

# NIH Public Access

**Author Manuscript** 

Sci Eng Ethics. Author manuscript; available in PMC 2014 March 14.

# Published in final edited form as:

Sci Eng Ethics. 2013 June; 19(2): 321–335. doi:10.1007/s11948-011-9327-6.

# Hype and Public Trust in Science

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# Abstract

Social scientists have begun elucidating the variables that influence public trust in science, yet little is known about hype in biotechnology and its effects on public trust. Many scholars claim that hyping biotechnology results in a loss of public trust, and possibly public enthusiasm or support for science, because public expectations of the biotechnological promises will be unmet. We argue for the need for empirical research that examines the relationships between hype, public trust, and public enthusiasm/support. We discuss the complexities in designing empirical studies that provide evidence for a causal link between hype, public trust, and public enthusiasm/support, but also illustrate how this may be remedied. Further empirical research on hype and public trust is needed in order to improve public communication of science and to design evidence-based education on the responsible conduct of research for scientists. We conclude that conceptual arguments made on hype and public trust must be nuanced to reflect our current understanding of this relationship.

# Keywords

Public trust; Hype; Biotechnology; Public support/enthusiasm; Responsible conduct of research

# Introduction

Several commentators have expressed concerns in regards to hype and promising the benefits of biotechnology. One of the main ethical issues is that hype can inflate public expectations and, if promises are unmet, the result is a loss of public trust in biotechnologies including, genetics and genomics research (Brown 2003; Caulfield 2005; Cunningham-Burley 2006; Evans et al. 2011; Steel 2005; Williams-Jones and Corrigan 2003), stem cell research (Bubela et al. 2009; Doerflinger 2008; Downey and Geransar 2008; Ogbogu 2006; Wilson 2009), biobanking and personalized medicine (Petersen 2009); nanotechnology (Williams-Jones 2004), and neuroimaging research (Caulfield et al. 2010; Illes et al. 2010; Murphy et al. 2008). Some of these arguments further suggest that the loss of public trust could lead to a concomitant loss in public enthusiasm or support of a biotechnology.

In this paper, we discuss several ethical and policy issues surrounding hype in biotechnology and focus on the argument that hype could lead to a loss of public trust and possibly reduce public enthusiasm or support. Although this argument seems intuitive, we found no

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published empirical papers supporting a causal relationship between hype, public trust, and public enthusiasm/support; instead, we have found one empirical study which suggests that the public may not be as easily swayed by hype in biotechnology. It is important to know the degree that hype in science can affect public trust, given the intimate role of science in our lives. Empirical research that examines the relationship between hype, public trust, and support is needed for several reasons: (1) to improve communication between scientists, science reporters and the public; (2) to augment evidenced-based education and training on the responsible conduct of research for scientists and other scholars; and (3) to contribute to the scholarly literature on the public understanding of science. In addition to our call for further research, we discuss the difficulties in designing an empirical study that could provide evidence of a causal relationship between hype, public trust, and public enthusiasm or support for a specific biotechnology. Although a lack of evidence does not mean that hype cannot lead to a loss of public trust and support, we argue that conceptual arguments on hype of biotechnology and public trust need to reflect this knowledge gap.

#### Sources of Hype

Much of the public understanding of science and biotechnology is through print, television, movies, videogames, news, documentaries, shows, and advertisements on the web. Scientific information in the popular media is delivered through a host of actors, including scientists, reporters, reporting editors, government spokespersons, lobbyists, politicians, members of the public, professional societies, and patient advocates and advocacy groups (Bubela et al. 2009; Conrad 1999, 2001; Nisbet and Lewenstein 2002; Petersen 2001). The Oxford American Dictionary of Current English (1999) defines hype as "promot[ing] (a product) with extravagant publicity." In the case of hyping biotechnology, this is usually reported as a positive portrayal of biotechnologies including the development of clinical products and services, economic prosperity, commercial benefits, and solving major health issues (Bubela and Caulfield 2010; Caulfield 2010; Dresser 2010; Nisbet 2004; Nisbet and Lewenstein 2002; Petersen 2001, 2009). A study by Kitzinger and Williams (2005) examining hype of stem cell research in the U.K. national press and TV news media found the use of catch phrases such as "a world free of sickness and disease" or that "stem cell research could herald the start of a medical revolution." An evaluation of genetics in print media is similarly portrayed in a positive light through the use of captivating titles, quotes from experts, references to peer-reviewed articles, and the heightened emphasis on genetic determinism; in addition, there is a downplay to full neglect of non-genetic and other factors (i.e., environmental) that contribute to disease etiology (Petersen 2001). The hype of biotechnology in the news media may be caused by an inaccurate portrayal of science by researchers, research institutions, and other experts the press rely on when reporting the news (Bubela and Caulfield 2004; Conrad 1999, 2001; Petersen 2001, 2009). In many cases, hyping the benefits of biotechnology present several ethical and policy challenges.

#### The Ethical and Policy Issues Surrounding Hype

Hype is a normal stage of technological development (Gartner.com 2011), and a certain amount of hype is an appropriate part of scientific communication with the public, as it helps to generate public interest and political support, secure initial investments in the technology, and encourage students to pursue careers in science and technology (Master and Ozdemir 2008; Schrage 2004). However, a balance is necessary to avoid many of the ethical and policy challenges attributed to hyping biotechnology. In this sense, many scholars discuss "hype" pejoratively to capture a range of questionable or unethical behaviors.

One issue with hyping science in the popular press is that it could distort the public's understanding of science since the media is the primary vehicle for communicating science to the public (Nelkin 1995). Additionally, hyping research by overemphasizing benefits,

A second concern of hype is that it may influence scientists, government officials, and politicians to concentrate efforts and resources towards particular avenues of research and divert funds and support from other laudable areas of science and health research. It is not uncommon for scientific researchers to jump on the "research bandwagon" and be one of the first to utilize novel technologies. This can be seen with gene transfer technology, gene knockout technology, genomic/proteomic studies, the derivation of human embryonic stem cells, and the recent push towards induced pluripotent stem cells (Liu 2009).

A third cause for concern of hype is that it could result in either the premature translation of research or drive the market towards providing unproven or potentially fraudulent treatments to the public. For example, hype in gene transfer technology may have resulted in premature translation of research into clinical trials such that the lack of basic science knowledge of gene transfer vectors and host-vector interactions could have contributed to the unfortunate circumstances resulting in severe harm or deaths of research participants (Kimmelman 2010; Kohn et al. 2003; Somia and Verma 2000; Wilson 2009). Similarly, excessive hype in stem cell research has been thought to contribute to the problem of effectively communicating that stem cell research is experimental and is not a proven therapy (Knowles 2009). Thus, stem cell hype may contribute to stem cell tourism (Ryan et al. 2010), a phenomenon where patients travel abroad to clinics that offer under or untested stem cell therapies for major debilitating diseases. In both cases, hype could, at least partially, lead to the premature clinical translation of research, which could result in physical harms to research subjects or patients. Although hype could have contributed to premature translation or the provision of untested treatments, other factors, including a lack of professional guidance or regulatory oversight, could also have impacted these practices. This point has been made in the case of stem cell tourism, as several scholars have argued for the development of international policies or regulations, education, and professional oversight as potential strategies to combat against clinics offering unproven stem cell therapies (Zarzeczny and Caulfield 2010; Master and Resnik 2011).

A fourth aspect is that intentionally hyping claims is at minimum inaccurate, deceptive, and potentially dishonest and defies many of the ethical and professional responsibilities scientists and other professionals are expected to uphold. Scientists are expected to behave honestly and be truthful in all aspects of research, and they have an ethical obligation to educate and inform the public about their research and its implications (Resnik 1998; Shamoo and Resnik 2009). Scientists also have an obligation to portray their work accurately (Jones 2007). With this responsibility to educate the public, one must recognize the difficulty in making valid predictions of scientific futures and hype. Hype would be an overestimation of the significance of a new discovery, invention, or application of science and focus more on the benefits and less on the risks. Publicity and promotion also help to generate public support for research (i.e., funding), hold scientists accountable to the public, and address some of the public's worries and concerns about science and technology. It may be difficult to determine whether publicity/promotion constitutes hype, because one may not know whether it is excessive until the field of science that is being publicized delivers (or fails to deliver) on its promised goals. With the benefit of hindsight, we can say that exaggerations of the public health impacts of gene therapy were made in the early 1990 s, but we might have not have known this as clearly when the field was just emerging (Gottweis 2002; Yarborough and Sharp 2009). History is often the best judge of whether a form of communication constitutes hype or appropriate promotion and publicity. Yet despite

From examining the ethics, policy and politics of hype, we can build on the earlier dictionary definition of hype as promoting something with extravagant publicity (The Oxford American Dictionary 1999) to include several additional elements such as the interpretation of facts and evidence, and intent. In the context of hyping the promises of biotechnology, the information provided to publics can be represented as a linear scale with one end having publicity that is fully fact based with little prediction of scientific futures outside the known facts, to the opposite end where there are inaccurate predictions or complete exaggerations without any insight or factual support; as we move from left to right, hype increases (Fig. 1). In this sense, hype can be either positive or negative predictions about scientific futures and the extent of hype depends on the accuracy in predicting scientific futures. This takes into account not only the known facts about the scientific, technological, economic, political, ethical, legal and social hurdles, but also one's approach to predicting scientific futures. Experts including scientists, politicians, governmental spokespersons and others asked to predict scientific futures can be cavalier or even careless in how they incorporate and interpret knowledge about a particular technology. Alternatively, experts can be sensible or overtly cautious in their approach.

responsibilities of many professionals. The public trusts scientists and other researchers to

do what is in the public's best interest over their own.

A final aspect in redefining hype surrounds ethics and the intent of individuals who predict scientific futures. As noted earlier, culpability is an important aspect when assessing ethical misbehaviors; intentionally lying about scientific futures to suit one's personal agenda is deceptive, whereas honest mistakes or carelessness in prediction, although it still impacts the extent of hype, may be more ethically acceptable. An accurate portrayal with some hype in predicting possible scientific futures is ethically reasonable. But as we move towards exaggerated predictions, one may be left wondering whether the expert predicting scientific futures is being careless or intentionally dishonest.

#### Public Trust and the Public Understanding of Science

Much of our understanding of public trust in science stems from research on the *public* understanding of science. Our conception of the public understanding of science has shifted from the science illiteracy or deficit model, where favorable public attitudes and acceptance of science depended on a higher literacy or understanding of science (Durant et al. 1989; Evans and Durant 1995; Thomas and Durant 1987), to a picture that acceptance of science is not fully dependent on one's knowledge of science, but rather is based on people's lived experiences, morality, worldviews, beliefs, concepts of risks, and trust in various social institutions (Mooney 2010; Nisbet and Goidel 2007; Priest 2001; Siegrist 2000; Siegrist and Cvetkovich 2000; Turney 1996; Ziman 1991). In particular, the more recent literature on public trust in biotechnology reveals some interesting predictions including the notion that one's acceptance of a biotechnology may have more to do with trust in, and in between, different institutions including, but not limited to, industry, environmental groups, consumer organizations, media, and government (Priest et al. 2003). For example, studies on the public support for stem cell research have shown a higher degree of trust for research performed by publically funded researchers as opposed to privately funded scientists (Critchley 2008; Liu and Priest 2009). Moreover, trust in religious leaders and familiarity of stem cell research also produced significant effects on the perception of the benefits of stem cell research (Liu and Priest 2009). In one nationwide survey to understand public perspectives on human cloning, the Wellcome Trust researchers found that participants felt a lack of trust in scientists and those who manage or control the research (Wellcome Trust 1998).

Despite the trust individuals have with a host of players involved in different aspects of various biotechnologies, there is some evidence suggesting that people's perceptions can change. Although preliminary data correlating science education and acceptability of science cannot account for the full picture of public acceptance of science and technology, there is evidence suggesting that scientific information does influence one's perceptions about the acceptability or not of a biotechnology. In one study, participants were asked for their opinions on genetic technologies pre and post the provision of educational material on genetics. Interestingly, between a third and a half of the participants changed their attitudes and not necessarily in a predictable fashion; those largely in favor may have become more skeptical or cautious over genetic technologies and vice versa (Wellcome Trust 2005).

# **Research Needs: Hype and Public Trust**

The argument that hype causes a loss of public trust and could lead to a loss in public enthusiasm and support of a biotechnology seems inherently logical, but there is no published research supporting these claims. Furthermore, designing studies that explore causal relationships between hype, public trust, and enthusiasm/support are difficult. Studies can be designed to measure (A) hype in a biotechnology and whether that results in a loss of trust by different publics, and (B) whether a loss of trust by different publics results in the loss of enthusiasm or support for a particular biotechnology or in science and technology more generally. In this section, we provide general considerations for designing research studies, followed by an outline of a research agenda to measure hype and its relationship with trust and enthusiasm/support for science.

Studies surrounding hype and public trust can be undertaken empirically using quantitative and qualitative methods. Several research studies have already been performed discussing the occurrence of hype in mainstream media (Brown 2003; Kitzinger and Williams 2005; Nisbet 2004; Nisbet and Lewenstein 2002; Petersen 2001, 2002). Similarly, there have been several social science studies examining the public's trust in science and research (Barnett et al. 2007; Critchley 2008; Eiser et al. 2009; Priest et al. 2003; Siegrist 2000; Siegrist and Cvetkovich 2000; Tang and Hallman 2005). Since most commentators probably mean "public" as the general population, one approach is to measure public attitudes of the general population instead of specific publics. Quantitative studies of large populations are difficult to conduct, expensive, and risk exclusion of certain groups. As there is some data to suggest that public attitudes change with time, it may be necessary to track longitudinally the public's perceptions on hype and trust of a particular biotechnology in order to have a deeper understanding of the relationship between hype and public trust. Several controls would need to be incorporated into longitudinal studies, including how specific reports of hype of a particular biotechnology affect trust, the exposure of participants to different sources of media, their understanding of science, and their belief systems, worldviews and perceptions of risk. As the participants are likely to know that the study is measuring trust in science due to hype, there is likely to be some sort of reporting bias.

#### Hyping Biotechnology Causes a Loss of Public Trust

Hype in biotechnology has been successfully demonstrated. Research can be designed to measure hype through a variety of sources including websites, blogs, movies, billboards, magazines, scientific publications, and press releases. We have previously outlined a few studies analyzing the use of hyped statements as it pertains to stem cell research, genetics, and other biotechnologies. Although many studies demonstrate the occurrence of hype in the

media, there is a lack of published evidence demonstrating whether hype can affect public trust.

Empirical research is also needed to determine whether hype causes a loss of public trust over a particular biotechnology. When measuring public trust, we need to first consider the terms "public" and "trust". Public may refer to the general population (i.e., the American people), or it may refer to specific publics, such as, human research participants, a particular racial/ethnic group (e.g., African Americans), or a particular community (e.g., a Native American tribe). It is important to define the public that is being studied, because different publics may have different expectations of scientific research, and therefore have different levels of trust (Mooney 2010; Resnik 2011). Policies and practices that safeguard the trust of one type of public may undermine the trust of another. For example, patients dying from terminal illnesses, such as HIV/AIDS and cancer, have demanded that regulatory agencies make new treatments available as quickly as possible by relaxing regulatory requirements; but some bioethicists, scientists, and drug safety advocates have argued that new treatments should be made available only after rigorous testing (Dresser 2001). This example illustrates that trust in the regulatory system by specific publics can differ. It is likely that commentators who claim that hype leads to a loss of public trust probably refer more to the general population than specific publics. Since "public" may refer to the general or specific publics, activities that undermine the trust of specific publics may have little impact on the general public's trust.

There is also a need to closely examine the notion of trust. As others have shown, trust is complicated and different individuals trust (or distrust) science in different ways (Resnik 2011). First, the public may trust scientists to adhere to standards of professional conduct and ethics. Scientists who perform careless research, or violate ethical or legal standards, would violate this type of trust (Whitbeck 1995). An example of a loss of trust in scientists may have resulted from the research scandal of South Korean scientist Dr. Hwang who claimed to have been the first to derive cloned human embryonic stem cells after somatic cell nuclear transfer (Kakuk 2009). Second, the public may trust the science or scientific institutions differently. Several social science studies have shown that there is a higher degree of trust in research performed by publically funded researchers over scientists working in private institutions (Critchley 2008; Liu and Priest 2009). Institutions that compromise the integrity of research oversight would violate this type of trust (Krimsky 2003). Third, major violations of research ethics norms can affect the trust of specific, or perhaps general, publics of clinical research. For example, the unethical Nazi Nuremberg experiments and numerous ethically questionable research post World War II has served to muddy trust of human research more broadly (Beecher 1966; Berger 1990; Carlson 2006; Tyson 2000). Some of the larger scandals include the Jewish Chronic Disease Hospital in 1963 where physicians injected live cancer cells into chronically ill patients without informing them and obtaining consent (Katz et al. 2003) and the Tuskegee Syphilis study (Brandt 1978). Specifically, the Tuskegee Syphilis study (1932–1972) enrolled 399 African American men with syphilis without their consent and who were denied medical treatment for several decades in order to see the long-term progression of the disease which, as a result, has significantly impacted the trust of African Americans in medicine and medical research today (Corbie-Smith et al. 1999; Freimuth et al. 2001).

In a more recent example, in April 2010, Arizona State University (ASU) settled a lawsuit with the Havasupai Indian tribe pertaining to the alleged misuse of blood samples donated for research purposes. Members of the tribe claimed that investigators from ASU violated the informed consent agreement by using the samples for purposes other than diabetes research, such as studies of the genetics of schizophrenia and inbreeding, and in evolutionary genetic experiments tracing the tribe's ancestry (Mello and Wolf 2010).

Members of the tribe have said they will no longer participate in any studies involving ASU investigators. While this episode has clearly had a negative impact on the tribe's trust in the scientists at ASU and perhaps ASU as a research institution, it is not clear whether they lost enthusiasm in science performed by scientists at other research institutions or whether they lost trust in science and technology more generally.

Given that scandals in research have reduced trust in science by specific, and possibly, the general publics, it is unclear whether hyping biotechnology will result in similar extents of loss of public trust. One interesting study on hype and public trust examined the opinions of embryo donors who underwent assisted reproduction, recipients of two disease groups (Parkinson's disease and diabetes mellitus), and the general public on hype as seen in the media. The most remarkable finding was that all four groups, despite their level of knowledge, were not "taken in by the media hype surrounding embryonic stem cell research" (Peddie et al. 2009). Interestingly, the general public group believed that they were least taken in by media hype because they were more objective since they did not suffer from health problems and were not looking for treatments, and thus could discern information better due to their perceived scientific knowledge and intelligence (Peddie et al. 2009). A closer analysis of the results of this study demonstrated that several participants did not trust the media. Because all participants groups were not taken by the media hype, one can infer from this study that the public may expect hype surrounding science from the media and this would not inflate their expectations about the clinical promises of research. Such a realization could actually serve to combat a loss of trust from hype in biotechnology since "you can't believe everything you hear."

In line with determining which aspect of trust needs to be measured, it is also clear that the term "biotechnology" needs to be specified. Is distrust happening for science and technology in a general sense or for specific particular biotechnologies such as, stem cell research, genetics, information technology, nanotechnology, or plant or food biotechnology? For example, a significant percentage of Europeans do not trust that genetically engineered foods are safe for human health and the environment, but this does not necessarily mean they also distrust other areas of science, such as climate change research, nanotechnology, physics, or stem cell research (Enserink 1999). While the distrust of genetically engineered foods may not be a direct result of hype, it illustrates how trust (and distrust) can be difficult to measure.

#### Loss of Public Enthusiasm or Support for a Biotechnology

It is important to try and differentiate between the public's loss of enthusiasm and loss of support. A loss of support for scientific research would be the direst of responses to a loss of public trust. Indeed the question of what is meant by a "loss of public enthusiasm or support" for a particular biotechnology requires clarification. Public support can be measured by several *indirect* measures such as the provision of funding, the number of researchers in a particular field, the participation of subjects in research, research output (e.g., publications, products and services), loss of political support, a re-distribution of funds, a loss of industry support, or the reduction in the number of researchers entering the field. Public enthusiasm/support can also be assessed by surveying public attitudes towards supporting a particular area of science. In the example used previously, the Havasupai Indians may have lost enthusiasm to support researchers at ASU, but may still support research and would volunteer to be research participants performed by scientists at other institutions. Would a person who has had a bad experience as a research subject necessarily mean they do not trust science, or does not want scientific research to continue? Would the distrusting individual advocate to their Congressperson to cease support towards a particular biotechnology? Does this distrust translate to not using a technological product, i.e., a

genetically modified apple or an iPhone? The concept of public enthusiasm or support for science is complicated and multifactorial. Indirect measures of public support are not necessarily indicative of differences in public trust. For example, a reduction in public funds for a particular biotechnology may not be a reflection of a loss of enthusiasm or support by the general public, but it is perhaps reflective of a loss of enthusiasm by a specific group of people i.e., key politicians and decision-makers involved in appropriations and research funding priorities. Thus, conceptual claims that a loss of public trust could result in a loss of public enthusiasm/support need to be cautiously made because the concept of public enthusiasm/support is amorphous.

# A Proposal for Qualitative Research

We will sketch out possible research study designs that could be developed to fill empirical gaps in knowledge discussed throughout the paper. Given that several studies examining various media sources have shown the portrayal of hype in many areas of modern biomedical science, including genetics, nanotechnology and stem cell research, we will begin with the understanding that hype of science does exist in the media. We will focus our research on building an empirical understanding of the relationships between hype, public trust and public enthusiasm/support of a biotechnology. We will use hype in genetics research as an example.

Both quantitative and qualitative approaches can be used to assess the relationships between hype, public trust and public enthusiasm/support of science. A quantitative approach could capture the views of a large population using online, paper based, or telephone surveys. While this approach can provide important information about public attitudes, opinions, and beliefs, it has a limited ability to capture a rich and contextualized understanding of the relationships among hype, public trust, and public support for science. There is, of course, tremendous value in employing all empirical and conceptual methods to further understand these relationships, but since little is known currently about how hype can affect public trust and enthusiasm or support, we discuss the design of an exploratory research project using qualitative research methods.

Various qualitative approaches are readily used in many social studies in the health sciences including participant observations, citizen juries and other deliberative methods, focus groups, and individual interviews. For our purposes, we propose a study based on grounded theory and constant comparative analysis (Charmaz 2006). Semi-structured interviews with several specific stakeholders including genetics researchers, media representatives, patient advocates, other academic researchers (i.e., ethicists, lawyers, and social scientists), physicians, ethics review board members, patients with genetic diseases, government spokespersons, and politicians could be performed. Also, members of the general public would be interviewed. Not all of the stakeholders discussed need to be included, as the study design would depend upon the relevant focus of the topic, the current governance system for genetics research, the extent of engagement of various stakeholders in contemporary debates on genetics, and pragmatic concerns, such as accessibility of different individuals and groups. Interviews would be recorded, transcribed and coded, and analysis would be performed by constant comparison-comparing instances, accounts, categories, actions, views and experiences from the same individuals at different points, and comparing categories and instances with each other. The objective would be to move beyond simple descriptions and to develop conceptual relations between the data and the underlying theory of public trust and hype, and public trust and support/enthusiasm for genetics.

It is clear from many previous studies that trust in science depends on several factors including knowledge of science, concepts of risk, ideologies, religious beliefs, trust in

various actors and institutions including government, public and private researchers, politicians, and different media representatives. The creation of a semi-structured interview guide should be designed to help the interviewer flesh out participants' perceptions on trust and hype, trust in various actors and social institutions that make predictions about genetic futures, and how this trust affects their support of genetics research and technologies. Questions should tease out participants' understanding of genetic futures, the benefits or harms they foresee, knowledge of genetics, their sources of information on genetic futures, and the frequency at which participants consume information on genetics. Furthermore, the interview should try and uncover their understanding, views, and beliefs surrounding hype. For example, if participants know there is hype reported in the news about genetic discoveries (Peddie et al. 2009), one could ask how they take this into account, whether they trust the hype information, how they distinguish between hype and fact, to what extent are they "taken in" by the hype, and how their understanding of hype affects trust in the actors who deliver information on genetic futures.

Interviewers must also collect data on how hype and trust in actors and their institutions influences the participants' enthusiasm and support for the genetic sciences. Enthusiasm and support need to be considered broadly, including volunteering, charity work, participating in research, donation to research, learning about genetics, teaching, public speaking, letter writing, advocacy, and public demonstration. Most importantly, many might feel they have enthusiasm or support for genetics without having a direct way of showing or articulating it. Through different scenarios about predicted genetic futures, participants could be asked whether and how their support may or may not sway in light of hype and whether genetic futures will or will not be realized. It is important to note that in order to reduce possible interviewer bias, questions need to be phrased in ways that refrain from leading participants' responses. Discussion should occur naturally and the conversation flow freely. Such a discussion would provide researchers with meaningful data to analyze and heighten our conceptual understanding of the relationships between hype, public trust, and public enthusiasm and support for the genetic sciences.

# Conclusions

Public trust is important to the advancement of science and technology. The field of the public understanding of science is beginning to elucidate the factors that influence people's trust in science. Yet one area that can benefit from further empirical research is the role of hype in public trust of science. In this paper, we have begun to illustrate the difficulties in providing evidence for a causal relationship between hype, public trust and enthusiasm/ support for science in hopes that further empirical research can shed light on this complex relationship. We have also attempted to remedy this empirical gap by proposing a research plan that could provide some clarity. Our paper also points to the fact that conceptual arguments made on hype and public trust need to reflect our current understanding of the science behind these complex phenomena. Ever since President Richard Nixon drummed up support for cancer research with his "war on cancer" in 1971, U.S. presidents have expressed strong support for cancer research. This has resulted in advances in chemotherapy and radiotherapy, identifying markers to target tumor cells, small molecular drugs, immunotherapy, gene transfer studies, targeting tumor angiogenesis, combinatorial regimens, and most recently, targeting cancer stem cells (Nature 2006). However, there remains no effective treatment for the majority of cancers, but public support for cancer research has not waned despite the continued hype. By performing more social science research on public trust in science, we will be able to better understand the effects of hype on public trust, and develop better tools to engage the public and enhance openness in the communication of science.

#### Acknowledgments

We are grateful to Professor Timothy Caulfield for the insightful comments on several iterations of this manuscript. We would also like to thank Dr. Bruce Androphy and the reviewers of this manuscript for providing helpful feedback. This research was supported, in part, by a generous grant from the Cancer Stem Cell Consortium and the Stem Cell Network. The work presented here does not represent the views of Health Canada or the Canadian government. This research is also the work product of an employee or group of employees of the National Institute of Environmental Health Sciences (NIEHS), National Institutes of Health (NIH), however, the statements, opinions or conclusions contained therein do not necessarily represent the statements, opinions or conclusions of NIEHS, NIH or the United States government.

# References

- Barnett J, Cooper H, Senior V. Belief in public efficacy, trust, and attitudes toward modern genetic science. Risk Analysis. 2007; 27(4):921–933. [PubMed: 17958501]
- Beecher HK. Ethics and clinical research. New England Journal of Medicine. 1966; 274(24):1354–1360. [PubMed: 5327352]
- Berger RL. Nazi science—the Dachau hypothermia experiments. New England Journal of Medicine. 1990; 322(20):1435–1440. [PubMed: 2184357]
- Brandt AM. Racism and research: The case of the Tuskegee syphilis study. The Hastings Center Report. 1978; 8(6):21–29. [PubMed: 721302]
- Brown N. Hope against hype—accountability in biopasts, presents and futures. Science Studies. 2003; 16(2):3–21.
- Bubela TM, Caulfield T. Do the print media "hype" genetics research? A comparison of newspaper stories and peer-reviewed research papers. Canadian Medical Association Journal. 2004; 170(9): 1399–1407. [PubMed: 15111473]
- Bubela TM, Caulfield T. Role and reality: Technology transfer at Canadian universities. Trends in Biotechnology. 2010; 28(9):447–451. [PubMed: 20598388]
- Bubela T, Nisbet MC, Borchelt R, Brunger F, Critchley C, Einsiedel E, et al. Science communication reconsidered. Nature Biotechnology. 2009; 27(6):514–518.
- Carlson, EF. Times of triumph, times of doubt: Science and the battle of public trust. Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press; 2006.
- Caulfield T. Popular media, biotechnology, and the 'cycle of hype'. Houston Journal of Health Law and Policy. 2005; 5(2):213–233.
- Caulfield T. Stem cell research and economic promises. Journal of Law Medicine and Ethics. 2010; 38(2):303–313.
- Caulfield T, Rachul C, Zarzeczny A. 'Neurohype' and the name game: Who's to blame. AJOB Neuroscience. 2010; 1(2):13–15.
- Charmaz, K. Constructing grounded theory. A practical guide through qualitative analysis. London: Sage Publications Ltd; 2006.
- Conrad P. Use of expertise: Sources, quotes, and voice in the reporting of genetics in the news. Public Understanding of Science. 1999; 8(4):285–302.
- Conrad P. Genetic optimism: Framing genes and mental illness in the news. Culture, Medicine and Psychiatry. 2001; 25(2):225–247.
- Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. Journal of General Internal Medicine. 1999; 14(9):537–546. [PubMed: 10491242]
- Critchley CR. Public opinion and trust in scientists: The role of the research context, and the perceived motivation of stem cell researchers. Public Understanding of Science. 2008; 17(3):309–327. [PubMed: 19069082]
- Cunningham-Burley S. Public knowledge and public trust. Community Genetics. 2006; 9(3):204–210. [PubMed: 16741351]
- Doerflinger RM. The problem of deception in embryonic stem cell research. Cell Proliferation. 2008; 41(Suppl 1):65–70. [PubMed: 18181947]

- Downey R, Geransar R. Stem cell research, publics' and stakeholder views. Health Law Review. 2008; 16(2):69–85.
- Dresser, R. When science offers salvation. New York, NY: Oxford University Press; 2001.
- Dresser R. Stem cell research as innovation: Expanding the ethical and policy conversation. Journal of Law Medicine and Ethics. 2010; 38(2):332–341.
- Durant JR, Evans GA, Thomas GP. The public understanding of science. Nature. 1989; 340(6228):11–14. [PubMed: 2739718]
- Eiser JR, Stafford T, Henneberry J, Catney P. 'Trust me, I'm a scientist (not a developer)': Perceived expertise and motives as predictors of trust in assessment of risk from contaminated land. Risk Analysis. 2009; 29(2):288–297. [PubMed: 18826417]
- Enserink M. Ag biotech moves to mollify its critics. Science. 1999; 286(5445):1666–1668. [PubMed: 10610558]
- Evans G, Durant T. The relationship between knowledge and attitudes in the public understanding of science in Britain. Public Understanding of Science. 1995; 4(1):57–74.
- Evans JP, Meslin EM, Marteau TM, Caulfield T. Deflating the genomics bubble. Science. 2011; 331(6019):861–862. [PubMed: 21330519]
- Freimuth VS, Quinn SC, Thomas SB, Cole G, Zook E, Duncan T. African Americans' views on research and the Tuskegee syphilis study. Social Science and Medicine. 2001; 52(5):797–808. [PubMed: 11218181]
- Gartner.com. Gartner hype cycle. 2011 http://www.gartner.com/technology/research/methodologies/ hype-cycle.jsp#.
- Gottweis H. Gene therapy and the public: A matter of trust. Gene Therapy. 2002; 9(11):667–669. [PubMed: 12032683]
- Illes J, Moser MA, McCormick MB, Racine E, Blakeslee S, Caplan A, et al. Neurotalk: Improving the communication of neuroscience research. Nature Reviews Neuroscience. 2010; 11(1):61–69.
- Katz, J.; with Capron, AM.; Glass, ES. The Jewish chronic disease hospital case. In: Emanuel, E.; Crouch, RA.; Arras, JD.; Moreno, JD.; Grady, C., editors. Ethical and regulatory aspects of clinical research. Readings and commentary. Baltimore, MD: The Johns Hopkins University Press; 2003. p. 11-15.
- Jones NL. A code of ethics for the life sciences. Science and Engineering Ethics. 2007; 13(1):25–43. [PubMed: 17703607]
- Kakuk P. The legacy of the Hwang case: Research misconduct in the biosciences. Science and Engineering Ethics. 2009; 15(4):545–562. [PubMed: 19247809]
- Kimmelman, J. Gene transfer and the ethics of first-in-human research. Lost in translation. New York, NY: Cambridge University Press; 2010.
- Kitzinger J, Williams C. Forecasting science futures: Legitimising hope and calming fears in the embryo stem cell debate. Social Science and Medicine. 2005; 61(3):731–740. [PubMed: 15899330]
- Knowles LP. Stem cell hype and the dangers of stem cell 'tourism'. Ethics White Paper for the Stem Cell Network. 2009 http://www.stemcellnetwork.ca/uploads/File/whitepapers/Stem-Cell-Hype.pdf.
- Kohn DB, Sadelain M, Glorioso JC. Occurrence of leukaemia following gene therapy for X-linked SCID. Nature Reviews Cancer. 2003; 3(7):477–488.
- Krimsky, S. Science in the private interest. Lanham, MD: Rowman and Littlefield; 2003.
- Liu SV. Fast protest against a fast hype on iPS cells. Top Watch. 2009; 4(2):44-47.
- Liu H, Priest S. Understanding public support for stem cell research: Media communication, interpersonal communication and trust in key actors. Public Understanding of Science. 2009; 18(6):704–718.
- Master Z, Ozdemir V. Selling translational research: Is science a value-neutral autonomous enterprise? American Journal of Bioethics. 2008; 8(3):52–54. [PubMed: 18570104]
- Master Z, Resnik DB. Stem-cell tourism and scientific responsibility. EMBO Reports. 2011; 12(10): 992–995. [PubMed: 21799519]

- Mello MM, Wolf LE. The Havasupai Indian tribe case—lessons for research involving stored biologic samples. New England Journal of Medicine. 2010; 363(3):204–207. [PubMed: 20538622]
- Mooney, C. Do scientists understand the public?. Cambridge, MA: American Academy of Arts and Sciences; 2010.
- Murphy ER, Illes J, Reiner PB. Neuroethics of neuromarketing. Journal of Consumer Behaviour. 2008; 7(4–5):293–302.
- Nature. Nature milestones cancer (Milestones Timeline). Nature. 2006:S7–S23. http://www.nature.com/milestones/milecancer/timeline.html.
- Nelkin, D. Selling science. New York, NY: WH Freeman; 1995. (revised edition).
- Nisbet M. Explaining majority support for stem cell research. Skeptical Inquirer. 2004 http:// www.csicop.org/specialarticles/show/explaining\_majority\_support\_for\_stem\_cell\_research/.
- Nisbet MC, Goidel RK. Understanding citizen perception of science controversy: Bridging the ethnographic-survey research divide. Public Understanding of Science. 2007; 16(4):421–440.
- Nisbet MC, Lewenstein BV. Biotechnology and the American Media: The policy process and the elite press, 1970 to 1999. Science Communication. 2002; 23(4):359–391.
- Ogbogu U. A review of pressing ethical issues relevant to stem cell translational research. Health Law Review. 2006; 14(3):39–43.
- Peddie VL, Porter M, Counsell C, Caie L, Pearson D, Bhattacharya S. 'Not taken in by media hype': How potential donors, recipients and members of the general public perceive stem cell research. Human Reproduction. 2009; 24(5):1106–1113. [PubMed: 19168873]
- Petersen A. Biofantasies: Genetics and medicine in the print news media. Social Science and Medicine. 2001; 52(8):1255–1268. [PubMed: 11281408]
- Petersen A. Replicating our bodies, losing our selves: News media portrayals of human cloning in wake of Dolly. Body and Society. 2002; 8(4):71–90.
- Petersen A. The ethics of expectations: Biobanks and the promise of personalized medicine. Monash Bioethics Reviews. 2009; 28(1):05.1–05.12.
- Priest SH. Misplaced faith: Communication variables as predictors of encouragement for biotechnology development. Science Communication. 2001; 23(2):97–110.
- Priest SH, Bonfadelli H, Rusanen M. The 'trust gap' hypothesis: Predicting support for biotechnology across national cultures as a function of trust in actors. Risk Analysis. 2003; 23(4):751–766. [PubMed: 12926568]
- Resnik, DB. The ethics of science: An introduction. New York, NY: Routledge; 1998.
- Resnik DB. Scientific research and the public trust. Science and Engineering Ethics. 2011; 17(3):399–409. [PubMed: 20803259]
- Ryan KA, Sanders AM, Wang DD, Levine AD. Tracking the rise of stem cell tourism. Regenerative Medicine. 2010; 5(1):27–33. [PubMed: 20017692]
- Schrage M. Great expectations. Technology Review. 2004; 107(8):21.
- Shamoo, AS.; Resnik, DB. Responsible conduct of research. 2nd ed.. New York, NY: Oxford University Press; 2009.
- Siegrist M. The influence of trust and perceptions of risks and benefits on the acceptance of gene technology. Risk Analysis. 2000; 20(2):195–203. [PubMed: 10859780]
- Siegrist M, Cvetkovich G. Perception of hazards: The role of social trust and knowledge. Risk Analysis. 2000; 20(5):713–719. [PubMed: 11110217]
- Somia N, Verma IM. Gene therapy: Trials and tribulations. Nature Reviews Genetics. 2000; 1(2):91–99.
- Steel M. Molecular medicine: Promises, promises? Journal of the Royal Society of Medicine. 2005; 98(5):197–199. [PubMed: 15863761]
- Tang JT, Hallman WK. Who does the public trust? The case of genetically modified food in the United States. Risk Analysis. 2005; 25(5):1241–1252. [PubMed: 16297228]
- The Oxford American Dictionary of Current English. "hype". Oxford University Press; 1999.
- Thomas G, Durant J. Why should we promote the public understanding of science? Science Literacy Papers. 1987; 1:1–14. http://www.core.org.cn/NR/rdonlyres/Science–Technology–and-Society/ STS-014Spring-2006/2737FE74-34D6-4A16-A7DD-95F0FBE60BA0/0/durant\_promote.pdf.

Turney J. Public understanding of science. The Lancet. 1996; 347(9008):1087-1090.

- Tyson P. 'The Experiments' in results of death-camp experiments: Should they be used? NOVA online (Holocaust on Trial). 2000 http://www.pbs.org/wgbh/nova/holocaust/experiside.html.
- Wellcome Trust. Public perspectives on human cloning. 1998 http://www.wellcome.ac.uk/About-us/ Publications/Reports/Public-engagement/WTD003422.htm.
- Wellcome Trust. Information and attitudes: Consulting the public about biomedical science. 2005 http://www.wellcome.ac.uk/About-us/Publications/Reports/Public-engagement/WTX026430.htm.
- Whitbeck C. Truth and trustworthiness in research. Science and Engineering Ethics. 1995; 1(4):403–416. [PubMed: 11657785]
- Williams-Jones B. A spoonful of trust helps nanotech go down. Health Law Review. 2004; 12(3):10–13.
- Williams-Jones B, Corrigan OP. Rhetoric and hype: Where's the 'ethics' in pharmacogenomics. American Journal of Pharmacogenomics. 2003; 3(6):375–383. [PubMed: 14672518]

Wilson JM. A history lesson for stem cells. Science. 2009; 324(5928):727–728. [PubMed: 19423804]

- Yarborough M, Sharp RR. Public trust and research a decade later: What have we learned since Jesse Gelsinger's death? Molecular Genetics and Metabolism. 2009; 97(1):4–5. [PubMed: 19285443]
- Zarzeczny A, Caulfield T. Stem cell tourism and doctors' duties to minors—a view from Canada. American Journal of Bioethics. 2010; 10(5):3–15. [PubMed: 20461636]
- Ziman J. Public understanding of science. Science, Technology, & Human Values. 1991; 16(1):99–105.



**Fig. 1.** Hype and publicity