



## Communicating in context: a priority for gene therapy researchers

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# EXPERT OPINION

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## Communicating in context: a priority for gene therapy researchers

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History shows that public opinion of emerging biotechnologies has the potential to impact the research process through mechanisms such as funding and advocacy. It is critical, therefore, to consider public attitudes towards modern biotechnology such as gene therapy and more specifically towards the ethics of gene therapy, alongside advances in basic and clinical research. Research conducted through social media recently assessed how online users view the ethics of gene therapy and showed that while acceptability is high, significant ethical concerns remain. To address these concerns, the development of effective and evidence-based communication strategies that engage a wide range of stakeholders should be a priority for researchers.

**Keywords:** biomedical ethics, communication, gene therapy, online health, public attitudes

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### 1. Introduction

Research in gene therapy has been advancing rapidly since the first patients were treated in 1990 and has gained significant momentum in recent years, in particular due to successes in treating eye disorders such as Leber's congenital amaurosis. Alongside basic and clinical research advances, ethical considerations specific to gene therapy have been well-articulated by the ethics community [1] and have significantly intensified after the death of clinical trial participant Jesse Gelsinger in 1999 [2].

While the contributions of the ethics community on the topic of gene therapy are of critical importance to maximize the benefits and minimize the harms in moving the science forward, the voices of the general public must also be added to the conversation. Public opinion of biotechnologies has the potential to significantly impact the research process through mechanisms such as funding structures, patient advocacy and lobbying [3,4].

In the 1990s and early 2000s, a number of studies used traditional methods such as surveys and interviews to measure public opinions and attitudes about gene therapy [5-8]. In a methodological shift that harnesses the interactive environment of new media, more recent research has investigated public attitudes towards the ethics of gene therapy in a way that is responsive to the latest developments in the field. In a first study, the question-and-answer platform Yahoo! Answers was mined for questions relating to gene therapy, and both questions and their answers were analyzed for thematic content [9]. A subsequent online survey explored the ethics themes expressed on Yahoo! Answers in greater depth [10]. Results from these studies are discussed in this article.

### 2. Expectations

The public draws its information in large part from traditional and novel forms of news media, which have been seen to emphasize the medical benefits and promises of new biotechnologies [11]. As a result, hopes that gene therapy will cure a number

**Table 1. Ethical concerns related to gene therapy: percentage distribution of participants based on their ratings of concerns related to gene therapy.**

Ethical concern	Most concerning	Neutral	Least concerning
<i>% of survey participants (n = 467)</i>			
Not receiving all the information	57	35	8
Changes to identity	43	35	22
Changes to personality	41	43	16
Adverse medical side-effects	36	40	24
Passing on genetic material to offspring	30	39	31
Pressure from doctors/families about decision	14	43	43
Having the same genes as others	13	34	53
Going against nature	12	25	62
Going against my beliefs	9	18	73

Adapted from [10], with permission.

of genetic and non-genetic conditions alike are on the rise. In the online survey, nearly 75% of respondents agreed or strongly agreed that genetic treatment for diseases will have an overall positive impact on society and that, one day, gene therapy will be able to provide a possible cure for a large number of diseases. In support of the latter statement, unprompted and freely contributed questions on Yahoo! Answers revealed hopes that gene therapy will treat or cure over 45 different diseases and illnesses, ranging from benign conditions such as cold sores and acne to severe, fatal conditions such as fatal familial insomnia and Alzheimer's disease.

### 3. Acceptability

Since the initial investigations into public attitudes towards gene therapy in the early 1990s, the acceptability of gene therapy has increased. In freely contributed content on Yahoo! Answers in the recent study, 75% of users indicated that they are in favor of gene therapy in general, and 39% of users indicated that they are in favor of gene therapy for non-therapeutic applications such as enhancing appearance or intelligence. When queried formally through an online survey, over 90% of participants indicated that gene therapy for therapeutic applications such as treating Alzheimer's disease should probably (25%) or definitely (66%) be allowed, and over three-quarters of participants felt that non-therapeutic applications such as enhancing normal memory should probably (41%) or definitely (36%) be allowed.

### 4. Ethics

Several ethics themes were identified in freely contributed questions and answers about gene therapy on Yahoo! Answers. The main ethics concern expressed by users was that gene therapy would have an impact on society by leading, for example, to exponential population growth as a result of a decrease in the incidence of disease. Other societal impacts included changes due to significantly increased human longevity and the creation of different classes of individuals

based, for example, on their ability to afford gene therapy for enhancement purposes. Yahoo! Answers users were also concerned about the impact of gene therapy on a person's sense of self, in particular in cases where gene therapy is applied to the brain. Specific examples included changes to sexual orientation or religious affiliation as a result of undergoing gene therapy.

### 5. Communication

In order to explore public attitudes towards the ethics of gene therapy in greater depth, the ethics themes expressed in the Yahoo! Answers data set were compiled and integrated into a survey question involving a short scenario. Survey participants were asked to imagine a situation in which they are receiving gene therapy for a brain-related condition and then to rate nine ethical issues related to the scenario from 'most concerning' to 'least concerning' (Table 1). Above all other concerns, participants ranked 'not receiving all the information about the treatment' as most concerning. Lack of adequate information about gene therapy trumped physiological concerns such as adverse medical side-effects as well as hypothetical situations such as undergoing changes to personal identity. The concern that the survey participants expressed about communication strongly supports the process of informed consent as described in the traditional ethics literature. Further, this finding highlights the importance of effective, evidence-based and broad-reaching strategies for communicating about gene therapy for both the research and the medical communities.

### 6. Conclusions

Results from two recent studies probing online users' attitudes show that a rich discussion is taking place online about gene therapy and its implications for people and society. As both studies took place through online platforms, it is important to acknowledge the limitations of our samples: while both Yahoo! Answers and Amazon's Mechanical Turk boast high

traffic and broad user demographics, the attitudes of their users may not reflect those of the public as a whole and those of non-internet users in particular. Despite these limitations, the studies offer insights into the sentiments expressed by online users of sites receiving upward of 25 million unique users each month.

Interestingly, the ethics concerns raised by these online users do not necessarily map onto those raised in academic settings. In 2007, two European Union programs for the advancement of gene therapy held a 'think tank' on the ethics of human clinical gene transfer, an event that brought together an international and multidisciplinary group of stakeholders. Ethics concerns expressed in the context of this meeting were reported by King and Cohen-Haguenauer [1]. While some overlap exists between the concerns uncovered in our studies and those expressed at the international event, in particular with regard to issues such as non-therapeutic applications and the need for informed consent, gene therapy stakeholders were more concerned with the ethical implications of research (e.g., selection of trial subjects) and of specific potential outcomes (e.g., germline modification), and online users are more concerned with broader concerns such as the impact of gene therapy on the self and on society. While these differences are not surprising, these findings highlight the need to consider the voices of various stakeholders when moving forward with research in biotechnologies.

## 7. Expert opinion

Many of the ethical considerations raised by online users can be at least partially addressed through effective communication. Great expectations for new biotechnologies are often fueled by the media and by a lack of context and of evidence-based information [12]. However, the impact of media hype can be mitigated by improving how researchers communicate to the press and to the stakeholders [13,14]. Concerns about the ethics of biotechnologies should be explored and addressed through a multidirectional conversation involving ethics scholars, researchers, patients and members of the public.

Moving forward, gene therapy researchers ought to consider the following three strategies for disseminating their work:

- 1) Discuss basic and clinical research findings in their proper context. Disclose the research model used and the limitations of the work, and include timeframes when discussing clinical implications.
- 2) Acknowledge the realistic ethical implications of the research and proactively anticipate what might follow down the road based on experiences of the past.
- 3) Engage in knowledge exchange activities to ensure that all stakeholders – scientists and nonscientists alike – are involved in the process of discovery.

Effective multidirectional engagement and evidence-based communication about research and clinical advances are critical to ensure a positive social context for continued gene therapy research to thrive.

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