# Perceptions of Synthetic Biology and Neural Engineering

**Key Findings from Qualitative Research** 

# **Submitted To:**

The Woodrow Wilson International Center For Scholars Synthetic Biology Project

By Hart Research Associates

April 18, 2014

Hart Research Associates 1724 Connecticut Avenue, NW Washington, DC 20009

# Methodology

In April 2014, Hart Research Associates conducted two focus groups on behalf of the Woodrow Wilson International Center for Scholars Synthetic Biology Project to gauge awareness of synthetic biology and neural engineering, associations that people make with these scientific developments, and reactions when they are given information about them. The research included gauging participants' reactions to brief descriptions of each of these areas of science and to potential applications for them, as well as a discussion about preferences for oversight of synthetic biology. While this is the first time we have conducted qualitative research that involved a discussion of neural engineering, the discussions about synthetic biology are a continuation of similar exploration in 2011 focus groups, as well as quantitative research from 2008 through 2013.

The two sessions took place in Towson, MD, (suburban Baltimore, MD) on April 2, 2014. One group was comprised of nine non-college graduates (individuals with less than a four-year college degree) and the other group included ten college graduates (individuals with a four-year college degree or higher). Participants in both focus groups were screened to represent a mix of basic demographic and ideological factors such as gender, age, race, religion, and political affiliation.

Both sessions provide an important qualitative perspective on uninformed and informed impressions of synthetic biology and neural engineering, and how members of the public weigh potential benefits and risks of these areas of scientific research and technology. However, because only a small number of people participated in these focus groups, the results cannot and should not be generalized to represent the entire population of adults. These findings should instead be considered as a rich and contextualized glimpse into the nature of the public's attitudes toward synthetic biology and neural engineering.

In this report, we summarize key takeaways from these focus groups. While there were some differences in the discussions – mainly around the degree to which participants focus on potential risks and concerns about synthetic biology – these differences are not enough to draw conclusions about how attitudes vary by level of educational attainment or other characteristics.

## **Overview**

#### **Synthetic Biology:**

The 2014 discussions about synthetic biology reinforce the findings from the 2011 qualitative research in many ways.

- There has been no discernable change in awareness of this area of scientific and technological research – none of the participants in the sessions were familiar with it – but they make associations and inferences about it based on their understanding of the terms "synthetic" and "biology."
- Participants express both optimism about potential benefits of synthetic biology and concern about potential risks. And on balance, most of them feel this is an area of science that holds great promise and is one that should continue to be pursued, albeit with oversight by a variety of entities, including scientific bodies, university scientists and researchers involved in synthetic biology, NGOs and watchdog groups, and U.S. federal government agencies.
- The discussions reinforce the degree to which specific applications for synthetic biology impact individuals' attitudes about this area of science. Medical applications with the potential to improve human health generate the most positive reactions. While there is real interest in and optimism about potential applications to create biofuels, clean up the environment, or detect harmful contaminants, these applications also raise concerns about unintended consequences. Applications that would be used to create chemicals such as food flavorings and artificial sweeteners generate the most skepticism and concern because they would be ingested by humans and are generally seen as not needed. An application to modify the DNA of brown rats so they cannot reproduce also raises concerns. The discussions indicate that the potential applications that accompany any introduction of synthetic biology have the potential to impact an audience's response.
- Concerns about the risks of synthetic biology are focused primarily on unforeseen, unintended consequences that could result both in the shortterm and for future generations. Participants in the sessions focus more on the risks of unintended consequences than on a fear that this technology could fall into the wrong hands and be intentionally used for harm.

#### **Neural Engineering:**

While neural engineering is not a field of scientific or medical research that these audiences have heard of, they are very optimistic about its potential to improve people's lives.

- The discussions about neural engineering are less nuanced than those about synthetic biology because participants see few downsides to neural engineering. To the extent that there may be risks, they feel they are minimal and contained to the individual who chooses to receive a treatment that involves neural engineering.
- The element of choice is an important distinction. If it is possible for a paralyzed or otherwise disabled individual to choose neural engineering as a treatment, they embrace giving individuals this option. There is the sense that an individual can weigh the potential benefits and risks for themselves personally, but there is little concern about adverse consequences beyond the individual patient, unlike applications of synthetic biology which could disrupt the food chain or natural order of life. Even when specifically asked about the potential for hacking into the wireless system of applications involved in neural engineering, participants are not particularly concerned.
- To the extent that concerns about neural engineering do surface, some worry there will not be equitable access to it and that the benefits will only be available to the select few who can afford to pay for it.

# **Synthetic Biology: Key Findings**

# 1. These participants are not familiar with synthetic biology, but they make inferences about what it entails based on their understanding of the words "synthetic" and "biology."

No one in either group had heard about synthetic biology before the focus groups. Nonetheless, they do make associations with other types of scientific developments based on the links they make to the terms "synthetic" and "biology." In addition to thinking of areas of science like cloning and stem cell research, participants tend to focus on the concept of something that is artificial and/or man-made. Below are a list of some of the words and phrases that come to participants' minds when they hear the term "synthetic biology."

- Cloning
- Stem cell research
- Fake/artificial
- Man-made
- Plastic
- Artificially created cells
- Man altering nature to develop a different end result/product
- ✤ GMOs
- Hormones
- ✤ Genetic research
- Creating artificial elements in order to improve people's quality of life (i.e.: health products)
- Not real, maybe genetic
- ✤ Greenhouse gases
- Prosthetics
- ✤ Gas and fuel alternatives
- Fake organs
- Nano machines
- Something that is made up not natural
- Replacement for "natural" biology
- "If you think it, we can make it."

#### 2. While they surmise that there could be some important human health and environmental benefits to synthetic biology, participants are quick to question what the potential downsides to this area of science may be.

Upon seeing a brief animated video explaining what synthetic biology is and involves (but which does not outline potential applications), participants express an openness to and interest in learning more about potential applications and benefits of this field of science. They maintain a balanced approach, however, that also takes into account potential risks or side effects.

"It seems real futuristic. I don't know . . . it could be bad, it could be good." -Baltimore non-college graduate

"We understand that it's to take away things that are going to cause a problem...but they clearly said it's different than in genetic engineering, because it's creating something that is new and different, not copying something, not eliminating something or adding something; creating something new. So that would be my concern." -Baltimore non-college graduate "Basically, it's . . . like they're trying to add something to your, you know, your DNA that basically might have any type of side effects that you might not know, you might not have the side effects now, but it might be somewhere down the line that you find that you have side effects from it."-Baltimore non-college graduate

"I was just thinking the same thing. I mean, like when they were saying it on the video and all, it sounds like it's really easy, and it can be done, and it's all going to work out great. But, you know, it doesn't talk about what could go wrong or side effects . . . It's, it just, it sounds real good, but I would be hesitant too." –Baltimore noncollege graduate

"For me, I think it's interesting progress, because I put it in the same camp as any other kind of medicine, you know. It's just a different tool to solve a problem, essentially. So I don't have a line. It's just, it's kind of a down the road where is humanity going to take it, and how far is it going to push it kind of? But I'm for the progress as long as it's monitored and studied as, for long-term use, yeah." -Baltimore college graduate

Discussion of modifying DNA raises some concerns, particularly in the context of humans. Some participants indicate greater comfort with this area of scientific study when provided with additional information stating that synthetic biology involves constructing or redesigning "living organisms, like bacteria" (See Appendix B). This focus on DNA modifications at the basic level of a bacterium puts some participants at greater ease that it is not about modifying human DNA – at least at this point. Even in this context, however, there is a general awareness of and concern about the unknown and unintended consequences in this field of science.

3. Discussion of potential applications changes the tone of the conversation from one of questioning and hesitancy to one of tempered optimism about real benefits for society. Different applications generate divergent reactions, however, and concern about potential risks remains.

Participants were provided descriptions of various applications for synthetic biology – some quite general and some very specific. Some of these were brief written descriptions, and two of them were edited videos of scientists (Dr. Christina Smolke and Dr. Kristala Prather) discussing the applications they are developing using synthetic biology.

Reactions to the applications tested in the groups are generally positive overall, with these audiences excited about the potential to improve human health, generate alternative liquid fuel, and reduce pollution and harmful contaminants in our environment. Their optimism is coupled, however, with concern about the unintended consequences of some of these applications. These audiences want to know that scientists are considering the full picture – maximizing potential benefits while simultaneously determining and minimizing potential risks.

# **Hart Research Associates**

The discussions suggest that these audiences more readily expect the benefits to outweigh the risks when the applications seem to be an improvement over the current situation, such as a more effective way to treat disease or an alternative to something that is very difficult or costly to find in nature. For these applications, the potential gains seem to justify the risks. On the other hand, when current options in nature or society seem adequate, or when the use of synthetic biology could disrupt the natural order by either introducing new micro-organisms into the ecosystem or altering the genetic makeup of animals, concerns are more acute.

"I mean, I personally think half this stuff probably has been going on for years, but I'm all for it. And I think all of it's great. As long as you know the side effects and, you know, the tests have been there, and everything is, it's been proven that this works just as is, there's no side effects, we've studied over this many years, I'm for all for it." -Baltimore non-college graduate

"Initially, I think it all sounds fantastic. I mean, that's why it's the first page we're learning about this. They have to make everything sound optimistic. I'm all for research for bettering, I mean, fighting disease and cancer as that does sound fine. But . . . it's scary to me to try to modify my white blood cells to make them stronger. How do you know if 60 years from now they're not going to turn on me and attack my liver?

And even generations from now, after I have children and they have children who were modified slightly different, you know, now my great grandchild's going to be the Hulk . . . It's just scary to me. It's a whole new thing that the general public is going to take many generations to get used to this type of idea." -Baltimore college graduate

Only a couple of participants across the two groups express objections to synthetic biology on religious or moral grounds. For the most part, participants' concerns tend to focus on their apprehension about interfering with nature in a way that could have long term, adverse, unintended consequences.

"I think that God made everything the way it's supposed to be made, and he made enough of everything, so I don't really feel that it's necessary to add to what's already here." -Baltimore college graduate

"Sounds like the first positive page of something that needs more reading, because they're going to bring up the things you want to hear first. But then again, you run the risk of messing with certain natural orders and codes down the road. It's a very short-term solutions to current problems kind of a scenario, but it's the kind of thing that you just need to understand a long-term plan and hear more of the scenario." -Baltimore college graduate

### **Hart Research Associates**

4. Participants are most positive about the benefits of using synthetic biology to more effectively treat disease and provide an alternative ingredient to something not easily found in nature. While there is real interest in the development of biofuels and microorganisms to clean up the environment, concern about the unintended consequences of releasing new organisms into our environment tempers reactions. The applications which generate the most concern about potential risks are altering the genes of brown rats to control their population and the development of chemicals, such as flavorings (e.g. vanilla and citrus) and artificial sweeteners, for foods.

The applications tested during the discussions are broken into three categories below based on participants' reactions to them – a) those for which they have the most positive reactions, b) those for which positive reactions are tempered by concerns about potential risks, and C) those that elicit concern and skepticism across both groups.

A) <u>Applications that generate the most positive reactions</u>: Overall, these audiences are most positive and optimistic about those applications that would enable **better and more cost-effective treatment of disease**. The discussions suggest that medical applications would be particularly appealing if they allow the treatment of a disease affecting a loved one and the ability to extend a loved one's life. Even with these applications about which many participants are quite hopeful, some wonder about potential side effects.

"My dad, he died of pulmonary hypertension, which is like one in a million...if there could've been something to introduce into his body that would help his endothelial cells relax or not grow in his lungs, you bet I would've taken it." -Baltimore college graduate

"I think the first two with the diseases. I think those were real positive things . . . Because it would be pretty amazing, you know, to compare somebody who is fighting leukemia, you know, 20 years ago with someone who is fighting it now. So I just think of what this would do, you know, how much easier of a treatment plan it would be." –Baltimore non-college graduate

"They sound really positive. But I'd like to know maybe side effects or things that could go wrong, because I find it really hard to believe that they can just create something from scratch that is 100% better, that's supposed to boost up your cells and fight diseases and stuff. I don't know, I'd like to know the side effects and kind of what he said, like how did you get there? What were the side effects that other people have had in the process?" -Baltimore non-college graduate

#### Synthetic Biology Applications That Generate The Most Positive Reaction

*More effective ways to treat disease*: Researchers are using synthetic biology to reengineer white blood cells to be stronger than naturally occurring cells and help fight leukemia tumors.

**Drugs for treating disease**: American researchers have modified single-cell organisms using synthetic biology to produce an anti-malaria drug at a tenth of the cost of the current drug.

Engineered immune cells: Research that takes an immune cell, and modifies it to more

therapeutic activity in the body. Researchers develop and design molecules that they can put into cells that act as information processing and control devices. Clinicians then take these devices and use them to control the therapeutic activity of engineered immune cells

as other diseases. (Dr. Christina Smolke)

*Skin care lubricant*. Squalane is a key lubricant for many skin care products, as well as some vaccines. A key source of squalane is the livers of deep-sea sharks, and around 3,000 sharks are needed to produce 1 ton of squalane. A company has found a way to use synthetic biology to produce squalane from crushed sugarcane, and is producing synthetic squalane in Brazil in a joint venture with a French ingredients supplier that sells the product to brand-name makers of skin care products and cosmetics.

While some would appreciate hearing about it in more simple, layman's terms, participants see important benefits in Dr. Smolke's research to **engineer immune cells to more effectively control therapeutic activity in a patient's body**. Notably, even with this optimism about the benefits, there are some participants who wonder about the potential side effects of this type of immune therapy.

"Seems like a very valid use of synthetic biology. Good idea to alter cells to fight cancer and other diseases more effectively." –Baltimore non-college graduate

"Seems plausible and promising. I like the idea of boosting the efficiency of natural white blood cells; sounds safer than more invasive treatments." –Baltimore non-college graduate

"I felt more comfortable talking about creating molecules – more scientific." –Baltimore college graduate

"For medical use to improve the life of a person and prevent cancer, diabetes, high blood pressure are all positive factors!" –Baltimore college graduate

"Immune cells recognize disease cells (cancers, infectious disease). If synthetic biology could replace chemotherapy (less chemicals, not harming other cells, no long-term side effects) I am for it – as long as it could be isolated for this purpose. People would still die – they might just die of something else." –Baltimore college graduate "Information cells – sounds great in theory. I am all for saving people who are sick. We need our white blood cells; would enhancing them cause them to overload a patient with too many "smart cells"? What if a bad cell found its way to mate with this smart cell and then destroyed all other cells at a much quicker rate?" –Baltimore noncollege graduate

"I would have to hear more, sounds very useful but could be too powerful. Being able to detect a disease and engineer the cells to behave in a curing manner could be great, but what other effects would it have?" -Baltimore college graduate

Another application that generates a positive reaction is **using synthetic biology to produce squalane** – a key lubricant used in many skin care products. There is a resounding belief that it is preferable to use this synthetic version of squalane and thus spare the lives of thousands of deepsea sharks who are killed for the squalane found in their livers. Even some who are skeptical of the unintended consequences of synthetic biology seem to see this as a positive step.

"It's not particularly clear whether the synthetic squalane is like chemically identical to the stuff you get from sharks. But . . . if you wind up with the exact same stuff, and it's just a matter of how you get it, then I have no problem with it at all. It sounds like a great idea." –Baltimore non-college graduate

"Well, I thought it was a good idea not to kill the sharks, because to me skin cream, if they can come, even if this isn't as good, it's not that important, it's skin cream . . . I mean, we all want skin cream. But to me it's like if you kill sharks for skin cream when they can imitate it, I would go for the imitation." –Baltimore non-college graduate

"Yeah. I mean, I'm in support, generally, with what everyone's saying, especially with animals, sharks, or any kind of top predator that's . . . waterfall effect if you influence their numbers, it's just going to screw up so many other things in that ecosystem. But I don't think any animal or ecosystem is worth altering for unnecessary products." –Baltimore college graduate

"I'm in support of the synthetic version, because, I mean, if it's something that we can grow and control or, you know, things like that, it's more reasonable than interfering with an ecosystem that already exists." –Baltimore college graduate

"All for it. It's better than killing all the sharks." –Baltimore college graduate

"I don't want to hurt the ecosystem with the sharks and any kind of living thing, because I know without them, we'd have too much of something else, and we're just really messing up things."-Baltimore college graduate B) <u>Applications for which interest and excitement is tempered by</u> <u>concern about unintended consequences</u>: Participants anticipate real and important benefits to using synthetic biology to create biofuels, clean up the environment, and sense harmful contaminants. While some focus almost entirely on the upside potential, others wonder if the potential benefits outweigh the potential risks. While no one in the groups is resolute in believing that the risks outweigh the benefits, some participants have real concerns and wonder about the ability to fully anticipate risks in the long-term.

#### Synthetic Biology Applications That Generate Mixed Reactions

*Creating biofuels*: Kristala Prather genetically engineering plants to be more easily degraded, and to make a sugar compound that can eventually be used as fuel. Using synthetic biology, the team is developing custom designed microbes that can be used to convert the sugars that these plants make into liquid fuel replacements for diesel and gasoline that are compatible with existing infrastructure.

**Cleaning up the environment**: Using synthetic biology, researchers are working on constructing micro-organisms that could be used in factories to remove pollutants before they are released to the environment.

**Sensing harmful contaminants**: Using synthetic biology, organisms could be constructed to detect harmful bacteria like E. coli, or to detect chemical pollutants in the soil, air, and water.

Dr. Prather's research, focused on the **development of biofuels**, is generally appreciated by participants as a positive development, both in terms of the potential to reduce of emissions and impact climate change and its ability to reduce America's dependence on other nations for fuel. Some participants are skeptical of the genetic engineering of plants that is involved in this application. Indeed, there is a lingering concern expressed by some about GMOs, and their comments suggest it is important to be clear that the plants modified for this application are not for human consumption.

"It will cut costs and lower the cost and give the natural resources a chance to replenish themselves for later uses." –Baltimore non-college graduate

"Excellent ideas. If they work then we can reduce our dependence on other (hostile) countries for oil. Reduced emissions is also a nice extra benefit." –Baltimore non-college graduate

"Anything that has a chance of reversing the climate crisis is worth a try. I love this plan." –Baltimore non-college graduate

"Positive for the environment, for humans I would want to learn more." –Baltimore non-college graduate

"That sounds like a good potential solution to one of the largest issues we face." –Baltimore college graduate

"Never made before? How and on whom will it be tested? Not activated until processed? Will it not spread #2 climate change? Could reverse more 'bad things' that it would create. Cost-benefit analysis." -Baltimore college graduate

"It addresses the environmental concerns with regards to oil emissions, and the problems of oil dependence, but makes changes to our food supplies?" –Baltimore college graduate

"Car thing sounds good. I do not think we should mess with plants though. We already know the harm chemicals do to us." -Baltimore college graduate

"Cool – using natural sugars and foods to power vehicles? Awesome. But I do not want to eat it. It is putting it in my body that scares me." -Baltimore college graduate

"Do not mess with plants for this purpose. A switch may flip that makes this barrel out of control. We are already seeing signs of negative feedback with Monsanto. Those dinosaurs died for a reason." –Baltimore college graduate

The concept of using synthetic biology to **develop new ways to clean up the environment and detect harmful contaminants in the environment** is something that generates both excitement and concern. They wonder what the effects of introducing new microorganisms into the ecosystem would be. There is some wariness of creating new problems with solutions to existing problems.

"I really like cleaning up the environment . . . if we can, anything that makes industry cleaner. And, I mean, like it occurred to me after reading this, you could totally do that in theory. Bacteria could just eat some of this bad stuff, and you just grow that, and wherever the smoke is belching out, and they just consume it. So and, I mean, like I said, I don't know how close we are to that, but it's worth looking into, I think." –Baltimore non-college graduate

"But then what happens to them? Like do they grow because of this? Or do they just die off? Do you have to clean them up after?" – Baltimore non-college graduate

"And then cleaning up the environment, one of my concerns with that is what he was talking about with cleaning up the oil, you know, whatever they were using to do that, what would be the long-term effect with having those newly developed things in the environment? Kind of like looking at the long-term plan, like he was saying, you know, that might be good right now, but how's that going to impact the environment in the long term? Is that something that's just going to like fade away or get into other things and alter those, and then we have to come up with something else to fix that?" –Baltimore college graduate C) <u>Applications that generate the most concern</u>: Using synthetic biology to modify the DNA of brown rats in the United States or to develop naturally occurring chemicals such as flavorings and artificial sweeteners mainly elicit uneasiness. While the benefits of controlling the brown rat population may be appealing, it is not clear to participants that the benefits trump the risks. On the other hand, participants generally do not feel that it is necessary to create synthetic versions of food flavorings or artificial sweeteners and they have real concerns about human consumption of these outputs.

#### Synthetic Biology Application That Generates The Most Concern

**Control brown rat population**: The brown rat is an invasive species in the United States that is viewed as a disease-spreading pest in large cities, but which occurs naturally in Europe. Scientists have found a way to use synthetic biology to modify the genes of animals so that brown rats only produce female offspring, which would reduce breeding and control their population in U.S. cities. However, if this genetic modification spread to the European brown rat population, the scientists could introduce a second modification to allow the rats to breed normally again.

*Chemicals*: Scientists are increasingly able to develop naturally occurring chemicals using synthetic biology, including flavorings like vanilla and citrus, artificial sweeteners, and key ingredients in household products like paint.

While these participants have no love for brown rats and there is a general preference for ridding our cities of them in the abstract, many participants are wary of the unintended consequences of **altering the DNA of brown rats**. What will it do to the food chain and the cycle of life? Their comments also reveal their concern of the slippery slope when it comes to altering the DNA of animals – where will it stop? Will this extend to altering human DNA to design for specific traits or characteristics?

"It gives me a weird feeling messing with genetic modification . . .I just don't like messing, there seems, I don't know. Maybe there's another way of controlling the rat population. It just seems kind of strange, I don't know. It seems like a, I don't know how to describe it, like a science fiction movie or something." -Baltimore non-college graduate

"It's almost like we don't have the right to do it. . . And they talk about reducing, it's not going to reduce the population if it truly does what it says it's going to do. It's going to eliminate it. I mean, so, and then to create another modification for them to be able to breed, it's just messing with stuff we shouldn't mess with." -Baltimore noncollege graduate

"Because I don't think we have the right to genetically modify grains, animals. I mean, I know they are rats, but what's next? I mean, I just, you know, if people don't like a certain color of cats, are they going to do that too? I mean, I just don't like messing with it." – Baltimore non-college graduate "I'll look at what eats rats? Okay. So if there's no rats for that animal to eat the rats, what are they eating then? What's it eating then?...You start this cycle....You find it cycles. But where does it, what's the downstream effect?" -Baltimore non-college graduate

"Oh, I was just going to, I was thinking of Jurassic Park . . . with the phrases they say, something will find a way or . . . Life will find a way. It just seems like, yeah, they will evolve. And it just came to mind that thing in Jurassic Park, so . . ." –Baltimore non-college graduate

"I don't really have any strong feelings about it, like I wouldn't really mind them doing it that much as long as like we knew that it worked. But, on the other hand, I just don't see rats as that big a problem. So I feel like the risks, the gains should justify the risks." -Baltimore non-college graduate

"Okay. Let me say this. I do not like rats. But I'm not in agreement with this, with modifying their genes to produce only female offspring...Because it's like unnatural." –Baltimore college graduate

"I have more questions than comments. What would the affect be on animals that fed on the rats? Which is probably, you know, feral dogs and cats in the city. And how long to reverse, they noted reversing the first initial modification with the second one? My question is, well, how long is it going to take to reverse the first one? I mean, it's, chances are it's not going to be immediately, so how long is that going to linger before it'll reverse back? And by that time, will we have another problem we've got to reverse?" -Baltimore college graduate

"Well, I said, what if a good old American rat decided to have a good time with a female rat that's modified, what offspring would they have, and what new diseases could develop because of that? I don't know. It sounds dangerous to me." –Baltimore college graduate

"My thing is reconstruction of DNA, I mean, if you can do that in a rat, you can do that in a human. This is reconstructing the DNA. That's messing with peoples' genes, and like you said, turning into Frankenstein. I can just, I just want boys, so shoot me up. I just want boys. I want to bear boys. Okay. I don't want to bear girls, you know, so here we go." -Baltimore college graduate

"I just see, yeah, it's just that the problem, and, yeah, just wanting boys or just wanting girls, if you then got involved with humans, you just want skinny humans not fat humans. I mean, you know, those with blue eyes, those that are, it's, you're just getting way, way scary." –Baltimore college graduate Another application that generates a lot of criticism and concern is using synthetic biology to **develop** "naturally occurring chemicals using synthetic biology, including flavorings like vanilla and citrus, artificial sweeteners, and key ingredients in household products like paint." The discussions reveal that participants are not so much concerned about developing synthetic ingredients for paint as they are about developing synthetic food additives that humans would ingest. When it comes to vanilla, there is a sense that we have what we need and so a synthetic version is not needed – it would create a potential risk for no good reason. The discussions reveal that many of these participants already have concerns about existing artificial sweeteners, so they are not excited about creating new versions.

"I think, well, it seems good again, except the last one. I just think that it takes years to figure how these things are developing, from breeding cancer or things in our body. So I would be really careful about consuming the chemicals that they create with it. Maybe some things chemical-wise would be good. But I don't think ones for consumption would be good, because we would need years of studying to figure out.

We need years of studying the reaction of the chemical in the human body to know. I mean, they could come up with something tomorrow, and it could be great. And then the whole generation is going to get a certain kind of cancer from it. So I would be real leery about the chemical use in humans." –Baltimore non-college graduate

"These things seem like they're doing good already. Why would they mess with it? Maybe the paint could have different chemicals in it, but vanilla seems fairly healthy, you know." –Baltimore non-college graduate

"Artificial sweeteners already . . . [are] messed up." –Baltimore noncollege graduate

"They're already saying you will get cancer from them [artificial sweeteners]." –Baltimore non-college graduate

"I love A, B, C, and D. E really bothers me, because we hardly need any more synthetic or artificial things that we're ingesting in our own bodies on an everyday basis. Like why would you want to do artificial flavors like vanilla? Why? I mean, I'm all about eating the natural products and trying to eat organic, and it's like, okay, do we really need, is there a shortage of vanilla bean, you know? . . . But if it is, I will leave off vanilla. I just won't use it." -Baltimore college graduate

### **Hart Research Associates**

5. There is a clear and strong desire for full study and monitoring of potential risks of synthetic biology – particularly potential unintended consequences, but these participants do not have a strong sense of what the structure of oversight for this field of research should be. While there is skepticism of various parties who may have a vested interest in the furthering of synthetic biology, there is also recognition that it is important that those overseeing this research be knowledgeable about it. Thus, these audiences see a role for a variety of entities in overseeing advances in synthetic biology.

The discussions repeatedly come back to concerns about unknown and unintended consequences of applications developed using synthetic biology. Risk mitigation is deemed critical, and these participants indicate at least some confidence in a variety of bodies to oversee it.

The preference is for oversight to be in the hands of experts in synthetic biology who do not have a vested interest in applications, but these audiences recognize the challenge in finding such individuals. Thus, their solution is to see a role for a variety of entities.

Participants have the highest levels of confidence in scientific bodies (e.g. The National Science Foundation), university scientists and researchers involved in developing applications using synthetic biology, and NGOs and watchdog groups to maximize the benefits and minimize the risks of synthetic biology. While many are skeptical of the federal government's effectiveness or motivations, some see a role for the federal government to play in terms of independent oversight – though as part of a broader panel involving the groups previously mentioned. There is greater skepticism of companies playing an oversight role, given the belief that they will be mainly driven by potential profits of bringing new applications to market. These audiences have very little confidence in the U.S. Congress playing a role in oversight.

"I don't want the government just, I don't want just, you know, the researchers or just the EPA, or whatever. I want somebody from each of them, get in a room and, yeah . . . And there can be, you know, there can be people on the board like part of the companies. But then there should be something to offset that. You know, everyone's interest should be represented in the panel that's designing." -Baltimore non-college graduate

**Role for University Scientists and Researchers:** 

"I think I would definitely trust them of, with handling risk, because they don't really have, I mean, I don't want to say they don't have a monetary interest in, you know, what's going on, because I'm sure they're getting grant money and all sorts of things for it as well, but I feel like they're not, they're more of a third party that can take an outside perspective of looking at things." –Baltimore college graduate "I think that, yeah, they are investing in it to develop it, or whatever, and they want to get funding. But when you're, I think scientists, in general, want it to be righteous, I'm thinking, you know. So I think they would be a good source to make sure it's on the up-and-up." -Baltimore non-college graduate

"They know what's going on. They know what's out there. They, there's a whole reason they are doing it, and they want it to be, to work. They don't want to put their product out there that they spent years investing in and trying it out just so they can get a name, because they are not going to get a name unless it works." -Baltimore non-college graduate

"What I like about the university scientists and researchers, they're all spread out. It's not one central little body that holds the key, you know. That's what I like about it." –Baltimore college graduate

**Role for Scientific Bodies:** 

"Same reason as before, that they have their hands in it. That's what they do every single day. They see what other people are making, they do research just to figure out what needs to, what do we need to be made right now out of this engineering, bioengineering?" -Baltimore non-college graduate

"Because that's a panel that's made of up like your top scientists and people who regulate it, and they want to see that their results are accurate. And, you know, there's a little more scrutiny. They scrutinize other scientists' work." –Baltimore college graduate

"I just think you need that independent group that has no, you know, vested interest in any of the companies that are doing the research, to kind of be a watchdog over them." –Baltimore non-college graduate

**Role for NGOs/Watchdog Groups:** 

"I think that that would be the best, you know, if you had to pick from someone here, that's . . . Because they're independent, because they probably want a combination of what's best for the people in the country individually, and companies, if they produced a good product, have a right to, I just think that they are very neutral." –Baltimore non-college graduate

#### **Role for Government:**

"Oversight seems to me to be kind of like one of the main things the government is for, I mean, on our behalf, as the people. But as for like what, which part of the government, it really depends on the application, individual application. So like for medicine, you would have like the FDA or other medical things. And for like the, for the like the thing in Clip 2 with the . . . biofuel, you would have like the EPA, for instance, like regulating that and overseeing it." -Baltimore non-college graduate

"I just think that the government is trying to control everything way too much. And so if they have the power, which I believe that they do in this case, then they can do whatever they want." -Baltimore college graduate

"Basically, my concern is that we've got so much corruption in the government that, you know, the basic laws are not even really being followed right now." –Baltimore non-college graduate

"Because you've got lobbyists and you've got ulterior motives that I can't even imagine going on behind the scenes for what does and doesn't get approval. I just don't know if I would put in the hands of a government agency." –Baltimore non-college graduate

**Role for Companies:** 

"It's like the fox watching the hen house. I mean, they are the ones that went to, I mean, they're probably decent companies, and they're working hard. But somebody else should be deciding, after they have come with their product, if it's successful or not. I mean they can't judge themselves." -Baltimore non-college graduate

### **Neural Engineering: Key Findings**

# 6. Similar to synthetic biology, neural engineering is not a field of scientific or medical research that these audiences have heard of, but they form ideas and thoughts about it based on the terminology.

No one in either group was familiar with neural engineering before beginning the conversation about it. When asked what words or phrases they associate with it and what they think it is, participants think of general neuroscience and brain-mapping, as well as the improvement of brain functionality and the rebuilding of brain cells and nerves.

# **Hart Research Associates**

Following are some of the words and phrases that come to participants' minds when they hear the term "neural engineering," as well as selections from the descriptions participants wrote down before they were informed with a definition of the term.

- Brain function
- Brain mapping
- Neuroscience
- Neurons
- Engineering the brain to control certain functions
- Brain repair/brain restructuring
- Increased cognitive functioning
- Synapses, neurotransmitters
- Curing epilepsy, Alzheimer's, Parkinson's
- ✤ Engineering brain cells
- Changing the functionality of the brain
- Determining what areas of the brain are defective
- Manipulation of certain brain functions
- The rebuilding of damaged parts of the brain by reprogramming brain cells
- Working with the brain, changing transmissions
- Creating something artificial or jumpstarting neural pathways to create synapses between neurons to allow people to move or have sensations that they could not have otherwise
- 7. After hearing a description of neural engineering (see Appendix F), both audiences speak positively and hopefully about the possible benefits of developing this field of science, especially as it relates to helping individuals who have lost certain functions due to an injury or disease. Unlike the discussions about synthetic biology, participants focus almost exclusively on the benefits. There is a general belief that the potential benefits of neural engineering will outweigh the potential risks.

There is a sense that this type of development serves to help people become fully functional or "whole" again, without changing any natural order. The applications that participants are later exposed to during the sessions only fortify these perceptions.

The discussions about neural engineering are noticeably less nuanced than those about synthetic biology because participants see few downsides to neural engineering. To the extent that there may be risks, they feel they are minimal and contained to the individual who chooses to receive a specific treatment. And given the potential that these applications have to improve the lives of people with severe disabilities, there is a strong belief that individual patients should have the option to choose this treatment if and when it becomes available. "I mean, why would you not? I mean, if somebody had a car accident or was in the military and, why would you not want them to have this? I think it's great. I think it sounds wonderful." -Baltimore college graduate

"Yeah, controlling like prosthetics, prosthetic limbs with your brain, that's awesome. That's super cool." –Baltimore non-college graduate

"And like life-changing for the people that need that." -Baltimore non-college graduate

"I said, keep improving, especially for the troops coming home, because I think the brain is like a frontier we don't know enough about. And there's a lot of, I think there could be a lot of research and a lot of good come out of it." –Baltimore non-college graduate

"It's not making more. It's just making people back to being whole. It's not making them do something that they weren't capable of before that others aren't capable of. It's just trying to get them to the normal functioning level that the rest of us are." -Baltimore non-college graduate

8. Reactions to the specific neural engineering applications provided are similarly positive. Participants in both groups express their desire for more research and advancement in the field based on the possibilities these cases raise. Neither of the two applications raises the same concerns that come up when discussing synthetic biology.

#### **Neural Engineering Applications**

Some patients lose normal functioning of an arm or leg from an injury to the spinal cord or large nerves. The information from a person's brain can no longer make its way to the muscles in the arm or leg. Scientists are working on a way to bypass injured areas by letting the brain "talk" directly to the arm or leg. This would involve a neural implant or sensor placed directly in or on the brain by surgery that could send signals wirelessly to sensors in the arm or leg. The sensors in the arm or leg would use the information from the brain to stimulate the arm or leg to move. Following extensive patient training on using the system, information from the brain, including the person's thoughts, could be used to control the arm or leg and help the person regain some function (such as walking or grabbing objects).

Some individuals with permanent partial or total body paralysis might be able to use a detached robotic device to perform tasks that would usually require someone else's assistance. This would involve a neural implant or sensor placed directly in or on the brain by surgery, so that the brain could "talk" electronically with the robotic device. After the patients receive extensive training, information from the brain, including the patient's thoughts, could be used to control the robotic device. For example, a user's desire for a drink of water could signal a robotic device to bring a glass of water or a user's intention to move around the room could be used to control an electric wheelchair.

"I think it's amazing. It's just like that's the beautiful stuff that humanity can bring to help people to be able to do things like that. That's what it's all about. Right?" -Baltimore college graduate

"Amazing. Amazing, the, Case Number 2 I think is just, I mean, it definitely can happen, like Christopher Reeves, people moving around in their wheelchairs without any, the stuff. But it's just so crazy. And it's really cool that technology is advancing that much to be able to help people, so they can basically telepathically get their water." -Baltimore non-college graduate

"It allows people to have more independence instead of relying on somebody else to, you know, wait on you hand and foot, because you're, you have a disability, so I think it alleviates some pressure on both ends." –Baltimore college graduate

"Anything that can help someone regain function is a positive thing." -Baltimore non-college graduate

"Like the first case, I cannot imagine how this could be anything but good. I hope it pans out." –Baltimore non-college graduate

"This would be a wonderful concept to help the person feel more independent. I feel as though they have a use for this on a larger scale." -Baltimore non-college graduate

The concept of individual choice is a clear distinguishing factor between neural engineering and synthetic biology, which both audiences raise. For example, if it is possible for a paralyzed or otherwise disabled individual to choose neural engineering as a treatment, they embrace giving individuals this option. Participants support the idea that an individual can regain normal functioning, their independence, and other basic human skills they may have lost, and there is no potential risk they can think of that would undermine this fact.

Participants feel that since the individual can weigh the potential benefits and risks to them personally, there is little concern about any large-scale adverse consequences. This level of acceptance was absent from discussions of synthetic biology which was sometimes being applied on a macro level and involved modification of the DNA of a plant or animal which raised concerns about the impact future generations. Even when specifically asked about the potential for hacking into the wireless system of applications involved in neural engineering, participants are not particularly concerned, as the upside potential was deemed overwhelmingly positive. "You could also choose to use it or not use it. If you decide that it has some kind of negative effect like, oh, well, I can get feelings in my finger now, but I'm having terrible dreams at night because of it, you could say, you know what, it's not worth it to me, and you can consciously choose not to do it. When you're injecting yourself with something in the other scenario, there's no turning back from that." -Baltimore college graduate

"I thought all of it was good and how it would basically help a person regain something they lost, regain independence. I think it would be wonderful. A lot of people, when they lose independence, they feel less than a person sometimes. And it would help them regain their independence and help them live a much happier life." -Baltimore non-college graduate

"I mean, the only malicious thing is somebody like hacking into the wireless system and making me take a bunch of drinks of water that I don't want, you know. But, I mean, like, I feel like, I mean, we laugh, but I know it's a possibility, but I still feel like I would rather slap myself 100 times and be able to like take a drink of water for myself. I mean, I don't know who's going to hack into like some handicappers and ..." -Baltimore college graduate

Minor concerns about neural engineering were raised in the non-college-educated group. A few participants worry about how this technology will be administered to the people that need it. The worry is that there will not be equitable access to it and that the benefits will only be available to the select few who can afford to pay for it.

"Participant 1: Right. I would be concerned about who isn't getting it, if it becomes a money thing or insurance thing. But that's a whole different . . .

MODERATOR: So it would be equitable in terms of access to the ...

Participant 2: I would want it affordable.

Participant 3: We'll get there probably."

-Baltimore non-college graduates

#### Appendix A

#### **Overview of discussion focused on synthetic biology:**

- Query group on awareness of synthetic biology and ask for images and associations that come to mind.
- > Show video introduction to synthetic biology; participants discuss reactions.
- Provide written description of synthetic biology (see Appendix B); participants discuss reactions.
- Provide handout with five potential general applications of synthetic biology (see Appendix C); participants discuss reactions.
- Provide handout with descriptions of two specific applications for synthetic biology (see Appendix D); participants discuss reactions.
- Show videos of two scientists discussing the applications for synthetic biology that they are pursuing (Christina Smolke and Kristala Prather); participants discuss reactions.
- Inform group of recent development in which scientists at John's Hopkins University unveiled the first completely synthetic yeast chromosome; participants discuss reactions.
- Provide handout with various entities that could play a part in regulating advancements in synthetic biology (see Appendix E) and ask participants to indicate their level of confidence in each one to manage potential risks related to synthetic biology. Participants discuss ratings and confidence in each entity.

#### **Overview of discussion focused on neural engineering:**

- Query group on awareness of neural engineering and ask for images and associations that come to mind.
- Provide written description of neural engineering (see Appendix F); participants discuss reactions.
- Provide handout with descriptions of two specific applications for neural engineering (see Appendix G); participants discuss reactions.

#### **Appendix B**

#### Handout given to participants defining synthetic biology:

#### WHAT IS SYNTHETIC BIOLOGY?

Synthetic biology is the use of advanced science and engineering to construct or redesign living organisms—like bacteria—so that they can carry out specific functions.

Synthetic biology is an emerging field which combines biology with the principles of engineering in order to build new organisms. Synthetic biology involves engineering the genetic code (i.e., the DNA) of plants and animals to give them new or improved properties. In the past, genetic code has been modified through selectively breeding plants or animals and through genetic engineering. But while traditional approaches to genetic engineering use material from existing living organisms, synthetic biology can lead to the construction of new, man-made genetic material from scratch. This new genetic code can be constructed on a computer and from laboratory chemicals.

#### Appendix C

# Handout given to participants outlining five general applications for synthetic biology:

- a) Drugs for treating disease: American researchers have modified singlecell organisms using synthetic biology to produce an anti-malaria drug at a tenth of the cost of the current drug.
- **b)** More effective ways to treat disease: Researchers are using synthetic biology to re-engineer white blood cells to be stronger than naturally occurring cells and to help fight leukemia tumors.
- **c)** Sensing harmful contaminants: Using synthetic biology, organisms could be constructed to detect harmful bacteria like E. coli, or to detect chemical pollutants in the soil, air and water.
- **d)** Cleaning up the environment: Using synthetic biology, researchers are working on constructing micro-organisms that could be used in factories to remove pollutants before they are released to the environment.
- e) Chemicals: Scientists are increasingly able to develop naturally occurring chemicals using synthetic biology, including flavorings like vanilla and citrus, artificial sweeteners and key ingredients in household products like paint.

#### Appendix D

# Handout given to participants outlining two specific applications for synthetic biology:

#### **APPLICATION 1:**

Squalane is a key lubricant for skin care products, including moisturizers, sunscreens, eye makeup, lipstick and foundation. It is also an ingredient in some vaccines. But one key source of squalane is the livers of deep-sea sharks: It is estimated that around 3,000 sharks are needed to produce 1 ton of squalane. While there are also botanical sources of squalane like refined olive oil, California company Amyris has found a way to use synthetic biology to produce squalane from crushed sugarcane. The company is now producing the product in a facility in Brazil in a joint venture with Soliance, a French ingredients supplier that sells the product to brand-name makers of skin care products and cosmetics. It is also sold as luxury oil.

#### **APPLICATION 2:**

The brown rat is an invasive species in the United States, but occurs naturally in Europe. In large cities, the rats are viewed as a disease-spreading pest. Scientists have found a way to use synthetic biology to modify the genes of animals, which could help control their population in U.S. cities: The modifications, for instance, could make it so brown rats only produce female offspring, which would reduce breeding. However, if this genetic modification spread to the European brown rat population, the scientists could introduce a second modification to stop the initial modification and allow the rats to breed normally again.

### Appendix E

# Handout given to participants listing entities that could play a part in regulating advancements in synthetic biology:

Α	U.S. Federal Government Agencies, such as the Environmental Protection Agency and Department of Agriculture
В	Companies that are developing applications using synthetic biology
С	University scientists and researchers involved in developing advances in synthetic biology
D	Scientific bodies or panels such as the National Science Foundation
E	NGOs and Watchdog groups such as the Sierra Club
F	The U.S. Congress

#### Appendix F

#### Handout given to participants defining neural engineering:

#### WHAT IS NEURAL ENGINEERING?

Neural Engineering is the use of engineering and brain science to build devices that restore or improve human functioning.

Neural engineering is an emerging field which combines the science of the brain and nervous system with the principles of engineering in order to build devices to substitute for or assist with human functioning. Devices may sense how the brain or nerves are working and communicate this information, or they may stimulate the brain or nerves to work in certain ways. Some devices are worn on the outside of the body and some are implanted in or near the brain or nerves.

Most devices are designed to help people who have lost some function due to brain or nerve damage. For instance, people who have lost partial functioning of an arm or leg may have devices that stimulate the brain or spinal nerves to help restore function. Or people who have lost all function of arms or legs may have devices that sense brain or nerve signals and use this information to control other devices, like a computer cursor or a robotic hand.

#### Appendix G

# Handout given to participants outlining two specific applications for neural engineering:

**Case 1.** Some patients lose normal functioning of an arm or leg from an injury to the spinal cord or large nerves. The information from a person's brain can no longer make its way to the muscles in the arm or leg. Scientists are working on a way to bypass injured areas by letting the brain "talk" directly to the arm or leg. This would involve a neural implant or sensor placed directly in or on the brain by surgery that could send signals wirelessly to sensors in the arm or leg. The sensors in the arm or leg would use the information from the brain to stimulate the arm or leg to move. Following extensive patient training on using the system, information from the brain, including the person's thoughts, could be used to control the arm or leg and help the person regain some function (such as walking or grabbing objects).

**Case 2**: Some individuals with permanent partial or total body paralysis might be able to use a detached robotic device to perform tasks that would usually require someone else's assistance. This would involve a neural implant or sensor placed directly in or on the brain by surgery, so that the brain could "talk" electronically with the robotic device. After the patients receive extensive training, information from the brain, including the patient's thoughts, could be used to control the robotic device to bring a glass of water or a user's intention to move around the room could be used to control an electric wheelchair.