

AMIA Response to NIH Strategic Plan for Data Science 2023-2028 RFI

Link to Draft Strategic Plan: [NIH-STRATEGIC-PLAN-FOR-DATA-SCIENCE-2023-2028-final-draft.pdf](#)

**Five overarching goals:**

- *Goal 1: Improve Capabilities to Sustain the NIH Policy for Data Management and Sharing*
- *Goal 2: Develop Programs to Enhance Human Derived Data for Research*
- *Goal 3: Provide New Opportunities in Software, Computational Methods, and Artificial Intelligence*
- *Goal 4: Support for a Federated Biomedical Research Data Infrastructure*
- *Goal 5: Strengthen a Broad Community in Data Science*

**The NIH seeks comments on any of the following topics:**

1. The appropriateness of the goals of the plan, the strategies and implementation tactics proposed to achieve them; including potential benefits, drawbacks or challenges.

The American Medical Informatics Association (AMIA) commends NIH updating the Strategic Plan for Data Science to address the acceleration of new technologies (e.g. artificial intelligence and machine learning) to prepare for the rise in the quantity of data, develop programs to increase the workforce of data researchers and continue supporting biomedical research.

AMIA appreciates NIH's acknowledgement of other technological breakthroughs beyond AI, and the intersection with biomedical research being relatively less-explored area compared to other disciplines. NIH's planned expansion investments in emerging technologies will indeed better position the biomedical research community and ready the current and future workforce.

One overall challenge is how will NIH disseminate the program and training offerings to fully leverage the potential of the Strategic Plan for Data Science. NIH's development of each goal and weaving in how the agency will incorporate incentives, programs, fellowships, trainings, etc. is admirable. This will require the agency to network new partnerships and consider the role professional organizations, like AMIA, can assist in connecting their membership to promote NIH's offerings.

How will NIH Support training programs and activities for under-represented groups to expand use of SDOH/Behavioral/EDoH data models and data collections. NIH UNITE? NIH SchARe?

Below are AMIA's comments for each goal:

## **Goal 1: Improve Capabilities to Sustain the NIH Policy for Data Management and Sharing**

### *Objective 1-1: Support the Biomedical Community to Manage, Share, and Sustain Data*

AMIA supports NIH's implementation tactics for goal one. The NIH Policy for Data Management and Sharing does emphasize good data management and sharing, as well as promoting practices accepted within the research communities. The Findable, Accessible, Interoperable, and Reusable (FAIR) and Transparency, Responsibility, User focus, Sustainability, and Technology (TRUST) principles are appropriate standards for data management and sharing, and the data repositories managed by NIH.

AMIA would like for NIH to see through the agency's exploration for funding and governance models for NIH data sharing infrastructure for researchers, NIH staff, and for data stewards and librarians, with the inclusion of individuals at low resourced institutions. This would include the establishment of a data steward program where associations can assist in trainings.

## **Goal 2: Develop Programs to Enhance Human Derived Data for Research**

### *Objective 2-2: Adopt Health IT Standards for Research*

AMIA recommends continuing to promote and develop the Unified Medical Language System (UMLS) because this resource is a key component for data standardization and interoperability. Implementing programs to convene researchers and developers to test and validate standards while providing feedback to NIH is a fine tactic to engage the research community. In addition, AMIA encourages NIH's investment in ongoing evaluations, implementations, and extensions of common data models through key use cases, including the Observational Medical Outcomes Partnership (OMOP) and United State Data for Interoperability (USCDI).

NIH's promoting development, training, and adoption of HL7's Fast Healthcare Interoperability Resources (FHIR®) will assist in breaking down the silos and allow for organizations, providers, and patients to gain access to data across institutions. AMIA recommends NIH host more webinars and programs to build off the progress from programs like the *Advancing the Use of FHIR® in Research* virtual workshop NIH hosted in 2020, as well as supports cutting edge research in extending FHIR and the relationship between FHIR, common data models, and real world systems (e.g., OMOP-on-FHIR and use cases requiring novel FHIR-enabled resources such as FHIR-façade capabilities).

### *Objective 2-4: Cross-disciplinary Training to Empower Clinical Data Science*

AMIA applauds NIH's recognition of maintaining and enhancing clinical research informatics as a career path. AMIA concurs that clinical research informatics requires not only clinical training but also training in informatics, analytics, ethics, data standards, and implementation science

with a focus on health information technology to enable research. NIH might also consider the synergy of investment in learning health system sciences as has been made with the Agency for Healthcare Quality and Research and the Patient-Centered Outcomes Research Institute and these competencies can augment associated informatics training particularly for improvement through digital health, pragmatic trials, and other T3/T4 research. The rise in clinical research informatics will only aid in accomplishing the Strategic Plan for Data Science.

### **Goal 3: Provide New Opportunities in Software, Computational Methods, and Artificial Intelligence**

*Objective 3-1: New Opportunities to enhance Artificial Intelligence, including ethical AI for biomedicine*

AMIA agrees with NIH's objective has made progress in medical diagnoses but there are well documented risks associated with all aspects of the design, deployment and maintenance of AI systems, particularly with respect to the potential for bias in many forms, including algorithmic bias<sup>1</sup>. We appreciate NIH strategically outlining how the agency will manage the risks and potential harms to lead to more trustworthy AI systems.

### **Goal 4: Support for a Federated Biomedical Research Data Infrastructure**

*Objective 4-1: Develop, test, validate, and implement ways to federate NIH data and infrastructure*

AMIA commends NIH's goal to promote interoperability for data research while implementing controlled access to ensure privacy through the Researcher Auth Service. This goal aligns with AMIA's public policy statement that implementation of data standards and incorporation of FAIR data principles that can be used for consumer- and patient-generated data that could be useful to convey summary data in a usable format, individual participant data and metadata for different types of research to help amplify scientific knowledge while minimizing risks to privacy<sup>2</sup>.

### **Goal 5: Strengthen a Broad Community in Data Science**

AMIA is filled with members and student members to partner with NIH's commitment to growing a stronger and broader community of data scientists who are skilled in areas that include bioinformatics, AI/ML, clinical informatics, cloud computing, statistics, computational science, software design and programming, bioinformatics, foundational models, visualization,

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<sup>1</sup> AMIA Public Policy Principles and Policy Positions: <https://brand.amia.org/m/2e7af7b35c4b5154>

<sup>2</sup> AMIA Public Policy Principles and Policy Positions: <https://brand.amia.org/m/2e7af7b35c4b5154>

predictive analytics, modeling and simulation, and data management and sharing. AMIA could be a resource in identifying and developing our student members and students attending our member academic institutions.

*Objective 5-1: Increase training opportunities in Data Science*

AMIA supports *Objective 5-1: Increase training opportunities in Data Science* and should highlight the opportunities in health and biomedical informatics.

## 2. Opportunities for NIH to partner to achieve these goals.

AMIA members have unique expertise in data science and research to assist NIH's Strategic Plan for Data Science 2023-2028. With this rise in quantity and diversity in data, NIH will need partnerships with informaticists who have cross-disciplinary backgrounds to connect all disciplines.

Below are areas where AMIA and its membership could potentially partner with NIH:

### **Goal 1: Improve Capabilities to Sustain the NIH Policy for Data Management and Sharing**

*Objective 1-1: Support the Biomedical Community to Manage, Share, and Sustain Data*

AMIA would be willing to partner with NIH when the agency establishes a data steward program to support training.

### **Goal 2: Develop Programs to Enhance Human Derived Data for Research**

*Objective 2-2: Adopt Health IT Standards for Research*

AMIA membership has the unique skills and expertise to assist in the implementation tactics for Objective 2-2. There are AMIA members with the ability to participate in programs that develop, test, validate and adopt health IT technologies and standards based on scientific use cases and provide feedback to NIH based on lessons learned. Also, there are AMIA members who could provide or research use cases outlining how health data standards can benefit and enhance scientific data analysis.

*Objective 2-3: Enhance the Adoption of Social and Environmental Determinants of Health for Health Equity*

Members of AMIA have and can research examples that could support NIH projects to test how best to capture SDoH/EDoH of health data for interoperable electronic data exchange.

*Objective 2-4: Cross-disciplinary Training to Empower Clinical Data Science*

AMIA and its membership are distinctively positioned to partner with NIH in maintaining and enhancing the clinical research informatics career path. AMIA's work was pivotal in the creation of board certification in clinical informatics subspecialty<sup>3</sup>, and can assist NIH in promoting the field. AMIA has a substantial network of academic programs in biomedical, health, and nursing informatics that could efficiently coordinate efforts with NIH.

AMIA membership would be a model expert serving NIH in networking opportunities for clinical and data science researchers to develop collaborations, build teams, and learn from AMIA members as experts on various topics (e.g. data sharing, management, transparency, provenance, and data quality for clinical research).

AMIA members also can support the implementation tactic: *support cross-training between data scientists, clinical researchers, and nurses engaged in research at various stages of the academic tracks*. Clinical research informaticists are in the field connecting with colleagues through the health science research ecosystem.

### **Goal 3: Provide New Opportunities in Software, Computational Methods, and Artificial Intelligence**

*Objective 3-1: New Opportunities to enhance Artificial Intelligence, including ethical AI for biomedicine*

AMIA and its membership are interested in NIH establishing and operationalize community engagement for diverse, equitable and inclusive data, methods, and sources for AI. Also, we would like to stay connected on the objective of NIH developing tools and training opportunities to help researchers create and prepare data that are FAIR and AI-Ready, including ontologies, schema, and data quality measures. One of AMIA's current policy priorities is to advocate for evidence-based care and decision-support through informatics, including through machine-learning and AI<sup>4</sup>.

*Objective 3-3: Supporting FAIR Software Sustainability*

Develop mentorship programs that pair experienced software engineers with early-career researchers and software developers. AMIA members have been working in this arena and could be potential partners in developing programs. AMIA has been taking an active role in helping the community identify oversight mechanisms to ensure the safe, effective use of AI applications in healthcare through the association's AI Evaluation Showcase<sup>5</sup>.

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<sup>3</sup> Clinical Informatics Subspecialty: <https://amia.org/careers-certifications/clinical-informatics-subspecialty>

<sup>4</sup> Current Policy Priorities: <https://amia.org/public-policy/current-policy-priorities>

<sup>5</sup> AMIA 2024 Artificial Intelligence Evaluation Showcase: <https://amia.org/education-events/amia-2024-artificial-intelligence-evaluation-showcase>

**Goal 5: Strengthen a Broad Community in Data Science**

*Objective 5-4: Broaden and Champion Capacity Building and Community Engagement Efforts*

AMIA could be a potential partner to assist NIH in this objective where has focused on data science workforce development and training, including certification programs and continuing education.