NIH CITIZEN SCIENCE WORKING GROUP

CITIZEN SCIENCE WORKING GROUP DESCRIPTION
This trans-NIH working group of program officers, scientific review officers, and others from across NIH is interested in investigating the utility of and furthering the incorporation of citizen science methodologies into biomedical research in a way that maintains NIH’s high level of scientific and ethical standards. Citizen Science is a collaborative approach to research involving the public, not just as subjects of the research or advisors to the research but as direct collaborators and partners in the research process itself. This group investigates, shares best practices and engages in discussion with other agencies and groups promoting citizen science in other fields.

AREAS OF INTEREST
Ethical, legal and social implications (ELSI) of citizen science in biomedical research: IRB and OHSRP implications
How games and online/mobile puzzles can be made to help biomedical research Ex: Foldit, EteRNA, Eyewire, Cell Slider, Worm Watch, Malaria Spot
Data science Issues: Data governance and provenance as well as the complexities of dealing with often unstructured citizen collected or donated data
Challenge competitions: How can challenge platforms be best utilized to answer biomedical questions? How can the public be incentivized to help us solve biomedical problems?
Do-it-Yourself Science/Maker Movement: Scientific experiments, devices, etc. performed by people of all ages and expertise levels, outside of the traditional college, university, industry, or government laboratory.
The Science of Citizen Science: Which methods work best for which kinds of projects, and how?

ENGAGEMENT ACROSS THE FEDERAL GOVERNMENT
We have engaged several federal agencies to learn about their citizen science, crowdsourcing, and challenge competition efforts including EPA, NASA, and the GSA. We participate in the Federal Community of Practice on Crowdsourcing and Citizen Science (CCS), a trans-agency citizen science community of practice that shares developments in citizen science and crowdsourcing research methodology, and plans related workshops. The CCS was recently involved in assembling a toolkit on Federal citizen science and crowdsourcing in collaboration with the Office of Science and Technology Policy (OSTP), and are now working to develop a catalog of Federal citizen science and crowdsourcing projects, to be launched in Spring 2016.

THE BIOMEDICAL CITIZEN SCIENCE HUB
The Biomedical Citizen Science Hub, CitSciBio.org, is sponsored by the Division of Cancer Biology and the Division of Cancer Control and Population Sciences at the National Cancer Institute, one of the 27 Institutes and Centers at the National Institutes of Health. Our intent is to create an online collaboration space for the growing and virtually dispersed biomedical citizen science resources, projects, references, methods, and communities to be discovered and engaged by interested stakeholders. Please go to citscibio.org or follow us on twitter @CitSciBio for more information.
PAST WORKING GROUP ACTIVITIES

Implementation Barriers & Metrics of Success (September 2, 2015): Representatives from across the Federal government came together to discuss the barriers to implementing federally-run or funded citizen science projects, and what metrics were used to measure success of the projects.

Workshop to Explore the Ethical, Legal, and Social Implications (ELSI) of Citizen Science Related to the NIH Mission (January 13 - 14, 2015): Experts from the fields of bioethics, data science, privacy, advocacy, academia, community-based participatory research, environmental health (and members of the federal government) were brought together to share their perspectives, experience, and expertise on ELSI issues in biomedical citizen science. The purpose of this workshop is to identify the ELSI challenges raised by Citizen Science in the context of biomedical research, and identify ways for NIH to address these ELSI issues. For more: http://livestream.com/GenomeTV/events/3690325

Think Tank: Game Developers & Biomedical Researchers (December 8 - 9, 2014): The office of the Associate Director for Data Science (ADDS) within the National Institutes of Health (NIH) sponsored this one and a half day meeting that brought together game developers and biomedical scientists with research issues that involve big data. The meeting included discussions by participants about meta-issues in the development of games to facilitate research, including the development of recommendations to address these issues. For more: https://datascience.nih.gov/sites/default/files/bd2k/docs/BD2K_GDBRsummary.pdf

NIH Citizen Science Working Group: Think Tank on Citizen Engagement in Biomedical Research (May 2013): The working group invited experts from the non-profit, for-profit, and academic sectors who had successfully run biomedical citizen science projects. The key recommendation from this group: the opportunity is vast and the methods work, but NIH entry into this space would bring a much-needed level of scientific rigor that the community would welcome.