ENGAGING CITIZEN SCIENTISTS TO ADVANCE BIOMEDICAL RESEARCH

A symposium on biomedical citizen science and crowdsourcing

July 14, 2017  |  10:30 am – 3:00 pm
Natcher Conference Center Rm E1/E2
National Institutes of Health, Bethesda, MD

Please note that this symposium is being recorded for archival purposes, to be made available for future viewing by NIH staff only. WebEx is being used so that NIH employees working remotely are able to participate.
MESSAGE FROM THE PLANNING COMMITTEE

Welcome to our first NIH symposium on citizen science and crowdsourcing! Our goal is to excite you, our fellow NIHers, about using citizen science and crowdsourcing to engage public participation in scientific research. We’ll start by showcasing a few citizen science and crowdsourcing projects with experiences shared by both the researchers and citizen scientists, then make connections through the working lunch, and end by learning more about some of the myths and truths of federal citizen science and crowdsourcing. We hope you enjoy yourselves today!

Sincerely,
The Planning Committee

<table>
<thead>
<tr>
<th>Steven Becker, NEI</th>
<th>Olga Brazhnik, NCATS</th>
<th>Elaine Collier, NCATS</th>
<th>Jennifer Couch, NCI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elizabeth Gillanders, NCI</td>
<td>Jean McEwen, NHGRI</td>
<td>Katrina Theisz, NCI</td>
<td></td>
</tr>
</tbody>
</table>

AGENDA

10:00 a.m. – 10:30 a.m. Registration opens (Natcher Rm E1/E2)

10:30 a.m. – 10:45 a.m. Interactive Introductions
Olga Brazhnik, NCATS

10:45 a.m. – 11:00 a.m. Welcome
Jennifer Couch, NCI

11:00 a.m. – 12:30 p.m. Citizen Science & Crowdsourcing: Success Stories and Challenges Faced Along the Way
Insights from investigators and citizen scientists

   EyeWire
   Amy Sterling & Melissa Martin

   The Metastatic Breast Cancer Project
   Nikhil Wagle & Corrie Painter

   Barcode Long Island
   Dave Micklos & Elizabeth Scianno

12:30 p.m. – 1:45 p.m. Working lunch (PRE-ORDER lunch boxes from Eurest; find a table in the atrium)

12:30 p.m. – 12:45 p.m. Grab your lunch and choose a table in the atrium (upstairs, overlooking the lower level conference rooms)!

12:45 p.m. – 1:45 p.m. Goal is to meet others and to talk to people you don’t know

1:45 p.m. – 2:45 p.m. Panel Discussion: Busting Citizen Science and Crowdsourcing Myths
Jay Benforado, EPA
Sophia B. Liu, USGS
John McLaughlin, NOAA
Tammy White, GSA

2:45 p.m. – 3:00 p.m. Concluding Remarks/Adjourn
INSIGHTS FROM INVESTIGATORS AND CITIZEN SCIENTISTS

Amy Sterling

Amy Robinson Sterling is the Executive Director of EyeWire, a game to map the brain. EyeWire crowdsources neuroscience, challenging hundreds of thousands of players around the world to solve 3D puzzles and map out neurons, allowing neuroscientists to chart synaptic connections and model information processing circuitry. Sterling has advised The White House OSTP and the US Senate on crowdsourcing and open innovation. Under her leadership, Eyewire’s neuroscience visualizations have appeared at TED, the United Nations, and in Times Square NYC. She helped create the world’s first neuroscience virtual reality experience. Sterling curates the NIH 3D Print Exchange Neuroscience collection, which features several 3D printable neurons discovered by Eyewire gamers. Fast Company credits Amy with "making neuroscience into a playground for the hot tech du jour."

Melissa Martin

Melissa Martin has been participating in online-based citizen science projects since 2012. She developed an interest in science at an early age and, after receiving a B.S. in Wildlife Management from the University of Arkansas at Little Rock, still enjoys dabbling in the sciences as much as she can. A second-generation zookeeper, she spends the majority of the time she's not tracing mouse neurons caring for primates and other exotic animals, or volunteering at her local therapeutic riding center.

Nikhil Wagle

Nikhil Wagle is an Assistant Professor of Medicine at Harvard Medical School, a medical oncologist at Dana-Farber Cancer Institute, and an associate member of the Broad Institute of MIT and Harvard. He is the Deputy Directory of the Center for Cancer Precision Medicine at Dana-Farber Cancer Institute. He received his MD from Harvard Medical and completed his residency training in internal medicine at Brigham and Women’s Hospital, where he also served as chief medical resident, and completed his fellowship training in hematology/oncology in the Dana-Farber/Partners program. Dr. Wagle leads a translational research program in the field of breast cancer genomics and precision (or "personalized") cancer medicine. The major goals of his work are to better understand the biology of metastatic breast cancer and to develop new ways to overcome or prevent drug resistance in patients with advanced breast cancer. Ultimately, his research aims to identify characteristics of tumors that might improve clinical decision-making for patients with advanced cancer.

He also leads The Metastatic Breast Cancer Project (mbcproject.org), a nationwide direct-to-patient research initiative that engages patients with advanced breast cancer through social media and seeks to empower them to accelerate cancer research through sharing their samples and clinical information. The project’s outreach program, developed in collaboration with advocacy organizations and patients, serves to connect thousands of patients around the U.S. with metastatic breast cancer research, allowing them to participate regardless of where they live.
Corrie Painter

Corrie Painter is the Associate Director of Operations and Scientific Outreach at the Broad Institute. A trained cancer researcher with a Ph.D. in biochemistry, Painter partners with advocacy groups and engages patients for genomics studies conducted at the Broad Institute where patients can consent online to donate their stored tumor samples, saliva, medical records and their voice to directly accelerate the pace of discovery. These efforts can be followed on Twitter #MBCproject, @MBC_project, @Corrie_Painter, #ASCproject, on FaceBook, The Metastatic Breast Cancer Project, as well as The Angiosarcoma Project Working Group.

Painter, an angiosarcoma survivor, is also a passionate leading patient advocate who co-founded and serves as the Vice-president of Angiosarcoma Awareness Inc, an organization that supports research and awareness efforts surrounding this disease.

Dave Micklos

Dave Micklos is founder and Executive Director of the DNA Learning Center (DNALC), the nation's first science center devoted to public genetics education. The DNALC is an operating unit of Cold Spring Harbor Laboratory, ranked #1 worldwide for citation impact in molecular biology and genetics. The DNALC has an annual operating budget of US $4 million and employs a multidisciplinary staff of 25 biologists, certified teachers, science communicators, designers, and computer programmers. With satellite centers in Nassau County and Harlem, the DNALC’s six teaching laboratories provide hands-on science experiences to 30,000 students per year. An estimated 300,000 students per year use methods and commercial lab kits developed by the DNALC. The DNALC was the model for teaching laboratories established at 16 museums and higher education institutions around the world, which provide labs for 130,000 students annually. The DNALC’s Internet portal hosts 22 proprietary content and bioinformatics sites, along with other digital multimedia, receive 7 million visitors and downloads annually. Mr. Micklos’ three textbooks, DNA Science, Laboratory DNA Science, and Genome Science, as well as many articles have helped popularize DNA education in high school and college classrooms. He received the 1990 Dana Award for Pioneering Achievement in Education, the 2011 Science Prize for Online Resources in Education, and the 2012 Genetics Society of America Award for Excellence in Education. He is a Fellow of the American Association for the Advancement of Science (AAAS) and is the only CSHL staff member to receive an honorary Doctor of Science degree from its Watson School of Biological Sciences.

Elizabeth Scianno

Elizabeth is currently a 12th grader attending William Floyd High School on Long Island, NY. She has been involved in scientific research since the 9th grade, and has worked with Barcode Long Island and Cold Spring Harbor’s DNA Learning Center for 3 years on her projects. Her favorite scientific subjects include biology and marine life. Even though she does not plan on pursuing a major in science in college, she hopes to continue looking into marine ecosystems in order to help discover ways to improve the world around us. Her hobbies include reading, singing, researching new topics, and writing.
BUSTING CITIZEN SCIENCE AND CROWDSOURCING MYTHS

Jay Benforado
Chief Innovation Officer, Office of Research and Development
Jay Benforado is a senior executive in the U.S. EPA’s Office of Research and Development. As Chief Innovation Officer, he encourages new approaches to sustainability, including a competitive program that provides internal awards to EPA scientists for high-risk, high-reward research – from sustainable alternatives to toxic chemicals to net zero approaches for water, waste, and energy in communities. Other innovation activities include challenges and prizes, development of real-time environmental sensors for air and water pollution, and using citizen science to empower communities. Previous positions at EPA include Director of the National Center for Environmental Innovation and Deputy Associate Administrator for Policy, Economics and Innovation in the Office of the Administrator.

Sophia B. Liu
Dr. Sophia B Liu is the first Innovation Specialist at the U.S. Geological Survey (USGS) working with the Science and Decisions Center, the Energy and Minerals mission area, and the Office of Enterprise Information. She is also the Co-Chair of the Federal Community of Practice for Crowdsourcing and Citizen Science (CCS) as well as the CCS Coordinator for USGS and the Department of Interior. During her USGS Mendenhall Postdoctoral Fellowship (2011 - 2015) research on crowdsourcing, citizen science, and civic hacking, she previously worked at the USGS National Earthquake Information Center on the Tweet Earthquake Dispatch project, at the St. Petersburg Coastal Marine Science Center on the "iCoast - Did the Coast Change?" project, and at the USGS National Center on Visualizing Critical Minerals data. Dr. Liu was also awarded a National Science Foundation (NSF) Graduate Research Fellowship in 2006 and received her Ph.D. at the University of Colorado, Boulder in an interdisciplinary program called Technology, Media, and Society. Her doctorate research focused on how the use of social media pertaining to historically significant crises facilitated socially distributed curation to share and manage crisis information in the social media landscape. She also received a B.A. at University of California, Irvine in Social Science with a minor in Information & Computer Science and in Digital Arts.

Dr. Liu applies human-computer interaction and computer-supported cooperative work techniques to better understand the social and behavioral uses of information and communication technology and inform the design of future crowdsourcing, citizen science, and civic hacking efforts that improve government services. She also explores the Socio-cultural, Technological, Organizational, and Policy (STOP) opportunities and challenges with integrating data from the general public and how data science is enabling the communication of information and science online in more interactive ways.

John McLaughlin
John McLaughlin is a Program Manager at NOAA's Office of Education. He also serves as NOAA’s Citizen Science Coordinator and established a Community of Practice to facilitate communication among people within the Agency interested in empowering the public to participate in NOAA science. He represents the Agency in efforts to expand citizen science government-wide, as well as in partnerships with the broader field. Prior to coming to NOAA he worked for the GLOBE Program, where he trained teachers around the world to collect and analyze environmental measurements and organized field campaigns partnering scientists and students. John enjoys measuring precipitation and observing clouds and contrails.

Tammy White
Tammy White is the senior communications and IT platform specialist for Challenge.gov at the U.S. General Services Administration (GSA). In her role, she provides customer/agency training, supports the program's outreach and communications efforts, and guides Challenge.gov’s technology roadmap. Tammy has a demonstrated track record of conceptualizing and implementing communications and new media strategies for agencies, including GSA and the Department of the Navy, as well as private-sector brands like AOL Time Warner, CNN AccentHealth and Revolution Health. As a web strategist and social media engineer, she believes that developing strong customer engagement begins with clear, concise and credible content complemented by simple, attractive user-focused visual systems. Tammy holds both a B.S. in Biology and a B.A. in English from the University of Mary Washington (formerly Mary Washington College).
This meeting was sponsored by the Division of Cancer Biology (DCB)
For more information about DCB please go to: cancer.gov/DCB