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**FOR FURTHER INFORMATION CONTACT:** P. Jon White, MD, Health IT Director, Agency for Healthcare Research and Quality, [jonathan.white@ahrq.hhs.gov](mailto:jonathan.white@ahrq.hhs.gov).

**SUPPLEMENTARY INFORMATION:** A primary purpose of this RFI is to gather information that AHRQ can bring to the AQA (<http://www.aqaalliance.org>), a multistakeholder health care improvement organization formed to advance and implement clinician-level performance measurement. To carry out its statutory mandates to improve health care quality and specifically through quality measurement, AHRQ was a primary convener and has been a participant in AQA alliance from its inception. A full list of AQA participants is available at its Web site, referenced above. The AAQ (<http://www.aqaalliance.org>) has extensively discussed, in relation to its activities and objectives, the utility of having a NHDSE. The AQA has outlined and recommended processes for performance of quality measure selection, as well as for the underlying data sharing and data aggregation activities necessary to develop and apply performance measures, and public reporting of performance data. The following framed text contains excerpts from AQA proposal documents.

### **National Health Data Stewardship Entity**

#### *Proposed Mission*

The public/private entity will set uniform operating rules and standards for sharing and aggregating public and private sector data on quality and efficiency; offer guidance on implementation of such national operating rules and standards; and provide a framework for collecting, aggregating and analyzing data, to afford means of more effective oversight of health care data analyses and reporting in the United States.

#### *Proposed Precepts*

In performing activities, the entity shall follow certain precepts:

- To be objective in its decision making.
- To weigh carefully the views of its constituents in developing concepts and operating rules and standards.

- To bring about needed changes in ways that minimizes disruption to current aggregation efforts.
- To review the effects of past decisions and interpret, amend or replace operating rules, standards and processes in a timely fashion when such action is indicated.
- To follow an open, orderly process for setting policies, operating rules and standards that precludes placing any particular interest above the interests of the many stakeholders who rely on health care information.

#### *Proposed Scope of Work*

As previously noted, a wide range of activities need to be undertaken to advance health data exchange and use, including the development of measures and setting data transmission/IT technical standards. While all of these activities are important, the entity's responsibilities would primarily focus on specific issues relating to data collection, aggregation, analysis, and sharing.

The scope of work shall include setting policies, rules and standards for:

- Data aggregation—Should address various data aggregation issues including required characteristics of aggregators (e.g., they should be trusted and respected entities), transparency of aggregation processes, control and ownership rights of the data, potential liability within data aggregation processes, and issues that arise when competing aggregation efforts are in a single market area; should ensure that the experience of existing aggregation efforts are leveraged.
- Data collection (includes identification of data sources)—Should set policies, rules and standards for collecting public and private sector data from relevant stakeholders, including providers, employers, health insurance plans and others based on an agreed-upon measurement set; should assess the pros and cons of using data derived from administrative data (e.g., claims, pharmacy and lab data), medical record review and surveys, and develop policies that prioritize data sources based on various dimensions.
- Attribution—Should address at what specific level(s) data should be aggregated (e.g., individual physician level or group practice level). When making this determination, should consider sample size issues and physician/practice identifier issues.
- Methodologies—Should set methodological rules and standards for aggregating data, including those addressing risk adjustment, measure weights and sample size.

- Data analysis—Should set data analysis rules and standards, including those relating to trending, benchmarking, distribution, outlier analysis, correlation analysis and stratified analysis (variance between regions and states).

- Data validation (audits)—Should set policies, rules and standards to ensure that the validity of the data submitted is independently audited.

- Uses of data—Based on current law, should recommend allowable and nonallowable uses of data. Allowable data uses may include quality and efficiency improvement, consumer reporting, accountability, and pay for performance programs; also should, address allowable secondary uses of raw/primary data.

- Data access—Should specify who should have access to data and applicable limitations, such as confidentiality and privacy rules; should consider policies which allow contributors, including both public and private sector entities, to have access to their own data as well as information which allows them to compare their data against benchmarks.

- Data sharing and reporting—Should develop guiding principles for public reporting and reporting back information to clinicians. Screening processes to ensure valid reporting also should be addressed.

#### *Proposed Characteristics*

1. Objective—Be objective in its decision-making and have the ability to preclude placing any particular interest above the interests of many.
2. Independent—Have a governing structure that is independent of all other business and professional organizations.
3. Knowledgeable—Demonstrates knowledge and expertise in the area of health care delivery, data management, and security or acceptable proxy for this.
4. Responsive—Insure input and use from key experts who possess knowledge of health care quality assessment, health data transmission, IT standards, physician and hospital systems design and a concern for the public interest in matters of health care quality analysis, reporting, and patient privacy. Represent key stakeholder groups that are measured and users of this information.
5. Trustworthy—Is recognized as a trustworthy organization by multi stakeholder groups.
6. Adaptable—Be flexible enough to address issues and key stakeholder needs as the market evolves.
7. Transparent—Have an existing stable infrastructure for consensus

decision making that is transparent and involves the broad stakeholder communities.

8. Timely—Have the ability to carry out activities and achieve goals in a timely manner.

9. Collaborative—Have the ability to engage and work with other organizations to ensure effective implementation of rules and standards.

10. Sustainable—Have adequate resources to meet long and short term goals.

The concept of a national entity responsible for setting rules and standards for sharing and using healthcare quality measurement data has also been supported by the Institute of Medicine in their 2005 report Performance Measurement. IOM additionally proposed that this entity would be responsible for several other roles in performance measurement, including articulation of national goals, selection of measures, aggregation of data, reporting of results and performance measurement research. It is recognized that the role of a NHDSE might extend to domains beyond health care performance measurement. Respondents are encouraged to describe such domains and provide information relating to NHDSE roles and characteristics, with the understanding that any such information will be considered and will be presented by AHRQ to AQA but may not be acted on in the immediate future.

#### *Information Requested*

For the purpose of achieving a broader understanding of the need for a nationwide health data stewardship entity, and what form it might take, input is requested from interested parties. It is not necessary to answer all questions. In your response, please indicate which question you are addressing in your comments. Specific areas for comment include:

1. Whether or not there is a need for a national health data stewardship entity with reasons, including value such an entity might bring and issues it might solve

2. Desirable governmental and private sector roles in such an organization or in health data stewardship more generally

3. The roles and responsibilities currently assumed by other existing entities that might be addressed by a NHDSE, as well as roles that should not be fulfilled by a NHDSE

4. The relationship of a NHDSE and its work to other quality improvement organizations and activities

5. The relationship of a NHDSE and its work to other initiatives which set national standards for health information, such as the ANSI Health IT Standards Panel (HITSP)

6. Key challenges to creation and maintenance of a NHDSE

7. The risks of creating a NHDSE

8. The appropriate role(s) of a NHDSE in advancing quality measurement

9. The appropriate role(s) of a NHDSE in characterization and evaluation of the comprehensiveness, accuracy and reliability of shared and aggregated health care quality measurement data

10. The appropriate role(s) of a NHDSE regarding the transmission of shared and aggregated data

11. The appropriate scope of activities for a NHDSE beyond quality measurement (in such domains as research and population health)

12. The key stakeholders that would be impacted by a NHDSE and how to structure interactions with a NHDSE

13. Appropriate governance model(s) for a NHDSE

14. Means to assure NHDSE objectivity and independence

15. Means to achieve trustworthiness or trust in a NHDSE, and how that would best be achieved

16. Recommendations for achieving timeliness in NHDSE decision making

17. Recommendations for achieving compliance with NHDSE recommendations, rules or standards

18. The essential external inputs to a NHDSE

19. Recommendations for achieving organizational flexibility for a NHDSE

20. The potential organizational infrastructure needs of a NHDSE

21. Potential funding requirements and sources of funding for a NHDSE

22. The organizational skill set required of a NHDSE

23. Priority activities for NHDSE to support data sharing and aggregation

24. Issues concerning the above-excerpted AQA characterizations of a NHDSE

25. The suitability of one or more existing organizations to fulfill the role of a NHDSE

#### *Potential Responders*

Responses are both requested and anticipated from a broad range of individual organizations that have interests in healthcare data. Examples of commenters from whom we would hope to hear include, but are not limited to:

Health care professional societies  
Payers, including public and private insurers  
Health maintenance organizations

Purchasers, including employers and healthcare consumers

Consumer and patient interest groups

Community health delivery systems

State and local health agencies

Interested Federal agencies

University-based health systems

Advocacy groups and public interest organizations

Trade industry organizations

Health information technology industry vendors

Regional health information organizations

Interested individuals

We look forward to receiving constructive comments representing diverse perspectives.

Dated: May 25, 2007.

**Carolyn M. Clancy,**

*AHRQ, Director.*

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## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Administration for Children and Families**

#### **Proposed Information Collection Activity; Comment Request**

##### *Proposed Projects:*

*Title:* Communities Empowering Youth (CEY) Program Evaluation.

*OMB No.:* New collection.

*Description:* This proposed information collection activity is to obtain information from Communities Empowering Youth (CEY) grantee agencies and the faith-based and community organizations working in partnership with them. The CEY evaluation is an important opportunity to examine the outcomes achieved through this component of the Compassion Capital Fund in meeting its objective of improving the capacity of faith-based and community organizations and the partnerships they form to increase positive youth development and address youth violence, gang involvement, and child abuse/neglect. The evaluation will be designed to assess changes and improvements in the structure and functioning of the partnership and the organizational capacity of each participating organization.

*Respondents:* CEY grantees and the faith-based and community organizations that are a part of the partnership approved under the CEY grant.