

too much hovering will erode patients' sense of personal responsibility or that hovering in one area might distract providers or patients from other important health issues. Others may worry that hovering is too intrusive or paternalistic — though patients could easily opt out, and it's arguably no more paternalistic than traditional approaches to improving patient outcomes. It will be important to ensure that new hovering efforts are evaluated carefully, with assessment of both intended and potential unintended consequences.

And of course, there is a considerable amount we don't know about these approaches: the kinds of patients, conditions, or settings for which they will be the most useful; the organizations (hospitals, employers, or insurers) that should be the ones to

deploy them; and how to make them heard over the din of everything else that competes for attention while remaining unintrusive enough that nudges don't become self-defeating nags. There are both clinical and research opportunities in pursuing an approach that is just as rigorous as our approach to other areas of medicine. Careful iterative testing is essential because these new forms of patient engagement, whatever shape they take, will be central to improving population health in our future health care system.

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## Geographic Variation in Access to Care — The Relationship with Quality

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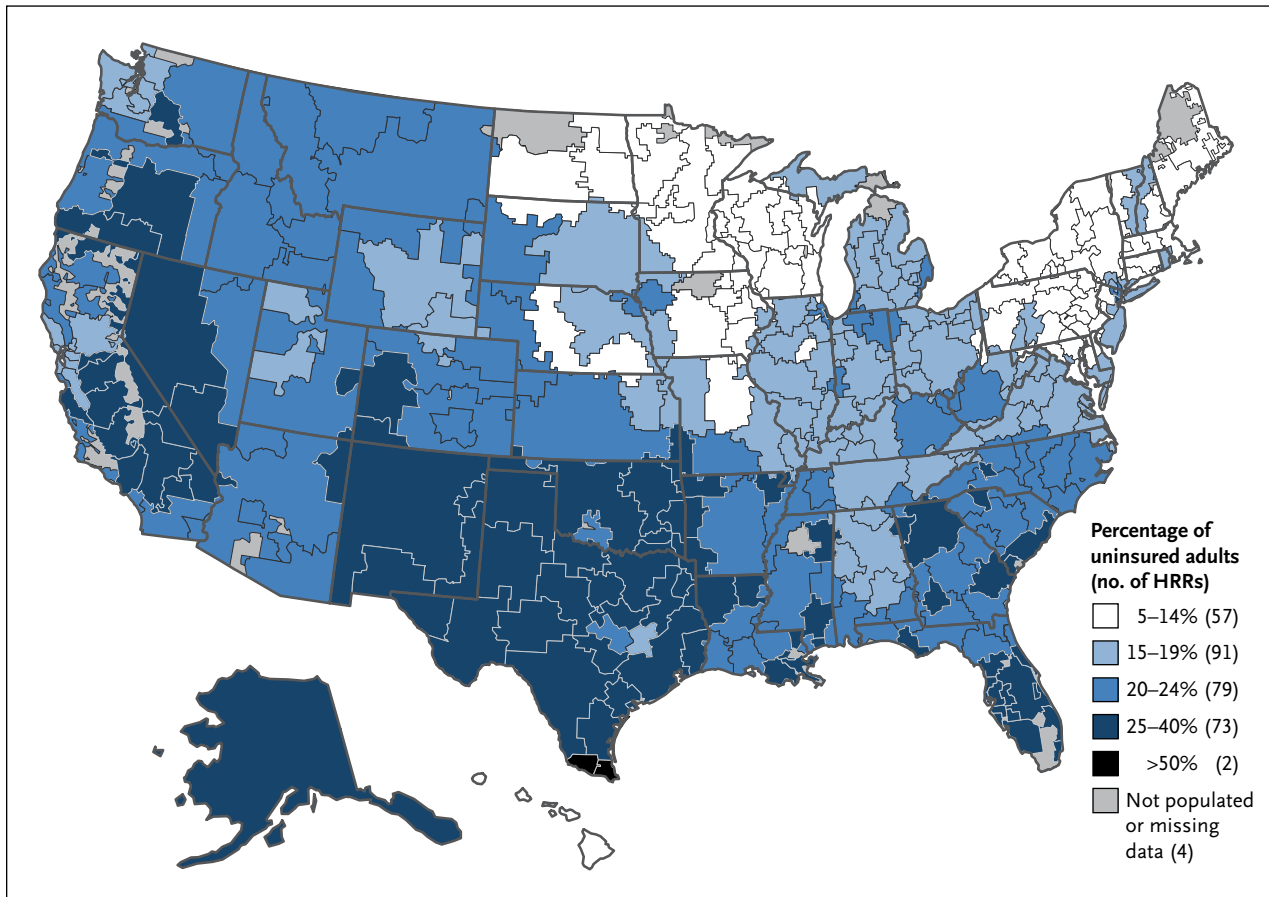
Three decades of research focused predominantly on costs and the use of services among Medicare beneficiaries has repeatedly found wide regional variations in health care experiences and health system performance.<sup>1</sup> Much less attention has been paid to variations in access to care and their associated implications for quality of care and health outcomes. Our recent Commonwealth Fund report, "Rising to the Challenge: Results from a Scorecard on Local Health System Performance,"<sup>2</sup> shows that when we look beyond state averages, there are staggeringly wide

gaps in people's ability to gain access to care in different communities around the country. We also find a strong and persistent association between access and health care quality, including the receipt of preventive care.

Simply put, where a person lives matters — it influences the ability to obtain health care, as well as the probable quality of care that will be received — though it should not matter in an equitable health care system. This and other Scorecard findings have important implications that are relevant to national policy reforms and to newly available resources

for improving access and quality of care.

The Scorecard tracks 43 health system performance measures grouped into four dimensions: access, prevention and treatment, potentially avoidable hospital use and cost, and healthy lives. The analysis examined the range of variation across all 306 hospital referral regions (HRRs) — regional health care markets defined with the use of patient-flow data for the Dartmouth Atlas of Health Care — and drew largely from publicly available data, generally from 2008 to 2010. (See the Supplementary Appendix, available



#### Percent of Adults 18 to 64 Years of Age Who Were Uninsured, 2009–2010.

Data are from analysis of the U.S. Census Bureau, 2009–2010 American Community Survey, as presented in the Commonwealth Fund Scorecard on Local Health System Performance, 2012. There are no hospital referral regions (HRRs) with rates of uninsured adults from 41 to 50%.

with the full text of this article at NEJM.org, for detailed methods used in the Scorecard, data sources, and definitions of indicators.)

The variation among U.S. regional health care markets in residents' ability to obtain care — even variation on such fundamental measures as having health insurance or a connection to a regular source of care — is sobering. For example, in 2009 and 2010, the proportion of adults 18 to 64 years of age without health insurance ranged from about 5% in the three HRRs in Massachusetts, where a strong state policy mandates that all residents have coverage, to more than 50% in the two areas in Texas with the highest rates of uninsured resi-

dents (see map). Wide ranges of variation are also seen in the proportion of adults who went without care because of cost (5 to 33%), the proportion who report having a regular doctor (59 to 93%), and the proportion of adults 50 years of age or older with a diagnosed chronic disease who visited a doctor in the past 2 years (67 to 95%).

Unfortunately, too few adults 50 years of age or older routinely receive recommended preventive care, including screenings for cancer and an annual influenza vaccine, and too few adults with diabetes receive appropriate care to manage their illness. For both measures, we found a greater-than-twofold variation between

the best-performing and worst-performing HRRs (preventive care, 26 to 59%; diabetes care, 27 to 69%). Even more worrisome is that in at least half of all areas, less than 50% of people who were eligible received appropriate and timely preventive care (see table).

It is not surprising that on each of these indicators, people with insurance fare far better than their uninsured counterparts. People with insurance are far more likely to have a regular doctor and far less likely to forgo care because of cost. But being insured is not always enough. Health insurance should be affordable and provide adequate financial protection for people who need care. Even among the in-

Variations in Selected Indicators of Access to Care and Preventive Care, According to Health Insurance Status.*						
Indicator	Range across All HRRs (Whole Population)		National Average by Insurance Status		Range across All HRRs (Insured Only)	
	Worst	Best	Uninsured	Insured	Worst	Best
			<i>percent</i>			
Adults who went without needed care because of cost in the past year	33	5	47	9	16	2
Adults with a usual source of care	59	93	44	88	73	97
High-risk adults who visited a doctor for a checkup in the past 2 years	67	95	60	89	74	96
Adults 50 years of age or older who received recommended screening and preventive care	26	59	25	46	31	58
Adult patients with diabetes who received recommended diabetes care	27	69	26	48	28	71

\* All indicators were defined with the use of data from the Behavioral Risk Factor Surveillance System as listed in the Supplementary Appendix. The years of data used varied by indicator, depending on when the appropriate question or questions were asked. All indicators used 2 years' worth of data — some combination of 2008, 2009, and 2010. Additional detail on definitions of indicators is provided by Radley et al.<sup>2</sup>

sured, high premiums and out-of-pocket costs strain family budgets,<sup>3</sup> and people too often go without the care they need. In fact, we observed eightfold variation (2 to 16%) across HRRs in the proportion of insured residents who went without needed care because of cost. Wide regional variations also persist in the proportion of people with health insurance on other indicators of receiving recommended preventive and chronic disease care (see table), demonstrating a pressing need for strengthening primary care and assuring affordable access in all communities.<sup>4</sup>

The impact of inadequate access radiates broadly throughout local health systems. Areas that lag on access — concentrated in parts of Florida, Georgia, Louisiana, Mississippi, Oklahoma, Texas, and California — also show relatively poorer quality on a number of indicators. As compared with regions that scored in the bottom decile on measures of access and affordability, areas with strong access among all adults had fewer Medicare beneficiaries who received prescriptions for unsafe

medicines (18% vs. 32%) or who experienced a potentially avoidable visit to the emergency department (193 vs. 204 per 1000 beneficiaries). Deaths from conditions that are preventable with timely health care were also less common (75 vs. 110 per 100,000 population), and fewer people reported having poor health-related quality of life (24% vs. 34%).

High rates of uninsured residents within a community have been shown to pull down the quality of health care for insured and uninsured residents alike.<sup>5</sup> This finding is particularly troubling, given that nearly half the U.S. population, about 155 million people, live in places where at least one in five adults between 18 and 64 years of age is uninsured. Uninsured people who are sick or injured often delay seeking treatment or end up relying on high-cost care in hospital emergency departments. They may also have more difficulty affording follow-up care on test results or timely preventive care. Moreover, providers who are constrained by providing uncompensated care may have fewer resources to de-

vote to quality-improvement activities or to make broad investments in protecting the health of the communities they serve. Equitable and affordable access to care and robust primary care systems can play off each other within a community, translating into better care for all residents, even well-insured Medicare beneficiaries.

Health insurance expansions, including full coverage of preventive care, enacted as part of the Patient Protection and Affordable Care Act of 2010 (ACA) have set the stage for improving not only access but also quality of care for people throughout the country, with potential gains in health and quality of life for insured and uninsured residents alike. The ACA provides new resources and investment in primary care, as well as opportunities for physicians to work together to make delivery systems more accountable for care experiences, outcomes, and costs through timely preventive care and the effective management and coordination of care of patients with complex conditions. The Center for Medicare and

Medicaid Innovation, newly established by the ACA, has the authority to partner with care systems to stimulate innovation, and other ACA payment and care system reforms provide states and local systems with increased flexibility to improve.

Ultimately, ensuring timely access and improving the quality of care delivered will depend on collaboration among local clinicians, hospital leaders, insurance companies, policymakers, and other community stakeholders in strategic efforts to redesign health care systems. National reforms provide support for raising the bar across the country, helping to reduce geographic variation, and giving communities

new tools and resources for meeting benchmarks of top performance. These include funds to support insurance expansion and improve primary care teams, investment in information systems, and new public health resources. If such changes are well implemented, quality of care and health outcomes will improve, as we build a much stronger foundation of access throughout the country.

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## Justice for Injured Research Subjects

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Critics have long argued that U.S. ethics guidelines protect researchers more than they protect research subjects. The U.S. system of oversight, writes Laura Stark, was developed as a “technique for promoting research and preventing lawsuits.”<sup>1</sup> Consider, for example, the obligations of U.S. research sponsors when a study goes wrong. If a research subject is seriously injured, neither the researcher nor the sponsor has any legal obligation to pay for that subject’s medical care.<sup>2</sup> In fact, only 16% of academic medical centers in the United States make it a policy to pay for the care of injured subjects.<sup>3</sup> If a subject is permanently disabled and unable to work, sponsors have no obligation to pay compensation for his or her lost income. If a subject dies, sponsors have no financial obli-

gations to his or her family. Not a single academic medical center in the United States makes it a policy to compensate injured subjects or their families for lost wages or suffering. These policies do not change even if a subject is injured in a study that is scientifically worthless, deceptive, or exploitative.

Such policies may be unfair, but they are not news. For nearly 40 years, national commissions have been calling attention to the injustice of making injured research subjects pay for their own medical care, but their recommendations for change have been ignored. The first national commission to recommend compensating injured subjects was an ad hoc panel convened by the Department of Health, Education, and Welfare (HEW) in 1973 after the Tuskegee syphilis study. Four

years later, another HEW task force concluded that society has an “obligation to repair (so far as is possible) injury done to individuals” in research studies, by providing financial compensation and medical care.<sup>2</sup> Such obligations were affirmed in one form or another by national bioethics commissions in 1978, 1982, 1995, and 2001 and by the Council of International Organizations of Medical Sciences and the Institute of Medicine in 2002. In late 2011, the Presidential Commission for the Study of Bioethical Issues released a report titled *Moral Science: Protecting Participants in Human Subjects Research*, in which it reiterates that “human subjects should not individually bear the costs of care required to treat harms resulting directly from that research.”<sup>4</sup> This report seems likely to produce approximately