

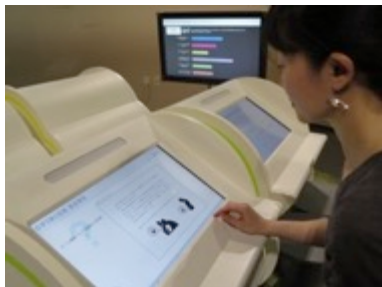


Engaging the Public

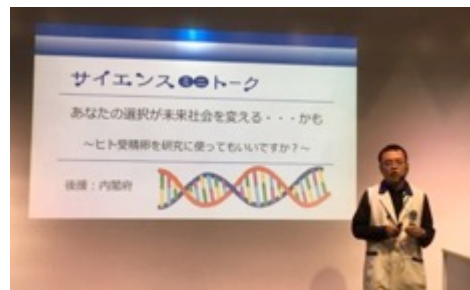
**National Museum of Emerging Science
and Innovation (Miraikan)**

Masako Takuma

Various Activities



Opinion Bank



15 minutes talk



Workshop for School



Public Meeting
with Specialist and Patients



2 days experiment
& discussion course



Public Meeting
with Governmental Official

We want our participants to....

Realize the existence of the issue

Start thinking about it

Listen to others' opinions

Form their own opinions

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Agenda

1. A public meeting with specialists, people affected by heritable diseases, and the public
2. Workshops for high school students
3. A public meeting with a governmental official and the public

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More than 70 people
May 29, 2016



What are the concerns?

Dr. H. Akutsu,
reproductive medicine specialist



Dr. K. Muto,
ethical, legal and social issues specialist



different backgrounds, different opinions

Woman at-risk
of Huntington's Disease



Woman with Marfan Syndrome



different backgrounds,
different opinions

Woman at-risk of Huntington's Disease



“I strongly want genome editing used to
eliminate the disease.

This is the curse of our family.

Even if there are risks, I accept them.”

different backgrounds,
different opinions

Woman with Marfan Syndrome



“I fear potential risks. If I choose to use this technology to help my child’s health and then some unpredicted results occurs, I don’t think I would be able to endure that as a parent.”

32% changed their thoughts

“Before the event, I thought we should not use genome editing for germ line cells in any case. But now my opinion is wavering.”

“I thought it was a good thing to treat diseases, but now I realize the issue isn’t so simple.”



Coming to a consensus

“Attending the event, I know we have to consider a lot of things.”

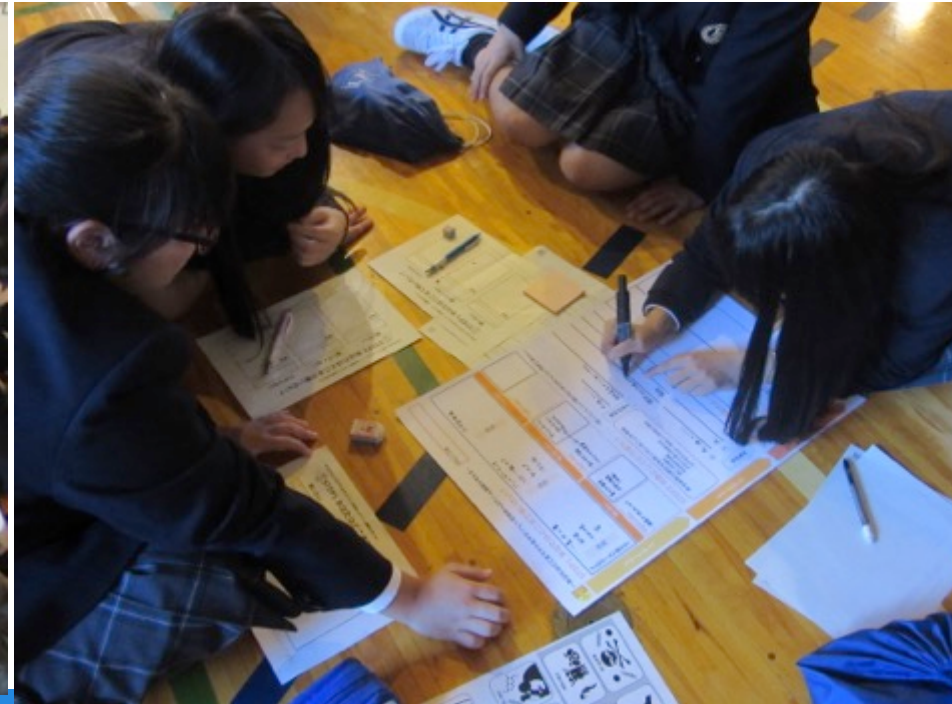
“The most important thing is to have lots of public discussion on this issue.”

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Workshop for students

More than 200 students at once in the high school



Workshop for high schools

At Miraikan



Students...

- low motivation to attend the workshop
- less knowledge about genome editing

BUT, IT'S NOT A PROBLEM !

Once the issue was explained to them,
they became quite interested.

School event means....

All know each other

Sometimes it causes PROBLEMS

This situation inhibits them from giving opinions opposite the student leaders.

When inhibition happens

- Ask the leaders their reasons for their opinions
- Introduce other opinions collected in previous workshops



Become comfortable in giving their opinions

Impressive student opinions....

“Using this tech, my future daughter would be born with perfect beauty..., meaning, she would be quite different from me.

In this situation, I would wonder if I would be able to feel that she is my daughter.”

Impressive student opinions....

“If we don’t discuss it, politicians would make rules by themselves.

However, the result of their decision will affect our future, not theirs. ”

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Direct explanation

- Why does the government make rules?
- What's the purpose of the rules?
- What are the concerns?



Dialogue...



あなたの声を聞かせてください //

～ヒト受精卵を研究に使ってもいいですか？～

今、政府の専門調査会では「ヒト受精卵にゲノム編集技術を用いる研究」をどの目的なら認めるかを検討しています。みなさんの意見を聞かせてください。

論点①

動物の受精卵ではダメ？

論点②

実際に治療してほしい患者はいる

論点③

人間になれる受精卵を使うの？

論点④

研究で外国に遅れをとるよ

論点⑤

利益と倫理を天秤にかけるの？

論点⑥

本当に基礎的研究で止められる？

体づくりのしくみ

体づくりのしくみの理解、生殖補助医療の成績向上など。

OK

NG

わからない

病気の治療

遺伝性の病気やがんなどの治療法の開発など。

OK

NG

わからない

容姿・能力

高い知性や運動能力、望み通りの容姿を得る方法など。

OK

NG

わからない

Building Trust Relationship

“It is very nice to know what kind of people are making rules and what they’re thinking during their consideration.

I know Dr. Harayama and I can believe she will create good guidelines.”

Learn from activities....

1. Voices from persons directly suffering make people think deeper and more seriously
2. Having little knowledge in the beginning is not a big problem
3. Direct conversations can help build a community of trust

Conclusion....

Direct conversations
can help build a community of trust
from which actions can result

Acknowledgments

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Our team of Miraikan

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Tomokazu Fukui	Haruyoshi Soyama

Saitama Prefectural Ageo Takanodai High School
Mito Kiryo High School

and All participants