

## Chapter Seven: Reaching Those Who are Underserved

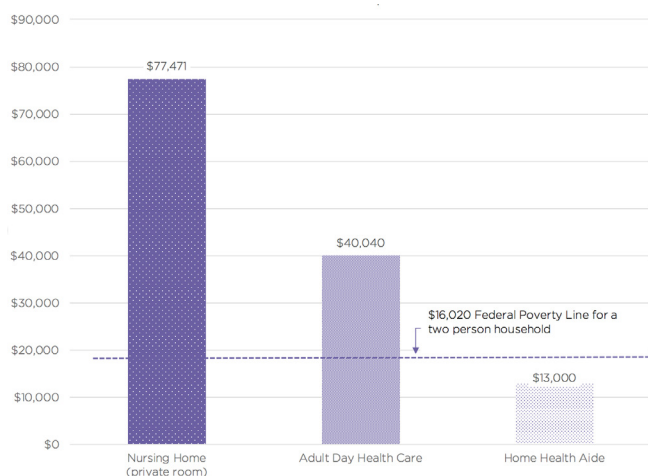
Throughout the development of the state plan for Alzheimer’s disease and related dementias, the Task Force worked to keep in mind the needs of all North Carolina populations, with a special consideration for those who are disproportionately affected by these conditions, as well as those who have also been historically underserved within health care and health research. The Task Force examined the needs of these populations and developed recommendations to improve research, data collection capacity, and health care quality for all North Carolinians.

As discussed in Chapter 2, there are several populations that are disproportionately affected by Alzheimer’s disease and related dementias, including people with intellectual and/or developmental disabilities and a number of minority populations. In addition, in North Carolina, there are geographical disparities in access to care due to the large rural areas of the state.

Individuals with Down’s syndrome also have a three- to five-times higher risk for Alzheimer’s disease than the general population. Alzheimer’s tends to develop at a younger age (40s or 50s) for people with Down’s syndrome than for other adults. Autopsy results have shown that nearly all people with Down’s syndrome have markers in the brain that are associated with Alzheimer’s disease.<sup>1</sup> Caregivers for people with Down’s syndrome may also experience their own type of “sandwich generation” dilemma, as they themselves and/or their spouses may be at risk of developing dementia around the same time as their children. At the same time, there is opportunity for communities to learn from the experiences of individuals with intellectual and developmental disabilities and their families. Having navigated a similarly complex array of services and facilities, such families and service providers may offer many appropriate lessons for those wishing to develop dementia-capable communities.

Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer’s disease.<sup>2</sup> In the 65-74 age group, African Americans have the highest prevalence of Alzheimer’s disease at 9.1%, compared to 7.5% for Latinos and 2.9% for non-Latino whites. For individuals over 85, Latinos have a prevalence rate of 62.9%, compared to 58.6% among African Americans, and 30.2% among non-Latino whites.<sup>2</sup> Women are twice as likely to develop Alzheimer’s as men,<sup>3</sup> primarily because women tend to live longer than men.<sup>4</sup>

**Figure 7.1: Costs of Care Often Exceed What People Can Afford**



Source: Lines LM, Sherif NA, Weiner JM. Racial and Ethnic Disparities Among Individuals with Alzheimer’s Disease in the United States: A Literature Review. Research Triangle Park, NC: RTI Press; 2014.

Disparities in Alzheimer’s care reflect disparities in health care more generally for North Carolinians. People in rural areas are about equally as likely to be uninsured as are those in urban areas (16.5% versus 15.7% respectively).<sup>5,6</sup> Many rural communities also experience shortages of key health professionals, including primary care, specialty care, mental health care, and allied health care. Overall there is increased demand on the primary care workforce due to aging baby boomers, population growth, and increased rates of insured people.<sup>7</sup> North Carolina has 66 counties (or parts of counties) that are designated as primary care shortage areas, 22 counties (or parts thereof) that are designated as behavioral health shortage areas, and 69 counties (or parts thereof) that are designated as dental shortage areas.<sup>a</sup> Of those designated communities, 48 of the primary care health professional shortage areas (HPSAs) are in rural counties. As discussed in Chapter 4, properly assessing health system capacity, including rural disparities in the health care workforce, is an important step in improving care for people with Alzheimer’s disease or related dementia.

As communities focus resources and efforts on addressing disparities in rates of Alzheimer’s disease and related dementia, they must also keep cultural competency in mind. Cultural competency is defined as understanding different groups’ history, diversity, and culture. As is the case in emphasizing person-centered care within health care settings (see Chapter 4), a culturally competent approach will value others’

<sup>a</sup> The HPSAs designated as Single County, Geographical Area, and Population Group were counted on August 15, 2013.

**“ Individuals with Down’s syndrome also have a three- to five-times higher risk for Alzheimer’s disease than the general population. ”**

experiences, respect their viewpoints, and refrain from judgement.<sup>8</sup> The following recommendations are directly related to underserved populations but have been included in chapters reflecting the broader constructs:

- Recommendation 3.1: Increase awareness and promote education about Alzheimer’s disease and related dementias and available resources through incorporating Alzheimer’s disease and related dementia-specific information in current health promotion and education programs.
- Recommendation 4.1: Promote appropriate care settings for people with Alzheimer’s disease and related dementia.
- Recommendation 4.3: Assess health system capacity for people with Alzheimer’s disease and related dementias.
- Recommendation 4.4: Improve telehealth services for people with Alzheimer’s disease and related dementias.
- Recommendation 4.5: Increase access to medical and community services for people with Alzheimer’s disease and related dementia.
- Recommendation 4.8: Improve care coordination for people with Alzheimer’s disease and related dementia through new models of care.
- Recommendation 5.1: Promote integration and accessibility of dementia-specific resources through a comprehensive caregiver toolkit and virtual resource center.
- Recommendation 5.2: Ensure adequate funding for family caregiver support services including dementia-specific respite through Project CARE.
- Recommendation 5.5: Examine outcomes and impact of home- and community-based programs.
- Recommendation 5.6: Expand the Medicaid Home- and Community-Based Services Waiver Program.
- Recommendation 6.1: Increase awareness of legal protections and vulnerabilities of people with Alzheimer’s disease or related dementia.
- Recommendation 6.3: Examine state statutes to determine adequate legal safeguards and protections for people with Alzheimer’s disease or related dementia.
- Recommendation 6.4: Integrate elder fraud and abuse data to improve services for people with Alzheimer’s disease or related dementia.
- Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.
- Recommendation 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.
- Recommendation 7.3: Improve prevalence data through accurate death certificate completion.
- Recommendation 7.4: Improve data on Alzheimer’s disease and related dementia prevalence through implementing a statewide data reporting system.

In addition, there are also wide discrepancies in the ability of individuals with Alzheimer’s disease or related dementia to pay for care and services. In 2014, 10% of North Carolinians over the age of 65 had incomes below the federal poverty level (\$20,090), and an additional 24% had incomes between 100% and 199% of the federal poverty level. The median income for North Carolinians over 65 years of age was \$35,204.<sup>9</sup> People and families with incomes at the poverty level, as well as middle class families, do not qualify for Medicaid and often face difficulty in paying for any care not covered by Medicare or private insurance. There is only a small subset of families who can afford to pay privately for services or for long-term care insurance (see Chapter 4 for additional information on payment for long-term services and supports).

**“ Federal funding for research on Alzheimer’s lags behind other major diseases. ”**

**Research**

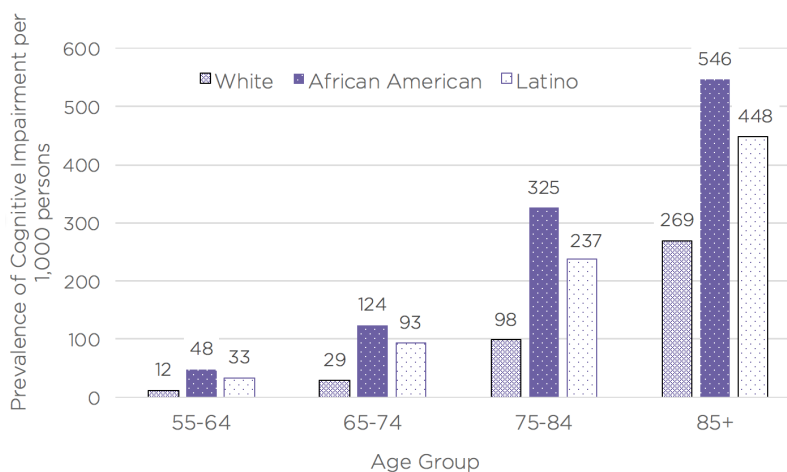
Although Alzheimer’s disease affects approximately 5.3 million Americans and costs the federal government up to \$215 billion annually<sup>11</sup>, federal funding for research on Alzheimer’s lags behind other major diseases. For FY 2016, the federal government allocated \$638 million to research for Alzheimer’s disease. In the same year, the federal government allocated \$5.5 billion for cancer and \$2 billion for cardiovascular disease. In late 2015, however, increased attention to Alzheimer’s disease and dementia and their impact on individuals and families resulted in a proposed increase of \$350 million for fiscal year 2016 (a 59.7% increase over FY 2015) for the National Institute of Health’s Alzheimer’s disease and related dementia research funding.<sup>12</sup>

“ Compared to non-Latino whites, Latinos and African Americans are at a higher risk for developing Alzheimer’s disease.

While increased federal funding for research is crucial, there is much that can be done at the state level to increase the body of knowledge on Alzheimer’s and related dementia. Researchers at academic research institutions and private businesses across our state are studying Alzheimer’s and related dementia. In 2014, Duke University and the University of North Carolina at Chapel Hill, along with other academic research institutions, received a \$130,000 grant from Alzheimer’s North Carolina to launch the North Carolina Regional Consortium for Brain Health in Aging. The mission of the consortium is to “draw together the state’s major academic institutions that are engaged in Alzheimer’s disease research, along with potential partners in industry, primary care, and other stakeholders, into a collaborative network to spur research and innovation” towards better prevention, treatment, and cure for Alzheimer’s disease.<sup>13</sup> By combining efforts and sharing knowledge, the Consortium aims to speed up the pace of discovery and improve collaborative efforts toward prevention and treatment. Starting in 2016, the Consortium is known as the Memory and Brain Aging Research Coalition (MBARC).

One of the goals of the consortium is to develop a statewide registry of healthy individuals and diagnosed dementia patients, cross-referenced with a current database of clinical trials, to facilitate a shared network and inform research regarding dementia treatment and prevention. Finding individuals to participate in research studies can significantly slow down the research process. An optional Alzheimer’s and related dementia registry would be a place for people with Alzheimer’s disease and related dementias and healthy individuals to indicate their interest in participating in research and clinical trials. Academic researchers could use the registry to share information about their research and identify studies that need participants. A registry can also be used to share the latest news and research findings on Alzheimer’s and related dementias.

**Figure 7.2: Older African Americans and Latinos More Likely to Have Cognitive Impairment**



Source: Genworth. North Carolina State-Specific Data from the Genworth 2013 Cost of Care Survey. Richmond, VA: Genworth; 2013. [https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/North%20Carolina\\_gnw.pdf](https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/North%20Carolina_gnw.pdf). Accessed December 8, 2015.

A key priority for the statewide registry would be to expand outreach to underserved populations in North Carolina, for the purpose of participation in clinical trials and research studies, as well as to promote awareness of and resources for those dealing with dementia. As discussed above, there are disparities in rates of Alzheimer’s disease and related dementia between many racial and ethnic groups. There is also a disparity among research participants, with fewer minorities participating in clinical trials and other research studies. While the reasons for this vary, contributing factors include higher levels of additional health problems, language barriers, mistrust of clinical research, under-diagnosis, and higher caregiver burdens.<sup>14</sup>

African Americans are twice as likely to have Alzheimer’s disease as non-Hispanic whites, are most burdened by the disease, are most likely to get a late (or no) diagnosis, and have the worst health and caregiving outcomes of

the disease. In addition, persons in rural and underserved counties have poorer outcomes than those in urban areas, especially those close to universities and health care systems. North Carolina A&T University’s Center

for Outreach in Alzheimer's Aging and Community Health (known as COAACH) aims to understand genetic factors that predispose African Americans to Alzheimer's disease. The Center was founded as a result of lower literacy and engagement among African Americans in research, clinical trials, interventions, and care management skills. Researchers began conducting Alzheimer's genetics work among African Americans in 2002 with investigators at Duke University. The Center was a major contributor to publishing the largest Alzheimer's genome-wide association study (with 6,000 participants) in African Americans in 2013. In finding a cure, intervention, or therapy for Alzheimer's, it is important to include all populations, including underrepresented groups, to reduce generalizability of research results.<sup>b</sup>

**“ The Alzheimer's Association estimates that about half of individuals with Alzheimer's have never been given a diagnosis by a health care provider. ”**

### **Recommendation 7.1: Support research through the establishment of a statewide collaborative registry.**

Establish a statewide registry/clinical trials network of people diagnosed with Alzheimer's disease and related dementia and healthy individuals, in order to better inform research into Alzheimer's disease and related dementia treatment and prevention. The collaborative network should:

- Build on the existing work of the Memory and Brain Aging Research Coalition (MBARC) to expand partnerships, establish continued funding, and determine appropriate methods of sustainability.
- Focus on inclusion of underserved and underrepresented populations in Alzheimer's disease and related dementia treatment, prevention, and clinical trial participation.
- Work to apply research findings to education/awareness campaigns on Alzheimer's disease and related dementia prevalence, symptoms, and opportunity for participation in clinical trial research.
- Promote the ways in which a statewide registry may have a positive economic impact on North Carolina.

Lead: Academic institutions, including Duke University, University of North Carolina at Chapel Hill, Wake Forest University, North Carolina A&T University, North Carolina State University, Appalachian State University, Western Carolina University, University of North Carolina at Asheville, and University of North Carolina at Wilmington.

Partners: Philanthropic organizations, Alzheimer's North Carolina, and the Alzheimer's Association.

### **Data Collection**

Informed action requires data. Data plays a critical role in achieving the goals of the Task Force by both raising awareness of the scope of Alzheimer's disease in our state, and also by measuring progress towards improved services, care, and potential treatments for Alzheimer's disease and related dementia.

Rates of Alzheimer's disease are estimated through the use of US Census data and from large population-based studies of affected populations. The Alzheimer's Association also uses data from the Chicago Health and Aging Project, which studies chronic diseases in older adults, to estimate Alzheimer's prevalence. For other forms of dementia, the Aging, Demographics, and Memory Study provides useful prevalence data.<sup>15</sup> However, while these studies provide a population-based estimate of prevalence, because Alzheimer's and other dementias are significantly underdiagnosed in the community, the Alzheimer's Association estimates that about half of individuals with Alzheimer's have never been given a diagnosis by a health care provider.<sup>15</sup> In addition, because Alzheimer's disease is progressive, it is difficult to get an accurate estimate of the number of individuals in any given stage of the disease. Remaining stigma and lack of awareness around Alzheimer's disease also result in reduced accuracy of prevalence data, as families either may not recognize symptoms as distinct from normal cognitive aging, or may be hesitant to seek a formal diagnosis. Improved data collection may also be helpful in identifying potential environmental risks by geographical area that impact the development of Alzheimer's disease and related dementia.

In order to fully evaluate the problem and impact of Alzheimer's disease and related dementia, as well as to determine if other Task Force goals and recommendations are reached, more robust methods of data collection are needed, in addition to greater coordination and linked analysis of data.

<sup>b</sup> Byrd G. Professor of Biology and Dean. College of Arts and Sciences, North Carolina A&T State University. Written (email) communication. February 4, 2016.

### *Behavioral Risk Factor Surveillance System (BRFSS)*

In North Carolina, the State Center for Health Statistics, conducts an annual population-based survey of North Carolina residents aged 18 and older. The survey was created in the late 1980s by the Centers of Disease Control and Prevention (CDC) and is conducted in all 50 states via household telephones.

In 2011, the North Carolina BRFSS included, for the first time, a CDC Healthy Aging Program-developed module on cognitive impairment.<sup>16</sup> The 2011 cognitive impairment module consisted of one question: “During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?” For 2016, North Carolina plans to include the cognitive impairment module again.

In addition to the cognitive impairment module, BRFSS also offers a module consisting of questions about caregiving. While not specific to dementia, this module captures data on caregiving such as caregivers’ relationship to the person being cared for, the condition/illness for which the person is receiving care, caregivers’ experiences, and the impact of caregiving on caregivers’ health and well-being.<sup>17</sup> North Carolina last included the caregiving module in 2011. States that have implemented the caregiver module have learned that caregivers for people with Alzheimer’s or related dementias provide care for a longer period of time and were more likely to report health problems related to caregiving than caregivers for other conditions.<sup>18</sup>

While the BRFSS data provides helpful information about rates of cognitive impairment and aspects of caregiver experiences, there are limitations to this data. Estimates of cognitive impairment collected by BRFSS are meant to be used on a population level within states and communities, and not be compared with (or replace) other measures of cognitive impairment. Because the data is self-reported, it is also not intended to be used as an estimate of prevalence. The data is also limited, given that BRFSS is conducted via single family households, and does not include people living in nursing homes or other residential facilities. By survey design, BRFSS only includes people who are able to verbally respond to the full survey and thus also would not capture data on individuals who are too severely impaired to participate.<sup>17</sup> Despite limitations to the BRFSS data, the Task Force identified continued inclusion of the cognitive impairment and caregiver modules as a necessary component of improving data and understanding of the impact of dementia and resulting caregiving on North Carolina.

### **Recommendation 7.2: Continue inclusion of cognitive impairment and caregiver modules of the Behavioral Risk Factor Surveillance System.**

In order to better track the demographic and economic impact of Alzheimer’s disease and related dementia on the state of North Carolina, dementia advocacy groups should continue to fund the cognitive impairment module of the Behavioral Risk Factor Surveillance System on a five-year interval, measuring self-reported cognitive decline, and consider continued inclusion of the caregiver module at an appropriate interval. Resulting data should be used to inform public awareness campaigns and data dissemination efforts by state policymakers, state agencies, and advocacy organizations. Data should also be analyzed for potential connection with other behavioral and lifestyle risk factors tracked by the statewide survey.

Lead: State Center for Health Statistics and dementia advocacy organizations.

### *Dementia and Death Certificate Completion*

When a person dies, a physician is required to provide information on cause of death for the death certificate. This information consists of an immediate cause of death, as well as opportunity for the physician to provide an underlying cause of death, defined as “disease or injury that initiated the events resulting in death,” and other significant conditions contributing to death (but not resulting in the underlying cause or immediate cause of death).<sup>19</sup>

**Figure 7.3: BRFSS Cognitive Impairment Module**

- 1. During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?**
- 2. During the past 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?**
- 3. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities?**
- 4. When you need help with these day-to-day activities, how often are you able to get the help that you need?**
- 5. During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?**
- 6. Have you or anyone else discussed your confusion or memory loss with a health care professional?**

Source: Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System (BRFSS) cognitive decline module. Centers for Disease Control and Prevention website. <http://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm>. Published July 1, 2015. Accessed February 12, 2016.



Because of uncertainty around dementia diagnosis or identification of dementia as immediate/underlying cause of death or as contributing to death (i.e., Alzheimer's cannot be definitively diagnosed except through autopsy, physicians may lack information on dementia background of an individual, etc.), it is difficult to assess the accuracy of death certificate data when it is used to estimate prevalence, identify population health needs, or other research needs. Research has shown that Alzheimer's disease in particular is underreported as cause of death on death certificates, and that attempts to capture a single immediate cause of death do not always capture the reality of individuals' deaths resulting from dementia.<sup>20</sup>

Families may also have concerns about the classification of death resulting from dementia. For some families, it may be important to have an official classification of Alzheimer's disease or dementia as a cause of death. These families may seek to increase awareness of the severity of Alzheimer's and want to honor their loved ones through an accurate representation of their illness and resulting death. Other families may feel differently—they may feel that identifying Alzheimer's or dementia as a cause of death will further stigmatize their loved one and family, and may prefer to not acknowledge dementia as a cause of death. Conversations about death certificate completion and families' wishes around the identification of dementia as a cause of death would be appropriate to include in broader conversations about end-of-life care and advanced care planning.

Because of the importance of identifying dementia as an underlying cause of death and/or contributing condition, the Task Force identified the need for additional physician and medical examiner training in dementia identification and accurate completion of death certificates.

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### **Recommendation 7.3. Improve prevalence data through accurate death certificate completion.**

In order to improve data collection on rates of death from Alzheimer's disease and related dementia, the lead agency and partners should offer continued medical education training on the identification of Alzheimer's disease and related dementia as cause of death and the importance of accurate identification of Alzheimer's disease and related dementia. Medical schools and residency programs should also offer education and training in this area.

Lead: North Carolina Office of the Chief Medical Examiner.

Partners: North Carolina Area Health Education Centers programs and the Office of Vital Records.

#### *Diagnostic Coding and Claims Data*

In 2012, researchers at the University of North Carolina at Chapel Hill School of Medicine, in collaboration with Carolinas HealthCare System in Charlotte, began a project aimed at improving prevalence and diagnostic data for dementia. This project, through the Carolina Data Warehouse for Health, consisted of analyzing coding practice data from the two participating organizations' electronic medical records and provider charts, in order to produce an accurate estimate of number of patients with dementia and the diagnosis and treatment practices for these patients.<sup>21</sup> Experts hope that new diagnostic codes released under the 2014 revision of the International Statistical Classification of Diseases and Related Health Problems (ICD) 10th Revision, known as ICD-10, will provide additional clarification on the diagnosis and coding of dementia. The ICD-10 codes categorize diseases, symptoms, and other health circumstances and causes, as classified by the World Health Organization.<sup>22</sup>

Prescription claims also provide potentially useful data about the prevalence and distribution of dementia. Prescriptions of Aricept or other clinical treatments for dementia can provide information in the absence of formal diagnosis of Alzheimer's or other forms of dementia.

However, both diagnostic coding data and prescription claims data have limitations, most notably being that this data is currently accessible only to policymakers and researchers and is therefore of limited use. Several states have created all-payer claims data (APCD) systems to help provide state-level data that can improve accuracy of prevalence data for dementia. These claims data systems also support quality improvement activities, compare prevalence or utilization patterns across the state, identify successful cost containment measures, and evaluate health care reform efforts on costs, quality, and access. The data included in APCD systems generally consists of claims data from hospitals, physicians, pharmacists, and dental care claims from public and private insurers, and may include payment information such as plan charges and member liabilities (e.g., co-pay, deductible payments, and co-insurance).<sup>23</sup>

As of late 2015, 18 states had fully functional APCD systems or were considering building APCD systems.<sup>24</sup> In 2012, the North Carolina Department of Health and Human Services created a workgroup to examine the

possibility of creating a similar APCD or confederated data system to capture data from multiple existing data systems that could be used in North Carolina to examine population health, cost, and quality issues across the state. Such a system could provide important data on health care costs, including those for specific procedures, providers, or health systems. However, North Carolina's efforts are currently on hold while the state is implementing other major health information technology efforts, with several groups continuing to hold interest meetings regarding whether to move forward on APCD or a united data system.

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**Recommendation 7.4: Improve data on Alzheimer's disease and related dementia prevalence through implementing a statewide data reporting system.**

Collaborate to create a statewide, mandatory data reporting system to enhance claims transparency for medical care and health care services and improve prevalence and diagnosis data for Alzheimer's disease and related dementia. This collaborative effort should include input from additional stakeholders on database use and access, and participating stakeholders should include employers, provider professional associations, private and public payers, community members, consumer advocates, academic and clinical researchers, and the pharmaceutical and data management industry.

Lead: North Carolina General Assembly.

Partners: North Carolina Department of Insurance, the North Carolina Department of Health and Human Services, health care systems, and insurers.

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