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Biden pleads for open data for cancer moonshot

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“Why can’t we do the same kind of thing in the **fight against cancer?**” Biden asked the seventh annual “Health Datapalooza” conference on Monday. The meeting brought nearly 1500 health researchers, entrepreneurs, patient advocates, health insurance representatives, and health care providers to Washington, DC this week, in addition to health officials from Australia, Canada, France, Israel, and the United Kingdom.

“Big data and computer power” can explain how genomics, medical history, lifestyles and genetic changes could trigger cancer, Biden said. But first this data must be standardized in compatible formats, so that it can be shared.

“Today different technology systems can’t talk to each other,” he said. “Most major cancer centers don’t have an easy way—and in many cases the motivation—to share data, including patient records, test results, family histories, and treatment responses.”

Biden called for an “open national network that allows any researcher, physician or patient access to raw data in a privacy-protected manner.”

Under President Barack Obama, the federal government has released vast amounts of data about the care provided by hospitals, doctors and other health care providers to millions of older Americans in the Medicare program, along with patient outcomes and cost. The data has enabled federal officials to measure and rate Medicare providers and even penalize them for poor quality of care.



AP Photo/Andrew Harnik

Previous “Health Datapalooza” conferences focused on the need to identify and release health data and make it accessible, said Niall Brennan, Medicare’s chief data officer and director of its Office of Enterprise Data and Analytics.

“We have made a significant amount of progress, so now the question becomes not what can we release, but what people should be doing with the data,” he said.

Biden wants researchers and entrepreneurs to do more than analyze health care data to measure the quality of care or spending patterns.

“I desperately need your input,” said Biden, whose son died last year of brain cancer. “Every day thousands of people are dying, and millions more are desperately looking for hope, for another day, one more month, maybe another year.”