



NATIONAL INSTITUTES OF HEALTH



Using Public Engagement to Inform the Use of Data in Biomedical Research Workshop at University of California, San Diego February 27, 2023 (All Times PST)

Goals:

To use public feedback to inform potential constructive policy action for biomedical research by:

- Convening designers, developers, and users of novel types and ways to use data to discuss how they consider the values and potential implications of this type of research for individuals and communities, and how they account for these considerations throughout the innovation and research process
- Contextualizing community conversations NIH has held across the U.S. in a broader bioethical framework to ascertain lessons learned
- Integrating public feedback to assess implications for NIH programs and policies. (Fig 1)

Background:

In June, 2021, the NIH Novel and Exceptional Technology Research Advisory Committee (NExTRAC) Working Group (WG) on data science and emerging technology was charged to:

- **Phase 1:** Define and characterize the types of research questions that require increasing granularity and aggregation of data about individuals that are likely to be addressed through emerging technologies [in data science]
- **Phase 2:** For those questions and technologies defined above, consult with stakeholders to discuss and assess the value of and potential implications for individuals, groups (i.e., families, specific regions or populations), and society.

In Phase 1 of the effort, the NExTRAC WG identified three overarching topics (and [corresponding research questions](#)) to seek public input on in Phase II: New Types of Data (e.g. from wearable devices, social media), New Types of Analyses (e.g. Artificial Intelligence, Machine Learning), and Data Linkage and Aggregation. To assist Phase 2 of the effort, NIH is facilitating public engagement events to integrate perspectives from a variety of communities on perceived risks and benefits to inform and guide the development of biomedical research initiatives and policies. NIH has held community conversations to inform this effort, engaging ~150 individuals from diverse communities across the US. These conversations have provided rich perspectives on how different people view the use of their health data in biomedical research.

On Feb 27, 2023 the NIH will hold a workshop at the University of California, San Diego to contextualize this public feedback through the lenses of research, ethics, technology development, and application to clinical and public health contexts with the goal of integrating public feedback to assess implications for NIH programs and policies. The NIH will host discussion panels, including panelists from Pyxis Partners who facilitated the community conversations to share key points and takeaways, ethicists, biomedical researchers, technology engineers and developers of hardware and software, public health experts, and clinician researchers who might utilize these technologies. The NExTRAC WG will consider the discussions from this event to inform the NExTRAC deliberations, which will ultimately be conveyed to NIH when finalized by the NExTRAC.

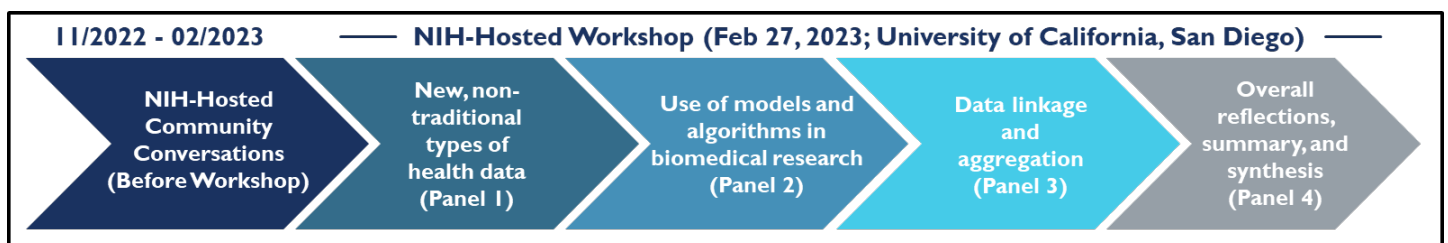


Fig. 1: A framework for integration of public engagement to inform data science number