# 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, gene-editing 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.

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## 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.

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## 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.

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## 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.]