



July 27, 2011

Office of Minority Health Resource Center
U.S. Department of Health and Human Services
Attn: Affordable Care Act Section 4302 Data Standard Comments
P.O. Box 37337
Washington, DC 20013-73337

RE: PUBLIC COMMENTS on HHS Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act.

Citizens' Council for Health Freedom is a non-profit national health care policy organization. CCHF exists to support patient and doctor freedom, medical innovation and the right of citizens to a confidential patient-doctor relationship.

CCHF makes the following public comments regarding the proposed government collection of each patient's **sexual orientation and gender identity** and the proposed collection of **race, ethnicity, primary language, sex and disability status** data from all patients cared for in America under Section 4302 of the Affordable Care Act.

Subcategories of these public comments:

Process Comments:

- Hidden Notice
- Improper Notice
- Controversial Notice at Height of Summer Relaxation
- Request for Action

Specific Comments

- Divisiveness by Definition
- Intrusive and Coercive Questions
- Failure to Notify Patients of Right to Refuse
- Hidden Civil Rights Agenda
- False Classifications
- Faulty Data
- Discouraging the Practice of Medicine
- Data-Driven Damage
- Limited Authority to Collect Data Under Law

CCHF Recommendation

PROCESS COMMENTS:

- **Hidden Notice** - The Department proposes to begin collecting data on the sexual orientation and gender identity of all patients and citizens. The collection of race and ethnicity data is very controversial, but this very specific controversial plan to collect sexual orientation and gender identity data is not listed anywhere in the title of the Notice. It is not until the final column of the last page that this plan is mentioned. *Indeed, unlike the other data that have additional material to consider — including the proposed questions patients will be asked — the collection of sexual orientation and gender identity data is only mentioned once and without any details given.*

By all appearances, HHS has followed the strategy of too many newspapers that claim objectivity by waiting until the last three paragraphs of the article to include any discussion of the other side of the issue in question. Thus, the hidden nature of the plan to collect sexual orientation and gender identity data appears to be a purposeful attempt to hide this controversial data collection plan from the public.

- **Improper Notice** - Because this Notice does not say HHS will be issuing a separate request for comments on sexual orientation and gender identity, it appears that this Notice is the only one to be given to the public on the proposed collection of sexual orientation and gender identity data. However, given the controversial nature of the government’s plan to collect this data on every patient and citizen, the June 30, 2011 Notice is not the proper notice or a proper request for public comments. This data collection plan should be given a separate Notice.
- **Controversial Notice at Height of Summer Relaxation** – The notice and request for public comments was published five days before the 4th of July holiday. The opportunity for the public to comment was essentially limited to the month of July, the most popular month of the summer for vacations and other summer activities. Mailed comments only had 28 days if one includes the date of publication.

The nature of this entire data collection proposal is extraordinarily controversial, yet the Department chose to publish its request for comments when much of the nation was essentially on vacation and “at play.” This too appears to be a purposeful attempt to hide this controversial data collection plan and prevent the Department from getting public comments that oppose its plan.

Request for Action: To give the public more time to respond, HHS should extend the comment period for this entire data collection proposal. If this controversial data collection proposal moves forward, CCHF calls on HHS to publish a new and separate notice for the proposal to standardize, collect, analyze and report sexual orientation and

gender identity data. HHS should widely announce the new notice in a press release and also begin a new public comment period specific to sexual orientation and gender data.

SPECIFIC COMMENTS:

Divisiveness by Definition

The United States has elected its first black president, yet Mr. Obama’s defining act, the so-called Patient Protection and Affordable Care Act (PPACA), seeks to divide patients and citizens by race, ethnicity, sex, sexual orientation, gender identity, primary language, disability status and “any additional demographic data” the Secretary of HHS decides to collect and analyze.

We believe this data collection plan may ultimately lead to the use of civil rights laws, government “quality” measurement of doctors and hospitals, and the Americans with Disabilities Act to advance a national health care system.

Although the U.S. Department of Health and Human Services may seek advice, HHS officials will define and standardize these terms (race, ethnicity, sex, disability status, language, sexual orientation, gender identity, etc.) as they see fit. The federal law provided no definitions. For instance, who gets to decide what a disability is? How broad could that definition eventually be? Mental? Physical? Behavioral? Genetic? Emotional?

The notice mentions that this may be only the beginning of the authorized data collection plan. By law HHS can broaden this collection to innumerable “additional demographic data.” Socioeconomic level, age, religion, literacy level, mental health, insured status and geographic location may be next.

HHS is then required by law to collect, analyze and report the data collected according to HHS definitions of these categories. The definitions and data standards will likely be used to meet the Department’s and the Administration’s policy and political agendas.

Intrusive and Coercive Questions

For all the pronouncements of the Administration about being patient-centered and privacy-sensitive, this proposed data collection is intrusive and just one more reason for citizens to try to avoid the U.S. Census Bureau surveys and patients to begin to view the doctor’s office and hospital not as a sanctuary for help in a desperate time of need, but as a place where their rights to privacy and against involuntary research are violated.

At a very vulnerable and potentially fearful and painful time in their lives, patients will be asked to place themselves into government-designed boxes of classifications for a permanent record of that classification even if the classification (e.g. race, ethnicity, sexual orientation) is not relevant and often not real.

Since the data will be used for “quality” measurement (pay-for-performance metrics), clinics and hospitals may apply pressure on patients to obtain answers to the federal questions. The clinic will become as much a data collection center as a place of health and healing. No patient should be asked to classify themselves for the purpose of building government databases, enabling federal interpretation, and supporting social engineering research.

Failure to Notify Patients of Right to Refuse

The proposed data collection standards do not make it crystal clear to citizens and patients that they are NOT required by law to answer these questions. The PPACA says health care programs have to “collect and report.”

The PPACA requires no citizen to submit to the data collection — they need not answer even one question — however the proposed data collection standards (nor any other part of the Notice) do not announce this fact to citizens, patients, practitioners, hospital and clinic administrators or government surveyors.

Instead census takers will pressure citizens and clinics and hospitals will pressure patients to answer the following questions and either admit or deny the HHS-provided multiple-choice answers:

1. Are you Hispanic, Latino, or Spanish origin?
2. What is your race? (One or more categories may be marked)
3. What is your sex?
4. How well do you speak English?
5. Do you speak a language other than English at home?
6. [If so,] What is this language?
7. Are you deaf or do you have serious difficulty hearing?
8. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
9. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
10. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
11. Do you have difficulty dressing or bathing? (5 years old or older)
12. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (15 years old or older)

As noted above, the Notice only mentions sexual orientation and gender identity collection once—in **a single sentence**. The Notice does not include proposed questions regarding sexual orientation and gender identity for public comment. However, given the following and only statement on the issue in the Notice, we believe HHS plans to include sexual orientation and gender identity in list of questions for the data collection:

“The Department is also in the process of developing and validating standard approaches for collecting data about sexual orientation and gender identity.

“With this notice, the Office of Minority Health requests comment from the public and interested stakeholders on the proposed data collection standards for race, ethnicity, sex, primary language, and disability status.”

Hidden Agenda?

We are concerned about the real purpose behind this data collection. According to two commissioners, writing a dissent to a “reducing health disparities” report published by the U.S. Commission on Civil Rights, the purpose of the “reducing health disparities” agenda is the advance of national health care. About the report, they wrote,

“...the report goes way beyond enforcement to advocate not only a whole new bureaucracy, but a national strategy to achieve a ‘leveling’ in health care delivery, research, and financing. While we support much of what is in the report about the failures of Federal civil rights enforcement, the report is a thinly-veiled endorsement of universal health care, and advocates policies to achieve specific outcomes where market failures have not been demonstrated.” (*SOURCE: The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Volume II The Role of Federal Civil Rights Enforcement Efforts, A Report of the United States Commission on Civil Rights, September 1999*)

False Classifications

CCHF finds great ambiguity possible in the proposed data collection. What is “race”? What is “ethnicity”? What if people claim one classification one day and another classification the next? What does it mean when individuals claim a certain “race” when there are options? As was widely reported in the news, President Obama marked “black” on the 2010 U.S. Census rather than “black and white.” R.C. Lewontin, Alexander Agassiz Professor Emeritus of Zoology at Harvard University, writes about the subject of “race”:

“...there is no objective way to assign the various human populations to clear-cut races. Into which “race” do the Hindi and Urdu speakers of the Indian sub-continent fall? Should they be grouped with Europeans or with Asians or should a separate race be assigned to them? Are the Lapps of Finland and the Hazari of Afghanistan really Europeans or Asians? What about Indonesians and Melanesians? Different biologists have made different assignments and the number of “races” assigned by anthropologists and geneticists has varied from 3 to 30.”

“...there is no clear criterion of how much difference between groups of genetically related individuals should correspond to the category “race.” If it had

turned out that groups of related populations were clearly different in the great majority of their genes from other groups, then racial categories would be clear and unambiguous and they would have great predictive power for as yet unstudied characters. But that is not the way it has turned out, at least for the human species.

“...For purposes of medical testing we do not want to know whether a person is “Hispanic” but rather whether that person’s family came from a Caribbean country such as Cuba, that had a large influx of West African slaves, or one in which there was a great deal of intermixture with native American tribes as in Chile and Mexico, or one in which there was only a negligible population of non-Europeans. Racial identification simply does not do the work needed. What we ought to ask on medical questionnaires is not racial identification, but ancestry. “Do you know of any ancestors who were (Ashkenazi Jews, or from West Africa, from certain regions of the Mediterranean, from Japan)?” Once again, racial categorization is a bad predictor of biology.

“...There has been a constant pressure from social and political practice and the coincidence of racial, cultural and social class divisions reinforcing the social reality of race, to maintain “race” as a human classification. If it were admitted that the category of “race” is a purely social construct, however, it would have a weakened legitimacy. Thus, there have been repeated attempts to reassert the objective biological reality of human racial categories despite the evidence to the contrary. [All emphasis added] (“Confusions About Human Races,” R.C. Lewontin, June 7, 2006)

John H. Relethford, author of *The Fundamentals of Biological Anthropology*, adds, “Race is a concept of human minds, not of nature.”

Faulty Data

The data in the proposed data collection will not be reliable. Not only will individual pick and choose their answers, HHS does not discuss how patients and citizens will respond when they learn their data is shared with the federal government for race-based and gender-based government research and analysis? Will they refuse to answer? To protect their privacy, might they just make random choices from the list of possible answers?

To secure “pay for performance” bonuses (*see below*), will doctors, nurses and census surveyors begin to answer the government’s questions when individuals refuse? As reported in *PEDIATRICS*, and as summarized in *AAPS News* (July 2011), it’s clear that outside observers will often not guess the same answer the patients would choose:

“To document achievement of the goal of eliminating ‘healthcare disparities,’ the race/ethnicity of the patient must be determined. In a study of race as a risk factor for neonatal hyperbilirubinemia, the race documented in the medical record frequently did not match self-reported race. Of 145 mothers classified as white,

only 64% self-reported as white: 13% said they were Hispanic, 3% Middle Eastern, and 11% of two or more races. Of 427 classified as black, only 70% self-reported as black, with 23% describing themselves as mixed race. For Asian and Middle Eastern categories, there was only 35% and 50% agreement, respectively (Pediatrics 2006; 117: 1618-1625).”

Discouraging the Practice of Medicine

Physicians, hospitals and clinicians of all licensures and certifications have cause for concern with this proposed data collection. The Notice states that,

“The law also requires that these data collection standards be used for this purposes of measuring quality and reporting for any federally sponsored, federally conducted, or supported health care or public health program, activity, or survey.”

In short, this collection of data will be used to determine government payment for care. It may determine health plan payments. It will determine whether doctor receive “quality” bonuses or financial penalties. It may also be used for certification and licensure. It will be reported on public “report cards.” It may be used to claim that a doctor or hospital treats one kind of “race” or a patient of a certain sex or of a certain declared sexual orientation or gender identity “better” or “worse.”

How will a doctor disprove these outside-the-exam-room-looking-in allegations? How much will it cost them to do so? How many will want to continue practicing medicine with such a serious threat hanging over their heads?

Civil rights allegations could emerge based on “race” or sex or disability status or sexual orientation classification. What will it mean to have the government determining the “quality” of care provided to any person of any declared classification? What will it mean to be facing federal allegations of civil rights violations? What will it mean for a doctor to try to prove that he or she gave the best care they could give regardless of sex, “race,” sexual orientation, or any other defined HHS “disparities” category?

Physicians and other clinicians may decide that another job, preferably 9 to 5, is in their best interest. Students may reconsider becoming physicians and nurses at a time when this country needs more of them than ever. Discussing the impact of baby boomers entering Medicare, the CEOs of New York-Presbyterian Hospital and Johns Hopkins Medicine write that the United States is facing a critical shortage of doctors:

“According to the Association of American Medical Colleges, we will need at least 90,000 additional doctors by 2020 to meet this increased demand, almost equally divided between general practice physicians and specialists. Five years later, the need for doctors is expected to grow to 130,000.” (“We Can’t Afford to Train Fewer Doctors,” Herbert Pardes and Edward D. Miller, *The Wall Street Journal*, July 12, 2011.)

Data-Driven Damage

This federal Notice of Availability of Proposed Data Collection Standards claims that the federal law “focuses on standardization, collection, analysis, and reporting of health disparities data.” It also admits, “...data alone will not reduce disparities”—regardless of what HHS defines as a “disparity”—and promises to integrate and intrude further into the privacy of each individual and the confidential patient doctor relationship:

“[Data] can be foundational to our efforts to characterize the disparities, design effective responses, and evaluate our progress.”

In short, HHS admits that it doesn’t even know how to characterize—describe or define—“disparities.” This intrusive data collection is thus meant to develop that characterization and likely to foist it upon the American people in new laws, new regulations and oppressive government monitoring toward “health equality for all.”

CCHF believes that citizen and patient data, regardless of accuracy or clarity, will be used under this proposal to fuel federal intervention and interference in private lives, corporate policies and the practice of medicine. Under the guise of reducing HHS-defined and HHS-manufactured “disparities,” health freedom, patient freedom and individual and practitioner liberty will be lost.

Limited Authority to Collect Under Law

This Notice on the proposed data collection standards does not quote the PPACA law. However the law specifically limits the data collection to federal programs. By not clearly pointing out this limitation in the Notice, the Secretary implies that the collection of race, ethnicity, sexual orientation, gender identity, primary language, sex, and disability status data must take place at all levels of the American health care system. Perhaps this is the Secretary’s intent, however, the PPACA law in Section 4302 states:

“The Secretary shall ensure that, by not later than 2 years after the date of enactment of this title, any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) collects and reports...”

Thus, the Secretary of HHS must not overreach her authority, or omit information from a public notice in an attempt to convince patients, doctors and others that all institutions must participate in this federal plan to get patients to self-classify themselves within the government’s “disparity” investigation categories and open themselves up to becoming government research subjects used to advance divisive federal government policies and agendas.

CCHF Recommendation

To preserve the privacy, patient and human subjects rights of individuals, to protect

individual liberty and a free-market health care system, to advance unity rather than divisiveness within the United States, to prevent coercive and intrusive questionnaires in the exam room and to preserve the integrity and confidentiality of the patient-doctor relationship, Citizens’ Council for Health Freedom calls on the Secretary of HHS to recommend to the Obama Administration that HHS abandon this divisive and intrusive proposed collection of data from clinics and hospitals, and data from federal surveys conducted by the U.S. Census Bureau and the U.S. Bureau of Labor Statistics. HHS should also begin now to take immediate steps to withdraw the proposed data collection.

Sincerely,

Twila Brase, RN, PHN
President