

November 5, 2015

Jocelyn Samuels  
Director, Office for Civil Rights  
Department of Health and Human Services  
Attention: 1557 NPRM (RIN 0945-AA02)  
Hubert H. Humphrey Building Room 509F  
2000 Independence Avenue, S.W.  
Washington, DC 20201

***Re: NPRM on Nondiscrimination in Health Programs and Activities***

Dear Ms. Samuels:

On behalf of our nearly 5,000 member hospitals, health systems and other health care organizations, the American Hospital Association (AHA) appreciates the opportunity to comment on the Department of Health and Human Services' (HHS) proposed rule on nondiscrimination in health programs and activities and to reaffirm hospitals' commitment to providing high-quality, patient-centered, appropriate care to all, regardless of their race, ethnicity, primary language, age, gender, sexual preferences, physical or mental abilities, or other characteristics. Hospitals strive to provide the right care at the right time, in the right setting to each and every patient they see and appreciate HHS taking steps to promote equal access to care for all.

We support the overall intent behind and direction of the proposed rule. However, we are concerned that, as written, the rule could inhibit effective care in some instances. Our comments focus on three specific issues:

- 1) The rule should promote the delivery of safe and effective care that is based on scientific evidence.
- 2) The rule should adopt a flexible approach to account for the continuing evolution and future learnings of genomics.
- 3) The rule should permit a more efficient and effective approach to assist people with limited English proficiency.



## **PROMOTING SAFE AND EFFECTIVE CARE BASED ON SCIENTIFIC EVIDENCE**

Risks and benefits of treatments may differ due to characteristics such as age, gender, physical stature and genetics. We urge HHS to make clear in the final rule that, when treatment is differentially provided in keeping with the scientific evidence or with common sense approaches to ensuring safe, high-quality care, it would not be considered a discriminatory action in violation of the law and this rule. We provide a few examples such of treatment differences below.

*Example 1: Care differences based on risks.* It is possible for men to develop breast cancer, but the disease is far more common in women, particularly older women. Mammograms are a relatively simple means of screening for breast cancer, but they carry some risk due to exposure to radiation as well as false positives that can lead to unnecessary invasive procedures. Based on the best available science, experts have judged that, for men and younger women, absent a known family history, the risks associated with the radiation exposure from routine mammograms outweigh the benefits. Thus, practice guidelines suggest not administering screening mammograms to women under a certain age or to men. We assume that the HHS did not intend to suggest that this kind of difference in treatment would be considered discriminatory.

Further, transgender individuals at various stages of transition, and even post-transition, may retain some risks for diseases or disorders more commonly affecting the gender of their birth. As it is currently worded, the proposed rule suggests that clinicians who recommend screening tests and similar services usually performed only on those of the individual's birth gender may be acting in a prohibited manner. We do not believe this was HHS's intention.

*Example 2: Differences based on physical attributes.* Physical size and other such characteristics often are associated with age or racial heritage. Because size and other physical characteristics are important to some diagnostic determinations and therapeutic regimens, the correct approach to treating some patients may differ across age or racial groups. For example, medication dosing is often determined by patient weight, so that children and the frail elderly may receive smaller doses of medications than young adults being treated for the same diagnosis. Further, low birth weight in infants is associated with an increased risk of mortality, complications and developmental delays. However, as described in a study conducted at El Camino Hospital<sup>1</sup> and in other data collected by the Centers for Disease Control and Prevention, normal birthweights often differ by ethnic groups, with lighter babies with smaller bodies and heads being born more frequently to women of Southeast Asian heritage. Decisions about whether an infant is in need of the additional testing and care given to low birth weight infants must take into consideration whether the infant is abnormally small for a child of his or her heritage. We do not believe that the proposed rule intended to impinge on such medical judgements.

*Example 3: Purpose-driven clinics and groups.* Much of health care is organized around the special knowledge required to care for individuals with differing needs. For example, pediatric

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<sup>1</sup> Ashima Madan, Sharon Holland, John E. Humbert, William Benitz, "Racial differences in birth weight of term infants in a Northern California population."

clinics serve patients only up to the age of adulthood. This is in part because children and adolescents tend to have different health needs than adults, and because the instruments and equipment needed to care for children need to be scaled for them. Similarly, behavioral health group therapy sessions may be organized for groups of individuals facing similar concerns so that they might better support each other in recovery. That might mean that groups formed as part of a treatment for female rape victims may need to exclude males to promote a more open dialogue, or groups formed to help transgender individuals deal with the prejudices they face would only include transgender individuals. Similarly, support groups formed to help patients or family members facing the health consequences of a disease that is most prevalent in a particular racial or ethnic group may have little diversity among the members. Diseases such as cystic fibrosis, Tay-Sachs, sickle cell anemia, Thalassaemia and hereditary hemochromatosis are dominantly experienced by individuals of a particular heritage. **We would like confirmation that HHS would not view these common sense approaches to organizing care as violating the letter or spirit of the proposed rule simply because they are predominantly comprised of patients of a particular background.**

#### **FLEXIBLE APPROACH NEEDED TO ACCOUNT FOR THE EVOLUTION AND FUTURE LEARNINGS OF GENOMICS**

The ways in which genomics will influence how we diagnose and treat various conditions are just beginning to emerge. But already science has begun to suggest that there may be ways to better predict an individual's risk for being afflicted by a particular disease based on his or her genetic makeup. In addition, there are indications that certain existing medications or new medications may work better for individuals with specific genetic sequences.

It is possible that the genetic codes that make patients susceptible to particular diseases or disorders or more responsive to specific medications or treatments may be linked to the genes that determine race, ethnicity, gender or other characteristics. **As we continue to work to ensure the best possible outcomes for patients, we want to be certain that this rule will not inadvertently suggest that all patients must be treated in the same manner when science suggests the best outcomes can be achieved through genetically determined treatment approaches. We urge HHS to keep the emphasis on striving for the best possible outcomes for all.**

#### **ASSISTING THOSE WITH LIMITED ENGLISH PROFICIENCY**

We appreciate the proposed rule's emphasis on ensuring that those who are less proficient in English know that they can access translation services to aide in their care. However, we question whether placing notices in 15 different languages in multiple places around the hospital, or placing 15 or more taglines on the hospital's website, is the correct way to achieve this goal. Many of our members serve diverse communities where more than 15 different languages are used. All individuals, regardless of their primary language, should be able to understand that there is someone who can help them communicate with the doctors, nurses and therapists who are treating them. One possible solution would be to develop and seek international recognition

Jocelyn Samuels  
November 5, 2015  
Page 4 of 4

of an icon that is meant to convey that translation services are available. Placing that symbol at various points in the hospital and on the hospital's website could communicate quickly and effectively that translation services will be made available to the individual without them having to scan 15 different notices hoping that they can read one or more of them.

Please feel free to contact Nancy Foster, AHA vice president for quality and patient safety policy, at (202) 626-2337 or [nfoster@aha.org](mailto:nfoster@aha.org) if you have questions about our comments or if there are any ways in which we can be of further assistance as HHS refines this proposed rule.

Sincerely,

/s/

Ashley Thompson  
Acting Senior Executive, Policy