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**COVERING PEOPLE WITH PRE-EXISTING CONDITIONS:
REPORT ON THE IMPLEMENTATION AND OPERATION OF THE PRE-EXISTING
CONDITION INSURANCE PLAN PROGRAM**

Executive Summary

Before the Affordable Care Act, Americans with pre-existing conditions who did not receive health coverage through their employers had few affordable options to get the care they needed. In most states, insurance companies could refuse to sell them coverage, charge high premiums, or offer coverage excluding benefits for their pre-existing health conditions. The result has been Americans with serious health conditions – like cancer and heart disease – have been unable to afford health insurance or to pay out of pocket for their own medical care. Thanks to the Affordable Care Act, people with pre-existing conditions have new options. The health reform law contains significant benefits for people who are living with pre-existing conditions, expands access to private insurance, and gets rid of the worst insurance industry practices by putting patients first.

As a bridge to 2014, when insurance companies are banned from discriminating against all Americans because of a pre-existing condition, the law created a new program designed to help Americans who have been locked out of the insurance market due to their health status. The Pre-Existing Condition Insurance Plan (PCIP) is a temporary high-risk health insurance program that makes health coverage available and more affordable to uninsured individuals who have been denied health insurance because of a pre-existing condition.

Since its inception, PCIP has cumulatively helped 134,708¹ people with medical conditions access the health care they need but have been unable to afford without health insurance. The average cost per enrollee in 2012 was \$32,108 per year and varied widely by state, from a low of \$4,276 per enrollee to a high of \$171,909 per enrollee. Not only do costs vary by state they also vary per enrollee. In one year, 4.4 percent of PCIP enrollees accounted for over 50 percent of claims paid. This report documents the growth the program has experienced, the characteristics of people covered under the program, the measures CMS has taken to contain costs, and the challenges of covering people in high risk pools versus broader health insurance pools like those that begin in 2014 through new Marketplaces, or Exchanges.

PCIP Overview

PCIP was established by Section 1101 of the Affordable Care Act as a temporary high risk health insurance program in all 50 states and the District of Columbia for uninsured people with pre-existing conditions. In 2010, twenty-seven states elected to operate their own program, often in coordination with existing High Risk Pools, and 23 states and the District of Columbia opted instead to have a federally-administered program.

To qualify, people applying for the Pre-Existing Condition Insurance Plan (PCIP) must:

¹ This information is derived from the Federally-administered PCIP data as of 11/30/12 and the latest monthly data, as of 11/30/2012, received by the state based PCIPs. This number is the total number of individuals that have received coverage under the PCIP and does not represent the current monthly enrollment.

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- Have been without health coverage² for at least six months,
- Have a pre-existing condition or have been denied health coverage because of a health condition, and
- Have U.S. citizenship or legally reside in the U.S.

Eligibility is not based on income and people who enroll are not charged a higher premium because of their medical condition. The law appropriated \$5 billion for the payment of claims and administrative expenses in excess of the premiums collected from people enrolled in the program.

Federal-State PCIP Partnership

The Affordable Care Act offered states the flexibility to establish a PCIP program themselves, or to work with the Department of Health and Human Services (HHS). In 2010, twenty-seven states, a state or state-designated nonprofit entity (such as an existing High Risk Pool) elected to operate a PCIP and receive funding for administrative and claims expenses in excess of enrollees' premium contributions. Under this arrangement, the state-based PCIP, with the concurrence of HHS and consistent with guidelines, establishes premium rates and benefits, procedures for enrollment, disenrollment, appeals, and determines how applicants satisfy the program's pre-existing condition requirement as provided by the law. In the remaining twenty-three states and the District of Columbia, HHS put in place a program operated through interagency agreements with the Office of Personnel Management (OPM), the Department of Agriculture's National Finance Center (NFC), and a contract with a third-party health plan administrator. In the federally-administered PCIP, NFC processes enrollment applications, bills and collects premiums, and manages a customer call center, while OPM makes eligibility determinations, adjudicates appeals of eligibility, and oversees the third-party health plan administrator's contract. Appendix A includes detailed information on enrollee characteristics.

Premiums and Benefits

People who are enrolled in PCIP receive health coverage at premium rates based on what healthy people pay in the individual insurance market. By law, premiums may vary only on the basis of age (by a factor not greater than four to one), geographic area, and tobacco use. PCIP covers at least 65 percent of total allowed costs for covered benefits, and limits member out-of-pocket expenses for covered, in-network services to the amount established under Federal law for individuals enrolled in a high deductible health plan with a Health Savings Account. Under the federal tax code, this out-of-pocket amount is set each calendar year. In 2013, this amount increased to \$6,250 from \$6,050 in 2012.

PCIP coverage begins immediately upon the plan's effective date, which is unlike some types of insurance coverage currently available in the individual market that impose pre-existing condition limits or exclusion periods. PCIP offers a competitive benefit package of services that

² Section 1101(d)(2) of the Affordable Care Act states that an eligible individual must not have been covered under creditable coverage (as defined in section 2701(c)(1) of the Public Health Service Act in effect on the date of enactment of the Affordable Care Act) during the 6-month period prior to applying for coverage.

includes hospital inpatient and outpatient services, mental health and substance abuse services, professional services for the diagnosis of treatment of injury, illness, or condition, non-custodial skilled nursing services, home health services, durable medical equipment and supplies, diagnostic x-rays and laboratory tests, physical therapy services, hospice, emergency services, prescription drugs, preventive care, and maternity care.

PCIP Demographics: Comparison to Existing High Risk Pools

Before the PCIP program, many states operated high risk pools to cover people with pre-existing conditions. However, there are major differences between the benefit structure for and the covered population in existing state high risk pools as compared to the PCIP program, such as:

- **No Waiting Period for PCIP Coverage:** Many state high risk pools have pre-existing condition exclusion periods ranging from three to twelve months that are applied to new enrollees who lack prior coverage. Under this exclusion, those with pre-existing conditions are not immediately covered for those conditions while they are paying monthly premiums. In contrast, PCIP does not impose a waiting period, so high cost conditions are covered from the first day that PCIP coverage begins.
- **PCIP Enrollees Have Immediate Need for Care:** Many enrollees in state high risk pools have had prior coverage and are eligible for the pool by virtue of rights afforded to them under the Health Insurance Portability and Accountability Act of 1996. Such individuals were likely already receiving ongoing treatment of their pre-existing conditions prior to the effective date of their state high risk pool coverage, whereas PCIP enrollees are likely to have unmet medical needs for their condition(s) from their uninsured status prior to enrollment.
- **PCIP Enrollee Cost:** The PCIP program serves a disproportionate number of older individuals, a contributing factor to higher per enrollee costs compared to the state high risk pools.

PCIP Enrollees Have High Medical Claims

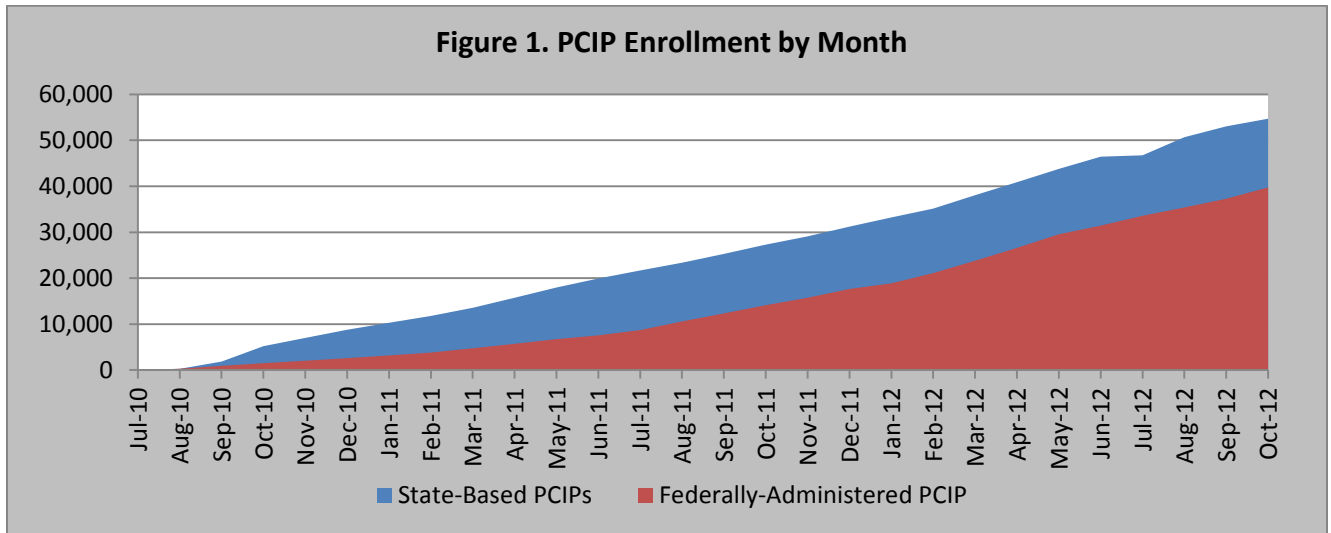
Initial Program Estimates

In April 2010, prior to the launch of PCIP, the CMS Office of the Actuary (OACT) estimated that roughly 375,000 people would gain coverage through the PCIP program in 2010, and that the initial \$5 billion in federal funding for this program would be exhausted by 2012.³ These estimates were based on health spending and patient characteristics from the Medicare Expenditure Panel Survey (MEPS), which were used to identify the number of people who might be eligible for the program and their associated spending. However, as described below, the actual experience in the program has seen fewer but much more expensive enrollees, underscoring the challenges associated with insuring people with pre-existing conditions through high-risk pools.

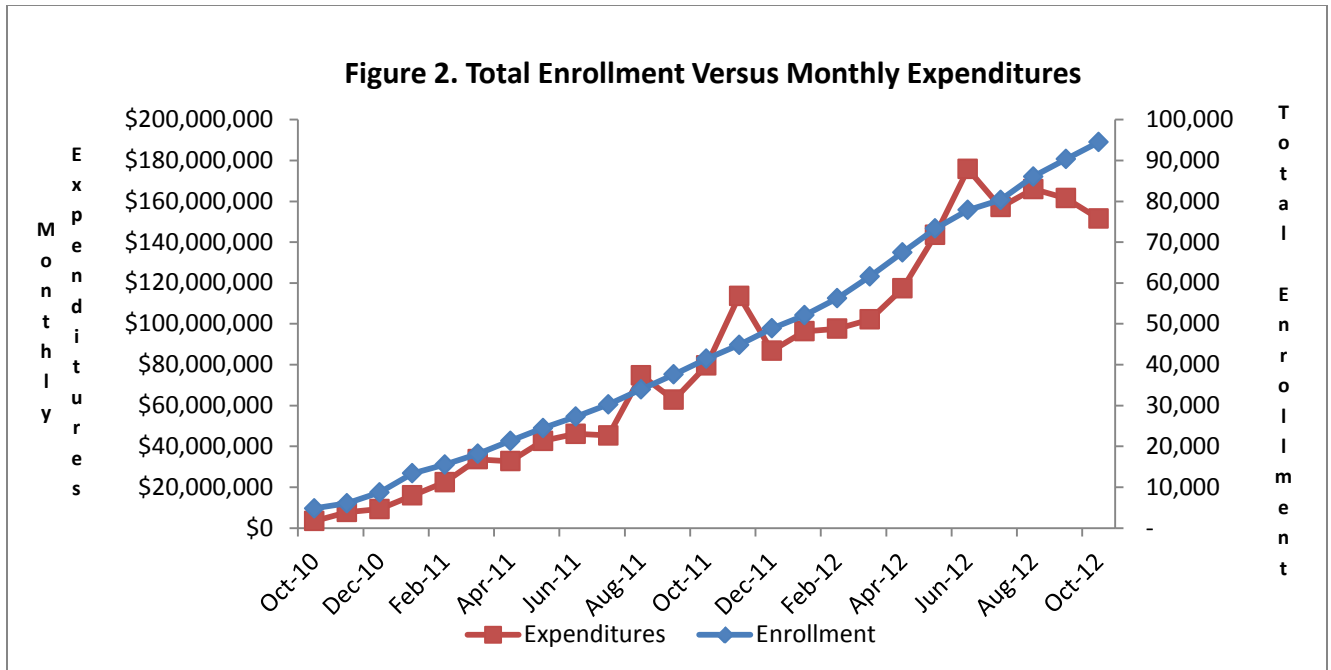
³Foster, R.S., "Estimated Financial Effects of the 'Patient Protection and Affordable Care Act,' as Amended," 22 April 2010. http://www.cms.gov/ActuarialStudies/downloads/PPACA_2010-04-22.pdf

Enrollment

While less than originally projected, PCIP has experienced significant, sustained growth since the program launched in 2010. Figure 1 represents the number of people enrolled in state-based PCIPs and the federally-administered PCIP since the program began. PCIP monthly enrollment will exceed 100,000 by early 2013. During the months of July 2012 through October 2012, the PCIP program received approximately 10,000 new applications every month, a 30 percent increase from the same time period in the previous year. As Figure 2 demonstrates, the program continues to experience increasing monthly costs as enrollment continues to grow. From May 2012 until October 2012, combined federal and state expenditures averaged \$160 million per month.



Sources: State-Based PCIP Monthly Reports and the Office of Personnel Management and National Finance Center weekly and Monthly Reports for the Federally-Administered PCIP.

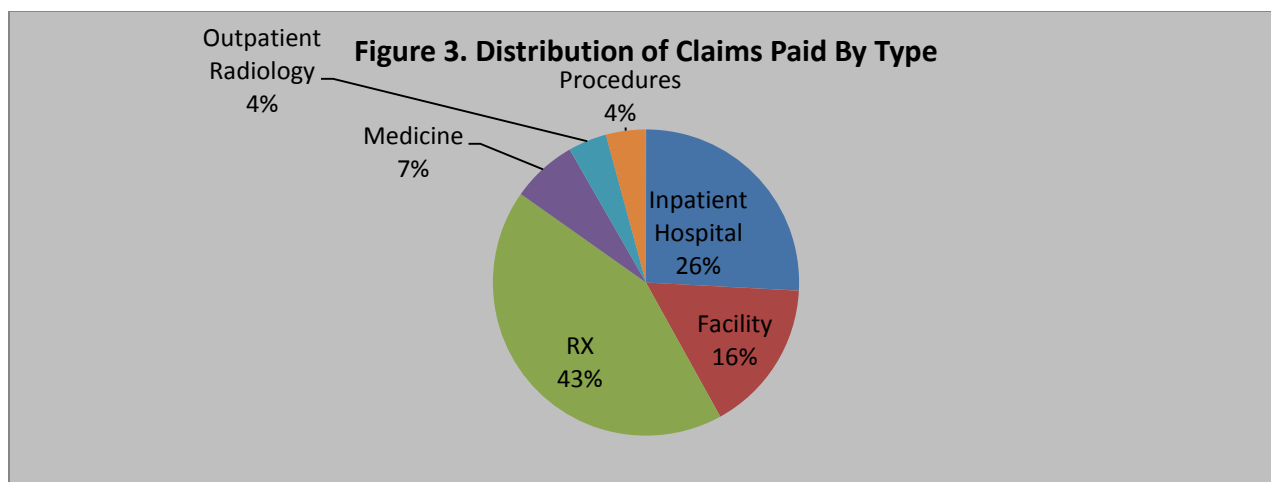


Sources: State-Based PCIP Monthly Reports and the Office of Personnel Management and National Finance Center Weekly and Monthly Reports for the Federally-Administered PCIP. Expenditure data is generated from monthly draw down reports of actual cash expenditures.

Total Program Cost

Many PCIP enrollees have serious health conditions that require immediate and ongoing medical treatment. In the federally-administered PCIP, the top four diagnoses or procedures by cost vary by state, but typically include cancers, ischemic heart disease, degenerative bone diseases, and the follow-up medical care required after major surgery or cancer treatments. Claims paid for these four diagnostic categories constituted over 36 percent of benefits paid in 2012. With heart disease among the most costly conditions to treat, in 2012 the federally-administered PCIP served 4,997 enrollees with this diagnosis, including 694 enrollees diagnosed with heart failure. Also in 2012, the federally-administered PCIP had covered more than 2,200 people suffering from cancer, including nearly 1,000 of whom had a diagnosis of breast cancer. The top diagnoses present in the PCIP population require intensive, costly treatments typically delivered in inpatient and facility-based settings. Of PCIP claims paid in 2012, approximately 60 percent were for care delivered by an acute care hospital or another facility on an inpatient or outpatient basis. Figure 3 below shows the distribution of claims paid by the type of care for PCIP enrollees in the federally-administered PCIP.

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Source: Federally-Administered PCIP, 2013. Includes medical claims paid from January 1, 2012 through December 31, 2012. Facility Services include: Ambulatory Surgery Center; Outpatient Services; Rehabilitation Facility; and Skilled Nursing Facility. Outpatient includes: Professional; Laboratory; Pathology; Procedures; and Other Outpatient Services. Other includes: Ambulance; Anesthesia; Evaluation & Management; and Undefined Services. Rx includes: all pharmaceutical claims filled by a pharmacy or by mail order.

In 2012, the average annual claims cost per enrollee was \$32,108.⁴ Costs varied widely across the states from a low of \$4,276 per enrollee to a high of \$171,909, with a median of \$30,953.⁵ Not only do claims cost vary across states they also vary across enrollees. In fact, the relatively high average claims per member in the PCIP program are a result of a small percentage of enrollees with average annual claims of \$225,000 per person. A recent analysis of claims incurred over a one-year period showed that 4.4 percent of PCIP enrollees accounted for over 50 percent of claims paid, while approximately two-thirds of enrollees experienced \$5,000 or less in claims paid over the same period. Individuals incurring high annual costs tend to present with multiple, complex diagnoses, including cancer, heart disease, and degenerative bone diseases.

Managing Cost Growth in PCIP Program

Several measures have been implemented to manage the program's share of claims costs. In August 2012, CMS switched provider networks used by the federally-administered PCIP, reducing both its negotiated and out-of-network payment rate for providers. The federally-administered PCIP also negotiated additional discounts on reimbursement rates with targeted hospitals that were treating a disproportionate number of PCIP enrollees. PCIP changed its coverage of specialty drugs to require that those drugs be dispensed by only those pharmacies and providers that were most cost effective. Finally, to help control plan costs in the federally-administered PCIP for 2013, we consolidated three benefit plan options into one and increased the maximum out-of-pocket limit from \$4,000 to \$6,250 for in-network services. In addition, CMS has conducted clinical and non-clinical audits to ensure that its state-based and federally-administered PCIPs are complying with the program's rules and regulations. Audits are underway and will encompass all 27 state PCIP programs and the federally-administered PCIP by the end of 2014. Core compliance areas included in the audits are program enrollment and

⁴ The average cost per enrollee represents the combined average cost from both the federally-administered and state-based programs

⁵ Average cost totals were derived from the September 2012 cost proposals submitted by the States.

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disenrollment, premium billing, eligibility and benefit coverage, appeals, finances of the risk pool, and medical and pharmaceutical claims payments and payment safeguards.

Conclusion

Program experience confirms that PCIP has helped uninsured people with pre-existing conditions who otherwise face surcharged premiums, temporary or permanent exclusionary riders, or outright denials of coverage. PCIP covers people with serious medical conditions such as ischemic heart disease, various forms of cancer, osteoarthritis and related diseases, and hemophilia and the lifesaving procedures they need range from chemotherapy to transplants. Experience with PCIP confirms that, while they provide critical assistance, high-risk pool programs incur a variable level of high subsidy costs to cover a limited number of individuals. It is important to recognize that PCIP serves only as a temporary bridge to reform that begin in 2014. Rather than concentrating people with pre-existing conditions in high-risk pools like PCIP, the Affordable Care Act pools a substantially larger number of people with high and low health care risks in new health insurance marketplaces called Exchanges where they can choose private plan options without being denied coverage or charged more due to a pre-existing condition.

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Appendix A. Number of People Actively Enrolled in the Federally-Administered PCIP by Gender and Age at Time of Application

Federally-Administered PCIP*	Gender		Age at Time of Application					
	Female	Male	18 and Younger	19-34	35-44	45-54	55-64	65 and Older
Alabama	399	426	4	161	162	201	268	29
Arizona	1,985	2,074	84	532	593	1,044	1,622	184
Delaware	157	139	8	41	28	65	136	18
District of Columbia	39	49	0	21	20	21	24	2
Florida	4,741	4,215	56	1,081	1,291	2,352	3,820	356
Georgia	1,830	1,698	45	614	745	912	1,058	154
Hawaii	91	81	0	16	25	40	77	14
Idaho	608	441	12	199	181	287	345	25
Indiana	909	723	39	206	209	398	725	55
Kentucky	624	473	13	174	181	304	388	37
Louisiana	566	741	6	291	275	387	320	28
Massachusetts	18	9	0	10	4	4	8	1
Minnesota	368	331	12	102	88	160	309	28
Mississippi	246	152	4	71	68	109	130	16
Nebraska	196	202	3	66	56	109	150	14
Nevada	738	586	28	222	221	298	485	70
North Dakota	50	47	1	22	16	25	27	6
South Carolina	1,048	825	31	202	252	481	798	109
Tennessee	940	877	5	282	315	513	644	58
Texas	4,754	4,009	189	1,414	1,396	2,221	3,165	378
Vermont	1	1	0	0	1	1	0	0
Virginia	1,307	1,018	33	445	385	574	760	128
West Virginia	103	60	2	33	27	32	62	7
Wyoming	174	118	4	57	28	68	125	10
Total for Federally-Administered PCIP	21,892	19,295	579	6,262	6,567	10,606	15,446	1,727

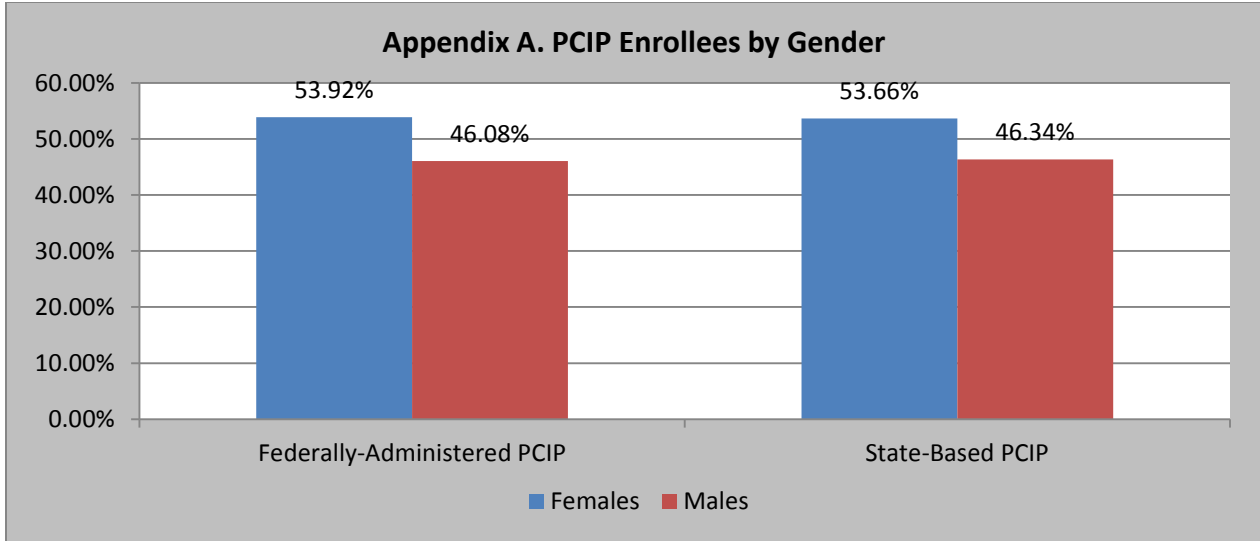
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Appendix A. Number of People Ever Enrolled in State-Based PCIPs by Gender and Age at Time of Application								
State-Based PCIPs*	Gender		Age at Time of Application					
	Female	Male	19 and Younger	20-34	35-44	45-54	55-64	65 and Older
Alaska	66	35	2	36	14	26	23	0
Arkansas	581	422	19	274	173	250	284	3
California	9,214	7,750	218	4,655	3,099	3,999	4,855	138
Colorado	1,235	992	48	637	415	498	611	18
Connecticut	512	414	8	93	116	267	415	27
Illinois	2,005	1,905	44	777	572	1,054	1,437	26
Iowa	264	239	3	108	66	136	181	9
Kansas	450	342	11	170	126	186	294	5
Maine	23	38	1	8	8	14	30	0
Maryland	743	630	6	264	226	375	457	45
Michigan	1,159	1,159	26	517	434	638	681	26
Missouri	1,284	1,525	67	592	498	801	821	30
Montana	333	239	12	178	108	121	152	1
New Hampshire	566	540	10	254	177	330	331	4
New Jersey	1353	815	33	644	347	514	589	41
New Mexico	1,012	864	23	482	316	446	583	26
New York	3,102	3,239	13	1,293	1,107	1,611	2,191	126
North Carolina	3,947	2,801	92	1,233	1,240	1,729	2,422	40
Ohio	2,276	1,812	57	714	542	967	1,792	17
Oklahoma	633	580	32	244	178	301	443	5
Oregon	1,441	1,401	47	816	576	612	768	23
Pennsylvania	6,181	4,658	21	1,670	1,743	3,019	4,302	87
Rhode Island	159	137	2	52	55	77	109	1
South Dakota	172	173	12	64	46	99	124	0
Utah	1,419	1,154	211	759	420	533	631	19
Washington	685	868	12	504	334	354	333	16
Wisconsin	1,221	1,188	21	459	357	725	839	8
Total for State-Based PCIPs	42,036	35,920	1,051	17,497	13,293	19,682	25,698	741

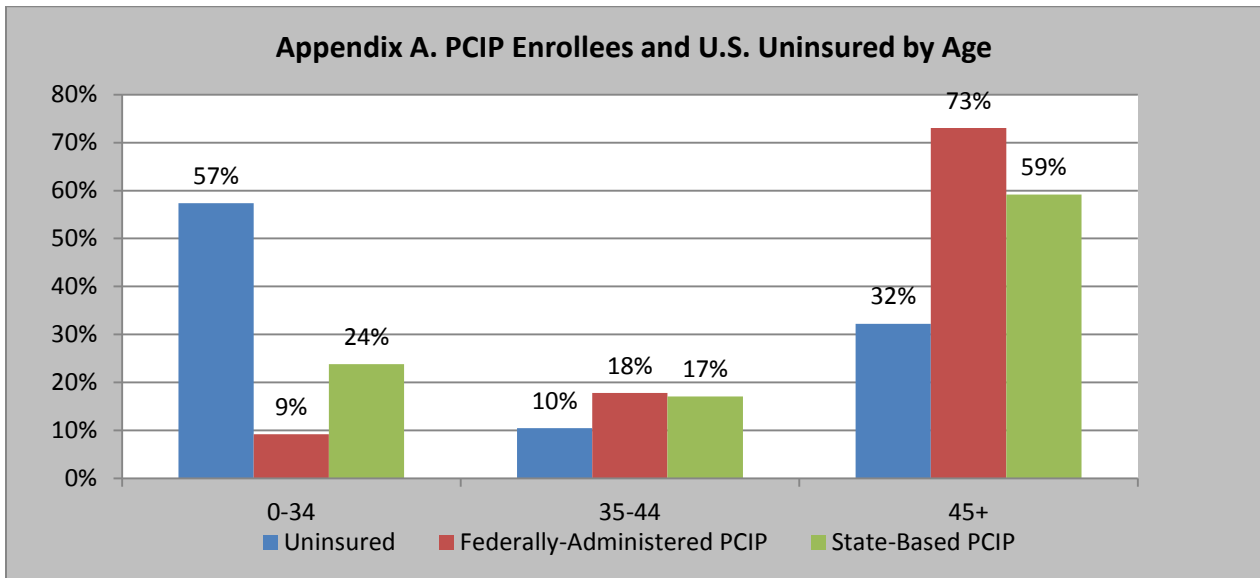
* State-Based PCIPs and Federally-Administered PCIP use slightly different age bandings.

Sources: State-Based PCIP Monthly Reports through January 2013 and NFC Reporting Center Query as of January 10, 2013 for the Federally-Administered PCIP

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Sources: November 2012 State-Based PCIP Monthly Reports and NFC Reporting Center Query as of January 9, 2013 for the Federally-Administered PCIP



Sources: October 2012 State-Based PCIP Monthly Reports and NFC Reporting Center Query as of January 10, 2013 for the Federally-Administered PCIP; U.S. Census Bureau, Current Population Survey, Table 8. "People without Health Insurance Coverage by Selected Characteristics: 2010-2011." Available at: <http://www.census.gov/prod/2012pubs/p60-243.pdf>; Accessed January 8, 2013.