Bringing People's (Sensitive) Data Back to the People: Privacy, Ownership, Accessibility, and Fitness-for-Use of VGI in the Context of Public Health

John Palmer - Universitat Pompeu Fabra; Aitana Oltra - CREAT; Jaume Piera - ICM-CSIC; Frederic Bartumeus - Centre d'Estudis Avançats de Blanes

Public access to data is an important principle for scientific research, particularly when that research depends on observations shared by citizen scientists, and even more so when the research bears on important public health questions. Yet, shared data related to public health often raises privacy and ownership considerations, especially when it includes volunteered geographic information and photographs. Moreover, the public access imperative entails making data accessible and useful for a range of actors. These considerations can be difficult to navigate, and can lead to delays in release or shortcuts that undermine the core values at stake. In this presentation we share experiences and best practices learned from Mosquito Alert, a citizen science observatory of disease vector mosquitoes that has opened its data through a webmap, a set of public health management portals, a RESTful API, and a daily archiving protocol. The Mosquito Alert data set contains expert-validated information about the geographic distribution of Tiger Mosquitoes and Yellow Fever Mosquitoes shared by citizen scientists around the world and vital for the fight against Zika, Chikungunya, Dengue, and other diseases that these species carry. But the data set also contains geolocations, photographs, and participants’ notes, and it consists of a complicated set of tables in a large relational database that is constantly changing. We explain how we have navigated these complications in order to make the data most useful to the general public, the Mosquito Alert participants themselves, public health and environmental management agencies, the United Nations Environmental Program, and others.

Citizen Science in Disasters, Exposure Assessment, and Public Health

April Bennett - National Institute of Environmental Health Sciences; Aubrey Miller - National Institute of Environmental Health Sciences; Liam O’Fallon - National Institute of Environmental Health Sciences; Chip Hughes - National Institute of Environmental

Discuss the rapidly evolving areas of citizen science (CS) and community based participatory research including highlights of both the opportunities and challenges for furthering our understanding of environmental exposures and health effects. Methods Disaster responses and other investigations, such as the Gulf Oil Spill and hydraulic fracturing, incorporating community engaged research will be discussed to provide additional context and understanding of data acquired through such non-traditional forums. Challenges include the use of non-validated data, harmonization of disparate data sets, and the interpretation and communication of findings. Case studies will highlight the benefits, as well as the challenges, in using CS approaches to promote environmental justice and public health. Focus will include user-friendly tools and technologies for assessing environmental exposures, data quality & management, and interpretation of information and risk communications. Results Attendees will gain insight into: 1) the important need and role of CS in supporting responses to emerging environmental threats and disasters; 2) the use and limitations of CS exposure assessment tools and data; 3) the generation of useful data through effective planning and partnerships; 4) interpretation of data, ethical considerations, and communicating results; and 5) the need to foster CS to help measure and understand environmental exposures. Conclusions While complex and often challenging, CS approaches have the positive benefits of bringing local expertise and knowledge to the table, improving community involvement, providing data to impacted and vulnerable populations, understanding, and acceptance of the environmental information used for decision-making.
Enabling Personal Health Data Donation for Public Good Research

Cinnamon Bloss - UC San Diego; Cynthia Cheung - UC San Diego; Matthew Bietz - UC Irvine; Kevin Patrick - UC San Diego

Those seeking to donate or share their personal health data may face challenges on multiple levels, particularly with respect to informed consent, data access, privacy and security, and interoperability. On May 17, 2016, with support from the Robert Wood Johnson Foundation, the Health Data Exploration (HDE) Project hosted its second annual Network Meeting with the theme of "enabling personal health data donation for public good research." Presentations were focused on successful models of data donation, as well as barriers and facilitators to future efforts in this area. The meeting brought together over 100 stakeholders from several fields and sectors, including industry, academia, healthcare, and policy. As part of the meeting, a brainstorming session was facilitated in which attendees were self-assigned to one of 10 small groups with pre-assigned facilitators and specific prompts. Examples of prompts included, "defining the stakeholders," "participant protection," "researcher-participant relationship," and "industry incentives." In this presentation, we will describe the results of this breakout session. Several prominent themes emerged from the small group discussions, including the need to manage data heterogeneity, interoperability, and parity; governance of the data that is donated; electronic versus in-person consent; participant incentives to donate data; representativeness of the data and social justice issues; privacy risks, as well as privacy barriers that hinder research; standards for metadata; participant education opportunities and givebacks; and navigating the tension between individual- and aggregate-level data. These themes will be discussed in detail.

Public Engagement in Extraction Transparency: Sharing Knowledge Through the FracTracker Alliance

Kirk Jalbert - FracTracker Alliance; Samantha Rubright - FracTracker Alliance; Karen Edelstein - FracTracker Alliance

Unconventional oil and gas extraction is fueling a wave of resource development often touted as a new era in U.S. energy independence. However, assessing the true costs of extraction is made difficult by the vastness of the industry and lack of regulatory transparency. This presentation focuses on the efforts of the FracTracker Alliance, a national nonprofit dedicated to enhancing public understanding of the industry by collecting, interpreting, and visualizing data in partnership with concerned citizen groups. The presentation also demonstrates how these activities facilitate critical knowledge flows across sectors. This is argued in three case studies: the first tells the story of how FracTracker Alliance worked with community stakeholders to map municipalities in New York State that had passed local drilling prohibitions; the second mapped crude oil train routes across the nation's railways to reveal at-risk communities. The third is a collaborative digital storytelling project done in partnership with citizen scientists working to protect watersheds threatened by energy extraction. Taken together, these case studies reveal how efforts to fill knowledge gaps taken up by capacity building organizations and concerned citizen groups can assist in making informed decisions as well as critiques regarding extraction industry governance.