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**HHS Interagency Workgroup for the NHQR/NHDR:** Girma Alemu (HRSA), Chisara N. Asomugha (CMS), Kirsten Beronio (ASPE), Nancy Breen (NCI), Miya Cain (ACF), Victoria Carl (NIH), Steven Clauser (NCI), Wayne Duffus (CDC), Olinda Gonzalez (SAMHSA), Kirk Greenway (IHS), Chris Haffer (CMS-OMH), Linda Harlan (NCI), Rebecca Hines (CDC-NCHS), Edwin Huff (CMS), Deloris Hunter (NIH), Sonja Hutchins (CDC), Ruth Katz (ASPE), Tanya Telfair LeBlanc (CDC), Shari Ling (CMS), Darlene Marcoe (ACF), Tracy Matthews (HRSA), Karen McDonnell (CMS), Curt Mueller (HRSA), Karen Nakano (CMS), Iran Naqvi (HRSA), Ann Page (ASPE), Kimberly Proctor (CMS-OMH), D.E.B. Potter (ASPE), Asel Ryskulova (CDC-NCHS), Adelle Simmons (ASPE), Alan Simon (CDC-NCHS), Marsha Smith (CMS), Caroline Tafpin (ASPE), Emmanuel Taylor (NCI), Sayeedha Uddin (CDC-NCHS), Nadarajen Vydelingum (NIH), Chastity Walker (CDC), Barbara Wells (NHLBI), Valerie Welsh (OASH-OMH), and Tia Zeno (ASPE).

**AHRQ QDR Team:** Roxanne Andrews (CDOM), Barbara Barton (SSS), Doreen Bonnett (OCTK), Cecilia Casale (OEREP), Karen Chaves (CQuIPS), Frances Chevarley (CFACT), Beth Collins-Sharp (OEREP), Denise Dougherty (OEREP), Noel Eldridge (CQuIPS), Zhengyi Fang (SSS), Erin Grace (CQuIPS), Darryl Gray (CQuIPS), Kevin Heslin (CDC), Anika Hines (Truven), Leif Karell (SSS), Anil Koninty (SSS), Eric Lui (CQuIPS), Atlang Mompe (SSS), Ernest Mox (CQuIPS), Janet Pagán-Sutton (SSS), Susan Raetzman (Truven), Vera Rosenthal (CQuIPS), Veronica Soileau (CQuIPS), Lily Trofimovich (SSS), Yi Wang (SSS), Nancy Wilson (CQuIPS), Sean Yin (SSS), and Chava Zibman (CFACT).

**HHS Data Experts:** Clarice Brown (CDC-NCHS), Anjani Chandra (CDC-NCHS), Laura Cheever (HRSA), Frances Chevarley (AHRQ), Robin Cohen (CDC-NCHS), Steven Cohen (AHRQ), Rupali Doshi (HRSA), Paul Eggers (NIH), John Fleishman (AHRQ), Elizabeth Goldstein (CMS), Beth Han (SAMHSA), Haylea Hannah (CDC), Kimberly Lochner (CMS), Marlene Matosky (HRSA), William Mosher (CDC-NCHS), Cynthia Ogden (CDC-NCHS), Robert Pratt (CDC), Asel Ryskulova (CDC-NCHS), Alek Sripipatana (HRSA), Alan Simon (CDC-NCHS), and Xiaohong (Julia) Zhu (HRSA).

**Other Data Experts:** Dana Auden (Oklahoma Foundation for Medical Quality [OFMQ]), Timothy Chrusciel (OFMQ), Mark Cohen (American College of Surgeons National Surgical Quality Improvement Program [ACS NSQIP]), Sheila Eckenrode (MPSMS-Qualidigm), Beth Forrest (USRDS), Selena Gonzalez (CDC-HIV), David Grant (UCLA), Michael Halpern (American Cancer Society), Matthew Haskins (National Hospice and Palliative Care Organization), Clifford Ko (ACS NSQIP), Allen Ma (OFMQ), Richard Moser (NCI), Wato Nsa (OFMQ), Nicholas Okpokho (OFMQ), Robin Padilla (University of Michigan), Bryan Palis (American College of Surgeons, NCBD), Pennsylvania Patient Safety Authority, Royce Park (UCLA), William Ross (Fu Associates), Scott Stewart (OFMQ), VA National Center for Patient Safety, Yolanta Vucic (OFMQ), Reda Wilson (CDC-ONDEH-NCCDPHP), Richard Wolitski (CDC-HIV), and Claudia Wright (OFMQ).


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PERSON- AND FAMILY-CENTERED CARE

National Healthcare Quality and Disparities Report

This Person- and Family-Centered Care Chartbook 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 2012, although rates of uninsurance have been tracked through the first half of 2014. 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).

Changes for 2014

Beginning with this 2014 report, findings on health care quality and health care disparities are integrated into a single document. This new National Healthcare Quality and Disparities Report highlights the importance of examining quality and disparities together to gain a complete picture of health care. This document is also shorter and focuses on summarizing information over the many measures that are tracked; information on individual measures will still be available through chartbooks posted on the Web [http://www.ahrq.gov/research/findings/nhqrdr/2014chartbooks/](http://www.ahrq.gov/research/findings/nhqrdr/2014chartbooks/).

The new QDR and supporting chartbooks are further integrated with the National Quality Strategy (NQS). The NQS has three overarching aims that build on the Institute for Healthcare Improvement's Triple Aim® and that support HHS’s delivery system reform initiatives to achieve better care, smarter spending, and healthier people through incentives, information, and the way care is delivered. These aims are used to guide and assess local, State, and national efforts to improve health and the quality of health care.

To advance these aims, the NQS focuses on six priorities that address the most common health concerns that Americans face. Quality measures tracked in the QDR have been reorganized around these priorities, and a chartbook will be released marking progress for each NQS priority. Person- and family-centered care is one of these NQS priorities and the topic of this chartbook.
Key Findings of the 2014 QDR

The report demonstrates that the Nation has made clear progress in improving the health care delivery system to achieve the three aims of better care, smarter spending, and healthier people, but there is still more work to do, specifically to address disparities in care.

- **Access improved.**
  - After years without improvement, the rate of uninsurance among adults ages 18-64 decreased substantially during the first half of 2014.
  - Through 2012, improvement was observed across a broad spectrum of access measures among children.

- **Quality improved for most NQS priorities.**
  - *Patient Safety* improved, led by a 17% reduction in rates of hospital-acquired conditions between 2010 and 2013, with 1.3 million fewer harms to patients, an estimated 50,000 lives saved, and $12 billion in cost savings.
  - *Person-Centered Care* improved, with large gains in provider-patient communication.
  - Many *Effective Treatment* measures, including several measures of pneumonia care in hospitals publicly reported by the Centers for Medicare & Medicaid Services (CMS), achieved such high levels of performance that continued reporting is unnecessary.
  - *Healthy Living* improved, led by doubling of selected adolescent immunization rates from 2008 to 2012.

- **Few disparities were eliminated.**
  - People in poor households generally experienced less access and poorer quality.
  - Parallel gains in access and quality across groups led to persistence of most disparities.
  - At the same time, several racial and ethnic disparities in rates of childhood immunization and rates of adverse events associated with procedures were eliminated, showing that elimination is possible.

- **Many challenges in improving quality and reducing disparities remain.**
  - Performance on many measures of quality remains far from optimal. For example, only half of people with high blood pressure have it controlled. On average, across a broad range of measures, recommended care is delivered only 70% of the time.
  - As noted above, disparities in quality and outcomes by income and race and ethnicity are large and persistent, and were not, through 2012, improving substantially.
  - Some disparities related to hospice care and chronic disease management grew larger.
  - Data and measures need to be improved to provide more complete assessments of two NQS priorities, *Care Coordination* and *Care Affordability*, and of disparities among smaller groups, such as Native Hawaiians, people of multiple races, and people who are lesbian, gay, bisexual, or transgender.
Chartbooks Organized Around Priorities of the National Quality Strategy

1. Making care safer by reducing harm caused in the delivery of care.
2. **Ensuring that each person and family is engaged as partners in their care.**
3. Promoting effective communication and coordination of care.
4. Promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease.
5. Working with communities to promote wide use of best practices to enable healthy living.
6. 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 by the National Quality Strategy (http://www.ahrq.gov/workingforquality/index.html).

**National Quality Strategy Priority 2**

<table>
<thead>
<tr>
<th>Priority 2: Ensuring that each person and family members are engaged as partners in their care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LONG-TERM GOALS</strong></td>
</tr>
<tr>
<td>1. Improve patient, family, and caregiver experience of care related to quality, safety, and access across settings.</td>
</tr>
<tr>
<td>2. In partnership with patients, families, and caregivers—and using a shared decision-making process—develop culturally sensitive and understandable care plans.</td>
</tr>
<tr>
<td>3. Enable patients and their families and caregivers to navigate, coordinate, and manage their care appropriately and effectively.</td>
</tr>
</tbody>
</table>

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- and Family-Centered Care from the QDR
  - Figures illustrating select measures of Person- and Family-Centered Care

- Introduction and Methods contains information about methods used in the chartbook.
- Appendixes include information about measures and data.
- A Data Query tool (http://nhqnet.ahrq.gov/inhqrdr/data/query) provides access to all data tables.

Summary of Trends Across National Quality Strategy Priorities

<table>
<thead>
<tr>
<th>Total (n=168)</th>
<th>Person-Centered Care (n=20)</th>
<th>Effective Treatment (n=46)</th>
<th>Healthy Living (n=38)</th>
<th>Patient Safety (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>3</td>
<td>5</td>
<td>3</td>
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<tr>
<td>102</td>
<td>17</td>
<td>24</td>
<td>18</td>
<td>14</td>
</tr>
</tbody>
</table>

Key: n = number of measures.
Note: For most measures, trend data are available from 2001-2002 to 2012. For each measure with at least four estimates over time, weighted log-linear regression is used to calculate average annual percentage change and to assess statistical significance. Measures are aligned so that positive change indicates improved access to care.

- **Improving** = Rates of change are positive at 1% per year or greater and statistically significant.
- **No Change** = Rate of change is less than 1% per year or not statistically significant.
- **Worsening** = Rates of change are negative at -1% per year or greater and statistically significant.

- Almost all Person-Centered Care measures improved compared with 60% of all quality measures.
### Summary of Trends Across National Quality Strategy Priorities

Average annual rates of change of quality to care measures through 2012, by National Quality Strategy priority

<table>
<thead>
<tr>
<th>Measure</th>
<th>Average Annual Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Safety (n=31)</td>
<td></td>
</tr>
<tr>
<td>Person-Centered Care (n=20)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Healthy Living (n=38)</td>
<td></td>
</tr>
</tbody>
</table>

Key: n = number of measures.

Note: Large red diamonds indicate median values. For each measure with at least four estimates over time, weighted log-linear regression is used to calculate average annual percentage change. Measures are aligned so that positive change indicates improved quality of care.

- Median change in quality was 2.9% per year among measures of Person-Centered Care.

### Person-Centered Care Measures That Achieved Success, Improved Quickly, or Showed Worsening Quality

- Two Person-Centered Care measures achieved 95% performance and will no longer be reported in the QDR.
  - People with a usual source of care for whom health care providers explained and provided all treatment options
  - Hospice patients who received the right amount of medicine for pain management

- No Person-Centered Care measures:
  - Improved quickly, defined as an average annual rate of change greater than 10% per year
  - Showed worsening quality
Disparities in Person-Centered Care Measures

Number and percentage of person-centered care measures for which members of selected groups experienced better, same, or worse quality of care compared with reference group

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 85% 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 Measures With Elimination or Widening of Disparities

- Two Person-Centered Care measures showed elimination of Asian-White disparities:
  - Adult hospital patients who sometimes or never had good communication with doctors
  - Adults who had a visit in the last 12 months whose health providers sometimes or never listened carefully to them

- Four Person-Centered Care measures showed widening of disparities for some groups:
  - Family caregivers who did not want more information about what to expect while the patient was dying
  - Hospice patient caregivers who perceived patient was referred to hospice at right time
  - Hospice patients who received care consistent with their stated end-of-life wishes
  - Hospice patients who received the right amount of medicine for pain management

Measures of Person- and Family-Centered Care

- The National Healthcare Quality and Disparities Report tracks a growing number of person-and family-centered care measures.
- The measures focus on three aspects of care:
  - Communication: doctor’s office, hospital, and home health care
  - Engagement in decisionmaking
  - End-of-life care

Communication

- 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.

Communication Measures: Doctor’s Office

- Adults who had a doctor’s office or clinic visit in the last 12 months who reported poor communication with health providers, by insurance, ages 18-64 and age 65 and over, 2002-2012
- Adults who had a doctor’s office or clinic visit in the last 12 months who reported poor communication with health providers, by ethnicity and education, 2002-2012
- Children who had a doctor’s office or clinic visit in the last 12 months whose parents reported poor communication with health providers, by ethnicity and language spoken at home, 2002-2012
From 2002 to 2012, the percentage of adults who reported poor communication with health providers significantly decreased among all groups except Medicare and other public insurance. There were no statistically significant changes for this group.

- **Adults ages 18-64:**
  - Private insurance: 10.4% to 6.7%
  - Public insurance: 15.6% to 14.6%
  - Uninsured adults: 18.8% to 15.3%

- **Adults age 65 and over:**
  - Medicare and private insurance: 6.6% to 5.6%
  - Medicare and other public insurance: 8.6% to 6.4%
  - Medicare only: 8.7% to 5.2%

In 2012, adults ages 18-64 with public insurance and uninsured adults were significantly more likely to report poor communication compared with adults with private insurance.

There were no statistically significant differences by insurance among adults age 65 and over.
From 2002 to 2012, the percentage of adults who reported poor communication with health providers significantly decreased for Whites, Hispanics, and all education groups. There were no statistically significant changes among Blacks.

- **Ethnicity:**
  - Whites: 9.8% to 6.9%
  - Hispanics: 15.6% to 10.9%

- **Education:**
  - Less than high school: 13.4% to 11.5%
  - High school grad: 10.9% to 8.9%
  - Any college: 9.7% to 6.7%

In 2012, Hispanics and Blacks were significantly more likely than Whites to have poor communication with their health providers.

Also in 2012, 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.
Poor Communication With Health Providers: Children

From 2002 to 2012, the percentage of children whose parents reported poor communication with health providers significantly decreased for all ethnic groups and both language groups.

- **Ethnicity:**
  - Whites: 5.6% to 3.3%
  - Blacks: 7.1% to 4.1%
  - Hispanics: 10.2% to 4.8%

- **Preferred language:**
  - English: 6.3% to 3.5%
  - Other: 11.7% to 4.7%

In 2012, parents of Hispanic children were significantly more likely to report poor communication compared with White adults. There were no statistically significant differences between Blacks and Whites or by preferred language.
Communication Measures: Hospital

- Adult hospital patients who reported poor communication with nurses and doctors, by age, 2009-2013
- Adult hospital patients who did not receive good communication about discharge information, by race, 2009-2013

Poor Communication With Doctors and Nurses in the Hospital

- From 2009 to 2013, the percentage of patients reporting poor communication significantly decreased among all age groups.
  - Communication with doctors:
    - 18-44 years: 5.0% to 4.6%
    - 45-64 years: 5.7% to 5.4%
    - 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 4.2%
• In 2013, 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 2013, 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.

Poor Communication About Discharge Information

![Graph showing the percentage of patients who did not receive good communication about discharge information, by race, from 2009 to 2013.](image)

Key: AI/AN = American Indian or Alaska Native; NHOPI = Native Hawaiian or Other Pacific Islander.

Source: Centers for Medicare & Medicaid Services, Hospital CAHPS (Consumer Assessment of Healthcare Providers and Systems), 2009-2013.

Note: Good communication about discharge information means hospital staff talked with patients about help they might need and gave patients information in writing about potential symptoms after discharge.

• From 2009 to 2013, the percentage of patients who did not receive good communication about discharge information significantly decreased for all racial groups:
  
  - White: 15.5% to 11.5%
  - Black: 18.2% to 13.0%
  - Asian: 17.0% to 13.1%
  - Native Hawaiian or Other Pacific Islander (NHOPI): 17.2% to 12.3%
  - American Indian or Alaska Native (AI/AN): 17.4% to 12.7%

• In 2013, Blacks, Asians, and AI/ANs were significantly less likely than Whites to receive good communication about discharge information. There were no statistically significant differences between Whites and NHOPIs.
Communication Measures: Home Health Care

- Provider-patient communication among adults receiving home health care, by language spoken at home, 2013
- Provider-patient communication among adults receiving home health care, by race/ethnicity, 2013

Provider-Patient Communication Among Home Health Care Patients

- In 2013, 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 significantly less likely to always have the provider listen carefully to them compared with English- and Spanish-speaking adults.

- Adults speaking Spanish at home were significantly more likely to report that the provider always listened carefully to them compared with English-speaking adults.

Denominator: Adults who had at least two visits from a Medicare-certified home health agency during a 2-month look-back period.
Note: Patients receiving hospice care and those who had “maternity” as the primary reason for receiving home health care are excluded.
In 2013, among home health care patients, compared with Whites:

- Asians, AI/ANs, and Hispanics were significantly less likely to always be informed about when their provider would arrive.
- Asians, NHOPIs, AI/ANs, and Hispanics were significantly less likely to always have things explained in a way that was easy to understand.
- Asians, NHOPIs, and AI/ANs were significantly less 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.

**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.
Engagement in Decisionmaking Measures: Providers Asking Patients To Assist in Making Treatment Decisions

- Adults with a usual source of care whose health providers sometimes or never asked for the patient’s help to make treatment decisions, by insurance and education, 2002-2012
- People with a usual source of care whose health providers sometimes or never asked for the patient’s help to make treatment decisions, by number of chronic conditions and ethnicity, 2002-2012

Providers Who Sometimes or Never Asked for Patient's Help in Making Treatment Decisions

![Graph showing the percentage of adults with a usual source of care whose health providers sometimes or never asked for the patient’s help to make treatment decisions by insurance and education from 2002 to 2012.]

- In 2012, among adults ages 18-64, those who were uninsured those with public insurance were significantly less likely than those with private insurance to be asked by their health providers to help make treatment decisions.
- Also in 2012, adults with less than a high school education and high school graduates were significantly less likely than those with any college education to be asked to help make treatment decisions.
• Significant improvements were observed from 2002 to 2012:

  - **Insurance:**
    - Any private: 20.6% to 11.5%
    - Public: 27.2% to 15.9%
    - Uninsured: 25.2% to 15.2%

  - **Education:**
    - Less than high school: 25.9% to 15.4%
    - High school graduate: 22.6% to 14.2%
    - Any college: 19.4% to 11.6%

• In 2012, among people with a usual source of care, patients with 4 or more chronic conditions were significantly less likely than those with 0 or 1 condition to be involved in their treatment decisions.
• Also in 2012, Blacks and Hispanics were significantly less likely than Whites to be involved in their treatment decisions.
• Significant improvements were observed from 2002 to 2012:
  
  ▪ By number of chronic conditions:
    1. 0-1 chronic conditions: 21.9% to 12.2%
    2. 2-3 chronic conditions: 20.7% to 13.6%
    3. 4+ chronic conditions: 26.7% to 15.4%
  
  ▪ By ethnicity:
    1. Whites: 19.9% to 11.5%
    2. Blacks: 26.4% to 16.4%
    3. Hispanics: 27.6% to 14.5%

**End-of-Life Care**

• Hospice care is generally delivered at the end of life to patients with a terminal illness or condition who desire 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 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).

**End-of-Life Care Measures**

• Hospice patients who received care consistent with their stated end-of-life wishes, by age and ethnicity, 2008-2013
• Hospice patients who received the right amount of help for feelings of anxiety or sadness, by ethnicity and race, 2008-2013
• Hospice patients who received the right amount of medicine for pain, by sex and race, 2008-2013
Hospice Patient Care Consistent With End-of-Life Wishes

- From 2008 to 2013, the percentage of hospice patients age 65 and over who received care consistent with their stated end-of-life wishes significantly improved from 94.4% to 95.1%. There were no statistically significant changes for the 18-44 and 45-64 age groups.
- From 2008 to 2013, White (94.7% to 95.6%) and Black (87.8% to 89.9%) hospice patients showed significant improvement, whereas Hispanics showed no statistically significant changes during this period.
- In 2013, hospice patients ages 18-44 were significantly less likely than patients ages 45-64 and age 65 and over to receive care consistent with their stated end-of-life wishes.
- In 2013, Black and Hispanic hospice patients were significantly less likely than White patients to receive care consistent with their stated end-of-life wishes.

Note: White and Black are non-Hispanic. Hispanic includes all races.
Hospice Patients With Right Amount of Help for Anxiety or Sadness

- From 2008 to 2013, 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.
- In 2013, 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 2013, Blacks, Asians and Other Pacific Islanders (APIs), and AI/ANs were significantly less likely than Whites to receive the right amount of help for feelings of anxiety or sadness.
Hospice Patients With Right Amount of Medicine for Pain

- From 2008 to 2013, the percentage of hospice patients who received the right amount of medicine for pain significantly improved for both sexes and for Whites.
- In 2013, Blacks, APIs, and AI/ANs were significantly less likely than Whites to receive the right amount of medicine for pain.

**References**