stm.
[1003] Kitzinger J and Williams C (2005) Forecasting science futures: legitimising hope and calming fears in the embryo stem cell debate *Social Science & Medicine* **61(3)**: 731-40.
[1004] BBC Trust (2011) *BBC Trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 5.
[1005] Caulfield T (2004) The commercialisation of medical and scientific reporting *PLoS Medicine* **1(3)**: 178-9, at page 175.

understanding or interpreting the social consequences of science and technology. This can be reinforced when journalists fail to distinguish between 'fact', as established through scientific methods, and simple opinion or unsupported speculation by a scientist or clinician.

- **Excessive science or technological optimism**, for example, focusing only on benefits, or under-reporting – or indeed failing to report – risks.[1006]

- **Hype about the *object* of the research**, an example of which occurred when research on the human genome was presented in a very deterministic way as the 'holy grail' of research, or the "language in which God created life".[1007]

- **Hype about the significance of a research *finding***, for example overstating findings as breakthroughs to play to a 'wow factor'; a tendency to leap to unwarranted conclusions (for example, the translation of research findings in rats to human application), over-simplified accounts which fail to address the incremental nature of scientific exploration, and the uncertainty of outcomes.[1008]

- **Hype about the *practical applications* of the research findings**: for example, accounts which suggest the imminent use of a technology which has only just been funded for research, or which 'clinicalise' fundamental discoveries in biology and anticipate medical benefits which may or may not occur.[1009] Accounts may also exaggerate how soon an application will be available, overstate the *number* of people who will benefit (for example, stating that *all* patients with a particular illness will be potential users, when only a proportion would benefit), or presenting a 'breakthrough' as a global solution without acknowledging that its delivery might be context- and resource-dependent.[1010]

Concerns about representations of novel neurotechnologies

9.32 As noted by one response to the Working Party's consultation,

> "[i]n the case of neurotechnologies this habit [of hype in biomedicine and biotechnologies] is likely to be exacerbated by their novelty, by the apparent authority of very sophisticated and complex science, and by the awe that direct intervention in the brain is likely to inspire."[1011]

This is borne out to a considerable extent by the available evidence.[1012] Many of the features listed paragraph 9.31 can be found in media representations of novel neurotechnologies specifically, and related concerns about this seem to be increasingly recognised within the neuroscience community. For example, following a recent workshop on the challenges of communicating about neuroscience, one expert stated that:

[1006] See, for example, Petersen A (2001) Biofantasies: genetics and medicine in the print news media *Social Science & Medicine* **52(8)**: 1255-68.

[1007] BBC News Online (26 June 2000) *Leaders' genetic code warning*, available at: http://news.bbc.co.uk/1/hi/uk_politics/806819.stm.

[1008] For example, see: The Telegraph Online (20 July 2009) *Stem cells can rescue the memory from Alzheimer's disease, claim scientists*, available at: http://www.telegraph.co.uk/science/science-news/5873215/Stem-cells-can-rescue-the-memory-from-Alzheimers-disease-claim-scientists.html.

[1009] BBC Trust (2011) *BBC trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf, at page 47.

[1010] Turner-Stokes L, Kitzinger J, Gill-Thwaites H *et al.* (2012) fMRI for vegetative and minimally conscious states *British Medical Journal (Clinical Research Edition)* **345:e8045**, at page 7.

[1011] Jackie Leach Scully, Janice McLaughlin, Simon Woods and Michael Barr of the Policy, Ethics and Life Sciences Research Centre, Newcastle University, responding to the Working Party's consultation.

[1012] A large portion of the literature looking at the media representation of novel neurotechnologies concerns coverage of neuroimaging technologies such as fMRI. Here we have attempted to limit our discussion to the representation of the kinds of technologies with which we are concerned in this report. These are increasingly gaining attention in analyses of media coverage.

> "[media] communication outside the academic literature is a vital source of information flow, but its value is heavily yoked to timeliness and accuracy, and to the trade-off of hope and hype."[1013]

One widely discussed study confirms this conclusion. A media analysis of major UK and US print news sources identified 1,256 articles featuring neurotechnology (published from 1995 to 2004).[1014] The study found that certain techniques such as functional magnetic resonance imaging (fMRI) and neurostimulation gained significantly more coverage than other neurotechnologies over the time period examined and that "[o]verall, the tone of the media coverage was optimistic (featuring benefits or research and its applications) or neutral (no mention of benefits, risks or challenging issues)".[1015]

9.33 An earlier analysis, which was conducted by some of the same authors, examined press coverage of neurostimulation techniques only and underscored concerns about hype in this field.[1016] For example, 41 per cent (of a total of 235) of articles emphasised the promise of new treatments with headlines such as "Currents of hope: a revolutionary device. An electrical pacemaker implanted in the brain gives welcome relief to people afflicted by the shakiness of Parkinson's disease."[1017] In addition, 19 per cent of headlines were classified as those which signalled new scientific breakthroughs with headlines such as "With tiny brain implants, just thinking may make it so."[1018] The 'human interest'-effect was also evident in this study's sample, as personal accounts were indicated by 29 per cent of articles.

> "This included first person narratives of patients and sometimes of celebrities undergoing neurosurgery with DBS. Some statements resembled 'miracle stories' of patients cured of PD [Parkinson's disease], dystonia, and Tourette's syndrome."[1019]

9.34 Overall, the research found an imbalance in the reporting of risks versus benefits. For example, 51 per cent of the articles about neurostimulation featured only the benefits of research on neurostimulation and its application, whilst 31 per cent of articles were "balanced", featuring both benefits *and* risks or issues. However, the authors note that, in their sample, they "did not find any statements discussing the reliability of neurostimulation techniques, discrimination and stigma, or policy and public involvement."[1020]

9.35 One analysis – describing what it characterises as an "enthusiastic media shock wave" following the publication of a study associating DBS with improved memory function – has drawn parallels between contemporary media portrayals of DBS and the overly optimistic media representation of leucotomy and other forms of psychosurgery in the 1930s and 1940s.[1021] The analysis criticises the fact that there was no mention in the media coverage of

[1013] David Kopf Instruments (2009) *Communicating ethics and neuroscience*, available at: http://www.kopfinstruments.com/Carrier/downloads/Carrier68.pdf, at page 2.
[1014] Racine E, Waldman S, Rosenberg J and Illes J (2010) Contemporary neuroscience in the media *Social Science Medicine* **71(4)**: 725-33.
[1015] Ibid, at page 728.
[1016] Racine E, Waldman S, Palmour N, Risse D and Illes J (2007) "Currents of hope": neurostimulation techniques in US and UK print media *Cambridge Quarterly of Healthcare Ethics* **16(3)**: 312-6.
[1017] The Buffalo News (11 May 2002) *Currents of hope: a revolutionary device. An electrical pacemaker implanted in the brain gives welcome relief to people afflicted by the shakiness of Parkinson's disease*, available at: http://www.buffalonews.com/apps/pbcs.dll/article?AID=/20020511/CITYANDREGION/305119971.
[1018] New York Times (13 April 2004) *With tiny brain implants, just thinking may make it so*, available at: http://www.nytimes.com/2004/04/13/health/with-tiny-brain-implants-just-thinking-may-make-it-so.html?pagewanted=all&src=pm.
[1019] Racine E, Waldman S, Palmour N, Risse D and Illes J (2007) "Currents of hope": neurostimulation techniques in US and UK print media *Cambridge Quarterly of Healthcare Ethics* **16(3)**: 312-6, at page 314.
[1020] Ibid, at page 314.
[1021] Gilbert F and Ovadia D (2011) Deep brain stimulation in the media: over-optimistic portrayals call for a new strategy involving journalists and scientists in ethical debates *Frontiers in Integrative Neuroscience* **5(16)**: 1-6, at page 2.

DBS of any ethical issues potentially raised by its use in vulnerable populations, for example in patients with Alzheimer's disease.[1022]

9.36 Other commentators draw attention to bias in use of compelling stories or images. For example, in relation to psychiatric uses of DBS it has been emphasised that:

> "it is an ethical requirement to help patients, their relatives, and the public at large to separate solid data from hype. [...]. Public events [...] about DBS sometimes risk conveying mainly treatment benefits by presenting patients with large motor and quality of life improvement who report about the treatment success and have not experienced any adverse event. In contrast, short-, medium- or long-term adverse events, e.g., hemorrhages, dysarthria, psychosocial misadjustments or insufficient treatment responses are hardly ever reported in such a demonstrative and intriguing way, e.g., by displaying computed tomography scans or by inviting patients who have experienced complications.[1023]

Box 9.1: Examples of hype in the UK media headlines

BCIs

"Paralysed man's mind is "read"[1024]

The article reports that electrodes were implanted into the brain of a man who had developed 'locked-in syndrome' following a car crash. It explains that the experiment used the brain signals he creates to drive "speech software", and further notes that there is a huge difference between the technique being described, which is able to pick up signals the subject wants to be picked up, and being able to "delve deep into the mind". It is also concedes that reading people's minds is still a far-off prospect, a sentiment that is not conveyed through the headline.

Neural Stem Cell Therapies

"Stem cells can rescue the memory from Alzheimer's disease, claim scientists"[1025]

The article goes on to explain that scientists at the University of California had shown that stem cells injected into the brain could rescue memory in mice. Professor LaFerla, director of the university's Institute for Memory Impairments and Neurological Disorder, is also quoted as saying "this gives us a lot of hope that stem cells... will be a useful treatment for Alzheimer's disease." However, this message is not conveyed by the article's headline.

TMS

"Coma victim able to speak again after pioneering magnetic field therapy"[1026]

The article opens by stating "[a] man who suffered brain damage in a car crash can speak again after doctors waved a magnet against his head while he was in a coma. Doctors believe the electromagnetic field encouraged nerve cells to send a 'wake-up' signal to the brain." The article later concedes that neuroscientists said that it was "too soon to say whether magnets made any difference."

DBS

"Alzheimer's: deep brain stimulation 'reverses' disease"[1027]

The article reports that scientists in Canada "have raised a tantalising prospect – reversing Alzheimer's disease." The article explains that, in two patients, the hippocampus had *grown* rather than shrunk (shrinkage is normal in Alzheimer's disease). However, only one of the two patients had experienced an improvement in their "symptoms"; it is unclear whether these included indications apart from memory.

[1022] Gilbert F and Ovadia D (2011) Deep brain stimulation in the media: over-optimistic portrayals call for a new strategy involving journalists and scientists in ethical debates *Frontiers in Integrative Neuroscience* **5(16)**: 1-6, at page 2.

[1023] Schlaepfer TE, Lisanby S and Pallanti S (2010) Separating hope from hype: some ethical implications of the development of deep brain stimulation in psychiatric research and treatment *CNS Spectrums* **15(5)**: 285-7, at page 286.

[1024] BBC News Online (15 November 2007) *Paralysed man's mind is 'read'*, available at: http://news.bbc.co.uk/1/hi/health/7094526.stm.

[1025] The Telegraph Online (20 July 2009) *Stem cells can rescue the memory from Alzheimer's disease, claim scientists*, available at: http://www.telegraph.co.uk/science/science-news/5873215/Stem-cells-can-rescue-the-memory-from-Alzheimers-disease-claim-scientists.html.

[1026] The Daily Mail Online (16 October 2008) *Coma victim able to speak again after pioneering magnetic field therapy*, available at: http://www.dailymail.co.uk/health/article-1077947/Coma-victim-able-speak-pioneering-magnetic-field-therapy.html.

[1027] BBC News Online (28 November 2011) *Alzheimer's: deep brain stimulation 'reverses' disease*, available at: http://www.bbc.co.uk/news/health-15890749.

9.37 Closely related to the problem of hype is that of speculation. Commentators have pointed to the temptations and dangers of excessive speculation observing, for example, that the topic of mindreading is particularly likely to attract media attention.[1028] Referring to headlines such as "[p]aralysed man's mind is 'read'", it has been suggested that such reports deal predominantly with *future* possibilities. They note that this is not objectionable in itself if it helps potentially problematic developments to be appropriately considered, acknowledging that "it is logical that future expectations do play a role in ethical analyses and in communication between scientists and journalists".[1029] However, they also comment:

> "The big question, of course, is what constitute reasonable expectations concerning which point (nearby, distant) in the future. It is precisely regarding these aspects that self restraint and clarity are called for. When talking to the press about BCI it, therefore, would be advisable to be extremely reluctant to engage in speculations concerning anything beyond the near future (3-5 years or so) or depending on breakthroughs that, at present, are not foreseeable."[1030]

9.38 A survey of 145 BCI researchers recorded their concern about inaccurate representations of BCI as meaning that science is now capable of "reading people's thoughts and dreams", though, as we have already discussed, the kinds of brain signals used by BCI devices do not permit anything of the sort (see paragraph 4.37).[1031] The same survey noted that BCIs feature with increasingly prominence in popular culture, for example in popular television shows such as House and Star Trek.[1032]

9.39 Examples of hype and of unjustified extrapolation have been highlighted in the discussion of neural enhancement in Chapter 8 of this report. For instance in the coverage of brain stimulation research in terms of discoveries that will allow users to "unlock their inner genius".[1033] As we have observed, this way of framing research findings is unlikely to be warranted by the methods and observations of small exploratory studies (see paragraphs 8.12 to 8.14). However, it is instructive to note that the implication that neurostimulation might 'unlock genius' was not solely a gloss added by journalists; the academic publication referred to by this report itself describes neurostimulation as revealing "savant-like" capacities.[1034] The introduction of speculation and hype is therefore by no means the preserve of journalists alone. Nor are such unwarranted extrapolations from research findings solely a problem affecting small studies conducted in competitive academic or commercial domains. Similar hype may also be observed in references to "military modifications and the rise of the supersoldier"[1035] in the reporting of large publically-funded neurotechnology research programmes such as those supported by the US Defense Advanced Research Projects Agency (DARPA).

[1028] BBC News Online (15 November 2007) *Paralysed man's mind is 'read'*, available at: http://news.bbc.co.uk/1/hi/health/7094526.stm; UCtelevision (2011) *Reading the mind: brain-computer interface*, available at: http://www.youtube.com/watch?v=Gweo_ipsYLg.

[1029] Haselager P, Vlek R, Hill J and Nijboer F (2009) A note on ethical aspects of BCI *Neural Networks* **22(9)**: 1352-7, at page 1356.

[1030] Ibid, at page 1356.

[1031] Nijboer F, Clausen J, Allison BZ and Haselager P (2011) The asilomar survey: stakeholders' opinions on ethical issues related to brain-computer interfacing *Neuroethics*, at page 2.

[1032] Ibid.

[1033] The Daily Mail (30 Sept 2008) *The 'thinking cap' that could unlock your inner genius and boost creativity*, available at: http://www.dailymail.co.uk/sciencetech/article-1064431/The-thinking-cap-unlock-inner-genius-boost-creativity.html.

[1034] Snyder A (2009) Explaining and inducing savant skills: privileged access to lower level, less-processed information *Philosophical Transactions of the Royal Society: Biological Sciences* **364(1522)**: 1399-405; Snyder A, Bahramali H, Hawker T and Mitchell DJ (2006) Savant-like numerosity skills revealed in normal people by magnetic pulses *Perception* **35(6)**: 837-45.

[1035] Wired (6 September 2012) *Military modifications and the rise of the supersoldier*, available at: http://www.wired.co.uk/news/archive/2012-09/06/supersoldiers.

The role of social media[1036]

9.40 Newspapers, radio and television are not the only sites of representation of novel neurotechnologies. The internet allows the possibility of mainstream media circulating via new forms – for example, 'newsworthy' stories may be amplified in historically unprecedented ways as they spread, or even 'go viral', via social media. It also allows journalists to be bypassed altogether as, for example, scientific researchers can publish blogs that reach their online followers directly. Indeed, early-career scientists and researchers are actively encouraged to adopt a social media profile.[1037] Individual members of the public can also gain a platform for their views, for example by maintaining blogs about their experiences of ill health or treatment (see paragraph 9.46 below). In addition, it is possible that by posting material about their products or services, companies can use social media as a promotional environment (for example see Box 9.2).

9.41 One advantage of the internet in general, and social media more specifically, is that both scientists and journalists can reach new audiences and engage them in dialogue. However, care has to be taken in assuming that this aspect of social media always plays a 'democratising' role. Recent research looking at the behaviour of journalists on Twitter concluded that, although using social media offers a good way to market oneself, they did not "advance accountability or transparency in any meaningful way".[1038] They found that 43 per cent of Tweets contained "at least an element of opinion" and 16 per cent were *primarily* opinion.[1039] This shows a significant deviation from the traditional role of journalists as providers of non-partisan information. The use of the internet for the communication of scientific research may be seen as offering opportunities for increased public engagement, transparency and trust, but also threats in terms of the quality and integrity of the reporting taking place online.[1040]

9.42 Social media are often seen as 'empowering' users because they are granted access to people and information around the world.[1041] However, it is also argued that through these connections, social media can exploit users by connecting them to corporations; turning users into a source of valuable income. It is therefore important to consider the types of messages and content available on social media platforms, what types of connections are taking place, and whether users of social media are benefitting from these connections.

9.43 A snapshot study of the coverage of novel neurotechnologies on social media platforms, conducted to inform this report,[1042] raised questions about the extent to which private individuals were generally responsible for posting content.[1043] For example, use of the search term "neural stem cell therapy" on social media video platform YouTube revealed that the US-based health care provider StemCellRegenMed had uploaded five of the first 20 videos returned by that particular search, the US Government-funded agency the California Institute of Regenerative Medicine (CIRM) had uploaded three of the videos, and the US research foundation the Neural Stem Cell Institute had uploaded two of the videos. Another search of

[1036] Research informing paragraphs 9.40 to 9.46 was carried out as part of a study commissioned by the Working Party to provide a brief overview of the representation of novel neurotechnologies on social media platforms: Purcell-Davies, A (2013*) Novel neurotechnologies in social media: final report*, unpublished manuscript. More information about this study can be found at appendix 2.

[1037] Minocha S and Petre M (2012) Handbook of social media for researchers and supervisors available at: http://www.vitae.ac.uk/CMS/files/upload/Vitae_Innovate_Open_University_Social_Media_Handbook_2012.pdf

[1038] Lasorsa DL, Lewis SC and Holton AE (2012) Normalizing Twitter *Journalism Studies* **13(1)**: 19-36, at page 27.

[1039] Lasorsa DL, Lewis SC and Holton AE (2012) Normalizing twitter *Journalism Studies* **13(1)**: 19-36, at page 30.

[1040] See, for example, Allan S (2011) Introduction: science journalism in a digital age *Journalism: Theory, Practice and Criticism* **12(7)**: 771-7.

[1041] van Dijck J (2012) Facebook and the engineering of connectivity: a multi-layered approach to social media platforms *Convergence: The International Journal of Research into New Media Technologies*: 1-15, at page 4.

[1042] Purcell-Davies, A (2013*) Novel neurotechnologies in social media: final report*, unpublished manuscript. The methodology included categorising the first 20 results returned by entering the search terms "deep brain stimulation", "brain computer interface" and "neural stem cell replacement therapy" into each of the social media platforms Delicious, Facebook, Twitter and YouTube. The generic search engine Google Blog Search was used to search for blogs.

[1043] Purcell-Davies, A (2013*) Novel neurotechnologies in social media: final report*, unpublished manuscript.

YouTube using the term "deep brain stimulation" revealed that health care providers published 16 of first 20 videos returned by search results. This suggests that YouTube, as a social media platform, is being used to a great degree by health care providers or research institutes to promote their work or to market their services.

9.44 One video uploaded to YouTube illustrates the use of social media by research institutes seeking to communicate their work directly to the public, but also reflects some of the problematic aspects of hype that we have noted in relation to traditional media. A professionally produced video depicts three different types of BCI research taking place at the University of California, San Diego.[1044] However, the video is titled *Reading the mind: brain-computer interface* and the presenter introduces the research as a "world where computers read our thoughts and emotions". There is little discussion of when BCI-based assistive technologies might be widely available, which could promote the idea that the results of the experiments can be replicated outside of the laboratory, and that such developments will soon be widespread. The author of the snapshot study of novel neurotechnologies in social media noted:

> "Furthermore, there is no discussion of the ethics of such applications or the potential side effects of these technologies. It is assumed that the research being conducted is beneficial and that such neurotechnological products will become the norm. The posting shows scientists and researchers as active participants in the creation of products and procedures, in order to help those with neurodegenerative disease; but those with neurodegenerative disease are not given a voice within the video."[1045]

9.45 As we discuss further below, the risk is that hype about the therapeutic promise of novel neurotechnologies may exploit the desperation of patients who lack other options for treatment. This risk is especially acute if the media conveying this hype are also marketing unproven or unregulated treatment services. We have noted in our earlier discussions that limited availability of licensed therapies, including neural stem cell therapies, and the high costs of some therapeutic neurotechnologies risk encouraging people to travel for treatment in countries with potentially less well-regulated systems of protection (see Box 3.5). The direct marketing of these medical tourism services online compounds the problem of effective oversight and protection of patients, as both the services themselves and the online environments in which they are advertised are very likely to be located or hosted overseas and therefore lie outside the competence of UK regulators (see Box 9.2).

Box 9.2: 'China Medical Tourism': social media representations of stem cell therapy

A video posted on YouTube by a company called 'China Medical Tourism' depicts the experience of one patient, a young woman, at a clinic in Guangzhou. It is explained in the blurb below the video that the patient was in a car accident in 2003. She was initially in a coma and is reported in the video to have "progressed from a vegetative state to being minimally conscious". The video commentary also says that the patient's parents felt that they had exhausted all treatment options in the US and thus decided to travel to the clinic in Guangzhou.[1046] The audience is also told that the patient was given "four stem cells injections via lumbar puncture and a nutritious stem cell cocktail treatment", and that she was admitted to the hospital for 60 days.

The video depicts the patient and her parents in the clinic. In the first shot, we see the patient's father and a clinician from the Chinese clinic encouraging her to sit up, but with little success. In the second shot the patient's father talks to the camera about her care and intensive physiotherapy routine at the hospital. We then see the patient's mother feeding her and the person behind the camera asks if she thinks her daughter can understand her. She says yes, the patient can understand her but cannot respond. The third shot shows the patient and her father, and he is asked what the result of

[1044] UCtelevision (2011) *Reading the mind: brain-computer interface*, available at: http://www.youtube.com/watch?v=Gweo_ipsYLg.
[1045] Purcell-Davies, A (2013) *Novel neurotechnologies in social media: final report*, unpublished manuscript.
[1046] China Medical Tourism (2012) *China medical tourism brain injury stem cell therapy three clip*, available at: http://www.youtube.com/watch?v=Lpre3UoObKs.

the treatment has been. He says that, two months after the treatment, the biggest difference is that the patient's eyes are considerably more alert and that her attentiveness seems to have improved. He also reports that the patient's neck and head control has improved, although he concedes that it might be hard to notice because she does not have full neck and head control. The patient's father suggests that she now tried to respond to requests such as "open your hand" but she is unable to complete these tasks. This video is apparently intended to promote the stem cell therapy services offered by the medical tourism company. However, the dubious and distressing representation of the patient's treatment outcomes means that it is not unambiguously promotional in its effect. What is apparent, however, is that it is neither an unmediated personal account given by the family who participated in video, and nor does it provide any journalistic 'framing' of the information presented which could provide a wider context or critical reflections on what has been filmed.

9.46 The snapshot social media study did, however, find evidence that the internet could provide a platform for voices which might not ordinarily be heard. For example, across the social media platforms examined by the study (YouTube, Facebook, Delicious, Twitter and Google Blog search), the search term 'deep brain stimulation' produced results of which 22 per cent were categorised as 'personal'.[1047] This was reported to be the result of social media platforms, blogs and social networking sites which record the personal experiences of those with Parkinson's disease and severe depression. These personal experiences were observed to be more complex than the representations of DBS surgery posted by health care providers. Detailed reports about the problems connected with DBS for an individual with Parkinson's disease are often absent from the mainstream media reporting of novel neurotechnologies and their exploration in, for example, blog posts by individuals who have themselves undergone this kind of treatment, may be useful for people facing similar choices. For example 'Karyn's journey with DBS' is a blog which charts the experiences of a woman being treated for Parkinson's disease using DBS. One of her blog posts, entitled *'One week to go! Lots of questions'* provides a list of questions she asked her surgeon before surgery, while another blog post with the heading, 'Honeymoon is over; I retract the last post' arguably provides a more nuanced insight into what DBS users might expect.[1048]

Possible impacts of (mis)representation of novel neurotechnologies

9.47 Many scientists, clinicians and patient organisations express concern about the dangers of hype, premature claims, unbalanced coverage, and over-simplified reporting of novel neurotechnologies in the mainstream media, as well as what can be found on the internet.[1049] Communication in this field is an ethical matter because of the individual and social harm that may occur as a result of overstating the capabilities of these technologies or misrepresenting their risks. The protection of trust, at both an individual level and as a shared public interest, through responsible communication comprises one of the central elements of our ethical framework (see Chapter 4). In addition, realistic representations of the capacities and limitations of particular neurotechnologies to provide effective therapies for neurological and mental health disorders for which there are few other treatment options is crucial to supporting autonomous choice. This is particularly important in this complex area of technology and

[1047] The highest level of result-type were 'news reports', with 26 per cent. 'Personal' sources were categorised as such if the origin of the source of the information came from an individual. This category is difficult to assess and should be treated as indicative rather than definitive. On the internet, individuals are not always truthful about their motives and/or status. However, sources placed into this category had either uploaded media as an individual or had a personal profile. Even though they were placed into this category, some of these individuals advertised the fact that they were recipients or potential recipients of medical procedures for neurodegenerative disease, carers of people with neurodegenerative disease or had worked in neuroscientific companies and/or university research departments.

[1048] Karyn (24 August 2012) *Honeymoon is over; I retract the last post, on Young@Park [internet blog]*, available at: http://karynsjourneywithdbs.blogspot.co.uk/2011/08/honeymoon-is-over-i-retract-last-post.html.

[1049] Racine E, Waldman S, Palmour N, Risse D and Illes J (2007) "Currents of hope": neurostimulation techniques in US and UK print media *Cambridge Quarterly of Healthcare Ethics* **16(3)**: 312-6; Bell E, Maxwell B, Pat McAndrews M, Sadikot A and Racine E (2010) Hope and patients' expectations in deep brain stimulation: healthcare providers' perspectives and approaches *Journal of Clinical Ethics* **21**: 112; Racine E, Waldman S, Rosenberg J and Illes J (2010) Contemporary neuroscience in the media *Social Science Medicine* **71(4)**: 725-33; Schlaepfer TE and Fins JJ (2010) Deep brain stimulation and the neuroethics of responsible publishing *The Journal of the American Medical Association* **303(8)**: 775-6. Also see footnote 1049 below.

medicine because of the current paucity of evidence and, in some cases, the means by which these technologies achieve their effects, and about longer term and unintended effects. In previous chapters, we have outlined how this responsibility applies to the professional practices of clinicians and researchers – indeed the generation and dissemination of robust evidence is a key element of responsible research and innovation. In this chapter, we have considered what this means when applied to the practices of communications professionals. In order to understand the ethical significance of responsible communication in the context of media representations, it is important to understand the nature of the negative impacts that hype and misrepresentation may have. In the following paragraphs we explore the nature of these potential impacts.

Hope

9.48 It is hard to assess exactly what the impact of media representations may be on patients' behaviour and in particular their expectations and trust. It has been suggested that parallels may be drawn between the effects of representation of DBS in the media today and the relatively fast and widespread adoption of lobotomy in the early 20th Century, which may have, in part, been attributable to enthusiastic and optimistic media coverage of this new surgical procedure.[1050]

9.49 One key concern is that hype could mislead and cause distress, for example by offering false hope while failing to alert patients to possible risks, and the extent to which these may still be unknown. This may prompt patient groups to mobilise inappropriately and to create demands for treatments that may not be effective or suitable. Concerns of this kind were reflected by representatives from patient organisations contacted during the preparation of this report. These representatives suggested that media portrayals could 'spur' desperate patients into action, noting that there had been cases in the past where, following a misleading media portrayal, patients approached organisations for support in accessing treatments that remained highly experimental or not yet sufficiently evidence-based to be recommended in regular clinical practice (particularly as an alternative to available and established treatment). For example, one of the representatives reported:

> "[F]ollowing articles in the media about neurostimulation [for migraine], patients will call us and ask 'where do I get this, and how much does it cost?' And these treatments are not available in the UK, and we do not have any clinical guidelines for their use. But people would try absolutely anything they read about."[1051]

9.50 It cannot be assumed that everyone will react in the same way to therapeutic or assistive promises conveyed in the popular media. The effects may not always be detrimental. Hope can be an important sustaining force where individuals and those close to them are living with distressing or debilitating neurological or mental health conditions for which no other effective treatments are available. Raising awareness of new interventions might also alert individuals to the possibility of participating in clinical research, which might offers a sense of respect and purpose (see Box 5.2). Responsible communication recognises that information about emerging therapeutic applications of new technologies may therefore be valued by such individuals, but that it must be delivered in a realistic and honest way, making plain the limits of our knowledge and remaining sensitive to the potentially desperate circumstances of some who will receive these messages. This is essential to maintaining the trust in these new neurotechnologies that we identified as a key interest in our ethical framework.

[1050] Bell E, Mathieu G and Racine E (2009) Preparing the ethical future of deep brain stimulation *Surgical Neurology* **72(6)**: 577-86, at page 582; Diefenbach GJ, Diefenbach D, Baumeister A and West M (1999) Portrayal of lobotomy in the popular press: 1935-1960 *Journal of the History of the Neurosciences* **8(1)**: 60-9.

[1051] Joanna Hamilton-Colclough, Director, Migraine Action, personal communication, 10 May 2012.

9.51 Hope may not only be valuable to individuals but can also help create a framework for innovation and engagement. Without hope, there is the danger of denying recuperative potential and adopting a position of therapeutic nihilism that abandons patients – such as those assumed to be in a permanent vegetative state (PVS) or 'minimally conscious' – to a situation where they are 'warehoused' and ignored.[1052] However, hope can also be misleading, and even harmful. One UK study, for example, showed how families with a relative who is in a minimally conscious state or in a PVS may be influenced by the imperative 'not to give up' on their loved one, combined with the message that science and technology might offer future hope that is 'just around the corner'. This can lead them to press for life-sustaining interventions, often against the advice of clinicians. In retrospect, families may come to view the 'false hope' as having contributed to their relative being left in limbo, sustained in what the family may now view as "a fate worse than death".[1053] This research also highlighted the different perspectives regarding the investment in, or the rebuttal of, hope in different technologies. While the reporting of techniques such as DBS assume that trying to stimulate consciousness in a vegetative patient is a good thing, this was not a view shared by every family in this study. Some interviewees had come to view the return of some consciousness in a vegetative relative as a threat, rather than an aspiration. One family member, for example, commented: "to be honest I'd rather medical science didn't come up with anything", commenting that she had seen how patients who developed some minimal consciousness could become distressed. Another member of this family agreed, adding that if her daughter showed some signs of becoming aware of her situation, then she would be "scared", indeed "terrified" on her behalf.[1054]

9.52 A recent qualitative study examined how families of patients with severe brain injuries understood the potential of neurotechnologies such as fMRI and DBS to make a difference to these patients.[1055] This study found that some family members (especially those in the earlier stages of dealing with severe brain injury) responded with a strong sense of excitement and hope – echoing that expressed in the media – and for some families, any consciousness or possibility for communication is viewed with excitement and hope. However, other interviewees, especially those who had lived with the implications of severe brain injury for longer periods of time, reflected negatively on the effects of media representation, including complaining about disappointed hopes, misleading information and a narrow focus on technologies (see Box 9.3). This work also highlighted how the portrayal of families in media coverage (as happy and hopeful) left out the possibility of more varied and contextually complex reactions from families dealing with the realities of caring for a relative in such circumstances – families who raise questions about whether such technologies will really be deployed in a way which supports their relative.

[1052] Fins J (2010) Minds apart: severe brain injury, citizenship, and civil rights *Law and Neuroscience: Current Legal Issues* **13(18)**: 367-84.
[1053] Kitzinger J and Kitzinger C (2012) The 'window of opportunity' for death after severe brain injury: family experiences Sociology of Health & Illness: 1-18 doi: 10.1111/1467-9566.12020.
[1054] Kitzinger, J and Kitzinger, C (2013) Neuroscience in the news, lecture at Cardiff School of Biosciences, 15 February 2013 available at: http://www.cardiff.ac.uk/jomec/resources/fMRI_KitzingerTalk.pdf.
[1055] Samuel, G and Kitzinger, J (2013) Media publicity about fMRI and DBS for vegetative patients: reactions from families, *Working Paper*. Summary available at: http://www.cardiff.ac.uk/jomec/contactsandpeople/profiles/kitzinger-jenny.html.

Box 9.3: Example of quotes from families with experience of severe brain injury talking about media representation[1056]

"They [the newspaper articles] are really misleading cos they give you hope and I suppose whilst all you cry for is a bit of hope I do understand why they [doctors] don't give you it because when you get given it… you make your own conclusions don't you? And you twist what's been said… that's what doctors don't want you to do, they don't want you to hear something different from what they're saying and that's what the media does. It changes everything and makes you think there's answers out there that just aren't…"

One interviewee picked up on a newspaper's articles talk of 'hope' and said "I'm struggling with that word, not that I don't believe in an afterlife but it [what the article is referring to] is hope for this life. [...] my question would be there's hope for whom? For her to make any further recovery? Probably not. [...] …so basically hope for what?…"

Another interviewee responded angrily to the representation of a comatose woman and what new neurotechnologies might be able to do for her: "but why isn't there any discussion of whether she's getting good quality care, whether people are visiting her, it's totally divorced from humanity, she's just a brain […] This is just someone in a lab – who's going to pay for scans for the vast majority of people [and] it's the language of smoke and mirrors, this word 'recovery' – does it mean she can blink..? And there's no mention of expense, community, loved one's…as if the science determines it all, it should have been written by a philosopher or a psychologist. Scientists can't analyse this out of context"

Another talked about the hopes raised by the fMRI coverage, and then her own decision not to pursue this as she didn't want her partner to 'fail' the test: "People still now send me links about the fMRIs. This is amazing, maybe we can help [partner] through these amazing fMRIs. […] …I spent months really pressing for fMRIs, not really understanding what they were. I thought they were, you know, what everyone else thinks, I saw all the articles. And then I decided against them and I said, 'I don't want him to have one'. Because I don't want him to be judged against an fMRI when he may not be conscious. Do you know, he's got pockets of awakeness and sometimes he doesn't have a pocket for two or three days. Do you know, and I'm not going to take that away from him."

Autonomy and informed consent

9.53 One particularly problematic consequence of creating unrealistic expectations about how effective, well-established, or risk-free a novel therapeutic technology is, is that this may interfere with the capacity of individuals to make well-informed, autonomous choices – and therefore to give informed consent – to undertake interventions.[1057] A study of health care providers from five Canadian DBS centres, for example, identified extremely high expectations as a key challenge, which could undermine patients' understanding of risks and benefits, due, "[i]n part, to overestimated media reports on 'miracle cures' through DBS."[1058]

9.54 Similar problems may be particularly acute in the field of research into assistive BCIs, which is still at a relatively early stage of investigation in humans. It has been noted that "the presentation of BCI research within the public media is an important factor in the creation of reasonable expectations about the possibilities and limits of BCI."[1059] These authors emphasise that it is important to establish whether individuals understand the extent to which coverage of BCIs in the popular media has been 'glossed' or exaggerated, or whether they are "under the mistaken impression that BCI has already allowed communication by people who cannot otherwise communicate at all?"[1060] Problems for informed consent extend not only to decisions that individuals make about their own treatment or participation in research, but also to relatives or carers who are in a position of giving consent on behalf of individuals who lack capacity, and for whom hype only adds to the challenges of determining what is in the best interests of someone who cannot exercise their own choices.

[1056] Samuel, G and Kitzinger, J (2013) Media publicity about fMRI and DBS for vegetative patients: reactions from families, *Working Paper*. Summary available at: http://www.cardiff.ac.uk/jomec/contactsandpeople/profiles/kitzinger-jenny.html.
[1057] Bell E, Mathieu G and Racine E (2009) Preparing the ethical future of deep brain stimulation *Surgical Neurology* **72(6)**: 577-86, at page 582.
[1058] Clausen J (2011) Conceptual and ethical issues with brain–hardware interfaces *Current Opinion in Psychiatry* **24(6)**: 495-501, at page 497.
[1059] Haselager P, Vlek R, Hill J and Nijboer F (2009) A note on ethical aspects of BCI *Neural Networks* **22(9)**: 1352-7, at page 1352.
[1060] Ibid, at page 1353.

Policy and investment

9.55 One potential positive consequence of raising the profile of novel neurotechnologies is that this could inspire and support innovation by attracting both public and private funding.[1061] Conversely, however, raising the profile of these technologies could promote inaccurate or exaggerated representations which could impact negatively on future innovation trajectories, for example by channelling investment or policy support towards particular solutions such as hi-tech innovations, at the expense of alternative low-tech approaches. Here too, trust is important; as we note in Chapter 8, there is a concern that hyping the potential of a novel neurotechnology risks provoking a public backlash where promises are unfulfilled (see paragraph 8.61).

Perceptions of ourselves and others

9.56 A less concrete – but potentially no less influential – effect of representations of neuroscience in the mainstream media has been highlighted by some commentators. This is the potential problem of 'neuroessentialism', that is, the perception that the brain is the defining essence of a person.[1062] Some have argued that essentialist conceptions of the brain could lead to evidence of our brain structures or neural functions being used to reach decisions about what kind of person someone is, or to explain our behaviour and experiences.[1063] These concerns have been raised with particular reference to brain imaging. However, they also could also apply to the technologies with which we are here concerned, for example in respect of the perception that accessing information about our neural signals is the same as accessing information about our memories or emotions, or that the most effective treatment for neurological or mental health conditions will be direct technological interventions in the brain, rather than other kinds of care. A recent study echoes and expands upon these speculations, arguing that while clinical applications of neurotechnologies retain an important profile, neuroscience was:

> "more commonly represented as a domain of knowledge relevant to 'ordinary' thought and behaviour and immediate social concerns. Brain science has been incorporated into the ordinary conceptual repertoire of the media, influencing public understanding of a broad range of events and phenomena."[1064]

What constitutes good representation?

9.57 In the remaining paragraphs of this chapter, we consider the question of what constitutes 'good' representation in relation to novel neurotechnologies. Two key qualities are accuracy in conveying the findings of the research and clarity about the robustness of the research itself. These aspects have been long standing sources of concern. In 1999, the UK's House of Commons Science and Technology Committee's (responding to disputes in the UK) recommended that "media coverage of scientific matters should be governed by a Code of Practice which stipulates that scientific stories should be factually accurate."[1065] Since then, there have been a series of efforts to improve science reporting, including the production of guidelines (for example, through the collaboration in 2001 between the Social Issues Research Centre, the Royal Society, and the Royal Institution of Great Britain),[1066] the establishment of the SMC (in 2002),[1067] and a great many research projects and reviews. These reviews have

[1061] Bell E, Mathieu G and Racine E (2009) Preparing the ethical future of deep brain stimulation *Surgical Neurology* **72(6)**: 577-86, at page 582.
[1062] Racine E, Bar-Ilan O and Illes J (2005) fMRI in the public eye *Nature Reviews Neuroscience* **6(2)**: 159-64, at page 160.
[1063] Ibid.
[1064] O'Connor C, Rees G and Joffe H (2012) Neuroscience in the public sphere *Neuron* **74(2)**: 220-6, at page 22.
[1065] Select Committee on Science and Technology (1999) *Scientific advisory system: genetically modified foods* available at: http://www.publications.parliament.uk/pa/cm199899/cmselect/cmsctech/286/28604.htm, at paragraph 7.28.
[1066] Social Issues Research Centre (2001) *Guidelines on science and health communication*, available at: http://www.sirc.org/publik/revised_guidelines.shtml#guide1.
[1067] Science Media Centre (2013) *Science media centre*, available at: http://www.sciencemediacentre.org/.

included a report on the state of science journalism in the UK, commissioned by the Science and Media Expert Group on behalf of the UK Department for Business Innovation and Skills (2009),[1068] and the BBC Trust's review of the BBC's impartiality and accuracy of the BBC's coverage of science (2011).[1069]

9.58 Guidelines produced collaboratively by the Social Issues Research Centre, the Royal Society and the Royal Institution of Great Britain include recommendations that journalists should address issues such as:

- Source credibility, for example noting whether research been peer reviewed, and making it clear if it has not been;
- Research procedure and method, for example, how was the research was conducted;
- Relationships with other work, for example, that it should be clearly stated when findings are at variance with previous knowledge; and
- The significance of findings, with any limits clearly spelled out.[1070]

9.59 Transparency and clarity about the significance of findings is also a key concern. The SMC underlines the need for journalists to:

- "state the source of the story [...] ideally with enough information for readers to look it up or [access] a web link";
- "specify the size and nature of the study" and;
- "when reporting a link between two things, indicate whether or not there is evidence that one causes the other."

9.60 The SMC also suggest that journalists should give some indication of the speed with which a treatment may, or may not, become available, and be aware of the dangers of overstatement. The SMC guidelines recommend that journalists:

- "Give a sense of the stage of the research – for example, cells in a laboratory or trials in humans – and a realistic timeframe for any new treatment or technology";
- "Distinguish between findings and interpretation or extrapolation";
- "Be wary of scientists and press releases over-claiming for studies";
- "Headlines should not mislead the reader about a story's contents and quotation marks should not be used to dress up overstatement"; and
- "Remember patients; don't call something a 'cure' that is not a 'cure'."[1071]

The SMC also provides a '*Before the headlines*' service, which underpins these guidelines and supports adherence to robust reporting practices by providing independent statistical analyses of scientific papers.[1072]

9.61 In recognition of the role of professionals in the responsible communication of science and technology, similar guidance has also been issued to researchers themselves. For example, the

[1068] Cardiff University School of Journalism, Media and Cultural Studies (2009) *Mapping the field: specialist science news journalism in the UK national media*, available at: http://cf.ac.uk/jomec/resources/Mapping_Science_Journalism_Final_Report_2003-11-09.pdf.
[1069] BBC Trust (2011) *BBC Trust review of impartiality and accuracy of the BBC's coverage of science*, available at: http://www.bbc.co.uk/bbctrust/assets/files/pdf/our_work/science_impartiality/science_impartiality.pdf.
[1070] Social Issues Research Centre (2001) *Guidelines on science and health communication*, available at: http://www.sirc.org/publik/revised_guidelines.shtml#guide1.
[1071] Science Media Centre (2012) *10 best practice guidelines for reporting science and health stories*, available at: http://www.sciencemediacentre.org/wp-content/uploads/2012/09/10-best-practice-guidelines-for-science-and-health-reporting.pdf. These are the guidelines that the SMC was invited to submit by the Leveson inquiry (see paragraph 9.27 above).
[1072] Science and Media Centre (2013) *Before the headlines*, available at: http://www.sciencemediacentre.org/working-with-us/for-journalists/headlines-for-journalists/.

Committee on Freedom and Responsibility in the Conduct of Science recommends, among other things, that scientists should:

- "always be accurate and reflect the status of scientific evidence and uncertainty, and be realistic in estimating the importance and future implication of scientific results";
- "despite pressures to the contrary, public communication of new scientific findings should normally follow acceptance by peer review" and;
- "be transparent in communicating the limits of their own personal expertise and make the distinction between those areas of science in which they might reasonably be considered by their peers to have expertise and other areas on which they may express views."[1073]

9.62 The guidelines produced by the Social Issues Research Centre, the Royal Society, and the Royal Institution of Great Britain highlight further the need for all of those involved in communicating science to consider the likely public reaction and approach their tasks with empathy, considering the following hypothetical question:

> "Imagine you have a relative or close friend who is sensitive or vulnerable to information about a particular topic… If the only source of information available to that relative of close friend was the interview you are about to give, or the report you are about to publish, would you feel comfortable with the way you propose to characterise and interpret the story?"[1074]

9.63 The various sets of guidelines produced over the last 15 years and cited in the preceding paragraphs are extremely useful. Nevertheless, concerns about representation continue. This may be partly due to the (perhaps increasing) pressures on researchers, PR professionals, and journalists to communicate in certain ways (for example, to hype findings). It is also clear that the way in which research is represented can be a source of concern without necessarily being inaccurate or lacking key criteria such as peer review, and different stakeholders have diverse views on what counts as 'over-claiming' or exceeding expertise, or indeed, what may be a useful message for an audience. While there is some consensus about some basic issues, the broader questions of what constitutes good reporting will often be the subject of debate. This is, in part, because representation of any emerging technology involves complex medical, scientific and social information, and various types of speculation and value judgments. These include speculation about the expected effects of a technology, value judgments about the nature of the problems the technology addresses and how these should be solved, assessment of potential risks, contested predictions of the time-scale and scope of availability of applications, and assessments of the effectiveness of the policy context for management or delivery.

9.64 Different individuals working in communication might make judgments about these issues and shape messages according to their own perspectives – hence debates about what good reporting, and good PR 'look like'. For example, in a recent study, different science press-officers were interviewed. During the interview, they were shown press releases for key newsworthy studies on DBS and on fMRI. This study found that, while the press officers could agree on what constituted good technique for the press releases, they had different assessments of the values which imbued the information presented; for example, whether it was manipulative, over-optimistic or extrapolated too far beyond the available evidence.[1075] Similarly, it is not uncommon for there to be disputes between different clinicians and scientists

[1073] International Council for Science (2010) *Advisory note "science communication"*, available at: http://www.icsu.org/publications/cfrs-statements/science-communication/advisory-note-science-communication.
[1074] Social Issues Research Centre (2001) *Guidelines on science and health communication*, available at: http://www.sirc.org/publik/revised_guidelines.shtml#guide1.
[1075] Samuel, G and Kitzinger, J (2013) Media publicity about fMRI and DBS for vegetative patients: reactions from families, *Working Paper*. Summary available at: http://www.cardiff.ac.uk/jomec/contactsandpeople/profiles/kitzinger-jenny.html.

about whether a particular press report or documentary has been accurate or misleading, helpful or damaging.[1076]

9.65 It is possible to assess whether a research programme or clinical trial taken on its own terms delivers robust and consistent findings – but beyond these immediate assessments, it cannot tell us the 'true' nature of the wider impact of a technology. This is due to the incremental and non-linear nature of technological trajectories, which depend on wider social contexts beyond science and technology, including how the meanings and consequences of findings are presented. The questions of what 'good' communication and representation of novel technologies looks like, and by what principles these efforts should be guided, therefore require both insight into social and economic processes, and the consideration of ethical and social considerations that are judged to be most pressing.

Applying our ethical framework

9.66 Our ethical framework offers the means to negotiate the kinds of debates that may arise in determining what 'good communication' means in the context of novel neurotechnologies. It may not always provide easy or definitive answers and it will still be necessary to engage with the details of any particular situation. Our ethical framework does, however, provide the tools with which to characterise the various interests at stake and the virtues associated with responsible communication and representation practices. The framework invites all parties involved in communication about novel neurotechnologies to consider the kinds of challenges outlined in paragraphs below.

9.67 In recognition of the need for caution in the creation of expectations and hope, and thus in the protection of autonomous decision-making and trust, there is a need to attend to what constitutes a proportionate balance between communicating enthusiasm about the possible therapeutic applications of a novel neurotechnology, while also drawing attention to any limits in our knowledge of its efficacy, or of how it achieves its therapeutic effects. For example, the virtues of responsibility and humility each point to the importance of considering the extent to which celebrating the benefits of DBS for *some* people with Parkinson's disease might occlude clear messages about unintended effects of treatment, or the possibility that only a sub-group of patients might be eligible for, or able to access, DBS treatment. Hype, speculation, and misinformation expose vulnerable patients, prospective research participants (and indeed consumers) and those close to them to false hope. This could undermine their capacities to make the best decisions regarding treatment and care. Realistic and accurate communication is also essential to maintaining wider trust and understanding of therapeutic interventions in the brain.

9.68 Awareness of the demands of equity and justice (and the harm of raising unjustified hope) leads to the question of whether, in the contexts of economic austerity and global inequalities, it is fair or realistic to talk of particular treatments or assistive neurotechnologies as if they could soon be universally available to patients worldwide. Concerns about injustice also signal questions about whether portrayals of users of novel neurotechnologies might serve to reduce the stigmatisation of individuals living with particular neurological or mental health disorders. However, the corresponding risks of objectifying these individuals, or suggesting that technological solutions are the *only* appropriate response to their conditions, must also be considered.

9.69 We recognise that those communicating the capacities of emerging neurotechnologies may make a valuable contribution to promoting inventiveness and shaping a policy and funding

[1076] See, for example, Turner-Stokes L, Kitzinger J, Gill-Thwaites H *et al.* (2012) fMRI for vegetative and minimally conscious states *British Medical Journal (Clinical Research Edition)* **345:e8045**, and the subsequent rapid response from the science journalist, clinician, and scientist involved in the programme criticised, available at: http://www.bmj.com/content/345/bmj.e8045?tab=responses.

climate in which valuable therapeutic interventions can be developed. In the spirit of contributing to the inventiveness of others, it may be judged that positive representations of the therapeutic and commercial promises of novel neurotechnologies may play a necessary role in encouraging discussion, public acceptance, and incentives for investment which will each support the realisation of the potential of these technologies. However, there are also responsible reasons to avoid overly optimistic predictions and representations that suggest that particular neurotechnologies will deliver effective therapies within defined short-term timeframes such as 'within five to ten years'.

9.70 Responsibility also recommends considering what kinds of images or analogies would illustrate the role and effects of these technologies in realistic ways that promote trust and understanding. In the case of novel neurotechnologies, this might, for example, include reflecting on whether focusing on dramatic images of DBS reducing tremor in people with Parkinson's disease is responsible, when other less immediately visible effects such as those on mood, identity or personal relationships will not be captured by these images. Responsible communication also involves reflecting on social context and being aware of the history (as well as the future) of a technology in considering what are the most appropriate historical analogies. For example, this might involve asking whether highlighting the connection between novel interventions in the human brain and the (problematic) history of lobotomy and electroconvulsive therapy (ECT) – as we have in Chapter 1 of this report – would have the effect of evoking unjustified fears, or alternatively, whether it might operate as a strategy to distance the current explorations from past mistakes and abuses.

Responsible communication in the context of novel neurotechnologies: our recommendations

9.71 In view of the need to protect vulnerable individuals while promoting innovation and trust, we suggest that research scientists, press officers within research organisations, and journalists should each seek to exemplify the virtues of humility and responsibility by grounding their communication of the implications of research concerning novel neurotechnologies in the most robust evidence available. Furthermore, as we have emphasised in Chapter 6, generating and disseminating robust evidence is a central element of responsible research and innovation (RRI). In calling for responsible communication practices, we endorse the existing guidelines for the accurate and responsible reporting of science in general (cited at paragraphs 9.57 to 9.62) and re-emphasise the importance of adhering to these in light of the potential professional duress and incentives to exaggerate the capacities of novel neurotechnologies and the risks of hype in this field. Moreover, the importance of protecting the interests of trust and autonomous decision-making in relation to technologies that intervene in the brain means that responsible communication must also take into account the *impact* that the framing and style, as well as the content, of communications can have on people's lives, hopes and self-conceptions. Given the heightened public interest in neuroscience and the workings of the human brain, and the widespread lack of understanding of many of the complexities of these, it is important to avoid vague statements that could attract misleading interpretations. This is especially important given the particular pressures on patients and carers facing devastating brain injuries or degenerative conditions who could be damaged by representations which generate distorted expectations.

9.72 For these reasons, **we recommend that all actors working in professions involved in communicating the findings of research involving novel neurotechnologies have a responsibility to reflect upon how their representation of the current and future applications of novel neurotechnologies might impact on others and to remain circumspect about the promises of these applications (however exciting they may be to them professionally or personally).** In recommending this, we have deliberately not produced a simple checklist, but instead a set of considerations that are intended to not only guide the reflections of individual actors, but also to be taken into account by institutions and professional bodies involved in the entire circuit of neurotechnology communications in drawing up professional guidance on good practice in this field. **Specifically, we recommend that these professionals and organisations should attend to the following elements of responsible communication practices:**

- **to reflect on the pressures that may be imposed by institutional and structural forces to add a 'pinch of hype' and to consider the *successive and cumulative* effect of this upon on the way in which a story may enter the public domain;**

- **to resist pressure to publish only positive or PR-attractive findings;**

- **to be clear about any features of a research study's aims, scope or methodology that might preclude generalising its findings to wider populations or to practical real-world applications, and to resist the temptation to over-claim or engage in unjustified extrapolation beyond that which is supported by research evidence. It can be as important to say what the research does *not* imply, as what it does. Existing guidelines (from organisations including the SMC) have highlighted a similar imperative in relation to science reporting in general; we re-emphasise it here in the context of novel neurotechnologies where investigations are often pursued through single patient interventions or small studies;**

- **to be transparent about the source of funding of the research reported, especially if it has been conducted on behalf of, or supported by, an organisation with a commercial interest in the findings;**

- **while the use of vivid language, metaphors and images are intrinsic to professional communication practices, it is nevertheless important to refrain from misusing powerful visual devices or engaging personal stories in ways that might mislead. For example, where treatment outcomes are not unequivocally positive, accounts of patients with dramatically reduced symptoms should be accompanied by the stories of those who have different experiences. It may also be important to consider how using language such as 'promise' or 'therapeutic' to describe research outcomes might undermine efforts to communicate the uncertainties or limits of this research by eliding aspirations for a technology with its current capabilities;**

- **where an explicit connection is made between a neurotechnology and a particular therapeutic application, to be clear not only about the kinds of conditions the intervention would address and the balance of risks to benefits for patients, but also any continuing uncertainties, including those relating to longer term outcomes. Given the likely high cost of many novel neurotechnologies and the long development trajectories of stem cell-based therapies, it is also important to reflect accurately the realistic prospects for wide availability to patients;**

- **to acknowledge diversity in the perspectives of patients with neurological and mental health disorders and those close to them, by recognising that novel neurotechnologies may not be the only or indisputable means of addressing their needs and that, for some, a focus on restoring lost function or 'normalisation' might not represent their priorities or best interests; and**

- **to be aware of the broader social, legal, and political implications of research in the sensitive area of the human brain, including the ways in which the research might be applied to other domains**.

9.73 Our recommendations regarding the practices and virtues that would be exemplified by responsible reporting of novel neurotechnologies by researchers, press officers, and journalists are a significant part of ensuring responsible communications. However, insofar as these recommendations are made with a particular emphasis on preventing hype, they risk futility if the other components of the engine that drives hype remain unchecked. It is neither reasonable not desirable to excise all the reasons researchers have to be excited about and share the fruits of their inventiveness and inquiry – indeed, throughout this report, we have emphasised the need for greater dissemination of research and experimental findings. Nevertheless, in light of

the problems of hype in this field **we recommend that the UK governments, higher education funding councils and universities reflect on the effects that the 'impact agenda' might be having on the ways in which the promises and limitations of novel neurotechnologies are communicated by academic institutions and their researchers**.

9.74 **Businesses and universities developing and promoting commercial products from neurotechnological research should also reflect on their own responsibilities when seeking to publicise this research, attract funding for development, and market their products.**