STANFORD
CENTER
FOR BIOMEDICAL ETHICS

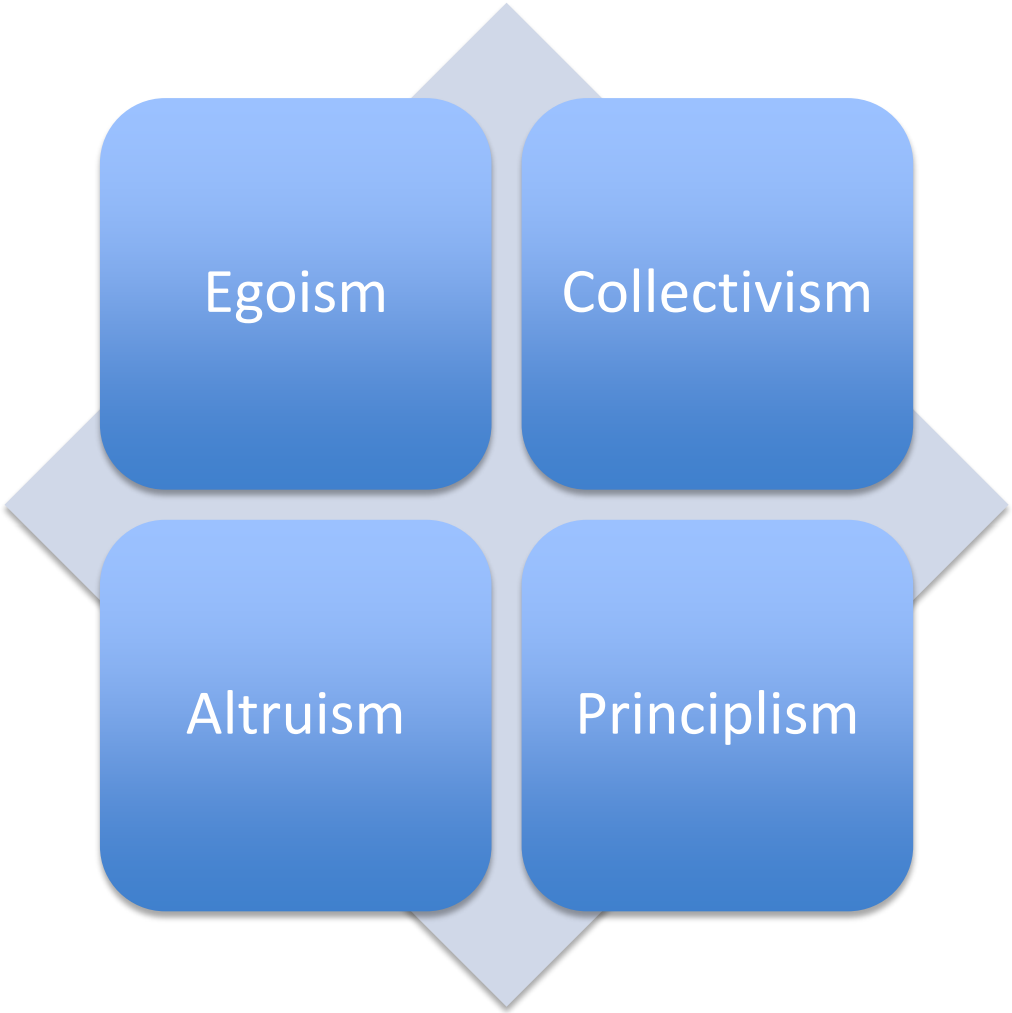
Hospital & Clinics ▪ School of Medicine
Lucile Salter Packard Children's Hospital

Citizen Science and Emerging Ethical Issues

Sandra Soo-Jin Lee, Ph.D.

Stanford University
Stanford Center for Biomedical Ethics
Stanford Center for Clinical and Translational Research and Education
Department of Pediatrics
sandra.lee@stanford.edu

Motivations for Participation



Bonney et al. 2009

Egoism

The data volunteers provide enhance my research

Collaboration with scientists enables me to open my horizons to new ideas and knowledge

Collectivism

Collaboration with volunteers can be helpful to others in the scientific community

Collaboration between scientists and scientific volunteers is beneficial for the volunteers

Altruism

Collaboration with volunteers helps educate them about scientific methods

Collaboration between scientists and scientific volunteers is beneficial for scientists

Principlism

Collaboration with volunteers is worthwhile because I believe that all scientific knowledge should be accessible to everyone, regardless of their expertise

Collaboration with scientists is worthwhile for making scientific knowledge accessible to the public and outside the scientific community

Emerging Relationships

Contributory projects	Collaborative projects	Co-created projects
• the public are recruited into projects conceived and designed by scientists	• scientists work with the public to collaborate on research design in addition to enabling the public to contribute data	• scientists and the public are involved in each phase of the research, beginning with its conception and following through to co-publication

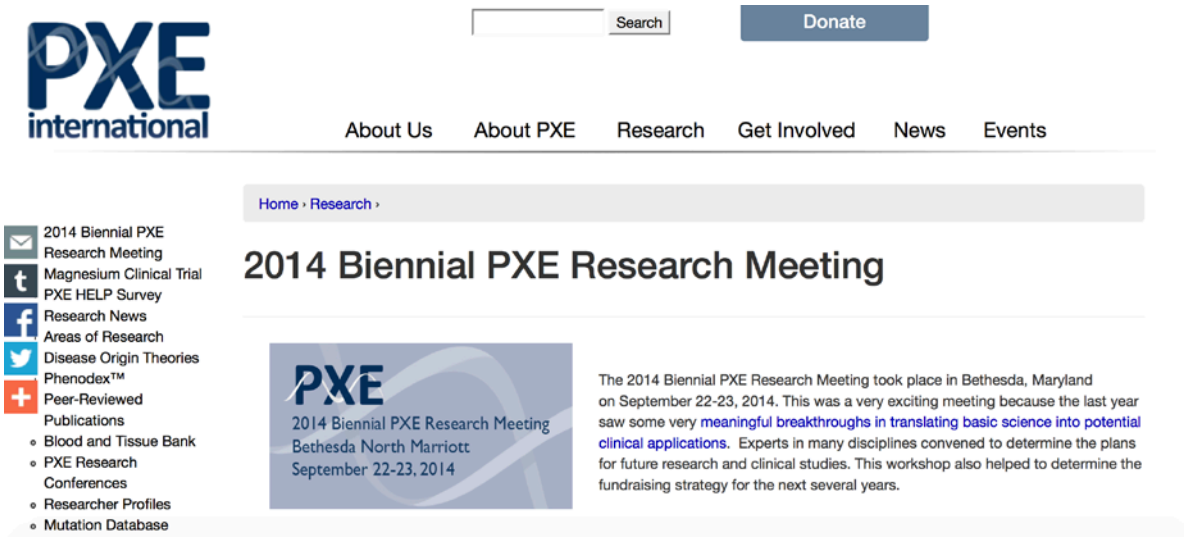
(Rotman et al. 2012)

Educative Dividend/Self Discovery

Learning something new and

valuable

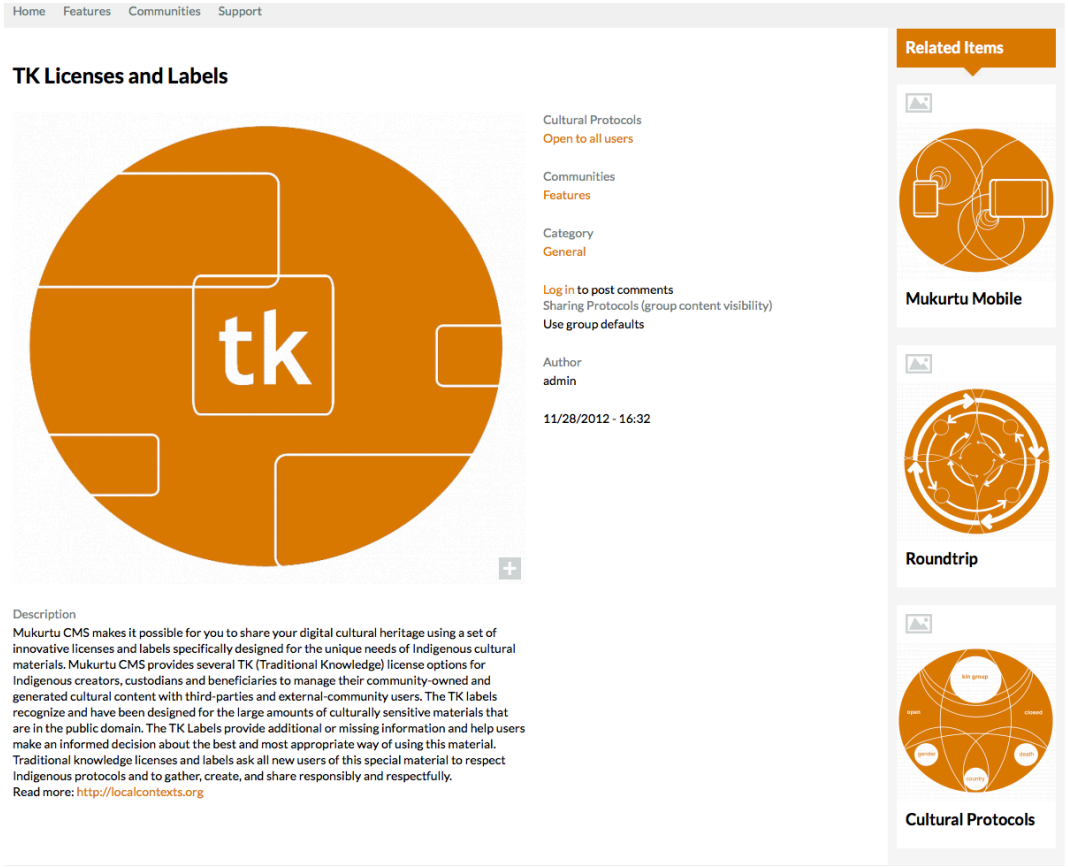
Who is able to participate? What level of expertise?
Who curates the data? What is the nature of quality control?
How are standards created?
What are the limits for “repurposing” and mining shared data in the name of “discovery”?



Goals and Tasks

Participants not only undertake tasks but help set goals

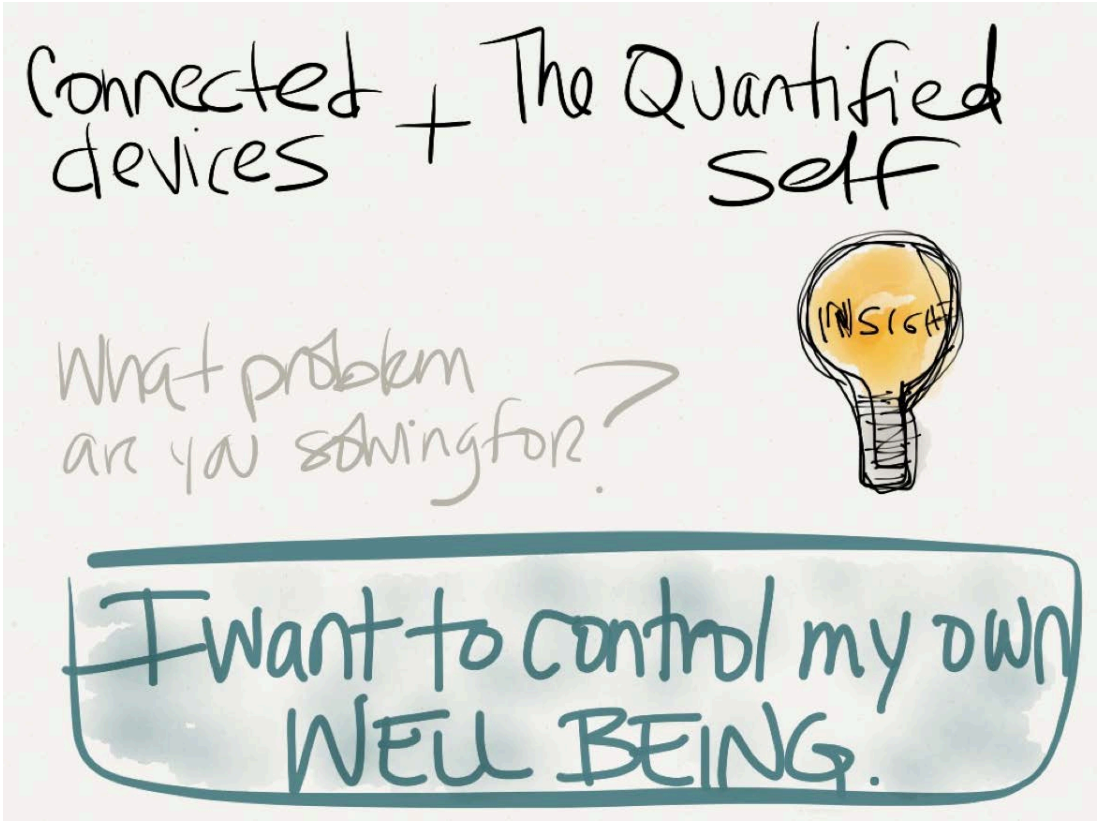
How are goals determined? Who sets the agenda?
Who participates in research design?
Who determines what the results mean?
How are results published? What constitutes acknowledgment and responsibility?



Resource Control

Participants get to control (own or use) resources, not merely produce them.

Who owns pooled resources? Are institutional interests apparent?
How does the ethos of open sharing impact the desire for control?
How is data protected and secured?
What rights do third party platforms have to resources?



Exit

Capacity to leave without penalty

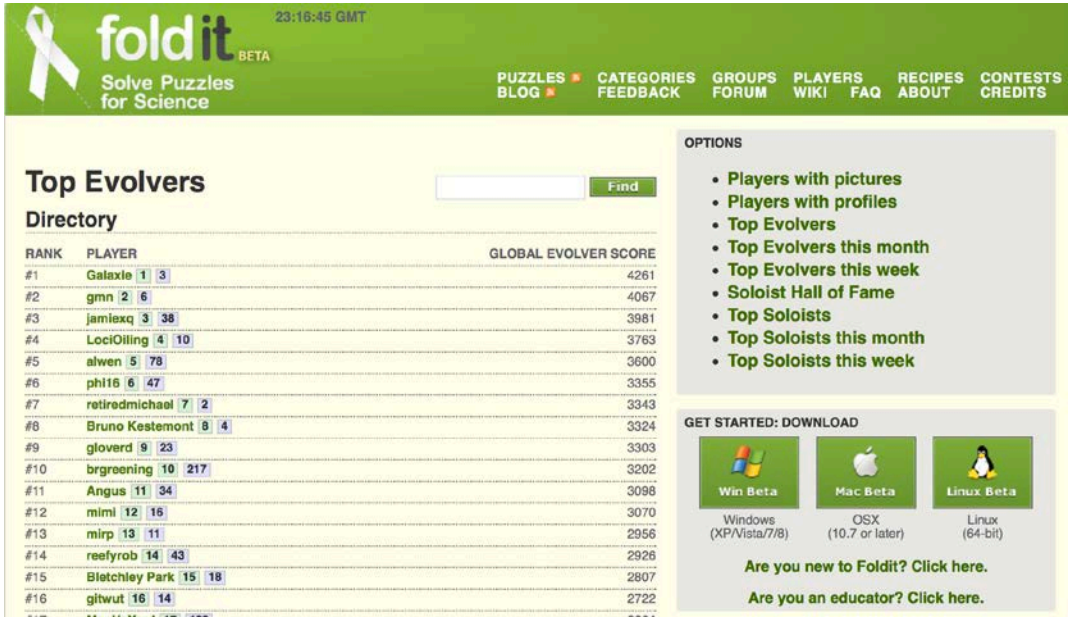
and with resources

Is exiting possible?
What assurances can be made that one has exited?
How to exit without some loss of data, access to network and other resources?

Voice

Opportunities to 'speak back' in order to influence use of data

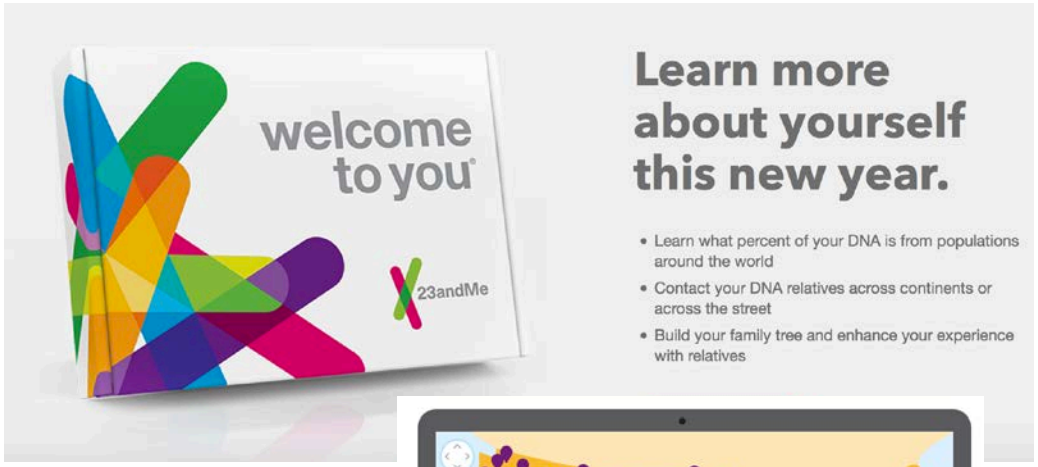
What are the rules of engagement?
What are effective models for “speaking back”?
What is the obligation to hear?
Whose voices? How diverse and representative are participants?

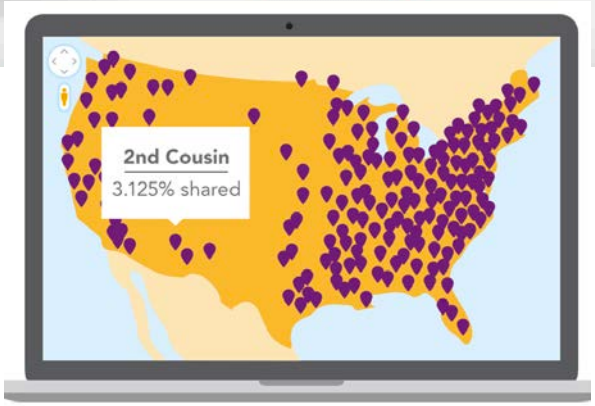


Visible Metrics/Gaming

Empirical demonstrations of the connection between participation and outcomes

What constitutes compensation for “participation”? Are there issues with blurring of “work” and “play”? Should we care whether it is a corporate entity or non-profit sponsoring the games?



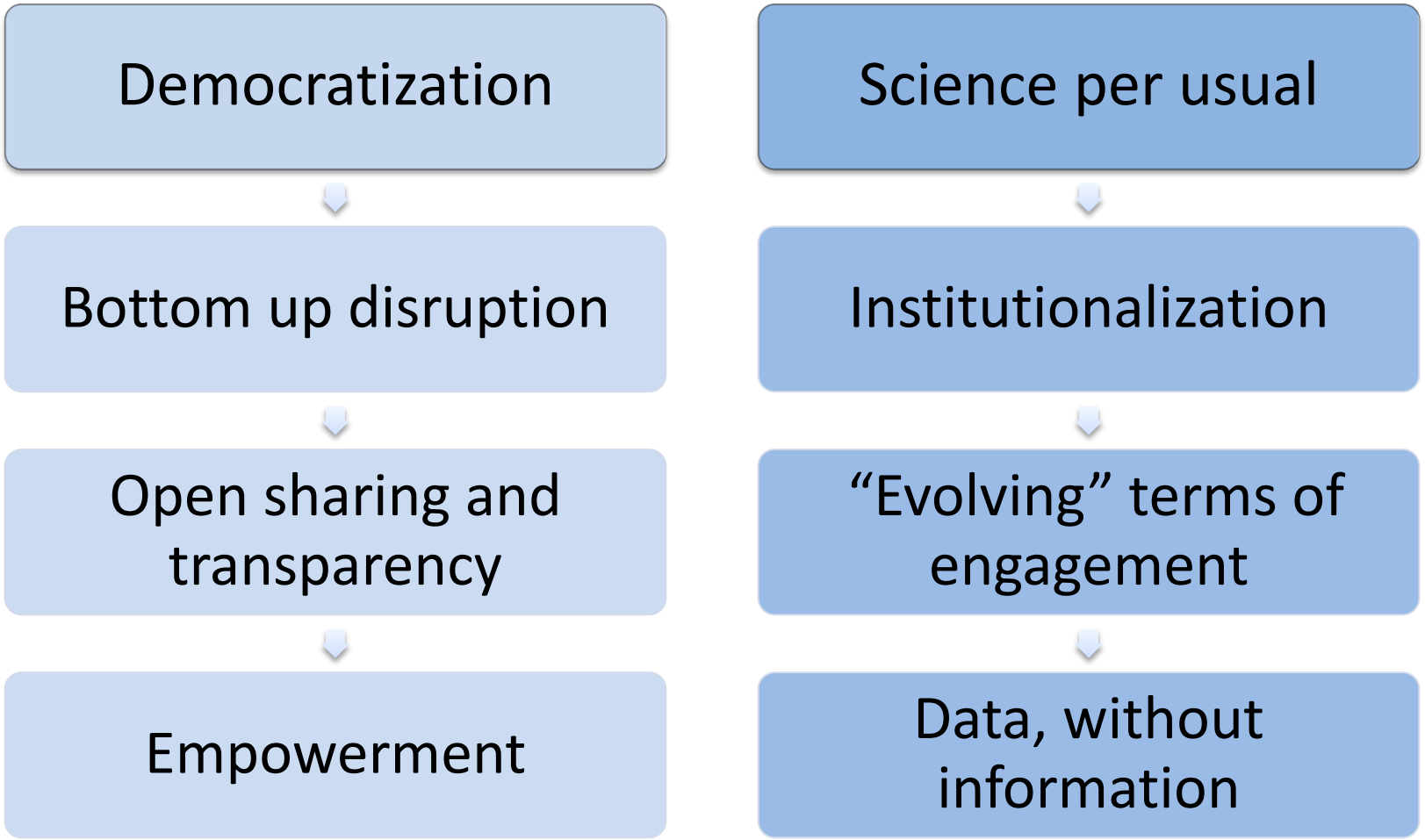


Affective/Visible Communicative Capacity

Participants have opportunities to to produce affect, affiliation, and sociability

What are expectations in the flow of information?
What should participants know about the limits of privacy and data security?
Should there be oversight of dissemination of “expertise” and self-research activities?

Discerning what is new



References

- Bonney, R., Ballard, H., Jordan, R., McCallie, E., Phillips, T., Shirk, J. and Wilderman, C. C. Public Participation in Scientific Research: Defining the Field and Assessing Its Potential for Informal Science Education - a CAISE Inquiry Group Report. , Center for Advancement of Informal Science Education,Washington, DC, 2009.
- Rotman, Dana, Jennifer Preece, Jennifer Hammock, Kezee Procita, Derek Hansen Cynthia Parr, Darcy Lewis, David Jacobs. Dynamic Changes in Motivation in Collaborative Citizen-Science Projects. February 11–15, 2012
- Christopher Kelty, Aaron Panofsky. Disentangling Public Participation In Science and Biomedicine. Genome Medicine. 2014, 6:8