JUNE 2011

Realizing Health Reform's Potential

Early Implementation of Pre-Existing Condition Insurance Plans: Providing an Interim Safety Net for the Uninsurable

Jean P. Hall and Janice Moore
University of Kansas

The mission of The Commonwealth Fund is to promote a high performance health care system. The Fund carries out this mandate by supporting independent research on health care issues and making grants to improve health care practice and policy. Support for this research was provided by The Commonwealth Fund. The views presented here are those of the authors and not necessarily those of The Commonwealth Fund or its directors, officers, or staff.

For more information about this study, please contact:

Jean P. Hall, Ph.D.
Associate Research Professor
University of Kansas
jhall@ku.edu

To learn more about new publications when they become available, visit the Fund's Web site and register to receive e-mail alerts.

Commonwealth Fund pub. 1509
Vol. 6

Abstract: The Pre-Existing Condition Insurance Plan (PCIP) is a temporary program implemented under the Patient Protection and Affordable Care Act to make health insurance coverage available to uninsured individuals with preexisting conditions until 2014, when exchange-based health insurance becomes available to all. The PCIP program began enrolling applicants in July 2010. This issue brief examines enrollment trends, early changes to plan structures and premiums, and estimates of out-of-pocket costs by utilization pattern and type of plan. It also provides information about the age and medical conditions of early PCIP enrollees. Although PCIP enrollment has been lower than expected due to affordability issues, a lack of public awareness, and the requirement that applicants be uninsured for six months, the plans are nonetheless playing an important role in making coverage available to otherwise uninsurable Americans with preexisting conditions.

★ ★ ★ ★ ★

OVERVIEW

The Pre-Existing Condition Insurance Plan (PCIP) is the national, temporary high-risk pool created by the Patient Protection and Affordable Care Act (Affordable Care Act). The program's purpose is to make health insurance coverage available to uninsured individuals with preexisting conditions until 2014, when insurers will no longer be allowed to deny coverage on the basis of health conditions. The health reform legislation mandated that the PCIP program be implemented within 90 days of passage and gave states the option of administering their own programs or allowing the federal government to do so. Currently, 27 states administer their PCIPs, while 23 states and the District of Columbia have federally administered programs.

The PCIP programs became operational between July 1 and October 25, 2010, with plans in all but two states (Rhode Island and California) becoming operational by September 1 (Exhibit 1). Because of the tight implementation timeline, PCIP coverage and premium structures had to be developed quickly and were often based on plans available through existing, state-based, high-risk pools (see the earlier Commonwealth Fund publication, *Realizing Health Reform's Potential: Pre-Existing Insurance Plans Created by the Affordable Care Act of*

2010).[1] To facilitate the rapid implementation, the U.S. Department of Health and Human Services (HHS) gave states broad latitude to design their programs. Initial PCIP program enrollment was relatively modest, with fewer than 8,000 individuals enrolled nationwide as of November 1, 2010. Now, several months into PCIP implementation, with more program experience and additional time to consider modifications, the federally administered and many state-administered PCIPs have added programmatic options, changed coverage or premium structures, and/or modified eligibility requirements.

EARLY ENROLLMENT IN THE PCIP

Enrollment Levels

Initial enrollment in the PCIP (Exhibit 1) has been lower than expected by the Centers for Medicare and Medicaid Services (CMS), which predicted that as many as 375,000 individuals would enroll in the program's first year.[2] The Congressional Budget Office estimated that, with the $5 billion allocated to the PCIP program nationally, the PCIP might cover 200,000 people annually.[3] However, these projections may not have been realistic. PCIP coverage is modeled in large part on state-based, high-risk pool coverage, and enrollment in these pools historically has been quite low relative to the eligible population.[4] Nevertheless, total PCIP program enrollment has grown steadily, with more than 21,000 people enrolled as of April 30, 2011.[5,6]

Explaining relatively low enrollment. There are many reasons for the relatively low PCIP enrollment. Given the short implementation timeline, PCIP administrators did not have ample resources available to conduct extensive outreach at the outset of the program. In 2011, CMS and states began to promote the PCIP more actively.[7] Several states, such as New York, attribute recent enrollment gains to these outreach efforts. However, as one administrator noted, people with preexisting conditions who have been uninsured for a long time may have stopped looking for insurance and may therefore be harder to reach via traditional outreach campaigns. One strategy to address this issue has been to conduct outreach through hospitals, doctors, and chronic disease organizations. In addition, HHS has arranged to have information about the PCIPs included in mailings to individuals who apply for disability benefits through the Social Security Administration. By definition, these individuals have preexisting conditions and many are likely to be uninsured because they are unable to work. Under current federal law, even if they receive a disability determination, they are required to wait two years before becoming eligible for Medicare coverage. Many large insurers are also including information about the PCIP in rejection letters to applicants, and insurance agents in many states also receive a payment for referral to the PCIP. On May 30, 2011, the Department of Health and Human Services announced that, this fall, agents and brokers in federally administered PCIP states will be paid a $100 fee for each referral that results in a successful enrollment. State-contracted plans that do not already offer such fees will be encouraged to do so.

Another possible limitation on enrollment is the Affordable Care Act's statutory requirement that an individual be uninsured for the six months prior to applying for PCIP coverage. Individuals with preexisting conditions not meeting this requirement may choose to enroll in state-based, high-risk pools that do not have this requirement, or they may find other coverage that excludes treatment of their preexisting conditions (i.e., a policy with a rider).

Still another reason for relatively low enrollment may be that the PCIP is unaffordable for many people. Because the PCIP coverage is based on the individual insurance market, premiums and out-of-pocket costs are generally higher than for people enrolled in group insurance plans. On the other hand, market-rate premiums for the PCIP are likely much less than the risk-rated premiums a person with a preexisting condition would be charged in the individual market, were they able to find a carrier who would offer such coverage. Nevertheless, PCIP coverage at standard risk rates is still beyond the means of many of the uninsured, who are predominantly people with lower incomes. Recent research found that almost 80 percent of people with high-cost chronic conditions who were without insurance over a long-term period had incomes of less than 400 percent of federal poverty level, which is equivalent to $43,560 for an individual.[8] While these individuals will qualify for premium and cost-sharing tax credits through the health insurance exchanges in 2014, the bridge coverage provided by the PCIP does not include direct subsidies for beneficiaries. Estimates of possible out-of-pocket costs for individuals enrolled in different PCIPs are provided below (Exhibits 4 and 5) and indicate that PCIP coverage would consume a large percentage of income for people in lower income brackets.

Finally, lower than anticipated enrollment may be, at least in part, because of misconceptions about the health reform law. In late 2010, for example, many heated election campaigns were declaring that health reform would soon be repealed and/or replaced, or at least de-funded. In early 2011, the U.S. House of Representatives voted to repeal the legislation. Although the PCIPs remain funded and operational, a large portion of the American public may not be aware of this fact. Indeed, a February 2011 poll by the Kaiser Family Foundation found that almost one-quarter of the American public believed that the Affordable Care Act had been repealed, while another quarter did not know the status of the law.[9]

Enrollment Trends

State by state enrollment trends are influenced by many variables, including the baseline individual insurance market (e.g., cost and number of carriers operating in the state), availability of public insurance (Medicaid and other state programs), the percentage of the population that is uninsured, affordability of PCIP coverage, and effectiveness of PCIP outreach to potential enrollees. For example, in Pennsylvania, which has one of the highest PCIP enrollments, the state had something of a captive market in the form of a waiting list of more than 400,000 people for a state-funded health insurance program. In combination with the low, flat premiums in the state and an aggressive marketing campaign, PCIP enrollment has been robust. Conversely, Massachusetts and Vermont, two states with little or no PCIP enrollment, had guaranteed issue legislation (i.e., laws that prohibit denial of coverage based on a preexisting condition) in place at the start of the program. Massachusetts also has an individual mandate to have insurance coverage and a purchasing exchange with income-based subsidies.

Enrollment in the federally administered PCIP grew much more quickly relative to the state-administered plans in early in 2011, when multiple changes to the program took effect (Exhibit 1). These changes included an almost 20 percent reduction in premiums for the original plan and the addition of two new coverage options. Overall, both the state and federally administered plans showed consistent growth, collectively more than doubling enrollment between November 2010 and April 2011. These changes do not reflect the effects of a recently announced plan to further lower premiums for 18 of the 24 federally administered programs.[10]

Exhibit 1. Early PCIP Enrollment Levels[c]

State	Date coverage for enrollees began in 2010	Reported enrollment 11/1/2010	Reported enrollment 2/1/2011[a]	Reported enrollment 4/30/2011
Alabama	1-Aug	33	61	91
Alaska	1-Sep	12	20	34
Arizona	1-Aug	112	270	457
Arkansas	1-Sep	127	147	226
California	25-Oct	513	706	1858
Colorado	1-Sep	368	434	699
Connecticut	1-Sep	12	22	42
Delaware	1-Aug	13	34	54
District of Columbia	1-Oct	0	10	21
Florida	1-Aug	293	613	925
Georgia	1-Aug	161	399	608
Hawaii	1-Aug	11	23	27
Idaho	1-Aug	19	42	47
Illinois	1-Sep	664	943	1261
Indiana	1-Aug	63	131	201
Iowa	1-Sep	56	80	143
Kansas	1-Aug	81	112	177
Kentucky	1-Aug	23	56	93
Louisiana	1-Aug	31	92	137
Maine	1-Aug	13	13	14
Maryland	1-Sep	62	145	348
Massachusetts[b]	1-Aug	0	0	1
Michigan	1-Oct	36	89	225
Minnesota	1-Aug	15	29	49
Mississippi	1-Aug	19	58	75
Missouri	15-Aug	101	166	322
Montana	1-Aug	149	153	214
Nebraska	1-Aug	12	39	61

CHANGES TO PREMIUMS, PLAN STRUCTURES, AND PROOF OF PREEXISTING CONDITION

With the immediate challenges of implementation behind them by October 2010 and several months of experience to build on, PCIP program administrators had time to consider changes to their premiums, plan structures, and eligibility rules for 2011. These changes included increased affordability of coverage for some age groups, more first-dollar services, and increased outreach through agent referral fees and distribution of PCIP information by commercial insurers. Taken together, these changes will likely help to increase program enrollment in 2011.

Significant revisions to the federally administered program for 2011 were announced in November 2010 and again in May 2011.[11] Initial plan adjustments, which took effect in January 2011, included a reduction in premiums by approximately 20 percent; the creation of a child-only premium; and the addition of two plan structures, one with a lower overall deductible and both with lower deductibles for drugs. Subsequent plan adjustments, to become effective July 1, 2011, lowered premiums another 2 percent to 40 percent in 18 federally administered programs, simplified the procedure for proving the existence of a preexisting condition, and provided agent/broker compensation for referrals. Officials also announced plans to work more closely with commercial insurers to notify people about the PCIP when an application for health insurance is denied.

To date, state-administered PCIP programs have also implemented many changes to coverage, premiums, and eligibility requirements in 2011 (Exhibit

Exhibit 1. Early PCIP Enrollment Levels[c] (continued)

State	Date coverage for enrollees began in 2010	Reported enrollment 11/1/2010	Reported enrollment 2/1/2011[a]	Reported enrollment 4/30/2011
Nevada	1-Aug	56	125	181
New Hampshire	1-Jul	43	78	148
New Jersey	15-Aug	108	216	507
New Mexico	1-Aug	133	198	354
New York	1-Oct	201	411	1075
North Carolina	1-Aug	513	674	1302
North Dakota	1-Aug	1	5	9
Ohio	1-Sep	634	726	1145
Oklahoma	1-Sep	148	190	291
Oregon	1-Aug	340	483	822
Pennsylvania	1-Oct	1657	2046	3191
Rhode Island	15-Sep	78	85	115
South Carolina	1-Aug	104	242	377
South Dakota	15-Jul	43	62	94
Tennessee	1-Aug	43	171	314
Texas	1-Aug	393	1007	1528
Utah	1-Sep	73	117	286
Vermont[b]	1-Sep	0	0	0
Virginia	1-Aug	75	204	320
Washington	1-Sep	75	139	341
West Virginia	1-Sep	4	15	24
Wisconsin	1-Aug	248	307	547
Wyoming	1-Aug	17	49	73
Total		7,986	12,437	21,454

Notes: [a] Enrollment in the federally administered program is shown as of Feb. 1, 2011, while enrollment in the state-administered programs is reported as of Dec. 31, 2010.
[b] Massachusetts and Vermont are guaranteed issue states that have already implemented many of the broader market reforms included in the Affordable Care Act that take effect in 2014. Existing commercial plans offering guaranteed coverage at premiums comparable to PCIP are already available in both states.
[c] Shaded states have a federally administered PCIP.
Source: U.S. Department of Health & Human Services. See: http://www.healthcare.gov/news/factsheets/pcip06102011a.html.

2). PCIP regulations dictate that premiums not exceed the standard risk rate (SRR) for the state or area in which the PCIP operates; most states initially set premiums at these rates. The adjustments for 2011 reflect state responses to local changes in SRR or recalculation of these rates. HHS is encouraging states to continue monitoring local risk rates, as well as using multiple strategies for calculating SRR, in case further adjustments might be possible.

Also in January 2011, many states decreased rates for children who were enrolled individually, as did the federally administered plan. This latter modification was in response to the fact that insurance companies in many states have stopped issuing child-only policies, making it difficult for parents to find affordable coverage for their children with preexisting conditions.[12]

Four states—Illinois, Michigan, Missouri, and New Jersey—added new plan options to their PCIP programs. These additions represent an effort to balance the affordability of premiums with out-of-pocket costs in the form of deductibles and coinsurance (i.e., some created plans with lower premiums but with higher deductibles and/or plans with lower deductibles but higher premiums.) Some states also made preventive services available with no cost-sharing, even though the Affordable Care Act's requirement to cover preventive services at no cost to enrollees does not apply to PCIP programs.

Exhibit 2. Summary of Plan Structures and Changes to Premium and Benefit Design

State[a]	Medical deductible, in-network ($)	Monthly premium, 50-year-old nonsmoker	Premium changes	Other changes
Federally administered states	$1,000 2,000 2,500	$288–559 214–416 222–432	(Jan. 2011) Premium for plan with $2,500 medical deductible reduced across all ages (July 2011) Premiums in 18 states reduced again	(Jan. 2011) Added child-only rate band (fixed premium for ages 0–18) Added two new plans with lower deductibles: one with $1,000 medical deductible and $250 prescription deductible, and the other with $2,000 medical deductible and $500 prescription deductible (July 2011) Will accept letter from medical provider as certification of preexisting condition Will begin working with commercial insurers to provide PCIP information to those denied individual coverage (Fall 2011) Will begin paying agents/brokers $100 referral fee per successful PCIP enrollment
Alaska	1,500	1,048	Increased premiums for all ages	Added child-only rate band (ages 0–18).
Arkansas	1,000	395	Decreased premiums for children (ages 0–18)	Added rate bands for children (ages 0–18) and young adults (ages 19–29) Changed oldest rate band from ages 60–64 to 60 and above
California	1,500	445–499	Decreased rates for children between the ages of 15 and 18 and adults age 60 and above	Added a child-only (ages 0–18) rate band that effectively lowered rates for children between ages 15 and 18
Colorado	2,500	377–428	Decreased premiums for adults age 60 and above; increased premiums for all other ages.	Added rate band for age 65 and above.
Connecticut	1,250	507	No change	Added a provision to ensure mental health parity
Illinois	1,000 2,000	292–391 253–338	Decreased premiums for children (ages 0–18)	Added $1,000 deductible plan Added child-only rate band (ages 0–18) Added preventive services with no cost-sharing Added a $50 referral fee for insurance brokers
Iowa	1,000	398	Decreased premiums for children (ages 0–18); increased premiums for other ages	Split rate band for children and young adults (ages 0–19) into 3 bands: ages 0–17, 18, and 19
Kansas	2,500	349–417	Increased premiums for all ages	Added preventive services at no charge
Maine	1,750 2,500	609–657 609–658	No change	Expanded list of eligible medical conditions
Maryland	1,500	274	No change	
Michigan	1,000 2,500 3,500	447 322 270	Increased premiums for children (ages 0–18)	Added plans with $2,500 and $3,500 deductible
Missouri	1,000 2,500 5,000	544 501 498	Decreased premiums for all ages	Added plans with $2,500 and $5,000 deductible; the latter is high-deductible health plan that is eligible for health savings account
Montana	2,500	434	Increased premiums for all ages	Reduced number of required denials of coverage from two to one

State[a]	Medical deductible, in-network ($)	Monthly premium, 50-year-old nonsmoker	Premium changes	Other changes
New Hampshire	1,000 2,000 2,500	493 670 396	Decreased premiums for all ages	Increased deductible for indemnity plan from $1,750 to $2,000 Eliminated annual and lifetime limits Expanded the list of eligible medical conditions Allowed third-party payers (payment of premium by parties other than beneficiary) Began accepting agent attestation of uninsurability in lieu of denial letter Added a $50 referral fee for insurance agents
New Jersey	0 2,500 2,500	531 419 396	Increased premiums for all ages	Added second $2,500-deductible plan with higher premium and lower (10%) coinsurance
New Mexico	500 1,000 2,000	465 417 374	Increased premiums for all ages	
New York	0	362 or 421	No change	
North Carolina	1,000 2,500 3,500 4,500	430 315 285 235	Decreased premiums for all ages	
Ohio	1,500 2,500	323–378 294–344	No change	
Oklahoma	2,000	327	Decreased premiums for children (ages 0–18)	Added child-only rate band (ages 0–18) Expanded list of eligible medical conditions
Oregon	500 750	649 611	Increased premiums for all ages	Increased out-of-pocket limits for $500 deductible plan from $1,000 to $1,500 for in-network services and from $2,000 to $3,000 for out-of-network services Increased emergency department copay from $100 to $200 Eliminated deductible carryover Removed cost-sharing from preventive services Adjusted limits on some benefits
Pennsylvania	1,000	283	No change	
Rhode Island	1,000	439	No change	
South Dakota	2,000	456	No change	
Utah	500 1,000 2,500 5,000	508 431 331 240	No change	
Washington	500 2,500	1,022 514	Increased premiums for all ages	
Wisconsin	500 1,000 2,500 3,500	559 458 330 277	Decreased premiums for children (ages 0–18)	Added child-only rate band (ages 0–18) Waived cost-sharing for preventive services Added provision for mental health parity

[a]Federally administered PCIP programs operate in Alabama, Arizona, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Minnesota, Mississippi, North Dakota, Nebraska, Nevada, South Carolina, Tennessee, Texas, Virginia, Vermont, West Virginia, and Wyoming.

Changes in Requirements for Proof of Preexisting Condition

Another area of change for the PCIP involved providing more options for consumers to prove the presence of a preexisting condition (Exhibit 3). Having a preexisting condition is a requirement for participation in a PCIP, but PCIP regulations provide flexibility in how programs verify this requirement. Initially, the federally administered program and many states required proof of denial of coverage by an insurer or proof of being offered coverage with a rider or exclusion for the preexisting condition. However, based on some accounts of individuals having difficulty obtaining these letters, the federally administered program changed eligibility rules to allow agent attestation of uninsurability in lieu of denial letters (Exhibit 3). As of July 1, the federal plans also will begin accepting a letter from a medical provider (doctor, physician assistant, or nurse practitioner) dated within the past 12 months certifying a condition that is present or has been present any time in the past. This option, which became available in February 2011 for children under age 19, will now apply to all applicants regardless of age.

The great majority of state-administered PCIP programs accept letters of denial or letters of offers of coverage with a rider or exclusion for the preexisting condition as proof of having a preexisting condition. Alternatively, most states also allow documentation of having a specific condition on a condition list as a means of proving eligibility. Like the federally administered program, some states recently provided more options for consumers to prove the presence of a preexisting condition. These changes included decreasing the number of denial or rider letters required, adding more conditions to their qualifying conditions list, or allowing provider or agent attestation. Finally, in some states, applicants who can show that they have been offered coverage with a premium above some threshold because of their preexisting condition are also considered eligible.

OUT-OF-POCKET COSTS

Discussion of health insurance affordability tends to focus primarily on premiums. However, the ultimate cost of benefits depends on a multilayered structure that includes deductibles, coinsurance and/or copayments, service limitations, in-network and out-of-network reimbursement rates, and in-network and out-of-network out-of-pocket limits. Variation in plan structures makes estimation of the total cost of coverage and plan comparisons difficult. For example, some programs have chosen to use copays as the cost-sharing mechanism while others use coinsurance, and still others use both. Because copays are a fixed amount, they are potentially easier to predict and budget for, while coinsurance is a percentage of total charges and is therefore variable and less predictable.

Another issue affecting out-of-pocket costs is the breadth of the provider network and the availability of reimbursement for out-of-network providers. In several state plans, including Colorado, New Jersey, and New York, all covered care must be obtained from in-network providers, except in emergencies or when preauthorized because no in-network provider exists. In such states, enrollees would pay the full cost of out-of-network services.

Difficulties in estimating costs also arise for plans that limit the number of covered visits for some services. Most plans limit at least some services, such as psychotherapy; physical, occupational, and speech therapies; chiropractic treatments; home health visits; hospice care; cardiac or pulmonary rehabilitation; and skilled nursing. Enrollees using these services beyond the allowed number will incur costs that often do not count toward the out-of-pocket cap.

Virtually all PCIP programs use prescription formularies, which may limit access to some medications or result in additional out-of-pocket costs. While formularies are a standard cost-control practice in most insurance programs, they can complicate the task of estimating costs, especially when specialized needs may be unanticipated.

Although, for these reasons, it is impossible to project out-of-pocket costs with complete accuracy, models are presented below to illustrate the cost of basic coverage at varying levels of utilization in a variety of states with differing plan structures and in the federally administered plan (Exhibits 4 and 5). The premiums cited are those for a hypothetical 50-year-old who does not smoke. This age was used for two reasons. First, the median age for PCIP participants in 10 states providing deidentified data for this brief is 48. Second, the prevalence of chronic conditions increases with age, making those 50 and older more likely to have preexisting conditions. In most states PCIP enrollees who are older than 50 will pay higher premiums and those who are younger will pay somewhat less—except in Pennsylvania and New York, which have flat rates. However, the Affordable Care Act limits the ratio of the premium charged to the oldest beneficiary to no more than four times that charged to the youngest. This ratio is a ceiling, and in many states and the federal plan the ratio is actually less.

The selected plans have a range of premiums, deductibles, coinsurance percentages, and out-of-pocket limits, as well as copay structures. Cost estimates are provided for five levels of annual medical claims: $2,000, $5,000, $10,000, $20,000, and $50,000 or more. The latter is included to demonstrate the maximum cost for those with very high medical needs. All scenarios assume that enrollees will only use in-network services. Because of higher copays and/or coinsurance and out-of-pocket limits for non-network providers, costs would increase accordingly for any out-of-network services. For plans with copays that are used in lieu of deductibles and coinsurance (e.g., New York), the cost estimates assume 12 office visits, 12 prescription copays, and/or at least one copay for an outpatient procedure. For the most high-cost scenario (annual claims of $50,000 or more), the estimate also includes two hospitalizations.

Federally Administered Plans

Premium estimates for the federally administered plans are based on simple averages of the premium for a 50-year-old in the 23 federally administered states and the District of Columbia (Exhibit 4). These premiums range from $289.08 per month for the standard option, which has a $2,000 deductible for medical expenses and a $500 deductible for prescriptions, to $388.96 per month for the extended option, which has a $1,000 deductible for medical expenses and a $250 one for prescriptions. Premiums for the high-deductible health plan (HDHP), which has a combined $2,500 deductible for medical and prescription expenses, average $300.29 per month. The HDHP offers no benefits prior to the deductible—except for preventive services—because the Internal Revenue Code does not allow HSA-eligible plans to do so. All three of the plan types represented in Exhibit 4 provide 100 percent coverage for preventive care upon enrollment.

Coinsurance for federally administered plans, as well as for most state-administered plans, is 20 percent; total out-of-pocket expenses, which do not include premiums, are capped at $5,950 for in-network services ($7,000 out-of-network). Exhibit 4 itemizes the total

Update to the Federally Administered PCIP Program

On May 31, 2011, the Department of Health and Human Services (HHS) made an announcement about several changes to the federally administered PCIP program. These changes include:

1. Premium reductions of up to 40 percent in 18 of the 24 plans, effective July 1 (premiums in Hawaii, Idaho, Massachusetts, North Dakota, Vermont, and Wyoming did not change).
2. The option to use a letter from a provider as proof of eligibility (this option was allowed for children previously), effective July 1.
3. Payments to agents and brokers for successfully referring eligible people to the PCIP, starting in the fall.
4. Efforts to have insurers provide information about the PCIP to people who are denied commercial coverage.

HHS believes these changes will make enrolling in the PCIP program easier for Americans with pre-existing conditions.

Exhibit 3. Proof of Eligibility for Pre-Existing Condition Insurance Plan (PCIP)

State	Criteria for Establishing a Preexisting Medical Condition[a]				
	Received letter of denial within designated timeframe[b]	Received letter of rider / exclusion within designated timeframe[b]	Medical condition on eligibility list[c]	Premium offered exceeded minimum threshold	Other possible criteria
Federally administered plans	X 12 mos.	X 12 mos.	—	For children younger than 19 and/ or residents of MA or VT: individual premium offered with preexisting medical condition in last year must meet or exceed 200% of premium for the state's standard option plan	Agent attestation of uninsurability; for children younger than 19 only, provider documentation of preexisting condition Starting July 1, provider documentation of condition within last 12 months (for all ages)
Alaska	X	X	X Physician letter	—	—
Arkansas	X 6 mos.	X 6 mos.	X For applicants under 19 only, with physician statement	For applicants under 19 only, premium offered must be at least twice that of state's PCIP	—
California	X 12 mos.	—	—	Offered premium that exceeds PPO rate for the state's high-risk pool	—
Colorado	X 6 mos.	X 6 mos.	X Physician letter	—	—
Connecticut	X 6 mos.	X 6 mos.	X Physician or hospital letter	—	—
Illinois	X 24 mos.	X 24 mos.	X Physician letter 24 mos.	Premium offered in past 24 months was at least 125% of standard rate	Physician statement confirming presence of preexisting condition
Iowa	X	X	X Physician letter	—	—
Kansas	X	X	X Physician letter	—	Statement from practitioner verifying presence of preexisting condition meeting internal criteria
Maine	—	—	X Physician letter	—	—
Maryland	X 6 mos.	X	X	Offered premiums that exceeded PCIP rates	—
Michigan	X 6 mos.	X	X Physician letter	—	—
Missouri	X	X	—	—	Provider letter
Montana	X 6 mos.	X	X Medical claim with ICD code or physician letter	—	—
New Hampshire	X	X	X	—	Agent attestation

State	Criteria for Establishing a Preexisting Medical Condition[a]				
	Received letter of denial within designated timeframe[b]	Received letter of rider / exclusion within designated timeframe[b]	Medical condition on eligibility list[c]	Premium offered exceeded minimum threshold	Other possible criteria
New Jersey	—	—	—	—	Documentation of a medical condition from a provider
New Mexico	X	X	X Either a letter from a physician or nurse practitioner or evidence from medical records	Offered premiums that exceeded 125% of NM's standard risk rates	In Eddy and Lea counties, children under 19 only, documentation within the past 6 months from a physician indicating preexisting medical condition
New York	—	—	X Either a letter from a physician or evidence from medical records or an online personal health record	—	Subject to medical review, any other condition verified by doctor
North Carolina	X	X	X	—	—
Ohio	X From 2 carriers within 6 mos.	X From 2 carriers within 6 mos.	X Letter from a physician or nurse practitioner letter within 6 mos.	—	Provider certification of other condition
Oklahoma	X	X	X	—	Children under 19 only offered coverage with premiums > 125% of standard risk rate
Oregon	X	X	X Physician attestation	—	—
Pennsylvania	X	X	X Either a letter from a physician or evidence from medical records		—
Rhode Island	—	—	X	—	—
South Dakota	X	X	X Medical documentation	—	—
Utah	—	—	—	—	Meets the required health underwriting criteria established by the state of Utah, i.e., has one or more condition that would likely result in a denial of coverage
Washington	X	X	X Physician letter	—	Other conditions considered
Wisconsin	X 9 mos.	X 9 mos.	HIV only	Offered coverage at a premium that meets or exceeds 150% of standard risk rates	—

Notes: [a] An "X" indicates an acceptable form of evidence for PCIP eligibility; unless otherwise noted, only one of the acceptable forms of evidence is required for eligibility. [b] Some states impose a time limit on letter or exclusion documentation. [c] Establishing a medical condition on a state list may require a letter from a physician or provider or another form of attestation as noted above.

cost for the five levels of utilization. These scenarios assume that enrollees will meet both the prescription and medical deductible and incur some coinsurance costs, except when utilization is less than the deductible. Coinsurance is capped when it would exceed total out-of-pocket limits if combined with deductibles.

As Exhibit 4 illustrates, total costs, including premiums, vary significantly. An individual who is covered by the standard-option plan and has $2,000 in annual claims would pay $5,469, while an enrollee in the extended-option plan who has $50,000 in annual claims would pay $10,618. Coinsurance is capped at $3,450 in the standard-option and HDHP plans, the amount at which the $5,950 out-of-pocket cap would be reached. The extended-option plan has lower deductibles, and thus coinsurance might be as much as $4,700 before the cap is reached. Another way to look at the burden associated with total costs is as a percentage of family income. Given the scenarios presented in Exhibit 4, a family with the U.S. median annual income of approximately $50,000 would pay between 11 percent and 21 percent of annual income for coverage of one family member.[13]

State-Administered Plans

Cost estimates for several state-administered plans are presented in Exhibit 5. These scenarios do not represent all of the plans available in state-run PCIP

Exhibit 4. Potential Annual Costs by Plan Type for Federally Administered PCIP Enrollees, Age 50 with an Annual Income of $50,000

	Level of Medical Claims Utilization				
Plan Type and Costs[a]	**$50,000+**	**$20,000**	**$10,000**	**$5,000**	**$2,000**
Standard Option					
Premium ($298.08 per month)[b]	3,469	3,469	3,469	3,469	3,469
Medical deductible	2,000	2,000	2,000	2,000	1,500
20% coinsurance on medical claims	3,450[c]	3,450[c]	1,500	500	0
Prescription deductible	500	500	500	500	500
Total out-of-pocket expense	5,950	5,950	4,000	3,000	2,000
Total costs with premium	**$9,419**	**$9,419**	**$7,469**	**$6,469**	**$5,469**
Total costs as percent of annual income	**19%**	**19%**	**15%**	**13%**	**11%**
Extended Option					
Premium ($388.96 per month)[b]	4,668	4,668	4,668	4,668	4,668
Medical deductible	1,000	1,000	1,000	1,000	1,000
Prescription deductible	250	250	250	250	250
20% coinsurance on medical claims	4,700[c]	3,750	1,750	750	150
Total out-of-pocket expense	5,950	5,000	3,000	2,000	1,400
Total costs with premium	**$10,618**	**$9,668**	**$7,669**	**$6,668**	**$6,068**
Total costs as percent of annual income	**21%**	**19%**	**15%**	**13%**	**12%**
Health Savings Account Option					
Premium $300.29 per month)[b]	3,604	3,604	3,604	3,604	3,604
Medical deductible	2,500	2,500	2,500	2,500	2,000
Prescription deductible	NA	NA	NA	NA	NA
20% coinsurance on medical claims	3,450[c]	3,450[c]	1,500	500	0
Total out-of-pocket expense	5,950	5,950	4,000	3,000	2,000
Total costs with premium	**$9,554**	**$9,554**	**$7,604**	**$6,604**	**$5,604**
Total costs as percent of annual income	**19%**	**19%**	**15%**	**13%**	**11%**

[a]Premiums as of July 1, 2011; does not include potential out-of-pocket costs for out-of-network services.
[b]Premium is calculated as a simple average of 24 participating program premiums.
[c]Coinsurance is reduced because out-of-pocket expenses are capped.

programs, but have been selected as illustrations of the range of plan types and costs that exists. The scenarios presented include one state plan from each coast and two from the central region of the U.S.

Under these scenarios, premiums for a 50-year-old nonsmoker range from $288.75 per month in Illinois (a simple average of the state's regional rates) for a policy that has a $2,000 deductible for combined medical and prescription expenses to $1,022 per month in Washington State for a plan with a $500 deductible for medical expenses but no prescription deductible. Washington State's plan has a low maximum out-of-pocket limit ($1,000 medical, $500 prescriptions), resulting in a low out-of-pocket cost once the premium is paid. However, it has a high premium, and thus the total cost of the plan would be $13,564 to $13,764, or 27 percent to 28 percent of a $50,000 annual income. Prescription estimates for the Washington State plans are capped at $500 in this scenario because the cost of brand-name prescriptions (10% coinsurance, maximum $50) is variable, and the maximum an individual might pay for 12 prescriptions could exceed the annual out-of-pocket prescription cap. On the other hand, generic drugs have a copay of $10 per prescription, so considerably more generic prescriptions could be purchased within the out-of-pocket limit.

Illinois and Kansas are shown not only because they represent typical premiums in the central U.S., but also because both states reimburse claims on a straight coinsurance basis, with no copays, leading to a simpler illustration. Both states have rates that vary by region and depending on tobacco use and both states calculate a separate premium for each year of age. They also combine medical and prescription deductibles into one. However, Kansas has 30 percent coinsurance compared with 20 percent in Illinois, leading to slightly higher overall costs. Estimated total costs in Illinois range from $5,465 for $2,000 of annual claims to $9,415 for claims of $50,000 or more, or 11 percent to 19 percent of an annual $50,000 income. In Kansas, costs range from $6,499 to $10,449, or 13 percent to 21 percent of a $50,000 income.

The plan scenario for the final state, New York, has the potential to be the least expensive because it combines a moderate premium with a flat copay structure. New York premiums are $362 for individuals who live in upstate counties and $421 for those who live in downstate counties, with no age differential. In the example shown in Exhibit 5, these rates are averaged to $391.50 per month. New York is the only PCIP with no deductible or coinsurance and all cost-sharing through modest copayments per service. For example, the coinsurance for hospitalization is only $500 per episode and for ambulatory surgery, $250 per episode. Office visits are $20 and brand-name prescriptions are $10 each. No copays are required for diagnostic radiology, laboratory services, or for generic prescriptions, and one eye exam per two-year period is fully covered. Given these low copays, the total out-of-pocket cost limit of $5,950 could potentially purchase a large volume of services.

New York's plan structure limits comparability to other states where the cost to beneficiaries of $50,000 in services is far greater because of coinsurance requirements. However, New York's program shows that out-of-pocket costs for the hypothetical numbers of 12 office visits, 12 brand-name prescription drugs, and one outpatient surgery would be very low. With premiums included, total plan costs would be just over $5,000, or 10 percent to 11 percent of an annual $50,000 income. With two inpatient admissions, costs would climb to slightly over $6,000. The main limitation of the New York plan is that only in-network services are covered, although out-of-network providers practicing within in-network facilities or offices are covered up to submitted charges, with no added cost to the enrollee. This situation often occurs when a physician other than the patient's primary care physician becomes involved in emergency care during a hospitalization.

The purpose of the illustrations presented in Exhibits 4 and 5 is to demonstrate the variability of PCIP programs among states and the resulting variation in total cost for a hypothetical consumer. In practice, consumers must purchase policies in the state in

Exhibit 5. Potential Annual Costs by Plan Type for Selected State-Administered PCIP Enrollees, Age 50 with an Annual Income of $50,000

	Level of Medical Claims Utilization				
Plan Type and Costs[a]	**$50,000+**	**$20,000**	**$10,000**	**$5,000**	**$2,000**
Washington					
Premium ($1,022 per month)	$12,264	$12,264	$12,264	$12,264	$12,264
Medical deductible	500	500	500	500	500
20% coinsurance medical claims	500[b,c]	500[b,c]	500[b,c]	500[b,c]	300
Total out-of-pocket costs	1,000	1,000	1,000	1,000	800
Prescriptions, 12 @ $50 (max)	500[b,c]	500[b,c]	500[b,c]	500[b,c]	500[b,c]
Total costs with premium	$13,764	$13,764	$13,764	$13,764	$13,564
Total costs as percent of annual income	28%	28%	28%	28%	27%
Illinois					
Premium ($288.75 per month)[d]	$3,465	$3,465	$3,465	$3,465	$3,465
Combined medical-pharmacy deductible	2,000	2,000	2,000	2,000	2,000
20% coinsurance medical and prescription claims	3,950[b]	3,600	1,600	600	0
Total out-of-pocket costs	5,950	5,600	3,600	2,600	2,000
Total costs with premium	$9,415	$9,065	$7,065	$6,065	$5,465
Total costs as percent of annual income	19%	18%	14%	12%	11%
Kansas					
Premium ($374.88 per month)[d]	$4,499	$4,499	$4,499	$4,499	$4,499
Combined medical-pharmacy deductible	2,500	2,500	2,500	2,500	2,000
30% coinsurance medical and prescription claims	3,450[b]	3,450[b]	2,250	750	0
Total out-of-pocket costs	5,950	5,950	4,750	3,250	2,000
Total costs with premium	$10,449	$10,449	$9,249	$7,749	$6,499
Total costs as percent of annual income	21%	21%	18%	15%	13%
New York					
Premium ($391.50 per month)[d]	$4,698	$4,698	$4,698	$4,698	$4,698
Combined medical-pharmacy deductible	NA	NA	NA	NA	NA
Coinsurance on medical and prescription claims	NA	NA	NA	NA	NA
Office visit copays (12 visits @$20 each)	240	240	240	240	240
Prescription copays (12 name brand prescriptions @ $10 each)	120	120	120	120	120
Outpatient procedure copay (1 procedure @ $250 each)	250	250	250	NA	NA
Inpatient admission copays (2 @ $500 each)	$1,000	NA	NA	NA	NA
Total out-of-pocket costs	$1,610	610	610	360	360
Total costs with premium	$6,308	$5,308	$5,308	$5,058	$5,058
Total costs as a percent of annual income	13%	11%	11%	10%	10%

Notes: [a]Does not include potential out-of-pocket costs for services used out-of-network. Premiums are based on rates for nonsmokers, where applicable. [b]Coinsurance is reduced because out-of-pocket expenses are capped. [c]The $500-deductible Washington plan has a $1,000 medical and $500 prescription out-of-pocket limit. dPremiums are calculated as a simple average of plan-defined regions in the state.

which they live, and for most PCIP beneficiaries the choice is limited to different levels of premium and deductible or different types of plan design (i.e., a preferred provider organization or HDHP). When the Affordable Care Act is fully implemented in 2014, the design of plans in the health insurance exchanges may become more standardized and states may offer tools to help consumers compare costs between companies and differing levels of coverage. However, because insurance products are inherently complex, choosing the best fit is likely to remain challenging.

A PRELIMINARY SNAPSHOT OF PCIP ENROLLEES

Demographics

Deidentified eligibility and medical claims data for early PCIP enrollees in 10 state-administered plans were obtained to examine their demographics and types of chronic health conditions. Exhibit 6 shows the states from which information was obtained and provides an overview of participants enrolled through December 31, 2010. (California enrollments are through January 31, 2011, because the program did not begin until late October.)

For the demographic information, only individuals who remained enrolled for at least one full month were tallied. As expected, enrollees tend to be relatively older, with a median age of 48 and a mode

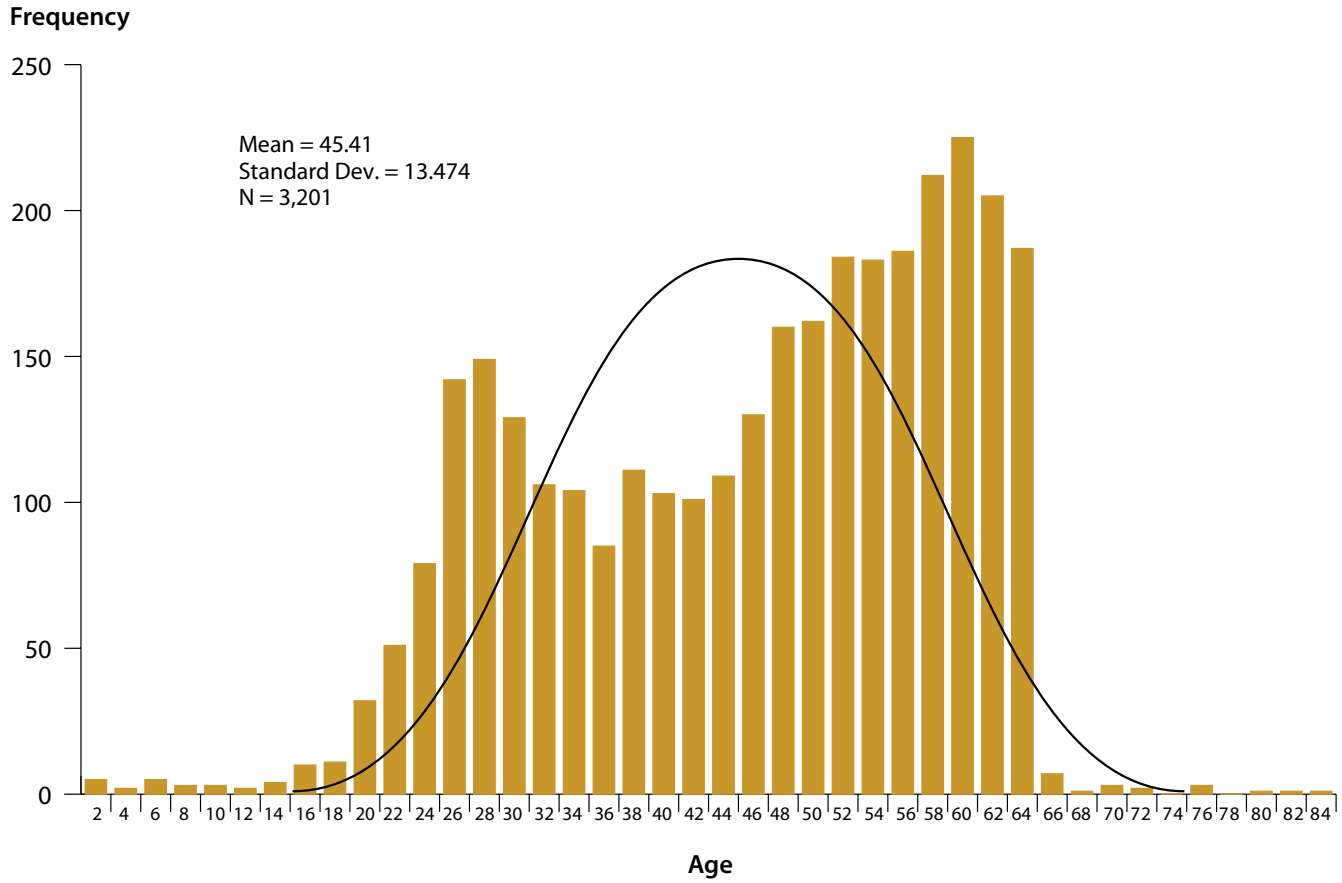
Exhibit 6. Demographics of 10 States' PCIP Enrollees

	N	Percent of Sample
Enrollment by state [a, b]		
Alaska	21	0.7
California	1,017	31.8
Iowa	86	2.7
Montana	162	5.1
New Hampshire	82	2.6
North Carolina	697	21.8
Oklahoma	195	6.1
Oregon	506	15.8
Utah	121	3.8
Wisconsin	314	9.8
Total	3,201	100.0
Eligibility for enrollment		
Denial of coverage	1,918	59.9
Rider	710	22.2
Excessive premium[c]	2	0.1
Condition from list	571	17.8
PCIP utilization [a,d]	2,033	63.5

	N	Percent of Sample
Gender		
Female	1,723	53.8
Male	1,478	46.2
Age distribution		
0-18	45	1.4
19-29	528	16.5
30-39	504	15.7
40-49	642	20.1
50-59	962	30.1
60-64	499	15.6
65+	21	0.7
Reason for disenrollment		
Voluntary	57	1.8
Death	9	0.3
Non-payment of premium	111	3.5
Other creditable coverage	8	0.2
No longer state resident	0	0
Misrepresentation/fraud	0	0
Total	185	5.8

Note: [a]Represents the period from July through December, 2010 except for California, where the enrollment period is Oct. 25, 2011 through Jan. 31, 2011. [b]Excludes those enrolled less than one month and newborns insured in the first month of life. [c]For these states, this eligibility code is only applicable in Wisconsin, California, and for children under 18 in Oklahoma. [d]Does not include beneficiaries with prescription claims only.

Exhibit 7. Histogram of 10 States' PCIP Enrollees by Age



of 63, with enrollment highest among those ages 50 to 64 (Exhibit 7). Enrollment also spikes at age 26, presumably because young adults are no longer covered by their parents' policies and/or are in early career jobs that do not provide health insurance coverage. Women make up slightly more than half of the enrollees. Individuals more often qualified for the program on the basis of having been denied coverage or having been offered coverage with a rider, but a substantial number of individuals also were eligible by virtue of having a condition on the state's eligible medical condition list. Six percent of the sample has disenrolled from the programs. Most who leave the PCIP programs do so voluntarily, or through nonpayment of premiums. About 4 percent of those who disenroll indicate they have found other creditable coverage; however, in many cases, a beneficiary simply stops paying premiums and does not notify the carrier of the reason.

Numbers and Types of Medical Conditions

In looking at medical conditions among early enrollees, only individuals who had been enrolled for at least two months and who had at least three medical claims were considered. These rules were used to limit the sample to people likely to have used services beyond an initial visit for preventive services. Using these criteria narrowed the sample size to 1,485 individuals. Nevertheless, approximately 23 percent of the sample had claims only for preventive care, acute care, or for accidents or injuries; these individuals likely have other underlying conditions that were not reflected in the claims they had filed. Others also had prescriptions filled, but prescription claims were not included in the analysis because they generally do not include diagnostic information. Exhibit 8 lists the prevalence of a variety of serious and chronic conditions among this

Exhibit 8. Comorbidities of 10 States' PCIP Enrollees [a]

Condition (ICD-9 Codes)	*N* [b]	Percent of sample
Immune disorders (042, V08, 279, 695.4)	48	3.2
HIV (042, V08)	44	3.0
Cancers (140–65, 170–72, 174–76, 179–208, 209.0–209.3, 230–34, 237.7, 237.8, 511.81, 789.51, V58.0–.12, V66.1–.2)	197	13.3
Endocrine (245.2–.3, 250, 252.01, 253, 255, 275, 277.1–.6, 277.8–.9, 758.7, V45.85, V58.67)	249	16.8
Diabetes (250)	219	14.7
Blood disorders (281.0, 282–90)	142	9.6
Psychiatric disorders (290, 294–301, 309.81, 310–11, V11.0–.1)	218	14.7
Neurological disorders (326, 327.2, 330–37, 340–45, 350–359)	135	9.1
Sensory disorders (360–65, 369, 386–89)	59	4.0
Vision (360–65, 369)	37	2.5
Hearing (386–89)	22	1.5
Cardiovascular disorders (393–98, 402, 410–17, 420–29, 440–53, V43.2–.3, V45.0, V53.3)	228	15.4
Stroke and cerebrovascular disorders (430–38)	41	2.8
Respiratory disorders (491–96, 500–07, 518, V46.1–.2)	140	9.4
Digestive disorders (070, 555–56, 569.6–569.7, V44.1–44.4, V55.1–55.4, 570–73, 577)	117	7.9
Renal disorders (580–86, V44.5–.6, V45.1, V55.5, V56)	36	2.4
Arthropathies (274, 696.0, 710–19, 725)	277	18.7
Dorsopathies (720–24, 731, 737, 738.4–738.6, 741)	219	14.7
Cancer history (V10, 457.0)	49	3.3
Transplant history or need (V42, V49.83, 996.8)	9	0.6
High-risk pregnancy (641, 649, 651, 654.5, 655–57, V23, V91)	34	2.3

Notes: [a] The 10 states represented in this table are Alaska, California, Iowa, Montana, New Hampshire, North Carolina, Oklahoma, Oregon, Utah, and Wisconsin. [b] n = 1,485 enrollees with at least two months enrollment and at least three medical claims.

sample. In addition, 34 high-risk pregnancies were covered for enrollees; infants (not included in enrollment totals) can be covered for up to 60 days on the parent's plan. Note that the prevalence rates reported in the table likely underestimate actual prevalence because the data are from early program experience when enrollees may not have fully understood or utilized their coverage, and claims may not have been fully processed.

Clearly, enrollees experience a large variety of serious medical conditions; especially notable is the high incidence of cancer, diabetes, psychiatric conditions, and cardiovascular disease. The high rates of arthropathies and dorsopathies (joint and back problems) likely reflect the higher percentages of older enrollees in the programs. Many of the conditions experienced by the enrollees have the potential to result in disability or death without adequate medical treatment.[14] While overall enrollment in the PCIPs has perhaps been lower than many expected, the PCIP coverage is clearly of critical importance to many of the people who have enrolled. Arguably, the PCIP coverage has also played a role in preventing some people's conditions from progressing to disability and forcing them to become dependent on federal disability programs (see Appendix: Personal Stories).

CONCLUSION

As a transitional program, the PCIP is playing an important role in making coverage available to otherwise uninsurable Americans with preexisting conditions. Structural elements of the program, including affordability of coverage and the requirement to have been uninsured for six months, are probably barriers to enrollment for many who might otherwise benefit. Nevertheless, increased outreach efforts and additional modifications to plans based on enrollment experience will likely result in continued growth in enrollment. Moreover, for those already enrolled, the PCIP programs are a critical source of bridge coverage until the health insurance exchanges are operational.

An important lesson from examining PCIP programs is the difficulty in comparing costs and coverage across plans in the absence of stricter federal guidelines on plan structure and coverage. The flexibility allowed for PCIP programs was a necessity for meeting the 90-day timeline for implementation, but it should not be a factor in the development of guidelines for the health insurance exchanges. Indeed, uniformity in exchange design will be essential for consumers to make informed decisions about the coverage that will best meet their needs and fit their budgets.

Notes

1 J. P. Hall and J. M. Moore, *Realizing Health Reform's Potential: Pre-Existing Condition Insurance Plans Created by the Affordable Care Act of 2010* (New York: The Commonwealth Fund, Oct. 2010). See: http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2010/Oct/1445_Hall_PCIPs_and_the_ACA_ib_FINAL.pdf.

2 R. Foster, *Estimated Financial Effects of the "Patient Protection and Affordable Care Act of 2009,"* as Proposed by the Senate Majority Leader on November 18, 2009 (Maryland: U.S. Department of Health and Human Services, Dec. 2009). See: https://www.cms.gov/ActuarialStudies/.../S_PPACA_2009-12-10.pdf.

3 Congressional Budget Office, "Letter to Senator Michael B. Enzi," June 21, 2010. See: http://www.cbo.gov/ ftpdocs/115xx/doc11572/06-21-High-Risk_Insurance_Pools.pdf.

4 U.S. Government Accountability Office, *Health Insurance: Enrollment, Benefits, Funding and Other Characteristics of State High-Risk Health Insurance Pools*, GAO–09–730R (Washington, D.C.: GAO, July 22, 2009). See: http://www.gao.gov/new.items/d09730r.pdf.

5 U.S. Department of Health and Human Services, *State by State Enrollment in the Pre-Existing Condition Insurance Plan, as of February 1, 2011*. See: http://www.healthcare.gov/news/factsheets/pcip02102011a.html.

6 U.S. Department of Health and Human Services, *State by State Enrollment in the Pre-Existing Condition Insurance Plan, as of April 30, 2011*. See: http://www.healthcare.gov/news/factsheets/pcip06102011a.html.

7 U.S. Department of Health and Human Services, *Uninsured Americans with Pre-Existing Conditions Continue to Gain Coverage through Affordable Care Act*. See: http://www.hhs.gov/news/press/2011pres/02/20110210a.html.

8 M. Merlis, *Health Coverage for the High-Risk Uninsured: Policy Options for Design of the Temporary High-Risk Pool, No. 2* (Washington, D.C.: National Institute for Health Care Reform, May 2010).

9 The Henry J. Kaiser Family Foundation, *Kaiser Health Tracking Poll*, Feb. 2011. See: http://www.kff.org/kaiserpolls/8156.cfm.

10 U.S. Department of Health and Human Services, "HHS to Reduce Premiums, Make it Easier for Americans with Pre-Existing Conditions to Get Health Insurance" (press release), May 31, 2011.

11 Ibid.

12 N. C. Aizenman, "Major Health Insurers to Stop Offering New Child-Only Policies," *The Washington Post*, Sept. 20, 2010. See: http://www.washington-post.com/wp-dyn/content/article/2010/09/20/AR2010092006665.html.

13 C. DeNavas-Walt, B. D. Proctor, and J. C. Smith, *Income, Poverty, and Health Insurance Coverage in the United States: 2009*, P60-238 (Washington D.C.: U.S. Census Bureau, 2010).

14 J. P. Hall, and J. M. Moore, "Does High Risk Pool Coverage Meet the Needs of a Population at Risk for Disability?" *Inquiry*, Fall 2008 45(3):340–52.

Appendix. Personal Stories

Numerous PCIP administrators have related personal stories told to them by enrollees in their programs, many of which include accounts of receiving life-saving services and treatments. Generally, these stories have been unsolicited. An example includes the following brief excerpt from a much longer letter:

"I can walk today thanks to [the PCIP]. I am a working and productive member of society, rather than a depressed person in a wheelchair."

Similar comments include:

"I applied online, and within 3 days I had been accepted into the [PCIP]. I made an appointment with the cardiologist immediately, and had to have emergency quadruple bypass surgery just 7 weeks after being enrolled. [The PCIP] literally saved my life."

"I tried to get insurance and was told that due to my preexisting condition [history of a brain tumor] they wouldn't be able to cover me. On multiple occasions I was hung up on by insurance companies once they found out I had a brain tumor. I wasn't able to afford MRIs so I stopped getting them and the tumor grew back. I have been unable to work full-time due to the brain tumor, so I can't get covered under group health insurance. I recently finished up chemotherapy and radiation. I needed insurance and now I have it at a very reasonable price due to the [PCIP]."

In contrast, some anecdotal information and media accounts indicate that other people have not been able to enroll in the PCIP due to the program's cost. For example, a comment posted to one of the PCIP Web sites indicated:

"I have 2 of the preexisting conditions listed. My premiums would be a minimum of $301/month with a $4,500 deductible for a nonsmoker. On a monthly income of $800, this is entirely unaffordable."

For those who can afford the coverage though, the PCIP seem to be very much appreciated. When the North Carolina PCIP sent a general query to enrollees asking if any would be interested in helping create informational video clips about the program, some 84 people responded positively. The PCIP programs in some states have also created Facebook pages with numerous "friends" and followers who share stories; these pages also serve as a form of outreach and provide information about the plans and other health reform initiatives.

About the Authors

Jean P. Hall, Ph.D., is an associate research professor at the University of Kansas. She has an extensive background in the evaluation of health care programs, especially for people with disabilities or chronic illnesses. Her research has included private, state, and federal projects related to health care, education, and employment for people with disabilities or chronic illnesses in the educational, welfare to work, workforce center, Medicaid, and Medicare systems. In addition to her work with The Commonwealth Fund, Dr. Hall is currently evaluating the Kansas Medicaid buy-in program and directing a federal project to study the nexus of disability, health, and employment. She recently completed an evaluation of the Kansas Demonstration to Maintain Independence and Employment. Dr. Hall earned her Ph.D. in disability studies from the University of Kansas.

Janice Moore, M.A., M.S.W., M.B.A., is a project coordinator and data manager at the University of Kansas, where she contributes to research on disability, aging, and health reform. Prior to entering health services research, her experiences included teaching, health care administration, clinical social work, and corporate communications within the insurance industry, all of which have informed her work in health policy research. She earned master's degrees in English, business, and social work from the University of Kansas.

Acknowledgments

The authors thank the PCIP directors and staff in the 10 sample states and the other member states of the National Association of State Comprehensive Health Insurance Plans (NASCHIP) for their assistance and support.

They also thank the staff at the Centers for Medicare and Medicaid Services, Center for Consumer Information and Insurance Oversight, for providing background information.

Editorial support was provided by Sarah Klein.


THE
COMMONWEALTH
FUND