

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

January 13 to 14, 2015  
5635 Fishers Lane, Rockville, MD

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**NIH Citizen Science ELSI Subgroup (Meeting Planners):** 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)

**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.

**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.

**AGENDA:**

	<b>TUESDAY, JANUARY 13, 2015</b>
<b>8:00 to 8:30 AM</b>	<b>Registration and Networking</b>
<b>8:30 to 10:30 AM</b>	<p><b>Session 1. Welcome, Landscape of Citizen Science at NIH, and Introduction to ELSI Issues</b></p> <p><i>Welcome and charge/workshop goals</i></p> <ul style="list-style-type: none"><li>• <b>Dave Kaufman, NHGRI</b></li><li>• <b>Charlisse Caga-anan, NCI</b></li></ul> <p><i>Lay of the land for Citizen Science at NIH</i></p> <ul style="list-style-type: none"><li>• <b>Jennifer Couch, NCI</b></li><li>• <b>Elizabeth Gillanders, NCI</b></li></ul> <p><i>Participant Introductions (Five rounds of paired discussion - 10 minutes total)</i></p> <p><i>Overview of Citizen Science methodologies</i></p> <ul style="list-style-type: none"><li>• <b>Pietro Michelucci, Strategic Analysis, Inc.</b></li></ul> <p><i>Initial elicitation and discussion of ELSI issues</i></p> <ul style="list-style-type: none"><li>• <b>Sandra Soo-Jin Lee, Stanford</b></li><li>• <b>Kelly Edwards, University of Washington</b></li></ul>

10:30 to 11:00 AM	Break
11:00 AM to 12:45 PM	<p><b>Session 2. Building the Relationship: Citizen and Community Engagement in the Development of Research Projects</b></p> <ul style="list-style-type: none"> <li>• Mildred Cho, Stanford University (Moderator)</li> <li>• Nick Anderson, UC Davis</li> <li>• Sally Okun, Patients Like Me</li> <li>• Holly Peay, Parent Project Muscular Dystrophy</li> <li>• Elizabeth Yeampierre, UPROSE</li> </ul>
12:45 to 1:30 PM	Lunch
1:30 to 3:10 PM	<p><b>Session 3. Planning the Study: ELSI Issues in Study Design and Governance</b></p> <ul style="list-style-type: none"> <li>• Sara Hull, NIH (Moderator)</li> <li>• Deborah Collyar, Patient Advocates in Research (PAIR)</li> <li>• Sarah Greene, PCORI</li> <li>• John Wilbanks, SAGE Bionetworks</li> <li>• Pearl O'Rourke, Board Chairman of PRIM&amp;R, Harvard/Partners</li> <li>• Effy Vayena, University of Zurich</li> </ul>
3:10 to 3:25 PM	"Think-Pair-Share"
3:25 to 3:45 PM	Break
3:45 to 5:30 PM	<p><b>Session 4. Conducting the Study: ELSI Issues in Data Collection and Analysis</b></p> <ul style="list-style-type: none"> <li>• Deven McGraw, Manatt, Phelps &amp; Phillips, LLP (Moderator)</li> <li>• Jason Bobe, The Personal Genome</li> <li>• Steve Wing, UNC-Chapel Hill</li> <li>• Jennifer Fishman, McGill University</li> </ul>
5:30 to 5:45 PM	Participants share one insight from the day that they are taking forward, in one sentence or phrase.

	<b>WEDNESDAY, JANUARY 14, 2015</b>
8:00 to 10:00 AM	<p><b>Session 5. After the Study: Roles and Responsibilities for Citizen Scientists/Researchers Once the Research Has Concluded</b></p> <ul style="list-style-type: none"> <li>• Sharon Terry, Genetic Alliance (Moderator)</li> <li>• Julia Brody, Silent Spring Institute</li> <li>• Laura Cleveland, Patient Advocate</li> <li>• Denise Dillard, Southcentral Foundation</li> <li>• Sacoby Wilson, University of Maryland</li> </ul>
10:00 to 10:30 AM	Break

<b>10:30 AM to 12:00 PM</b>	<b>“World Café” (3 rounds, 25 minutes per round)</b>
<b>12:00 to 12:30 PM</b>	<b>Lunch</b>
<b>12:30 to 3:00 PM</b>	<b>Session 6. Putting It All Together</b>  <b>Recommendations for ELSI Points to Consider in Conducting Citizen Science Research (12:30 to 1:45 PM)</b> <ul style="list-style-type: none"><li>• <b>Moderator: Kelly Edwards, University of Washington</b></li></ul> <b>Identifying Gaps in ELSI Research on Citizen Science (1:45 to 3:00 PM)</b> <ul style="list-style-type: none"><li>• <b>Moderator: Jeff Kahn, Johns Hopkins University</b></li></ul>
<b>3:00 to 3:30 PM</b>	<b>“Think-Pair-Share”</b>  <b>Participants share one insight from the day that they are taking forward, in one sentence or phrase.</b>  <b>Concluding Remarks</b>