

Cells to Self - Formative Evaluation

The Ethics of Genetics Card Sort

Joyce Ma

February 2019

THIS IS NOT A DEFINITIVE FINAL REPORT

FORMATIVE evaluation studies like this one often:

- **are conducted quickly**, which may mean
 - small sample sizes
 - expedited analyses
 - brief reports
- **look at an earlier version** of the exhibit/program, which may mean
 - a focus on problems and solutions, rather than successes
 - a change in form or title of the final exhibit/program

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PURPOSE

The *Ethics of Genetics* is a multiuser exhibit developed to encourage visitors to reflect on some of the ethical issues that arise in the collection, analysis and use of genetic information. Visitors are given 10 cards, each with an opinion that speak to a current topic in genetics with some background information, and are asked to place each card into four bins: (1) *Strongly Disagree*, (2) *Disagree*, (3) *Agree*, and (4) *Strongly Agree*. This evaluation was conducted to identify:

- What visitors found worthwhile about the exhibit experience.
- Visitors' reactions and sensitivities about the genetic issues raised by the exhibit. We were particularly concerned with detecting any strong negative feelings the issues may trigger.
- Visitors' points of confusion about the cards.
- Suggestions visitors had for improving the exhibit.

The evaluation's findings serve to inform the design of the next iteration of the *Ethics of Genetics*.

METHOD

The Prototype

The exhibit prototype is shown in Figure 1. It consisted of a table divided into two halves, separated by a short vertical barrier. Each side had four marked areas labeled *Strongly Disagree*, *Disagree*, *Agree*, and *Strongly Agree*, and one set of 10 cards. The front of each card had a claim about an ethical issue in genetics, while its back gave some background information about that issue (Appendix A). We set up the exhibit next to the former VIM wall, a quiet area in the Cells to Self prototype corridor, and placed stools on each of the two sides of the *Ethics of Genetics* table to encourage visitors to sit, stay, and reflect.

Special Considerations

Because of the possible sensitivity of the subject matter, the evaluation protocol was designed to

- Respect the privacy of the participants. The evaluator made it clear during recruitment that she would not be collecting data on how strongly visitors agreed with the opinions on the cards. The evaluator also sat so that she did not see how the study participants sorted the cards.

- Allow visitors to opt out of the experience at any time. When the visitors were first recruited and throughout their exhibit experiences, the evaluator made clear that they could stop using the exhibit whenever they wanted to.
- Monitor the emotional temperature of the interaction. The evaluator also listened for any charged speech and was ready to end the interaction if visitors sounded upset.

Multiple role playing rounds were used to prototype the evaluation instrument and to help train the assistant evaluator who recruited and conducted the interviews.

Figure 1. The Ethics of Genetics Prototype.



Participants

An assistant evaluator stood near the prototype and approached every other adult visitor who (1) crossed a predetermined imaginary line and (2) was in a group of two or three where everyone appeared 13 years old or older. The evaluator asked that visitor and his/her group if they would be willing to try a new exhibit. Because of the mature content and potentially difficult material, we chose to recruit only teenagers and/or adult participants. At the end of their exhibit experience, one person was randomly selected for an interview (Appendix B). However, if that individual was not interested, we asked another person from that group to answer our questions.

The study collected data on three separate days in February (2/9/2019, 2/10/2019, and 2/16/2019), two Saturdays and one Sunday. The demographic information of the study participants is shown in Table 1. In total, evaluators talked with 31 visitors for this formative evaluation. A very large percentage was adult peer groups, and consequently, most of the interview respondents were adults.

Table 1. Demographics of study participants

Age Group	Count	Gender	Count	Group Type	Count
Adult	30	Female	18	Multigenerational	2
Teen	1	Male	13	Adult Peer	29
Total	31	Total	31	Total	31

RESULTS

What visitors found worthwhile

Table 2 summarizes what visitors found worthwhile about their exhibit experience. About one-third of the visitors thought the cards were thought provoking, while 29% felt that the exhibit helped instigate good conversations and one-quarter appreciated the chance to compare their opinions with each other.

Table 2. What visitors found worthwhile with example quotes.

Visitors found it thought-provoking (11/31, 35%)

Visitor3: Asked me some questions, made me think about some things. Pretty good

Visitor6: It's thought-provoking

Visitor11: think about talking about

Visitor14: just taking the time to think about it

Visitor30: Helped me to solidify some of my thoughts on this topic. While I don't think there was anything I hadn't considered, I hadn't thought deeply about some of these topics

They thought it instigated good conversations (9/31, 29%)

Visitor4: Great conversation starter to discuss these very complex issues.

Visitor11: I think it was [pause]. It's not something I'd normally talk about.

Visitor20: P1: I think bringing up topics like this, if you're talking to the right person who's not closed minded. There's a lot of good things to talk about [like] if we're advancing as a society. We can talk about it later after the exhibit is done.

Visitor28: it becomes really interesting to talk about

Visitors liked comparing their opinions (8/31, 26%)

Visitor7: I liked it because I saw that me and my partner have a lot of the same viewpoints

Visitor13: learning a little more about the other person

Visitor15: especially with 2 people, father and daughter. Interesting to see [what we both think]

Visitor25: Interesting, had to really compare with someone else

Visitors' reactions and sensitivities about the genetic issues raised by the exhibit

Three visitors had strong negative reactions to the exhibit, as described in our observation notes:

Visitor2 --- While s/he was doing the activity, s/he said "No opinion," in a fairly strong/assertive tone and didn't sort the cards – s/he seemed slightly upset or offended by the activity. S/he read them all but kept them in a stack in her/his hand. Her/his [partner/friend] did sort the cards onto the table, and s/he waited while s/he did so. S/he said to me (either before or after I was asking her questions, I don't remember when), "I feel like this is a social experiment [seeing what people think]" and she sounded uncomfortable with that idea.

Visitor24 --- P2 looked at a few cards and then stacked them and put them back and said s/he didn't want to do it. S/he sat at P1 finished up quickly

Visitor26 ---"Actually I don't want to do this." S/he sat while P1 finished. I asked for feedback and s/he declined to answer questions, even after I clarified that I was interested in all feedback, including negative.

Otherwise, visitors talked about additional sensitivities and concerns with the exhibit. These included feeling scared or anxious about the subject matter, being confused about the point of the exhibit, worrying about how the other person at the exhibit might react, finding the exhibit incongruous with the 'typical' Exploratorium exhibit, being put off about sharing very personal thoughts in a public space, and questioning the hidden agenda behind the exhibit. Table 3 lists these concerns and gives example quotes from visitors.

Table 3. Other sensitivities with example quotes.

The exhibit content made visitors feel anxious (8/31, 26%)

Visitor5: felt a little bit of anxiety...Because I believe in god and think that's up to our god and what he has already decided what the fetus will be instead of using science to determine gender... feels like we're messing with fire... feels very weird and wrong

Visitor6: Scary for the future.

Visitor22: P1: The questions. P2: It is a hot-button issue. P1: Super hot-button... I felt conflicted

Visitor28: I don't know how I felt about this one. Kinda scary - cool and all for advances in medicine, but kinda scary

Visitors wondered what was the point of the exhibit (6/31, 19%)

Visitor9: Does this lead to something or is it just asking my opinions about stuff? Is there going to be a study? ...What's the point? Wondering if it's meant to draw some type of conclusion. I don't know.

Visitor29: What's the goal for this one? Maybe someone who's super skeptical - where are my answers going, what's my [answers] used for?

Visitor31: I don't really know what it did.

Visitors worried about difficult social dynamics with their exhibit partner (5/31, 16%)

Visitor7: I don't know how it would feel if we were polar opposites

Visitor10: Probably matters who you're doing it with. We (referring to person 1 and 2) are in our mid-50s, and we've known each other since we were 8 years old. And this (indicating person 3) is my spouse of 30 years. If it was someone visiting that you didn't know well and you just said 'let's go to the Exploratorium' and then you did this it might be weird.

Visitor29: [I'm] assuming if you're a parent, the ones involving your children, you might think about a little more and might be more room to feel judged

Visitors were put off because it wasn't the 'typical' experience (5/31, 16%)

Visitor12: It's not something I came here for, not that cool... seems like something you'd do in school, like an ethics class, didn't seem like an exhibit you'd interact with

Visitor24: I was thinking about looking at all the hands-on things (here)... what was the outcome of this? [In the other exhibits - You do this and do that and then you see something]. This seemed a little more ethereal.

Visitor27: P1: Went from colors and lights to kind of heavy.

Visitors felt the exhibit was asking them to reveal very personal and private thoughts in a public space (4/31, 13%)

Visitor2: Very private opinion... It's something I wouldn't do in a public setting

Visitor29: [I want a] privacy guard... a booth, to feel private from people around [so they can't look over your shoulder at where you place the cards]

Visitors perceived or assigned an agenda to the cards (and the Exploratorium) (2/31, 6%)

Visitor5: I wanted to question the person that came up with the questions. [Interviewer: "What would you want to ask?"] I would ask if they agreed, what their motive was, what responses you want to elicit - anxiety, anger, frustration, happiness

Points of confusion

Table 4 gives the complete set of responses of what visitors found confusing about each of the cards. In general, visitors struggled with some of the technical/scientific terms used (e.g., genome sequencing) and the definition of other words (e.g. consent).

Table 4. Points of confusion according to card.**In general (3/31, 10%)**

Visitor17: About half of them [were confusing]. Based on my opinions, are there associated laws, are there companies doing this?

Visitor25: Some were kind of the same - if you agree to have DNA/ genome sequenced, lump all those together whether they were used for specific purpose or not

Visitor31: Maybe say what genome is because we might not know.

Card 1 (7/31, 23%)

Visitor3: Didn't know what "get their genome sequenced at birth" meant.

Visitor5: I didn't know what "genome" meant.

Visitor6: "genome sequencing" - [was a] foreign concept. [Having it as the] first card, right off the bat [trailed off].

Visitor8: I don't know what "genome" is. I don't know much about DNA and genetics stuff; just because I don't have much knowledge about this stuff it was confusing to me. Just the stuff about DNA really - don't really

[inaudible] about that

Visitor11: like if you were trying to have a kid, the genome sequencing might come up

Visitor16: [indicating card 1], I'm not totally positive what this one means.

Visitor18: The use of the word genomes - when I flipped it over, I kind of got the gist of it but not really a definition

Card 5 (1/31, 3%)

Visitor15: [have] 2 parts of the question, [that I] would answer differently

Card 6 (3/31, 10%)

Visitor20: It had to be implied if your consent was there or not. Whether or not my consent was there was what was confusing to me on those.

Visitor21: We had a debate about a definition of which one. We put different things because he thought it (curing disease) was the only outcome, but I thought if it's the real world, it would just suck. So how much is this based in reality?

Visitor28: Is this for the profit of the hospital or is it for the treatment of [better] diseases? Because if it's just for profit, I know the hospitals will make it into a business.

Visitors' suggestions for improvement

We asked visitors for their thoughts on how we might improve the exhibit experience. Their responses, sorted into broad categories, are given in full in Table 5.

Table 5. Visitors' suggestions for improving the prototype.

Compare results with other (groups of) people (7/31, 23%)

Visitor5: I would be interested to see different cultures, races and compare their answers

Visitor6: It would be cool if you could see how all other visitors ranked it.

Visitor14: It'd be interesting to see where everybody that's played with it has landed - an accumulation of everyone else's thoughts

Visitor17: So I can understand where I fit and what the laws are, since this is kind of an emerging space.

Visitor18: generational tabulation - how do 20 year olds feel vs 60 year olds

Visitor23: I guess. It would be interesting to find out what other people were saying... I don't know how I feel about it.

Visitor24: A cool thing would be to see where you set on the average of people who did this exhibit ... Some sort of "And this is what this means" outcome - "you're more liberal thinking" ... "most people in America, or at the Exploratorium, or at this exhibit would answer this way."

Improve the instructions (3/31, 10%)

- Visitor10: have as optional [gesturing to sign] try it again after discussion and see if your ideas change
- Visitor16: I was wondering if I'd know what the others mean. And in the beginning, we weren't sure if we should do all of the cards or one-by-one
- Visitor29: wording of last prompt - emphasize that it (discussing answers) is optional

Have more categories for sorting (3/31, 10%)

- Visitor10: Maybe if visually it was more representative of - not a rainbow exactly - of a real continuum [pointing to lines between "agree/disagree" boxes]
- Visitor24: I wonder if there should be a "not sure" option or a "haven't thought about that" - there were a couple I put in "agree" and would have put in "not sure"
- Visitor28: Maybe add another category that's in-between, neutral. Some of the cards that I'm kind of unsure Agree/Disagree, I would have put in neutral

Help better see the results (e.g. what's different between the two sides) (3/31, 10%)

- Visitor11: Maybe if you could remove this [wall] and see the scattering, create a visual of how many and where they were plotted - for the visual people
- Visitor11: Maybe [we could] say these are the ones we have the same and not discuss those
- Visitor13: Make it more of a screen; flip around, so that the other person can see where you lined up and where you didn't
- Visitor18: Maybe making our information more visible [to the other person] after initial testing. Person 2: (wiggling the divider wall) - a screen. P1: flip down. P2: maybe an electronic tabulation of how different our answers are

Clarify relevance and connections to real life (2/31, 6%)

- Visitor3: Could give more info, what this could be applied to in your life ... talk about what scientists are doing with this right now
- Visitor29: Real-world example... Would be interesting to have information on current policies; state of the world

Improve the physical design (2/31, 6%)

- Visitor25: Make this (wall) slidable so you can see it (the other person's cards) while sitting down
- Visitor25: Make these (cards) where someone can't walk away with that
- Visitor29: privacy guard - a booth, to feel private from people around (so they can't look over your shoulder at where you place the cards

Make it more interactive (and attractive) (2/31, 6%)

Visitor6: Should be digital. Should be more interactive. Nothing about this table and these cards would attract me.

Visitor19: Should be electronic instead of cards - pressing buttons or moving it to a section - I wouldn't want to come sit if it was a card

Others

Visitor5: I think these questions need headgear - something to monitor your brain. No idea how you'd do that, but... what's firing. I know that we're born with 3 types of neurotransmitters - dopamine, serotonin

Visitor8: suggest an age range... not that is mandatory" "12+" [because kids who are younger might not understand, since they] "haven't covered the subject" [in school yet.]

Visitor10: Maybe identify some themes to notice when you're discussing this - privacy, transparency. Consolidating [info on the back of the card] into areas.

Visitor21: Probably need a time limit just because we probably would have camped out here for another hour or two just discussing this.

NEXT STEPS

Results from this formative evaluation suggest that there is some sensitivity around the issues raised by the cards in the *Ethics of Genetics*. A few visitors (3/31) had very strong negative reactions, opting to stop their participation early or mid-way through their exhibit use. Although different visitors can have different responses based on their own value systems and personal experiences, we may be able to mitigate the severity of their reactions:

- Make it immediately apparent to visitors what the exhibit is about so they can make an informed decision to engage or not. As some of the study participants pointed out, this exhibit felt very different from the typical hands-on exhibit at the Exploratorium. Instead of a playful interactive, the *Ethics of Genetics* deals with weighty issues and asks visitors to share potentially personal and sensitive opinions about controversial topics with their exhibit partners. Helping visitors see this upon approach would help them decide whether or not they want to engage with this experience with the group they are with.
- Give visitors a means to opt out once they've started using the exhibit. One way of doing so is to provide another bin in addition to *Strongly Agree*, *Agree*, *Disagree*, and *Strongly Disagree*. This bin, perhaps labeled *Neutral*, *Pass*, or *No Opinion*, could allow visitors to skip a card that they would rather not discuss with their exhibit partner.
- Place the exhibit in a quiet and less trafficked area to give visitors, who might be sensitive about sharing personal thoughts in a public space, a more private area for conversation.

In addition, this evaluation found some usability issues that could be addressed in the prototype's redesign. These include:

- Making clear that the card has two sides, one side with the claim to sort and the other with some background information about that claim. Otherwise, visitors may easily miss the fact that the cards are double-sided.
- Explain some of the more confusing terminology, as listed in Table 4.

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APPENDIX A: ISSUES CARDS

1	All children should have their genomes sequenced at birth.	<p>Things to consider:</p> <ul style="list-style-type: none"> • Although it's possible to sequence the genome of a fetus, this service is not yet offered. Currently, fetuses are only tested for chromosomal abnormalities that might cause birth defects. • Genome sequences can reveal future disease risk and other information too.
2	If it was legal to genetically modify human babies, I would use this technology to maximize my child's potential.	<p>Things to consider:</p> <ul style="list-style-type: none"> • Genetic modifications would be expensive - only available to the wealthy. • The vast majority of diseases can't be prevented through genetic modification.
3	Parents should be able to use genetic testing to choose whether their baby is a boy or a girl.	<p>Things to consider:</p> <ul style="list-style-type: none"> • At least one fertility center in the U.S. already offers sex selection, as well as eye color selection. • In some countries, such as China and India, boy babies are strongly preferred.
4	It's OK for law enforcement to identify criminal suspects by using DNA sequences from their relatives, stored in a public genealogy database.	<p>Things to consider:</p> <ul style="list-style-type: none"> • If police collect DNA from an unidentified suspect, they can compare it to samples in a public genealogy database. If the suspect DNA matches many samples from one family, "police can sometimes figure out who the suspect is."

5	Law enforcement should be allowed to keep DNA samples of someone accused of a crime, even if that person was not convicted.	<p>Things to consider:</p> <ul style="list-style-type: none"> • FBI agents cannot legally store DNA samples of a person not convicted of a crime. • The state of California has been sued for keeping DNA samples from innocent people.
6	It's OK if a hospital sells my DNA data to a pharmaceutical company if it helps create better treatments for disease.	<p>Things to consider:</p> <ul style="list-style-type: none"> • Federal law prohibits hospitals from sharing or selling your health information without your consent. • These laws don't apply to genetic data given to sequencing companies, such as 23andMe.
7	I would like to know as much as possible about my DNA/genome, even if it shows I have an increased risk of a deadly disease.	<p>Things to consider:</p> <ul style="list-style-type: none"> • For most diseases, your DNA sequences can't tell you for sure whether or not you will get it. They can only reveal an increased risk.
8	I would like to know as much as possible about my DNA/genome, even if it suggests that my ancestry is different from what I currently think.	<p>Things to consider:</p> <ul style="list-style-type: none"> • Many people who get their genome sequenced are surprised by the ancestry analysis. • In some cases, the ancestry analysis changes as the company's genome database grows.
9	DNA samples that I leave behind in public, such as hair or saliva, still belong to me.	<p>Things to consider:</p> <ul style="list-style-type: none"> • Currently, DNA left behind in public can be gathered and sequenced by police investigating a crime.

APPENDIX B: INTERVIEW QUESTIONS

Questions

May I ask you [*pick ONE person*] some questions. If there is a question you would rather not answer, just say 'Pass', and we can skip over it.

1. Did you look through most of the cards? Which ones? [*Pick out*]
2. Did you feel uncomfortable or awkward at any point during that activity? [*If YES Probe: Say more?*]
3. Were any of the cards off-putting in anyway? [*Only if they are confused: Perhaps it raised an uncomfortable subject?*]
 - a. Do you remember which one(s)? [*Pick out*]
 - b. In general, can you say a little bit about what was off-putting about these cards?
 - c. When you read one of the off-putting cards, what ***did you end up doing?*** For example, did you skip to the next card, decide whether you agreed/disagreed, discuss the card with the other person?
 - d. What did you ***want*** to do with the card?
4. Was there anything confusing about any of the cards?
 - a. Which ones?
 - b. [Go through at most 3. For each] How so?
5. Overall, did you feel that this exhibit experience was worthwhile to you? Why not? How so?
6. Do you have any ideas for how we might improve this exhibit?