



# CHARTBOOK ON PERSON- AND FAMILY-CENTERED CARE

National Healthcare Quality and Disparities Report



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# NATIONAL HEALTHCARE QUALITY AND DISPARITIES REPORT CHARTBOOK ON PERSON- AND FAMILY-CENTERED TREATMENT

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## PERSON- AND FAMILY-CENTERED CARE

### Background

This Chartbook on Person- and Family-Centered Care is part of a family of documents and tools that support the *National Healthcare Quality and Disparities Report* (QDR). The QDR includes annual reports to Congress mandated in the Healthcare Research and Quality Act of 1999 (P.L. 106-129). These reports provide a comprehensive overview of the quality of health care received by the general U.S. population and disparities in care experienced by different racial, ethnic, and socioeconomic groups. The purpose of the reports is to assess the performance of our health system and to identify areas of strengths and weaknesses in the health care system along three main axes: access to health care, quality of health care, and priorities of the National Quality Strategy.

The reports are based on more than 250 measures of quality and disparities covering a broad array of health care services and settings. Data are generally available through 2013. The reports are produced with the help of an Interagency Work Group led by the Agency for Healthcare Research and Quality (AHRQ) and submitted on behalf of the Secretary of Health and Human Services (HHS).

### Key Findings of the 2015 QDR

- Access to care has improved dramatically, led by sustained reductions in the number of Americans without health insurance and increases in the number of Americans with a usual source of medical care.
- Quality of care continues to improve, but wide variation exists across the National Quality Strategy (NQS) priorities:
  - Effective Treatment measures indicate improvements in overall performance and reductions in disparities.
  - Care Coordination measures have lagged behind other priorities in overall performance.
  - Patient Safety, Person-Centered Care, and Healthy Living measures have improved overall, but many disparities remain.
- Despite progress in some areas, disparities related to race and socioeconomic status persist among measures of access and all NQS priorities.
- Care Affordability measures are limited for summarizing performance and disparities.
- Disparities in access tend to be more common than disparities in quality.

### Chartbooks Organized Around Priorities of the National Quality Strategy

- Making care safer by reducing harm caused in the delivery of care.
- **Ensuring that each person and family is engaged as partners in their care.**
- Promoting effective communication and coordination of care.
- Promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease.

- Working with communities to promote wide use of best practices to enable healthy living.
- Making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models.

Person- and Family-Centered Care is one of the six national priorities identified in the National Quality Strategy (<http://www.ahrq.gov/workingforquality/index.html>).

The National Quality Strategy has identified three long-term goals related to person- and family-centered care:

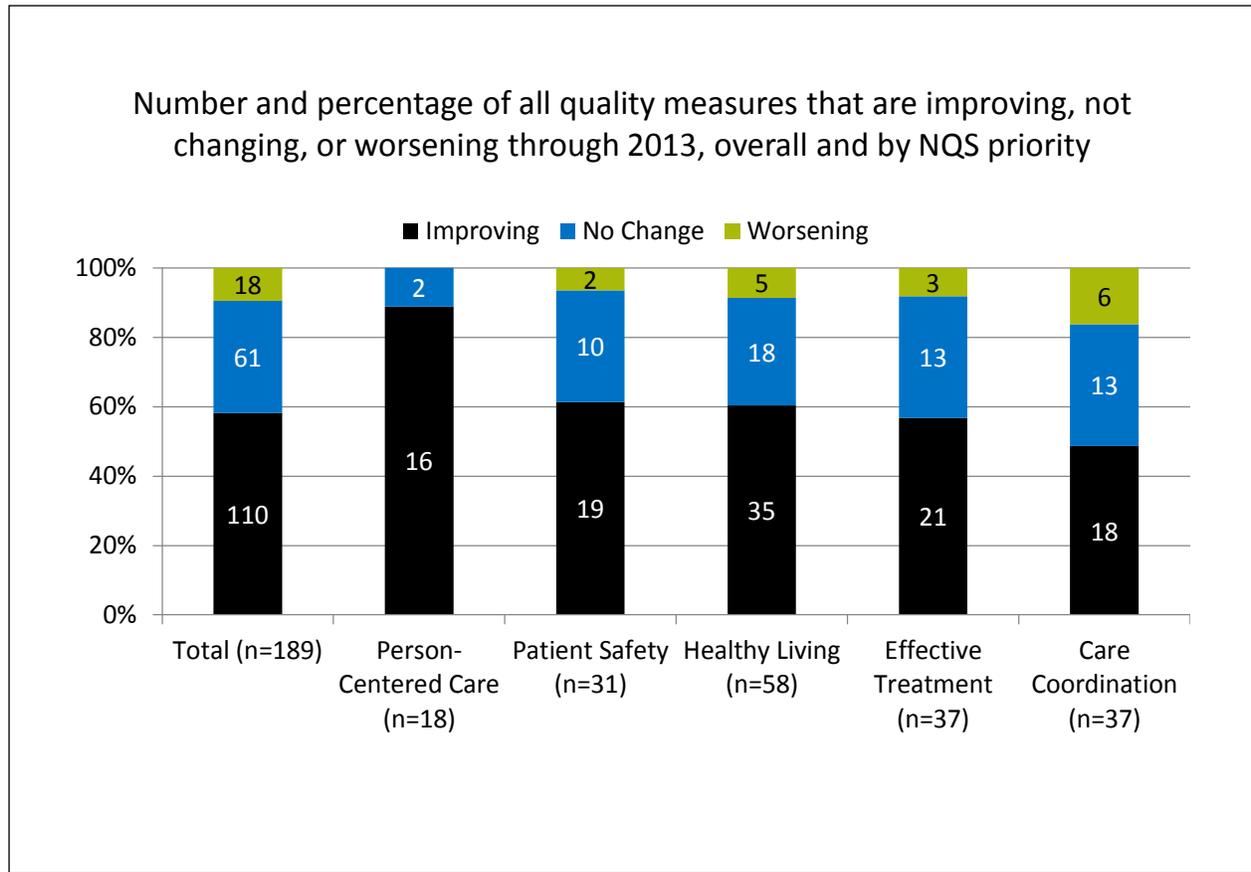
1. Improve patient, family, and caregiver experience of care related to quality, safety, and access across settings.
2. In partnership with patients, families, and caregivers—and using a shared decision-making process—develop culturally sensitive and understandable care plans.
3. Enable patients and their families and caregivers to navigate, coordinate, and manage their care appropriately and effectively.

Person-centered care means defining success not just by the resolution of clinical symptoms but also by whether patients achieve their desired outcomes. Some examples of person-centered care include ensuring that patients' preferences, desired outcomes, and experiences of care are integrated into care delivery; integrating patient-generated data in electronic health records; and finding additional ways to involve patients and families in managing their care effectively.

## Chartbook on Person- and Family-Centered Care

- This chartbook includes:
  - Summary of trends across measures of Person-Centered Care from the QDR.
  - Figures illustrating select measures of Person-Centered Care.
- [Introduction and Methods](#) contains information about methods used in the chartbook.
- A Data Query tool (<http://nhqrnet.ahrq.gov/inhqrdr/data/query>) provides access to all data tables.

## Trends in Quality Measures



**Key:** n = number of measures.

**Note:** For the majority of measures, trend data are available from 2001 to 2013. Measures of Care Affordability are included in the Total but not shown separately.

For each measure with at least four estimates over time, log-linear regression is used to calculate average annual percentage change relative to the baseline year and to assess statistical significance. Measures are aligned so that positive change indicates improved care.

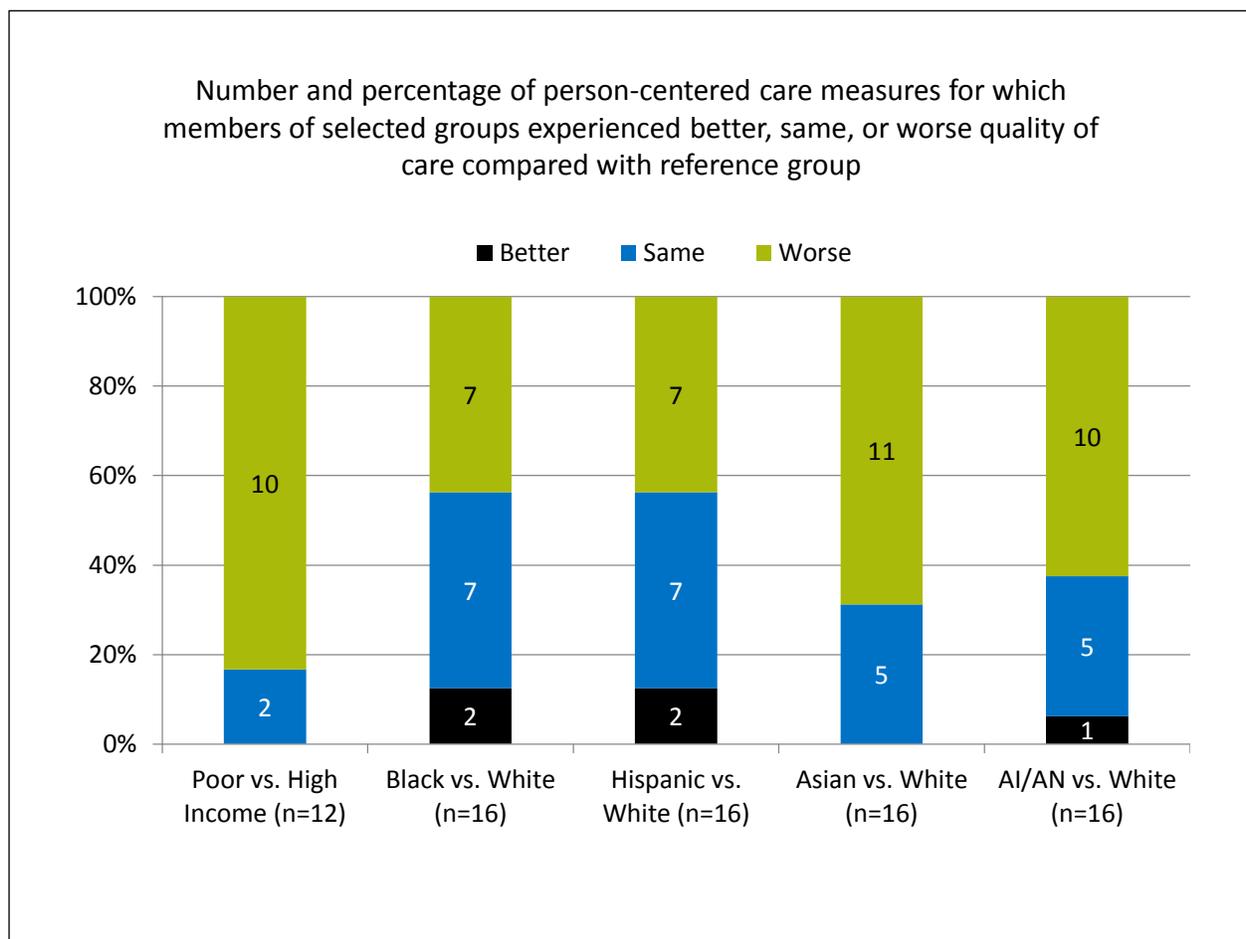
- **Improving** = Rates of change are positive at 1% per year or greater and are statistically significant.
- **No Change** = Rates of change are less than 1% per year or not statistically significant.
- **Worsening** = Rates of change are negative at -1% per year or greater and are statistically significant.
- Through 2013, across a broad spectrum of measures of health care quality, 60% showed improvement.
- Nearly all measures of Person-Centered Care improved.
- About 60% of measures of Effective Treatment, Healthy Living, and Patient Safety improved.
- Fewer than half of measures of Care Coordination improved.
- Fewer than a dozen measures of **Care Affordability** are tracked in the report, too few to summarize this way.

### Person-Centered Care Measures That Achieved Success

- Person-Centered Care measures that achieved 95% performance:
  - Children who had a doctor's office or clinic visit in the last 12 months whose health providers—
    - ◆ Sometimes or never listened carefully.
    - ◆ Sometimes or never explained things in a way they or their parents could understand.
    - ◆ Sometimes or never showed respect for what they or their parents had to say.
- No measures improved quickly (greater than 10% average annual percent change).

Measures that achieve 95% performance will no longer be reported in the chartbook. The measures will continue to be tracked and can be found in the QDR data query system.

### Disparities in Quality of Care



**Key:** n = number of measures; AI/AN = American Indian or Alaska Native.

**Note:** Poor indicates family income less than the Federal poverty level; High Income indicates family income four times the Federal poverty level or greater. Numbers of measures differ across groups because of sample size limitations. For most measures, data from 2012 are shown.

The relative difference between a selected group and its reference group is used to assess disparities.

- **Better** = Population received better quality of care than reference group. Differences are statistically significant, are equal to or larger than 10%, and favor the selected group.
  - **Same** = Population and reference group received about the same quality of care. Differences are not statistically significant or are smaller than 10%.
  - **Worse** = Population received worse quality of care than reference group. Differences are statistically significant, are equal to or larger than 10%, and favor the reference group.
- For 83% of person-centered care measures, people in poor households received worse care than people in high-income households.
  - Racial and ethnic disparities in person-centered care were also common.

### Person-Centered Care Measure With Elimination of Disparities

- Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never spent enough time with them

### Person-Centered Care Measures With Widening of Disparities

- Adults who had a doctor's office or clinic visit in the last 12 months who reported poor communication with health providers
- Children who had a doctor's office or clinic visit in the last 12 months whose parents reported poor communication with health providers
- Adult hospital patients who sometimes or never had good communication with—
  - Doctors in the hospital.
  - Nurses in the hospital.
- Rating of health care 0-6 on a scale from 0 to 10 (best grade) by—
  - Adults who had a doctor's office or clinic visit in the last 12 months
  - Children who had a doctor's office or clinic visit in the last 12 months
- Adult hospital patients who sometimes or never had good communication about medications they received in the hospital

The measures of poor communication for adults and children are composites of four measures, all of which individually showed widening of disparities:

- Adults [Children] who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never listened carefully to them
- Adults [Children] who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never explained things in a way they could understand
- Adults [Children] who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never showed respect for what they had to say
- Adults [Children] who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never spent enough time with them

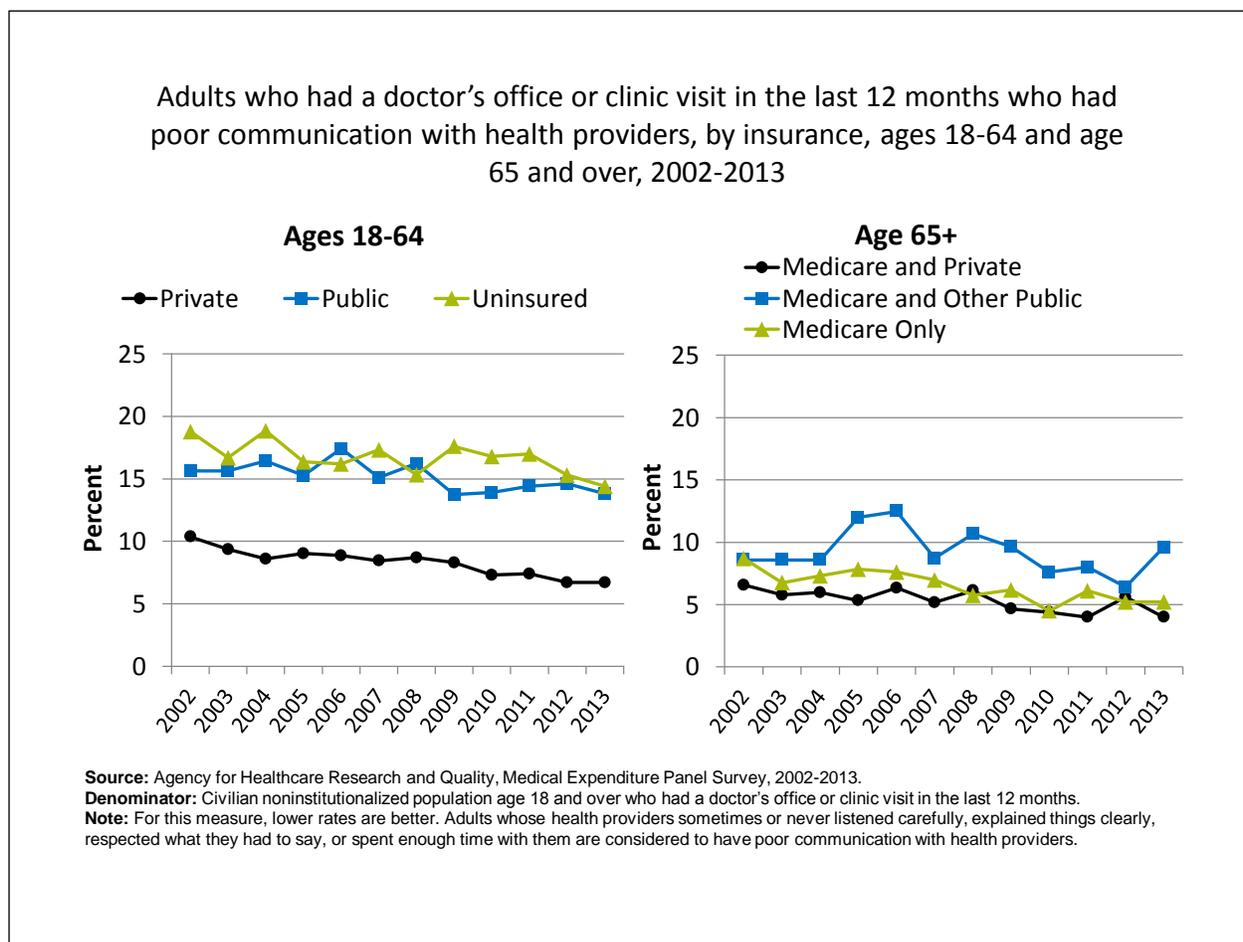
The last two measures are not included in this chartbook. Data are available through the QDR data query system (<https://nhqrnet.ahrq.gov/inhqdr/data/query>).

## Measures of Person- and Family- Centered Care

- Optimal health care requires good communication between patients and providers, yet barriers to provider-patient communication are common.
- To provide all patients with the best possible care, providers need to understand patients’ diverse health care needs and preferences and communicate clearly with patients about their care.
- The National Healthcare Quality and Disparities Report tracks a growing number of person- and family-centered care measures, focusing on three aspects of care:
  - Communication: doctor’s office, hospital, and home health care
  - Engagement in decisionmaking
  - End-of-life care

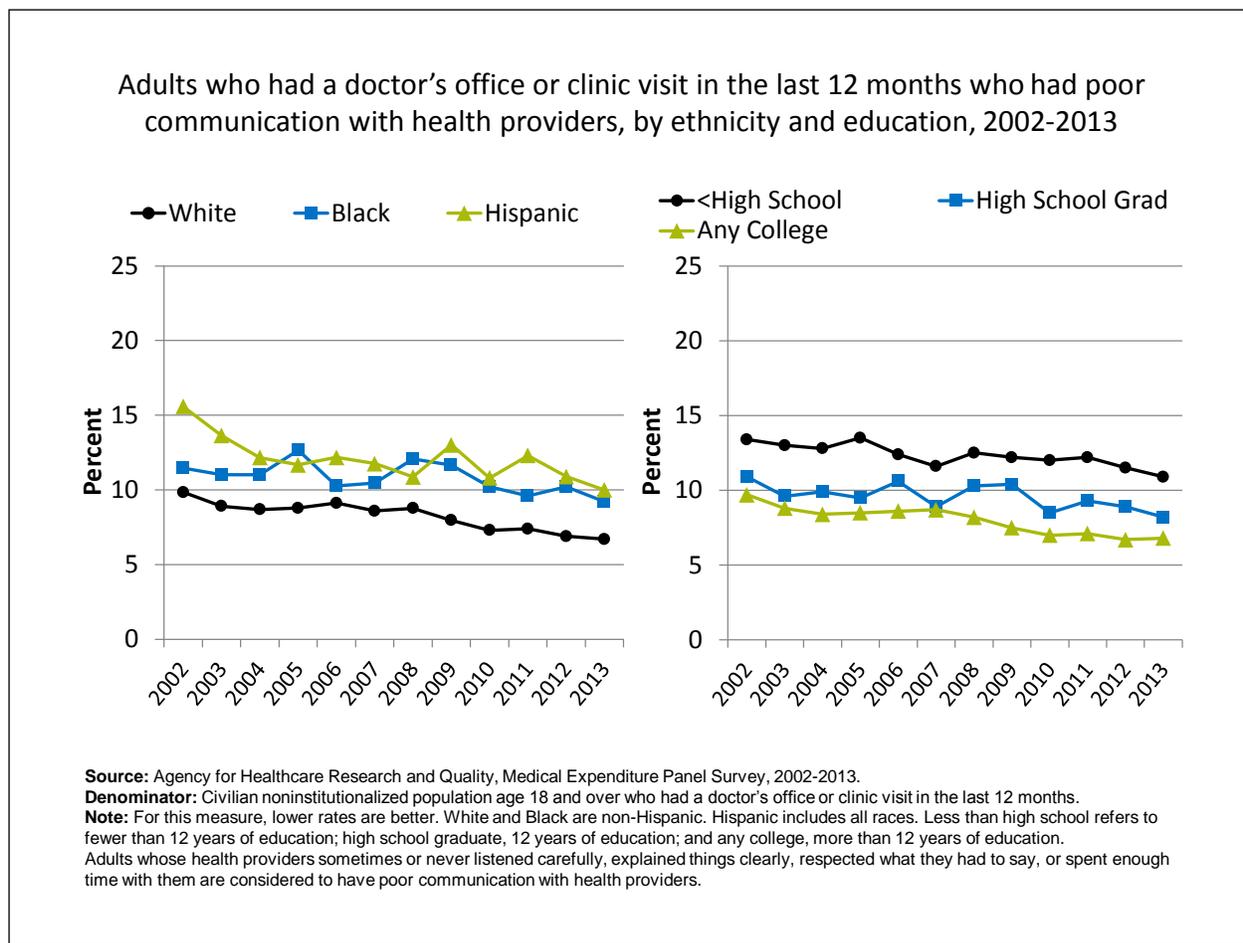
### Communication Measures: Doctor’s Office

#### Adults: Poor Communication With Health Providers, by Insurance



- **Overall Rate:** The percentage of adults who had a doctor's office or clinic visit in the last 12 months who had poor communication with health care providers decreased over time.
- **Trends:** From 2002 to 2013, the percentage of adults who had poor communication with health providers significantly decreased among all groups except Medicare and other public insurance.
  - Adults ages 18-64:
    - ◆ Private insurance: 10.4% to 6.7%
    - ◆ Public insurance: 15.6% to 13.8%
    - ◆ No insurance: 18.8% to 14.4%
  - Adults age 65 and over:
    - ◆ Medicare and private insurance: 6.6% to 4.0%
    - ◆ Medicare only: 8.7% to 5.2%
- **Groups With Disparities:**
  - In all years from 2002 to 2013, adults ages 18-64 who had public insurance or were uninsured were more likely than those with private insurance to have poor communication with their health providers.
  - Between 2002 and 2013, among adults ages 18-64, the gap grew between those with public insurance and those with private insurance, indicating worsening disparities.
  - In 9 of 12 years, adults age 65 and over with Medicare and other public insurance were more likely than those with private insurance to have poor communication with their health providers.

### Adults: Poor Communication With Health Providers, by Ethnicity and Education



- **Trends:** From 2002 to 2013, the percentage of adults who had poor communication with health providers significantly decreased for all ethnic groups and all education groups.

- **Ethnicity:**

- ◆ Whites: 9.8% to 6.7%
    - ◆ Blacks: 11.5% to 9.2%
    - ◆ Hispanics: 15.6% to 10.0%

- **Education:**

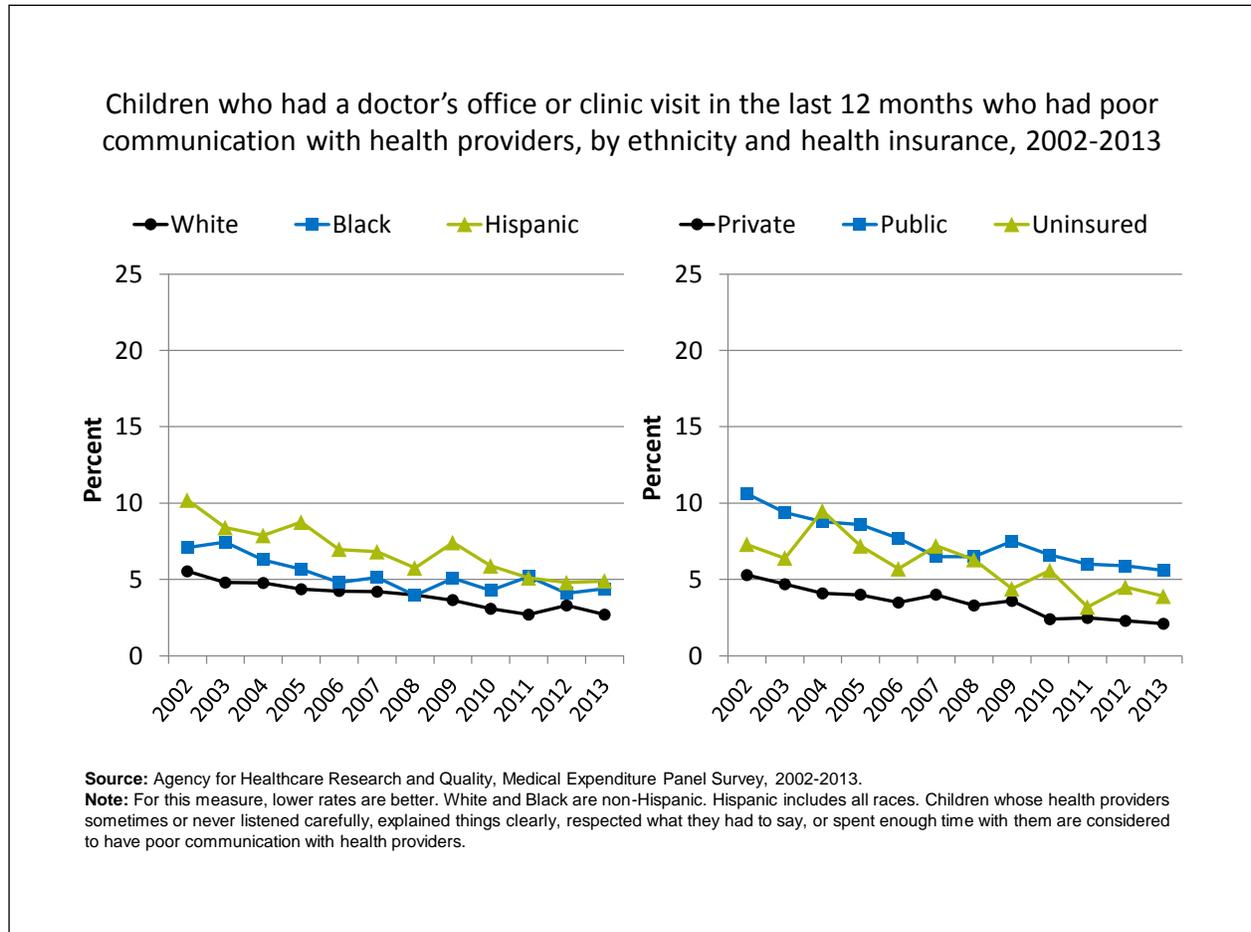
- ◆ Less than high school: 13.4% to 10.9%
    - ◆ High school graduate: 10.9% to 8.2%
    - ◆ Any college: 9.7% to 6.8%

- **Groups With Disparities:**

- In all years from 2002 to 2013, Hispanics and Blacks were significantly more likely than Whites to have poor communication with their health providers.

- In 10 of 12 years, high school graduates were more likely than those with any college to have poor communications with their health providers.
- In 2013, adults with less than a high school education and high school graduates were significantly more likely to have poor communication with their health providers than those with any college education.
- The gap is widening between adults with any college education and those with less than a high school education and high school graduates, indicating worsening disparities.

**Children: Poor Communication With Health Providers**



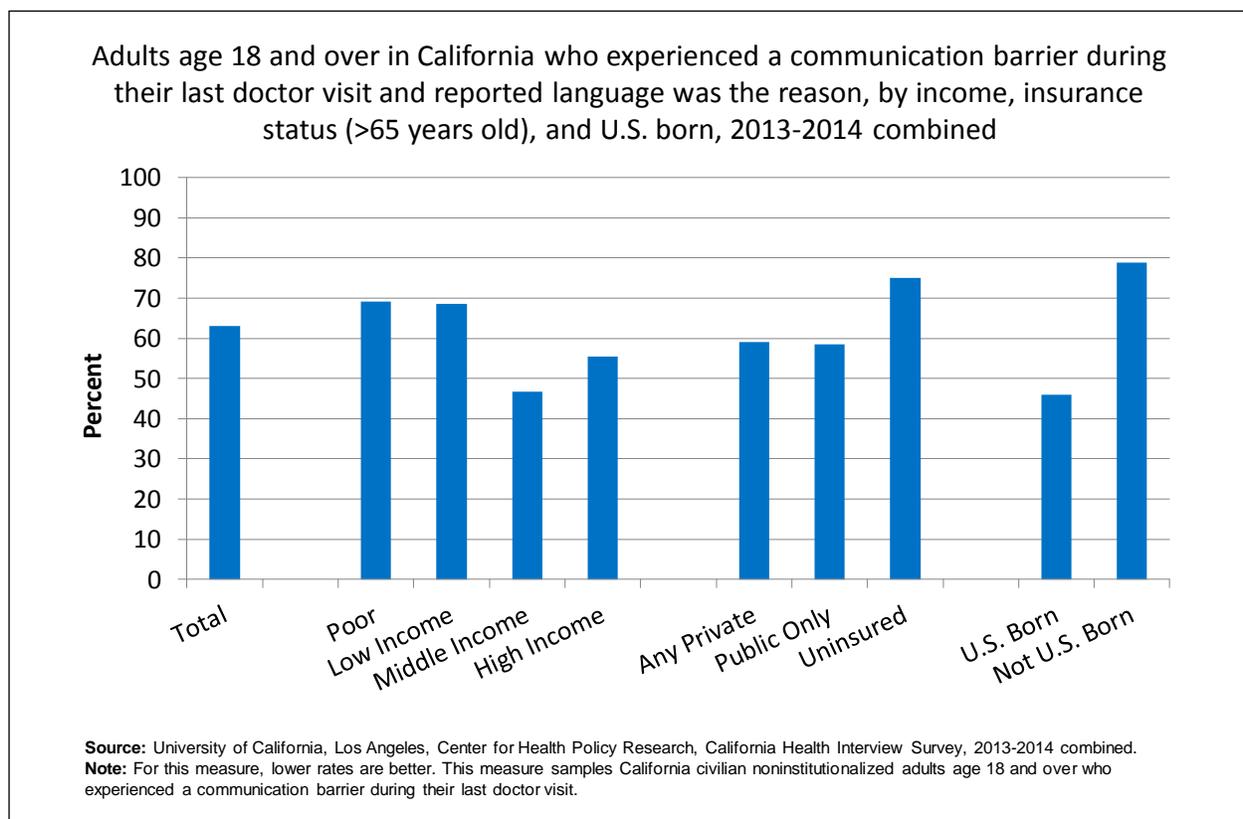
- **Trends:** From 2002 to 2013, the percentage of children whose parents reported poor communication with health providers significantly decreased for all ethnic groups and health insurance groups.
  - **Ethnicity:**
    - ◆ Whites: 5.6% to 2.7%
    - ◆ Blacks: 7.1% to 4.4%
    - ◆ Hispanics: 10.2% to 4.9%

- Health insurance status:
  - ◆ Private: 5.3% to 2.1%
  - ◆ Public: 10.6% to 5.6%
  - ◆ Uninsured: 7.3% to 3.9%

- **Groups With Disparities:**

- In all years from 2002 to 2013, Hispanic children were significantly more likely than White children to have poor communications with their health providers.
- In 2013, Hispanic children and Black children were significantly more likely than White children to report poor communication with their health care providers.
- In all years, parents of children with public insurance were more likely than parents of children with private insurance to report poor communication.

**Difficulty Understanding the Doctor Due to Language**

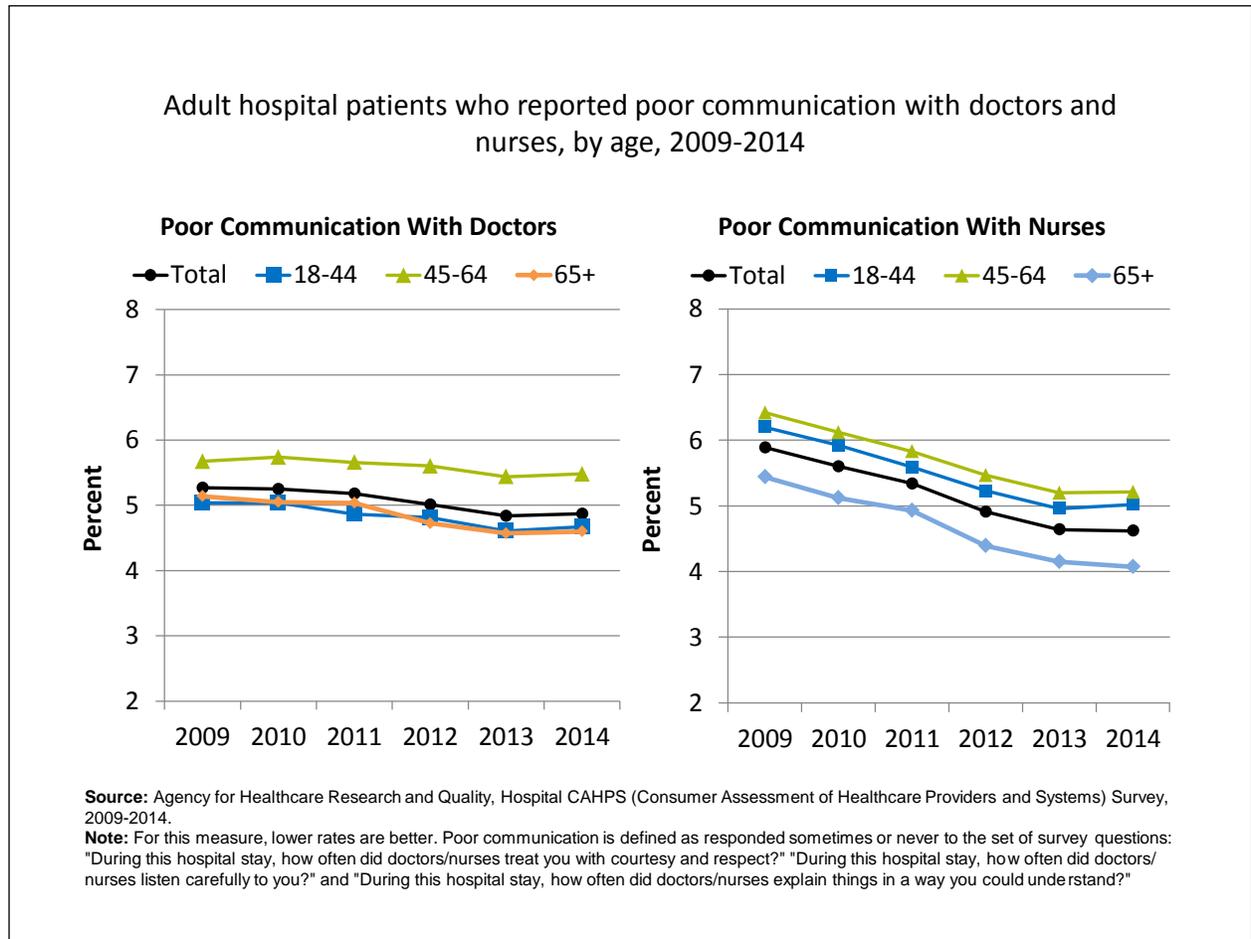


- **Groups With Disparities:**

- Among all adults who reported difficulty understanding their doctor during their last visit, the percentage who reported language was the reason was higher for individuals who were not born in the United States compared with those who were born in the United States.
- There were no statistically significant differences by income or insurance.

## Communication Measures: Hospital

### Adult Hospital Patients Who Reported Poor Communication With Doctors and Nurses



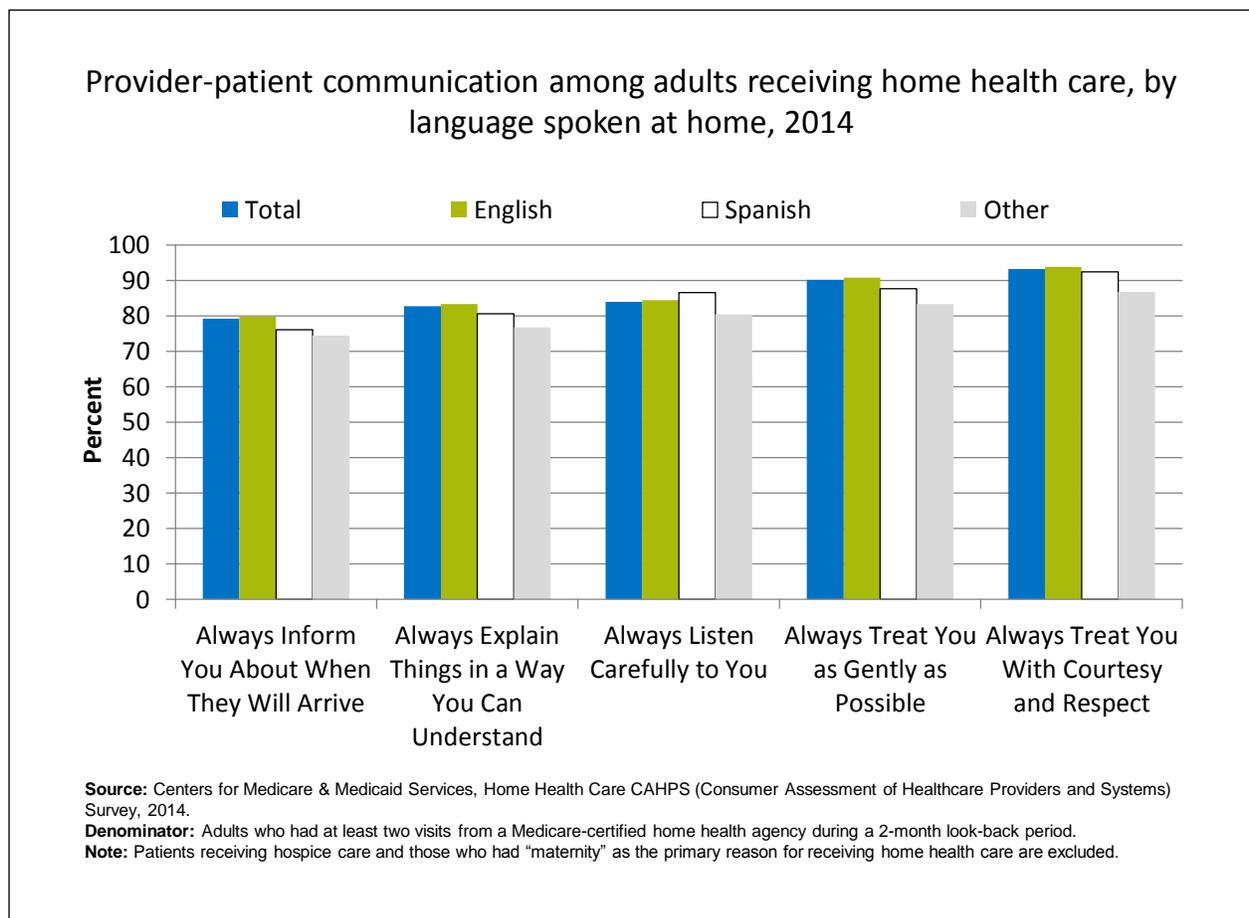
- **Overall Rate:** The percentage of patients reporting poor communication with doctors and nurses has decreased over time.
- **Trends:** From 2009 to 2014, the percentage of patients reporting poor communication significantly decreased among all age groups.
  - Communication with doctors:
    - ◆ 18-44 years: 5.0% to 4.7%
    - ◆ 45-64 years: 5.7% to 5.5%
    - ◆ 65 and over: 5.1% to 4.6%
  - Communication with nurses:
    - ◆ 18-44 years: 6.2% to 5.0%
    - ◆ 45-64 years: 6.4% to 5.2%
    - ◆ 65 and over: 5.4% to 4.1%

- **Groups With Disparities:**

- In 2014, hospital patients ages 45-64 years were significantly more likely to report poor communication with doctors compared with patients ages 18-44 years. There was no statistically significant difference between patients age 65 and over and those ages 18-44.
- In 2014, hospital patients age 65 and over were significantly less likely to report poor communication with nurses compared with patients ages 18-44 years. There was no statistically significant difference between patients ages 45-64 years and those ages 18-44.

## Communication Measures: Home Health Care

### Provider-Patient Communication Among Adults Receiving Home Health Care, by Language

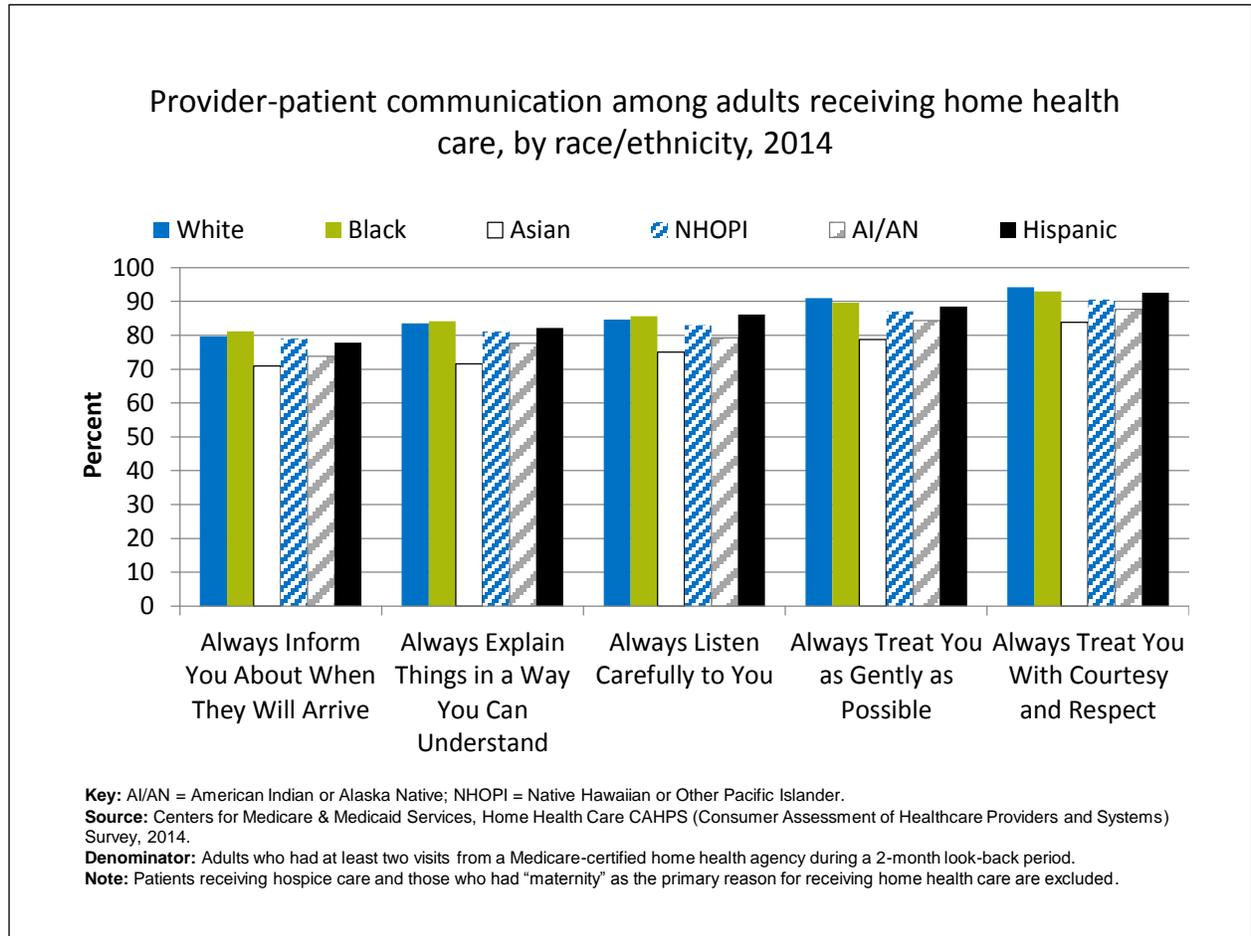


- **Groups With Disparities:**

- In 2014, compared with English speakers, adults speaking Spanish or another language at home were significantly less likely to:
  - ◆ Always be informed about when their provider would arrive.
  - ◆ Always have things explained in a way that was easy to understand.
  - ◆ Always be treated as gently as possible.
  - ◆ Always be treated with courtesy and respect.

- Adults speaking a language other than English or Spanish were less likely than adults speaking English at home to report that home health providers always listened carefully to them.
- Adults speaking Spanish at home were more likely than adults speaking English at home to report that home health providers always listened carefully to them.

**Provider-Patient Communication Among Adults Receiving Home Health Care, by Race/Ethnicity**

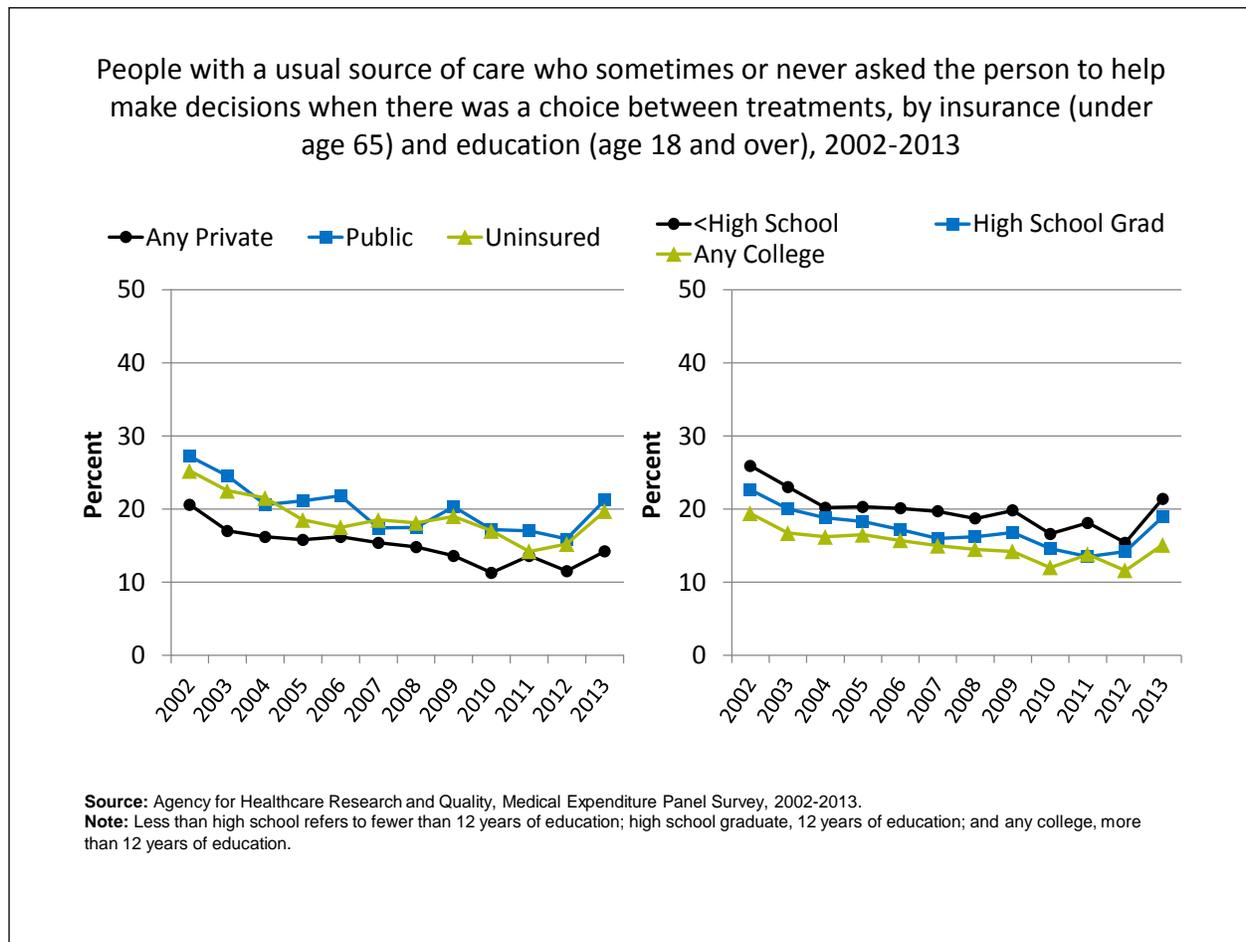


- **Groups With Disparities:** In 2014, among home health care patients, compared with Whites:
  - Asians and American Indians and Alaska Natives (AI/ANs) were significantly less likely to always be informed about when their provider would arrive.
  - Asians, AI/ANs, and Native Hawaiians and Other Pacific Islanders (NHOPIs) were significantly less likely to always have things explained in a way that was easy to understand.
  - Asians, AI/ANs, and NHOPIs were significantly less likely to always be listened to carefully. Hispanics were more likely to always be listened to carefully.
  - Blacks, Asians, NHOPIs, AI/ANs, and Hispanics were significantly less likely to always be treated as gently as possible.
  - Blacks, Asians, NHOPIs, AI/ANs, and Hispanics were significantly less likely to always be treated with courtesy and respect.

## Measures of Engagement in Decisionmaking

- The increasing prevalence of chronic diseases has placed more responsibility on patients, since conditions such as diabetes and hypertension require self-management.
- Patients need to be provided with information that allows them to make educated decisions and feel engaged in their treatment.
- Treatment plans also need to incorporate patients’ values and preferences.

### Providers Asking Patients To Assist in Making Treatment Decisions, by Insurance and Education



- **Trends:** From 2002 to 2013, the percentage of people with a usual source care who sometimes or never asked the person to help make treatment decisions significantly decreased for all insurance groups (under age 65) and education groups (age 18 and over).

■ Insurance:

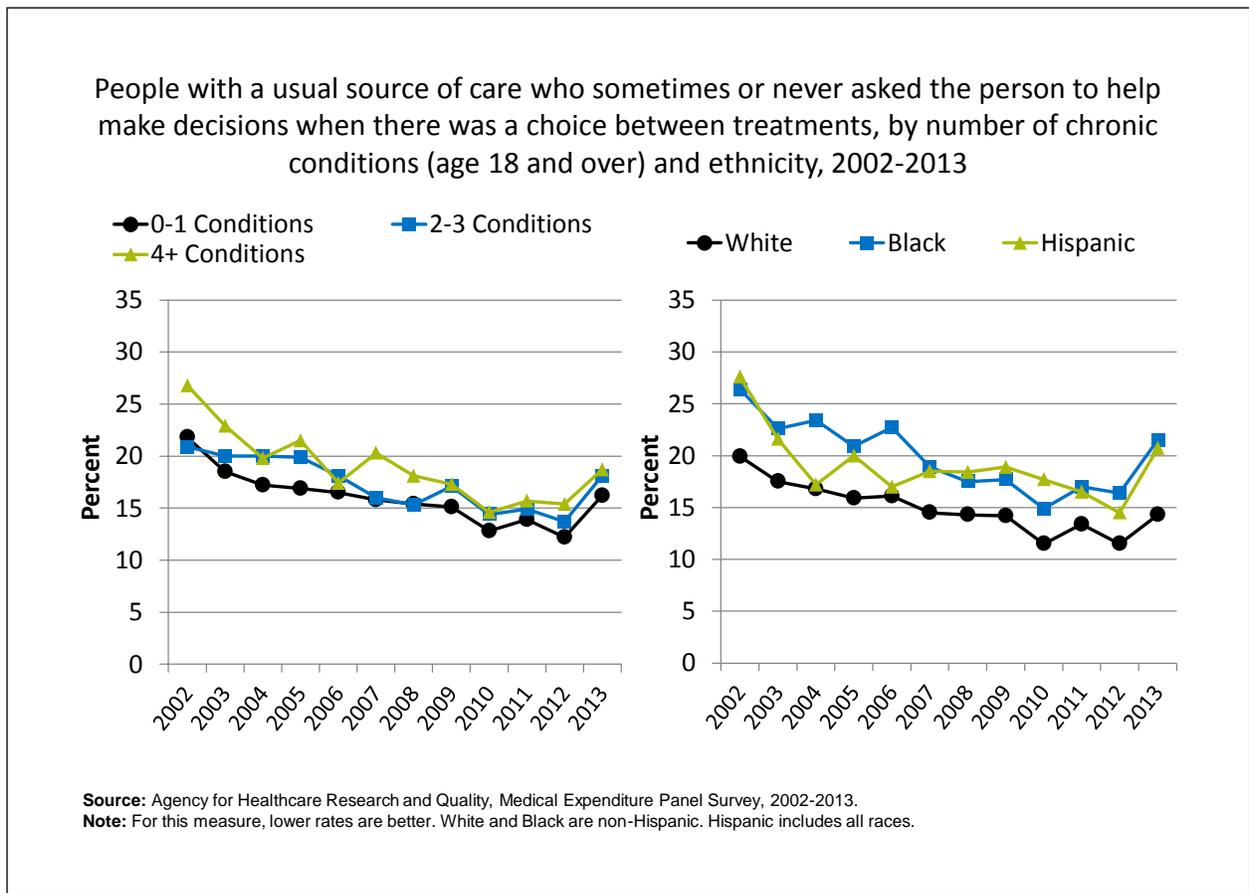
- ◆ Any private: 20.6% to 14.2%
- ◆ Public: 27.2% to 21.2%
- ◆ Uninsured: 25.2% to 19.7%

- Education:
  - ◆ Less than high school: 25.9% to 21.4%
  - ◆ High school graduate: 22.6% to 18.9%
  - ◆ Any college: 19.4% to 15.1%

- **Groups With Disparities:**

- In 2013, among adults ages 18-64, those who were uninsured and those with public insurance were more likely than those with private insurance to report that their health providers sometimes or never asked for their help to make treatment decisions.
- In 2013, adults with less than a high school education and high school graduates were more likely than those with any college education to report that their health providers sometimes or never asked for their help to make treatment decisions.
- In all years from 2002 to 2013, among adults age 18 and over, those with less than a high school education were significantly more likely than those with any college education to have a usual source of care who sometimes or never asked the person to help make treatment decisions.

**Providers Asking Patients To Assist in Making Treatment Decisions, by Number of Chronic Conditions and Ethnicity**



- **Trends:** From 2002 to 2013, the percentage of people with a usual source of care who sometimes or never asked the person to help make treatment decisions significantly decreased for all chronic condition and ethnicity groups.
  - Number of chronic conditions:
    - ◆ 0-1 chronic conditions: 21.8% to 16.2%
    - ◆ 2-3 chronic conditions: 20.9% to 18.1%
    - ◆ 4+ chronic conditions: 26.8% to 18.7%
  - Ethnicity:
    - ◆ Whites: 19.9% to 14.3%
    - ◆ Blacks: 26.4% to 21.5%
    - ◆ Hispanics: 27.6% to 20.7%
- **Groups With Disparities:**
  - In 2013, among adults age 18 and over with a usual source of care, people with 4 or more chronic conditions were significantly less likely than those with 0 or 1 condition to be involved in their treatment decisions.
  - In all years from 2002 to 2013, among people with a usual source of care, Blacks were more likely than Whites to be involved in their treatment decisions.
  - In all but 2 years from 2002 to 2013, among people with a usual source of care, Hispanics were more likely than Whites to be involved in their treatment decisions.

## End-of-Life Care Measures

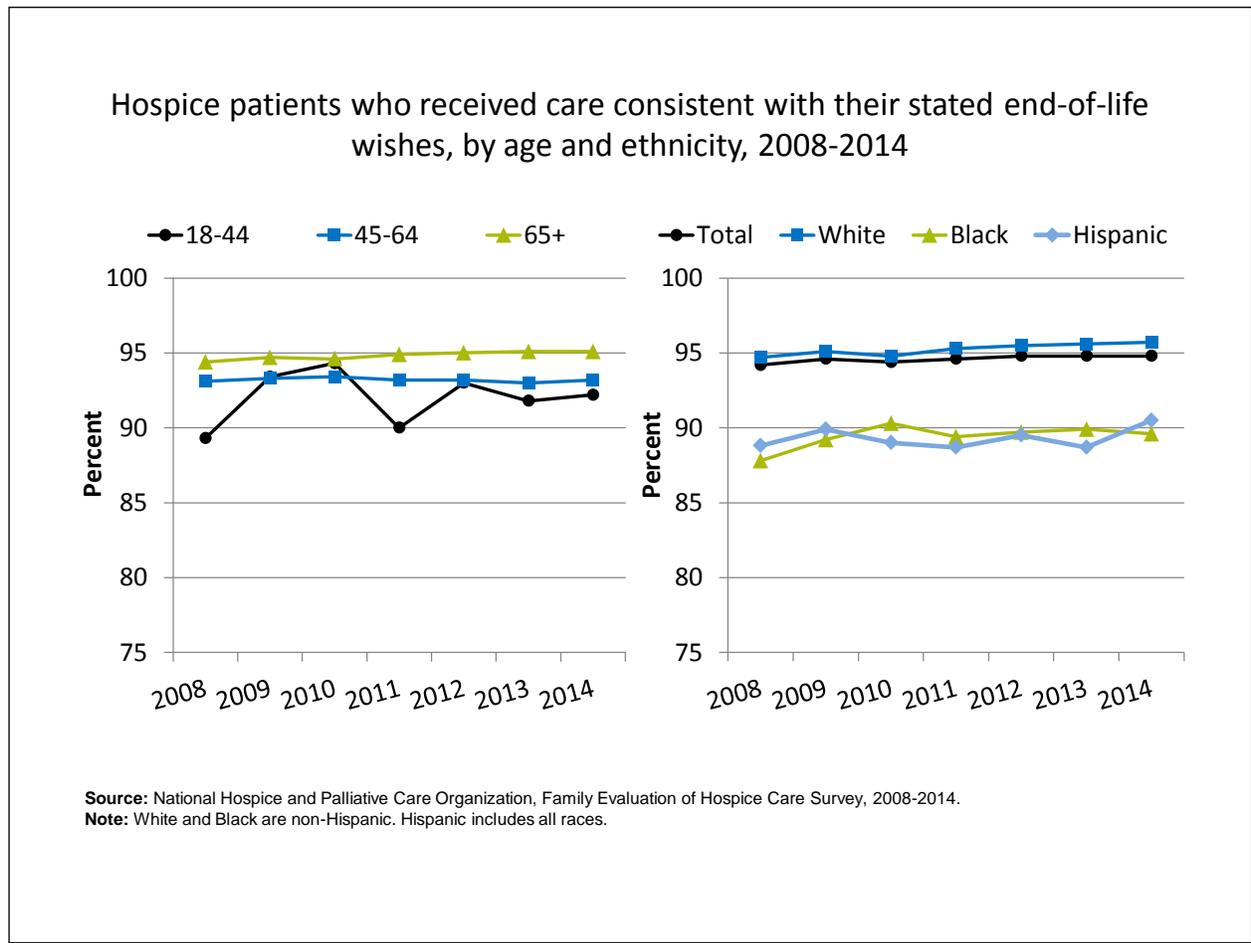
- Hospice care is generally delivered at the end of life to patients with a terminal illness or condition who want palliative medical care.
- Hospice care also includes practical, psychosocial, and spiritual support for the patient and family.
- The goal of end-of-life care is to achieve a “good death,” defined by the Institute of Medicine<sup>i</sup> as:

...free from avoidable distress and suffering for patients, families, and caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards (Field & Cassell, 1997).

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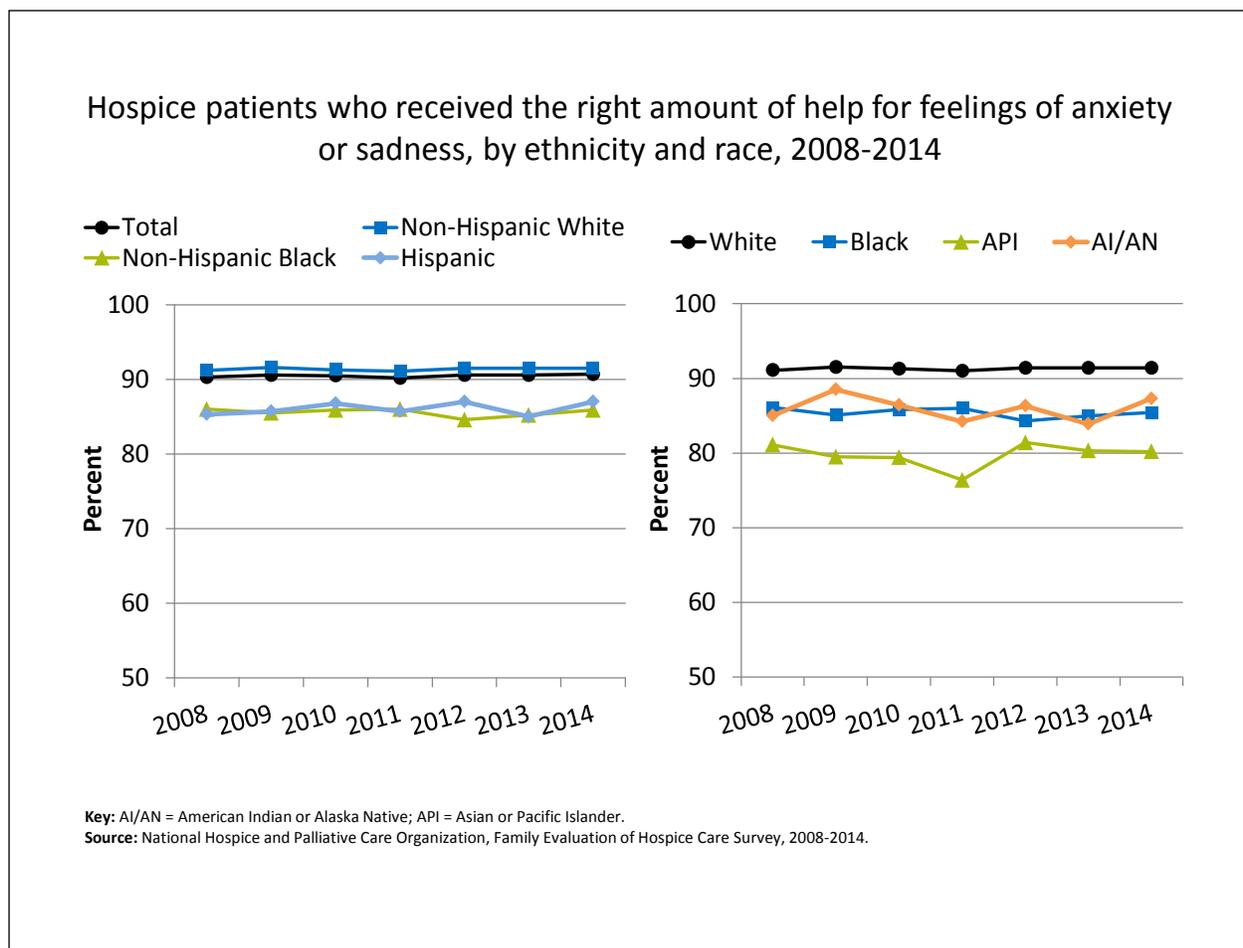
<sup>i</sup> On March 15, 2016, the division of the National Academies of Sciences, Engineering, and Medicine that focuses on health and medicine was renamed the Health and Medicine Division instead of using the name Institute of Medicine.

### Hospice Patients Who Received Care Consistent With Their Stated End-of-Life Wishes



- **Overall Rate:** In 2014, nearly all (94.8%) of hospice patients received care consistent with their stated end-of-life wishes.
- **Trends:**
  - From 2008 to 2014, the percentage of hospice patients age 65 and over who received care consistent with their stated end-of-life wishes improved from 94.4% to 95.1%. There were no statistically significant changes for those age 18-44 and ages 45-64.
  - From 2008 to 2014, the percentage of White hospice patients who received care consistent with their stated end-of-life wishes improved from 94.7% to 95.7%. There were no statistically significant changes among Blacks and Hispanics.
- **Groups With Disparities:**
  - In 2014, hospice patients age 65 and over were significantly more likely than patients ages 18-44 to receive care consistent with their stated end-of-life wishes.
  - In 2014, Black and Hispanic hospice patients were significantly less likely than White patients to receive care consistent with their stated end-of-life wishes.

### Hospice Patients Who Received the Right Amount of Help for Feelings of Anxiety or Sadness



- **Trends:** From 2008 to 2014, there were no statistically significant changes by ethnicity or race in the percentage of hospice patients who received the right amount of help for feelings of anxiety or sadness.
- **Groups With Disparities:**
  - In 2014, Hispanics and non-Hispanic Blacks were significantly less likely than non-Hispanic Whites to receive the right amount of help for feelings of anxiety or sadness.
  - Also in 2014, Blacks, Asians and Other Pacific Islanders, and AI/ANs were significantly less likely than Whites to receive the right amount of help for feelings of anxiety or sadness.

### References

Field M, Cassell C, eds. Approaching death: improving care at the end of life. Washington, DC: National Academy Press; 1997.