

Ethics in Citizen Science

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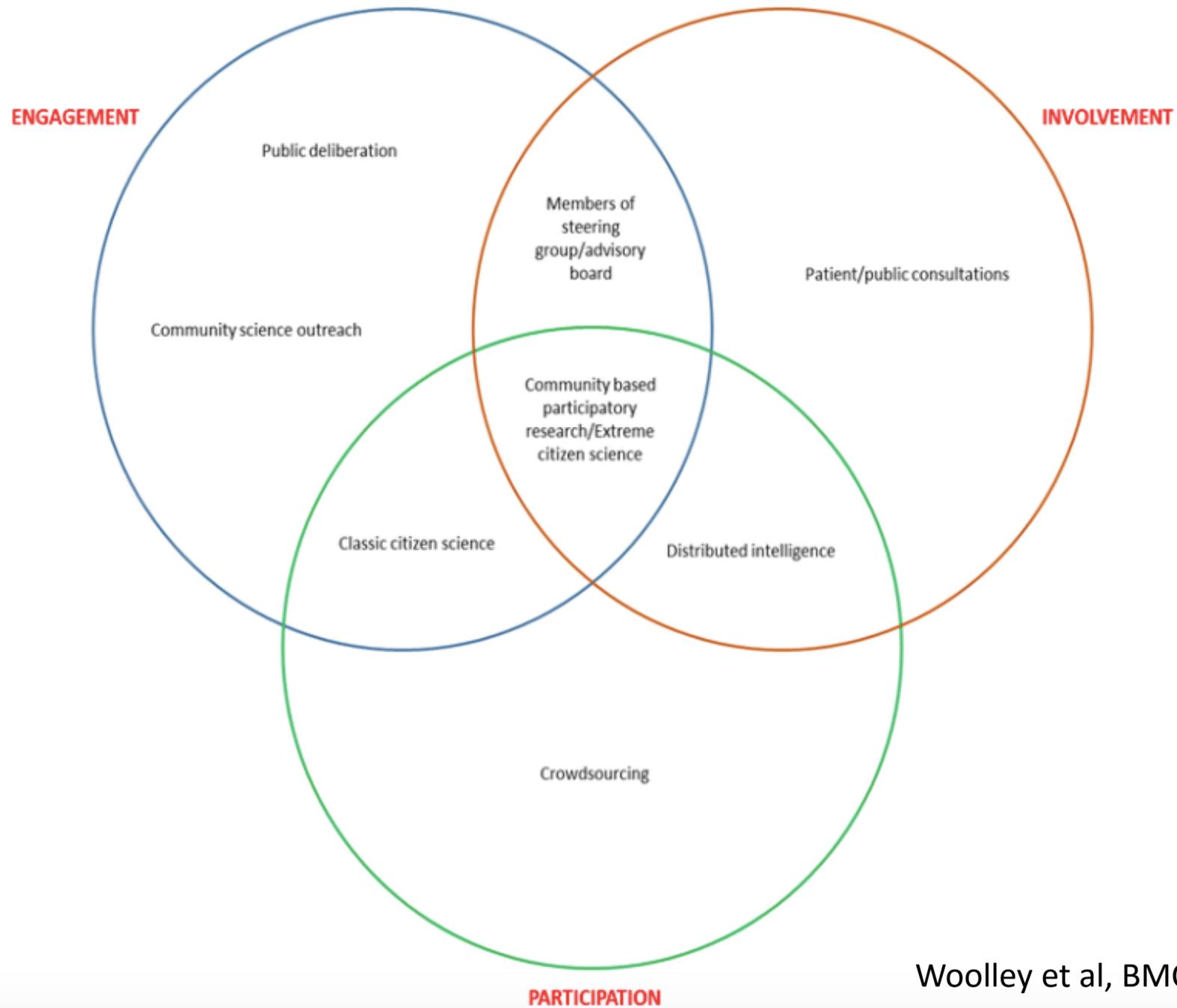
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Citizen Science

- “The collaboration between laypeople and professional scientists known as “citizen science” is an important trend in research and data gathering which offers important benefits to science and society.”
 - Resnick, Elliott, & Miller, *Env Sci Policy* 2015



Communities Drive Research

SCIENCE TRANSLATIONAL MEDICINE | EDITORIAL

POLICY

The study is open: Participants are now recruiting investigators

Recent events inspire optimism that a new age is dawning, one in which lay people have an active role in advancing biomedical research and health care delivery. Two ongoing experiments will deeply involve the public in these endeavors: the U.S. Precision Medicine Initiative (PMI) and the National Patient-Centered Clinical Research Network (PCORnet). PCORnet has already launched 20 patient-powered research networks designed to be led and animated by people who have an affinity with one another because of either shared disease, geography, experience, or identity (1). When U.S. President Barack Obama announced the PMI, he stated emphatically that

the investigators and not by all stakeholders. Participants want not only to be invited to the table but also to design and host the meal with other stakeholders. There is a great deal of “us and them” language in biomedical research. Investigators point to “those patients,” and activists complain about “those investigators.” Clinicians are often left out of the process completely. When these roles are considered dichotomous and separate instead of part of a continuum, it is difficult to create authentic partnerships.

Participants have a place throughout the research continuum, including the proposal and prioritization of research questions, study design, engagement of study participants and their recruitment and retention, conduct



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Sci Transl Med. 2017 Jan 4;9(371).

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“Dissolving the us versus them.” – Sharon Terry

Is Citizen Science unique?

Researcher-driven Science:

- Respect personal choice
- Provide information
- Minimize risks to individuals
- Design for beneficial outcomes
- Consider who benefits and who risks in the research
- Publish findings
- Research benefits others

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Citizen Science:

- Respect contributions
- Build capacity
- Broader risks to consider
- Community-driven questions and research design
- Disseminated to maximize impact and uptake
- Reciprocity expected

Los Angeles Ports: Example

- Environmental health researchers provided:
 - Health impact information
 - Instruments to track PM
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- Environmental health researchers provided:
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 - Analysis (descriptive) of PM
- Community Organizers provided:
 - Research questions
 - Data tracking and gathering
 - Data dissemination
 - Action steps

Challenges

- Who controls the research design and data?
- Who asks the research questions?



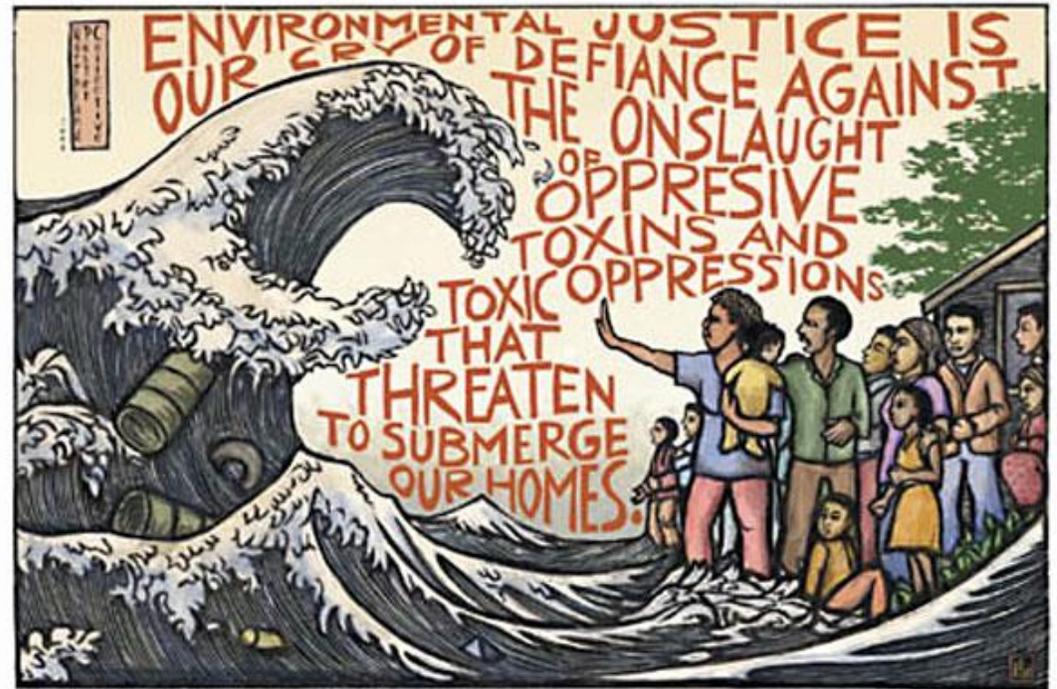
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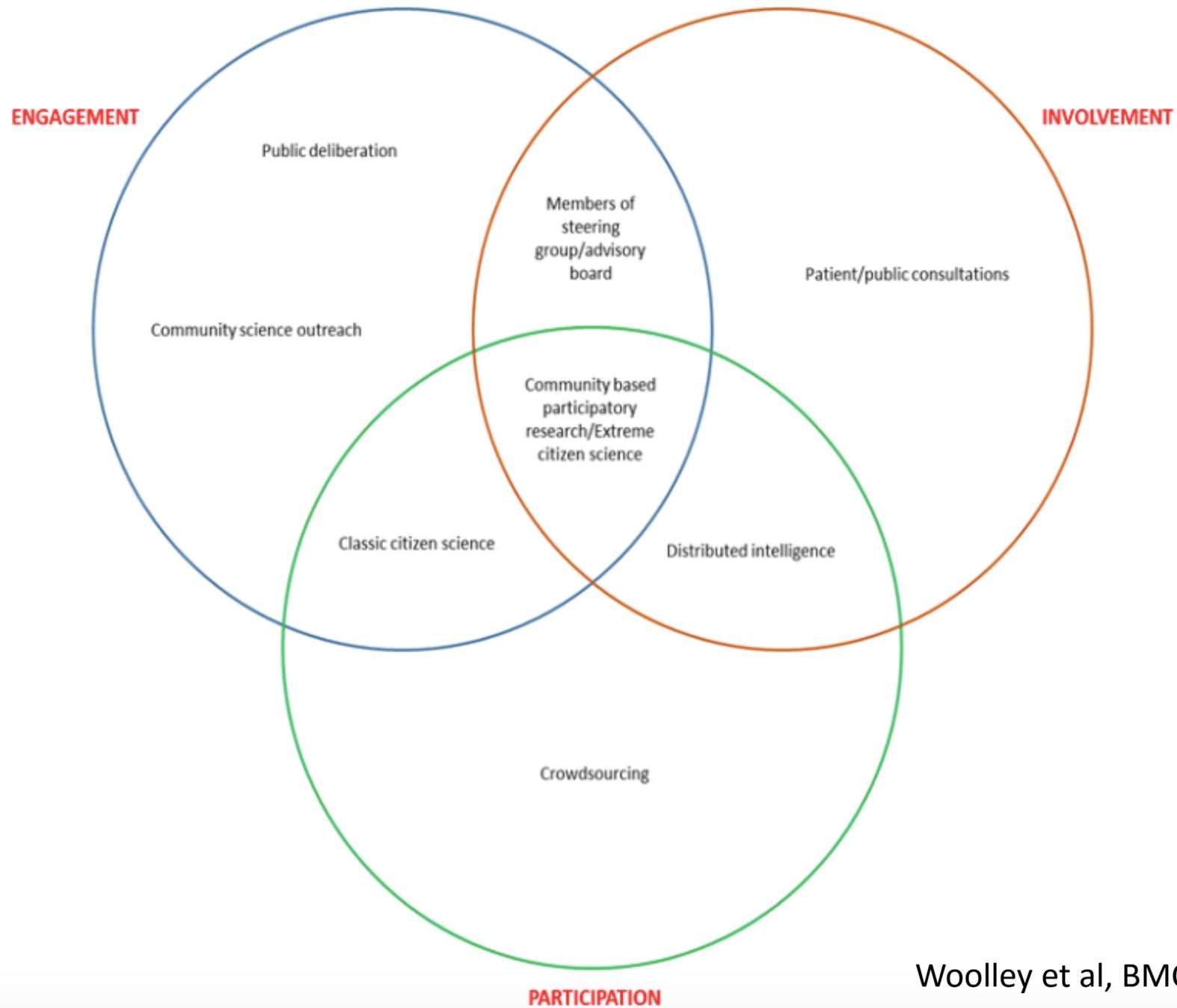
- Which evidence will be trusted?
Which will be trustworthy?



Challenges

- Inequities in existing system mean inequities will persist, regardless of design changes (unless we can disrupt the traditional power structures)





Thank you!

DEPARTMENT OF ENVIRONMENTAL & OCCUPATIONAL HEALTH SCIENCES



Interdisciplinary Center for Exposures, Diseases, Genomics and Environment



University of Washington
NIEHS and PEPH Networks