

**Workshop to Explore the Ethical,
Legal, and Social Implications (ELSI)
of Citizen Science Related to the
NIH Mission**

January 13-14, 2015

Rockville, MD

Welcome!



- Webcast: <http://1.usa.gov/N973or>
or search for Genome TV
- Twitter: #CitSciELSI
- **Acknowledgments**
 - Meeting sponsored by the National Cancer Institute (NCI), the National Human Genome Research Institute (NHGRI), and the National Center for Advancing Translational Sciences (NCATS)
 - Meeting planned by NIH Citizen Science ELSI Subgroup
Members: Charlisse Caga-anan (NCI), Dave Kaufman (NHGRI), Katrina Theisz (NCI); Steven Becker (NEI), Elaine Collier (NCATS), Jennifer Couch (NCI), Leslie Derr (OD), Symma Finn (NIEHS), Elizabeth Gillanders (NCI), Megan Kinnane (NIMH), Jean McEwen (NHGRI), Gabriel Rosenfeld (NIAID), Amanda Vogel (NCI), Carol Weil (NCI)

14 NIH Institutes Represented in Citizen Science Working Group

- **NCATS** - National Center for Advancing Translational Sciences
- **NCI** - National Cancer Institute
- **NHGRI** - National Human Genome Research Institute
- **NHLBI** - National Heart, Lung, and Blood Institute
- **NIA** - National Institute on Aging
- **NIAID** - National Institute of Allergy and Infectious Diseases
- **NIBIB** - National Institute of Biomedical Imaging and Bioengineering
- **NICHD** - Eunice Kennedy Shriver National Institute of Child Health and Human Development
- **NIDCR** - National Institute of Dental and Craniofacial Research
- **NIDDK** - National Institute of Diabetes and Digestive and Kidney Diseases
- **NIEHS** - National Institute of Environmental Health Sciences
- **NIMH** - National Institute of Mental Health
- **NLM** - National Library of Medicine
- **OD** - NIH Office of the Director

Background



- **Workshop Purpose**

- Citizen Science is an approach to research that involves the public directly in the research process itself as partners and collaborators. 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. The term "biomedical" is used in the broadest sense to include a wide range of research related to the NIH mission: biological, biomedical, behavioral, social, environmental and clinical studies that relate to understanding health and disease.

Background , cont'd

Workshop Goals

1. To identify prominent ELSI issues associated with various types of Citizen Science research projects (for consideration by NIH policymakers and for use by investigators leading such projects).
2. To identify gaps in ELSI research on Citizen Science relevant to NIH's mission.
3. To plan for continued, expanded engagement of Citizen Science and bioethics communities to further develop criteria and guidance for NIH Citizen Science research activities.

Background, cont'd

- Invited Participants
- Meeting Structure
 - Exploration of issues as they arise throughout research process
 - Emphasis on discussion
 - Encourage participation throughout the meeting

Housekeeping



- Slides – Please send to Katrina Theisz
- Microphones
- Internet Connectivity
- Food/Cafeteria
- Bathrooms
- Parking
- Hotel and Airport Transportation
 - Day 1: 5:45 PM Shuttle pick up at Fishers Lane Conf. Ctr.
 - Day 2:
 - 7:45 & 8AM Shuttle pick up at Hilton Hotel
 - After meeting: Coordinate "cab share" to airports

Thank you!

