Removing Barriers

Creating Health Care Access for Connecticut's Newly Insured

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This study examines the profile of newly insured residents of Connecticut and identifies the barriers that exist for individuals in getting health insurance coverage and obtaining safe and reliable health care. Based on findings from a national literature search as well as perspectives from a panel composed of national and local leaders, this report proposes a plan to address the problems by focusing on strategies, materials, and proven solutions from Connecticut and national experts. We would like to acknowledge that this report was made possible through a grant from the CT Health Foundation.
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Introduction

Connecticut Center for Patient Safety studied the profile of Connecticut residents who enrolled since October 2013 in health insurance plans through Access Health CT, also known as the Connecticut Healthcare Exchange. Access Health CT successfully enrolled more than 185,000 residents. While we do not, as of this writing, have a definitive number of newly insured, we know that Access Health CT ran one of the nation’s most successful health exchange sign-up programs. We identified what residents know and need to know to enroll successfully in and access services through their selected health insurance policies. A recent report from Access Health CT has been included as an addendum to this report.

Our research team wanted to understand the context of the study. We know that prior to the enactment of the Affordable Care Act, between 240,000 and 284,000 Connecticut residents were uninsured, of whom 65 percent were minorities. As of March 25, 2014, more than 60,500 have signed up for private health insurance through the exchange. According to a report in the CT Mirror, “an analysis published in the journal Health Affairs estimated that by 2016, Connecticut would still have 162,000 uninsured residents ... about 9 percent of state residents.” The effort to achieve universal access has just begun.

The racial and ethnic breakdown in Connecticut reflects wide and increasing diversity. In 2010, the US Census Bureau found that in Connecticut, 13.5 percent of the population is Latino; 9.5 percent is Black or African American; and 3.8 percent is Asian. Whites and non-Latinos are 71.4 percent of the population. From 2000 to 2007, Latino populations showed the most growth of any of Connecticut’s ethnic groups. In fact, according to journalists at Connecticut Health Investigative Team, Latinos are the fastest growing, youngest, and poorest segment of the state’s population. According to Access Health CT, 65 percent of the uninsured in Connecticut are minorities, while 26.4 percent of people with incomes that fall below $25,000 were uninsured. Furthermore, 30 percent of Connecticut residents with less than a high school education lacked health insurance. Finally, 82.5 percent of those who were uninsured came from families with at least one working member.

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A variety of sources, including the 2012 National Healthcare Disparities Report\textsuperscript{7} issued by Agency for Healthcare Research and Quality (AHRQ) and the US Census, indicate that disparities in access to health care and consequently poorer outcomes are often found among people of color. Since 1999, several Connecticut Department of Public Health reports have documented disparities across a range of health and social indicators, including birth outcomes, deaths, hospitalizations, access to health care, and risk factors for chronic diseases. Furthermore, minority residents are more likely to be of low socioeconomic status and living in poverty than the White non-Latino population in Connecticut.\textsuperscript{8}

On May 14, 2014, we gathered a group of national and regional experts in the Legislative Office Building in Hartford, Connecticut, with a twofold purpose. First, we wanted to gain input, based on real experiences, about barriers facing Connecticut residents in understanding their new insurance and accessing their medical care. Second, we intended to discuss ways to address these barriers, considering strategies just in the idea stage as well as some being used successfully elsewhere.

Findings from this panel have been incorporated into this report; some are noted with references to “the panel” or “the discussion,” or with the names of the panelists. A list of panelists and a summary of main points can be found near the end of this report.

Kathleen Sebelius, former secretary of the U.S. Department of Health and Human Services, states, “Preventing illnesses before they become serious and more costly to treat helps Americans of all ages stay healthier.”\textsuperscript{9} In order to reduce the cost of health care, reverse the current model of treating sickness rather than enhancing health, and support our population in efforts to stay healthier, those concerned with improving access to and effectiveness of health care need to help our residents make the best use of their new health insurance coverage.


Identifying the barriers

- Enrollees often do not understand what insurance products they are buying, how the insurance works, or the varying costs of coverage for medical services they will need.
- Overall, enrollees are not health literate. Health literacy is defined by the Department of Health and Human Services as the ability to obtain, process, and understand health information needed to make informed health decisions.
- Many enrollees do not have primary care providers and lack knowledge about how to navigate a changing and complex health care system.
- Enrollees are confused about health care costs, coverage, and cost sharing.
- Information that is important to the consumer is often not transparent in areas including, but not limited to, what insurance plans are available, formularies, costs of medical procedures, and what is and is not covered by their plans.
- Neighborhood and community support for health care and wellness programs is limited and inconsistent.
- Logistical issues such as transportation and availability of convenient appointment times can significantly delay getting needed care.
- Many providers are not culturally sensitive.
- Our health care system is focused is on treating sickness rather than supporting wellness.
Health literacy and choosing health insurance

“Health insurance literacy, although universally low, is highest for white, non-Hispanic adults and lowest for Hispanic adults. Lower income adults have low health insurance literacy. Health insurance literacy is particularly low among the uninsured, but there are significant racial/ethnic differences within the uninsured.”

A survey by the Urban Institute Health Policy Center uncovered some startling facts. Of the target population for the Affordable Care Act (ACA) — non-elderly adults who are above the national cutoff for Medicaid eligibility — “only 39.9 percent feel very or somewhat confident that they understand all the insurance terms the survey asked them about. Only 43.8 percent of the respondents said that they feel confident that they understand all five terms related to costs (premium, deductible, co-payments, coinsurance, maximum annual out-of-pocket spending) and only 50 percent say they understand all four terms related to access to care and benefits (provider network, covered services, annual limits on services, non-covered or excluded services).”

While consumer coverage is mandated, many people face challenges in comparing costs, services, and provider networks, and therefore do not fully understand what they have purchased. The reasons for selecting one plan over another include price, benefits, and provider options. However, 36 percent found some aspect of plan choice — comparing services, comparing costs, and comparing providers — to be difficult.

The three main criteria for choosing insurance products include finding the right benefits to meet needs, evaluating costs, and determining if their providers are covered. Of the newly insured, 32 percent claim that they chose their plans because they covered a wide range of benefits or a specific benefit that they need; 29 percent because their costs would be low; and 22 percent because plans had broad selections of providers or included their doctors.
However, 25 percent of adults reported problems with their current insurance plans coverage of specific benefits because they were denied coverage for services they thought were covered,\textsuperscript{14} and 37 percent of adults reported experiencing problems with coverage for specific benefits because out-of-pocket costs for services were higher than they expected.\textsuperscript{15}

One cause of such problems is lack of transparency about health care pricing. What other products do people purchase without knowing the end cost before making their decisions to buy? According to the Healthcare Financial Management Association, “As Americans pay a greater proportion of their healthcare costs out of pocket, they have an urgent need for meaningful and transparent price information.”\textsuperscript{16} According to panelists Steve Glick and Venton Forbes, many people buy insurance based primarily on the cost of premiums. Only later do they find out that they may have high deductibles, co-pays, and co-insurance.

Situations are common in which even physicians and other providers are unable to tell patients what out-of-pocket costs will be before procedures. In addition, we heard from panelist Luis Diez-Morales, MD, that sometimes pharmacists contact doctors because patients cannot afford co-pays and doctors did not know the prices of the drugs. He encounters patients calling from the pharmacy asking for different prescriptions with lower co-pays, and other patients with chronic medical conditions who have to space appointments further apart because co-pays for office visits are prohibitive.

\textsuperscript{14} Ibid.
\textsuperscript{15} Ibid.

\textsuperscript{6} \textit{Removing Barriers: Creating Health Care Access for Connecticut's Newly Insured}
A report from Connecticut Center for Patient Safety (www.ctcps.org)
Mr. Glick, president of Chamber Insurance Trust, told us how confused people are by terms used in their policies, and we know that about 60 percent are not comfortable with their degree of understanding. While determining if someone’s preferred physicians participate in a health plan is usually not difficult, it is much harder to determine the value to the individual of low initial cost of policy versus higher shared medical costs, or the reverse, and the value of plans that fall in between.

Although Connecticut has had great success so far enrolling residents in the health care exchange, many uninsured across the country are concerned that, even with insurance, they will not be able to pay for out-of-pocket expenses. Nationally, nearly half of those who were still uninsured near the end of the enrollment period said that they were not likely to sign up because of the high cost.\textsuperscript{17} Those who did sign up were often surprised by unanticipated out-of-pocket costs. Too often, insured people still could not afford co-pays, co-insurance, and deductibles. Others thought that they had coverage for conditions that are not covered. Oral health care is one example of such confusion as, through the ACA, mandatory coverage for oral health care extends only to children.

Dr. Diez-Morales, a primary care physician, related stories of newly insured people who, unable to afford their co-pays, co-insurance, and out-of-pocket costs, chose not to keep appointments. Mr. Forbes, executive director of FaithCare, a community faith-based outreach organization, talked about seeing people who thought they had purchased the best plans, only to learn they could not afford premiums or associated costs.

While the ACA aims to ensure coverage of at least a basic set of essential health benefits (EHB), many ancillary services — such as dental care — are not included in the EHB. Newly insured people may be surprised to learn what is not included in their plans.

Health care costs pose a challenge for low- and moderate-income families, even if they have coverage, whether through an employer or on their own. These costs translate to medical debt for many low-income adults, and medical bills can cause serious financial strain. Approximately 33 percent of low- and moderate-income adults covered by employers report that their share is somewhat hard or very hard for them to afford\textsuperscript{18} and 76 percent of low-income and 58 percent of moderate-income adults with individually purchased coverage report difficulty in paying premiums and costs.\textsuperscript{19} Even when consumers have insurance, half of adults with non-group coverage do not feel confident that they could afford costs related to major illness, given their coverage and financial situations.\textsuperscript{20}

\textsuperscript{18} Ibid.
\textsuperscript{19} Ibid.
\textsuperscript{20} Ibid.

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7 Removing Barriers: Creating Health Care Access for Connecticut’s Newly Insured
A report from Connecticut Center for Patient Safety (www.ctcps.org)
Health literacy and health care

Health literacy, including insurance literacy, refers to the “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Our research showed that lack of health literacy must be addressed in order to increase patient empowerment and to help ensure reliable and safe access to health care. It has been found that “approximately 80 million Americans have limited health literacy, which puts them at greater risk for poorer health outcomes.”

Improved health literacy leads to greater patient engagement, resulting in enhanced safety and quality of care, and to improved outcomes. Poor communication is a leading cause for sentinel events identified by the Joint Commission. A sentinel event is defined as an unexpected occurrence involving death or serious physical or psychological injury, or the risk thereof.

### Most Frequently Identified Root Causes of Sentinel Events Reviewed by The Joint Commission by Year

<table>
<thead>
<tr>
<th>Year</th>
<th>Human Factors</th>
<th>Leadership</th>
<th>Communication</th>
<th>Assessment</th>
<th>Physical Environment</th>
<th>Information Management</th>
<th>Operative Care</th>
<th>Care Planning</th>
<th>Continuum of Care</th>
<th>Medication Use</th>
<th>Care Planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011 (N=1243)</td>
<td>899</td>
<td>815</td>
<td>760</td>
<td>689</td>
<td>309</td>
<td>233</td>
<td>207</td>
<td>144</td>
<td>137</td>
<td>97</td>
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<td>2012 (N=901)</td>
<td>614</td>
<td>557</td>
<td>532</td>
<td>482</td>
<td>203</td>
<td>150</td>
<td>95</td>
<td>93</td>
<td>91</td>
<td>81</td>
<td>76</td>
</tr>
<tr>
<td>2013 (N=887)</td>
<td>635</td>
<td>563</td>
<td>547</td>
<td>505</td>
<td>155</td>
<td>138</td>
<td>103</td>
<td>97</td>
<td>77</td>
<td>76</td>
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Community Catalyst, a national nonprofit health care advocacy organization, reports that, “using culturally and linguistically competent materials, providing oral interpreters and conducting meetings in languages spoken by the community and in locations accessible to consumers with disabilities will help reduce barriers to participation and allow diverse perspectives to be heard in multiple settings.”

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According to the Health Power for Minorities website, a key factor contributing to racial and ethnic health disparities in Hartford, Connecticut, was too few multicultural health professionals. Providing medically trained language interpreters, for instance, would immediately improve patients’ ability to be partners in their own care.

During our panel, Steve Glick pointed out that many of the newly insured say that they need education to understand their coverage. Venton Forbes recommended that health care language should be at a level that patients can understand. According to another panelist, community health worker Jacqueline Ortiz Miller, patients who do not speak English face particular challenges. Qualified interpreters are often unavailable, and medical offices often have to use untrained staff to interpret. While some solutions exist, including various in-person and telephone translation services, Ms. Ortiz Miller said that patients are often uncomfortable sharing personal medical information with those they do not know or who are not directly involved in their care. Dr. Luis Diez-Morales noted that he is the only provider in his office fluent in Spanish; he is often called upon to help others with Spanish-speaking patients.
**Finding a primary care provider and navigating the health care system**

According to Pew Research Center, a nonpartisan fact tank, one out of four Latino adults in the United States does not have an ongoing relationship with a health care provider. According to Kaiser Family Foundation, most uninsured adults have little to no connection to the health care system. Only 51 percent reported having a usual source of care and only 33 percent had a regular doctor. When people do not have a connection to the health care system, they often go without care. Those who do have insurance are more likely to receive care. With more people obtaining health insurance, we would assume that more people would connect with the health care system to receive medical care.  

However, barriers exist. During the panel discussion, Ms. Ortiz-Miller noted that, with the changes in insurance, many newly insured have been told they cannot see the primary care doctors with whom they had developed relationships. Dr. Diez-Morales and community health care navigator Rebecca Santiago spoke of newly insured individuals who now needed primary care physicians but found that other physicians were not taking new patients, or learned that they would have to wait months for appointments.

Additionally, studies have shown that bringing the newly insured into the health care system might require community outreach to establish new patterns (for instance, no longer going to the emergency room for care). In Oregon and Massachusetts, emergency department usage continued even after the previously uninsured obtained insurance. In San Diego (CA) County, studies took place in which newly insured patients were counseled and referred to primary care providers to establish relationships prior the need for medical attention. Follow-ups were done by community clinics, helping to change patterns for seeking care. A UCLA Center for Health Policy Research study showed that, while emergency room use continued with the newly insured, it did decrease over time with community education and support.

Another concern focuses on the continuum of care involving transitions. During care hand-offs — whether from home to hospital, hospital to long-term care, or back home, and even from unit to unit within the same hospital — the likelihood of a medical error is increased. Such errors may mean additional hospitalization, post-acute stays, unnecessary readmissions, and needless pain and suffering for the patient.  

Too often, patients’ own knowledge about their care, or the knowledge of their family members, is not factored in by medical personnel. Patients and family members need clear information about what they can do to make transitions safer and less stressful.

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Lack of transparency of relevant information

Medicare and other government entities gather data on certain hospital-acquired infections, readmissions, “never events” (events that should never occur, such as wrong site surgery), and other markers of care. However, until recently, much of this information had been based on voluntary reporting and was not publicly accessible. With health care reform, more data are becoming available but much of the information is still not consumer friendly.

Many different rating systems exist for hospitals, doctors, long-term care facilities, and ambulatory surgery centers. “Among the organizations publishing these ratings and measures are government agencies, news organizations, healthcare accreditation and quality groups, and companies and not-for-profits focused on transparency.”25 Public attention to these rating systems has pressured hospital leaders to make changes in order to improve their scores, and the ratings have provided a marketing tool for health care services.

However, such ratings are often difficult to find and interpret. Different sources emphasize different concerns, with some focusing on factors reflective of safety, others on patient satisfaction, and still others combining multiple considerations. These variables make ratings of uncertain use to consumers, who may also be unsure about which rating systems address the information they are looking for.

Additionally, consumers need to know about providers who have had adverse actions against them, especially those with repeated disciplinary actions against them. These actions, such as medical fines and settlements, medical board disciplinary actions, and peer review sanctions, are reported to the National Practitioner Data Bank, operated by the Department of Health and Human Services’ Health Resources and Services Administration. However, since September 2011, individual physician data is accessible only to hospitals, insurers, and other authorized entities. Compounding this problem is the corporate exclusion created by the expanding ownership of private practices by hospital systems. As these hospital systems grow, individual physician names may be excluded from malpractice information about harm within that hospital. In this scenario, information about doctors with complaints against them will not be accessible to future employers, putting public safety in jeopardy.

Limited and inconsistent neighborhood and community support

Access to health care in communities varies by neighborhood. Some areas have clinics and hospitals within walking distance, while others lack public transportation to reach providers. Additionally, within individual communities, levels of service vary. The Community Health Needs Assessment Consortium found that barriers to health services affecting Hartford residents included not knowing about existing services (27 percent); lack of available services (22 percent); inability to pay (20 percent); and lack of transportation (20 percent). According to Mary Winar, a staff member the state Office of Rural Health (ORH), health care issues facing Connecticut’s 65 rural towns are similar to those faced by residents in urban areas. These issues include access to care, emergency services, insurance coverage, workforce shortages, and cultural competence. In rural areas “low population density, lack of infrastructure, and lack of government resources to address health care are the sources of many of these issues.”

Access to care was commonly cited as a primary concern to residents of rural areas. Connecticut’s 65 rural communities are spread over a large area and are sparsely populated. Transportation is a major concern; people depend on their own vehicles, very limited public transportation, and private car services. Regions with lower population density do not support large numbers or networks of providers, and specialty providers and mental health providers are few and far between. These concerns were noted during the panel discussion as also affecting urban centers. People often walk to get to where they have to go. When a community health center closed down, area residents were left to figure out how to get to the next nearest provider location.

While there is a wealth of information on the Internet, and options to receive some health care services are available online, those without easy access to the Internet are not able to benefit from this technology.

28 Ibid.
**Providers and cultural competence**

Differences in cultural understanding must also be addressed. Many health systems recognize the need to have interpreters available to help non-English-speaking patients. But cultural competency goes beyond language interpretation. It also means ensuring that health care workers are versed in the culture of specific communities. Medical providers who understand the cultures in which they work are more likely to be effective.\(^{29}\) As Ms. Ortiz Miller discussed, when doctors are familiar with the dietary customs of patients’ ethnic groups, they are better able to suggest healthier eating habits. If they are familiar with the community, they know what foods are locally available. Awareness of gendered social norms helps medical personnel avoid offending patients during exams. In end-of-life medical situations, health care providers need to be familiar with the rituals and beliefs of patients’ faiths.

Among Latinos, some of the challenges in obtaining care are related to concerns about immigration status, and the way Latinos think about health care. Joan Cruz, director of special projects for Hartford’s Hispanic Health Council, noted the tendency of Latinos to exhaust home remedies and over-the-counter medications before seeking medical care. “We were raised to try to solve these problems on our own. The last thing we want to do is go to the doctor.”\(^{30}\)

Eight out of ten Latinos report that they get their health care information from alternative sources, and the same number report that they received some health information from family members, friends, churches, and community groups.\(^{31}\) Mr. Forbes and Ms. Ortiz Miller spoke of the importance of both faith-based and non-faith-based community health care initiatives. Seven in ten Latinos say that they received information from doctors in the past year, and over eight in ten reported that they received health information through the media (with television influencing 68 percent of Latinos in the study) and acted on it. Pew Research Center found that Latinos who believed that their health care quality was poor attributed that problem to three primary issues: financial limitations; their race or ethnicity; and the way they spoke English or their accents.\(^{32}\)

The health status of African Americans is worse than that of the population overall. Their death rates exceed overall US rates for many major diseases; their life expectancy is years shorter than that of their white counterparts; and their infant mortality rate is almost double the national average. While there are a number of reasons for this situation, according to Jonathan Walker, MD, “African Americans as a group tend to be more apprehensive of the health care


\(^{32}\) Ibid.
system and are less likely to go to a doctor.” According to Melissa Welch, MD, African Americans have strong social support networks and a belief in the “well-being of the community.” They tend to use informal health care systems for information and generally distrust the medical establishment. She found that they have long used prayer and religion to address health concerns.

During our panel, Jacqueline Ortiz Miller pointed out the importance of health care providers’ understanding the cultural context of the communities in which they work. Aline Holmes, DNP(c), from the New Jersey Hospital Association, spoke about the different ways that cultural issues affect access to health care. She pointed out that in some cultures, respect for a medical provider may not allow a patient to question the provider, and noted that people might be more comfortable using folk remedies that their doctors are not familiar with.

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**Focusing on sickness rather than wellness**

According to the Health Power for Minorities website, several key factors contributed to racial and ethnic health disparities in Hartford, Connecticut. These factors include a low priority being placed upon preventive care due to lack of insurance, too few multicultural health professionals, and general distrust of the medical establishment. There was also an overall lack of awareness of and attention to early warning signs of medical problems.

While there is beginning to be a shift to accountable care organizations and medical home models, which emphasize wellness, much medical care is still based on a model of treating sickness. Financial incentives drive the free market and encourage providers of services and products to prescribe medications, devices, and procedures. Pharmaceutical companies make money by selling medications, and medical care providers are paid on a fee-for-service model. Accountable care organizations and medical homes are based on the idea that a network of doctors and hospitals is collectively responsible for an enrolled population (for instance, Medicare patients) and can create shared savings with improvements in the quality and efficiency of the care. Their reimbursement is tied to quality of care rather than being based on fee for service.
Translating findings to actions

Bringing safe and reliable health care to communities, particularly those experiencing significant health disparities, involves more than clinical interventions. We need to consider community health needs as well; often, improving health outcomes also requires solutions related to physical and cultural environments. Treatment for a medical condition may involve looking beyond medicine.

Asthma, for instance, is affected by factors such as building infrastructure, mold conditions, and air quality. Many people who have asthma live in poor, inner-city communities. Pew Research suggests, “the way to tackle the problem is to educate all the people and practitioners in urban neighborhoods about preventing and treating the disease, rather than focusing on a particular race, age group or gender.” Pew notes further that “when a particular ethnic group is prone to a disease, the challenge is finding an approach to education, prevention and treatment that will resonate with that group. Doing that might mean simply creating and distributing educational materials in a specific language. In addition, a broader approach might be to boost providers’ ‘cultural competency.’” Cultural competency includes recognizing language differences, cultural customs, behaviors, dietary customs, male-female social norms, and religions.

Reaching community members with information, education and tools to access their health care will be essential. Among all American adults over 18, only 64 percent of Black, non-Latino people have access to a high-speed broadband connection. That figure drops to 53 percent for Latinos. For those with no high school diploma, the rate drops to 37 percent and for people with annual incomes of less than $30,000, we see a rate of 54 percent. However, of the 10 percent of Americans who do not have broadband access, 32 percent do use smartphones. Smartphones appear to hold promise for engaging the newly insured in Connecticut. Although lower numbers of Latinos have broadband access, Pew Research Center found that among 18- to 29-year-old Latinos, 95 percent are Internet users and are significantly more likely than older adults to seek medical information online.

Our research has found successful programs in multiple communities, addressing many of the barriers previously identified. We have also found printed materials with information that should be provided to people before and during the time when they seek insurance and during the early stages of their being insured. In this section, we will discuss our findings. The end of this report features a resource list of reliable websites.

Our recommendations focus on three themes: education, health literacy and transparency.

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Our recommendations incorporate what has been referred to by Tom Evans, MD, president/CEO of Iowa Healthcare Collaborative as the four E’s: Engagement: Patients must be partners in their care; Education: What to do now that the patient is engaged; Execution: Go out and do what we know we need to do; and Excellence: How are we doing — frequent review and updating.37

Consumers of health care need to be educated and given the information to become health literate. They also need to have valid, unbiased, and accessible information on which to base choices. Partnering and collaborating with schools and community colleges to incorporate health education into programming is one possibility. Residents need to know how to determine which insurance will best suit their needs and priorities; how to understand their insurance and what is covered; how to understand health care–related costs; how to obtain appropriate medical services; how to self-advocate; and how to maintain health and manage chronic conditions. We must incorporate known quality and cost information on easily accessible websites and develop multiple methods for information dissemination. We must also provide ongoing, linguistically appropriate outreach on specific challenging areas such as billing, pharmacy, and specialty care.

Venton Forbes spoke about how his organization, FaithCare, “provides services and education for prevention of disease while assisting patients with disease management and helping them to assume responsibility for their own health.” He added, “The newly insured are the most vulnerable within our communities.”

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37 Webinar: CMS Partnership for Patients Master Class, Patient and Family Engagement Affinity Group: Medication Management and Readmissions; Tim Brown, PharmD, BCACP, FASHP, Director, Clinical Pharmacotherapy in Family Medicine, Center for Family Medicine at Akron General Medical Center; April 21, 2014.
Health literacy: Medical insurance and access to safe and effective care

Health insurance literacy and health care literacy must be improved for the newly insured to make the most appropriate decisions related to their care. To reiterate, health literacy, including insurance literacy, refers to the “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Health literacy includes skills such as knowing how to measure medications accurately, read and understand instructions, share medical information, and understand concepts involving self-care and disease management.

One of the first steps to improving health literacy level among Connecticut’s newly insured is to provide better support and transparency at the point of sale for insurance plans. Additional information about what policies cover and how much medical services will cost beyond premiums will help minimize billing surprises. However, a related problem is that often even the providers of care do not know how much certain services will cost. Additionally, costs can vary by thousands of dollars from one provider to another who may be only blocks away.

The Healthcare Bluebook, available online, can help consumers determine fair prices in their geographical areas for health care services. It is a starting point, but low health literacy impedes consumers in making fully informed medical decisions. Information to help consumers is available in a brochure titled Understanding Healthcare Prices: A Consumer Guide. The information is comprehensive, but the content may need to be delivered differently to be understood by all consumers. With insurance open enrollment periods now occurring annually, knowing about costs, even after a policy has been purchased, will help consumers understand what they need to consider in future policies to meet their needs. Connecticut needs to increase transparency of costs through passage and implementation of appropriate legislation.

Our research shows that consumers lack basic understanding about their insurance and are then further confused about how to navigate the health care system. Unless consumers are made aware in advance that purchasing insurance and navigating the health care system require knowledge, many may wait until a crisis and only then discover the limits of their policies and how they work. Increasing the health literacy of Connecticut residents can be done by building on the process that was developed for the Access CT rollout. Whether individuals have coverage from their employers or directly, they share similar confusion about costs and

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coverage. Our research suggests that new enrollees would benefit by having “point persons” who can answer questions before and after the initial purchase of insurance. In addition, it is recommended that employees receive health care information at their workplaces.

Consumers will benefit from learning that the cost of their insurance includes more than the premium. They need information about the meanings and implications of terms such as co-insurance, co-payment, deductible, and out-of-pocket expense. Additionally, policies need to be reviewed to determine what medical services and supplies are covered — including screenings, diagnostic tests, medical procedures, and medications — to avoid surprises at the point of service. According to information from Doris Peter, director of Consumer Reports Health Rating Center, consumers are paying more out of pocket for medications; additionally, they are largely unaware of insurance companies’ formularies and “step” therapy restrictions, and of the fact that some drugs are not covered at all. The Best Buy Drugs website provides unbiased and extensive consumer drug information in English and Spanish.

Various options exist for consumers to receive help with selecting the right plan. These include working one-on-one with navigators, going online to the Access Health CT website, or calling Access Health CT directly at (860) 757-5300.

Connecticut’s exchange — and the related infrastructure that includes using navigators to assist consumers in plan selection — has become a model for the country. Navigators were initially charged with conducting public education to raise awareness of exchange health plans, provide fair and impartial information regarding premium tax credits and enrollment, facilitate enrollment, and provide necessary referrals for enrollees. However, concerns remain that many consumers were not as well educated about insurance as they needed to be. Since the infrastructure here in Connecticut can be built upon to raise the overall level of health literacy, we recommend using that infrastructure as part of the solution.

We should capitalize on the relationships established during the sign-up process and nurture them to continue the momentum toward better health literacy.

As stated earlier, the primary responsibility for improving health literacy lies with public health professionals and the health care and public health systems — not with patients. The first step is to identify strategies to reach the target audience. We recommend that the community outreach that has taken place in the insurance sign-up process continue, with the mantra being to “go to where the people are." Consumers should be engaged through community health centers, emergency departments, barbershops and beauty parlors, booths at festivals, and all locations where insurance sign-ups occur. Connecticut should look at programs such as Dulce New Jersey, where health literacy has been successfully addressed with a systemic approach and where materials and information are successfully disseminated in a state where over a hundred languages are spoken.
Outreach and education

Members of the Latino and Black communities rely on local media for a significant amount of their health-related information. We need to work with trusted media in increasing awareness of health and wellness issues by leveraging existing relationships between the media and hospitals, provider groups, community organizations, and Access Health CT. Pew Research has noted that 71 percent of Latinos reported that they received information from doctors in the past year. An equal proportion reported obtaining health information through their social networks, including family, friends, churches, and community groups. An even larger share (83 percent) reported that they obtained health information from some branch of the media, with television being the dominant source. Not only are most Latinos obtaining information from media sources, but 79 percent say they are acting on this information.

Health fairs and the other methods should be used to inform residents about both available health care programs and best practices. All materials should be presented in person-first plain language at a fourth-grade reading level, and should use graphics and symbols wherever possible for universal understanding. People have different learning styles, preferences, and needs; cultural differences can also affect learning and ideas about who the “best” leaders/teachers might be. Best practice would be to use videos and other multimodal teaching tools, as described above.

The education process has several tiers. The fundamental process for obtaining safe and reliable health care should first be taught to the people, agencies, and organizations doing the community outreach — those who are designated as the “educators.”

Essential information would include the importance of promoting wellness; having a primary care provider and how to choose one; what information to present when making a medical appointment and when going to an appointment; what to consider after the appointment; what to do for appointment follow-up. This information, as well as the information about insurance gaps noted previously, is in an easy-to-read brochure, A Roadmap to Better Care and a Healthier You!, available in English and Spanish. This brochure can offer a basis for educational outreach without reinventing the wheel.

The Center of Medicare and Medicaid (CMS) website offers other tools for educational outreach including From Coverage to Care discussion guides for community partners, as well as posters, PowerPoint presentations, and videos. The discussion guides teach strategies for community leaders to speak with consumers about key health care topics, and offers health insurance talking points. Other organizations also offer tools to advance health literacy.

In today’s environment, doctors are spending less appointment time with patients. In addition to writing down questions ahead of time, consumers should be made aware of another strategy, based on the “Ask ME 3” program through the National Patient Safety Foundation: “There are three questions that every patient can ask their provider to make sure that they are involved in their care and are making informed choices about their health care…. What is my main problem? What do I need to do? and Why is it important for me to do this?” 43 Studies consistently show that people who understand health instructions experience speedier recoveries and better management of chronic problems, and make fewer mistakes in taking medications or preparing for medical procedures.

The following strategies also lead to increased safety and better outcomes:

- asking questions and understanding the answers about the risks and benefits of recommended treatments — or choosing no treatment at all;
- bringing someone with you to your appointments;
- recording instructions on a smartphone so you can replay them after you leave;
- knowing the names of your medications, the dosage information, and how and when to take them;
- when you hear something from a health care provider, repeating it back in your own words to be sure that you understood it correctly;
- making sure that you get the results of any lab work or diagnostic tests and review them with your provider;
- having one person who is in charge of your care and will coordinate it.

The Empowered Patient Coalition’s website provides a number of free tools. These include mobile smartphone apps, a Hospital Guide for Patients, The Empowered Patient® Journal, fact sheets, and checklists.

According to Community Catalyst, “consumer engagement, done well, fosters an atmosphere of active, ongoing collaboration and conversation that will benefit consumers and their caregivers, health plans and provider groups, and ultimately transform the health care delivery system.”

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“Although the CHW concept is not new, states and other health care providers are partnering more often with these workers to help individuals navigate a complex health care system, receive primary and preventive care, maintain healthy behaviors, and manage chronic conditions in culturally and linguistically relevant ways.”

Community health workers: Meeting patients where they are

Our panel members noted that programs involving community health workers (CHWs), social workers, exchange navigators, faith-based community health outreach efforts, and other community liaisons help create positive change in the health of community residents. As Jacqueline Ortiz Miller discussed, when CHWs are part of the health care team, they are particularly able to improve the treatment of chronic disease because their understanding of cultural differences allows them to gain the trust of the patients. Rebecca Santiago explained the value of community health care navigators in that they, too, have the trust of residents and often take extra time to notice how someone presents and to “navigate” them to appropriate care. She also suggested that medical assistants, who already have a foundation of knowledge, could be trained to serve as patient coaches and navigators.

Ms. Ortiz Miller also suggested that CHWs help patients learn better self-advocacy skills. She proposed that when patients are in a waiting room, CHWs could talk with them, using motivational interviewing techniques to help patients identify, before the appointment begins, why they are at the visit and what questions they would like answered during the appointment.

The panel also discussed outreach to rural areas where services are spread out and transportation systems limited. In those areas, access to care was commonly cited as a primary concern. Network providers and particularly specialty providers are sparse. In urban centers, care can become inaccessible because of residents’ inability to pay for transportation when a local practice or facility closes. The writers of this report recommend that the Department of Public Health and CT Medical Society map providers and centers of care and practices for the purpose of understanding patterns of care and better meeting residents’ needs.

Other outreach programs were presented at the roundtable panel by Aline Holmes, who discussed two programs that involved community health care workers. The first one was focused on the rollout of the Affordable Care Act (ACA). Funded by the New Jersey Health Initiative, the New Jersey Hospital Association (NJHA) did focused hiring for the position of certified application counselors with 25 veterans who had been unemployed for over one year. Those hired were all multilingual; they were then trained in cultural competency, certified in medical interpretation and NJ Medicaid, and given iPads and cell phones. As community health care workers, they reached out to the ethnically diverse communities where they were from

and participated in community events and health fairs, worked with provider networks, and interfaced with the media, all focused on signing up residents for health insurance. Now that the enrollment period is over, they are working with the newly insured to help them understand how to obtain services, access preventive care, and so on. When navigators are provided with additional education, they are able to use their trusted status to further support the newly insured.

Dulce New Jersey is based on the Project Dulce model out of the Whittier Institute in California. Project Dulce is designed to address the health care needs of diabetics in a culturally diverse population. Their team approach includes an RN, a medical assistant, and a dietitian. Their approach also includes training and using peer educators, guiding treatment by algorithms and clinical standards, use of an electronic registry to track information, and research-based group education curriculum to address the population’s cultural diversity. Dulce New Jersey is focused on diabetes management and on chronic heart failure. The model involves hiring and training community health workers from diverse ethnic communities in a state where over a hundred languages are spoken, and pairing those workers with nurses. Following training, the CHWs go back to their communities to work with individual patients. Since CHWs are familiar with the ethnic and cultural identities of the residents, they can help them access the best treatment options. In addition, before qualifying patients are discharged from hospitals, they are aligned with primary care providers and CHWs follow up to make sure that they keep their appointments and are on track with their care plans.

Because many people who were uninsured used emergency departments for primary care, we recommend that emergency departments be required to use community health workers to educate patients and families. In Connecticut, the newly insured need validated lists of primary care providers accepting new patients.

In Dulce New Jersey, the CHW’s community involvement also extends to daily situations affecting people’s health. For example, patients who were discharged on salt-restricted diets and instructed to eat a lot of vegetables were purchasing canned vegetables containing a lot of salt. The CHWs found that fresh vegetables were not available and asked local storekeepers to carry different products, thereby improving residents’ health. The use of CHWs has reduced hospital readmissions, produced better compliance with medical instructions, and achieved better care through greater cultural sensitivity and clearer communication. Implementation of successful programs such as Dulce New Jersey should be encouraged, and we in Connecticut should continue work with medical schools to improve the knowledge of health challenges for ethnically diverse populations.

Community health workers also play an important role in transition planning and care coordination. The National Institutes of Health (NIH) has found that assistance from CHWs

\[46 \text{"Project Dulce." Scripps Health. Scripps Health, n.d. Web. 06 June 2014.} \]
boosts follow-up care, reduces unnecessary readmissions, and leads to improvements in mental health after hospital discharge.⁴⁷ In addition, including CHWs in primary care practices has been shown to lower costs and improve health care outcomes as well as improving patient satisfaction scores.⁴⁸ This model of the patient-centered medical home is at the center of the accountable care organization model. A transition to this model creates a shift away from treating illness and emphasizes wellness and preventive care. Another of our recommendations is that all primary care practices incorporate community health care workers.

Connecticut should enlist neighborhood communities, including faith-based programs, in promoting health and wellness. Venton Forbes spoke of FaithCare’s vision of doing outreach through houses of worship. For instance, greeters at a service can mention a community health fair taking place later that day, or a play on how to deal with medical issues that is being staged by the church. FaithCare’s vision for the near future also includes using mobile vans to bring free health care directly into communities for people who lack access.

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Recommendations

Success will depend on continued diligence and an ongoing review process to assess enrollment and access to health care for those newly insured. In addition, those in a position to act must create a feedback loop from patients to providers to continually monitor their experience.

- Improve access to accurate and appropriate health information, by building on existing infrastructure.
  - Provide navigators with improved/additional education.
  - At point of sale, provide enrollees with linguistically appropriate literature written in person-first plain language.
  - Provide consumers with videos for learning about obtaining insurance and accessing health care.
  - Provide names and phone numbers for enrollees to call with questions.
  - Connect the newly enrolled with validated lists of providers accepting new patients.
  - Provide additional education and tools for more effective patient engagement. Some of these tools are available on the CMS website.

- Ask DPH and CT Medical Society to map providers and centers of care and practices.

- Develop new methods for information dissemination in addition to brochures, and provide ongoing, linguistically appropriate outreach to the enrolled on specific challenging areas such as billing, pharmacy, and specialty care.

- Require emergency departments to use community health workers to educate patients and families.

- Enlist community resources, including faith-based programs, in promoting health and wellness.

- Partner with schools and community colleges to incorporate health education in programming.

- Work with Connecticut media to increase awareness of health and wellness issues.

- Encourage all primary care practices to incorporate community health care.

- Work with medical schools to improve the knowledge of health challenges for ethnically diverse populations.

- Encourage implementation of successful programs such as Dulce in New Jersey.

- Incorporate known quality and cost information on easily accessible websites.

- Increase transparency of costs through legislation. (For instance, some states require the posting in providers’ offices of the cost for common procedures.)
Roundtable panel discussion summary

In May 2014, Connecticut Center for Patient Safety hosted a panel discussion with national and state experts to learn more about the experience of the state’s newly insured. Below is a list of panelists, and summaries of points they made:

| Moderator: | Randi Redmond Oster, president, Well Path Press |
| PANELISTS: | Luis Diez-Morales, MD, medical director, Saint Francis Center for Health Equity |
|           | Venton B. Forbes, executive director, FaithCare |
|           | Steve Glick, president, Chamber Insurance Trust |
|           | Aline Holmes, DNP(c), RN, New Jersey Hospital Association/NJ Hospital Engagement Network |
|           | Jacqueline Ortiz Miller, community health worker/health educator |
|           | Doris Peter, director, Consumer Reports Health Ratings Center |
|           | Rebecca Santiago, community health care navigator, St. Francis Hospital |

The panelists

Luis Diez-Morales, MD, medical director, Saint Francis Care, Center for Health Equity. Dr. Diez-Morales spoke about obstacles faced by patients and providers every day in his clinic. Using case studies, he pointed to the difficulty finding providers; the long wait for appointments; the unaffordable cost of medications and medical care (even with insurance); cultural and language barriers faced by both patients and providers; and the restricted hours that most health care providers offer. He believes that those providing services need to move toward providing medical care based on a true patient-centered medical home model meeting the needs of our patients; he also noted that making this transformation presents its own set of challenges.

Venton Forbes, executive director, FaithCare. FaithCare, which has branches throughout the US and Africa, aims to integrate faith and medicine and helps connect people to free care. He expressed concern that we are still unsure of the real number of uninsured in Connecticut. He noted that while Connecticut’s uninsured rate was 9 percent (fewer than 240,000 people), 30 percent of people in some neighborhoods are uninsured. He confirmed other panelists’ observations that residents often have insurance but nowhere to go — no primary care providers. He also noted that many patients feel that doctors have lost their personal touch; that doctors are more interested in following protocol to make sure that they “cover their visit” in their EMRs (electronic medical records); that patients purchased the best plans they could but can’t afford the premiums, co-insurance, or co-pays. He also discussed the issue of oral health care, noting that many people, when they bought their plans, didn’t realize that dental wasn’t covered; others don’t realize that they do have dental coverage. Mr. Forbes discussed the importance of partnering community and faith-based organizations with health care providers, and of having mobile medical and dental units to bring health care to the communities that need it.
Steve Glick, president, Chamber Insurance Trust. Mr. Glick spoke about the need to improve health literacy among Connecticut residents in relation to understanding, buying, and then using medical insurance. More than 85 percent of people do not know the details of their plans. He has found that many are confused and find the process challenging. Many insurance terms and concepts are not understood due to language barriers and also to their innate complexity. Furthermore, patients are buying insurance and finding that they are not aware of what is and is not covered, and what requires co-pays or co-insurance. He also expressed concern about the reconstruction of drug-tier coverage and the complexity of the cost-sharing structure.

Aline Holmes, DNP(c), RN New Jersey Hospital Association/NJ Hospital Engagement Network. Ms. Holmes discussed the history and success of the Dulce New Jersey project, which is based on the Project Dulce model (Whittier Institute, CA). The project works to address chronic illness and reduce hospital readmissions, and highlights the success in improving health care by engaging patients, using CHWs, and creating culturally and linguistically sensitive support systems. Ms. Holmes discussed strategies used to address cultural and linguistic barriers in a state that has over a hundred primary languages. Strategies include using universal graphics, involving community and faith-based outreach in accessing care, using specially trained community outreach workers, and offering incentives such as waiving co-pays when clients are adhering to their medical care plans.

Jacqueline Ortiz Miller, community health worker/health educator. Ms. Ortiz Miller discussed the vital role of community health workers (CHWs) in addressing insurance and health care gaps; the value of CHWs as trusted members of their communities cannot be overstated. Her input highlighted challenges posed by transportation issues, environmental issues, psychosocial barriers, linguistic barriers, access to health care services, and limited access to information and technology. She spoke of concerns about the “fast food drive thru” feel of appointments due to shorter visit times, and the impersonal approach created when providers spend more time entering data into EMRs rather than speaking directly to patients. As medical care is moving toward the medical home model, she envisions using CHWs as part of the team — particularly in chronic disease management — a strategy that is working in other communities.

Doris Peter, associate director, Consumer Reports’ Health Rating Center. Ms. Peter discussed empowering consumers with health ratings. She pointed out that consumers are paying more out of pocket due to high deductibles, higher co-pays for drugs, and shrinking coverage. She spoke also about issues related to drugs; for example, drug advertising is misleading and can sometimes be false. She noted that drug errors are the number one cause of mistakes in hospitals, and during transitions in and out of hospitals. Consumer Reports offers drug comparisons and recommendations with the latest unbiased safety information. She discussed medication information gaps and what questions consumers need to ask, and pointed out that on some plans, finding if certain drugs are covered on the formulary is not easy; in one instance, she needed eleven mouse clicks to get an answer.
Rebecca Santiago, community health care navigator, St. Francis Hospital. Ms. Santiago presented the story of an uninsured man with untreated chronic medical conditions who, as the result of intervention by a community health care navigator, had his life turned around. He received medical attention, signed up for insurance, now has a primary care physician, and has his diabetes and hypertension under control. Her story exemplified the benefits of community level intervention and support, and the potential of that support for improving community health.
**Audience questions and discussions**

**What strategies can be used dealing with shortened appointment times with doctors?**

- Ms. Peter suggested that patients use “Ask Me 3” question model.
- Dr. Diez-Morales said that patients should prepare ahead, writing questions at home. Physicians need to come up with a solution to how to better use the EMRs, perhaps through the use of bilingual scribes.
- Open Notes or other patient portals can be used to improve the provider/patient relationship.

**What can be done to educate and involve the community?**

- Mr. Forbes suggested that patients could share ideas with each other through the creation of patient-to-patient peer support; for example, asking, “What did you do in that situation?”
- Ms. Ortiz Miller suggested more use of motivational interview strategies to help people self-advocate. She also suggested having discussions with patients when they are in waiting rooms to help them go into appointments more prepared.
- Ms. Holmes recommended the Dr. Eric Coleman Care Transitions Program.
- Ms. Santiago spoke about coaching and navigation — the importance and value of using those who are there already, for instance by training people such as medical assistants to be navigators or coaches.
- Mr. Glick said that he was going to take the idea of community coaching and community navigators back to the business communities, where it is a novel idea.
- The panelists noted that one way to empower patients is to convey that it is okay to be disliked and to make providers uncomfortable.
- Dr. Diez-Morales discussed his belief that the office experience has to be reinvented. The office of the future needs to use IT support in a creative way to improve patients’ time with physicians.
- Consider using Medicare as model for consumer education.

**How are we going to roll out these recommendations? How do we make sure that people in positions to bring about changes hear the message?**

- Ms. Peter suggested that we look to the National Center for Farmworker Health, where there is a model to address literacy for different populations.
- Ms. Ortiz Miller pointed out that community members must be involved, and that information being transmitted must be simple and clear so that everyone can understand it.
• Mr. Forbes pointed out that health messages can be transmitted through places of worship by being incorporated into sermons, and shared through drama ministries; health-related events could be also held following worship services. Faith-based organizations (e.g., Council of Churches and Minister Alliance of Churches) can be avenues for the further discussions of these strategies.

• Dr. Diez-Morales said that he holds a community forum at the Center for Health Equity, where they invite the community to participate.

• Ms. Holmes pointed out that physicians have power and should be looked to for their participation in bringing about cultural change.

• Ms. Santiago told of a town hall meeting where community members were not represented and there was not enough time to ask questions. She recommended that community forums should be smaller groups to address specific concerns.

• Mr. Glick brought the perspective of the business owner who has concern about these issues but little time. He said that business owners want information, but it is not being brought to them.

• We heard that the PACE (Program for All-Inclusive Care for the Elderly) committee at St. Francis Hospital has been encouraging and facilitating communication with members of the community.

• Jean Rexford, executive director of Connecticut Center for Patient Safety, noted that 20 percent of the US economy is about sickness. To improve access to health care, systems need to be rebuilt based on patient needs and not industry needs.
Resources

- Ask Me 3 [www.npsf.org/for-healthcare-professionals/programs/ask-me-3/]
- Healthcare Bluebook at [www.healthcarebluebook.com]
- *Obamacare got them insurance, but patients still face barriers to care*
- Project Dulce | Scripps [www.scripps.org/services/metabolic-conditions__diabetes/why-choose-scripps__project-dulce]

Links to publications and organizations mentioned in this report

- Access Health CT: [www.accesshealthct.com]
- Agency for Healthcare Research and Quality (AHRQ): [www.ahrq.gov]
- Centers for Medicare & Medicaid Services (CMS) — From Coverage to Care: [http://marketplace.cms.gov/technical-assistance-resources/c2c.html]
- Community Catalyst: [www.communitycatalyst.org]
- Connecticut Health Investigative Team: [www.c-hit.org]
- Consumer Reports Best Buy Drugs: [www.consumerreports.org/cro/health/prescription-drugs/best-buy-drugs/index.htm]
- Consumer Report’s Health Rating Center: [http://consumerhealthchoices.org]
- Eric Coleman, MD: Care Transitions Program: [www.caretransitions.org/caregiver_resources.asp]
- Empowered Patient Coalition: [www.empoweredpatientcoalition.org]
- FaithCare: [www.faithcare.net]
- Health Power for Minorities: [www.healthpowerforminorities.com]
- National Patient Safety Foundation: [www.npsf.org]
- Open Notes: [www.myopennotes.org]
- Pew Research Center: [www.pewresearch.org]
- Project Dulce: [www.scripps.org/services/metabolic-conditions__diabetes/why-choose-scripps__project-dulce]
- St. Francis Care, Center for Health Equity: [www.saintfranciscare.com/HealthEquity]
- Urban Institute, Health Policy Center: [www.urban.org/center/hpc]