**Health Care Cost Institute Frequently Asked Questions**

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1. **What is the Health Care Cost Institute?**Health spending is the single biggest financial issue facing the nation. It has critical implications for families, businesses, and for both federal and state budgets. The Health Care Cost Institute (HCCI) is an independent, non-profit research institute. Its mission is to promote independent research and analysis on the causes of rising US health spending, to provide policy makers, consumers, and researchers with better, more transparent information on what is driving health care costs, to help ensure that, over time, the nation is able to get greater value from its health spending.

The Institute’s initial work program is comprised of two sets of activities. First, the Institute will produce a twice-yearly health care cost tracker report, showing what is driving increasing health care costs. Second, the Institute will support/provide relevant data for topical research projects from independent researchers at leading universities, think tanks and other research organizations. The Institute expects such research projects to cover areas including the effect of the recession on health care costs, or the impact of aging on health care costs.

1. **How is it governed?**   
   The Institute is an independent non-profit governed by a distinguished board of experts. The following individuals are currently serving on the Institute’s [Board of Directors](http://www.healthcostinstitute.org/governing-board):  
     
   *Dr. Elizabeth Nabel, MD, President of the Brigham and Women's/Faulkner Hospitals  
   Professor David Dranove PhD, Northwestern University  
   Professor Alan Garber MD, Provost of Harvard University  
   Professor Martin Gaynor PhD, Carnegie Mellon University (chair of the HCCI board)  
   Professor Jonathan Gruber PhD, Massachusetts Institute of Technology  
   Professor Stephen Parente PhD, University of Minnesota  
   Ted Prospect FSA, MAAA, UnitedHealth Center for Health Reform and Modernization  
   Dale Yamamoto FSA, MAAA, President-Elect of Conference of Consulting Actuaries*  
   *Dr. Harvey Fineberg MD*, President, Institute of Medicine will serve as external advisor to the HCCI's Governing Board.
2. **How did this initiative come about?**The Institute is the result of increasing interest among academics, researchers and others for access to comprehensive and timely health spending data. A number of academics had been asking health plans for access to their extensive data covering employer-sponsored and individually-insured populations, so as to build a comprehensive and valid national picture of health care cost drivers.  
     
   The Institute’s goal is to streamline the process for researchers to obtain relevant data for their research projects
3. **Where will the data come from?**The Institute has access to data from health plans operated by Aetna, Humana, Kaiser Permanente and UnitedHealthcare. It is expected that additional data will be available from other health plans at some point in the future.
4. **Will the organizations granting access to their data be able to dictate the results of academic research produced using it?**No. The Institute’s governing board is controlled by independent national physician leaders and academic researchers. The board is currently putting in place proper procedures to ensure the integrity of the Institute’s work. Likewise, the universities where the research will take place have clear protocols to ensure the integrity of their academic output. Data contributors will continue to meet relevant legal requirements associated with data sharing and usage, including applicable HIPAA and antitrust standards.

1. **Who will benefit from this initiative?**This is an effort by many parties who believe that greater transparency into the drivers of health care costs will better equip the country to make difficult decisions about health care spending.
2. **When will the first research using the data be published? What is the focus of that research and who is doing it?**The first report on health care costs and utilization is [available now](http://www.healthcostinstitute.org/2010report). Published studies and an updated spending report will be available later in 2012. The research will focus on a variety of topics that deal with the drivers of US health care costs. Independent academic and actuarial researchers who meet appropriate qualifications can apply for access to the data to perform specific research projects.
3. **How will privacy concerns around the use of this data be addressed?**The Institute was established, and its relationships with data contributors and researchers are structured, strictly in accordance with HIPAA’s and other applicable privacy and security standards. In addition, the Institute has established a Data Integrity Committee whose primary focus is on governance of data privacy, security and integrity and antitrust compliance.
4. **How will the Institute decide who gets access to the data?**The Institute’s Board and committees including the Scientific Review Committee are responsible for the development of research standards to govern access to the data.
5. **How frequently will the data be updated?**Initially, the data will be updated semi-annually, consistent with the timing of the published health care costs and utilization reports. The Board of HCCI will decide in the future if more frequent updates (e.g. quarterly) are warranted.
6. **How large is the database that will be available to researchers?**Over 5 billion medical claim records, representing more than $1 trillion dollars of health care spending from 2000 to present is included, including about $200 billion in 2010. Data on more than 5000 hospitals and 1 million different medical service providers are included.
7. **All of the four plans participating cover a portion of public populations though SCHIP, Medicare, and Medicaid patients – are data from those patients included? Are any populations left out?**Medicaid data will not be available initially, but Medicare Advantage data from each participating plan will be included.
8. **Does the database provide utilization data as well as cost data?**YES. The utilization and cost data is available. All data is de-identified and there are limitations on how the data can displayed because of confidentiality and antitrust reasons.