# New Health Insurance Estimates Improve Measuring Program Participation in the National Breast and Cervical Cancer Early Detection Program

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### ABSTRACT

This article evaluates the participation rates of uninsured low-income women in the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) using small area estimates of health insurance coverage. The small area model uses data from the Current Population Survey and various types of administrative records. The modeled estimates of uninsured women and the administrative records from the NBCCEDP are used separately; the two data sources are not combined. Estimates of the participation rates for these programs are analyzed at the state-level. For the Breast Cancer Early Detection Program, state participation rates were from 5.0 to 83.4 percent. In general, this article outlines a useful tool for evaluating programs that have the main criteria of eligibility as being uninsured.

Keywords: small area model, health insurance, low-income, participate rate

### 1. Introduction

The Centers for Disease Control and Prevention (CDC) administer the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The NBCCEDP ensures that lowincome, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services [6]. The population eligible for the program is narrowly defined (lowincome, uninsured women between the ages of 18 and 64 years) making it challenging to estimate the number of women eligible for the program for small areas. This is particularly the case at the local level (e.g., county or congressional districts) because of unavailability of insurance and income data [11]. Because the implementation of the NBCCEDP takes place at the local level, local estimates are crucial for program planning, outreach, resource allocation, and evaluation.

To estimate program participation rates, CDC needs national- and state-level estimates of the number of low-income, uninsured women by race, Hispanic origin, and age. In the past, tabulations of the Annual Social and Economic Supplement to the Current Population Survey (CPS ASEC) have been used to evaluate participation in the program at the national and state level [20, 22]. For many states, the state-level confidence interval of the number of programeligible women is too large (e.g., confidence intervals have a lower bound that is less than zero) to provide reliable data for outreach, program evaluation, and resource allocation purposes [21]. In response, CDC partly sponsors the work of the U.S. Census Bureau's Small Area Health Insurance Estimates (SAHIE) program to create model-based state and county estimates that provide reliable data for program eligible women. The Census Bureau's SAHIE program publishes state health insurance estimates by age, sex, race, and Hispanic origin (i.e., demographic characteristics) by income categories (0–200 percent and 0–250 percent of the poverty threshold, and total), as well as by age, sex, and income categories at the county-level. The state-level estimates have been analyzed by comparing estimates from a model and estimates that are solely based on tabulation of the survey data; SAHIE estimates were consistent with the survey estimates and had smaller confidence intervals [15]. The model improvement that has occurred since 2008 has the flexibility to estimate more income categories when a larger sample is used such as the American Community Survey [13].

This article focuses on participation rates of uninsured low-income women in the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) using small area estimates (state and county) of health insurance coverage. Essentially, this paper replicates some previous work on the participation rates of the NBCCEDP that use direct CPS ASEC estimates [20, 21]. However, many participation rates based on model-based estimates on the program-eligible are not possible using the direct CPS ASEC estimates. The specific method of calculating participation rates given the target population is a general application, not specific to the NBCCEDP.

#### The National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

Age-appropriate breast cancer screening with mammography and routine Papanicolaou testing for cervical cancer has helped reduce breast and cervical cancer death rates [17]. The U.S. Preventive Services Task Force recommends that women aged 40 and older be provided with screening mammography every 1–2 years; begin cervical cancer screening within 3 years of the onset of sexual activity or age 21 (whichever is earlier) and have follow-up screening at least

every 3 years [17]. Breast and cervical cancer screening rates among low-income, uninsured, and under-insured women are low [19, 23]. Women without health insurance are less likely to receive screening on the basis of current screening guidelines for breast and cervical cancer and are at greater risk for a late diagnosis than are women with health insurance [18, 19].

In response to the Breast and Cervical Cancer Mortality Prevention Act of 1990, CDC established the NBCCEDP in 1991 to ensure access to quality breast and cervical cancer screening services for underserved and uninsured women [7,10]. The NBCCEDP provides funding, consultation, and technical assistance to all 50 states and the District of Columbia, as well as to five U.S. territories, and 12 American Indian/Alaska Native jurisdictions. The NBCCEDP, through these entities, provide breast and cervical cancer screening services. Generally, those eligible for the NBCCEDP are women aged 18 to 64, who do not have health insurance coverage or whose insurance does not cover breast and cervical cancer screening and diagnostic services, and whose family incomes are at or below 250 percent of the federal poverty level. Nearly all NBCCEDPs set their income criteria at 200 percent or 250 percent of the federal poverty level [6]. In 2005 (the reference year for this research), these income-level criteria corresponded to the annual dollar amounts of \$41,000 (200 percent) or \$52,000 (250 percent) for a family of four [4]. For the NBCCEDP, noncontiguous states (Alaska and Hawaii) have a higher poverty level than the other states that is not reflected in the U.S. Census Bureau's definition of poverty [6].

Because the program operates through a series of individual cooperative agreements with the grantees, the operational focus across grantees may differ noticeably. For instance, programs direct their efforts on the basis of area mortality trends or known high-risk subpopulations, and they may use different strategies and organizational structures to screen women for breast cancer.

#### **Program Evaluation Using Participation Rates**

One common approach to measure participation rates at the local level (e.g., county) is to use closely related data to predict the number of program-eligible people. Typically, a regression is used to predict the percent of uninsured using national surveys. The regression coefficients are then applied to local (e.g., county) information from the Census 2000 sample data (i.e., the long form). The covariates of the regression have to be the same as information from the long form (race, Hispanic origin, income, etc.). This produces a synthetic estimate of the proportion of uninsured that can be easily translated into numbers [24]. This approach assumes the demographic and income categories do not differ from the decennial Census year (2000) to subsequent years. It further assumes that the regression estimates are relevant to the specific small area and does not question whether the regression based on national data is relevant to a county in a specific state.

Knutsen et al. (2008) used this type of approach to estimate the eligible population for the breast cancer early detection program in California. Because California has a large state-specific survey, their estimates of the eligible population were better than those based on a national survey. However, their estimates still assume that the demographic and income characteristics of a county and state are similar to the population represented in the county and state decennial Census sample data (similar approaches were used for breast cancer prevention with another state survey by German 1996 and Mendez-Luck et al. 2007 used this framework for an asthma project).

Estimates of uninsured low-income women are important to measure the number of women eligible for the NBCCEDP and the percentage screened by the program. These estimates are crucial for program planning, outreach, resource allocation, and evaluation.

### 2. Methods

#### Data

The SAHIE program constructs statistical models that relate health insurance coverage, as measured by survey-based estimates from the CPS ASEC, to population estimates and administrative records. The CPS ASEC provides annual national- and state-level estimates based on a sample of about 100,000 addresses. All health insurance coverage and income questions refer to the previous year, and family size is determined at the time of the interview. Dividing family income, for a given family size, by the appropriate poverty threshold indicates a family's income group [4].

The SAHIE model used direct estimates of the CPS ASEC aggregated at the county and state for the number of uninsured by sex, age, and program-relevant income categories. At the state-level, race and Hispanic origin are also included. Predictor variables for income and health insurance are: Census 2000 sample data, number of federal tax exemptions, the number of Supplemental Nutrition Assistance Program (formerly known as the Food Stamp Program) participants, number of Medicaid and State Children's Health Insurance Program participants, the number of people employed in different sized firms as shown in administrative records. All of these predictors are aggregated to the county- and state-level [13].

The NBCCEDP participants collect surveillance data on women served through the program. Funded partners report data to CDC that describe the demographic characteristics,

residence at the time of screening, screening location, screening history, and screening and diagnostic outcomes for these women. Reporting of race and Hispanic origin is optional [16]. These administrative records are known as the Minimum Data Elements (MDE). The MDE data are subject to privacy protection and are aggregated to the county- and state-level. Part of the agreement to use the MDE data was not to disclose any state names.

To make estimates of the CCEDP program, the method is the same as a previous article [22]. To adjust the SAHIE estimates to the relevant population for the CCEDP, the estimates have to be adjusted with auxiliary data to make a "cervical cancer" adjustment. This adjustment is needed because some women do not have a cervix due to a hysterectomy and the percent of women that have had a hysterectomy varies substantially by state. The auxiliary data that has hysterectomy information, the Behavioral Risk Factor Surveillance System (BRFSS), was only able to support age groups in the adjustment and not a race / ethnicity adjustment because of its sample size.

#### Statistical Model

The model for producing the SAHIE estimates is a Fay-Herriot style model [8]. This means that estimates from the survey are combined with the modeled results to create a new, final estimate. The SAHIE model is an area-level model [25] (e.g., the input data are aggregated to the county or state and county/state are the unit of analysis) as opposed to a unit-level model (e.g., a person-based health insurance model [14]). The model used to produce health insurance estimates is a combination of two hierarchical models. The Income-to-Poverty model estimates the number of people in an income and demographic group by county. The Insurance model estimates the proportion insured within those groups. The number insured is the product of the

number in a group and the proportion insured. The overall model produces estimates for county, age, sex, and income groups that cover the entire population under age 65. Calculation for a separate state model is conceptually the same as the county model [2]. The model was programmed in C by Census Bureau staff.

In the Income-to-Poverty model, proportions were constructed by dividing the individuals in an income category by the relevant demographic group (i.e., age, race, sex, and Hispanic origin). The CPS ASEC estimate of the proportion in the demographic and income groups by county is assumed to be normally distributed with mean values equal to the true proportion in the group. The logistic transformation of the true proportions are assumed to follow a normal distribution. The predictors include county, age, sex, and proportion Hispanic; in the state model, an estimate of the proportion of people that are not in the federal tax records is also used. Other predictors enter the model via their distributions, conditional on the numbers in the county, demographic, and income groups. The Census 2000 estimate of the number in the income group, and totals derived from tax records and from Supplemental Nutrition Assistance Program participation, are each assumed to be normally distributed with the mean equal to a linear function of the number in the appropriate group. The predicted number in the income and demographic group is the product of the proportion in the group and a demographic estimate [4].

In the Insurance model, the logistic transformation of the true proportion insured within a county assumes that demographic and income groups follow a normal linear model. For the CPS ASEC estimate of the proportion insured within a county, demographic and income groups are assumed to be normally distributed with the mean equal to the true proportion insured. The number receiving Medicaid in a county, age, and sex group is assumed to be normally distributed

with a mean equal to a linear function of the number insured within the lowest income group. For technical reasons, the model is based on the insured population, not the uninsured [2].

Variances of the CPS ASEC estimates and administrative records are assumed to follow particular functional forms, with parameters that are estimated. Prior distributions are given to parameters, so that the model is fully Bayesian. Markov chain Monte Carlo techniques are used to estimate the posterior distribution. The estimates are posterior means [2].

The state estimates are consistent with the national survey estimates for many of the key demographic and income categories. The county health insurance estimates are also consistent with the modeled state estimates [4]. This does not affect the analysis.

#### **Calculating Participation Rates**

The NBCCEDP provides free or low-cost mammography screening to low-income, uninsured women aged 40–64 years old. Using the MDE data for 2005–2006, participants were defined as women who were screened for breast cancer by the NBCCEDP. To measure the proportion of eligible women screened by for breast cancer program, ideally, the underlying CPS ASEC data from years 2005–2006 would be used instead of (the calendar year average) 2004– 2006 for the denominator. However, the sample size of the CPS ASEC does not support a 2-year average at the local level. Based on the number of women screened (from the MDE data) and estimates of the program-eligible population (from CPS ASEC data), we estimated the percentage of program-eligible women, for states, who received a program-funded mammogram at least once in 2005 or 2006. Essentially, this is a modification of a previous study [22]. However, the difference is that this article focuses on modeled estimates. The participation rate is calculated as the number of women who participated in the program divided by the number of those eligible (uninsured low-income women aged 40–64).

$$PR = \left(\frac{\#of \ women \ screened}{\#of \ eligible \ women}\right) *100 \qquad (equation \ 1)$$

$$se_{PR} = se_{\#eligible} * \begin{pmatrix} \#of women \ screened / \\ / \#of \ eligible \ women^2 \end{pmatrix} * 100 \quad (equation 2)$$

The approximate standard error of the participation rate is derived by a Taylor series approximation. The 90 percent confidence interval is PR  $\pm 1.645$ \*SE<sub>PR</sub> and "1.645\*SE<sub>PR</sub>" is the margin of error.

With county level estimates, the relative standard error (RSE) ( $RSE = 100 * \frac{se}{mean}$ ) is used to assess the quality of the number eligible for the BCEDP. In general, an RSE below 30 percent indicates that the estimate is of adequate quality [4]. The numbers of eligible for the BCEDP are used, as opposed to participation rates, because of non-discloser of the MDE as well as the problem of displaying all counties in a graph.

The analysis will be on the participation rate of low-income, uninsured women aged 40 to 64 in the Breast Cancer Early Detection Program (BCEDP) and the Cervical Cancer Early Detection Program (CCEDP). At the state level, there are additional results for Hispanic women. Income-to-poverty ratios of 200 percent or 250 percent generally match the income eligibility for the state programs. For states that have different thresholds of eligibility (185 percent or 225 percent), the state grantee chose the income-to-poverty threshold of 200 or 250 percent. Throughout the analysis, we used the low-income definition that the state grantee has chosen.

# 3. Findings

Table 1 shows the participation rate of woman participating in the BCEDP and/or the CCEDP program for states. For both programs, suppression took place when the participation rate was higher than 100 percent; 3 state were suppressed in the CCEDP program. The estimates range from 5.0 percent to 83.4 percent for the BCEDP and 5.3 percent to 73.6 percent. The CCEDP has a higher participation rate because the denominator is smaller because of the cervical cancer adjustment. Further, the adjustment factor is less accurate as sample size goes down. The number of screened eligibles was roughly similar across programs.

Estimates of race and Hispanic origin are useful because programs often target underserved minorities. Currently, there is not a state-level survey estimate for the NBCCEDPeligible population in these risk groups. The SAHIE estimates include demographic detail for Hispanic persons and non-Hispanic blacks. For illustrative purposes, Hispanic women are the focus of this section. In the CPS ASEC survey estimates, Vermont and West Virginia have no respondents in the CPS ASEC that are uninsured low-income Hispanic women aged 40–64.

The modeled estimates of the number of Hispanic eligible persons have an RSE from 4.6 to 13.6 percent and adequate reliability. Figure 1 shows the estimated participation rates for the BCEDP for Hispanic women aged 40–64 in order of lowest to highest participation. In general, the width of the confidence intervals increases as the participation rate increases. For the highest participation rate, the estimated "true" value had a 90 percent confidence interval of 39 percent to 61 percent. For the lowest participation rate, the range was 4.0 percent to 6.0 percent. Because reporting race and Hispanic origin is optional in the MDE data, this range in participation rates are different than the "truth."

The RSEs are the only measure of accuracy available and will be used to evaluate the estimates for the number of uninsured low-income women aged 40–64 (i.e., those eligible for BCEDP services). This decision is partially based upon the non-disclosure requirements for state and county MDE data. The participation rates have RSEs that are very similar to the RSEs for the number of uninsured low-income women. The county's total population size is important because the expectation is that the larger the sample size (i.e., large counties), the more reliable the participation rate. The size categories are less than 20,000, greater than or equal to 20,000 but less than 65,000, and 65,000 and over.

Figure 2 illustrates the modeled RSEs for the participation rate in the BCEDP for women aged 40–64 by population size. Even though it would be expected that the larger counties have more reliable estimates for this population because they would have larger sample sizes, the estimated RSEs do not show this. The highest RSEs are in Alaska's Northwest Arctic Borough (53.8 percent), Wade Hampton Census Area (50.1 percent), and Mississippi's Tunica County (51.8 percent); the estimated numbers of low-income women in these counties are, respectively, 26, 34, and 61. When the estimate is a small number, the width of the confidence intervals tends to become relatively larger. It is reasonable to say that the quality of these three estimates is inadequate for many policy-oriented purposes. Overall, the estimates meet the Census Bureau's standard that the median of the RSE is at or below 30 percent; 50 percent had an RSE below 30 percent. Counties with RSEs below 10 percent are the District of Columbia, Los Angeles County in California, and Clark County in Nevada.

Although counties cannot be identified because of restrictions on the MDE data, a range of participation rates can be reported. The MDE data had 38 counties that had missing information. For all other counties (3,102), the average participation rate was 21.1 percent, the median was 14.3 percent, and the quartile range was 7.3 to 26.5 percent.

### 4. Discussion

All of these results are participation rates that where impossible using CPS ASEC data but are possible uses SAHIE estimates. For uninsured low-income Hispanic women aged 40–64, the participation rate varied from 4.6 to 67.4 percent. At the county level, the lowest relative standard error (the best estimate) was 7.5 percent for the District of Columbia.

#### Limitations

A limitation of this model based on the CPS ASEC is that it cannot be readily applied to other income-to-poverty ratios because of the limitations in the sample size. For the NBCCEDP, Kansas, Nebraska, and Oklahoma use thresholds other than 200 percent or 250 percent of poverty and therefore data from these states do not have the correct denominator for the NBCCEDP-eligible. Further, a state partner in the NBCCEDP might consider raising the state's income threshold from 200 percent to 225 or 250 percent of poverty, and it would be important to predict the cost. The current estimates are, at best, a guide to make this decision by comparing, at the state level, the number of uninsured women at or below 200 percent of poverty with the number at the 250 percent criterion. When the SAHIE program starts using the American Community Survey, this limitation will probably be eliminated.

### **Conclusions**

These modeled estimates can be used in conjunction with administrative data to form participation rates for other public health programs that have trouble measuring the size of their eligible population because of the lack of local-level data. Stakeholders for other CDC programs, such as the Well Integrated Screening and Evaluation for Women Across the Nation (WISEWOMEN) and the Colorectal Cancer Comprehensive Program (CCCP), could easily construct participation rates and the confidence interval by following the approach outlined above. The WISEWOMEN program helps uninsured low-income women reduce their risk for heart disease, stroke, and other chronic diseases [1]. The CCCP purpose is to increase population-based colorectal cancer screening among persons aged 50 years and older, focusing on uninsured low-income persons with an average risk of colorectal cancer for screening [5].

Besides CDC-related programs, SAHIE estimates for children could be used to target outreach efforts for uninsured, low-income children and their participation rate for programs that offer health insurance or medical services. With auxiliary data, other new policy-relevant estimates can be produced, such as uninsured low-income children who have a disability. In each case, the SAHIE data combined with auxiliary data from a different survey will produce a better estimate than if the two sources of data were not combined.

The SAHIE estimates, as well as other approaches to improve the estimates of the uninsured population, have an important role in shaping policy decisions for the program. Participation rates are useful for state and county policymakers to determine the success of a particular program. Better estimates benefit the public because this enables policymakers to allocate funds more efficiently and evaluate programs more effectively. The NBCCEDP provided a concrete application of the usefulness of these health insurance estimates to calculate participation rates.

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**BCEDP** Participation Rate of Hispanics Aged 40-64

Figure 1: Participation Rates (and 90% Confidence Intervals) for Eligible Hispanic Women For the BCEDP Aged 40–64 in the NBCCEDP, by State Participation Rate



**RSE of the Number of BCEDP Eligibles** 

Aged 40-64, Counties

Figure 2: Relative Standard Error of the Number of Low-Income Uninsured Women Aged 40-64, by County Size