

# Unique Insights From Shared Data

# FACT SHEET: PRIZE BACKGROUND

The Open Science Prize is a collaboration between the National Institutes of Health (Bethesda, Maryland, USA) and the Wellcome Trust (London, UK), with additional funding provided by the Howard Hughes Medical Institute (Chevy Chase, Maryland, USA) to unleash the power of open content and data to advance biomedical research and its application for health benefit.

The prize provides funding to encourage and support the prototyping and development of services, tools, or platforms that enable open content – including publications, datasets, codes, and other research outputs – to be discovered, accessed, and re-used in ways that will advance discovery and spark innovation.

The prize also aims to forge new international collaborations of open science innovators to develop services and tools and whose reach transcends national and disciplinary boundaries, benefiting the global research community and the wider public. Teams applying for the prize are required to have at least one member based in the United States and at least one member based in another country.

First announced in the fall of 2015, the Open Science Prize initially received 96 submissions representing 45 countries from around the world. From those, 6 were awarded Phase 1 prizes of \$80,000 to build prototypes to make their proposed ideas a reality. The public is now invited to review the 6 resulting prototypes and cast their vote for the most novel and impactful ones. The 3 prototypes receiving the highest number of public votes will advance to a final round of review by a panel of science experts and judges from NIH and Wellcome Trust. A single, grand prize of \$230,000, jointly funded by the collaborators, will be announced in early 2017.



Cast your vote to help shape new directions in health research by selecting the most promising and innovative prototypes.

Vote at OpenSciencePrize.org







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# Unique Insights From Shared Data

# **OpenAQ: Real-Time Air Quality Data**

# PROVIDING REAL-TIME INFORMATION ON POOR AIR QUALITY BY COMBINING DATA FROM ACROSS THE GLOBE

Poor air quality is responsible for one of eight deaths across the world. Accessible and timely air quality data are critical to advancing the scientific fight against air pollution and essential for health research. OpenAQ aims to provide more timely information on poor air quality by combining the world's publicly available, official real-time data onto one open-source and open data platform.

#### THE TEAM



Christa Hasenkopf, OpenAQ Michael Brauer, University of British Columbia Joseph Flasher, Development Seed Asep Sofyan, Institut Teknologi Michael Hannigan, University of Colorado

### HOW THE PARTNERSHIP WAS FORMED:

"The OpenAQ team hails from the U.S., Canada, Indonesia and Portugal, but the OpenAQ Community is much larger. Software developers, journalists and scientists from Mongolia to Spain to Rwanda have been helping create the open-source platform, building on top of it, and using the data. The seed of OpenAQ emerged a few years ago from a small open air quality project in pollution-prone Ulaanbaatar, Mongolia, launched by Joe Flasher and Christa Hasenkopf along with colleagues at the National University of Mongolia.

Amazed at the outsized-impact a little open, real-time air quality data can have on a community, Christa, an atmospheric scientist, and Joe, a software developer, wondered: what would happen if all of the world's air quality data were made available for the public to explore? Sitting in their living room about a year ago, they quit wondering, started building, and asking passionate people around the world to help."

## CONTACT INFORMATION: CHRISTA HASENKOPF (CHRISTA@OPENAQ.ORG)









Unique Insights From Shared Data

# Real-Time Evolutionary Tracking for Pathogen Surveillance and Epidemiological Investigation

PERMITTING ANALYSIS OF EMERGING EPIDEMICS SUCH AS EBOLA, MERS-COV, AND ZIKA

The goal of this project is to promote open sharing of viral genomic data and harness this data to make epidemiologically actionable inferences. The team will develop an integrated framework for real-time molecular epidemiology and evolutionary analysis of emerging epidemics, such as Ebola virus, MERS-CoV, and Zika virus. The project will use an online visualization platform where the outputs of statistical analyses can be used by public health officials for epidemiological insights within days of samples being taken from patients.

### THE TEAM



**Richard Neher**, Max Planck Institute for Developmental Biology **Trevor Bedford**, Fred Hutchinson Cancer Research Center

### HOW THE PARTNERSHIP WAS FORMED:

"Trevor Bedford studies viral phylodynamics at Fred Hutch in Seattle and Richard Neher studies adaptive evolution at the Max Planck Institute for Developmental Biology in Tübingen, Germany. The initial discussions and prototyping of the nextflu project happened while we were attending a workshop at the Kavli Institute for Theoretical Physics in Santa Barbara, California, in 2014. Further development work continued split between the U.S. and Germany and eventually resulted in the website <u>http://nextflu.org</u>. The Open Science Prize gives us a platform to expand this project to a host of other viruses via the website <u>http://nextstrain.org</u>. We hope to provide a platform for real-time data sharing and analysis in a variety of outbreak scenarios."

## CONTACT INFORMATION: TREVOR BEDFORD (TBEDFORD@FREDHUTCH.ORG)









# Unique Insights From Shared Data

# **Open Neuroimaging Laboratory**

# ADVANCING BRAIN RESEARCH BY ENABLING COLLABORATIVE ANNOTATION, DISCOVERY, AND ANALYSIS OF BRAIN IMAGING DATA

There is a massive volume of brain imaging data available on the Internet, capturing different types of information such as brain anatomy, connectivity, and function. This data represents an incredible effort of funding, data collection, processing, and the goodwill of thousands of participants. The development of a web-based application called BrainBox will enable distributed collaboration around annotation, discovery, and analysis of publicly available brain imaging data, generating insight on critical societal challenges such as mental disorders, but also on the structure of our cognition.

#### THE TEAM



Amy Robinson, Wired Differently, Inc. Roberto Toro, Institut Pasteur Katja Heuer, Max Planck Institute Satrajit Ghosh, MIT

### HOW THE PARTNERSHIP WAS FORMED:

"At its vibrant frontier, neuroscience is becoming the playground of a worldwide interdisciplinary community which our team reflects well: we come from four different continents and diverse backgrounds. Roberto, Katja, and Satra met at a BrainHack unconference, an event of art, science, and sleepless nights. Later, Katja met Amy in a conference on arts and neuroscience, and at MIT, a neurotechnology class linked Amy, Satra, and eventually Roberto. We share a passion for open science and collaboration, a keen interest in neuroanatomy and visualization, and a drive to engage humanity in understanding ourselves better in health and in disease. Amy, through Eyewire, is allowing thousands of people to map the brain through games and Roberto has been pleading with all of us around him to work on crowdsourced solutions for brain imaging. The Open Science Prize competition gave us the opportunity to merge these interests and to hopefully attract a worldwide community."

## CONTACT INFORMATION: ROBERTO TORO (RTO@PASTEUR.FR)











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# ENABLING BETTER ACCESS TO DRUG APPROVAL PACKAGES SUBMITTED TO AND MADE AVAILABLE BY THE FOOD AND DRUG ADMINISTRATION

**OpenTrialsFDA** 

OpenTrialsFDA aims to increase access, discoverability, and opportunities for re-use of a large volume of high quality information in the publicly available Federal U.S. Food and Drug Administration drug approval packages. These review packages often contain information on clinical trials that have never been published in academic journals. However, despite their high value, these FDA documents are notoriously difficult to access, aggregate, and search. As a consequence, they are rarely used by clinicians and researchers. The project will allow third party platforms to access, search, and present the information, thus maximizing discoverability and impact.

THE TEAM

OpenTrialsFDA

Emma Beer, Paul Walsh, James Gardner, Open Knowledge Int. Erick Turner, Oregon Health & Science University Ben Goldacre, University of Oxford

#### HOW THE PARTNERSHIP WAS FORMED:

When he was a research investigator working at the NIH, Erick Turner believed he had access to everything researchers, doctors, and patients needed to know about medications. Later, when he became an FDA reviewer, he realized that a great deal of clinical trial information known to the FDA as part of the drug approval review processes is never reported in the scientific literature. While the information is available via the Drugs@FDA archive, it is quite hard to use, and so this information is often neglected. After Erick left the FDA, he wished this valuable trove of data could be unlocked. Then, Erick met Ben Goldacre, an academic, book author, TED speaker, and the force behind high-profile transparency-promoting initiatives, including OpenTrials, AllTrials, and COMPare. Through in-person meetings on each other's home turf, Drs. Goldacre and Turner found they were kindred spirits. Together, and alongside Open Knowledge, they are developing a way to make the FDA's documents more accessible, and make OpenTrialsFDA a reality.

### CONTACT INFORMATION: EMMA BEER (EMMA.BEER@OKFN.ORG)









# Unique Insights From Shared Data

# Fruit Fly Brain Observatory

### ALLOWING RESEARCHERS TO BETTER CONDUCT MODELING OF MENTAL AND NEUROLOGICAL DISEASES BY CONNECTING DATA RELATED TO THE FLY BRAIN

Mental and neurological disorders pose major medical and socioeconomic challenges for society. Understanding human brain function and disease is arguably the biggest challenge in neuroscience. To help address this challenge, smaller but sufficiently complex brains can be used. This application will store and process connected data related to the neural circuits of the fruit fly brain. Using computational disease models, researchers can make targeted modifications that are difficult to perform in vivo with current genetic techniques. These capabilities will significantly accelerate the development of powerful new ways to predict the effects of pharmaceuticals upon neural circuit functions.

#### THE TEAM



Ann-Shyn Chiang, Chung-Chuan Lo, National Tsing Hua University

Aurel Lazar, Lev Givon, Yiyin Zhou, Nikul Ukani, Chung-Heng Yeh, Columbia University

Daniel Coca, Luna Carlos, Adam Tomkins, Dorian Florescu, Paul Richmond, University of Sheffield

### HOW THE PARTNERSHIP WAS FORMED:

"Ann-Shyn Chiang and Chung-Chuan Lo (National Tsing Hua University, Taiwan), Daniel Coca and Paul Richmond (University of Sheffield, U.K.), and Aurel A. Lazar (Columbia University, U.S.) all approach understanding the function of the fruit fly brain from different but complementary perspectives.

Given the wealth of research indicating the usefulness of the fruit fly (Drosophila) in shedding light on the molecular mechanisms of many human neurodegenerative diseases, the teams realized their joint work could potentially contribute invaluable insights into the neural circuitry of their pathologies. Aurel Lazar's own sense of urgency comes from first-hand experience with the devastation such diseases have wrought upon family members through Alzheimer/Dementia and Parkinson's Disease."

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# MyGene2: Accelerating Gene Discovery with Radically Open Data Sharing

### FACILITATING THE PUBLIC SHARING OF HEALTH AND GENETIC DATA THROUGH INTEGRATION WITH PUBLICLY AVAILABLE INFORMATION

Approximately 350 million people worldwide and over 30 million Americans have a rare disease. Most rare diseases are Mendelian conditions, which means that mutation(s) in a single gene can cause disease. Over 7,000 Mendelian conditions have been described to date, but the causal gene is known for only half. Consequently, close to 70 percent of families who undergo clinical testing lack a diagnosis. MyGene2 is a website that makes it easy and free for families with Mendelian conditions to share health and genetic information with other families, clinicians, and researchers worldwide in order to make a match.

#### THE TEAM



Tudor Groza, Craig McNamara, Edwin Zhang, Garvan Institute of Medical Research

Jessica Chong, University of Washington

Michael Bamshad, University of Washington

### HOW THE PARTNERSHIP WAS FORMED:

"Our team is composed of geneticists and computer scientists who have spent their careers finding better ways to discover genes underlying rare diseases. Families with rare diseases increasingly want to participate directly in the gene discovery process. One way they can do so is to publicly share their own health information and genetic data with scientists and other families. The problem is that this is hard to do effectively, safely, and in ways that make the information searchable. We learned this firsthand from families working with us, and they urged us to develop tools to make sharing easy. We heard this loud and clear, and it inspired us to create MyGene2—a web-based tool that enables families, clinicians, and scientists to publicly share health and genetic data with one another in order to help families find a precise genetic diagnosis and researchers to discover and study rare genetic diseases."

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