

# Citizen Science Common Fund Initiative

January, 2014  
Council of Councils

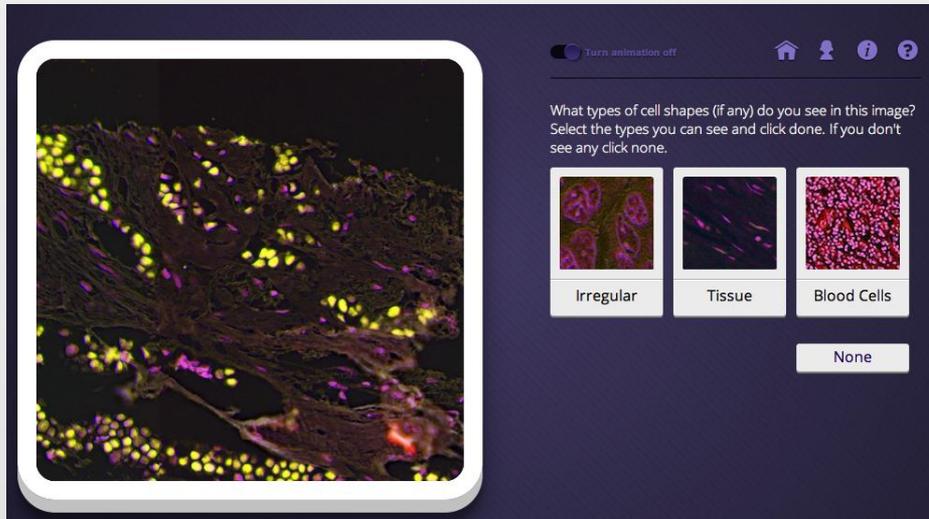
Speaker  
Jennifer Couch, NCI

# Citizen Science Program Background

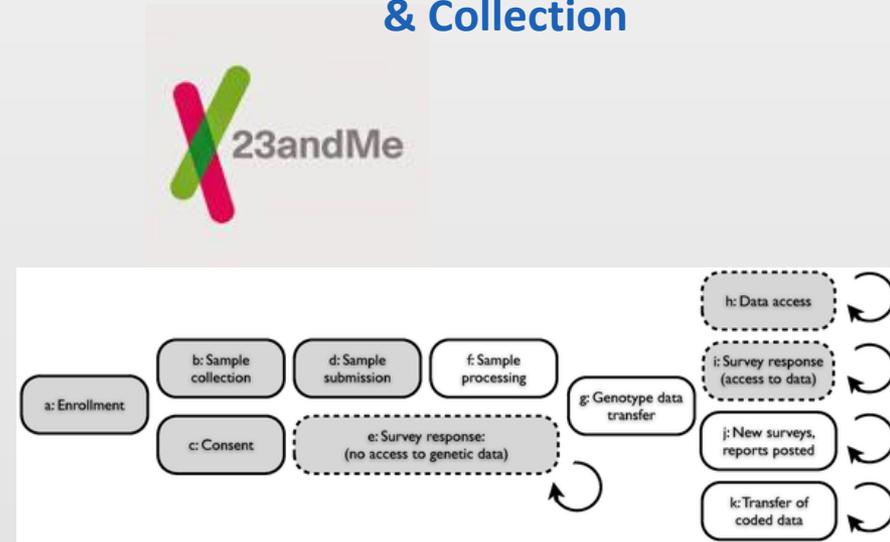
- Citizen Science is a collaborative approach that enables 'Citizens' to more actively participate in the full spectrum of scientific research.
- Citizen Science has a successful history of use in other disciplines.
- Biomedical Research can benefit from the creativity and problem solving skills of the crowd and from citizen collected data and insights not obtainable through conventional approaches.
- Biomedical research poses unique challenges for Citizen Science.
- Biomedical Citizen Science will benefit from a rigorous scientific assessment.
- These new methods have the potential to complement existing research approaches. An NIH Common Fund program is needed to assess the value and impact as well as determine which scientific questions are best addressed by citizen science approaches.

# Examples of Citizen Science Potential

## Data analysis: Cell Slider



## Data Contribution & Collection



## Scientists Ask Public To Find Cure For Cancer Using Interactive Website, Cell Slider



OPEN ACCESS Freely available online

PLoS GENETICS

## Web-Based Genome-Wide Association Study Identifies Two Novel Loci and a Substantial Genetic Component for Parkinson's Disease

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# Citizen Science Working Group

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# May 2013 Think Tank

## Citizen Science: Citizen Engagement in Biomedical Research



Ushahidi?



Personal Genome Project



**DIGITAL MILL**  
we are sharing stories



THE LONG NOW  
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# Strategy for Information Gathering and Concept Refinement

## Workshops conducted

- **Think Tank on Citizen Science: Citizen Engagement in Biomedical Research**, May 2013
- **New Visions for Citizen Science-** A Wilson Center Roundtable Discussion on Open Innovation and Science, Nov 2013
  - The Wilson Center roundtable brought together over 120 people across federal agencies and other outside stakeholders

## Experts Consulted

- Individuals in the areas of bioethics, mHealth, data science, challenges/prizes, and advocacy at NIH and among other federal agencies and other groups such as PCORI

## Portfolio Analysis

- Projects fitting our definition of citizen science are limited within the NIH funding landscape: small ELSI component exists, limited funding of mHealth, games, community and public participation efforts as fitting our definition.

# What We've Learned- Challenges

- Citizen Science methodologies are new to biomedical research.
- Current biomedical research policies, regulations and practices were not designed for Citizen Science methods.
- The creation of flexible infrastructure and governance models that enable multiple levels of participation while maintaining data security, integrity, and scientific rigor is essential.
- Methods need to be developed/adapted and rigorously tested in biomedical research so we know what works and doesn't work.
- Dissemination of tools, best practices, and training resources will be important for researchers and citizens to use citizen science methods effectively.
- Evaluation criteria for Citizen Science approach to biomedical research needs to be developed.

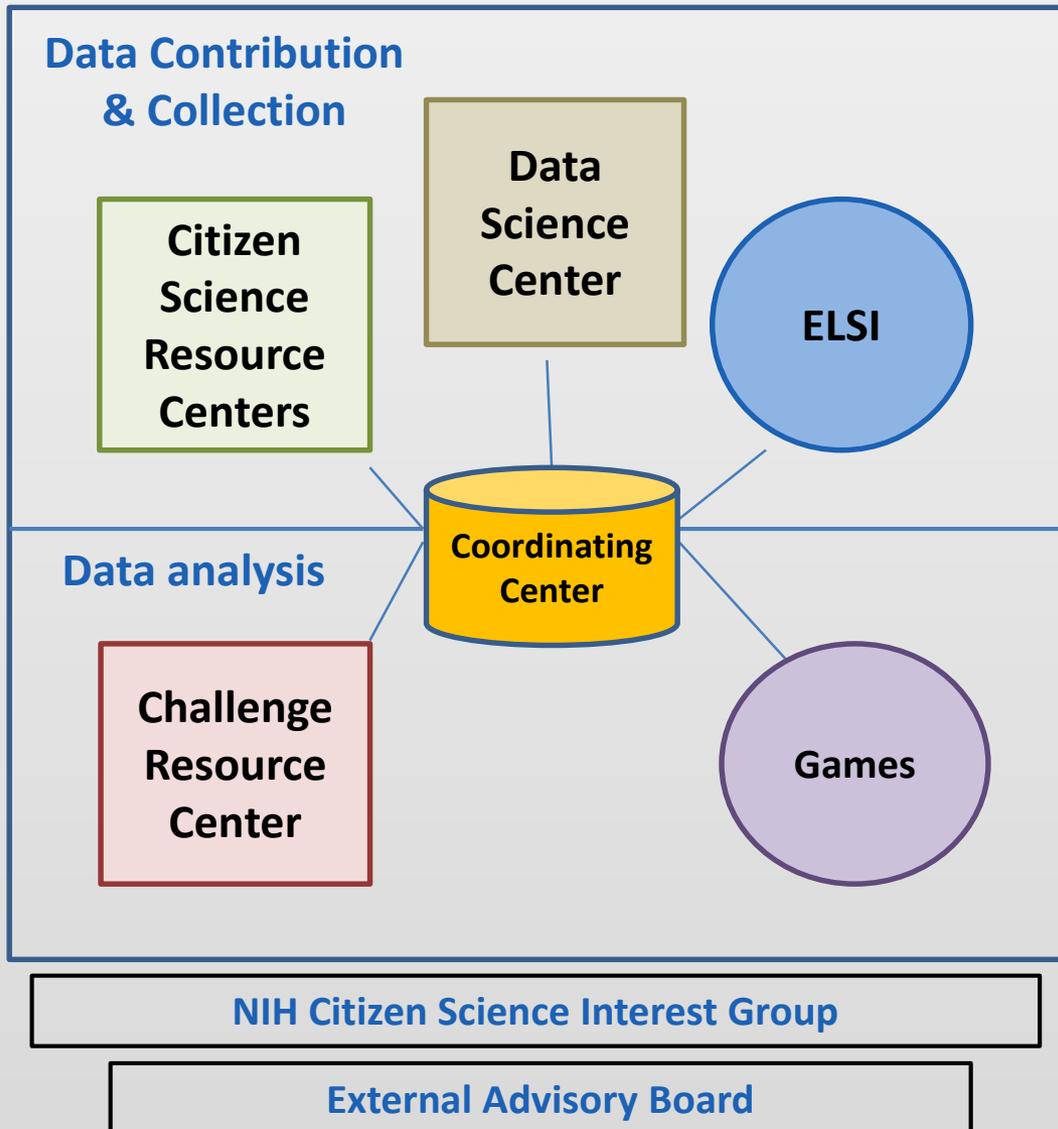
# What We've Learned- Opportunities

- Citizens are eager and able to solve problems if presented with the right tools and opportunities.
- Patients and healthy individuals are motivated to collect and share personal health data.
- Initial applications of Citizen Science methods in biomedical research have shown utility, however currently these efforts are largely going on outside of the NIH.
- Applied effectively citizen science provides an opportunity to accomplish research we cannot accomplish using traditional methods.
- There is an need to assess and evaluate Citizen Science methods, to determine the value add of this new collaborative model in biomedical research.

# Goals of Citizen Science Common Fund Program

- Create a scientifically rigorous environment within which to adapt, test, and validate citizen science methodologies applied to biomedical research.
- Investigate the “Science of Citizen Science” to determine what works and what doesn’t. Assess which kinds of scientific questions are best addressed using Citizen Science approaches.
- Communicate knowledge, best practices, and successful citizen science methodologies to the biomedical researcher community.
- Assess the infrastructural needs and computational demands associated with direct engagement of patients and the public in data collection, data donation, and data analysis.
- Investigate the ethical, legal, and social implications of biomedical research that uses citizen science methodologies.
- Develop appropriate metrics of evaluation for citizen science methodologies in biomedical research.

# Citizen Science Consortium



## Deliverables

- **Rigorously tested methods** validated on biomedical research questions
- **Best practices:** an understanding of which approaches work best for categories of research questions
- **Clearinghouse:** dissemination of citizen science opportunities and methods.
- **Evaluation criteria** for citizen science methods in biomedical research

# Long Term Outcomes

- NIH involvement at this critical stage of development of biomedical citizen science will ensure that citizen science methodologies in biomedical research are incorporated in a way that meets our rigorous scientific standards and can be effectively reviewed in our granting system.
- A Common Fund program in Citizen Science will rigorously test and evaluate the use of citizen science methodologies and approaches in biomedical research.
- Costs required to maintain the benefit of the program: Successful methods and approaches will be disseminated to the research community as complementary research strategies. Limited on-going costs may be required for clearing house functions.

**Comments?**