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American Voices on Ways Human Enhancement Could Shape Our Future

Focus group participants discuss biomedical developments that could boost the performance of people's bodies and brains

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As far-reaching biomedical technologies emerge from research labs, Americans are beginning to grapple not only with how these breakthroughs might enhance people's health and abilities, but also with the profound ethical and moral questions the discoveries raise.

How much change in the physical makeup of humans is possible and acceptable? When does enhancement of human abilities cross a line by giving some people unfair advantages over others? What oversight and regulation of body- and brainchanging procedures is necessary? And how should the government or insurance marketplaces respond to the availability of life-altering technologies?

Pew Research Center explored Americans' attitudes toward these issues in a <u>nationally representative survey of more than 4,000</u> <u>respondents</u> more than 4,000 respondents, supplemented with six focus groups across five regions of the country with a total of 47 participants. The focus groups were deliberately structured to include highly religious Christians as well as Americans who have no religious affiliation. The participants were racially and ethnically diverse, including whites, Latinos and blacks. And, since new biomedical developments are more likely to affect younger generations, the groups included a mix of Millennials and middle-aged adults.

This report describes the wide-ranging discussions that occurred in those focus groups, which, like the survey, centered around three potential kinds of human enhancements: gene-editing

Themes in focus group discussions of biomedical developments that could enhance body and brain

1. Many felt that while no effort should be spared to help the sick, society should proceed with caution before allowing biomedical advancements to boost the capacities of healthy people, fearing a slippery slope toward creation of "superhumans" or human "robots."

2. While each of these enhancements could be seen as humans "playing God," some participants argued that these advances can be morally justified because God intended for humans to make the most of their abilities and to better humankind.

3. Potential risks and abuses of these enhancements highlight the need for oversight; the guideposts for regulation should be "do no harm" and "be fair."

4. There was broad consensus that no enhancement should ever be imposed on anyone against his or her will.

5. The calculations and guideposts people use have a distinctive character depending on the type of enhancement.

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techniques that could give healthy babies a reduced risk of serious diseases over the course of their lives, computer chips implanted in the brains of healthy people that may help improve their concentration and ability to process information, and transfusions of synthetic blood designed to increase oxygen levels and give healthy people greater speed, strength and stamina.

While all these technologies are currently being developed in one form or another, none are widely available today to augment "healthy" people's abilities. Accordingly, participants in the focus groups were asked to think about scientific advances that were, in many cases, unfamiliar to them and then to perform acts of moral imagination, anticipating societal reactions to possible biomedical interventions. The conversations were aimed at eliciting different viewpoints and understanding the participants' moral reasoning.

Though focus groups do not provide a representative portrait of the general public, they can yield insights into how individuals think about complex topics.

The three kinds of human enhancements – though far from an exhaustive list of biomedical technologies now under development – were chosen to cover a range of procedures (from blood transfusions to brain surgery) and goals (improved physical abilities, improved thinking abilities, improved offspring). To help distinguish between therapies aimed at healing the sick or correcting serious disabilities and human *enhancements* designed to give people greater capabilities and longer lives, the focus groups were asked to consider medical interventions on otherwise *"healthy"* people.

Within these limitations, the participants engaged in thoughtful and often passionate conversations. Their discussions revealed a number of clues about how and where Americans draw moral boundaries when considering scientific breakthroughs. And, to a considerable extent, the focus groups gave voice to concerns echoed in a representative survey of the general public. See "<u>U.S. Public Wary of Biomedical</u> <u>Technologies to 'Enhance' Human Abilities</u>."

Focus group discussions centered on three potential enhancements for healthy individuals

- Using gene-editing techniques on healthy babies to improve the immune system, allowing people to live with dramatically reduced risk of disease and illness.
- Implanting devices in the brains of healthy individuals, giving people significantly improved concentration, memory, ability to think and process information.
- Giving healthy individuals transfusions of synthetic blood substitute, enabling people to perform all sorts of tasks with significantly improved speed, strength and stamina.

See Appendix A for full descriptions.

Often, the conversations reflected optimism about the march of science and technology, mixed with darker fatalism about social change. The focus groups were not pressed to reach agreement. But the general arc of the discussions, paraphrased broadly, might go something like this: Progress with technology and medical research is inevitable. It's exciting to imagine what might happen, and there are plenty of reasons to hope these changes will make life better. Still, such developments are disquieting. Some people will be left behind as human enhancements become available, and someone or some part of the government will need to watch carefully to rein in potential abuses, because we are heading to a place where the boundary between human and nonhuman becomes quite blurry.

One participant summed it all up this way:

"I wouldn't use the word fundamentally changing [when I hear these scenarios], but I do see us on that path. ... There are going to be those who are for it, those who are against, those who think it benefits them [and] those who think, 'I don't want to be messing with this here.' And then you're going to have your people in the middle. ... And sometimes it takes a while for things to actually hit, you know, because it takes a while for society as a whole to accept things as the world progresses."

- 52-year-old black man in Atlanta

Six focus groups: locations, dates and composition

Each focus group consisted of seven or eight adults coming together for an hour and a half to two hours for a discussion led by a professional moderator. **Baltimore, Maryland, Jan. 19, 2016** Black adults ages 18 to 65 **Birmingham, Alabama, Jan. 21, 2016** White, non-Hispanic Christian adults ages 18 to 45 who say they attend religious services at least weekly or who say religion is very important in their lives **Phoenix, Arizona, Jan. 27, 2016**

Hispanic adults ages 18 to 65 **Dedham, Massachusetts, Jan. 28, 2016** Religiously unaffiliated adults ages 18 to 35

Atlanta, Georgia, Feb. 4, 2016 Black adults ages 18 to 65 Atlanta, Georgia, Feb. 4, 2016 White, non-Hispanic Christian adults ages 45 to 64 who say they attend religious services at least weekly or who say religion is very important in their lives

As they were asked to weigh pluses and minuses of these possibilities, many alternated between thinking about what they would do if their personal circumstances led them to consider an enhancement and thinking about how society would change if these enhancements were made available to everyone. It was telling that all the focus groups could easily construct substantial lists of advantages and disadvantages that might emerge if these new biomedical technologies become widely available to healthy people. Participants in each focus group were selected to have some shared characteristics (such as race, ethnicity, age or religious background) to facilitate open discussion. The six groups (details in accompanying sidebar) were designed to elicit a variety of viewpoints.

Each group was convened with a moderator and seven or eight participants. All of the groups were recruited to include a balanced mix of men and women, and overall they were diverse in age (ranging between 18 and 64), household income and levels of educational attainment. Respondents were offered a small monetary incentive for their participation, with the exact amount varying by location. The focus groups were managed by Princeton Survey Research International and held at five sites around the country. For more details on how the discussions were facilitated, see the moderator guide in <u>Appendix A</u>.

Specific sets of broad principles about the subject matter were rarely embraced by everyone in every case. Still, some themes and tendencies stood out. The rest of this report explores these themes in greater detail.

Many felt that while no effort should be spared to help the sick, society should proceed with caution before allowing biomedical advancements to boost the capacities of the healthy, fearing a slippery slope toward the creation of "superhumans" or human "robots."

Many focus group participants felt strongly that people with life-threatening diseases or significant disabilities deserve every chance to get whatever treatments might benefit them. However, they were equally insistent that brain-boosting or body-altering assistance for the wealthy, the vain or the excessively ambitious is a different matter. Most participants believed that healthy people should not gain immediate access to enhancements, especially if their main purpose is to gain advantages that "ordinary" people would not have.

"I just think that there's that place where you're going beyond healthy, you're going to super strength or computer [chip] thinking, [then] I think that's unnatural. So to me it would just be like the – if I just had to change a gene in my body so I wouldn't have diabetes and I wouldn't pass it on to my kids, sure, I would do that. ... But I don't ... have to go beyond that to be the super great, to get to the highest level just because I have a computer chip in my brain. I think that being healthy, productive, good quality of life is where I would draw the line."

– 50-year-old Hispanic woman in Phoenix

While they often found reasons to support – or at least tolerate – gene editing, brain chip implants and synthetic blood transfusions, many participants expressed anxiety about how far the pursuit of human enhancement will go. Relatively few had clearly defined views of what is acceptable and

what is not. Instead, they worried more generally about the social strife that might arise when some people can order up improvements that make them stronger and smarter, while others cannot.

Further, many said they fear how human enhancement technologies in the wrong hands could be used for the purpose of eugenics, to create "superhumans" who might impose their will on others. One man thinking about the synthetic blood scenario put it this way: It could be "used to make supermen ... almost like super-physical men." Another added that those who got the enhancements "could probably get away with anything and nobody could stop [them]."

He was not alone in feeling that recipients of these procedures may feel superior and act that way.

"If it starts to sound Hitler-like, [trying to create] a perfect specimen of man and woman ... then people who are not perfect might be treated badly."

- 59-year-old white woman in Atlanta

"I could imagine [synthetic blood] impacting your social life or your relationships because of how you are perceived or how you might perceive others that they are unhealthy or not moving fast enough or they're not strong. That might create insecurity or create a superiority complex."

- 31-year-old black man in the Boston area

"I hate to sound like a jerk, but I think ... this comes with a certain amount of arrogance when you get this. Because now you go from being 'normal Dave' in the room to the smartest guy in the room. Being able to – can't have a fight with your wife because you remember every single word that was said because now you have increased memory and everything else. "

- 40-year-old Hispanic man in Phoenix

Some participants worried that, in the pursuit of perfection through enhancement, humans could also lose their individuality and humanity, becoming more like robots than people. Many agreed that these issues should be confronted sooner rather than later because they affect essential notions about who humans are and what they can do.

"You kind of ... lose individuality because you have all these kind of superpeople that can remember everything, [but there are] no individuals anymore. They're all just the same robotic people." - 59-year-old white woman in Atlanta

"I think [synthetic blood] would sort of fundamentally change who we are. ... You would have this culture of people just obsessed with being bigger, stronger, faster, and just outperforming everybody."

- 35-year-old black man in Atlanta

In the eyes of these focus group participants, widespread use of human enhancements by healthy people has the potential to upend some of the most important aspects of human existence. These include family relations, workplace dynamics, dealings between socioeconomic classes and connections among racial, ethnic and religious groups.

For instance, the Boston group of religiously unaffiliated young adults discussed what would happen to families when more than three generations are alive at the same time.

"Now, everybody is living 'forever' and the importance of a life cycle in terms of family relations and society relations [changes]. If you now have five generations alive at the same time, what [does] that mean for society and the relationship between the 120-year-old people and the brand new generation? A lot of change in society happens as new generations come into adulthood and that's because the older generation is dying out and if that does not happen, what does that mean for change in society and within families and communities?"

- 33-year-old white woman in the Boston area

Others envisioned changing workplaces, with enhancements being used as a means for career advancement.

"Who gets the promotion at work? Because you could afford to have an implant so you get it? I mean, what about everybody else? ... It's not fair to people who wouldn't be able to afford that."

- 50-year-old Hispanic woman in Phoenix

Some participants expressed concern that gene editing would lead to a less diverse human race. In general, people spoke out in favor of genetic diversity for its perceived health and species-survival benefits. As one woman thought about the impact on future generations, she speculated that if

both she and her husband had nearly identical "perfect genes ... and you have a kid, it's probably going to be all messed up because you don't have different gene pools to make a healthy child."

Some also worried creativity would suffer if a process like gene editing homogenized the species. As one participant put it: "At what point do we only have three different types of people as opposed to having all of the great diversity that we have? That's what makes us us." Another focus group member said she was worried there would eventually be "one race of people" and that would make for a diminished human experience.

While each of these enhancements could be seen as humans "playing God," some participants argued that these biomedical advances can be morally justified because God intended for humans to make the most of their abilities and to better humankind.

Every focus group had members who opposed at least one of these enhancements on moral grounds. Many expressed the expectation that all three kinds of enhancements would be opposed by people of faith because they affect the basic makeup and capacities of humans. Yet even some of the most highly religious people in these groups noted that the human condition has been vastly improved by a long line of technological and medical advancements. For participants who took this view, these procedures seemed more like "evolutionary" advances, rather than "revolutionary" departures:

"That's always a sticking point with technology and advancements in medicine. ... There are those who don't believe you should be touching what God has created. If God wanted you to be sharp in the mind ... then you would have been born that way. That's the thought of some religious people. But, I'm probably in that category where the Lord gave people the ability to come up with a way to help you [and it's OK to take advantage of that]."

- 52-year-old black evangelical Protestant man in Atlanta

Questions about God's will came up frequently in the focus groups, with two common (and opposite) views. One line of thought was: If God created humans – and, indeed, all animals – to be the way they are, then any kind of manipulation of natural abilities is altering God's plan. "You shouldn't be doing that, playing with God's natural [order]," said one evangelical Christian woman.

Another Christian woman, in Atlanta, expressed the belief that technology cannot actually change or evade God's plans for each person. "I believe that we all have a certain time to live, to die," she said.

One participant noted the tension between his personal religious beliefs about God's plan and his generally accepting attitude toward technological change. He said that although he may feel that human enhancements are acceptable, in the abstract, if he had to personally receive them, he would be conflicted religiously.

"I think that's one of those things where you don't realize the religious effect it has on you personally until it affects you personally. It's easy to say no, that's OK, that's OK, until it's you and then you have to deal with it, you have to sleep at night."

- 40-year-old Hispanic Christian man in Phoenix

An opposing line of thought embraced by some, including members of the religiously engaged groups, was that all preventive medicine could be interpreted as people honoring God's wish for them to strive to make life better. This view emphasizes that God gave people the ability to take care of themselves and responsibility for each other. As one man in Atlanta put it, "... they're already playing God now."

"I think God has given a doctor the talents to fix us. ... I think he has given these people the talents to do so. I don't think it is the doctors or medical gurus [trying] to play God."

– 44-year-old white mainline Protestant man in Birmingham, Ala.

"Just because you have faith in God, does it make you not go have your gallbladder [or] your tonsils taken out? I mean, people do things every day to lengthen their life and to be healthier."

- 50-year-old Hispanic evangelical Protestant woman in Phoenix

One exchange among Christians in the Atlanta region highlighted disagreements over the basic question of whether these procedures should be deeply questioned or accepted as just the latest examples of progress in health care. "It seems like if you're fooling around with gene editing and changing DNA, you are fundamentally changing something about the way a human being is originally created," said a white evangelical Christian man in the group who opposed the idea. Another white Christian sitting nearby replied: "I see this is sort of the evolution of life because, I mean, [in] the 1900s, people were dying of whooping cough. They figured out what that was, and now nobody is dying from that. I think this is just another function of that."

An Atlanta participant sought to split the difference, in a sense. He said he would like to apply a standard so that those who want enhancements for "moral reasons" could get them and those seeking enhancements for "amoral reasons" would be weeded out.

Some noted, too, that their wariness about the societal impact of enhancements could change if they, or a loved one, personally faced some of the challenges that these procedures might alleviate. A man described his own change in thinking due to family circumstances:

"I was always told steroids are wrong. But then when my wife was pregnant and we knew the baby was going to be a premature baby. ... The doctor said they were [going to] do steroids for the baby, so the baby could develop faster. Then all of a sudden steroids were good. So it depends."

– 25-year-old Hispanic man in Phoenix

Potential risks and abuses of these enhancements highlight the need for oversight; the guideposts for regulation should be "do no harm" and "be fair."

As a rule, focus group participants expressed the view that policies covering the availability of these procedures should hew to two broad principles. The first is the basic medical ethic: "Do no harm." Many participants worried about the unforeseeable effects of editing the human genome and implanting foreign material into healthy people's brains. What if these procedures actually made people sicker or affected people's immune systems? Worse, what if a particular gene change spun out of control?

When focus group members talked about the impact of brain chips, they worried about possible brain damage during the chip implant process, side effects that might be hard to undo, the possible diminution of creativity, bad behavior that could not readily be explained but might be related to the chips, and brain manipulation that might make people less autonomous. A common refrain was that corporate makers of chips, criminals or hackers might gain access to people's brains and even have the capacity to control them. A sampler of their concerns:

"Are we becoming robots, is that what the whole society's going to become? And then pretty soon someone will hack the computer system that you hook up to and throw a little virus in your brain and then what? You lose your identity as a person."

- 50-year-old Hispanic woman in Phoenix

"The thing just keeps going over in my brain is that you're altering the brain. It's such a high risk. ...When you think about DNA, OK, but it's your brain. It's so complex and I just feel this is very, very high risk."

- 27-year-old white woman in the Boston area

"Well, I just started to think about <u>'I, Robot</u>' and those type of movies where you have just people out of control and just because they [have] all these superpowers all of a sudden."

- 38-year-old black man in Baltimore

"Like all technology, it breaks down. And how long will it last? Is there no guarantee on how long it will last inside the brain?"

- 48-year-old black man in Atlanta

"Your whole personality would change. You'd be what the chip wants you to be."

- 48-year-old white man in Atlanta

They also spoke about possible abuses. One woman in the Boston area said she would be wary of embracing human enhancements like this unless she had answers to the questions: "Are there limits? Are there structures [of evaluation]?" A companion in the group added: "People do a lot of crazy things for vanity, so I think that's where [we] need to draw the line."

The second principle many participants said they would want applied is to "be fair" in making human enhancements obtainable. There was a consistent view that people in dire medical need should get first crack at the new techniques, while those whose needs were cosmetic or seemingly trivial (e.g., to cope with conditions that are the equivalent of a "runny nose" or people who "want to change their eye color") should not be able to get enhancements like gene editing, many focus group members argued.

There were also concerns about new kinds of clashes between socioeconomic groups. "I don't think it would be fair to offer it to a certain group of people and not offer it to everybody," one man in Atlanta said. Another put it this way: "I think we are always going to be pushing the line, so, again, [if] there is equal access and everyone can get [it] and it's available to the poor, the rich, the white, the black, then I don't see an issue with it." Focus group participants were particularly anxious about gene editing and the possibility that it would be available to the wealthy, but not fully available or affordable for others.

"It makes me think about this movie called <u>'Gattaca'</u> where they had gene splicing and everything, but it was only available to the higher income, like the 1%, those who can hire the company [that performs gene editing]. ... Will they be doing [real gene editing now] for the good of society or will it be good to line their pockets? You know, only that 1% have the availability of such [advanced] medical technology [now]. "

- 48-year-old black man in Atlanta

Inevitably, some felt those with enhancements would be in advantageous positions, which would go against the principle of fairness and prompt futuristic versions of inequality.

"If it's there for everybody to get, then it's a good thing. But if only a certain sector of society can get it, then that's never good."

- 52-year-old black man in Atlanta

"You might have someone who's very wealthy look down upon someone who's not wealthy just because of their wealth. Now it could be, well, not only are they not wealthy but they're sick, look at those sick people down there, I'm up here on my horse [and don't care about them]."

- 40-year-old Hispanic man in Phoenix

Several took the argument to a broader level by arguing that the long-term impact of unequal access to human enhancements would be that the wealthy and their offspring would have better survival rates and be more productive than those from less-well-off families, because richer people would have the best immune systems. That could deepen class fissures and lead to dystopia.

"I would [worry about creating a gap] in society between the haves and have nots. ... Now the [haves] will have eliminated or eradicated or substantially reduced the risk of contracting any other illness or disease, while those that aren't healthy are just left behind. "

- 31-year-old black man in the Boston area

Some pushed back against these dystopian notions, however. The focus group made up of white Christians in Atlanta included people who were not convinced that social strife would ensue, and who compared future enhancements to existing technologies that have not worsened social divisions.

"I'm a religious person and while I've had issues with genetics things, this I really don't see crossing that field. [It's more like] bad vision that [you correct by] wearing eyeglasses. That's making an improvement on something you already have and it's not really changing much."

- 61-year-old white evangelical Protestant man in Atlanta

"It's just enhancing what we already have. It doesn't imply that it's changing how we think. ... Really, what's the difference between [a brain chip] and taking a bunch of vitamins that improve our memory?"

- 46-year-old white evangelical Christian woman in Atlanta

At the same time, some noted that social divisions have always existed and thought these potential enhancements would be in keeping with what we already experience in society.

"Just because you've got a mental chip, doesn't mean your thinking is going to be any different. So that's not necessarily saying that if you are a janitor and there's a person who's a CEO of that same company, [and] you both get computer chips in your brain. That doesn't mean that your knowledge base of what to do is any different."

- 23-year-old black man in Baltimore

"We talked about [changing the] body and making a [level] playing field for everybody. But right now it's not. There's no equality. There's no [level] playing field. Some people ... are just stronger than others; some people are just faster than others. Some people are smarter than others. So there's really no equality. ... [Synthetic blood transfusions] would just give it a little mountains higher and valleys a little lower."

- 25-year-old Hispanic man in Phoenix

"I think we may be overthinking this because some people are already generally faster and have more strength. ... You're just going to be stronger than me always; it's not going to be a today or tomorrow; we're already living in that world."

- 31-year-old black woman in the Boston area

For some, the fairness concept also concerned the way enhancements would be applied. They said it would be permissible to use enhancements to help those with clear physical or mental deficits, but would be too much to make well-functioning people perform at an even higher level. For instance, a participant in Birmingham said he would approve of enhancements to "bring people up to normal" levels of performance, but would not back improvements that would give someone superhuman abilities.

There were disagreements about who should oversee the rollout of enhancements. Many talked about their concern that "the government" was not trustworthy. The best oversight would come from experts in the medical field, argued a woman from Baltimore. "I don't think it should be the government," she said. Another participant in that group worried that "the federal government has [its] hands in everything."

But others thought a government agency like the federal Food and Drug Administration (FDA) would be the best candidate to make rules and enforce them. When pondering access to brain chip implants, focus group participants talked about age limits, screening committees of doctors and review boards composed of people with diverse interests to handle patient requests.

"I would think it would be sort of a board or committee with health officials, government officials, like different groups but together, so you don't have to just have one group running it."

- 35-year-old black man in Atlanta

"If you're going to have only certain people get it, kind of like cosmetic surgery, then you do need a governing body pretty much handing out the licenses and having the powers to deactivate it if you do something stupid with it."

– 25-year-old Hispanic man in Phoenix

Others doubted whether regulation would even be possible. "Can you really regulate what people want to do if it is available and they have the money to pay for it? I don't know," one woman said.

A Millennial woman added: "I think [gene editing] is inevitable; I think that you can't stop technology."

A number of participants made the case there should be screenings of candidates for enhancements. "I think there has to be a line that you say, 'OK, how do we regulate this? How do we not let this get out of hand?'" said an Atlanta man. Another in his group said there should be close scrutiny of the creators of these enhancements: "What kind of group is inventing this technology? Are they doing it for the betterment of our society or are they doing it to make a great buck?"

A Hispanic man drew nods from others in the Phoenix-region group when he said, "I think there are certain processes that are going to be involved that just not everybody can have it. And maybe that's financial, maybe that psychological, maybe – what have you. But I don't think that it should be available just to everybody." He argued that the process should block those with bad intentions and it should bar practitioners who were indiscriminate in providing enhancements.

There was broad consensus that no enhancement should ever be imposed on anyone against his or her will.

This was the one principle that was largely unchallenged when it came up in the groups: that getting these procedures should be a decision left up to individuals.

Several of the groups turned the discussion at times into an exploration of whether societies might move toward a kind of preventative medicine model, but none of those who pondered these issues liked the idea of a public health mandate or incentive structure to push people into getting these enhancements. If enhancements were embraced by wide segments of the industry and government, people said, what's to prevent them from becoming mandatory?

Some participants speculated that if there were no restraints on new biomedical procedures, companies might require employees to get enhancements in order to be more productive – or educational institutions might insist that their students get enhancements so that all students would be focused, productive and never absent. This troubled focus group members. A woman in Baltimore worried that enhancements might be implemented through communities to "control" them and make inhabitants "robots" and order them to "do this, and this and this."

One young adult from the Boston area put it this way: "I wonder if we could ever get to the point where you could say then that it is required like vaccinations for schools. ... Are we going to have

kids that aren't able to attend certain places because their DNA hasn't been changed?" She did not think that would be a good outcome.

Most felt that a mandatory application of these enhancements would be disastrous to the social fabric of society. It should be "up to the person" whether to get an enhancement or not and should not be a policy dictate, said a Phoenix woman. "It would cross the line if you are making it a requirement and forcing people to do it," argued a woman in Atlanta.

"I shouldn't have more control over somebody's ability to figure out what's going to work best for them. I think if it causes harm to the collective and causes harm to general society, then yeah, we need to have it evaluated. But if it's going to affect their individual life and they can take the superdrug and ... that's what they need to do, fine. For myself personally, I don't think I would need those things."

- 31-year-old black woman in the Boston area

The moral calculations and guideposts people use have a distinctive character depending on the type of enhancement.

While common themes emerged in the focus group discussions about all three kinds of enhancements, each of the individual scenarios elicited unique moral calculations.

Gene editing for healthy babies to reduce risk of serious diseases

As participants thought about this scenario, they often agreed that the promise of gene editing would be healthier, longer-living humans. Some found the idea of protecting their children from a lifetime of disease very appealing. At the same time, people expressed concerns about the long-term impact on society. Some were anxious about the impact on future generations, on the diversity of the human species, on people's creativity, on core identity issues for recipients and on inter-generational relations. Further, people expressed concern about the use of gene-editing techniques on such things as parents ordering up "designer babies" or abusive tyrants trying to engineer their populations.

The prospect of using gene editing to prevent disease struck some as a profound alteration. "It seems like if you're fooling around with gene editing and changing DNA, you are fundamentally changing something about the way a human being is originally created," noted a white, evangelical Christian man who opposed the idea.

But some focus group participants were upbeat about the potential for gene editing to conquer diseases like cancer and Alzheimer's, with a likely increase in human longevity. "If I'm going to live to be 120, I could start two other careers and have a lot of time for fulfillment and fitting a lot more into your life," noted one woman in the Boston area.

"The fear [of living with a genetic disease or illness] really affects your relationships. ... [You] always have that fear that will come back, and it really makes you insecure. [With gene editing] you don't have that insecurity. If you knew that 'I would never get again' ... it would have a profound positive effect."

- 58-year-old white woman in Atlanta

There was intense conversation in the focus groups around several issues related to the implementation of gene editing because of possible implications for both present and future generations. When asked about edits to germline cells (i.e., changes that would be passed on to future generations), a Phoenix man pointed out: "[This is] powerful, whether you agree with it or not ... because you are affecting ... your descendants." Some saw the possibility of affecting future generations as positive. A Boston-area man claimed that "it would make me more inclined to have this done to myself if I knew I could pass on those genes that I had implanted in me going forward."

Brain chip implants for greater concentration and memory

Many focus groups members worried about the wisdom and ethics of tampering with people's brains. This seemed to them a more perilous and less rewarding activity than gene editing because the process of implanting brain chips could affect people's individuality, thinking abilities and emotions. Several Christians made references to the "mark of the beast" in the Bible's book of Revelation, a symbol tied to the Antichrist and Armageddon, and argued that such implants could especially be susceptible to manipulation for evil purposes. "That's talking about what they talked about in the Bible," noted one evangelical Christian in Phoenix. "It's scary."

In separate groups that were made up of relatively active religious participants – including whites, Latinos and blacks – participants also made this connection.

"It just reminded me of like the mark of the beast. ... I know in Revelations it talks about [how] there's going to be like some markings and pretty much that's getting you ready for the end of times."

- 23-year-old black man in Baltimore

"If you have studied the Bible or gone to church or whatever, could this be like the mark of the beast?"

- 34-year-old white evangelical Protestant woman in Birmingham

The brain is precious territory to people, the center of where people's identities and emotions arise. "We're playing God when we're messing with the brains," said a Christian man in Atlanta. Several were especially concerned that tampering might affect people's mental or emotional makeup. They worried about how chip implants might signal that humans were relinquishing control of their thinking and their emotions to technology. One wondered: Where does the chip stop and the person start? "I [worry about] the extent that it would affect my empathy and my emotions," an Alabama man said.

Many made the point that brain chips for enhanced concentration and memory might be nice if they worked, but they did not seem vital to human well-being. One participant likened it to "cosmetic surgery for the brain." A Baltimore woman described it as "a vanity thing, you know, like teeth whitening [or] Botox." A fellow member of that group added: "I feel like it's low value. I feel like it's just going to be another thing that increases our vanity. … It just feels shallow to me."

At the opposite end of the spectrum, others were concerned that people might rely too much on the chip for their thinking processes. As one Atlanta woman put it: "That chip might be your God."

A cross section of participants, ranging from highly religious people in Atlanta to religiously unaffiliated Millennials in the Boston area, expressed related fears about how chip implants could lead to humans becoming robot-like – and to brains being hacked. "It would be like somebody would be married to a robot," argued one participant from Atlanta.

Transfusion of synthetic blood substitutes for physical speed, strength and stamina

While there were some who seemed taken with the idea of synthetic blood, the overall tenor of the group discussions about this scenario was largely negative. Many participants referred to doping by athletes trying to cheat their way to a competitive advantage, saying it was hard to see how the use of synthetic blood could be anything but a corner-cutting boost to higher human performance.

One woman from the Atlanta area said: "We see people in sports who are using steroids, [and] we want to discount them. We believe ethically, that doesn't work, so this could be the same thing."

Another participant suggested an outcome might be an akin to an arms race among individuals to best each other. The availability of synthetic blood might induce people to push past reasonable

physical limits and hurt themselves, or it may prompt bosses to pressure workers into getting transfusions of synthetic blood to increase their capabilities.

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Appendix A: Moderator guide for focus group discussions

As the group is assembling, participants complete a short questionnaire prior to the discussion. Initial introductions and ground rules for discussions included the following: Hello my name is [MODERATOR NAME] and I'll be your moderator this evening. We're doing focus group interviews for Princeton Survey Research Associates International, an independent research company based in New Jersey. We are interested in understanding how people in different parts of the country think and feel about some new issues in technology, biology, genetics and medicine.

Over the next 1.5 hours or so, we'll discuss your views and experiences related to some new options being developed to treat people with diseases or medical conditions. Our goal is to think through what our world might be like if, instead of using these options for treatments, they were available and used by healthy people.

Scenario 1: Gene-editing for stronger immune system and reduced risk of disease and physical illness

Read aloud and hand out to participants:

New developments in genetics and genome editing techniques are opening new possibilities that could be used to boost a person's immune system. Because the immune system is critical to protecting the body from disease and infection, these kinds of changes could potentially allow individuals to live with significantly less disease and illness. These techniques involve changes to the DNA (that is, the genetic material) of specific cells in your body either by injecting material that affects these cells or by first removing these cells from a person's body, changing the DNA of the cells in the lab, and then replacing these cells back in the person's body. Currently, geneediting techniques are used to treat people who have an immune system disorder of some kind.

In the future, gene-editing techniques could be developed for use by healthy individuals to significantly improve their immune system and dramatically reduce their risk of disease and illness. The idea we want to discuss is what it would be like if gene-editing techniques that improve the immune system were available for HEALTHY individuals, allowing people to live with dramatically reduced risk of disease and illness.

QUESTIONS FOR DISCUSSION

1. That's a lot of pretty technical information and I want to learn more about what you each think. Just a show of hands...

• How many of you would be interested in using these gene-editing techniques FOR YOURSELF to significantly strengthen your immune system and dramatically reduce your risk of disease and illness? And how many of you would NOT be interested in this for yourself?

Remembering there are no right or wrong answers here...

- How many of you say that doing this is an appropriate use of medical, technical or scientific knowledge? And how many of you say that doing this is NOT an appropriate use of medical, technical or scientific knowledge?
- 2. Now I'd like to hear more about what you think or feel about the idea of using gene-editing techniques to significantly strengthen the immune system of healthy people and dramatically reduce their risk of disease and illness. On the paper in front of you, I'd like you to write down one advantage and one disadvantage of using these techniques for healthy individuals for those who have this gene-editing technique done or for society as a whole.

(Allow respondents a minute to write their responses. When most seem done, resume discussion.)

- Let's start first by talking about some the ADVANTAGES gene editing might have for healthy individuals.
- Now let's talk about some of the DISADVANTAGES that developing gene editing for healthy individuals might have.
- 3. Still thinking about possible advantages and disadvantages, what effects do you think using these gene-editing techniques might have on:
 - Family or other personal relationships
 - Work how people do their jobs
 - Society in general: Between different races or ethnic groups, between different religious groups, between different income groups?
- 4. Regardless of how you feel about this idea, personally, do you think it is important that everyone should have equal access to use these techniques perhaps by making sure that insurance will pay or by having rules to make sure these techniques are widely available or don't you think it is important to make sure there is equal access to this option?
- 5. **[REQUIRED PROBE]** Are there any limitations, safeguards or rules you would like to apply to how gene-editing techniques like this are used to significantly strengthen the immune system of healthy people and dramatically reduce their risk of disease and physical illness? [IF YES, PROBE: What type of rules? Who should be in charge of rules and safeguards?]

- 6. When you step back and think about a world where this is possible, do you think people have a moral responsibility to improve their abilities to the extent that medical and technical options like this are available to them? Or do we, perhaps, have a moral responsibility for the opposite to leave these kinds of options for treatment of disease but nothing else?
- 7. **[REQUIRED PROBE]** What would you think about this idea IF the gene editing is done in a way that the genetic modifications could be passed on to future generations if they later have children, and over the long term could change the genetic characteristics of the population? The alternative is when genetic modifications are done on somatic cells and CANNOT be passed on to any children a person later has. How does that distinction change your thinking about this idea, if at all?
- 8. **[REQUIRED PROBE]** As we talk, do you think of this idea as fundamentally changing people as human beings? Or, do you, perhaps, see this as similar to other ways humans have tried to improve their abilities over the years with new tools and machines, medicines and education? Tell us a little about your thinking on this.

Scenario 2: Brain implant to improve concentration, memory, ability to think and process information

Read aloud and hand out to participants:

New developments in understanding the brain – in the field of neuroscience -- are creating the possibility that doctors will be able to surgically install implants inside the brain that could interact with computers and prosthetic devices. These techniques involve surgically implanting a small computer chip in the brain. Currently, these implanted devices, sometimes called neuroprosthetics, are being developed for use by people with some kind of problem or disability.

In the future, these implanted devices could potentially be developed for use by healthy individuals. The idea we want to discuss is what it would be like if these devices were available for HEALTHY individuals, allowing people to function at home, work and in everyday life with a significantly improved concentration, memory, ability to think and process information.

QUESTIONS FOR DISCUSSION

1. That's a lot of pretty technical information and I want to learn more about what you each think. Just a show of hands...

• How many of you would be interested in these types of devices for YOURSELF in order to significantly improve your ability to concentrate and think clearly? And how many of you would NOT be interested in this for yourself?

Remembering there are no right or wrong answers here...

- How many of you say that doing this is an appropriate use of medical, technical or scientific knowledge? And how many of you say that doing this is NOT an appropriate use of medical, technical or scientific knowledge?
- 2. Now I'd like to hear more about what you think or feel about the idea of using these implanted devices by healthy people. On the paper in front of you, I'd like you to write down one advantage and one disadvantage of using these implanted devices for healthy individuals for those getting these devices or for society as a whole.

(Allow respondents a minute to write their responses. When most seem done, resume discussion.)

- Let's start first by talking about some the ADVANTAGES these implanted devices might have for healthy individuals.
- Now let's talk about some of the DISADVANTAGES that developing these implanted devices for healthy individuals might have.
- 3. Still thinking about possible advantages and disadvantages, what effects do you think these implanted devices might have on:
 - Family or other personal relationships?
 - Work how people do their jobs?
 - Society in general: Between different races or ethnic groups, between different religious groups, between different income groups?
- 4. Regardless of how you feel about this idea, personally, do you think it is important that everyone should have equal access to these implanted devices perhaps by making sure that insurance will pay or by having rules to make sure these devices are widely available or don't you think it is important to make sure there is equal access to this option?
- 5. **[REQUIRED PROBE]** Are there any limitations, safeguards or rules you would like to apply to how implanted devices like this are used to significantly improve healthy people's concentration, memory, ability to think and process information? [IF YES, PROBE: What type of rules? Who should be in charge of rules and safeguards?]
- 6. When you step back and think about a world where this is possible, do you think people have a moral responsibility to improve their abilities to the extent that medical and technical options

like this are available to them? Or do we, perhaps, have a moral responsibility for the opposite – to leave these kinds of options for treatment of disease but nothing else?

7. **[REQUIRED PROBE]** As we talk, do you think of this idea as fundamentally changing people as human beings? Or, do you, perhaps, see this as similar to other ways humans have tried to improve their abilities over the years with new tools and machines, medicines and education? Tell us a little about your thinking on this.

Scenario 3: Transfusion of synthetic slood substitutes for physical speed, strength and stamina

Read aloud and hand out to participants:

New developments in biochemistry are creating the possibility of using synthetic blood substitutes to significantly boost people's oxygen levels in their blood stream. A higher concentration of oxygen in the blood stream would be carried from the lungs to the muscles and could significantly improve people's physical speed, strength and stamina. Currently, transfusions with synthetic blood substitutes are being used to treat people who have significant blood loss from an accident or disease when few donors are available to provide blood for a transfusion.

In the future, a transfusion with this kind of synthetic blood substitute could be developed for use by healthy people to significantly improve their speed, strength and stamina. That could allow people to function in extreme conditions – at high altitudes, holding their breath underwater, or after hours of exertion – or simply to perform everyday tasks with greater speed, strength and stamina. The idea we want to discuss is what it would be like if a transfusion with this kind of synthetic blood substitute were available for HEALTHY INDIVIDUALS, allowing people to perform all sorts of tasks with significantly improved speed, strength and stamina.

QUESTIONS FOR DISCUSSION

- 1. That's a lot of pretty technical information and I want to learn more about what you each think. Just a show of hands...
 - How many of you would be interested in using a transfusion with this kind of synthetic blood substitute FOR YOURSELF to significantly improve your speed, strength and stamina? And how many of you would NOT be interested in this for yourself?

Remembering there are no right or wrong answers here...

- How many of you say that doing this is an appropriate use of medical, technical or scientific knowledge? And how many of you say that doing this is NOT an appropriate use of medical, technical or scientific knowledge?
- 2. Now I'd like to hear more about what you think or feel about the idea of having a transfusion with this kind of synthetic blood to significantly improve healthy people's speed, strength and stamina. On the paper in front of you, I'd like you to write down one advantage and one disadvantage of using these techniques for healthy individuals for those who have a transfusion with this kind of synthetic blood substitute or for society as a whole.

(Allow respondents a minute to write their responses. When most seem done, resume discussion.)

- Let's start first by talking about some the ADVANTAGES gene-editing might have for healthy individuals.
- Now let's talk about some of the DISADVANTAGES that developing gene-editing for healthy individuals might have.
- 3. What effects do you think having a transfusion with this kind of synthetic blood substitute might have on: [MODERATOR NOTE: if participants bring up sports/athletic contests, please probe for implications to people working in other aspects of everyday life such as for physically-demanding jobs.]
 - Family or other personal relationships
 - Work how people do their jobs
 - Society in general: Between different races or ethnic groups, Between different religious groups, Between different income groups?
- 4. Regardless of how you feel about this idea, personally, do you think it is important that everyone should have equal access to a transfusion with this kind of synthetic blood substitute perhaps by making sure that insurance will pay or by having rules to make sure these techniques are widely available or don't you think it is important to make sure there is equal access to this option?
- 5. **[REQUIRED PROBE]** Are there any limitations, safeguards or rules you would like to apply to the option of healthy people having a transfusion with this kind of synthetic blood substitute? [IF YES, PROBE: What type of rules? Who should be in charge of rules and safeguards?]
- 6. When you step back and think about a world where this is possible, do you think people have a moral responsibility to improve their abilities to the extent that medical and technical options like this are available to them? Or do we, perhaps, have a moral responsibility for the opposite -- to leave these kinds of options for treatment of disease but nothing else?

7. **[REQUIRED PROBE]** As we talk, do you think of this idea as fundamentally changing people as human beings? Or, do you, perhaps, see this as similar to other ways humans have tried to improve their abilities over the years with new tools and machines, medicines and education? Tell us a little about your thinking on this.

III. FINAL QUESTIONS

I'd like to take these final few minutes to talk about where you think moral considerations should enter the picture when we think about these kinds of medical, scientific and technical developments as potentially being used to enhance the capacities of healthy individuals.

- Do you have a sense of where you'd draw the line between changes to people that would be OK to you because they improve people's abilities in some way, compared with changes that would make people "fundamentally unnatural" in some way?
- Do you have any final thoughts on the availability, morality, or regulation of these potential developments being used for healthy people?

[OPTIONAL NOTE: Let me remind you that none of the ideas we discussed today are, in fact, available for healthy individuals today. The purpose of our discussion was to better understand whether people think there should be limits to how these kinds of options could be used in the future and what kinds of limits people think are important.]