Editing Our Evolution: Rewriting the Human Genome

Introduction

We're glad you're thinking of hosting the "Editing Our Evolution: Rewriting the Human Genome" forum! A forum is an event where participants have a chance to learn about a topic and then engage in a guided conversation and make a plan of action. In this case, the participants are both scientists and members of the public, the topic is potential human applications of gene editing technology, and the plan is whether and how to pursue these applications. Participants get the chance to practice critical thinking skills and apply them to a real-world socio-scientific issue.

This document contains instructions for hosting the forum, including tips on how to make it welcoming and engaging to different types of participants. In this document, you'll find:

How to Do It: Quick Start Guide

The following is a quick start guide for running this event. This section will give you the highlights, but it's best to read through the entire packet before getting started preparing to run the forum.

1. This forum is intended for audiences ages 16 and up. It is intended to take two hours.

2. The program is as follows:
    a. Welcome, 5 minutes
    b. (Recommended) Video or speakers (see below), 30 minutes
    c. Introduction, 5 minutes
    d. Scenario 1, 25 minutes
    e. Scenario 2, 20 minutes
    f. Scenario 3, 15 minutes
    g. Report Out, 10 minutes
    h. Survey, 5 minutes

3. (Recommended) You may want to use a presentation to kick off your conversation and give your participants some background information. If so, your options are:
    a. Recruit one or two local scientists to speak on the topic. If you want to invite a speaker, make sure to give them plenty of time to plan ahead. Give them some idea of what you'd like them to cover (e.g. methods for human genome editing, what applications it enables, what current applications are being developed, a brief history of genetic modification and gene therapies, somatic vs. germline editing, CRISPR/Cas9, where this technology could go, societal questions, ethical questions, considerations for policy, what questions arise when thinking about regulation, and what is the role of citizens in this process, etc.). When choosing speakers, keep in mind not only their area of expertise, but also their comfort and style in speaking to a group at a level appropriate for a general audience to understand. If you get two scientist speakers, it can be good to split up their topics so that one covers the scientific background and the other covers the societal and ethical questions. Make sure they understand how long they have to speak and that you will cut them off at that time. Ask to see their slides in advance to make sure they're at an appropriate level for your audience, and be prepared to help them adjust the slides if needed.
    b. Or, choose one or both of the videos chosen from the options below:
        i. What Is Gene Editing and How Does It Work (4:22)

            https://www.youtube.com/watch?v=XPDb8tqgfjY

        ii. Genetic Engineering Will Change Everything Forever (16:03)
            https://www.youtube.com/watch?v=jAhjPd4uNFY

If you want to use either of these or any other video, make sure you watch it before showing it to your participants.

4. The following materials should be placed at each table before the conversation gets underway. If you need more copies of the materials, you can find digital copies on the thumb drives included in your materials box.

    a. Individual Packet (6 pages, double-sided, 8.5"x11"). Put one copy per person at each table.

    b. Group Question Sheets (6 pages, single-sided, 8.5"x11"). Put one copy of each at each table.

    c. Table Sign (1 page, double-sided, 8.5"x11"). Put one copy at each table, ideally in a sign holder.

5. During the forum, you should follow this process:

    a. Divide participants into groups of no more than eight and no less than four (groups of six are ideal). Try to get a mix of scientists and members of the public at each table. Remind the scientists ahead of time that they are there to participate, not quiz the other participants.

    b. Read the introduction script included in the guide. Feel free to use this as is or modify it.

    c. Share the agenda for the forum using the Agenda slide in the Conversation Countdown Slides.

    d. (Recommended) Introduce the topic and the speakers, if applicable.

    e. (Recommended) Show the video(s) or have the speakers speak.

    f. Have the groups start following the instructions on the front page of the individual packet (i.e. have the group members introduce themselves and read the scenario, etc.). Once you've started the process, the groups should mostly be able to facilitate themselves, although table facilitators can be helpful (see the Possible Variations section for more details). Start the Conversation Countdown Slides. During the conversations, you (and the speakers, if you have them) can go from table to table to check in, answer questions, and make sure the groups understand the process.

    g. Help groups stay on time by reminding them to move on to the next step at the appropriate time. The Countdown Slides will advance automatically, but verbal reminders are still helpful and are included in the notes field of the slides.

6. At the end of the time, have one person from each table report out to the rest of the group about the most interesting thing that came up in their discussion. Ask each table to take no more than 30 seconds. If you have speakers, they can share some final thoughts after the tables report out.

Learning Goals

1. Although changing the genes of an organism has been possible for a long time, new human gene editing technologies present inherent risks, opportunities, and benefits for different people.

2. Everyone has valuable perspectives and views to add to the conversation. Understanding these perspectives help scientists make better decisions in their research.

3. Scientist participants will learn about the diversity of public views on the topic of human gene editing.

4. Non-scientist participants will learn about the potential applications of human genome editing and the societal and ethical questions raised by these applications.

Materials

- o Editing Our Evolution Guide (this document)
- o Individual Packets
- o Group Question Sheets
- o Table Signs
- o Conversation Countdown Slides
- o Forums Manual (Download from BuildingWithBiology.org/forums)
- You will also want to provide:
  - o Pens
  - o Paper for taking notes

Tips and Tricks

- General
  - o Designed for ages 16+.
  - o Many museums have found that it works best to hold the forum as a separate event from the museum opening hours, and evenings often work well. It's a different target audience, and having it at a separate time means adults won't be there with their children. Another option is to provide an alternate activity for children so that their parents can participate.
- Preparation
  - o Watch the videos yourself before the event, so that you are more familiar and comfortable with the topic and able to answer some questions. The videos are

helpful to give background information to participants and give them some shared reference points. Using the videos (or speakers) is strongly recommended and is generally worth the time it adds to the event.

- o It is helpful to do a practice run of the forum, whether or not you've run one before. You can do this by gathering a small group of staff and/or museum volunteers (even a group as small as 4 will work), in as little as an hour to an hour and a half. During the practice run, you can familiarize yourself with the format, materials, and goals of the forum. You will feel a lot more confident on the day of the event if you've had a chance to do a practice run.

- Recruitment

  - o Marketing is important. Forums work best with a diverse audience with varied viewpoints. Make sure you spend time letting people know that the event is happening.

  - o In your advertising, you may want to let people know that the event lasts for two hours. Sometimes attendees are surprised that the event is longer than an hour, if they are not notified in advance.

- Logistics

  - o It's best to have the event in a room separate from an exhibit hall.

  - o Round tables work well. Generally, the room setup has a number of round tables with chairs, a projector and a screen, and a podium for the host and the speaker, if there is one. For an example floorplan and photos, see the Forums Manual that is available on the website.

  - o Make sure tables aren't too close together, so that people aren't distracted by each other's conversations or reading aloud. Six people per table is a good number. Four to eight people works best. Fewer than four doesn't really work, and more than eight means that some people won't get to speak.

  - o Leave space at tables for latecomers, because there will be some.

  - o If possible, have refreshments for your participants.

  - o If possible, have a handheld microphone available for a person from each table to use during the report out, especially if your audience is older, or your group is large. A microphone enhances accessibility for everyone.

- Scientists

  - o Tell the scientists that at the forum, they will be participants, rather than facilitators. They don't need to do anything to prepare for the forum, because they will participate on the same footing as members of the public.

  - o Have the scientists identify themselves in some way. This can be writing on their nametag, a sticker, or having scientists raise their hands at some point during the introduction to the forum.

- It's best if you can get scientists who are familiar with synthetic biology techniques, but it can also be good to have scientists who are more familiar with the medical side of things.
- Remind the other participants that the scientists are not here to lead the discussion or teach the topic. They are participants as well.
- Put scientists at each table, if possible. Don't have them all sit together.

Possible Variations

- Preparation
  - You may want to find a speaker to give a short presentation on the topic of genome editing. If you are not able to host a speaker, we have provided 2 videos you can choose from. You can use either or both of the videos suggested, or find your own that are better targeted to the interests of your institution or audience. If your speaker is particularly specialized, you can supplement their talk with one or more of the videos.
  - If you had a chance to run a practice forum in advance, you may want your attendees from the practice run to facilitate at the tables of your event. They can help make sure the group stays on topic, that everyone gets a chance to speak, and that no one person dominates the conversation.
- Audience variations
  - For older or more hands-on participants, you can print extra copies of the materials so that each participant can have their own set.
  - You may want to run the forum with a group of youth. It's a great opportunity for them to meet scientists. Keep in mind that this forum works best with participants ages 16+, although 14+ can work. If you are collecting survey data from your participants, remember that participants under 18 can't complete the surveys.
- Logistics
  - If you want to reuse the materials, it will help to laminate them.
  - You may want to hold your forum offsite, if your institution doesn't have a way to hold after-hours events. One idea is a local makerspace. Other options are a community center or a library.
  - If you choose to hold the forum as an evening event for adults, you may choose to serve alcohol as part of the event. If you are receiving a stipend, it cannot be used to pay for alcohol.
  - If you choose not to use the Countdown Slides, you will need to periodically let people know about how much time they have remaining, and which part of the process they should be working on.

- If it's right for your audience, you can ask people who came together to split up among the tables so that they meet new people and share their views. Some groups will not like this, though, so be thoughtful about whether it makes sense for your group. You can also consider breaking up large groups of participants who know each other.

- Timing options

  - Things might take longer than planned. The overall event should take two hours, but if people have gotten engaged in the topic, they may want to continue their conversations after the event is over.

  - We've found that two-hour-long forums work the best for balancing getting enough people to show up with getting through the materials. Fewer people may sign up for a 2.5 or 3 hour event, especially in the evening.

  - However, if you think a longer event would work better with your institution, you can change the timing in certain ways.

  - Keep the 2 hour forum the same, but have only one, 15-minute speaker or video and add the remaining 15 minutes for speakers evenly to the three scenarios.

  - Have a 2.5 hour forum, and add between 5-10 minutes to each scenario with the remainder being distributed how you see fit to sections like speaker talks, share out, or opening comments.

  - We would recommend against adding too much time to speaker talks. One of the main purposes of this forum is to encourage interpersonal conversations and engagement between the public and scientists in a way where the public feels as though their voice has power and importance.

- Modifying materials

  - You may modify any of the materials to better suit the needs or interests of your institution.

  - You may modify the timing of the forum, for example to give participants more or less time to talk or to give a speaker a longer time to speak and answer questions. You can modify the Conversation Countdown Slides to fit your timeline.

  - If you choose not to have a speaker or video, you should remove that line from the Conversation Countdown Slides. If you have a speaker or video, update the slide to reflect your choice.

Preparation and Event Checklists

Before the event:

- Choose a date, and reserve a location
- Find and confirm speaker(s), if desired, and let them know logistical information
- Find synthetic biologists and other scientists to attend as participants
- Publicize the forum
- If desired, create a registration list for participants to sign up
- Make sure the space will be ready, including:
    - A/V equipment
    - Tables and chairs
    - Refreshments, if applicable
    - Lighting, climate control, and access to the room
- Make sure you have enough copies of the materials, and make more if needed
- Gather additional materials (pens and paper)
- Modify slides as needed
- Make signs to direct people to the location

Day of the event:

- Bring materials to the event location and put them on the tables, including:
    - Instructions Sheet
    - Personal Worksheets
    - Supplemental Information Sheets
    - Group Question Sheets
    - Table Signs
    - Pens and notepads for each table for taking notes
- Post signs directing people to where the event is being held
- Make sure the space is ready to use
- Test the A/V equipment and make sure the video plays with sound, if you're using one
- Put up the Countdown Slides
- Coordinate with the speaker(s) to get their slides up, if applicable

After the event:

- Clean up the materials and collect your pens and paper

- Collect the participant packets and mail them to the Museum of Science using the envelope provided

- If your site is receiving a stipend, collect the worksheets from each table and mail them to the MOS forums team using the provided mailing slip.

- Write a thank you note to your speaker(s), if applicable

Intro Script

(Speak Slowly!)
Have example materials with you to hold up.

[Slide 1] Hello and welcome to our 'Editing Our Evolution' forum at _____. My name is _____ and I'm excited that you're here today. We're going to be talking today about an interesting topic, human genome editing, and hopefully we'll have some fun, too. For those who aren't familiar with the format, a forum is a guided conversation that is informed by some scientific background information. At the end, we'll be asking for your opinions! We'll take your recommendations, combine them with those from other sites holding this same conversation, and share them with scientists who are working on this technology.

[Slide 2] Our agenda for the evening is pretty exciting. We'll be here for about two hours. [Recommended] *First, we'll [watch a video/hear from (speaker's name(s))] to get an introduction to the topic, and then we'll dive into group discussions where you will be considering three hypothetical scenarios about human genome editing.* [Otherwise]*We'll be having group discussions about three hypothetical scenarios about human genome editing.*

[If applicable, introduce first speaker or video]

[Slide 3] [If applicable] Thanks [speaker's name] for an informative presentation.

[If applicable, introduce second speaker or video to follow up first speaker]

[If applicable] Thanks [second speaker's name] for that great talk. Both [first speaker's name] and [second speaker's name] will be around during our conversations to answer any questions you might have. If you have any questions for them, please write them down and the speakers can answer them when they get to your table. We also welcome people to stick around after the program to talk about anything else that's on your mind related to this topic.

[Slide 4] Now I'll explain the process for our conversation. This forum is part of a conversation happening at more than 20 other institutions around the US this year, and it's designed to

encourage conversations about the important societal issues arising from advances in human genome editing.

This forum is based on the report on human genome editing written by the National Academy of Science committee on human genome editing. We've put together three hypothetical scenarios representing some of the most critical ethical and societal questions raised by human genome editing. You'll discuss the line between therapy and enhancement, issues of equity and access, and the difference between editing your own genome and editing the genome of an embryo that could pass the changes down through generations. The treatments described in the scenarios don't currently exist on the market. Some of them are likely to be available soon, while others are farther off. We hope that by working through these scenarios with your groups, you'll have a chance to share your thoughts about issues you haven't considered before.

[Optional] If you're sitting with people you came with, I'd like to invite you to mix up your tables so that you're sitting with people you don't know. But you're welcome to stay with your friends if you prefer.

[If people are unevenly distributed between tables] If you're sitting at a table with more than 8 people or fewer than 4, I suggest you take this opportunity to move to a table where you'll have four to eight people. This way you'll have the best chance for a good conversation.

I'd also like to have anyone who identifies as a synthetic biologist raise their hand. Because part of the point of this forum is to have scientists and members of the public learn from each other, I'd like to encourage you all to spread out so that you're evenly distributed among the tables. To everyone else, please keep in mind that synthetic biologists are also people! Their role is not to facilitate the discussion, but just to participate like everyone else.

[Slide 5] Looking on your table, each person should have an **individual packet** in front of them. On the front page is the **instructions sheet**, which we will all go over together in a moment.

The next few pages have the **scenarios** that you will be reading and discussing tonight as well as the questions that we'd like you to talk about and answer. Please fill out these sheets, as we'll be using your answers and the answers from all of the other locations that are hosting this event to help give scientists a better sense of how people feel about issues surrounding human genome editing.

The second to last page of the packet has an optional **demographic survey** that we ask that you fill out at the end of the forum. We'll talk more about this after you go through the scenarios, but this survey will help us understand how people are thinking about human genome editing.

And the last page in your packet has **supplemental information**, which you can look at if you want more information about any of the diseases, treatments, or other issues described in the scenarios.

Finally, your table should also have a set of **group answer sheets**. Some of the questions tonight ask you to come up with an answer as a group and write that answer on one of these sheets instead of your individual packet.

[Slide 6] Okay, now let's look through the instructions on the first page of the packet together.

Step 1: Introductions
We'll start by having each person introduce themselves including their name and what they found most interesting about [the introductory presentation][our speaker(s)].

Step 2: Scenarios
- For each scenario, start by having one person read the prompt at the top of the page out loud.
- Then, as a group, work through the questions below the prompt. Discuss each question as a group before you record your answer. Some questions ask you to record your personal answer in your individual packet, while others ask your to record your group's answer on the group answer sheets.
- When time is up for each scenario, the moderator will introduce you to the next scenario.
- Keep in mind, scenario 1 has two parts, so be sure to leave time to read the second prompt and answer the questions below it as well.

Step 3: Share Out
One person from each table will have 30 seconds to share the most interesting thing that came up in their group discussion. Don't worry about covering your entire conversation. Did anything surprise you? Was anything controversial?

[Slide 7] Before we get started with our first group discussion, I also want to establish some ground rules. This topic might feel controversial for some people, whether because of their faith or a personal connection, so we want to encourage respectful conversation as our top priority. There are no right or wrong answers and everyone's opinion is important, even if you haven't thought about this topic before.
Please:
- Respect others' opinions and ideas
- No interruptions – one person talks at a time
- Listen carefully to what others have to say
- It's ok to disagree with others
- Respect others' experiences and backgrounds
- Take part in the discussion
- Give everyone a chance to speak
- Keep comments brief and to the point

[Slide 8] This first scenario has two parts. The first part will ask you to put yourself into the position of a parent in the not-too-distant future, where human genome editing has allowed for a cure to Duchenne Muscular Dystrophy. In the second part of the scenario, you'll consider a more distant future where technology allows us to enhance physical abilities. For this and the rest of the scenarios you'll be discussing tonight, because the treatments don't exist yet, we don't know exactly how bad or how frequent the risks will be. However, for the purposes of this discussion, we ask that you assume these treatments have been approved by the FDA and have risks and side effects that are in the same range as traditional treatments.

We'll have slides up keeping track of the time as we go through the discussion. If your table runs into any issues, you can raise your hand and one of us will come over to help. Our speakers will also be available to answer questions. Are there any questions before we begin? Let's get started by introducing yourselves at your table and then reading the prompt!

[Start countdown slides]

[When there are 10 minutes left in scenario 1] We're about halfway through this scenario, so make sure you have time to move on to the second part of the scenario. In the first part of this scenario, we asked you to think about using gene therapy to cure a genetic disorder, but the second part is about how gene therapies could also be created to enhance certain genes in healthy people.

[When there are about 2 minutes left in scenario 1] We've only got a few minutes left in this scenario. Start wrapping up your discussion and writing down your answers.

[When Time's up for scenario 1] Time's up! Take a second to write down any final thoughts you have about this scenario before we move on.

In the next scenario, we'll be asking you to think about issues of equity and access that may come up as more gene therapies are developed. You'll be putting yourselves into the shoes of a person living with sickle-cell disease and discussing who should be responsible for providing access to life-saving gene therapies. You can have someone start reading scenario 2 now.

[When there are about 2 minutes left in scenario 2] We've only got a few minutes left in this scenario. Start wrapping up your discussion and writing down your answers.

[When Time's up for scenario 2] Time's up! Finish writing down your last thoughts before we move on to our final scenario for the night.

This next scenario brings up an important consideration when we talk about editing the human genome. Many potential gene therapies will cure a person's disease within their own body, but genome editing also offers the potential for changes that can be passed down from generation

to generation. This means it could be possible to completely eliminate certain genetic diseases and mutations, but it also brings up practical and ethical concerns about what it means to change genes in a way that could have impacts across generations. You'll be considering these questions by looking at BRCA mutations, which are major risk factors for developing breast cancer. Have someone read scenario 3 now.

[When there are 10 minutes left in scenario 3] We're about halfway through this scenario, so make sure you have time to move on to the second part of the scenario. The first part of this scenario asked you to think about a treatment that would only affect you, but part 2 is about the far-reaching effects of a treatment that could be passed down to future generations.

[When there are about 2 minutes left in scenario 3] We've only got a few minutes left in this scenario. Start wrapping up your discussion and writing down your answers.

Don't forget to choose someone to report out for your group. We'll all share our plans once we've finished our conversation."

Closing Script

(Speak Slowly!)
[Once groups have finished making their plans, when the Conversation Countdown Slides say "Time is up!"] And that's all the time we have for scenario 3. Finish recording your thoughts and then we'll go around and give each table 30 seconds to share the most interesting thing that came up in their group discussion. Does anyone want to go first?"

[After all groups have shared] Thanks to each of our reporters, and thanks to all of you for coming and putting so much thought into your plans.

[If applicable] "Do our speakers have any thoughts they want to share after hearing all of these plans?"

"Thank you for participating in today's forum! As part of this forum, the Museum of Science, Boston is collecting information on your answers to these questions and some demographic information to get a better idea of how people are thinking about the issue of human genome editing. To do so we'll be collecting the data from your individual packets, and we would also like you to complete a the 3-5 minute demographic survey on the second-to-last page in your packet. Your participation is voluntary, all your answers are confidential, and all the questions are optional. If you don't wish to participate, you may take your packet with you or throw it away.

Once you've completed this, you may leave the surveys on the table or hand them to myself or other staff in room as you leave. Please let me know if you have any questions and we greatly appreciate your help."

Thanks again for coming!

[If there are any logistical details to mention (parking, getting out of the building, etc.), you can share them here, or whenever makes sense for your audience.]

Related Resources

Included on the Building with Biology website (www.buildingwithbiology.org) is a general guide to public forums, called the Forums Manual. There are many more details there, including information on planning, preparation, setup, marketing, registration, facilitation, cleanup, and what to do after the forum is over.

There is also a guide to Public Engagement with Science, which can be found at http://publicengagementwithscience.org/.

The Building with Biology website has more resources for hosting this forum as well as evaluation resources and other project information.

The NISE Network website (www.nisenet.org) contains additional training resources to introduce participants to the relationship between technology and society and to have conversations with them.

Appendix

Sample points to mention in an email to scientists about the forum:

- A forum is an event where participants have a chance to learn about a topic and then engage in a guided conversation and make a plan of action. In this case, the participants are both scientists and members of the public, the topic is potential applications of gene editing technology, and the plan is whether and how to pursue these applications. Participants get the chance to practice critical thinking skills and apply them to a real-world socio-scientific issue.

- This forum is an opportunity for people to discuss different applications of human genome editing technology. This is an opportunity for a more in-depth conversation that takes approximately two hours. It's targeted at older ages (16+).

- During the forum, participants learn the basics about human genome editing and the related ethical and societal issues. Then, through the forum conversation, they get the opportunity to consider the viewpoints of others on the topic of various applications of this technology. Finally, participants form a plan about whether and how to pursue these applications using the information they learn, their background knowledge, and their values.

- Participating in the "Editing Our Evolution: Rewriting the Human Genome" forum is a way to interact with people with various backgrounds, ages, and experiences in a conversation about the ethical and societal implications of human genome editing.

Credits and Rights

Supplemental Information Sheet Images:

Sickle Cell: https://upload.medbullets.com/question/7109/images/risk-factors-for-sickle-cell-anemia.jpg

Muscular Dystrophy: http://www.jdshospital.com/wp-content/uploads/2011/03/Muscular-dystrophy-in-biceps.png

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