Sage Bionetworks Selected to Build Biomedical Data Fabric Toolbox by Advanced Research Projects Agency for Health

The project will create an open-source, digital system that can make health data more accessible and usable, improving clinical decisions and patient care.

7 core modules comprise the ARPA-H BDF Toolbox

SEATTLE, WA, UNITED STATES, October 24, 2024 /EINPresswire.com/ -- Huge volumes of data are being collected every day in research labs and clinical centers. This data can be used to inform clinical decisions, help us better understand diseases, or discover new treatments.

Unfortunately, data is often not collected in a standardized way. Researchers and clinicians don't have the right means or motivation to share the data widely. Consequently, these data often remain in their own silos and don't have common methods for being combined and understood. This creates a major bottleneck when it comes to making optimal health decisions and advancing new therapeutics.

With an award from the Advanced Research Projects Agency for Health (ARPA-H), Sage Bionetworks is building a Biomedical Data Fabric (BDF) Toolbox that can seamlessly connect siloed research and clinical data, enabling researchers to perform more efficient and evidence-based research on large, multimodal biomedical datasets. □□

"Biomedical data acts as the medium for the communication loop between researchers, clinicians, and patients, " says Milen Nikolov, PhD, Project Director of the BDF Toolbox at Sage. "The ARPA-H Biomedical Data Fabric will empower these different groups to integrate data so that we can gain new insights into the prevention, workings, and treatment of diseases."

The initial focus of the Toolbox will be on cancer and rare disease data, eventually expanding to other diseases to maximize its application to a broader population.

“Data and specimens contributed by people living with a rare disease are inherently valuable and scarce,” says Robert Allaway, PhD, Principal Data Scientist at Sage Bionetworks. “The ARPA-H BDF Toolbox will revolutionize the way rare disease researchers, advocates, and organizations will be able to collect, interconnect, and use these data.”

Connecting patients, and those entrusted with patient data, to the outputs of researchers and clinicians gives agency to all parties. Sage will develop a toolset that automatically preserves the privacy and attribution of data upon its collection and curation. This governance framework will increase transparency in data use, protect individuals’ personal information, and will help streamline data contribution and processing workflows.

“We hope to meaningfully connect data using AI-assisted methods and digital dignity principles,” says Jineta Banerjee, PhD, Principal Data Scientist at Sage Bionetworks. “Our project will help researchers and clinicians collaborate in finding breakthroughs for cancer and rare disease patients who are still waiting for life-saving treatments.”

Overall, the Biomedical Data Fabric Toolbox will make new and existing research data more accessible for reuse so that scientists can accelerate innovation and doctors can make more informed healthcare decisions.

The Toolbox will consist of 7 core modules:
- AI curation: to accelerate data sharing and improve discoverability.
- Data provenance: to enable digital dignity through attribution.
- Data use conditions: to streamline the navigation of ethical data use.
- Data interoperability: to bridge silos and empower innovative analyses through dataset recombination.
- AI readiness: to remove barriers for rapid hypothesis generation.
- Data flow transparency: to build trust by displaying dataset sharing status.
- Standardized data processing: to improve data reliability at scale.

Sage Bionetworks will be joined in this multicenter collaboration by several other leading institutions, including Stanford University, University of Alabama at Birmingham (UAB), Massachusetts Institute of Technology (MIT), Netrias, New York University, and others. A full summary of performers and projects is available in the ARPA-H press release.

The Toolbox will be an open-source, digital system that aims to democratize access to biomedical data. The data and associated algorithms will be freely available for the community to use, allowing scientists, patients, and clinicians to be more proactive in seeking the data they need and answering questions they may have.

“This landmark project feels like a modern-day parallel to the early internet's development in the 1960s, when the need to share supercomputing resources across institutions drove the creation

of a connectivity infrastructure for everyone's benefit" says Luca Foschini, PhD, President and CEO of Sage Bionetworks. "Similarly, The BDF Toolbox aims to unlock the potential societal health benefits of learning from shared health data. Our biggest challenge is striking the right balance between open science and robust individual privacy protection."

ABOUT SAGE BIONETWORKS
Sage Bionetworks is a non-profit health research organization based in Seattle, Washington. Our mission is to drive a new age of scientific discovery through truly open science and radical collaboration. We guide responsible data sharing and reuse, benchmark scientific methods and results, and empower participants to be active partners in research. Learn more at sagebionetworks.org

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