

September 8, 2009

The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear President Obama:

The undersigned coalitions, groups, and organizations wish to express our concern with recent information indicating the possibility of eliminating data collection provisions in health reform legislation. As noted in an article published in the New York Times on September 3, 2009 titled, *Obama Aides Aim to Simplify and Scale Back Health Bills*, it was stated, “White House officials said Congress could also drop proposals requiring the government to create school-based health clinics and collect nationwide data on health and health care by race, sex, sexual orientation and ‘gender identity.’”

As you know, data collection is essential to track use and quality of care, document disparities and tailor interventions. Without data, it will not be possible to identify and properly address disparities in health and health care in a culturally and linguistically appropriate way.

Your Administration has continued to be supportive of data collection, including provisions in the *American Recovery and Reinvestment Act (ARRA)*. This statute requires the Department of Health and Human Services (HHS) to develop standards for collecting race, ethnicity and language data for electronic health records. The inclusion of this important provision was made with the support of your Administration and without any objection by the public or Congress.

Earlier this week, the Institute of Medicine released its report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. The report, commissioned by the Agency for Healthcare Research and Quality (AHRQ), notes the need for standardizing collection of race, ethnicity and language data for quality improvement and provides a number of recommendations. The report notes, “there is strong evidence that the quality of health care varies as a function of race, ethnicity, and language. Having quality metrics stratified by race, Hispanic ethnicity, granular ethnicity, and language need can assist in improving overall quality and promoting equity.”

We strongly urge you to continue your ongoing support of data collection and respectfully request the inclusion of specific data collection provisions in health reform legislation. Critical provisions impacting data collection have been included in health reform legislation including those for race, ethnicity, gender, gender identity, language, sexual orientation, and disability status. A final bill should include the data collection provisions outlined in the Senate Finance Committee’s *Description of Policy Options Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans*, Sec. 3301 from the *Affordable Health Choices Act*, and Title III from the *Health Equity and Accountability Act of 2009*.

Thank you for your ongoing leadership and support of issues impacting populations and communities that continue to suffer grave health and health care disparities. We would also like to thank you for your thoughtful consideration of this request and offer our assistance in

addressing this critical issue. Please contact Daniel E. Dawes, J.D., at (202) 682-5110 or ddawes@apa.org, if you would like any additional information.

Sincerely,

Academic Pediatric Association
ADAP Advocacy Association (aaa+)
AIDS/HIV Health Alternatives
Adventist HealthCare, Inc.
Advocates for Youth
Aetna
African Services Committee
AIDS Action Baltimore
AIDS Foundation of Chicago
AIDS Project Los Angeles
AIDS Taskforce of Greater Cleveland
Alliance to Develop Power
American Academy of Child and Adolescent Psychiatry
American Association for Health Education
American Association for Marriage and Family Therapy
American Association of People with Disabilities
American Association on Health and Disability (AAHD)
American Cancer Society Cancer Action Network
American Diabetes Association
American Health Services
American Heart Association/American Stroke Association
American Kidney Fund
American Psychological Association
American Social Health Association
American Society for Adolescent Psychiatry
Asian & Pacific Islander American Health Forum
Asian & Pacific Islander Wellness Center, San Francisco, CA
Asians & Pacific Islanders with Disabilities of California
Asian American Justice Center
Asian Counseling & Referral Service
Asian Pacific Islander Coalition of Washington State
Association for American Indian Development
Association of Asian Pacific Community Health Organizations (AAPCHO)
Association of Clinicians for the Underserved
Association of Language Companies
Association of Professional Chaplains
Association of University Centers on Disabilities (AUCD)
Boston Public Health Commission
Brain Injury Association of America
California Immigrant Policy Center
California LGBT Health and Human Services Network
California Pan-Ethnic Health Network
California Partnership

CANN - Community Access National Network
CAVDA-Citizens AIDS Project
Center for Advancing Health
Center for Community Change
CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder
Chicago House and Social Service Agency
Child Welfare League of America
CHIRLA - Coalition for Humane Immigrant Rights of Los Angeles
Colorado Progressive Action
Commissioned Officers Association
Community Catalyst
Community HIV/AIDS Mobilization Project (CHAMP)
Competech Smartcard Solutions
Council on Social Work Education
CulturaLink
Department of Gerontology, San Diego State University
Families USA
Family Equality Council
FOUND - Los Angeles, CA.
Global Justice Ministry of Metropolitan Community Churches
Granite State Organizing Project
Grass Roots Organizing, Missouri
Having Our Say Coalition
Hawai'i Public Health Association
HIV Medicine Association
HIV Prevention Justice Alliance
Human Rights Campaign
Idaho Community Action Network
Institute for Family Health
Interfaith Residence d/b/a Doorways
Ke Ali'i Maka'ainana Hawaiian Civic Club
Khmer Health Advocates, Inc
Korean American Resource and Cultural Center (KRCC)
Korean Resource Center
La Fe Policy Research and Education Center
Latino Agenda for Healthcare Reform
Latino Caucus of APHA
Latinos for National Health Insurance
Latinos for National Health Insurance and the Latino Agenda for Healthcare Reform
Lifelong AIDS Alliance
Magof Health- A Drug Free- Wellness Coalition in Guam USA
Main Street Alliance
Maine People's Alliance
Make the Road New York
Mental Health America
Missouri AIDS Task Force
NAMI
National Asian American Pacific Islander Mental Health Association
National Asian American Pacific Islander Mental Health Association

National Asian Pacific American Families Against Substance Abuse, Inc.
National Asian Pacific American Women's Forum
National Association for Public Health Statistics and Information Systems (NAPHSIS)
National Association of County and City Health Officials (NACCHO)
National Association of People With AIDS
National Association of School Nurses
National Coalition for LGBT Health
National Council of Jewish Women
National Council of La Raza (NCLR)
National Gay and Lesbian Task Force Action Fund
National Health Law Program (NHeLP)
National Hispanic Medical Association
National Hispanic Health Foundation
National Korean American Service & Education Consortium
National Latino Behavioral Health Association
National Minority AIDS Council
National Partnership for Women & Families
National Puerto Rican Coalition, Inc.
NCQA
New York Immigration Coalition
New York Lawyers for the Public Interest (NYLPI)
Northwest Federation of Community Organizations
Ocean State Action
Oregon Action
Organization of the Northeast
Ortho
Out of Many, One Coalition
Pediatric AIDS Chicago Prevention Initiative
Prevent Blindness America
Progressive Leadership Alliance of Nevada
Recovery Options - Los Angeles, CA
Research Institute for Independent Living
Society for Public Health Education
STOP AIDS Project
Summit Health Institute for Research and Education, Inc. (SHIRE)
The AIDS Institute
The Disparities Solutions Center at Institute for Health Policy - Massachusetts General Hospital
The Kibbe Group LLC
Translations for a Small World
Treatment Action Group (TAG)
Virginia Organizing Project
Voices for America's Children
Washington Community Action Network
Western Pacific Med/Corp