

POPULAR MEDIA, BIOTECHNOLOGY, AND THE “CYCLE OF HYPE”

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INTRODUCTION

There is growing concern about the potential adverse social implications of stories in the popular press that inappropriately “hype” biotechnology.¹ This concern is understandable. The media has emerged as an important, perhaps the most important, vehicle for communicating science issues to the general public. Moreover, the media can play a critical role in public debates about controversial technologies, such as human genetics and stem cell research.²

This article will draw together the available evidence and relevant commentary about popular representations of biotechnology, particularly as it appears in the popular press, to consider its possible impact on public understanding.³ This will illustrate that although the media is a primary conduit of scientific information, the message conveyed by the media is shaped by a variety of social forces, such as commercial pressure. These social forces create a particular spin on popular representations of biotechnology, which

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¹ See Timothy Caulfield, *Underwhelmed: Hyperbole, Regulatory Policy and the Genetic Revolution*, 45 MCGILL L.J. 437 (2001); Dorothy Nelkin, *Beyond Risk: Reporting about Genetics in Post-Asilomor Press*, 44 PERSP. IN BIOLOGY & MED. 199 (2001) [hereinafter Nelkin, *BR*]; Alan Petersen, *Biofantasies: Genetics and Medicine in the Print News Media*, 52 SOC. SCI. & MED. 1255 (2001); Editorial (no listed author), *Don't Feed the Hype*, 35 NATURE GENETICS 1 (2003).

² Matthew Nisbet & Bruce Lewenstein, *Biotechnology and the American Media*, 23 SCI. COMM. 359, 360 (“... the mass media comprise the principal arena where policy-relevant issues come to the attention of decisionmakers, interest groups, and the public. Not only do the media influence the attention of competing political actors and the public, but the media also powerfully shape how policy issues related to biotechnology are defined and symbolized.”).

³ This paper builds on themes that I explore in a number of other papers. See, e.g., Timothy Caulfield, *Biotechnology & the Popular Press: Hype and the Selling of Science*, 22 TRENDS IN BIOTECH. 337 (2004) [hereinafter Caulfield, *Biotechnology & the Popular Press*].

is usually an optimistic picture that minimizes possible risks and limitations.

In part, this optimistic messaging strategy is a result of the pressures placed on researchers by funding entities and the private sector. An enthusiastic message is picked up by the media and transmitted to the public, thus raising public expectations about genetic research and, perhaps, re-enforcing an essentialist view of the role genes play in human disease and behaviour. With public expectations raised, researchers must then pitch the next round of messages with even more enthusiasm. This “cycle of hype” is difficult to break and creates a number of challenging policy concerns, including the potential to erode public trust, damage confidence in the biotechnology sector and promote an essentialistic view of genetics that may, paradoxically, make it more difficult to conduct some forms of genetic research.

This article begins with a review of evidence regarding the nature and tone of media representations of biotechnology. The emphasis is on human genetics and stem cell research. Next is a consideration of the impact popular representations of biotechnology have on public perceptions. Finally, a number of key policy challenges created by the “cycle of hype” are examined.

I. NATURE AND SOURCE OF MEDIA COVERAGE

The coverage of science by the popular press is a major policy issue. Numerous policy-making entities have engaged the topic and there is a growing body of literature describing the nature and impact of media coverage, particularly in the context of genetic research.⁴ Much of this literature has criticized the popular press, speculating that media portrayals are simplistic, inaccurate, and create an adverse impact on public perceptions and attitudes.⁵

Few would disagree with the notion that the popular press, including newspapers, television and radio, simplify stories to make them interesting and entertaining.⁶ This practice undoubtedly im-

⁴ See Celeste Condit, *What is “Public Opinion” About Genetics?*, 2 NATURE REV. GENETICS, 811, 813–14 (2001); IAN HARGREAVES ET AL., TOWARD A BETTER MAP: SCIENCE, THE PUBLIC AND THE MEDIA, ECONOMIC AND SOCIAL RESEARCH COUNCIL (2003); SOCIAL ISSUES RESEARCH CENTRE ET AL., GUIDELINES ON SCIENCE AND HEALTH COMMUNICATION (2001), available at http://www.sirc.org/publik/revision_guidelines.pdf (last visited Oct. 9, 2005).

⁵ Nelkin, BR, *supra* note 1; Dorothy Nelkin, *Molecular Metaphors: The Gene in Popular Discourse*, 2 NATURE REV. GENETICS 555, 557 (2001).

⁶ See Edward Campion, *Medical Research and the News Media*, 351 NEW ENG. J. MED. 2436, 2436–37 (2004).

pacts the tone of the stories and may, by way of omission, cause the stories to be less than complete.⁷ In addition, there are a number of high-profile science stories that serve as examples of less-than-ideal science reporting—such as the coverage of human reproductive cloning and behavioral genetics.⁸ In these stories, the role of genetics is often sensationalized, and a deterministic view of genetics is stressed.⁹

However, there is a growing body of literature that shows that media practices may not be the sole source of “genohype.” Indeed, there is evidence that the media does a relatively good job reporting on some areas of research and that they accurately convey the message produced by the research community. For example, our research team at the University of Alberta recently did a study examining the accuracy of the newspaper coverage of genetic discoveries in Canada, the United States, Great Britain, and Australia.¹⁰

There is a tendency for health reports to describe events as exciting, major advances or as immediate, threatening dangers. Often there is a brief, touching anecdote about one patient that the public will see as convincing proof of a highly effective new treatment or of an imminent threat. Especially in the television news, complex studies tend to be simplified into one bite-sized message. New forms of technology make for good stories; studies with negative results do not. For any report, follow-up is rare. The focus just turns to tomorrow's news and the next advance.

Id.

⁷ See GAIL GELLER, LEARNING TO LIVE WITH THE HUMAN GENOME: WELL REASONED PRUDENCE OR FUTURE SHOCK?, CONFERENCE PANEL, WASHINGTON STATE BOARD OF HEALTH (Jan. 5, 2001), available at <http://www.doh.wa.gov/sboh/Priorities/Genetics/2001Conf/GeneticsLunchPanel.htm> (last visited Oct. 7, 2005).

Therefore, there is variation in the accuracy and content of stories emanating from each discovery, and the extent to which they balance the positive and negative implications of the discoveries. Although there are some false statements, most errors are ones of omission rather than commission. Because of such omissions, people may believe that discovery of new genes will have immediate implications for broad segments of the population.

Id.

⁸ See generally GENETICS AND HUMAN BEHAVIOUR: THE ETHICAL CONTEXT, NUFFIELD COUNCIL ON BIOETHICS (2002) (U.K.).

⁹ See PHARMACOGENETICS, ETHICAL ISSUES, NUFFIELD COUNCIL ON BIOETHICS (2003).

However, there may be a general tendency towards genetic exceptionalism, both in the media, in the arena of policy-making and indeed in funding for research in bioethics. The sources of genetic exceptionalism are diverse, but they include the idea that genes are a direct and deterministic cause of traits and conditions.

Id. See also Petersen, *supra* note 1; Muin Khoury et al., *Challenges in Communication Genetics: A Public Health Approach*, in LARRY GOSTIN, PUBLIC HEALTH LAW AND ETHICS: A READER 475–76 (2002). “Popular representations of genetics are often deterministic, reinforcing a view of humans as a product of their genes, to the exclusion of nongenetic factors.” *Id.*

¹⁰ Tania Bubela & Timothy Caulfield, *Do the Print Media ‘Hype’ Genetic Research?: A Comparison of Newspaper Stories and Peer-Reviewed Research Papers*, 170 CAN. MED. ASS’N J. 1399

We examined 627 newspaper articles that evaluated 111 papers from twenty-four scientific and medical journals, and to our surprise, only 11% of newspaper articles were categorized as inaccurate, having moderately high exaggerated or erroneous claims.¹¹ A 2003 study of the research community's impression of media coverage also found some interesting results. Even though the surveyed scientists "lack confidence in the national media . . . most (65.4%) indicated that they had been either 'very satisfied' or 'somewhat satisfied' with the coverage" of their own work.¹² In other words, the research community's bad impression of science reporting does not extend to reporting on researchers' personal projects.

Another significant emerging trend in the reporting of biomedical stories is an emphasis on benefits, such as near-future therapeutic applications, rather than potential risks or limitations. In our study, for example, we found that few of the newspaper articles (15%) and even fewer of the science articles (5%) dealt with risk.¹³ This data is consistent with other research on the reporting of biomedical studies.¹⁴

What is the cause of this bias toward positive reporting? While it is likely that the media's desire for a good story is at least partially to blame, available evidence indicates that much of the spin comes from researchers and research institutions. For example, medical journal releases often use "formats that may exaggerate the perceived importance of findings."¹⁵ While reporters rarely rely on

(2004) [hereinafter Bubela & Caulfield, CMA]; see also Timothy Caulfield & Tania Bubela, *Media Representations of Genetic Discoveries: Hype in the Headlines?*, 12 HEALTH L. REV. 53 (2004) [hereinafter Caulfield & Bubela, HLR].

¹¹ See Bubela & Caulfield, CMA, *supra* note 10; Caulfield & Bubela, HLR, *supra* note 10. The most commonly cited scientific journals were *Science* (31%), *Nature* (19%), *Nature Genetics* (16%), and *Cell* (16%). The majority of newspaper articles were categorized as having no (62.7%), or slightly exaggerated/erroneous claims (26.3%).

¹² Leverage Gething, "Them and US": *Scientists and the Media—Attitudes and Experiences*, 93 S. AFR. MED. J. 197, 200 (2003). See also M. Wilkes & R. Kravitz, *Medical Researchers and the Media: Attitudes Toward Public Dissemination of Research*, 268 JAMA 999 (1992) (discussing a study of first authors who interacted with the media: 86% rated coverage of their scientific studies as accurate, while only 3% called the coverage inaccurate).

¹³ See Bubela & Caulfield, CMA, *supra* note 10; Caulfield & Bubela, HLR, *supra* note 10.

¹⁴ Alan Cassels et al., *Drugs in the News: An Analysis of Canadian Newspaper Coverage of New Prescription Drugs*, 168 CAN. MED. ASS'N. J. 1133 (2003); Gideon Koren & Naomi Klein, *Bias Against Negative Studies in Newspaper Reports of Medical Research*, 266 JAMA 1824 (1991); Ray Moynihan et al., *Coverage by the News Media of the Benefits and Risks of Medications*, 342 NEW ENG. J. MED. 1645 (2000) (noting that, of 207 news stories on drugs used for disease prevention, only 15 percent of the stories presented both relative and absolute benefits).

¹⁵ Steven Woloshin & Lisa Schwartz, *Translating Research Into News*, 287 JAMA 2856, 2856 (2002).

press releases as a primary source of information,¹⁶ they do influence which stories get reported.¹⁷

This positive spin is hardly surprising. In addition to the enthusiasm that is naturally and understandably associated with the reporting of one's own research results, there is growing pressure to "sell" research in practical and exciting terms.¹⁸ And increasingly, funding agencies expect researchers to be able to describe research in terms of economic benefit.¹⁹ Indeed, entire areas of research, such as genetics, have to be "sold" to public funding agencies and politicians to secure the required long-term budgetary commitments that are often necessary to fulfill ambitious research agendas.²⁰

This means, of course, emphasizing the positive and downplaying risks or limitations. The private sector, however, seems to be one of the most powerful engines of hype. Academic biomedical researchers receive significant support from the private sector.²¹ This industry involvement influences the production of hype in two ways. First, there is evidence that research supported by the indus-

¹⁶ Tom Wilkie, *Sources in Science: Who Can We Trust?* 347 LANCET 1308, 1309 (1996); see also Bubela & Caulfield, CMA, *supra* note 10, at 1401.

¹⁷ See Vladimir de Semir et al., *Press Releases of Science Journal Articles and Subsequent Newspaper Stories on the Same Topic*, 280 JAMA 294 (1998).

¹⁸ See Keay Davidson, *Sticking a Pin in Genome Mappers' Balloon*, S.F. GATE, July 5, 2000, at A1, available at <http://sfgate.com/cgi-bin/article.cgi?file=/examiner/archive/2000/07/05/NEWS15753.dtl> (last visited Oct. 9, 2005) ("The majesty of that challenge [of mapping the human genome] was underlined last week at a White House news conference. There, flanked by big-shot geneticists, President Clinton oratorically toasted the mapping of the human genome and asserted, 'Today we are learning the language in which God created life.'").

¹⁹ For example, the enabling legislation for the Canadian Institutes of Health Research, Canada's major biomedical funding agency, *Canadian Institutes of Health Research Act*, R.S.C. 2000, c.6, § 4(i), states that the goals of the CIHR are to "encourag[e] innovation, facilitat[e] the commercialization of health research in Canada and promot[e] economic development through health research in Canada." *Id.* I explore the conflict more thoroughly in Timothy Caulfield, *Sustainability and the Balancing of the Health Care and Innovation Agendas: the Commercialization of Genetic Research*, 66 SASK. L. REV. 629 (2003).

²⁰ For an account of the Human Genome Project, see ROBERT COOK-DEEGAN, *THE GENE WARS: SCI., POL. & THE HUMAN GENOME* (1994); see also Lori B. Andrews, *Past as Prologue: Sobering Thoughts on Genetic Enthusiasm*, 27 SETON HALL L. REV. 893, 898 (1997) ("[The U.S.] Congress was convinced to fund [the Human Genome Project] on the promise that it would lead to diagnosis and cure of genetic disease."); Nelkin, *BR*, *supra* note 1, at 25 (describing the "language used by geneticists as they try to convey the importance of human genome research").

²¹ See generally David Blumenthal, *Academic-Industry Relationships in the Life Sciences*, 349 NEW ENG. J. MED. 2452 (2003).

try emphasizes benefits over risks.²² This includes a bias toward positive findings in peer-reviewed papers that are reporting on industry-supported research. While much of the analysis of this bias issue has been done in the context of clinical trials funded by the pharmaceutical industry, there is no reason to assume that a similar trend will not emerge in other areas of biotechnology.²³ And, as noted above, there is evidence that, to a large degree, the media conveys this industry-mediated message, relatively accurately, to the public.²⁴

A second ramification of increased industry involvement is the need for researchers to cast their work in a manner that makes it attractive to private investors.²⁵ Similarly, biotechnology corporations must speak with enthusiasm about possible near future profitable products in order to appeal to venture capitalists.²⁶ This

²² See COUNCIL ON SCIENTIFIC AFFAIRS, AM. MED. ASS'N, INFLUENCE OF FUNDING SOURCE ON OUTCOME, VALIDITY, AND RELIABILITY OF PHARMACEUTICAL RESEARCH (presented as CSA Report 10 at the 2004 AMA Annual Meeting, June 2004):

Studies with positive findings are more likely to be published than studies with negative or null results and an association exists between pharmaceutical industry sponsorship of clinical research and publication of results favoring the sponsor's products. Additionally, the publication of negative results may be delayed compared with the time to publication of studies with positive results.

Id.

²³ See Eliza Mountcastle-Shah et al., *Assessing Mass Media Reporting of Disease-Related Genetic Discoveries*, 24 SCI. COMM. 458 (2003). The goal of the study was to develop an instrument to assess the "content and balance of mass media stories about genetic discoveries relevant to human diseases." *Id.* at 459. Preliminary results include the following:

Nearly one-fifth of the stories that described a clinical application of one of the discoveries failed to mention an estimated time when the applications(s) would be available. Others exaggerated the nearness of the application, which can lead the public to expect a great number of predictive and diagnostic genetic tests to materialize sooner than is likely. More than half failed to mention that the discovery was applicable to high-risk families. According to our raters, a majority of the stories failed to mention possible risks of the discovery, and more than one-quarter exaggerated the benefits.

Id. at 474–75.

²⁴ See Bubela & Caulfield, CMA, *supra* note 10; Caulfield & Bubela, HLR, *supra* note 10. There are other reasons that industry-funded research may find its way into the popular press. As noted by Nisbet & Lewenstein:

Another type of influential source is industry. By providing the media with expensive information subsidies—including video releases, well crafted Web sites, and material produced by public relations professionals—industry interests are often able to make it easier for journalists to file their story on time and efficiently.

Nisbet & Lewenstein, *supra* note 2, at 362.

²⁵ Paul Nightingale & Paul Martin, *The Myth of the Biotech Revolution*, 22 TRENDS IN BIOTECH. 565, 566–67 (2004).

²⁶ *Id.*

hyperbolic rhetoric has become part of the way both the research and business communities speak about biotechnology.²⁷ As noted by Nightingale and Martin in their explanation as to why there is so much hype surrounding biotechnology:

A key factor is the need for innovators and their sponsors to create high expectations to get access to the very considerable resources (money, people, and intellectual property) required to develop new medical technologies. No one is going to invest in a start-up company, or a large-scale scientific endeavour, such as the Human Genome Project, unless they genuinely believe it has the potential to yield significant returns in a defined timescale.²⁸

Thus, the cycle of hype is created. For various reasons, including commercial enthusiasm and pressure from public funding agencies, the research community increasingly frames areas of research and research results in optimistic terms.²⁹ This positive message is transmitted to the public by the popular press and, as we will see below, creates a level of expectation.³⁰ This expectation must then be satisfied by more hype as an increasingly positive message is needed to stand out from the ever present background noise of hype. And around it goes. To make matters worse, there is very little to moderate the escalation of positive messaging—at least in the short term. This is because all the players, the researchers, the media, and industry benefit from the hype.³¹ However, as will be discussed below, there are significant social concerns that may eventually emerge as a result of this cycle of hype.³²

²⁷ See Diana Zuckerman, *Hype in Health Reporting: “Checkbook Science” Buys Distortion of Medical News*, 33 INT’L J. HEALTH SERV. 383, 383–84 (2003) (“Every day it seems there’s a story touting a ‘promising’ new medical product or treatment. Unfortunately, many of these news stories are based on public relations spin machines going into overdrive on behalf of the company that sells the product.”).

²⁸ Nightingale & Martin, *supra* note 25, at 567.

²⁹ It is important to note that there are many other sources of messages about biotechnology that are frequently optimistic in tone, such as when the health charities lobby politicians for support. This was a common element of the recent stem cell debates. While the hope of the health charities is usually justified—many of these areas of research, such as stem cell research, are tremendously promising—the overly optimistic language can add to the environment of hype.

³⁰ Timothy Caulfield, *The Commercialisation of Medical and Scientific Reporting*, 1 PLOS MED. 178, 178 (2004), available at http://medicine.plosjournals.org/archive/1549-1676/1/3/pdf/10.1371_journal.pmed.0010038-L.pdf (last visited Oct. 9, 2005).

³¹ See Zuckerman, *supra* note 27, at 384 (“It’s a win-win for the ‘experts’ and the companies.”).

³² See discussion *infra* Part IV.

II. "GENOHYPE" AND PUBLIC PERCEPTION

What impact does hype have on public perceptions?³³ There seems to be little doubt that the media is one of the primary sources of information about science and emerging scientific and ethical issues—a point noted by several policy documents and commentators.³⁴ It is, however, easy to overstate the role of the media in shaping the perceptions of individual responses to emerging technologies. It is not a simple equation.³⁵ In other words, individuals do not simply absorb the information provided by the popular media and adopt the message as their own.³⁶ Research by scholars such as Benjamin Bates has demonstrated that this information is likely used in a selective manner by individuals in the public, and its impact on public perception is greatly influenced by numerous factors, such as existing moral beliefs and an interaction between various media sources (e.g., films, documentaries, and books).³⁷ As Bates notes, "In discussing public culture, analysts of news media and sci-fi often overemphasize the message and under-emphasize the audience that receives the message."³⁸

³³ I recognize that defining the "public" is not an easy task. There are many "publics" and communities that may be affected in different ways by media messages about biotechnology. For example, an individual who belongs to a group that is "at risk" for a genetic disease may view media messages about that disease very differently from an individual outside that community.

³⁴ See HARGREAVES ET AL., *supra* note 4; see also SOCIAL ISSUES RESEARCH CENTRE ET AL., *supra* note 4. While this paper is focused on biomedical technologies, there is evidence that the media also plays a significant role in informing the public in other areas of science; Douglas Powell et al., *The Impact of Media on Public Perception and Policy Development Related to Meat Inspection in Ontario*, MEAT INSPECTION REV. (June 2004), <http://www.meatinspectionreview.ca/documents/mediainpact.pdf> (last visited Oct. 9, 2005).

³⁵ The belief that the public is a passive recipient of information and can be educated to understand and, by implication, "accept" emerging technological advances is a common theme in early writing about science communication in the context of the Human Genome Project. See Jon Turney, *The Public Understanding of Genetics—Where Next?*, 1 HUM. REPROD. & GENETIC ETHICS 5 (1995).

³⁶ Benjamin Bates, *Public Culture and Public Understanding of Genetics: A Focus Groups Study*, 13 PUB. UNDERSTANDING SCI. 1 (2004).

³⁷ *Id.*

³⁸ *Id.* Bates suggests:

Instead of transmission model of communication to discuss how public culture works to shape knowledge, we should be open to a model that is more complex. People do not simply receive messages and adopt them as their own understanding (or not). Audiences select some portion of the message to make their own while rejecting other portions of the same message.

Id. at 4. See also Margaret Locke et al., *Genetic Susceptibility and Alzheimer's Disease: The "Penetrance" and Uptake of Genetic Knowledge*, in LAURENCE COHEN & ANNETTE LEIBING, ANTHROPOLOGICAL APPROACHES TO ALZHEIMER'S DISEASE (forthcoming 2005); Hans Peter

Nevertheless, from the perspective of this paper, it is the role of the media as an information provider that remains critical. Even if you do not accept the simple linear relationship between popular media representations and public perceptions, it is difficult to deny that the media functions as a leading source of information about scientific developments.³⁹ Media portrayals do not necessarily determine public opinion, but they provide many primary elements of the discussion, including basic “facts” about a technology or discovery and information about possible social risks and moral concerns.⁴⁰ If the message is consistently positive (or, for that matter, consistently negative), it will likely influence expectations and the basic understanding of the value and risks of a given scientific development.⁴¹ After all, individuals can only work with the information available in the public domain, and the primary (and usually the first) way information about biotechnology gets into the public

Peters, *Is the Negative More Relevant than the Positive? Cognitive Responses to TV Programs and Newspaper Articles on Genetic Engineering*, at 1, 7 (paper presented at the 5th International Conference on Public Communication of Science & Technology, Berlin, Sept. 17–19, 1998), available at http://www.kommwiss.fu-berlin.de/pcst98/Paper_pdf?peters?1.pdf (last visited Oct. 9, 2005):

This reception study has shown that in contrast to simple stimulus-response hypotheses of mass media effects, the slant of media products is not easily transformed into opinions and attitudes held by the audience First, there is no obvious relationship between the slant of media publications on genetic engineering and the average slant of cognitive responses evoked by them. In particular, it is not true that the more favorable the coverage is towards genetic engineering, the more favorable are the recipients' responses.

Id.

³⁹ Matt Nisbet & Bruce Lewenstein, *A Comparison of US Media Coverage of Biotechnology with Public Perceptions of Genetic Engineering*, at 3, http://people.cornell.edu/pages/bv11/Bio_techPCST2001.pdf (last visited Oct. 9, 2005) (“When formal education in science ends, media becomes the most available and sometimes the only source for the public to gain information about scientific discoveries, controversies, events, and the work of scientists.”).

⁴⁰ See Powell et al., *supra* note 34, at 4 (“When asked about sources of information for health risks in Canada, news media were the primary source.”).

⁴¹ See Nisbet & Lewenstein, *supra* note 39, at 3:

Past research has shown that a rise in reaction against a scientific technology appears to coincide with a rise in quantity of media coverage of related controversy. When media coverage of controversy increases, public opposition to the technology in question as measured by opinion polls increases. When media coverage wanes, public opposition falls off.

Id. However, we again need to be careful not to simplify the impact of the media on individual opinions and perceptions. As noted in the study by Hans Peters: “A variety of thoughts may be evoked in different recipients by a single cue in the coverage, the distribution of which is difficult to anticipate. That the effects of coverage are diverse and hard to anticipate makes it difficult for communicators to manipulate the public.” Peters, *supra* note 38, at 17.

domain is via the popular media.⁴² Of course, the information will be interpreted through the lenses of personal values and experiences, but, in the aggregate, the media presentation of the information will have an impact on the tone of the public discourse and, perhaps, general public perceptions.⁴³

There is at least some evidence that media representations can influence the overall impression the public has about an area of research.⁴⁴ Much of the research is preliminary or is based largely on the broad correlation of trends.⁴⁵ While the relationship between media coverage and public perception is complex, the available evidence, though incomplete, does point to several emerging themes.

For example, evidence suggests that both the public and health care professionals have picked up on the largely positive message associated with the reporting of genetic research.⁴⁶ In general, the media is viewed as portraying genetics in a relatively positive light.⁴⁷ A survey of the U.S. public was done shortly after the completion of the Human Genome Project.⁴⁸ It sought to elicit the public's impressions of the media's coverage of the research and found that 51.7% of respondents recalled only positive messages and only 7.4% thought the media message dealt with the potential negative implications of the Human Genome Project.⁴⁹ A study designed to explore how new physicians reacted to the media coverage of the Human Genome Project found surprisingly similar results.⁵⁰ That study found that 54% of incoming house officers thought the media message was only positive, while only 21% thought it was negative or mixed.⁵¹

⁴² See Powell et al., *supra* note 34, at 4 (citing T.J. HOBAN & P.A. KENDALL, U.S. DEP'T OF AGRIC., CONSUMER ATTITUDES ABOUT THE USE OF BIOTECHNOLOGY IN AGRICULTURE AND FOOD PRODUCTION (1992)).

⁴³ *Id.*

⁴⁴ See Nisbet & Lewenstein, *supra* note 39, at 2.

⁴⁵ ANDREW LAING, CORMEX RESEARCH, A REPORT ON NEWS MEDIA EFFECTS AND PUBLIC OPINION FORMATION REGARDING BIOTECHNOLOGY ISSUES (a study commissioned by the Canadian Biotechnology Secretariat, Ottawa (July 2004)).

⁴⁶ Gail Geller et al., Abstract, *Houseofficers' Reactions to Media Coverage About the Sequencing of the Human Genome*, 56 SOC. SCI. MED. 2211 (2003).

⁴⁷ E. Tambor et al., *Mapping the Human Genome: An Assessment of Media Coverage and Public Reaction*, 4 GENETICS IN MED. 31, 34 (2002).

⁴⁸ *Id.* at 31.

⁴⁹ *Id.* at 34.

⁵⁰ See Geller et al., *supra* note 46.

⁵¹ *Id.* Interestingly, the study also found that the print media emphasized the medial implications more than, for example, radio, which emphasized "ethical issues." The message also played a role in shaping the perception physicians had about the value of the technology.

More importantly, this perception of a positive message also seems to influence the global impression the public has of the value of a given area of research, such as biotechnology.⁵² A recent study done by Andrew Laing, on behalf of the Canadian government, compared data on the extent and nature of media coverage with data on public attitudes toward biotechnology.⁵³ The study found two major trends. First, public awareness was correlated with the amount of media coverage.⁵⁴ Second, positive media coverage appears to lead to positive public attitudes toward biotechnology.⁵⁵

Laing summarizes his results as follows:

The second finding was a positive correlation between support for biotechnology products and applications and positive media coverage. Additionally, neutral/positive reaction to the term 'biotechnology' tended to positively correlate with positive/neutral coverage. There was no equivalent correlation between negative media coverage and negative attitudes towards biotechnology. This finding reflects the general improvement in tone of coverage towards biotechnology in recent years coupled with rising levels of support Moreover, the opinion research data indicated a strong correlation between familiarity and support: namely, that support for biotechnology products and processes tends to rise and fall along with professed levels of familiarity with the subject.⁵⁶

Other studies have suggested that the media also plays an important role in shaping how policy issues are framed and the degree to which ethical issues are perceived as important.⁵⁷ The media can serve as a means by which ethical issues are introduced to the public, thereby raising public (and policy maker) concerns that may not have existed prior to the media exposure.⁵⁸ A study by Nisbet and Lewenstein compared newspaper coverage of biotechnology with views of the opinion-leading public.⁵⁹ They found that "with an in-

"The degree of enthusiasm about the accomplishment reflects the content of the media coverage, and, at least for adult primary care houseofficers, probably reflects the increasing relevance of genetic discoveries to medical practice." *Id.*

⁵² LAING, *supra* note 45.

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ See Powell et al., *supra* note 34, at 4.

⁵⁸ Of course, there is an interactive relationship between the media and the public. The media representations reflect a perceived interest by the public. See *id.* "Media not only reflect public perceptions of an issue (journalist, at least in theory, cannot make up newsworthy stories and rely instead on sources and interviews) but shape public perception by telling society what to think about." *Id.*

⁵⁹ Nisbet & Lewenstein, *supra* note 39, at 2.

crease in the amount of media coverage of biotechnology, and a measured shift in the character of coverage [there was a] corresponding change in perceptions among the opinion-leading public.”⁶⁰ The trend suggests that popular representations of genetics and biotechnology in the media can shape and frame how technology is viewed.⁶¹ Other work by Nisbet confirms this trend, including a recent analysis of public opinion surveys and media coverage of the stem cell debate in the United States, which showed that the portrayal of stem cell research and the concomitant ethical issues have a powerful influence on public views.⁶²

In all, the analysis point to an important role for the media in shaping future public judgements of stem cell research and human cloning. Evidence of strong question wording effects, combined with the findings relative to low levels of public knowledge suggest that the public may be highly susceptible to influence by changes in media attention and media characterization of the issue.

The fact that positive media portrayals have a significant impact on public perception should hardly be surprising. The advertising industry is built on this premise, and one could argue that positive representations in the popular press are arguably more persuasive than advertisements. Media stories are messages that are largely disconnected from a commercial agenda and often involve a trusted voice, the academic researcher, who is perceived, perhaps wrongly, to be independent.

III. EXAMPLE CHALLENGES CREATED BY HYPE

A. Unrealistic Expectations

The most obvious social dilemma produced by the hype is the potential to create expectations that will be difficult to satisfy.⁶³ The public may, for example, come to “believe that the discovery of new genes will have immediate implications for broad segments of the population.”⁶⁴ When these expectations are not met, public trust

⁶⁰ *Id.* at 10.

⁶¹ *Id.*

⁶² Matthew Nisbet, *The Polls— Trends: Public Opinion About Stem Cell Research and Human Cloning*, 68 PUB. OPINION Q. 131, 139 (2004); see also Matthew Nisbet, *Explaining Majority Support for Stem Cell Research*, SKEPTICAL INQUIRER, Nov. 12, 2004, www.csicop.org/scienceandmedia/stem-cell/ (last visited Oct. 9, 2005) [hereinafter Nisbet, *Majority*].

⁶³ Caulfield, *supra* note 1.

⁶⁴ Mountcastle-Shah, *supra* note 23 at 475.

could erode, thus undermining the general support for basic biomedical research.⁶⁵

The problem of unmet expectations seems particularly problematic in the context of socially controversial technologies such as human genetics and stem cell research.⁶⁶ If the promise of tangible clinical benefits is used to counter an intuitive moral reservation about a given technology, we may be creating a circumstance where loss of public trust is inevitable.⁶⁷ Rightly or not, many individuals have serious concerns about the development of certain technologies.⁶⁸ Will the public feel betrayed if clinical benefits do not materialize?⁶⁹ While one could argue that the promise of cures and immediate benefits has always accompanied biomedical research, the moral concerns associated with much of biotechnology may make unfulfilled promises more damaging to public trust than in less socially contentious areas.⁷⁰

Despite the fact that the hype is, to some degree, a product of commercial forces, the hype may also have significant implications on the biotechnology industry and the support it receives from the public sector in the long term. Creating hype is inevitable when you

⁶⁵ The presence of "genohype" in the popular culture may also impact how individuals participate in policy discussions and the expectations individuals have concerning access to emerging genetic technologies. The latter concern may have implications for health care systems. See Caulfield, *supra* note 1; Caulfield, *The Media, Marketing and Genetic Services* (forthcoming).

⁶⁶ See Jane Kaye & Paul Martin, *Safeguards for Research Using Large Scale DNA Collections*, 321 BRIT. MED. J. 1146, 1146 (2001).

⁶⁷ *Id.*

⁶⁸ See Jennifer Sosin, *Biotechnology & Ethics: A National Survey of Consumers and Scientists*, KRC RESEARCH (June 2004); CNN.com, *Capitol Hill Faces Possible Struggle with Genome Technology* (June 26, 2000), <http://archives.cnn.com/2000/ALLPOLITICS/stories/06/26/genome.politics/> (last visited Oct. 9, 2005); *Stem Cell Research Debate Last Summer Paved the Way for Greater Acceptance of Human Cloning Research Today*, Ipsos News Center: Research, Opinion & Insights, Dec. 3, 2001, <http://www.ipsos-na.com/news/pressrelease.cfm?id=1368&content=full> (last visited Oct. 9, 2005); L. Saad, *Cloning of Humans is a Turn Off to Most Americans*, THE GALLUP ORGANIZATION, <http://poll.gallup.com/content/default.aspx?ci=6022&pg=1> (last visited Oct. 9, 2005).

⁶⁹ Nisbet, *Majority*, *supra* note 62, at 12 ("At risk is public trust in science. If ten years from now, the public, who overlooked their moral reservations in deference to the hope for cures, see no tangible benefits from the research, then faith in science could take a blow.").

⁷⁰ It should be noted that maintenance of public trust becomes a concern in a variety of contexts. See Kaye & Martin, *supra* note 66. "If there continues to be erosion of trust in the medical profession there is a real danger that controversial areas of research, such as genetics, will provoke increasing levels of public opposition. It is in this context that the proposals for the creation of a very large collection of DNA samples for genetic research should be examined." *Id.* at 1146; see also Peter Singer & Abdallah Daar, *Avoiding Frankendrugs*, 18 NATURE BIOTECH. 1225 (2000).

put market forces together with the innovation process.⁷¹ Michael Schrage suggests that making unrealistic "promises" is an indispensable element of the innovation ecosystem, writing that, "When artfully calibrated against actual progress, they keep markets salivating and investment—of both financial and human capital—flowing."⁷² These messages of hope and progress have also influenced national biotechnology policies throughout the world. As noted by Nightingale and Martin:

These high expectations now underpin much science and technology policy at the OECD, in the USA, the EU, and developing countries. Agencies at the regional, national and international levels are investing heavily in biotechnology and genomics to establish a foothold in what is seen as a key part of the "New Economy."⁷³

Indeed, in many nations biotechnology is viewed as a potential engine of economic growth, including in my home country of Canada.⁷⁴ But there has been so much hype surrounding biotechnology (it has been suggested that we are at the beginning of the "biotech century" and "biotech revolution"),⁷⁵ one wonders if the expectations can ever be met. If they cannot, investor confidence will unavoidably wane and, perhaps more importantly, politicians may become less willing to invest public funds in an area that has not delivered on past promises. In fact, there is already evidence that skepticism has crept into public discussions about the promise of biotechnology. One commentator made the following rather harsh observation about the Human Genome Project: "Is the mapping of the human genome the biological equivalent of the moon landing, an achievement that will revolutionize medicine and enable humanity to guide its future evolution? Or is it an overhyped stunt ballyhooed by biotechnology capitalists that will fall far short of its most romantic ambitions?"⁷⁶

⁷¹ Michael Schrage, *Great Expectations*, *TECH. REV.* 21, 21 (Oct. 2004), available at <http://cache.technologyreview.com/articles/04/10/schrage1004.asp?p=1> (last visited Oct. 9, 2005).

⁷² *Id.*

⁷³ Nightingale & Martin, *supra* note 25, at 564.

⁷⁴ See SCIENCE AND TECHNOLOGY EXCELLENCE IN THE PUBLIC SERVICE, COUNCIL OF SCI. AND TECH. ADVISORS (Aug. 2001), available at <http://www.csta-cest.gc.ca> (last visited Oct. 9, 2005).

⁷⁵ John Carey et al., *The Biotech Century*, *BUS. WK.*, Mar. 10, 1997, at 78.

⁷⁶ Keay Davidson, *Sticking a Pin in Genome Mappers' Balloon*, *S.F. GATE*, July 5, 2000, <http://sfgate.com/cgi-bin/article.cgi?file=/examiner/archive/2000/07/05/NEWS15753.dtl> (last visited Oct. 9, 2005). To date, at least some commentators feel that the performance of the biotechnology sector has hardly been "revolutionary." For example, while the science of human genetics is filled with promise, it has not produced a large number of clinically relevant products. See, e.g., Robert Matthews, *Gene Therapy is Just an Expensive Myth, Claim*

In the end, the creation of high expectations can, paradoxically, negatively affect long term investment in science. High expectations may serve the initial, short term goal of stimulating interest and coaxing public funding entities to invest. However, when expectations are not met, both public and private investors' confidence will deteriorate. More importantly, however, the hype may result in inappropriate research policy decisions within both the public and private sectors. "Unrealistic expectations are dangerous as they lead to poor investment decisions, misplaced hope, and distorted priorities, and can distract us from acting on the knowledge we already have about the prevention of illness and disease."⁷⁷ In fact, genohype, particularly that created by a private sector that focuses on near future clinical products, may cause both researchers and public funding agencies to de-emphasize research opportunities and health applications that may have valuable health benefits.⁷⁸

Scientists, TELEGRAPH, Oct. 31, 2004, <http://www.telegraph.co.uk/news/main.jhtml> (last visited Oct. 9, 2004); see also Nightingale & Martin, *supra* note 25, at 566 ("... [the] biotech revolution model of technological change is unsupported by empirical evidence. Instead, biotechnology is following a well established, historical pattern of slow and incremental technology diffusion.").

⁷⁷ Nightingale and Martin, *supra* note 25, at 568.

⁷⁸ See Khoury et al., *supra* note 9, at 478 ("Despite the excitement about new technologies such as a gene therapy or pharmacogenomics, it is important to consider that public health interventions based on genetic information are just as likely, if not more likely, to impact disease prevention at the population level."); see also Champion, *supra* note 6, at 2437 (discussing the selective media coverage of papers in the *New England Journal of Medicine*). Champion notes that the papers in the *NEJM* lead to "at least 450 original reports per month in the news media." *Id.* Most of these stories focus on stories of immediate interest to the general public. "There is little attention to the problems of health care costs and our health care system, and even less about world health problems such as malaria and tuberculosis. Again, the coverage in the media reflects the interests of the public, on whose attention the media themselves depend." *Id.*; see also Peter Tollman, et al., *The Boston Consultation Group, A Revolution in R&D: How Genomics and Genetics are Transforming the Biopharmaceutical Industry* (Nov. 2001), at 7, available at www.bcg.com (last visited Oct. 9, 2005) (a report by a Boston biotechnology consulting group emphasizing the importance of coordinating marketing with research strategies). In surprisingly frank terms, the report notes the role of marketing in dictating the direction of research. They suggest that, "[u]nprecedented coordination between marketing and R&D will be necessary. Marketing will need to have a say in deciding which markets and which genetic diseases R&D should concentrate on, and will need to become involved earlier than ever." *Id.*

B. Reinforcing Existing Prejudices?

As noted by Bates and others, the relationship between public perceptions and media coverage is undoubtedly complex.⁷⁹ The public does not passively absorb the stories conveyed by the media; they view media stories through the lens of their existing values.⁸⁰ However, media messages may reinforce already existing and less than positive social beliefs, such as racial stereotypes.⁸¹

For some time now, critics of the media coverage of genetic research have voiced concern about the potential for popular representations to create or legitimize inappropriate perceptions of biological difference.⁸² Not long after the start of the Human Genome Project, Dorothy Nelkin observed that simplistic media messages can easily be interpreted as an affirmation of existing racial categories.⁸³ "Above all, the gene appears as a source of difference. News reports, advice columns and stories use genetic images to reinforce existing social categories as 'natural' and therefore right."⁸⁴ With the growth of fields of study such as pharmacogenomics and population genetics,⁸⁵ there is reason to be concerned about how genetic information is presented to the public. These areas of study are largely based on the identification of genetic variation among groups and, when explained in a simplistic manner, may reinforce

⁷⁹ Benjamin R. Bates et al., *Evaluating Direct-to-Consumer Marketing of Race-Based Pharmacogenomics: A Focus Group Study of Public Understandings of Applied Genomic Medications*, 9 J. HEALTH COMM. 541 (2004).

⁸⁰ See generally *id.*

⁸¹ *Id.*

⁸² If anything, recent advances in human genetics have emphasized the biological fallacy of existing socially constructed racial categories. See, e.g., Morris W. Foster & Richard R. Sharp, *Beyond Race: Towards a Whole-Genome Perspective on Human Populations and Genetic Variation* 5 NATURE REVIEWS GENETICS 790, 790 (2004) ("[W]hen used to define populations for genetic research, race has the potential to confuse by mistakenly implying biological explanations for socially and historically constructed health disparities.").

⁸³ See Dorothy Nelkin, *Promotional Metaphors and Their Popular Appeal*, 3 PUB. UNDERSTANDING SCI. 25, 28 (1994).

⁸⁴ *Id.*

⁸⁵ See Barbara J. Evans et al., *Creating Incentives for Genomic Research to Improve Targeting of Therapies*, 10 NATURE GENETICS 1289, 1289 (2004):

Pharmacogenomics is the study of genetic variability in the way people respond to medicines, traced to the expression of genes related to disease susceptibility and drug response at the cellular, tissue, individual and population levels. It has potential to improve targeting of therapies through tests to identify, in advance, individuals who are genetically disposed to respond favorably or unfavorably to particular medicine.

Id.

and legitimize the belief that there is significant genetic variation between racial groups.

While emerging research shows that there *are* clinically relevant variations between identifiable populations, the story is complex. The small genetic variations that are relevant to pharmacogenomics are hardly an indication that there are broad biological differences between socially defined groups,⁸⁶ and, more importantly, the variations do not necessarily correspond to traditional racial categories.⁸⁷ Nevertheless, for the purposes of marketing and media coverage, a simplistic race-based message seems likely to prevail.⁸⁸ Most forms of popular media are not the best medium for an in-depth explanation of genetic variation between groups and, more significantly, it is not the kind of thing that will emerge in marketing strategies. "With the development of race-based genomic treatments, direct-to-consumer advertising for these products could and, likely, would become common."⁸⁹

Recent work by Condit, Bates and others has provided preliminary evidence to support the concerns associated with how the popular media represents issues involving race and genetics. For example, in one study the authors conclude that "some messages linking race, genes, and health produce increases in racist attitudes in some audiences."⁹⁰ If supported by additional research, such

⁸⁶ It is often said that humans share approximately 99.9% of DNA in common. Margaret A. Winker, *Measuring Race and Ethnicity: Why and How?*, 292 JAMA 1612, 1615 (2004); M.A. Rothstein & P.G. Epps, *Pharmacogenomics and the (ir)relevance of race*, 1 PHARMACOGENOMICS J. 104, 106 (2001).

⁸⁷ Rothstein & Epps, *supra* note 86, at 106.

⁸⁸ See, e.g., Colin O'Connor, *New Ethnic-Specific Drugs are to be Aimed at Blacks*, ROYAL GAZETTE, <http://theroyalgazette.com/apps/pbcs.dll/article?AID=/20041022/midocean/11022> (last visited Oct. 9, 2005).

However, for race-based niche marketing to work, drug developers will have to explore the ways that the races are biologically different. That troubles people who remember that biological determination of race produced the racist mock-science of eugenics. Ironically, geneticists are touting the miracle of new race-based drugs at a time when the softer sciences like anthropology and sociology have declared that race is a cultural construct, without any biological significance. In a 1998 position paper, the American Anthropological Association called race a social invention, with a variety of pernicious causes ranging from day-to-day bigotry to the Holocaust.

Id.

⁸⁹ Bates et al., *supra* note 79, at 542.

⁹⁰ See, e.g., Celeste Condit et al., *Exploration of the Impact of Messages About Genes and Race on Lay Attitudes*, 66 CLINICAL GENETICS 402 (2004) (reporting on a study that shows the potential for public health statements that associated race with disease predisposition to reinforce notions of racism.)

findings create real communication challenges. Will the harms created by the messaging and marketing outweigh the potential health care benefits created by areas like pharmacogenomics?⁹¹ Should society seek to control the messages emanating from researchers and industries involved in genomic research? Condit and her colleagues suggest that, at a minimum, we should proceed with caution: "The presentation of such messages to the public is not recommended until additional research clarifies this finding and perhaps describes mitigating vocabularies or approaches."⁹²

C. The Research Hype Paradox

The hype that permeates popular representations of genetics may also have an impact on how the public views the acceptability of genetic research. Whether the message is positive or negative, one of the underlying themes in most popular representations of genetics is that genetic information is special and of great significance. If you believe genetic information is special, you may be more cautious when considering donating a sample to a research project. Put another way, the public has bought the hype that has surrounded biotechnology, and genetics in particular, and this may make it more difficult to do research. If true, this creates an interesting paradox as much of the hype emanates from the very community, researchers, and research funding entities that want access to the genetic data. There is a good deal of evidence that the public does, in fact, view genetic information as special. Admittedly, it is unclear what role the media has in the creation of these perceptions. The research reviewed above, however, hints that the role may not be insignificant.

⁹¹ See Bates et al., *supra* note 79, at 556:

As a common practice, however, race-based genomics may naturalize phenotypic distinctions as differences that matter. Because of this naturalization, some practitioners fear that applied pharmacogenomics may sustain or encourage racism in other arenas. Any benefit that applied genomics has in the lab may be outweighed by its practice in the clinic and in society as a topic of invention by advocates of fundamental racial difference.

Id.

⁹² Condit et al., *supra* note 90, at 402. The authors go on to give the following caution:

If these results are replicated and if medical research eventually indicates that there are clinically useful differences in frequencies of conditions that have components that are strongly linked to particular genetic variations, the benefits of utilizing these tools will need to be weighed against the social harm of discussing them.

Id.

A 2001 Canadian survey found that 90% either strongly agree (61%) or agree (29%) that genetic information is different and rules governing access should be stricter than for other forms of personal information.⁹³ More recently, a survey found that the number of Canadians “very willing” to contribute genetic information to research has decreased substantially, from 56% in 2003 to only 37% in 2004.⁹⁴ Similarly, more Canadians feel that privacy (39%) should be given a greater focus than research (26%).⁹⁵ This essentialist message has been adopted by a variety of policy-making bodies. For example, article 4 of UNESCO’s 2003 International Declaration on Human Genetic Data declares that human genetic information *is* special because it can be used to predict genetic predispositions, has relevance to biological relatives, and may have cultural significance for persons or groups.⁹⁶ As a result, it is recommended that “[d]ue consideration should be given, and where appropriate special protection should be afforded to human genetic data and to the biological samples.”⁹⁷

It is important to note, however, that not all agree that genetic data is significantly different from other forms of sensitive health information. For example, the UK’s Nuffield Council on Bioethics suggested that other forms of sensitive health information (e.g., HIV status and cholesterol testing), have many of the same features as genetic data—including being predictive of possible future health

⁹³ POLLARA & EARNSCLIFFE RES. & COMM., PUBLIC OPINION RESEARCH INTO BIOTECHNOLOGY ISSUES THIRD WAVE 51 (Dec. 2000).

⁹⁴ DECIMA RES., PUBLIC OPINION ON BIOTECHNOLOGY: CANADA-U.S. TRACKING SURVEY FINAL REPORT (Mar. 2004).

⁹⁵ *Id.*

⁹⁶ UNESCO, INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA (2003), http://portal.unesco.org/shs/en/ev.phpurl_ID=1882&URL_DO=DO_TOPIC&URL_SECTION=201.html (last visited Oct. 9, 2005) [hereinafter UNESCO]. This idea that genetic information is special is also reflected in emergence of genetic discrimination laws. In the United States, most jurisdictions have laws that protect against genetic discrimination by limiting the ability of insurance companies and employers to use genetic information. For example, the National Conference of State Legislators noted that,

The majority of state legislatures have taken steps to safeguard genetic information beyond the protections provided for other types of health information. This approach to genetics policy is known as genetic exceptionalism, which calls for special legal protections for genetic information as a result of its predictive, personal and familial nature, and other unique characteristics.

To date, there are no genetic discrimination laws in Canada. NAT’L CONF. OF ST. LEGISLATORS, STATE GENETIC PRIVACY LAWS (2004) <http://www.ncsl.org/programs/health/genetics/prt.htm> (last visited Oct. 9, 2005).

⁹⁷ UNESCO, *supra* note 96.

concerns.⁹⁸ The Nuffield Council recommends that given the “similarities between genetic and other forms of personal information, it would be a mistake to assume that genetic information is qualitatively different in some way.”⁹⁹ Others have noted that we should be careful not to cast genetics as special because we risk legitimizing inappropriate and scientifically inaccurate views of genetics that may, paradoxically, heighten the chance that genetic data will be used to stigmatize and discriminate.¹⁰⁰

Nevertheless, it is the essentialist message that continues to inform policy development and more importantly, public perceptions.¹⁰¹ Therefore, researchers who seek to access and use human genetic material may be frustrated by both restrictive policies, as evidenced by the UNESCO statement,¹⁰² and an increasingly wary public.¹⁰³

CONCLUSION

It will not be easy to address the challenges created by the “cycle of hype.” Not only are all the relevant players complicit collaborators in the creation and elevation of enthusiastic messages, there is little reason for any individual player, such as a researcher, univer-

⁹⁸ NUFFIELD COUNCIL ON BIOETHICS, PHARMACOGENETICS: ETHICAL ISSUES 6 (2003).

⁹⁹ *Id.* The Nuffield Council suggests that because perception is often as significant as reality, policies will inevitably be influenced by the prevailing essentialist view of genetics. *Id.*

¹⁰⁰ See Burriss et al., *Public Health Surveillance of Genetic Information: Ethical and Legal Responses to Social Risk*, in GENETICS AND THE PUBLIC HEALTH IN THE 21ST CENTURY: USING GENETIC INFORMATION TO IMPROVE HEALTH AND PREVENT DISEASE 538 (Muin J. Khoury & Wylie Burke eds., 2000), available at <http://www.cdc.gov/genomics/info/books/21stcent5.htm#Chapter27> (last visited Oct. 9, 2005) (“Treating genetics as distinct from the rest of medicine may enhance the stigma of genetic testing, even as legislators attempt to remove its stigmatizing effects. This can create public fears and misapprehensions about genetics that could discourage individuals from seeking testing and treatment, and thwart future scientific progress.”).

¹⁰¹ There is a difference between viewing genetic information as *special*, a belief present in public opinion as indicated by available evidence, and adopting the deterministic messages present in many media representations. The public does not necessarily accept the deterministic view of the role of genes in the human condition. See Celeste Condit, *How the Public Understands Genetics: Non-Deterministic and Non-Discriminating Interpretations of the ‘Blueprint’ Metaphor*, 8 PUB. UNDERSTANDING OF SCI. 169 (1999).

¹⁰² UNESCO, *supra* note 96; see also *Genetic Databases: Assessing the Benefits and the Impact of Human & Patient Rights* (World Health Organization ed. 2003) at 3.

¹⁰³ The dilemma created by this situation is most evident in the context of human genetic databanks. See Timothy Caulfield, *Perceptions of Risk and Human Genetic Databases: Consent and Confidentiality Policies*, in BLOOD AND DATA: ETHICAL, LEGAL AND SOCIAL ASPECTS OF HUMAN GENETICS DATABASES 283–89 (G. Arnason et al. eds. 2004).

sity, or reporter, to lessen the hype.¹⁰⁴ Nevertheless, because science is becoming an ever larger force in contemporary society, how expectations are created and met also has greater significance. It seems essential to develop strategies that may be able to balance and, ideally, reduce the hype.

Given the social forces at play, particularly the private sector, it is unrealistic to presume that we could ever do away with all hype. Nor would that necessarily be a good thing. A degree of enthusiasm is undoubtedly needed to create momentum and generate initial interest. Also, many of the advancements in the area of biotechnology are genuinely exciting and can understandably lead to enthusiastic pronouncements. However, as we have seen above, there may be long-term implications to unchecked hype. Most significant would be a loss of public trust—once lost it will be tremendously difficult to regain. Much of the biotechnology sector depends on a solid foundation of public trust, including obtaining public funds for basic research, the participation of individuals in research projects, and support for the eventual “products” of the research enterprise. It would be a great paradox if the social forces that have largely created the hype for the purpose of promoting biotechnology, poison public support before true benefits materialize.

¹⁰⁴David F. Ransohoff & Richard M. Ransohoff, *Sensationalism in the Media: When Scientists and Journalists May Be Complicit Collaborators*, 4 *EFFECTIVE CLINICAL PRACT.* 185, 186 (2001) (detailing how scientists and hospitals benefit from publicity). There is currently a media arms race. Each player, including universities and industry, needs to out-hype their competitor. Caulfield, *Biotechnology & the Popular Press*, *supra* note 3, at 338.

