

# **Publieke kennis omtrent genetica**

Presentatie Forum Biotechnologie en Genetica 28-3-2018

Sam Riedijk (& Boy Vijlbrief)

# GMO is killing our children slowly



# The case of germline editing

SCIENCE

## Scientists in China edit human genome in embryos for the first time

19

*New study confirms rumors in the scientific community, heralds new debate over the ethics of human genetic engineering*

By James Vincent | @jjvincent | Apr 23, 2015, 6:10am EDT

Ian Sample, science editor

@iansample  
Thu 23 Apr 2015 15:08 BST

## Scientists genetically modify human embryos in controversial world first

New procedure used to modify disease-causing gene, but raises questions over whether restrictions should be placed on new wave of genetic techniques

[Home](#) | [News](#) | [Health](#)

DAILY NEWS 9 March 2017

## First results of CRISPR gene editing of normal embryos released

## Chinese paper on embryo engineering splits scientific community

FEATURE 2 December 2015

## Will CRISPR gene-editing technology lead to designer babies?

Controversial experiments editing the genomes of human embryos have already taken place, leading some to call for a ban. But what's the reality?

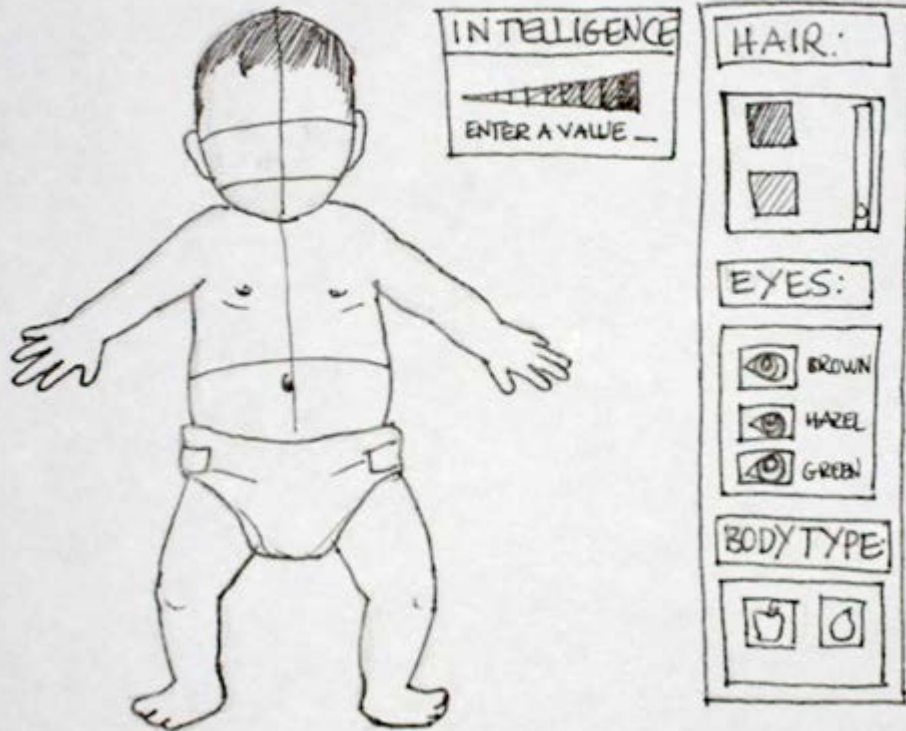


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# Trust, emotions and the designer baby

WOULD YOU LIKE TO CUSTOMIZE  
YOUR BABY ?



Janel  
DiBiccare

People rely on **affect**, especially negative emotions, as heuristic to evaluate risk and benefits of a technology  
(Pillai and Bezbaruah, 2017)

**Trust** in institutions that apply gene technology has a greater effect on people's risk/benefit perception of the technology than knowledge (Siegrist, 2000)

**Affective** cues reduce the positive impact knowledge  
(Lee et al., 2005)

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When people have little knowledge they tend to rely on **affective factors** as well as **trust** in institutional actors (Siegrist, 2000; Lee & Scheufele, 2006; Pillai & Bezbaruah, 2017)



# Genetic Literacy Project

SCIENCE NOT IDEOLOGY



**Viewpoint: Gene editing in humans should leave 'no room for suspicion' of 'closed door' research**

March 19, 2018

*The Royal Society has recently published the results of an extensive survey of the attitudes of the general public to ...*



**Europe missed out on GMO biotech revolution. What's going to happen with gene editing?**

March 14, 2018

*As a plant geneticist in Europe, I must carefully pick my way through some of the most onerous constraints to ...*



**More than 70% of UK public endorses human gene editing to treat disease**

March 16, 2018

*Scientists have been given a green light from members of the public to press ahead with developing gene editing therapies ...*

## **Collingridge dilemma:**

**‘When change is easy, the need for it cannot be foreseen.**

**When the need for change is apparent, change has become expensive, difficult and time-consuming’**

# Technology Assessment (TA)

Technology assessment is an analytic and democratic practice which aims to contribute to the timely formation of public and political opinion on societal aspects of science and technology.

Butschi et al., 2004



# Forms of TA

Classical TA: aims to improve the regulation of side effects of technology in society. It is a form of expert-based policy analysis.

Participatory TA: aims to broaden the political and public debate around social aspects of science and technology. Involves experts, stakeholders and citizens.

Argumentative TA: aims to deepen political and normative debate about science, technology and society. Expectations and value orientations are seen to have a real effect.

(Constructive TA: aims to address social issues around technology by influencing design practices)

# Technology assessment activities

Classical TA:

Debates at scientific conferences, position statements, FBG, Health Council



Participatory TA:

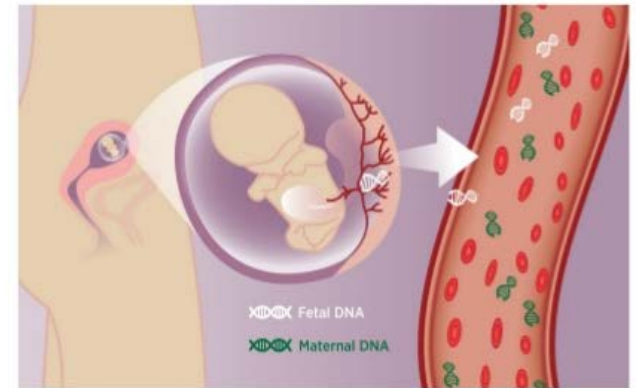
Stakeholders, citizens, experts, policymakers gather in organized debates, information afternoons, surveys etc

Argumentative TA:

Published opinions by ethicists and other trusted moral leaders

# Technology assessment in genetics

- GMO & Greenpeace (hardly any participatory TA)
- NIPT (good example)
- Germline editing..?
- Pharmacogenetic passport..?



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# 'Enabling informed opinions about Germline Editing'

Er zijn 19 vragen in deze enquête

## Voorkennis

Heeft u in 2017 berichtgeving in de media gezien over germline editing? \*

Kies het toepasselijke antwoord voor elk onderdeel:

Ja ☐ Weet niet ☐ Nee ☐

Indien ja, wat vond u van de toon van de berichtgeving in de media? \*

Selecteer alle mogelijkheden:

- ☐ Overwegend positief
- ☐ Overwegend negatief
- ☐ Geen mening

Kunt u kort beschrijven wat u denkt dat germline editing is? \*

## Beschrijving germline editing

Scoor op een 5-puntsschaal in hoeverre u het eens bent met de beschrijving van germline editing \*

Kies het toepasselijke antwoord voor elk onderdeel:

	1	2	3	4	5
Veelbelovend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Beangstigend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bedreigend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Duur	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bruikbaar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Onvermijdelijk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1 = zeer mee oneens

5 = zeer mee eens

Wat heeft invloed gehad op uw mening? \*

Kies tussen de 1 en 5 antwoorden

Selecteer alle mogelijkheden:

- ☐ Informatie uit de media
- ☐ Verdieping in het onderwerp bij studie of op eigen initiatief
- ☐ Ervaring met de gevolgen van een genetische aandoening (zelf of omgeving)
- ☐ Religieuze of culturele overtuigingen
- ☐ Anders, namelijk:

Publieksmiddag 'Wijzer over DNA: Genome editing wordt in de toekomst verplicht gesteld'

Zondagmiddag 5 november 2017, 12:30 – 17:00 uur

Voor het elfde achtereenvolgende jaar wordt er vanuit de onderzoeksschool MGC een publieksvoorlichtingsmiddag georganiseerd over 'Genetica' onder de noemer 'Wijzer over DNA'. De locatie is de Oranjerie in de Hortus Botanicus in Leiden. De recente ontwikkeling van genetische-modificatietechnieken zoals CRISPR/Cas kan een revolutie betekenen in zowel de humane biologie, dierwetenschappen, plantkunde als microbiologie. Maar moeten we alles willen wat technisch kan binnen deze toepassingsgebieden?

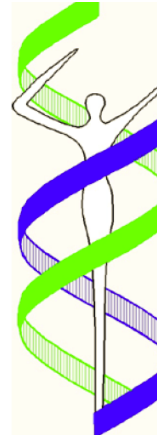
Rond de nieuwe gen therapie technieken en vragen die deze met zich meebrengen hebben we een programma samengesteld.

## Programma

12:30-13:00 Ontvangst en registratie

13:00-13:05 Opening  
Prof. Robert Hofstra – Klinische Genetica, Erasmus MC, Rotterdam

Project team: Sam Riedijk, Boy Vijlbrief,  
Klaas Dolsma en Robert Hofstra



# Three lectures

- 13:05-14:05    Genome editing bij planten: de verbetering van onze voedingsgewassen in de overdrive  
**Prof. Sjef Smeekens** – Molecular Plant Physiology, Universiteit Utrecht
- 14:05-15:05    Ons maakbare genoom: gentherapie en gen-editing bij de mens  
**Prof. Rob Hoeben** – Moleculaire Celbiologie, LUMC, Leiden
- 15:05-15:30    Koffie- en theepauze
- 15:30-16:30    Sleutelen aan menselijk DNA? Ethische kwesties rond gene editing  
**Dr. Eline Bunnik** – Medische Ethiek, Erasmus MC



# Results

## Participants:

Mean age 57

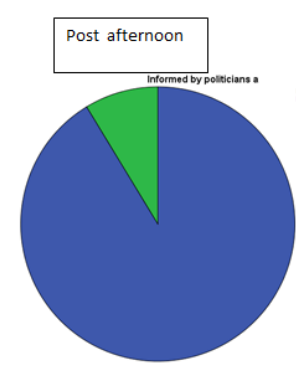
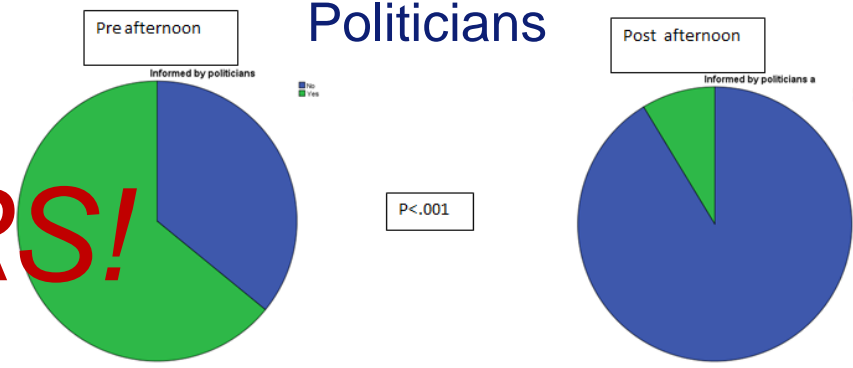
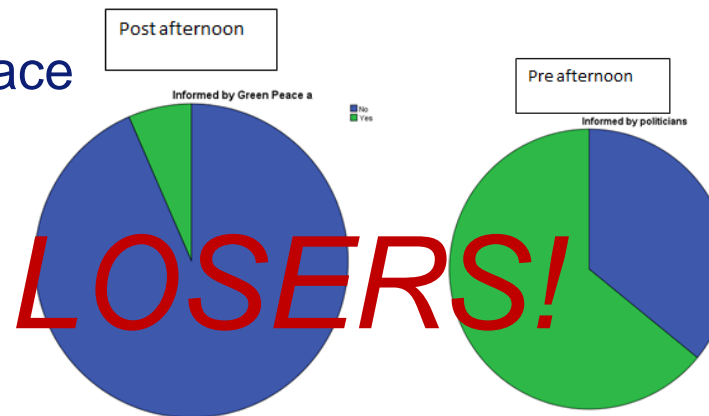
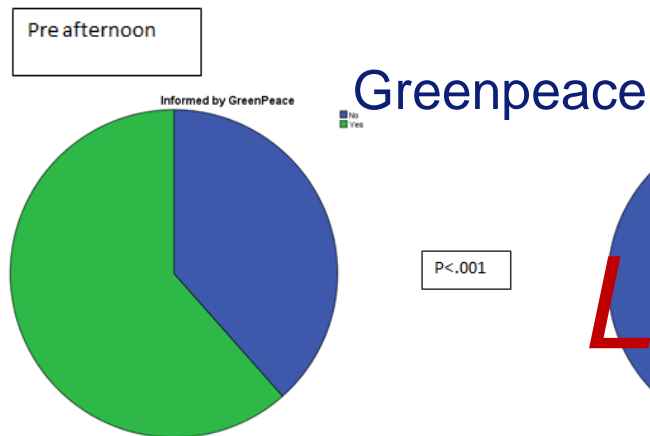
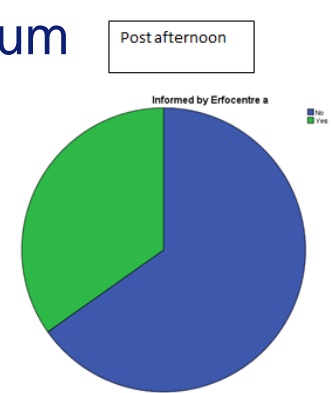
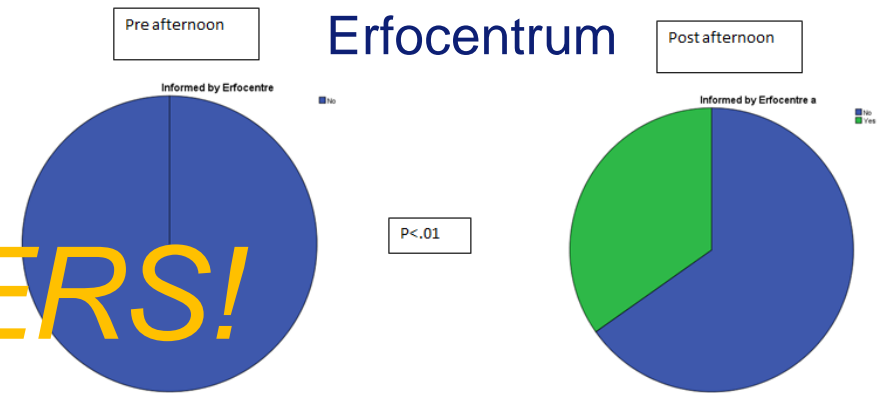
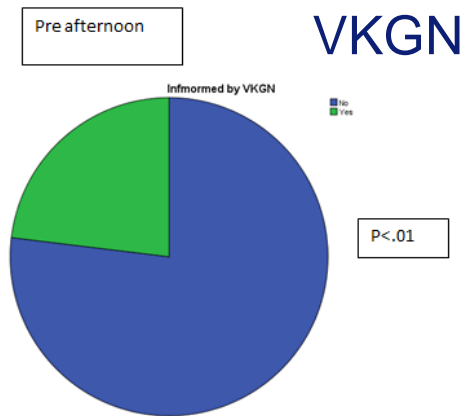
54% completely lay

11/39 (28%) familiar with genetic condition (self or loved one)

39/66 (59%) completed pre-and post afternoon measurement

- Shift in attitude in both directions post-measurement ( $P < .01$ )
- Shift in the preferred source of information ( $P < .01$ )
- Those in favor used more sources of information than those opposing ( $P < .001$ )
- At pre-measurement, opposing attendees relied more on opinions ( $P = .05$ ), at the post-measurement this ratio flipped
- At pre-measurement 67% of those familiar with genetic condition opposed to germline editing compared to 36% of those not familiar

# Ad Shift in preferred source of information



WINNERS!

LOSERS!

# Preliminary conclusions from pilot study

When people receive information from the genetics community, their trust in us as a reliable source of information and opinions increases

One afternoon of lectures impacts people's attitudes both positively and negatively

When people are familiar with a genetic condition, they probably perceive more risk of new techniques in addition to benefits → important insight when including patient communities in the debate

# Insights thus far

- Participatory technology assessment: we should engage experts, policymakers and citizens in debate, surveys and informational afternoons
- Trust is important
- Population-wide genetic literacy is a bridge too far
- Affect influences people's attitudes more strongly than knowledge
- For many people, an attitude is synonymous to an opinion

# Our struggle

**We want to enable informed opinions, but the strongest pathways to forming opinions, affective heuristics, hardly rely on knowledge**

Should we be focusing on affect and trust or on knowledge?

We are not activists, however, as a genetic community, we have a responsibility...

*By the way, who's paying?*



# Ultrafast developments



22nd International Conference on  
Prenatal Diagnosis and Therapy  
8-11 JULY 2018 ANTWERP · BELGIUM

## Wednesday | 11 July 2018

08:30–09:15

### Plenary Session

- Pioneer Award and Plenary Address

09:15–10:15

### Debate 3 | Gene editing should replace embryo selection following PGD.

For: Dagan Wells

Against: Joris Vermeesch

Moderator: Joe Leigh Simpson

10:15–10:45

**Beverage Break** with Exhibitors

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