



AcademyHealth Submits Comments on Federal Data Strategy Action Plan

On July 8, AcademyHealth submitted comments in response to a Draft Federal Data Strategy Action Plan. Our full submission follows.

AcademyHealth, the nonpartisan, professional home to more than 4,000 health services researchers, policy analysts, and practitioners, welcomes the opportunity to provide comments on the Draft 2019-2020 Federal Data Strategy Action Plan. The work of AcademyHealth's members is a critical component in the nation's efforts to address challenges in health and health care; they are both important sources of information for Federal agencies, as well as consumers of data from Federal agencies. In addition, AcademyHealth's leadership groups, including our Education Council and our Methods and Data Council serve as potential resources for some of the actions called for in the plan.

The issue of data sits squarely in the middle of a societal transformation. Society is experiencing significant advances in technology due to major innovations in computer capacity, speed, and analytical techniques, the internet of things (IoT), machine learning (artificial intelligence), and big data. This transformed world gives rise to questions about the implication of this new technology for governments, nonprofits, and the private sector. The transformation brought about by digital technical will be profoundly beneficial and will raise issues about social and individual values, privacy, security, and societal impacts. Navigating this new world will require both technical and adaptive skills and actions. This balance of the attending to both the technical issues and adaptive issues will be important in each component of the action plan.

Our comments address aspects of the Action Plan we believe require greater addition and clarification, including providing for adequate resources to implement the plan; ensuring harmonization of efforts across agencies; building on and improving existing policies and leveraging progress from previous initiatives; allowing for appropriate advisory mechanisms to inform the plan and its implementation, and building on and improving existing consent and sharing mechanisms. In addition, we encourage overall and close coordination with the implementation of the [Foundations for Evidence-Based Policy Act](#) of 2018 which builds off the work of the U.S. Commission on Evidence-Based Policymaking to strengthen data privacy protections, improve secure access to data, and enhance the federal government's capacity for producing and using evidence.

Detailed explanations of our comments follow:

- 1) **Resources.** The Action Plan should provide a pathway for agencies to obtain or redirect resources needed to accomplish the goal of making data a strategic asset.

Steps to improve access and use of data for decision-making by agencies (as well as providing for public use for research and holding government accountable) are resource intensive. For example, resources are needed to create public use files, link multiple data sources to provide maximum insight, manage systems for access to restricted use files, and evaluate risk of disclosure for each file where access to protected information is provided.

In “Practices for Leveraging Data as a Strategic Asset¹”, principle 10 addressed the importance of providing resources explicitly to leverage data assets. It is reasonable to expect that the Action Plan would provide guidance to operationalize this (for example, promulgate OMB expectations for how agencies would address this principle through the budget process). Unfortunately, in its current form, the Action Plan indicates that all but a limited number of cross-government steps are “expected to be completed with current agency funding resources.”

While we recognize the importance of incentivizing greater efficiencies, we suggest that additional resources may still be necessary to fully execute the plan. Accordingly, we recommend that steps be identified in the Action Plan to ensure that agencies will implement principle 10.

- 2) **Harmonizing Across Multiple Strategies.** The Action Plan should more explicitly address how the Federal strategy relates to and/or replaces existing agency-specific strategies, builds on the successes of those efforts, and/or addresses gaps and barriers that currently exist.

For example, AcademyHealth and its members are deeply engaged with data sources and data policies of the Department of Health and Human Services. Many health services researchers are advanced users of data from health-related surveys (e.g., those of the National Center for Health Statistics and the Agency for Healthcare Research and Quality), from administrative records (e.g., Medicare and Medicaid), and more recently from clinical registries, electronic health records and patient generated data. AcademyHealth has partnered with HHS on many of its data initiatives, including the annual Health Datapalooza, which grew out of HHS leadership in open data.

Our members have tracked HHS’ more recent efforts to address coordination and sharing of data resources across its components, including the “The State of Data Sharing at the U.S. Department of Health and Human Services²” and the pending follow up plan of action.

We recommend that the Federal Action Plan itself include reference to how it relates to the efforts of HHS and its counterparts, and how it will ensure that broad Federal strategies build on successes and are fully integrated, facilitating the engagement of stakeholders at appropriate points.

For example, the Action Plan should strongly embrace the uses of new methods and resources across disciplines to accelerate learning, speed the implementation of new knowledge and evidence into practice, and share best practices and innovations across agencies. In addition, expanding training and workforce development capabilities to apply new methods in information gathering and analysis have been emphasized by numerous advisory committees. Another aspect that would be important to address is emphasizing new models for access to data and enhance the privacy, confidentiality and security of data. Federal agencies could learn from each other and the private sector to accelerate their talents and technologies to strength

- 3) **Advisory Mechanisms.** The Action Plan should provide for ongoing input from external stakeholders in addition to internal Councils.

AcademyHealth is supportive of steps to create an OMB Data Council and to strengthen agency-specific Councils. Here again, lessons from existing efforts are instructive and may improve the efficiency and implementation of the

¹ <https://strategy.data.gov/assets/docs/federal-data-strategy-practices.pdf>

² https://www.hhs.gov/sites/default/files/HHS_StateofDataSharing_0915.pdf

Federal Strategy Action Plan. For example, the HHS Data Council has existed for several decades and could be recast to meet expectations under the Evidence-Based Policy Act and the Federal Data Strategy.³

As described, these mechanisms will be most useful in achieving greater internal coordination across government units. We are unaware of any formal mechanism (currently, or in the Federal Data Strategy) to ensure that agencies (and OMB) have the benefit of ongoing external perspectives on the availability and use of Federal data resources. Given that such access is a priority identified in the Federal Data Strategy, we recommend that the Action Plan include steps to ensure that OMB and agencies regularly obtain external input. For example, existing advisory committees like the National Committee on Vital and Health Statistics (and others, addressing the unique issues of their Agencies) could be charged with providing input to their Agencies on implementation of this Action Plan strategy and the intersection of Agency-specific strategies. In the agency of such committees, OMB should provide guidance on mechanisms for obtaining input, following OMB's own model in seeking public comment on the Action Plan.

4) Streamlining Access While Ensuring Protection. Further work is needed to balance important competing interests while providing more streamlined access to Federal data resources.

AcademyHealth is supportive of steps to promote and simplify access to Federal data resources. We are conceptually supportive of efforts to create a simplified – even “one stop” – entry point for access to protected data sources (Action 6). And, we are supportive of an additional Federal focus on approaches to mitigating the risk of disclosure of protected information (Action 4). Thus, the new application system needs to account for different levels of sensitivity for the data being accessed. The concept of tiered access should be reflected in the application process with the applicant being able to request a clearance level appropriate to the sensitivity of the data being requested.

In addition, because data is often shared under specific, binding agreements to protect patient and proprietary information, the considerations in providing access are complex and may not be generalizable to other data sources. Fortunately, the tech sector is moving fast with new ways to provide secure and traceable access, and agencies have the opportunity to innovate in this area, while preserving a strong commitment to respecting the principles of existing sharing agreements.

It is equally important to ensure transparency and full disclosure of any changes to the structure and/or availability of data throughout implementation of this plan and in perpetuity. Current and future research builds on comparisons of data across years and decades, and failure to broadly communicate changes to the form or structure of data could jeopardize the validity of analyses.

5) Timelines. We applaud the sense of urgency that is evident in the aggressive implementation timelines described in the Action Plan draft. We agree that a comprehensive Federal Data Strategy is needed to accelerate development of 21st Century technologies and public services. On the other hand, it is also important to ensure that there is adequate time allotted to critical tasks. In particular, it is imperative that there be sufficient time to allow all relevant federal agencies and stakeholders to provide their input and for the public to comment. With this in mind, some proposed timelines (e.g. 3 months to develop a Data Ethic Framework, 3 months to develop a Repository of Federal

³ <https://www.cep.gov/cep-final-report.html>

Data Strategy Resources and Tools, 1 month to constitute a Diverse Data Governance Body) may benefit from being extended.

- 6) Data Integration across Agencies.** As is clearly communicated in the proposed Federal Data Strategy, data is a very valuable resource. It becomes even more valuable as it acquires multiple dimensions. With that in mind, we recommend that Federal Data Strategy Action Plan encourage linkage and/or integration of available data resources across Federal Agencies when appropriate and feasible to do while protecting individuals. This would increase the value of data to its users exponentially. An example of data sets that could be linked are those from CMS and Veterans Administration, which could as a result provide a comprehensive picture of veterans' healthcare utilization both in- and outside of the Veterans Administration system.

- 7) Data Contributions from Outside of the Federal Government.** To further enrich the data resources available to academia, industry and the public we recommend that strategy to encourage data contributions from organizations outside of the Federal Government be considered. These data contributions could help create multidimensional data sets that could provide enormous value to their users. A variety of approaches, including preferential / discounted data access, have previously been successful in private data initiatives and could be considered.

AcademyHealth, its leadership Councils, and its members stand ready to assist you in considering these and other future revisions to the plan. Thank you for the opportunity to comment.

