Community Advisory Boards and Animal Research in Precision Medicine

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ILAR Roundtable
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Overview
Community Advisory Boards and Research in Precision Medicine

• Consider potential for controversy and concern
• Discuss how we might respond to these concerns
• Examine the strengths and limitations of community engagement activities
A Perfect Storm
Special Scrutiny, Public Concern

- Decreasing Support for Animal Research
- Increasing Concerns about Certain Kinds of Animal Research
- Increasing Political Activism
Decreasing Support for Animal Research

Americans’ Opinions About Moral Acceptability of Practices

% Morally acceptable (High or low points in trends are designated below)

GALLUP, MAY 3-7, 2017

Changes in Views of Issues as Morally Acceptable

Figures are percentages saying practice is morally acceptable

<table>
<thead>
<tr>
<th>Issue</th>
<th>2001 - First year asked</th>
<th>2017</th>
<th>Change</th>
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<tr>
<td>Medical testing on animals</td>
<td>65</td>
<td>51</td>
<td>-14</td>
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Medical testing on animals 51% ← LOW
Historic Reasons for Anticipate Controversy in PM Animal Research

- Worries about catastrophic outcomes
  
  *Ex. Genetically Engineered Mosquitos*

- Concerns about animal research models that approximate human experiences
  
  *Ex. Non-human primate research*

- Attention to species integrity - chimeras
  
  *Ex. “human neuron mouse”*
  
  - Harm to animals for uncertain benefit?
  - Altered moral status of genetically modified species?
Conceptual Reasons for Anticipate Controversy in PM Animal Research

Creating new strains of mice to serve an individual patient

Hubris

Genomic tinkering risks “playing God”

Animal Welfare

May increase number of animals used in research

How many mice should be sacrificed to save a human life?

Given the potential for controversy…
Discourse without Dialogue:
A Cynical View of the Future vs.

Have Rubella? I don't, thanks to SCIENCE.
“While public concerns are often dismissed as naïve or misguided, the public use of dystopian images also reflects their lack of trust in the scientific community and their skepticism in the capacity of government to regulate in the public interest.”

- E.F. Einsiedel
  “Public Perceptions of Transgenic Animals”
Lessons from Other Areas of PM Research
Havasupai Controversy

Henrietta Lacks
Biobank Community Advisory Boards
Mayo Clinic’s Approach

• A network of three regional Community Advisory Boards (CABs)
• Each board meets independently, 5-6 times each year
• CABs provide input to inform governance structures, procedures, and donor engagement
Biobank Community Advisory Boards
Three-site Network

Mayo Clinic Rochester
Est. 2009; 20 members

Sangre por Salud
“Blood for Health”
Est. 2014; 14 members

Mayo Clinic Florida
Est. 2014; 12 members
Mission

To provide ongoing feedback that helps guide the governance of the Mayo Clinic Biobank based on perspectives of individuals from Southeastern Minnesota and the Biobank participant population.

Roles & Expectations

- 5-6 meetings/year, 2-3 hours each
- Compensation is $75/meeting
- Term of 2-3 years, possibility to renew (not to exceed 6 years)
- Expect to receive regular communications in between meetings
- Some reading requested before meetings
- Respectful interactions recognizing plurality of views
Mayo Clinic CAB Network

Advises Mayo Biobank leadership on numerous topics:

- Informed consent process
- Communications about biobank research
- Underrepresented minorities
- Return of genetic findings
- Partnerships with industry
- Commercialization of biobank samples
- Use of new technologies such as whole-genome sequencing
Representation, Regulation and Governance

• CABs are not regulatory bodies

• CABs are not capable of fully representing their respective constituent interests

• CABs are able to represent a substantial portion of biobank donor interests

• CAB members serve as “proxy representatives” of biobank donors, and provide input to biobank managers and users
Challenges of Community Engagement

Recognizing Marginalized Voices

Reconciling Divergent Moral Views

If dialogue is needed... what form should it take?

And what should we expect from it?
The Philosophy of Compromise

Engaging opposing views, without seeking to reach moral consensus, but with the goal of negotiating uncomfortable positions of compromise.
The Modest Goals of Compromise

- Clarify moral differences
  - Identify areas of substantive disagreement
- Find agreement on some moral positions
  - What PM research requires animal models?
  - What would constitute unethical PM research?

Intended outcome: Avoid political entrenchment and moral extremism

If we can’t expect consensus, what’s the point?
Structuring Public Engagement on PM Animal Research

Informal

- General Education
- Public Forums

Formal

- Community Advisory Boards
- Political Negotiations
- IACUC Representation
- PM Res Advisory Committee
- Public Hearings
“Many forms of Government have been tried, and will be tried in this world of sin and woe. No one pretends that democracy is perfect or all-wise.”

“Indeed it has been said that democracy is the worst form of Government except for all those other forms that have been tried from time to time….”

- Winston Churchill
  11 November 1947
Conclusions
Community Advisory Boards and Research in Precision Medicine

• We should expect public concern, and even sustained controversy, re PM animal research
• Public engagement provides opportunities for transparency and trust building but is unlikely to produce substantive moral consensus
• Community engagement activities around PM should include discussions about animal research, however uncomfortable those discussions may be for its champions
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