

Nurturing the interface of citizen science

Jennifer Couch

Division of Cancer Biology, NCI, NIH

As much of biomedical research transitions from the realm of single investigator research into the realm of interdisciplinary team science and as integrated analysis of large data sets becomes more necessary and more common, new methods are needed to collect, share and integrate data. In addition to the technical challenges and opportunities, there is opportunity and potential to more directly engage all the stakeholders including patients and healthy individuals, in biomedical research in a more direct and more participatory way. Many fields have used citizen scientists and citizen participants to collect data and carry out research. By and large these efforts have focused on single task: either contributing new data through online tools and apps or recognizing patterns from existing data provided by scientists. These endeavors confirm that “many hands make lighter work” but more importantly they show that citizen are willing, and able, to participate in scientific research.

Biomedical research involves unique constraints and different opportunities for direct engagement of citizens. The sensitive nature of the data, privacy considerations, rigid and distinct regulatory constraints for clinical and research endeavors, traditional funding sources and reward systems, and simply old habits have contributed to silo clinical and research efforts. We are interested in breaking these silos and exploring ways that researchers, patients, and funders can work **together** to pursue biomedical research.

We would like to discuss the opportunities for citizen engagement in biomedical research. We are interested in identifying appropriate and effective methods for data re-use and participatory research that include identification of novel new directions for research. We will discuss the following

What are the risks and benefits of citizen-driven research?

What reward structure would be needed for the researchers who participate?

How to provide repeating value to each constituency?

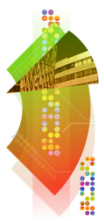
What obstacles and barriers specific to biomedical participatory research exist and how we might help to nurture these emerging partnerships?

How can research traditionally supported by NIH partner with citizen driven research?

Over to You

L- Nurturing the Interface of Citizen Science

G	Organization	Last name	First
L	Northwestern	Blizinsky	Kate
L	Cancer Information & Support Network	Chingos	Diana
L-Lead	NIH/NCI	Couch	Jennifer
L	NIEHS/NIH	Dearry	Allan
L-Anchor	Sage Bionetworks	Derry	Jonathan
L	OHSU	Heiser	Laura
L	Harvard Medical School	Hide	Winston
L-Anchor	Sage Bionetworks	Kellen	Mike
L	National Academy of Sciences	Levey	Cheryl
L	NIH	Mittleman	Barbara
L	UCSF	Oldham	Michael
L	Presage	Olson	Jim
L	Mt. Sinai School of Medicine	Schadt	Eric
L	Kaiser Permanente	Schaefer	Cathy
L	NIH/NCI	Seminara	Daniela
L	UCSC	Szeto	Christopher
L	BGI	Wang	Jun

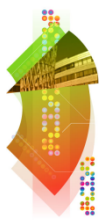


Nurturing the Interface of Citizen Science

Jennifer Couch, NCI/NIH

Project Overview- Major Themes

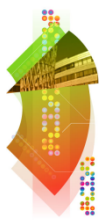
- What are the risks and benefits of citizen-driven research?
- What are the incentives for biomedical researchers who participate?
- What obstacles and barriers specific to biomedical participatory research exist and how we might help to nurture these emerging partnerships?
- How can researchers traditionally supported by NIH partner with citizen driven research?
- What kinds of research questions lend themselves to this model of research?



Needs and Possible Goals

- Enable the acquisition of high dimensional longitudinal data on individuals contributed in ways that make it possible to be used broadly by the biomedical research community.
- Engage the public and researchers: can we understand what kinds of research questions are most effectively answered by these kinds of data or this kind of approach.
- Are there commonalities in the projects that have succeeded? How can we share that?
- Match-making service for aligning researchers with citizen groups & individuals
- Gathering the registries
- Tools for effective data sharing and donation
- Sharing of strategies used by scientists who interact with citizens
- **Barriers & Hurdles**: heterogeneity in citizens' interest and ability to share and self report. Research is needed to understand the characteristics associated with willingness or ability to share and the impact of this on the representativeness of research using citizen science recruitment strategies.

Project L



One Year Goal

Continue this discussion...and...

Partner with an entity like Code for America to create a citizen science central website or portal that allows for content and information on what's working and what isn't; sharing strategies and methods; best practices