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VIA FEDERAL PORTAL [RFI: Inviting Comments on the Future of NLM's Extramural Research Programs \(NOT-LM-25-002\)](#)

Section 1: Vision for the Future

A. Significant unmet needs in biomedical informatics and data science, particularly those that require innovative, cross-domain solutions to drive transformative advancements across multiple areas of research.

- The health eco-system has been fractured and siloed for quite some time. With emerging technology and data sharing standards we now have secure, automated ways to create the connected, aligned and coordinated eco-system we need across healthcare, payers, the public, community partners, technology vendors and public health. DOH would like to see more research and investment in helping close these gaps and in finding ways to ensure public health is included. This is proven out in our health ecosystem through the preventive health measure stages. When we invest in the first stage, Primary Prevention (public health), we work to prevent disease or adverse health outcomes from ever occurring. When we do that well, we avoid costly Tertiary Prevention (treating disease or health condition, medical/clinical care).

B. Key challenges in biomedical informatics and data science that necessitate groundbreaking solutions, especially those that bridge multiple domains and have broad transformative implications for research and practice.

- While FHIR has proven its ability as a modern, efficient way to exchange health data, it is not proven to be well suited for analytics. If this challenge can be overcome, it would create an opportunity for efficiency in being able to save the data in one format for both exchange and analysis. DOH would like to see [more research done](#) in this space as it can benefit not only public health but research, healthcare and payers.

C. Foundational tools and methods that can be developed to support broad, scalable applications and enable next generation research.

- During the pandemic DOH used Bluetooth exposure notification to scale contact tracing once case counts were too high to keep up with manually. This tool was extremely effective and can be used for other daily public health purposes such as alerting the public about food recalls or when public beaches have algae blooms that should be

avoided. Research that expands the use of digital notification tools for both infectious and non-infectious conditions and behaviors related to health outcomes should be highly considered due to the practical benefit these types of tools can provide public health and the public.

- WA DOH has also been working with a new FHIR-based framework for sharing data we collect back to the public. SMART on FHIR Apps, SMART Health Cards and Links ([SMART Health Cards and Links](#)) provide a valuable way that the government can ensure the public can access their own medical records that we collect for public health purposes. This allows patients to have a secure and portable means for sharing their medical records for travel, new providers, or other purposes. Research should be done to extend the [patient summary](#) standard for both domestic and international purposes.

Section 2. Strategic Focus

A. Underexplored areas or specific gaps in NLM's current funding investments and how addressing these research gaps can lead to transformative impact or advancements.

- DOH would like to see more emphasis on Public Health Informatics research from NLM, especially research that would complement Data Modernization (DM) efforts. We saw firsthand how under-investment in public health data infrastructure impacted our ability to optimally respond to the pandemic. Public health agencies face the challenge of modernizing data systems with limited resources necessitating the prioritization of multiple needs. There is a lack of research that can be used to prioritize future funding of public health data modernization, and a need for systems research into approaches that facilitate success in implementing DM in public health agencies. This could include research into barriers and facilitators of DM implementation, and the development of predictive or other models that can be used to assess the value of different types of data and data systems for public health practice. This would align well with current funding from CDC to modernize public health infrastructure.

B. How existing biomedical informatics categories (i.e., bioinformatics, clinical informatics, translational bioinformatics, public health informatics, and personal health informatics) can evolve to align with contemporary challenges or evolve to address emerging scientific and technological challenges.

- A primary challenge for public health agencies is that they rely heavily on the secondary use of data collected primarily from and for healthcare encounters. Successful data modernization efforts will result in substantial increases in the availability of this data to public health, with clear benefits in the near to medium term. However, in the long-term, reliance on data from clinical encounters will limit the ability of public health to meet all of the essential services of public health. To fully benefit from healthcare data public health needs the ability to provide input into what data gets collected. DOH would like to see more alignment between public health informatics and personal health informatics, especially with regards to Patient Generated Health Data (PGHD). Public health has extensive experience collecting and using person generated data at the population level

through survey-based surveillance systems such as the Behavioral Risk Factor Surveillance System (BRFSS) and the Pregnancy Risk Assessment Monitoring System (PRAMS). A closer alignment between research in public health informatics and personal health informatics would benefit both fields. From public health's point of view, alignment between public health needs and clinical needs with PGHD would complement data collected through traditional surveillance systems and substantially increase the utility of this data, as well as potentially streamline the collection of data used by these surveys. We encourage NLM to fund more research in this area.

C. Emerging or underexplored areas in data science and biomedical informatics that have the greatest potential to drive transformative advancements and should be prioritized for future research investments.

- DOH is partnering with our state Medicaid agency (Health Care Authority) to implement our state's 988 Crisis Lifeline System. An unmet need we have found is a central registry that can house not just Mental Health Advanced Directives, but all types of advanced directives. DOH encourages more research and investment in the [PACIO FHIR IG](#) to harmonize a standard that can make all of the advanced directive documents interoperable and in helping to define them in the [USCDI+](#) for Behavioral Health domain being working on by ASTP/ONC. In addition, we would like to see this work aligned with the [International Patient Summary](#) and [SMART Health Links](#) to allow patients to be able to securely store, carry and share their advanced directives using their smartphones.
- DOH is also exploring novel reuse of the [eCR Now FHIR App](#). Its original purpose is to aid EHRs in submitting required notifiable case reports to public health. Because of its standards-based architecture it can also be reused to support other public health data exchange like cancer reporting, population health monitoring for chronic diseases, and reporting for the [CDC RESP-NET](#). Having a single app that is free, and open source can provide a lot of efficiency and cost savings for our health care partners. DOH would like to see NLM research into continued reuse of the app for other use cases not currently supported.

D. Emerging AI technologies that hold the most promise for advancing biomedical discovery, clinical decision-making, or public health interventions.

- Development of token tracing capabilities in LLM's, such as [OLMoTrace](#). This may be especially important for use of LLM's within government agencies where there is a duty to be able to justify and verify decisions and actions. Token tracing is one emerging technology that can enable LLM's to create traceable and explainable output. Development of improved deep research query modes that include explanations of reasoning and citations for sources, improving transparency for decision-making.
- Methodology for causal AI that can be applied at a population level to infer and guide population level interventions. Foundation models for population dynamics such as

[PDFM](#) open the possibility of large scale modeling of population health outcomes, factoring in geospatial, environmental, and mobility data.

- Methodologies that can capture or infer decision making within organizations at multiple scales. The potential of ML and AI methods to inform public health interventions may be limited in practice by the lack of data or challenges obtaining data about actions that are or are not made or taken. Without capturing data about actions or decisions it is difficult to create accurate counterfactual models which can be used to inform decision making.

E. New methodologies that are needed and key challenges to ensure AI systems are reliable, generalizable, secure and scalable across a variety of datasets, populations, and environments.

- DOH sees a need for methodologies for explainable AI methods and verifiable AI methods. Governmental public health agencies have a duty to be able to justify decisions and actions, many advanced AI approaches currently cannot explain how results are obtained or provide a verification of the accuracy of results.
- Alignment of AI system methodologies with FAIR principles: The NLM has built the FAIR principles for the advancement of data sciences in the biomedical sectors. Ensuring the ongoing transparency of NLM backed endeavors should ensure that issues of reproducibility in AI scaled data ecosystems are a priority for NLM research integrity. DOH also encourages alignment with the CARE (collective benefit, authority to control, responsibility, ethics) principles for tribal data sovereignty. Ensuring that increased data sharing and open data takes into account the contextual and historical power of indigenous data- opportunities and innovations in AI methodologies need to include populations that may have data rights and knowledge domains that require additional frameworks.

F. How AI can be leveraged to enhance the integration of complex, multi-modal data and address scalability challenges across research domains.

- AI foundation models provide unified representations of data from various streams using shared embeddings that allow disparate sources to “speak the same language”. Further integration of complex public health data could be accomplished via adoption of common data models and ontologies that could then be overlaid with multi-modal foundation models that serve as an integration layer to support ingestion of future data feeds. Serverless dataflows in a cloud environment could support stable scaling, and building AI/ML into pipeline operations would allow for quicker detection of issues.
- Existing policies and procedures for data privacy, sharing, governance in public health agencies were established before adoption of advanced AI and multi-modal AI. Without specific guidelines or frameworks, researchers may be reluctant to share or integrate. To lessen fears of non-compliance, DOH encourages research into a move from traditional

policies on de-identification for privacy to federated approaches or policy frameworks that can adapt to rapid technological advancement is needed.

G. The most significant cross-domain challenges where AI could have a transformative impact, and what foundational advancements are needed to address them.

- Current AI modeling has the potential to rapidly advance timely detection of emerging public health threats (zoonotic, environmental, et.) but privacy-preserving data agreements facilitating real-time access are necessary for this advancement to be explored.
- Another potential avenue of AI utility would be for situational simulation, for example hospital resource allocation and surge forecasting during emergency planning, integrating hospital capacity, supply chains, weather and environmental data, etc. to allow public health departments to plan detailed response scenarios. This requires cross-sector cooperation and validation for approach and outputs but could be a powerful tool for making the most of critical early hours during a public health response.

H. Critical challenges in data access, integration, and representation that hinder research advancements in data science and biomedical informatics.

- In Public Health Informatics there continues to be a challenge with the amount of data that is sent through manual means (fax, data entry into web portals, secure email). We have seen the value in automated data exchange using standards and secure transport. Much more work could be done across several domains (public health, clinical and translational) to continue to automate data exchange. Research that expands the use of existing standards and approaches such as [TEFCA](#), [Helios](#), and the [Public Health FHIR Implementation Collaborative](#), BULK FHIR, and Query/Response for Public Health Use Cases to further the automation of data exchange with public health agencies would enable more effective and efficient use of data within public health. Even when the transfer of data to public health has been successfully automated, the integration of this data into advanced analytical methods and generative AI tools remains a challenge, in part due to lack of standardization of methods and nomenclature. DOH believes that investing in research into the underlying infrastructure needed by public health agencies to effectively use the data they receive would have benefits to both public health research and practice, similar to the way research and development of clinical infrastructure that has been conducted or funded by the NLM has driven advances within clinical medicine.
- Existing policies and procedures for data privacy, sharing, governance in public health agencies were established before adoption of advanced AI and multi-modal AI. Without specific guidelines or frameworks, researchers may be reluctant to share or integrate. To lessen fears of non-compliance, research into a move from traditional policies on de-identification for privacy to federated approaches or policy frameworks that can adapt to rapid technological advancement is needed.

I. Strategies and or frameworks that NLM can implement to enable scalable and innovative data sharing while addressing privacy, security and accessibility concerns.

- Research into the use of TEFCA and Bulk FHIR needs more attention along with subscriptions. These strategies/frameworks have a lot of potential in advancing informatics for research, public health and clinical work. For example... this could advance work to allow death records to flow between state, local, tribal public health as well as to researchers and clinicians.

J. Infrastructure, tools or frameworks that are needed to support interdisciplinary and multi-institutional collaboration in biomedical informatics research.

- TEFCA is an emerging infrastructure that DOH sees as critical to ongoing efforts to create nation-wide interoperability across healthcare, payers, public health, researchers, the public and more. We would like to see the public health exchange purpose become required and would also like to see the research exchange purpose be developed through standard operating procedures and piloting. It is not effective or efficient to build individual connections to all the partners public health needs to exchange data with. TEFCA provides the right framework and needs to be further invested in and developed to support public health use cases.

Section 3. Additional Comments

- HHS reorganization and optimization of the CDC as a federal agency, appears to have decreased the amount of resources available for development, implementation research and evaluation for public health activities. DOH would like to see support from NIH to help offset decreased investment from CDC, ASTP/ONC and CMS for public health research and development opportunities. This will ensure new proven methodologies are available for future CDC investment.