Goal 4. Objective B: Enhance access to and use of data to improve HHS programs and support improvements in the health and well-being of the American people

Transparency and data sharing are of fundamental importance to HHS and its ability to achieve its mission. HHS data and information are used to increase awareness of health and human service issues and to set priorities for improving health and well-being. By making data and information more transparent and more available, HHS promotes public and private sector innovation and action, as well as provides the basis for new products and services that can benefit Americans.

HHS is strongly committed to data security and the protection of personal privacy and confidentiality as a fundamental principle governing the collection and use of data. HHS protects the confidentiality of individually identifiable information in all public data releases, including publication of datasets on the Web. By employing state-of-the-art processes for data prioritization, release, and monitoring, HHS increases the value derived from information in several ways. Consumers are able to access information and benefit directly from using it personally. Public administrators can use these information resources to enhance service delivery and improve customer satisfaction.

Expanded information resources also will bring new transparency to health care to help spark action to improve performance. For example, increased access to health care information can help those discovering and applying scientific knowledge to locate, combine, and share potentially relevant information across disciplines to accelerate progress. It can enhance entrepreneurial value, catalyzing the development of innovative products and services that benefit the public and, in the process of doing so can fuel economic growth through the private sector.

The HHS Data Council coordinates health and human services data collection and includes the following HHS components: ACF, AHRQ, ACL, ASPE, CDC, CMS, FDA, HRSA, IHS, NIH, ONC, OASH, and SAMHSA. All HHS agencies support the access and use of data. Below are performance measures related to use of data to improve health outcomes and well-being. The Office of the Secretary led this Objective's assessment as a part of the Strategic Review.

Objective 4.B Table of Related Performance Measures

Decrease the number of months required to produce MEPS data files (i.e. point-in-time, utilization and expenditure files) for public dissemination following data collection (MEPS-HC) (Lead Agency - AHRQ; Measure ID - 1.3.21)

	FY 2012	**FY 2013**	**FY 2014**	**FY 2015**	**FY 2016**	**FY 2017**
Target	10 months	10 months	9.5 months	9.5 months	9.5 months	9 months
Result	10 months	10 months	9.5 months	9.5 months	Sep 30, 2016	Sep 30, 2017
Status	Target Met	Target Met	Target Met	Target Met	Pending	Pending

Increase the combined count of webpage hits, hits to the locator, and hits to Substance Abuse and Mental Health Data Archive (SAMHDA) for SAMHSA-supported data sets (Lead Agency - SAMHSA; Measure ID - 4.4.10)

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
Target	6,000,300	1,792,523[88]	1,882,149[89]	2,390,402	1,700,000	1,700,000
Result	1,707,165[90]	2,298,464[91]	1,745,133[92]	N/A[93]	Dec 31, 2016	Dec 31, 2017
Status	Target Not Met	Target Exceeded	Target Not Met	Not Collected[94]	Pending	Pending

Increase the number of strategically relevant data sets published across the Department as part of the Health Data Initiative (Lead Agency - IOS; Measure ID - 1.2)

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
Target	285	288	1,200	1,800	2,000	2,025
Result	366	1,025	1,657	1,900	Sep 30, 2016	Sep 30, 2017
Status	Target Exceeded	Target Exceeded	Target Exceeded	Target Exceeded	Pending	Pending

Increase the electronic media reach of CDC Vital Signs through use of mechanisms such as the CDC website and social media outlets, as measured by page views at [http://www.cdc.gov/vitalsigns,](http://www.cdc.gov/vitalsigns) social media followers, and texting and email subscribers (Lead Agency - CDC; Measure ID - 8.B.2.2)

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
Target	1,169,208	1,215,976	2,924,842	3,858,339	6,875,000	7,500,000
Result	1,829,111	2,924,842	3,507,581	6,551,159	Oct 31, 2016	Oct 31, 2017
Status	Target Exceeded	Target Exceeded	Target Exceeded	Target Exceeded	Pending	Pending

Increase the number of consumers for whom Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey data is collected (Lead Agency - AHRQ; Measure ID - 1.3.23)

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
Target	144 Million	145 Million	145 Million	146 Million	147 Million	148 Million
Result	143 Million	143 Million	143 Million	143 Million	Dec 30, 2016	Dec 30, 2017
Status	Target Not Met	Target Not Met	Target Not Met	Target Not Met	Pending	Pending

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[88] Reduction in target reflects a change in the data collection methodology.

[89] Reduction in target reflects a change in the data collection methodology.

[90] There is no delay between fiscal year funding and the performance year.

[91] There is no delay between fiscal year funding and the performance year.

[92] There is no delay between fiscal year funding and the performance year.

[93] There is no delay between fiscal year funding and the performance year.

[94] Due to technical and programmatic changes associated with the website, 2015 data was not collected

Expand access to the results of scientific research (Lead Agency - IOS; Measure ID - 1.6)

	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
Target			N/A	3,250,000	4,000,000	4,500,000
Result			3,000,000	3,600,000	Sep 30, 2016	Aug 30, 2017
Status			Historical Actual	Target Exceeded	Pending	Pending

Analysis of Results

HHS is committed to making high-quality and useful health-related data easily accessible in a timely manner. The Medical Expenditure Panel Survey (MEPS) Household Component fields questionnaires to individual household members to collect nationally representative data on demographic characteristics, health conditions, health status, use of medical care services, charges and payments, access to care, satisfaction with care, health insurance coverage, income, and employment. MEPS data is being used to increase the awareness of health and human service issues and generate insights into how to improve health and well-being. Through their efforts from 2006 (baseline) to 2013, AHRQ has reduced the number of months to public release of data from 12 to 10. In FY 2015, it maintained a two week reduction achieved in FY 2014 of 9.5 for the number of months to public release of data from the end of data collection.

SAMHSA is tracking information usage from its publicly available resources by tracking a combined count of hits for a pool of key resources: the SAMHSA web site; the treatment locator; and the Substance Abuse and Mental Health Data Archive (SAMHDA). Since January of 2012, advancements are being made to assure the methodology of accurately counting web hits. These advancements resulted in target adjustments. Due to technical and programmatic changes associated with the website, FY 2015 data was not collected.

In addition to engaging the public, a high priority for the HHS Open Government Plan is to make HHS data more easily and broadly available through its Health Data Initiative (HDI). The mission of the HDI is to help improve health, healthcare, and the delivery of human services by harnessing the power of data and fostering a culture of innovative uses of data in a diverse array of public and private sector settings. This information can be used to increase agency accountability and responsiveness, improve public knowledge of the agency and its operations, further the core mission of the agency, create economic opportunity, or respond to need and demand as identified through public consultation. Also, researchers and analysts may use these data sets to add knowledge and understanding to existing health and human service issues. In FY 2015, HHS continued executing its Health Data Initiative Strategy and Execution plan. Currently, 1900 datasets are available on healthdata.gov, exceeding the measure target. A major focus of activity this year has been on enhancing the capabilities and functionalities of the healthdata.gov portal. A new contractor was hired and the site has been re-launched in beta as the IDEA Lab seeks to improve the look and feel of the site, improve performance including better sort and search, data preview capabilities with charts and maps, links to other datasets users might be interested in.

CDC Vital Signs is a monthly communications program that targets the public, health care professionals, and policymakers through fact sheets, social media, a website (http://www.cdc.gov/vitalsigns), and a linked issue of the Morbidity and Mortality Weekly Report (MMWR). The twelve annual *CDC Vital Signs* Program topics include the five topics coinciding with the five leading causes of death in the U.S. An additional three of these twelve topics are known risk factors of these five leading causes of

death, namely, obesity, tobacco use, and alcohol use. Its electronic media reach grew from 250,000 potential viewings (page views, social media followers, and texting and email subscribers) in FY 2010 to over 6.5 million potential viewings in FY 2015 due to print, broadcast and cable media interest, and continued promotion to add subscribers to its social and email dissemination channels. As a result of the continued use of mechanisms such as the CDC website and social media outlets, CDC expects the number of potential viewers for *CDC Vital Signs* to continually increase through FY 2017.

AHRQ has added a new measure to this report tracking Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys. CAHPS surveys ask consumers and patients to report on and evaluate their experiences with health care. These surveys cover topics that are important to consumers and focus on aspects of quality that consumers are best qualified to assess, such as the communication skills of providers and ease of access to health care services. In FY 2015, the CAHPS program missed its goal of 146 Million for whom CAHPS survey data is collected, with a result of 143 million, the same as the previous four years.

Increased access to research publications can help to support innovative breakthroughs and accelerate the pace of scientific discovery. Developed in 2000, PubMed Central (PMC) serves as a free digital archive for biomedical and life sciences journal literature. A priority in the Open Government Plan is to increase access to the results of federally funded research. Increased access to research publications can help to support innovative breakthroughs and accelerate the pace of scientific discovery. The total number of articles in Pub Med Central as of September 30, 2015 was over 3.6 million, exceeding its target. Weekday usage of PMC continues to increase, with an average of over 1 million unique users/weekday in September 2015. In FY 2015, the National Library of Medicine (NLM) undertook a redesign of the NIH Manuscript Submission (NIHMS) system to support the public access policies of new agencies who are using PMC as a public access repository for funded research. The redesign streamlined the authentication and manuscript submission processes and provide updated, relevant help information for new users directly on each screen. As part of this redesign, a new interface was also added to the NIHMS to allow agency funding administrators to track manuscript submissions associated with support from their agency. In conjunction with changes to the NIHMS system, PMC also expanded the available documentation on public access policies and PMC submission methods to help funded authors determine how to submit papers in compliance with public access. Agency-branded PMC portals / storefronts were also set up for participating funding agencies. These agencies are also being provided with access to PMC usage statistics for all of their funded papers in PMC to view the impact of their policies. PMC continues to accept and review applications from new journals wishing to participate (Note: Current number of journals that archive their complete contents in PMC is over 1700 as of October 2015).

Plans for the Future

AHRQ is seeking to reduce the amount of time from the point when MEPS Household Component data is collected to when the data is made available for public use. From FY 2015 through FY 2017, the MEPS will continue to take steps to accelerate data release, including batch processing, processing data sets concurrently, and combining similar processes. Starting in FY 2017 and beyond, MEPS data will be available two weeks earlier than previous fiscal years.

HHS expects the number of datasets published to increase in the coming years. Federation of datasets continues as HHS began acquiring health data from USDA and continues to work with federal agencies like the VA and CFPB to harness additional health specific datasets for a comprehensive catalog of data resources. The HHS IDEA Lab (formerly the Chief Technology Officer's office) is engaged in robust

outreach efforts to the HHS community and review of potential submissions. The IDEA Lab continues to educate our data communities on the content of HHS data through increased use of the HealthData.gov blog, expanded social media presence, while benefiting from health data focused events like the well-known Health Datapalooza. HHS is exploring, through an Innovator-in-Residence initiative titled "Demand-Driven Open Data" an infrastructure for requesting and discussing data that our community of data users can rely on while supporting one another in understanding and more efficiently using the available data resources.

AHRQ believes the CAHPS survey has been hampered by excess length, which may be affecting performance improvement. The CAHPS Team and National Committee for Quality Assurance (NCQA) are responding to this issue by conducting analyses to see which items can be eliminated (without affecting reliability or validity) from the CAHPS Core Items, which items need updating, and how data can be collected in the most cost-effective way.

CDC's active provider outreach has stimulated reporting of clinically-focused Vital Signs issues in widely read medical journals and web material such as The Journal for the American Medical Association (JAMA), American Academy of Family Physicians (AAFP) News, American Association of Nurse Practitioners (AANP) SmartBrief, and Medscape. CDC will continue to actively engage with the medical community to increase dissemination and use among health care providers.

HHS expects the number of journal articles in the NLM's PubMed Central Database to grow in 2017 as the Public Access Policy is expanded to include journal articles developed through funding from CDC, FDA, AHRQ and ASPR, and as NLM continues to archive other articles contributed by journal publishers. Starting in FY16, PMC will also be serving as the public access repository for non-HHS agencies, e.g., NASA. Staff are working to continue to improve documentation to help authors new to NIHMS and PMC in the coming year.

FY 2014 Strategic Review Objective Progress Update Summary

Please note that this section summarizes the result of the FY 2014 HHS Strategic Review process, limiting the scope of content to that available prior to spring of 2015. Due to this constraint, the following may not be the most current information available.

Conclusions: Progressing

Analysis: HHS has made progress in enhancing access to and use of HHS data to improve programs, promote improvements in health and health care, and enhance information for decision making in health and human services. Improvements are evident in increasing timeliness, quality, and public and internal access and dissemination of survey data, administrative and programmatic data, and public access to scientific and research data.

HHS statistical and programmatic and administrative data systems are not only essential to the success of the HHS mission, but they also provide most of the national statistical capacity to monitor the health and wellbeing of the population, the performance of the public health, health care and human services systems and progress on HHS priorities and initiatives.

Most of the major HHS survey programs have taken steps to shorten the turnaround time from data collection to availability through technology and other efficiencies while maintaining high standards of data quality. As a result of Open Data Initiatives and the Health Data Initiative, HHS agencies have posted links to over 1800 data sets and tools on healthcare.gov. Data.gov includes over 3000 health

related datasets and tools. In addition, HHS makes statistical and administrative data available for research and statistical analysis through a continuum of data access mechanisms while protecting the confidentiality of the information.

HHS is working to balance its goals for making data available, promoting electronic health record adoption and meaningful use, with other important priorities, such as protecting the privacy and confidentiality of individuals and organizations. It is a challenging balance to identify and apply the complex and multi-faceted safeguards and security controls necessary to protect privacy while still making useful data available publicly to support program improvement and enhancement. Challenges in electronic health record adoption and meaningful use attainment limits the extent and quality of data that the health center program is able to collect. Data reporting presents an administrative burden on health centers and results in a delay in having data readily available for program planning and evaluation. Administrative and programmatic data is largely a byproduct of program operations and management, and significant continuing resources are often needed to prepare the data for public access and utility. Statistical programs face increasing costs of field work as well as data documentation, curation and data access mechanisms.

HHS is considering reaching out to stakeholders to develop cost-effective ways of collecting Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey data that do not compromise validity or reliability. In addition, the Department is exploring options for making additional high value de-identified administrative data like Marketplace enrollment data or Marketplace plan offerings data available for research and evaluation in a privacy protected manner both internally within HHS and in a public research access venue. In another approach, HHS is organizing a challenge for software developers to create a semi-automated MS Word and Adobe Acrobat document conversion and remediation tool that would allow HHS to quickly and at low cost ensure all documents are accessible to individuals with disabilities and in compliance with Section 508 of the Rehabilitation Act.