

# Engagement Tacks for Exceptional Tech



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**National Institutes of Health**

*Novel and Exceptional Technology & Research Advisory Committee  
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N

# unnatural selection



Docuseries released October 18, 2019,  
focused on genetic engineering & DNA-  
editing with CRISPR







**> 151 million  
watching**

# Engagement of the Future

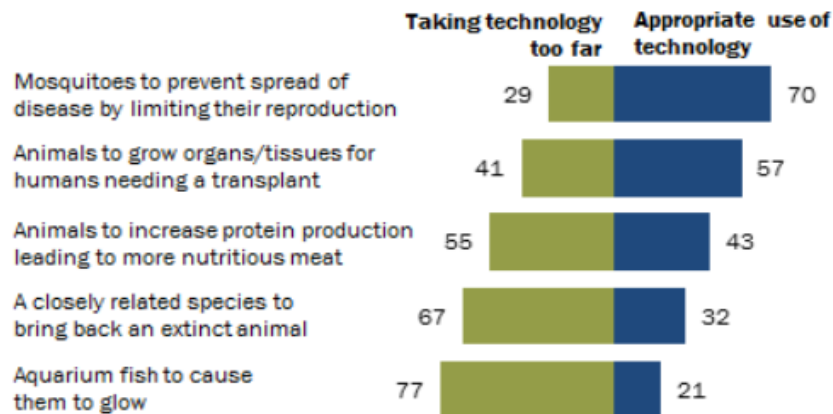
- **How might we better identify and reach target audiences in today's information communication landscape?**
- **How might we reimagine current engagement strategies to generate more meaningful results and outcomes?**



# Public Open to Novel Technologies

## Americans' views on genetic engineering of animals vary widely by its intended purpose

% of U.S. adults who say genetic engineering of each of the following is ...



Note: Respondents who did not give an answer are not shown.

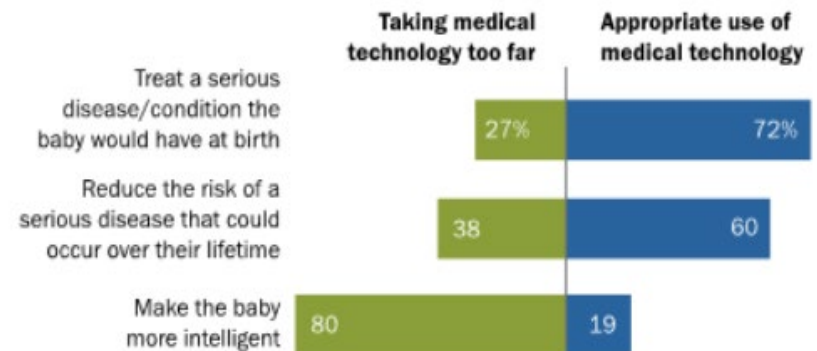
Source: Survey conducted April 23-May 6, 2018.

"Most Americans Accept Genetic Engineering of Animals That Benefits Human Health, but Many Oppose Other Uses"

PEW RESEARCH CENTER

## A majority of U.S. adults say changing a baby's genes to treat a serious congenital disease is appropriate

% of U.S. adults who say changing a baby's genetic characteristics for each of the following reasons is ...



Note: Respondents who did not give an answer are not shown.

Source: Survey conducted April 23-May 6, 2018.

"Public Views of Gene Editing for Babies Depend on How It Would Be Used"

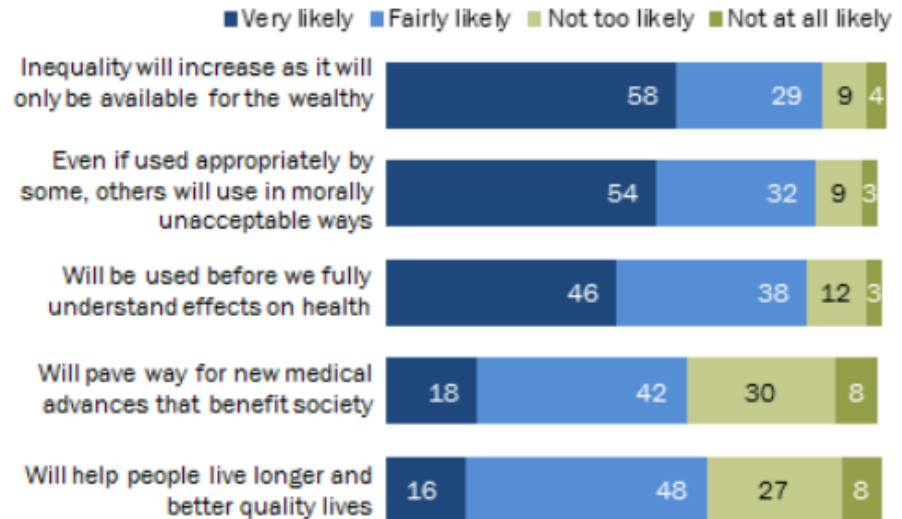
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# But Believe Negative Effects Are Likely

- Underscores the importance of engagement

## Larger shares of Americans believe negative effects of widespread use of gene editing are very likely

*% of U.S. adults who say each of the following would be \_\_\_\_\_ to occur if gene editing to change a baby's genetic characteristics becomes widely available*



Note: Respondents who did not give an answer are not shown.

Source: Survey conducted April 23-May 6, 2018.

"Public Views of Gene Editing for Babies Depend on How It Would Be Used"

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# Overview

- I. Past and present definitions of engagement, rationale & a typology of engagement
- II. Current example of engagement in the context of gene drive for vector control
- III. Future considerations for engagement relevant to novel technologies

# Engagement Challenges

- 1) Variation in engagement definitions, language & concepts, contributes to lack of clarity**
- 2) Vaguely articulated goals & lack of dissemination of engagement projects for novel technologies**
- 3) Few established ways to incorporate engagement results into decision-making**

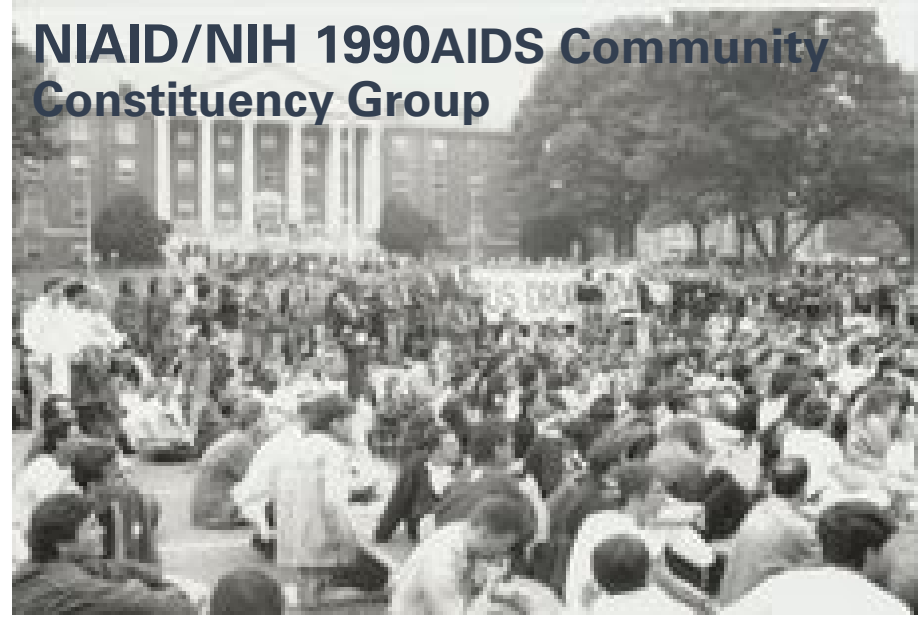


# **Part I**

## **Definitions, Rationale & A Typology of Engagement**

# Early Engagement in Research & Public Health

## NIAID/NIH 1990 AIDS Community Constituency Group



## Community Advisory Board Model

### US Centers for Disease Control “Principles of Community Engagement”

“...the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices” (CDC, 1997, p 9 – published in CDC Principles of Community Engagement Second Edition, 2011, p 3).



# Recent Reports & Guidelines Relevant for Gene Drive Trials

## National Academies of Science, Engineering, and Medicine

“Seeking and facilitating the sharing and exchange of knowledge, perspectives, and preferences between or among groups who often have differences in expertise, power, and values.”

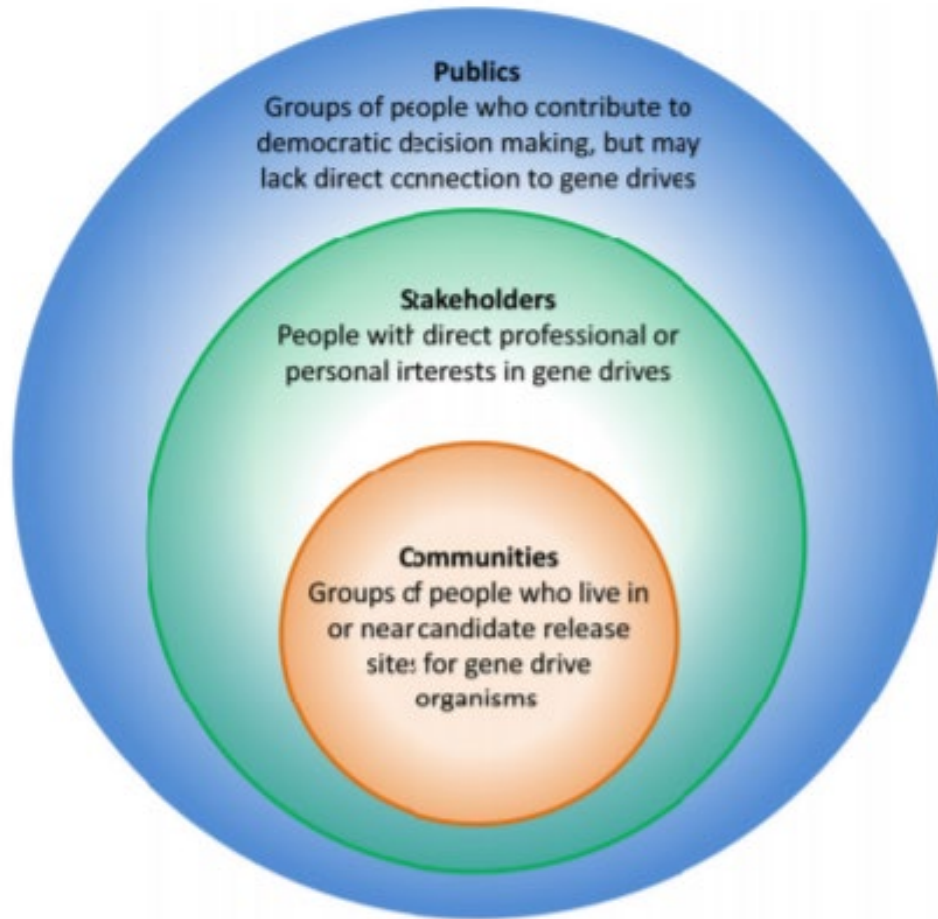
## World Health Organization

“Practices undertaken to inform stakeholders about the diseases and vectors of interest and goals of a proposed research study or intervention trial, and to understand their perspectives and reaction.”

## Foundation for the NIH (FNIH)

“Activities and processes undertaken by or on behalf of those conducting the field trial and involving residents or representatives of the community, with a view to negotiating mutually acceptable terms and conditions for the conduct of the trial.”

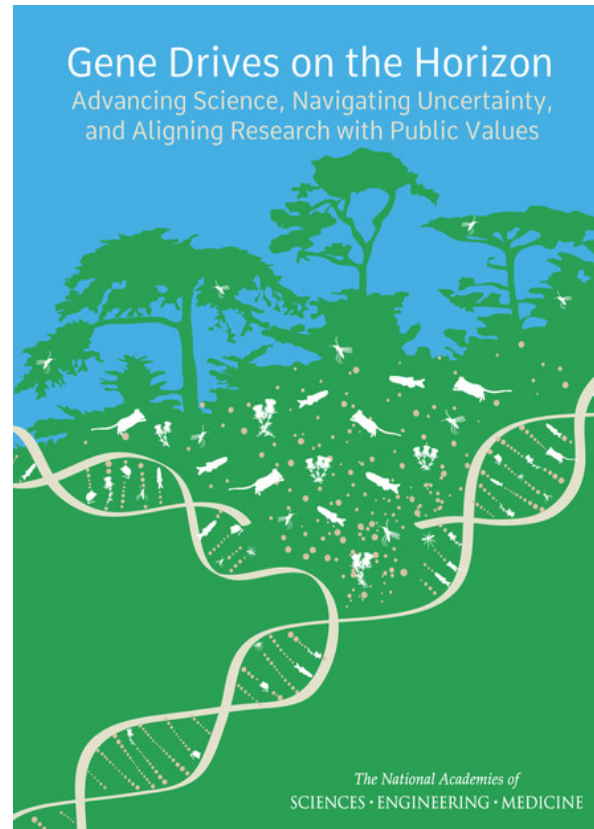
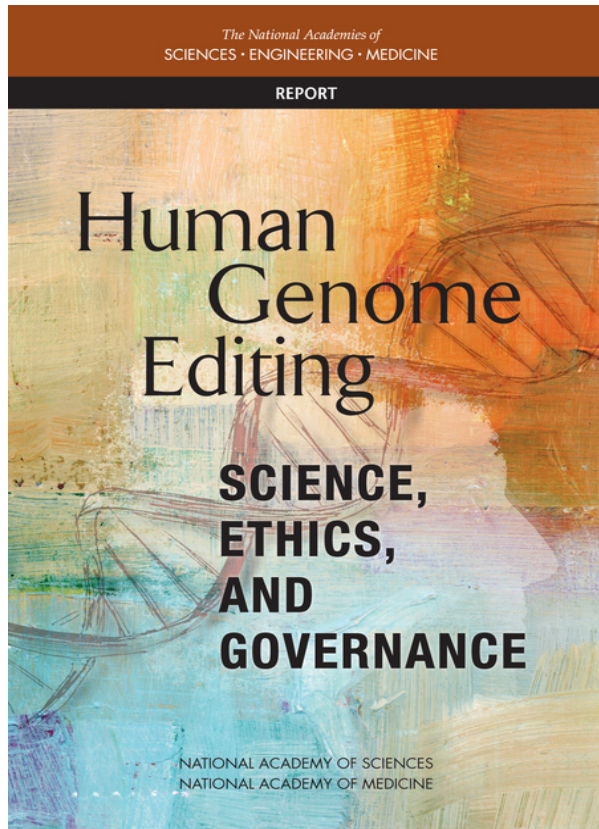
# Definitions of Communities, Stakeholders & Publics



- Audiences exist on a continuum
- People can belong to more than one group



# No Individual Informed Consent

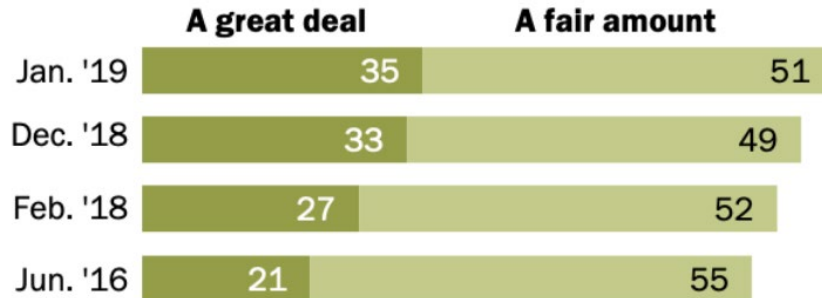


Engagement all the more important.

# Trust in Scientists but Trend Towards Democratization

## Americans' confidence in scientists to act in the public interest up since 2016

*% of U.S. adults who say they have \_\_\_ amount of confidence in scientists to act in the best interests of the public*



Note: Respondents who gave other responses or who did not give an answer are not shown.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

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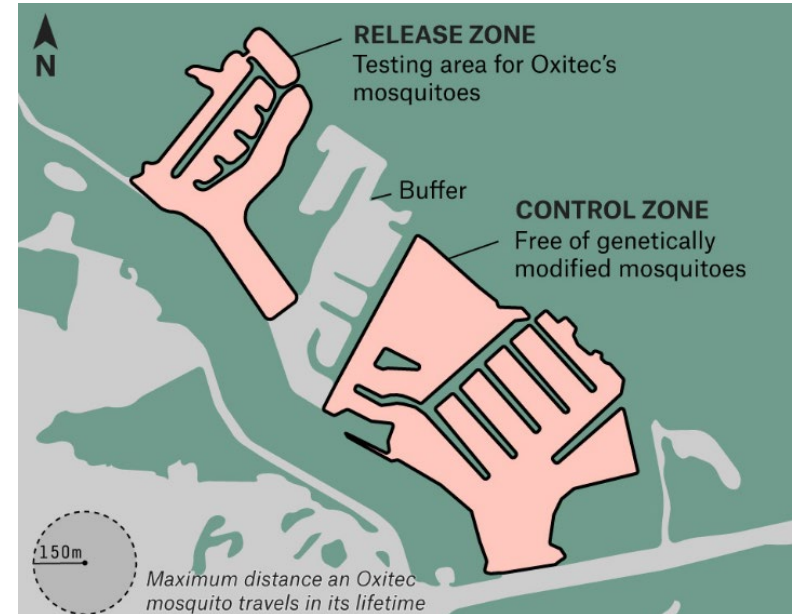
**Democratization  
Knowledge  
Expertise  
Decision-making**

**Engagement expected.**



# Public Input Can Influence Outcomes (Florida Trial)

- Genetically engineered Oxitec mosquitoes as a response to dengue outbreak (2009)
- By 2011, release of Oxitec mosquitoes planned and announced for Key Haven
- Vocal opposition among some residents despite community engagement



**Research Letter**  
August 15, 2017

**JAMA** The Journal of the American Medical Association

**Public Response to a Proposed Field Trial of Genetically Engineered Mosquitoes in the United States**

Cinnamon S. Bloss, PhD<sup>1</sup>; Justin Stoler, PhD, MPH<sup>2</sup>; Kimberly C. Brouwer, PhD<sup>3</sup>; et al



# Engagement Typology for Genetic Engineering in Vector Control

- **Goal**: Sought a way to organize activities into a typology based on easily identified and relevant features to identify learnings for future work
- **Approach**: Key informant interviews & analysis of documented examples of engagement



# Missing Documentation

## Projects

- Caged Field Trials in Mexico
- Eliminate Dengue/World Mosquito Project
- FNIH Working Group Series
- Gene Drive Outreach Ntwk
- LA 2016 Community Engagement Wkshps
- Marshall Interviews in Africa
- Mice Against Ticks
- Mosquito-Free Hawaii 2016
- NASEM 2015 Workshop
- NCSU 2016 Expert Wkshp
- Oxitec in Brazil
- Oxitec in Malaysia
- Oxitec in the US
- Venter Institute 2016 Wkshp

- 23 unique examples of engagement projects
- But...only 14 were documented



**Key Challenge:** Inconsistent dissemination and evaluation of engagement efforts.



# Identified Features & Categorized

## Projects

- Caged Field Trials in Mexico
- Eliminate Dengue/World Mosquito Project
- FNIH Working Group Series
- Gene Drive Outreach Ntwk
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## Features

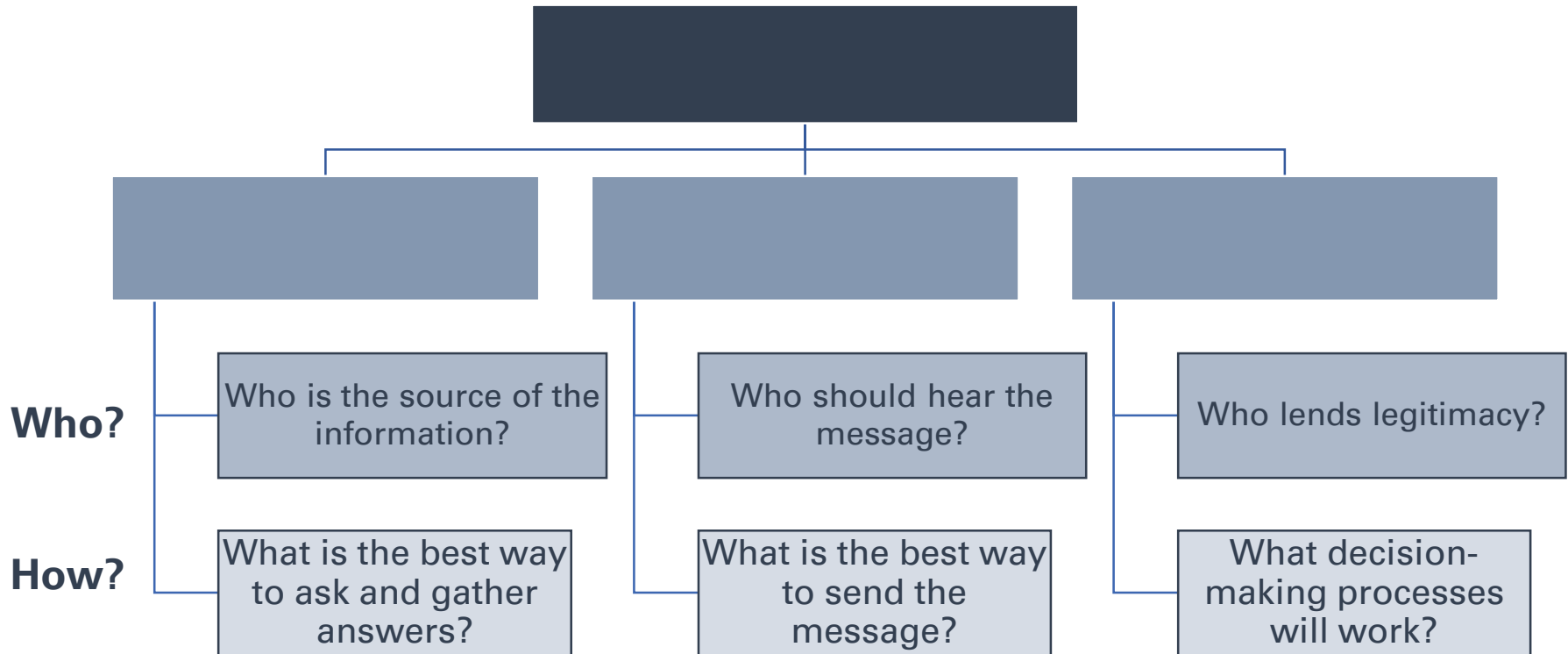
- Timing
- Initiators
- Targeted Groups
- Methods
- Stated Goals
- Who can act?
- Delegation of power?

# Patterns Across Engagement Cases

- **Timing**: No clear links with other features
- **Methods**: Not related to target groups
- **Goals**: Often poorly articulated, sometimes not matched to method

**Key Challenge**: Lack of established goals and tie-in to the chosen methods.

# Typology Based on the "Why" of Engagement





# Part I: Recommendations

- 1) Establish goals & choose methods linked to goals**
  - Consider the 3 “Whys” of engagement, the Who and the How will flow from that
  - Match engagement to phase
  
- 2) Disseminate engagement projects to build an evidence base**
  - Ways to incentivize
  - Possibly a dearth of venues

## Part II

# Current Example of Engagement in Gene Drive for Vector Control

*Engagement to Inquire*

# Team California Safe Genes



- **DARPA Safe Genes Program (2017)**
- Safely engineering various classes of gene drives to control a major invasive disease vector, *Aedes aegypti*
- Multidisciplinary team of University of California investigators



# Mandated Engagement Component

## Team CA Engagement Goals

- 1) Assess CA residents' general responses to gene drive systems under development
- 2) Assess whether there are responses that are actionable by Team CA scientists

- Aimed for well-articulated goals & planned dissemination
- Designed with it in mind to integrating results into research and development decision-making
- Tried to use novel methods of engagement

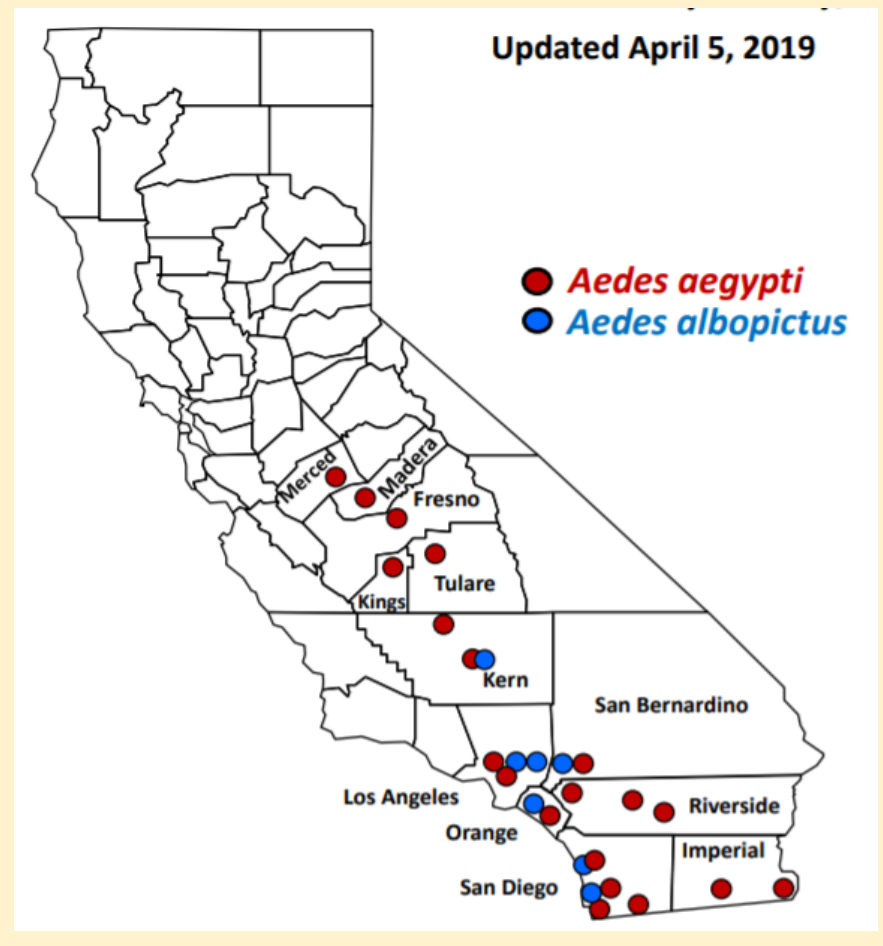
# Gene Drives in the Golden State

- **Strategic Sampling of California Residents**
  - Geographic (*Ae. Aegypti*)
  - Demographic (education)
- **Online, Chat-based Focus Groups**
  - Reach diverse sample
  - Promote standardization in protocol and implementation
- **Use of Narrated Slideshow Series**
  - Forced-choice polling questions
  - Prompts for open-ended discussion

## Invasive Mosquitoes

*Aedes aegypti*: 12 California Counties  
dengue fever, chikungunya, Zika fever

## Detection by County/City



# Slideshow Co-Development

**Intensive Collaboration:** Social and genetic scientists (~4 months), physical co-location

**Key Considerations:** Cover technical topics, language choice and metaphors, 90-min, KIS with 2-3 concepts followed by feedback

**Outcomes Focus:** Visible releases, # of mosquitoes, cost/effort

# Online Focus Group Interface

The screenshot displays a software interface for an online focus group. The main window shows a slide titled "Technology 1: Genetically Engineered (GE) Sterile Males". The slide content is as follows:

Technology 1:  
Genetically Engineered (GE) Sterile Males

Create GE Sterile Males in Lab

Release GE Sterile Males into wild population to mate with females

Eggs do not hatch: Fewer mosquitoes in next generation

The interface includes several side panels:

- Attendee List (9):** Lists participants including Stela FV Tech and -FV TECH- with IDs 119, 120, 123, 128, 129, and 130.
- Tech Contact Info:** Technician: Stela Mladenova, Phone: +1 678 504 4184, Email: smladenova@focusvision.com.
- Client Chat (Hosts):** Contains a conversation between Cynthia - Moderator and Stela FV Tech regarding participant attendance.
- Participant Chat (Everyone):** Shows a discussion about mosquitoes in the Inland Empire, with responses from participants 120, 123, 128, and 130.
- InterVu Live Marking Pod (2):** A panel for creating and managing marks during the session.
- FOR-FV-TECH-ONLY.zip:** A file upload area for technical participants.

The interface also features a top navigation bar with "Meeting", "Layouts", "Pods", and "Audio" options, and a bottom status bar showing the meeting duration as 0:02:11 / 0:05:50.

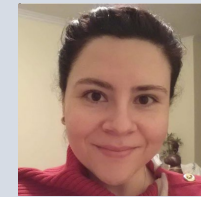


# Spanish Translation Using Team Science

- Science and technology disseminated via English-language outlets
- But effects not delimited by language/literacy
- ~15 million Spanish-speakers in CA



Cynthia Triplett  
Bloss Lab



Rebeca Carballar-  
Lejarazú, James Lab



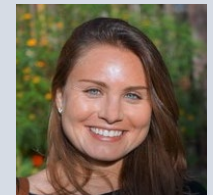
Stephanie Gamez  
Akbari Lab



Victor Ferman  
Marshall Lab



Gerard Terradas Rius  
Bier Lab



Valeri Vasquez  
Marshall Lab

Initial translation (Bloss Lab)

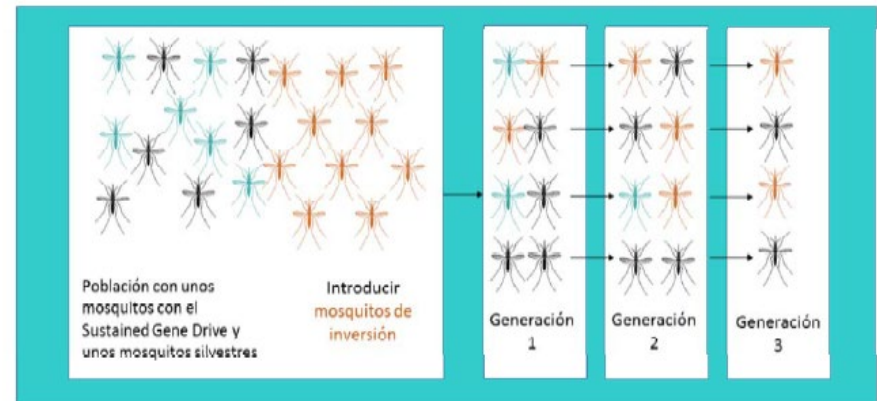
Review 1 (Akbari Lab)

Review 2 (James Lab)

Review 3 (Marshall Lab)

Review 4 (Bier Lab)

## Cómo funciona el control de los Sustained Gene Drives



# Actionable Public Responses/Requests

- **Sample:** 18 focus groups (N=136, English 107, Spanish 29)

## Request or Question (Quote)

## Action (Scientists)

### Role in Ecosystem

“I assume the bugs that eat mosquitoes are just as **willing to eat sterile/gene modified ones** as not?”

“Do you have any **data about the long term negative effects** of eliminating Mosquitoes?”

Determine and communicate role of mosquitoes in local ecosystem

### Specifics of the Method

“My suspicion about gene drive is that research would be required to **determine the mating rate and reproductive rate** to determine if a huge cloud of GE males would need to be released in order to be effective.”

Determine # mosquitoes needed

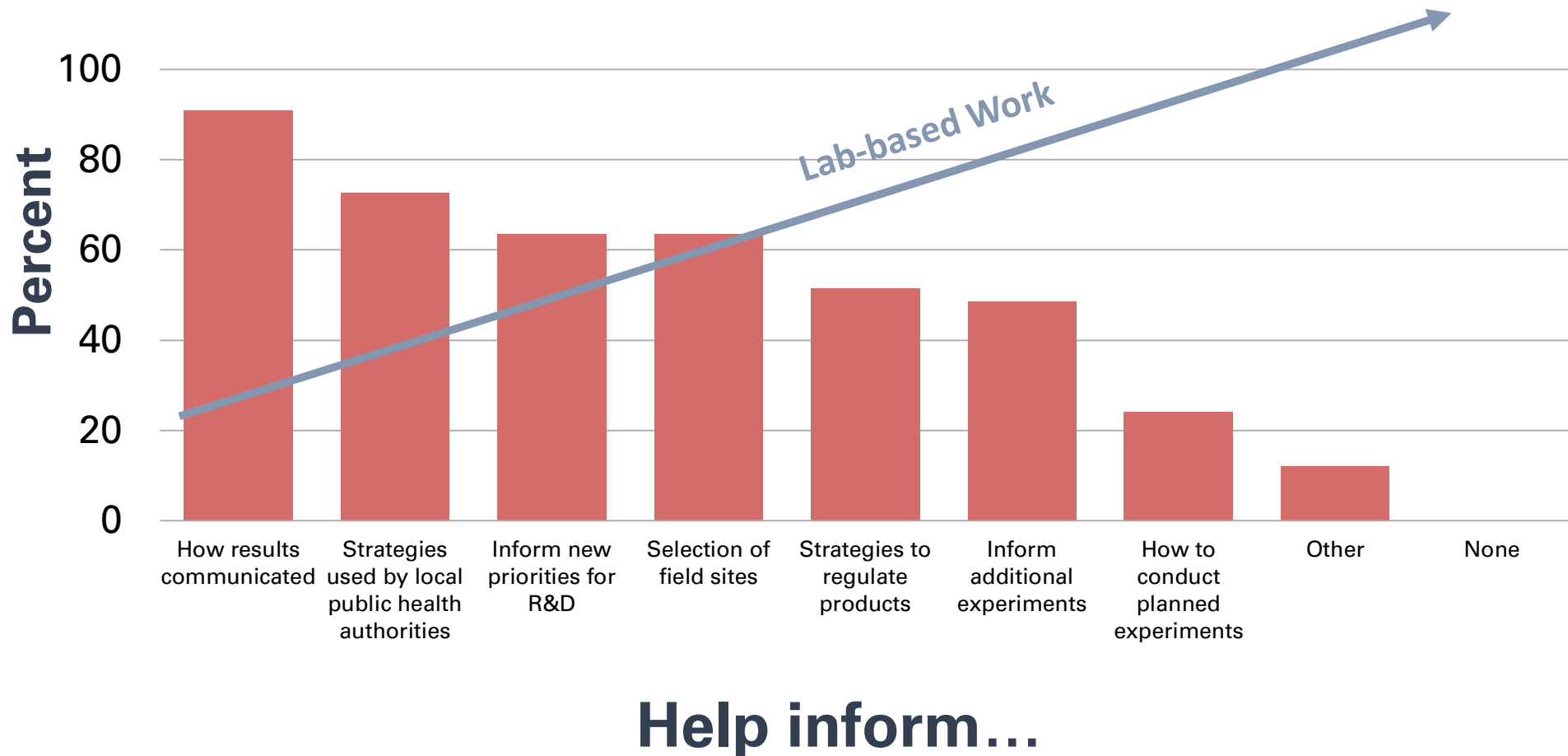
### Need for Call-back (Spanish)

“Creo que es importante que esté confinado aunque el costo sea un poco más alto” (I think it’s **more important that gene drive mosquitoes be confined**, even if the cost is higher) (916)

Ensure a confine/call-back mechanism, even at greater expense

# Scientists' Perceptions of Actionability

*How, if at all, do you think community/public engagement can make a meaningful impact on gene drives research (in general, may or may not be relevant to your work specifically)? Please select all that apply.*



# Part II: Takeaways

- Members of the public can provide nuanced perspectives on gene drives
- May be actionable by researchers, regulators and public health professionals, but additional work is needed
- Novel methods (strategic sampling, online communication, translation of concepts) can help reach diverse audiences/targets
- Team science can be a way to engage scientists/developers



## **Part III**

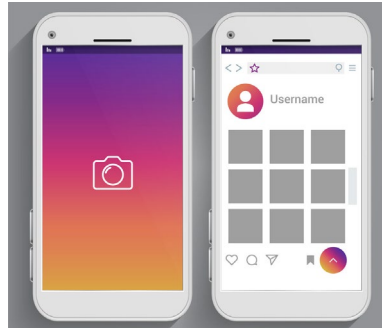
# **Considerations for Engagement of the Future**

# Engagement of the Future

- **How might we better identify and reach target audiences in today's information communication landscape?**
- **How might we reimagine current engagement strategies to generate more meaningful results and outcomes?**

# Leverage New Information Communication Tools

## New Information Communication Tools



**Cultural, Geographic & Linguistic Diversity**

**Rapid Pace of Scientific Advancement**

There are new tools that can be leveraged to help address familiar challenges in engagement.

# Use of Social Networks & Data

Cell Stem Cell  
Forum

CellPress

2016

## A Global Social Media Survey of Attitudes to Human Genome Editing

**>12,000 people recruited to gauge attitudes**

Tristan McCaughey,<sup>1,2,9</sup> Paul G. Sanfilippo,<sup>1,9</sup> George E.C. Gooden,<sup>3,9</sup> David M. Budden,<sup>4,9</sup> Gwyneth Rees,<sup>1</sup> Casimir MacGregor,<sup>7</sup> Lei Si,<sup>5</sup> Christine Chen,<sup>1,2</sup> Helena Hai Liang,<sup>1</sup> Timothy and Alex W. Hewitt<sup>1,3,5,10,\*</sup>

<sup>1</sup>Centre for Eye Research Australia, University of Melbourne, Melbourne, VIC 3002, Australia  
<sup>2</sup>Department of Surgery, Monash University, Melbourne, VIC 3800, Australia  
<sup>3</sup>Lions Eye Institute, University of Western Australia, Perth, WA 6150, Australia  
<sup>4</sup>Systems Biology Laboratory, University of Melbourne, Melbourne, VIC 3010, Australia  
<sup>5</sup>Menzies Institute for Medical Research, University of Tasmania, Hobart, TAS 7000, Australia  
<sup>6</sup>State Key Laboratory of Ophthalmology, Zhongshan Ophthalmic Centre, Sun Yat-sen University, Guangzhou, Guangdong 510060, China  
<sup>7</sup>School of Social Science, Monash University, Melbourne, VIC 3800, Australia  
<sup>8</sup>Department of Computing and Information Systems, University of Melbourne, Melbourne, VIC 3010, Australia  
<sup>9</sup>Co-first author  
<sup>10</sup>Co-senior author  
\*Correspondence: [hewitt.alex@gmail.com](mailto:hewitt.alex@gmail.com)  
<http://dx.doi.org/10.1016/j.stem.2016.04.011>

Ongoing breakthroughs with CRISPR/Cas-based editing could potentially revolutionize modern medicine, but there are many questions to resolve about the ethical implications for its therapeutic application. We conducted a worldwide online survey of over 12,000 people recruited via social media to gauge attitudes toward this technology and discuss our findings here.

Low cost platforms could be used to augment other methods, compare responses across geographic regions, languages.



# Consider Target Audience & Sampling

**FDA Public Notice & Comment  
(March 2016)**

**National, Self-selected Sample  
74% Opposed**

**Voter Referendum  
(November 2016)**

**Neighborhood Residents (FL)  
65% Opposed**

**County-wide Voters (FL)  
42% Opposed**

**Pew Research Center Study  
(May 2018)**

**National, Representative  
Sample, 29% Opposed**

# Match Engagement to Phase

Development Phase	Audiences	Message	Inquiry
<b>I. Research to Proof of Concept</b>	Popular, science, and business press, students, colleagues	We have a promising tech, but still much to learn.	Who might benefit from tech? Who will <b><u>decide</u></b> if it should be used?
<b>II. Seeking Field Trial Site</b>	Local leadership, residents	We think our tech will help with a problem you have, but we need to test it.	Will <b><u>local</u></b> political <b><u>interests</u></b> support a field trial?
<b>III. Seeking Regulatory Approval</b>	Regulators, local leadership, residents, popular, science, and business press	We are committed to designing responsible tests of safety.	Are regulatory agencies <b><u>trusted</u></b> to make a fair assessment?
<b>IV. Field Testing</b>	Residents	Regulators and local leaders agree this test poses limited risks.	What are resident's <b><u>concerns</u></b> about the trial?
<b>V. Bringing to Market</b>	Potential customers and their constituents	We have a solution to your problems.	Who decides if the technology is <b><u>purchased</u></b> ?



# Science Communication

## Between Experts and Lay Audiences

- Explaining science does not translate into more public support (Deficit Model debunked)
- Consider preexisting values, experiences, interests, and perceptions

# Prioritize and Measure Values, Interests & Outcomes

**Patient-Reported Outcome Measures**

Measure things that matter to patients and prioritize study of those things in research.

+

**Community Engagement**

Critical to any public health endeavor.

=

**Community-Reported Outcomes**

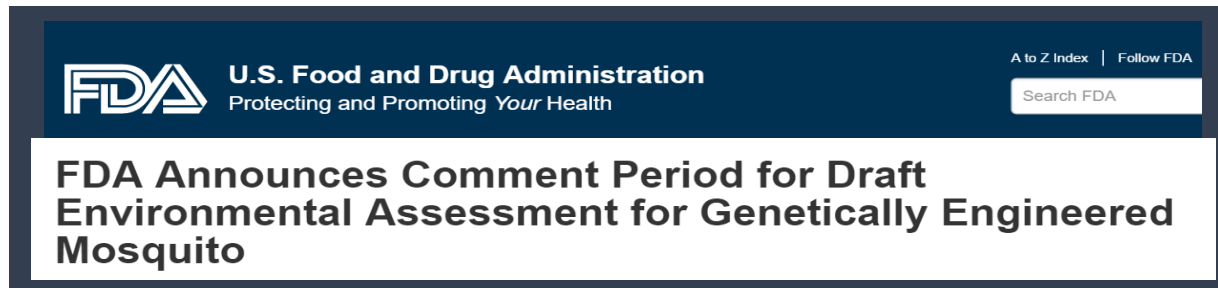
What matters to communities in research on gene drives (emerging biotech)?

**Key Point:** Risks and benefits are often unknown, but stakeholder interests and values don't have to be and could be measured systematically.



# Augment Environmental Assessment with “Social Assessment”

## Florida Trial - FDA Public Notice & Comment (March 2016)



**Key Point:** Systematic social assessment (e.g., using Community Reported Outcome Measures) could more authentically contribute to regulatory review.

# Summary & Closing

- I. Recommendations for building an evidence base for engagement
- II. Key takeaways from a current example in engagement for gene drives
- III. Thoughts on the future of engagement relevant to novel technologies





