Restoring Just Relationships in Research

Kelly Edwards, PhD
Associate Dean, Student & Postdoc Affairs, UW Graduate School
Professor, Bioethics, UW School of Medicine
Adjunct Professor, Environment and Occupational Health, School of Public Health
and UW College of Education
Regulations set the floor

Policies Provide
The Ladder

We need to reach for
Standards of Excellence

Regulations set the floor
Stories in Research

• Show us what is possible
• Expand our repertoire of options
• Illustrate a need or impact
• Give us the thick description of what and why something “worked”
• Inspire us to do more in our own work

“Stories tell you about how you live in the world as a human being.”
Roger Fernandez, Native Storyteller
Public Climate for Research

“Where did you go with my DNA?” – NYT 2010
Post HeLa: People have questions

- Who is using my data/specimens?
- Who decides?
- Who is making money?
- What will happen?
- Who is going to benefit from this?
- How will I know?

- Are we ready to answer them?
Asking the Right Questions

• Respect for Persons
  • How can our research processes enact respect?

• Beneficence
  • How can we assure our research is achieving benefits? And clear benefits for whom?

• Justice
  • How can we proceed equitably and fairly? Can we restore past injustices?
“The ethics of accountability in research (whose lives, lands, and bodies are inquired into and what do they get out of it?)”
- Kim Tallbear, 2014
Research Relationships

Contractual: Relational:
Responsible Justice

What could I do differently to assure benefits are achieved and shared?

What are the hopes and concerns of the participants?

Are the right people included in the project?

Goering et al 2008
Community Engaged Approaches:

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Role</th>
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<tbody>
<tr>
<td>Partner</td>
<td>Community Control</td>
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<tr>
<td></td>
<td>Delegated Power</td>
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<tr>
<td>Collaborator</td>
<td>Co-production</td>
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<td></td>
<td>Contributor</td>
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<td>Advisor</td>
<td>Consultation</td>
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<tr>
<td>Audience</td>
<td>Informing</td>
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Adapted from CDC
OHRP Guidance (2008):
Coded Private Information and Specimens

“Under certain limited conditions, research involving only coded private information or specimens is not human subjects research.”

45 CFR 46.102 Definitions:

(f) Human subject means a living individual about whom an investigator conducting research obtains:

(1) Data through intervention or interaction with the individual, or

(2) Identifiable private information.

People matter: Building a chain of trust

Fryer-Edwards&Fullerton 2006

Anderson&Edwards 2010
NOTHING ABOUT US WITHOUT US
Reputation and integrity rely on a foundation of trust. How are we trustworthy?
Building Trust

We share core values and interests
We are committed to a common cause
You have my best interest in mind
Your rules are transparent and consistent (or logical)
Someone I trust, trusts you
Guiding Principles for Just Partnerships

• Remember why we are here
• Forge unexpected alliances
• Come ready for success
• Be nimble, flexible, adaptable
• Remember people matter
• Know your biases, assumptions
• Know what you don’t know

• Edwards et al. Biobanking and Biopreservation (2016)
What the researcher can do:

• Ask relevant questions
• Share what you know
• Get information into the right hands
• Help discern good information from bad
• Share tools
• Enlist others

Additions from Indian Country:
• At the right time
• In the right way

• Modified from AAAS Public Communication Guide
Los Angeles Ports: Example

• Environmental health researchers provided:
  • Health impact information
  • Instruments to track PM
  • Training to community members to use tools
  • Analysis (descriptive) of PM

Andrea Hricko and Frank Gilliland, envhealthcenters.usc.edu
Los Angeles Ports: Example

- Environmental health researchers provided:
  - Health impact information
  - Instruments to track PM
  - Training to community members to use tools
  - Analysis (descriptive) of PM

- Community Organizers provided:
  - Research questions
  - Data tracking and gathering
  - Data dissemination
  - Action steps

Andrea Hricko and Frank Gilliland, envhealthcenters.usc.edu
What can respect look like?

- Partnership
  - Acknowledgement
  - Gratitude
  - Exchange
  - Benefit sharing

- Communication
  - Asking permission
  - Feedback
  - Updates
Becoming Trustworthy: Institutional Changes

• Academic reviews and promotions
  • Include community partner letters
  • Include public dissemination products

• Impact Assessments
  • Expanded from traditional impact scores of journal publications

• IRB reviews
  • Capacity building regarding research with tribes

• MOU review and approval
  • Publication review permitted when historic abuses present

• Payment Structures
  • Community consultants funded
  • Diversifying funding sources

• Budget Allocations
  • Travel planned
What responsibilities do researchers have?

• What questions are we working on?
• How we are allocating our scarce resources (time and attention)?
• Where do we publish our work?
• Who do we partner or collaborate with?
• Who do we mentor?
• What activities do we engage in?
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DEMAND ENVIRONMENTAL JUSTICE!

RACISM IS TOXIC!
Deep Gratitude and Acknowledgments

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  - Including Janice Brendible, Adib Jamshedi, Amy Paul, Jon Sharpe; NIEHS Supplement Partnership with Marti Lindsey, IngriQque Salt and team (UA)

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Trustworthy Practices

• Relationships:
  • Clear expectations
  • Transparent goals
  • Lines of communication
  • Proactive (not reactive)
  • Opportunity for exchange
  • Benefit sharing

• Accountability:
  • Can account for data
  • Transparent process
  • Value-based decisions
  • Clear repercussions

Yarborough et al 2007
Where do you consult stakeholders?

- Discovery
- Development
- Assessment & Priority Setting
- Outcomes
- Delivery
Barriers to Community Renewal

- Chronic disease
- Sick communities
- Disconnected from nature
- Poverty
- Imbalance
- Lost traditions
- Limited opportunities
- Local politics
- Pollution
- Lack of resources

Native TEACH Project 2009
Capacities for Community Renewal

- Commitment
- Passion
- Access
- Voice
- Creativity
- Local Insight
- Historical Perspectives
- Real issues at Stake
- Standing
- Web of relationships
- Flexibility