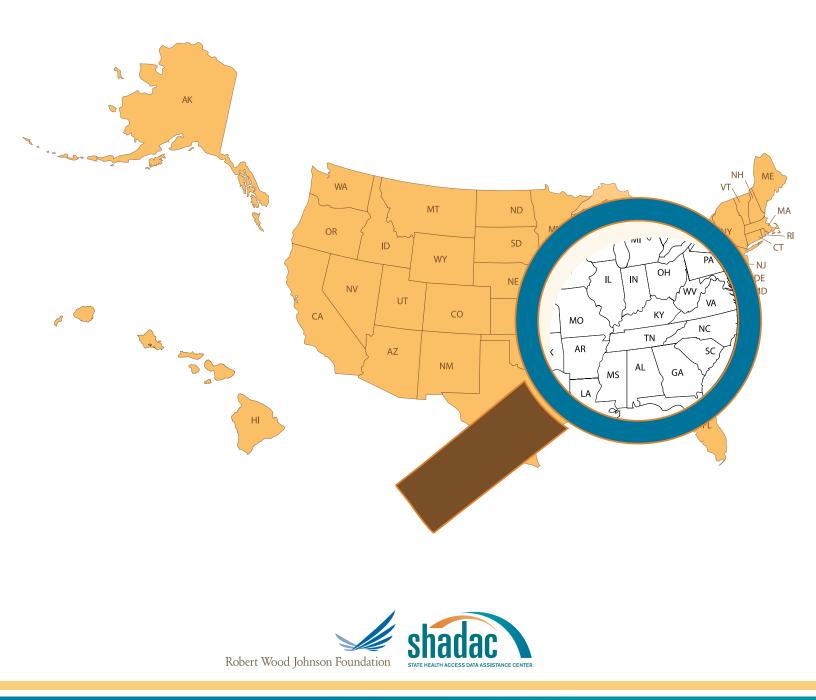


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## **Data Sources Used for Monitoring and Evaluating Health Reform at the State Level**



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The **State Health Access Reform Evaluation (SHARE)** is a National Program of the Robert Wood Johnson Foundation created to support the evaluation of health policy reform at the state level and develop an evidence-based resource to inform health reform efforts in the future. SHARE operates out of the **State Health Access Data Assistance Center (SHADAC)**, an independent health policy research center located at the University of Minnesota School of Public Health.



#### State Health Access Data Assistance Center (SHADAC)

SHADAC is funded by the Robert Wood Johnson Foundation to collect and analyze data to inform state health policy decisions relating to health insurance coverage and access to care. For information, please contact us at shadac@umn.edu or call 612-624-4802.



## Robert Wood Johnson Foundation (RWJF)

For more than 40 years the Robert Wood Johnson Foundation has worked to improve the health and health care of all Americans. We are striving to build a national culture of health that will enable all Americans to live longer, healthier lives now and for generations to come. For more information, visit www.rwjf.org. Follow the Foundation on Twitter at www.rwjf.org/twitter or on Facebook at www.rwjf.org/facebook.

## Introduction

The State Health Access Reform Evaluation (SHARE) is a National Program of the Robert Wood Johnson Foundation (RWJF) created in 2006 to support the evaluation of health policy reform at the state level. Key goals of the grant program are to disseminate informative, user-friendly findings for state and federal policymakers and agencies, as well as leading researchers, and to develop an evidencebased resource to inform future health reform efforts. SHARE operates out of the State Health Access Data Assistance Center (SHADAC), an RWJF-funded research center in the Division of Health Policy and Management, School of Public Health, University of Minnesota.

Over the past six years, the SHARE program has contributed toward assessing the impacts of health reform implementation at both the state and national levels. Since 2008, SHARE has awarded 33 research and evaluation grants, over three rounds of grant funding, totaling \$7.7 million.<sup>1</sup> Projects have ranged from three months to 30 months in duration, and from \$50,000 to \$600,000 in grant funding. (Appendix A lists SHARE grants to date.) SHARE research projects have primarily been studies of a single state or subgroup of states; nine of the projects have involved nation-wide analyses of health reform implementation. For more details about the SHARE program, please see the 2013 SHARE Program Report (http://www.shadac.org/SHAREProgramReport).

SHARE grants have funded research focusing on a wide range of policies and programs. A dominant focus of SHARE research has been Medicaid and CHIP policy and program reforms and their impacts on health insurance coverage and health care access and affordability. With the passage of the Affordable Care Act (ACA) in 2010, SHARE research has included topics that are specific to state implementation of ACA provisions, including ACA-specified insurance market reforms as well as Medicaid expansions. Table 1 lists the policies and programs studied by SHARE grants over the course of the program.

This report takes a high level look at the data sources behind SHARE research and evaluation findings. Based on a review of SHARE grantee documentation and products, data sources used in monitoring and evaluating health reform fall into four major categories: household survey data, medical claims data, enrollment data, and qualitative data. This report identifies each of these data sources, examines how the sources were used, and details researcher insights from the collection and/or use of such data to support SHARE research. The purpose of this summary is to highlight the type of data that can be used for rigorous state policy research and the advantages and disadvantages of each data source.

Table 2 summarizes the data sources used for each of the 33 SHARE grants to date. As indicated in the table, individual projects have often relied on multiple data sources to address evaluation questions, including pairing medical claims and enrollment data or supporting survey findings with qualitative information.

#### Table 1. Policies & Programs Studied by SHARE Grants

Insurance Exchanges	1
Premium Assistance	1
Young Adult Coverage	2
Comprehensive State Reform	3
Federal Reform	4
Employer Strategies	4
Benefit Design / Service Delivery	6
Medicaid / CHIP	13

Grant total exceeds 33 because one project examined two different policy areas.

<sup>&</sup>lt;sup>1</sup>Four of the 33 grant awards remain active. RWJF plans to award a fourth round of SHARE will award a fourth round of grant funding in October 2014.

#### TABLE 2. DATA SOURCES USED IN SHARE HEALTH REFORM RESEARCH AND EVALUATIONS

Grant Focus, Title & Principal Investigator	Survey Data	Claims Data	Enrollment Data	Qualitative Data
nsurance Exchanges				
Income Dynamics and Characteristics of Health Reform E	rpansion Populations			
Lara Schore-Sheppard (Williams College)	x			
Premium Assistance				
How Affordable Are State Coverage Plans?				
Elizabeth Kilbreth (University of Southern Maine)	x	x	x	x
oung Adults				
Evaluation of Extending Dependent Coverage to Young Ac	lults			
Joel Cantor (Rutgers University) - 1st Grant	x			x
Evaluation of State & Federal Young Adult Dependent Cov	erage Expansion Policie	s		
Joel Cantor (Rutgers University) - 2nd Grant	x			
comprehensive State Reform				
Achieving Universal Coverage through Comprehensive He	alth Reform: The Vermo	nt Experience		
Ronald Deprez (University of New England)	x		x	x
Understanding Health Insurance and Policy Using Massac	husetts Health Reform			
Amanda Kowalski (Yale University)	x	x		
An Evaluation of the Impacts of State Health Reform Initiat	ives in Illinois, Massachu	setts, and New York	c	
Sharon Long (Urban Institute)	x			
ederal Reform				
Expanding Coverage & Ensuring Access: The Challenges	& Opportunities of Imple	menting Health Refo	orm in Rural America	
Andrew Coburn (University of Southern Maine)				x
Developing a Monitoring Strategy for Health Reform's Prog	gress and Effects			
Len Nichols (George Mason University)				x
Strategies for Moving the SNACC Project to the Next Leve	el: Leveraging SNACC L	Data for Policy and E	valuation	
Mike O'Grady (NORC)				x
Implications and Options for State-Funded Programs unde	r Health Reform			
Theresa Sachs (Health Management Associates)				x
mployer Strategies				
Evaluating Small Group Employer Participation in New Me	xico's SCI Program			
Cynthia Boddie-Willis (The Hilltop Institute)			x	x
Evaluation of Risk Selection in Market-Based State Progra	ms			
Deborah Chollet (Mathematica Policy Research)	x	x	x	
Sheltering Employee Premium Contributions from Tax Usin	ng "Section 125 Plans"			
Mark Hall (Wake Forest University)	-			x
Evaluating the Implementation of the Rhode Island Health	Pact Plans and the Desig	n and Implementation	on of Rhode Island's Glo	bal Waiver
Edward Miller * (Brown University)			x	x
Benefit Design / Service Delivery				
Using Behavioral Nudges to Improve Disease Managemen	t: Cost-Effective Stratea	ies for Improving Ca	re of Low-Income Diabe	etics
Kate Baicker (Harvard School of Public Health)	3	x		
Medical Homes Measures in Household Survey Data: Stat	e-Level Estimates Using	Alternative Methodo	logical Approaches	
Lisa Clemans-Cope (Urban Institute)	x		. <u> </u>	

#### TABLE 2. DATA SOURCES USED IN SHARE HEALTH REFORM RESEARCH AND EVALUATIONS (CONTINUED)

Grant Focus, Title & Principal Investigator	Survey Data	Claims Data	Enrollment Data	Qualitative Data
Innovative Benefit Design for Connecticut State Employees				
Richard Hirth (University of Michigan)		x	x	
Effects of Medicaid Reform on Access to Care, Program Sustai	inability, and Admin	istrative Efficiency in	Kentucky and Idaho	
Genevieve Kenney (Urban Institute)		x	x	x
Behavioral Health and Care for Chronic Medical Conditions in	Pennsylvania: The	Role of the Medical I	Home	
Karin Rhodes (University of Pennsylvania)		x		
Achieving the Trip Aim in Medicaid: Evaluating the Access, Qua	ality, Health, & Cos	t Impacts of Coordina	ated Care Organizations	in Oregon
Jeanene Smith (Oregon Health Policy Research)	x	x		X
Medicaid/CHIP				
Evaluation of 12-Month Continuous Eligibility in Medicaid				
E. Richard Brown (UCLA)		x	x	
Rural Implementation and Impact of Medicaid Expansions				
Andrew Coburn (University of Southern Maine) - 2nd Grant	x			
Evaluating the Impact of Outreach and Enrollment Strategies in	California			
Michael Cousineau (University of Southern California)	x		X	X
Eligibility Determination Using Modified Adjusted Gross Income	e: Implications for E	nrolment under Hea	lth Reform	
John Czajka (Mathematica Policy Research)	X			
Planning for ACA Coverage Expansion: How Insurance Covera	age for CHildless A	dults Will Affect Utili.	zation	
Thomas DeLeire (University of Wisconsin - Madison)		x	X	
Assessing the First Use of Auto-Enrollment for a State Coverag	e Expansion			
Stan Dorn (Urban Institute)		x	X	x
Incremental Strategies to Cover Low-Income Uninsured Adults				
Lisa Dubay (Johns Hopkins University)				x
Evaluation of Three STates' Reforms to Cover All Children				
Jose Escarce (UCLA)	X			x
Small-Area Microsimulation to Study Geographic Variation in C	overage Expansion	s and Access under	the ACA	
John Graves (Vanderbilt University)	X			
Maryland Kids First Act Outreach Evaluation				
David Idala (Maryland Dept. of Health & Mental Hygiene)			X	x
Evaluating the Implementation of the Rhode Island HeatlhPact	Plans and the Desig	gn and Implementatio	on of Rhode Island's Glo	obal Waiver
Edward Miller* (Brown University)				x
Evaluating the Impact of Wisconsin's BadgerCare Plus Reform	Package on Enroll	ment, Efficiency, & C	hurning	
Thomas Oliver (University of Wisconsin - Madison)	X		x	x
Informing Medicaid Program Design for Low-Income Childless	Adults: The Promis	e of Self-Reported H	lealth Measures	
Lindsey Leininger (University of Illinois at Chicago)	x	x	x	
TOTAL	17	12	14	19

## **Survey Data**

Federal and state household surveys are used widely to monitor and evaluate health reform implementation, providing valuable information about insurance coverage; health care access and utilization; and health status. About 50 percent of SHARE grantees have utilized federal household survey data to conduct their research and evaluations; five grantees analyzed data from state household surveys; and four grantees employed both federal and state data to study outcomes such as coverage, affordability and access at the state level or nationwide.

#### **Federal Surveys**

SHARE researchers have used seven federal surveys (ordered by most used): Current Population Survey (CPS), Medical Expenditure Panel Survey (MEPS), American Community Survey (ACS), Survey of Income and Program Participation (SIPP), National Health Interview Survey (NHIS), National Survey of Children's Health (NSCH), and National Survey of Children with Special Health Care Needs (NS-CSHCN). Key characteristics of the federal surveys leveraged in the SHARE program are identified in Table 3, with additional detail on the use of these data by individual grants provided in Table 4.

Many federal surveys reduce the need for expensive and timeconsuming data collection by states as they are publicly available and specifically designed for use by researchers and policy makers. Most federal surveys offer large sample sizes overall, support multi-year analyses, and facilitate state and regional comparisons. However, these data are limited in terms of certain sub-group analyses (e.g., lower levels of geography) and certain individual characteristics (e.g., detailed information needed to determine eligibility for public health insurance programs).

For more information about the use of federal survey data in health policy research and evaluation, see Appendix B for a list of other SHADAC resources.

#### **State Surveys**

Some states have invested in their own household surveys to fill informational gaps in federal household survey data. SHARE grantees used five such state surveys to inform their research. See Table 5 for a list of the state surveys and their characteristics.

State-level surveys can offer several benefits, including larger statespecific sample sizes (in some cases) and opportunities for sub-state and sub-population analyses through targeted oversampling (e.g., rural areas, low-income populations). Furthermore, state survey instruments are more easily modified and relevant to the state policy environment through the addition of new survey questions or revision of existing questions to address changes in data needs. Despite these advantages, state surveys involve challenges including methodological limitations, uncertainty and inconsistency in funding, and timely and efficient data collection.

### Insights from the Use of Survey Data to Monitor and Evaluate Health Reform under SHARE

Federal survey data have been more easily accessed than state survey data, and federal survey methods are well-documented.

- Many federal surveys make available public use files for researchers to easily access. State survey microdata may not be as accessible for general use and may need special permission to obtain.
- Unlike federal surveys, which may offer user assistance in the form of manuals and other resources to document methodological complexities, such support may not accompany state survey data. SHARE grantees recommended allocating adequate resources for state survey data manipulation.
- Some SHARE projects have been interrupted by unexpected state survey suspensions. Alternative data sources should be considered in the event that states decide to stall survey administration or that other data delays occur.

## Consideration should be given to variation in state contexts in the analysis of federal and state survey data.

- Differences between federal and state policies (e.g., health insurance regulations) can make analysis of survey data and generalization of findings challenging, especially when researchers plan to pair state data with federal data.
- State policymakers have concerns about survey measures that are affected by differences in population health characteristics; these measures may have an inherent bias against less healthy states and produce statistics that erroneously reflect poorly on a state.

Shadac I state health access data assistance center

#### TABLE 3. FEDERAL SURVEYS USED IN SHARE-FUNDED RESEARCH\*

	<b>CPS</b> (Current Population Survey)	ACS (American Community Survey)	<b>MEPS</b> (Medical Expenditure Panel Survey)	<b>NHIS</b> (National Health Interview Survey)	NSCH (National Survey of Children's Health)	NS-CHSCN (National Survey of Children with Special Health Care Needs)
Survey Administrator	Bureau of Labor Statistics	U.S. Census Bureau	Agency for Healthcare Research and Quality	National Center for Health Statistics	Maternal and Child Health Bureau	Maternal and Child Health Bureau
Mode	Phone, in person	Mail, phone, in person, internet	In person	In person	Phone	Phone
Years Administered	Annual	Annual	Annual	Annual	2003, 2007, and 2011/2012	2001, 2005/2006, and 2009/2010
Target Population	Civilian non- institutionalized population	Total population including persons in group quarters	Civilian non- institutionalized population	Civilian non- institutionalized population	Non- institutionalized child population (0 to 17 years)	Non-institutionalized children with special health care needs (0 to 17 years)
Sample Size	202,634 in 2013	3,113,030 in 2012	33,622 in 2011	108,131 in 2012	95,677 in 2012	40,242 in 2009- 2010
Response Rate <sup>+</sup>	80% in 2012	97% in 2012	55% in 2011	78% in 2012	23% in 2011/2012 (landline/cell phones combined)	26% in 2009/2010 (landline/cell phones combined)
Sample designed to be state representative?	Yes	Yes	No, but representative for some states	No, but representative for some states	Yes	Yes
State level estimates available?	Yes	Yes	Selected estimates for largest states (25 in 2010)	Selected estimates for largest states (43 in 2012)	Yes	Yes
State-level analysis of sub-populations possible?	Yes, but limited by state sample size (SHADAC recommends combining data years)	Yes	Potentially, but limited by state sample size and survey design	Potentially, but limited by state sample size and survey design	Yes	Yes
Primary focus of survey	Labor force participation and unemployment	General household survey	Health care access, utilization, and cost	Population health	Children's health and well-being	Children's health and well-being

\*Adapted from SHADAC brief, "Using Recent Revisions to Federal Surveys for Measuring the Effects of the Affordable Care Act," by C. Planalp, J. Sonier, and J. Turner. 2014. Issue Brief #41. Minneapolis, MN: State Health Access Data Assistance Center, University of Minnesota.

<sup>+</sup>There is some variation in response rate calculation across federal surveys.

#### TABLE 4. KEY CHARACTERISTICS OF FEDERAL SURVEYS USED IN SHARE-FUNDED RESEARCH

	ACTERISTICS OF I	State & Deputation			Charles Co.
Principal Investigator	Policies & Programs	State & Population Studied	Survey & Data Years	How Survey Used	State Survey Used
Joel Cantor (1 <sup>st</sup> grant) Rutgers University	Young Adult Coverage	All states; 19-29 year olds	CPS 2001 – 2009	Assess impact of state young adult dependent coverage expansions on coverage	NJ Family Health Survey
Joel Cantor (2 <sup>nd</sup> grant)	Insurance Market Reform; Young Adult	All states except HI and MA; 19-25 year olds and	CPS 2005 – 11	Estimate relative impact of federal and state dependent insurance expansion policies on young adult coverage	_
Rutgers University	Coverage	27-30 year olds	MEPS 2010	Adjust for confounding trends in state economic conditions and health insurance markets	
<b>Deborah Chollet</b> <i>Mathematica Policy</i> <i>Research</i>	Employer Strategies	MA, NY, and ME; low- income adults ineligible for Medicaid	ACS 2008	Determine if demographics may have been a source of selection bias into the MA CommCare program	
Lisa Clemans-Cope	Benefit Design/	All states, shildren	NSCH* 2007, 2011 – 12	Understand and improve the validity of the Patient Centered Medical Home	
Urban Institute	Service Delivery	All states; children	NS-CSHCN <del>†</del> 2005 – 06, 2009 – 10	survey measure	
<b>Andrew Coburn</b> University of Southern Maine	Medicaid/CHIP; Insurance Market Reform	All states; low-income rural and urban non-elderly adults in all states	MEPS 2007 – 10	Compare rural-urban eligibility and participation pre-ACA Medicaid to eligibility post-ACA Medicaid, along with the characteristics associated with such differences	
<b>John Czajka</b> Mathematica Policy Research	Medicaid/CHIP	Uninsured non-elderly adults below 400% FPL	CPS 2011	Generate estimates of non-elderly adults by a measure of income that approximates Modified Adjusted Gross Income (MAGI)	
Ronald Deprez		VT:	CPS 2005, 2006, 2008, 2009	Assess the relative contribution of initiatives in VT (vs. national or regional trends) to changes in coverage	VT Household
University of New England	Comprehensive State Reform	VT; uninsured non-elderly adults	MEPS 2006, 2008, 2009	Assess impact of VT's health reforms on employer insurance coverage decisions and the risk of migration of employees to public programs	Health Insurance Survey
Jose Escarce		IL, PA, and WA; uninsured	CPS 2002 – 09	Assess impact of reforms on children's coverage, take-up of public coverage, and crowd-out of private coverage	
UCLA	Medicaid/CHIP	children	MEPS 2001 – 06	Calculate average premium price for private insurance and potential effects of reforms on out-of-pocket costs for children's coverage and medical care	
John Graves	Madiasid/CHIP	All states; uninsured non-	ACS 2008	Use local population totals from the ACS to weight the SIPP to create small area estimates of the insurance expansion population	_
Vanderbilt University	Medicaid/CHIP	elderly adults below 400% FPL	SIPP 2008	Combine longitudinal SIPP data with the ACS weights (above) to create small area estimates of the insurance expansion population	

#### TABLE 4. KEY CHARACTERISTICS OF FEDERAL SURVEYS USED IN SHARE-FUNDED RESEARCH (CONTINUED)

Principal Investigator	Policies & Programs	State & Population Studied	Survey & Data Years	How Survey Used	State Survey Used
Elizabeth Kilbreth University of Southern Maine	Premium Assistance	MA, ME, and VT; state employees and low-income working adults	CPS 2003 – 09	Estimate the population of individuals eligible for health reform programs before and after implementation	
			SIPP 2003 - 07	Use information on wages and employment to study changes in labor market outcomes for individuals who switch to and from employer-sponsored insurance	
<b>Amanda Kowalski</b> Yale University	Comprehensive State Reform	MA; uninsured adults	NHIS 2004 – 10	Use information on coverage, health plan premiums, and residence to estimate demand for coverage	
			MEPS 2004 – 10	Quantify differences in health expenditures to estimate the impact of community rating on demand for coverage	
Lindsey Leininger University of Illinois at Chicago	Benefit Design/ Service Delivery; Medicaid/CHIP	WI: low-income childless	NHIS 1997 – 2008	Assess the predictive utility of a wider _ variety of self-reported health measures	
		adults	MEPS 2009	than are included in WI's Health Needs Assessment and add a nationally	
	Medicaid/CHIP; Comprehensive State Reform; Young Adult Coverage		CPS 2005 – 09	Assess impact of reforms on coverage	
<b>Sharon Long</b> Urban Institute		IL, MA, and NY; adults	ACS 2008	Assess demographic characteristics and geographic distribution of the remaining uninsured in MA	
			NHIS 1999 – 08	Assess impact of reforms on coverage, access to and use of care, and out-of- pocket health care costs	
Thomas Oliver	Farala an Chatas	M/L children and thei	CPS 2006 – 07	Estimate eligibility denominators to assess take-up rates and coverage penetration	
University of Wisconsin - Madison	Employer Strategies; Medicaid/CHIP	WI; children and their parents/adult caretakers	ACS 2008	Create comparison estimates of uninsured and eligible populations; simulate potential benefit of auto- enrollment under federal reform	WI Family Health Survey
Lara Shore-Sheppard Williams College	Premium Assistance; Medicaid/CHIP; Insurance Exchanges	All states; adults ages 22 to 59 in households up to 400% FPL	SIPP 1996, 2001, 2004, 2008	Describe and analyze income dynamics and characteristics of families with incomes 0-400% of the Federal Poverty Level (FPL)	

\*National Survey of Children's Health †National Survey of Children with Special Health Care Needs

#### TABLE 5. KEY CHARACTERISTICS OF STATE SURVEYS USED IN SHARE-FUNDED RESEARCH

	New Jersey Family Health Survey	California Health Interview Survey	Vermont Household Health Insurance Survey	Wisconsin Family Health Survey	Oregon Health Study
Survey Administrator	Rutgers Center for State Health Policy	UCLA Center for Health Policy Research	Vermont Department of Financial Regulation	University of Wisconsin Survey Center	Oregon Health Authority
Mode	Landline; cell phone	Landline; cell phone	Landline; cell phone	Landline	Mail
Years Administered	2001, 2009	Biennially from 2001 – 2011; continuously since 2012	2000, 2005, 2008, 2009, 2012	Annually from 2000 – 2011, 2014	2009
Sample Size*	2,500 households; 7,300 individuals	50,000 households; 60,000 individuals	4,500 households; 10,000 individuals	2,400 households; 6,400 individuals	60,000 individuals
Response Rate†	45%	20%	48%	49%	52%
Sample Methodology	The state is divided into geographically contiguous areas with socioeconomically similar counties, and proportionate samples are drawn.	Sampling strata are the 41 most populated counties and 3 groupings of the remaining 17 counties.	The state is stratified into 4 regions of geographically contiguous counties, and proportionate samples are drawn.	The 72 counties are stratified into 7 geographic regions, which are randomly sampled at varying rates.	Initial sample included lottery participants who "won" the opportunity to enroll in the Oregon Health Plan Standard program for one year (i.e., treatment group) and lottery participants who "lost" the opportunity to enroll (i.e., control group).
Unique Feature	Over-samples young adults and low-income families	The largest state-based health survey in the nation	Over-samples households with at least one uninsured resident	Includes a stratum that consists of telephone prefixes that include at least 20% black respondents	Is longitudinal and is administered as part of the first-ever randomized controlled trial assessing the effect of Medicaid coverage
Key Topics	Health insurance coverage, health care access, utilization, and satisfaction, health status, socioeconomic and employment	Health insurance coverage, health care access, health status, housing and neighborhood environments	Health insurance, dental, vision, drug, coverage, health care access and utilization, health status, socioeconomic and employment	Health insurance coverage, health care access, health status, socioeconomic and employment, public program participation	Health care access and utilization, health status, personal finances, stress and strain

\*Sample sze is for the most recent survey year.

**†**Response rate is for the most recent survey year. State surveys may use different response rate calculations.

# Medical Claims and Enrollment Data

Eighteen of 33 SHARE grantees have accessed and analyzed medical claims and/or enrollment data to examine the effect of reform strategies. Medical claims are the documented, billable interactions between a publicly or privately insured patient and the health care delivery system; claims data are ideal for evaluating health care utilization and costs. Enrollment data, defined for the purposes of this report as administrative information that can be used to determine eligibility for and monitor participation in public or private health insurance coverage, may be used to assess the effect of health reform on take up of, duration of, and churning in and out of health insurance coverage. Enrollment data are often paired with

medical claims data to evaluate the impact of reform on health care access, costs, utilization, and/or quality over time.

Table 6 presents how SHARE researchers have employed medical claims and enrollment data and the types of data used. State Medicaid data have been accessed and analyzed most often due to the emphasis on evaluating Medicaid and CHIP reforms among SHARE researchers to date. Other types of claims and enrollment data used to answer SHARE research questions include non-Medicaid, state public program information, state employee data files, hospital discharge data, and All Payer Claims Databases (APCDs). To date, SHARE researchers have acquired all medical

claims and enrollment data from state agencies, except for state employee claims data obtained from two private sources.

### **Medical Claims**

Public and private medical claims data provide information on health care encounters of large populations of insured patients, offering more detailed, accurate, and standardized information on the use and cost of health care services than survey data, which rely on patient recall of services received. Medical claims data, however, are maintained for insurance program administration and billing purposes, and may not contain data elements or covariates important for research, such as data on health attitudes and behaviors and detailed demographic information, which limits researcher ability to identify key patient subgroups of interest and make comparisons across groups. Medical claims databases are typically insurer-specific; therefore, these data preclude care paid for by a different insurer or services received but not submitted or paid for by the plan. APCDs combine claims from all payers in a state (and often other administrative data), resulting in statewide information on costs, quality, utilization, and access to care.

#### **Enrollment Data**

Enrollment data (including enrollment start and end dates, eligibility qualification data, and benefit coverage) allow for the study of key outcomes including insurance plan participation or enrollment, take up rates, continuity of health insurance coverage, churning, and disenrollment. Like medical claims databases, these databases consist of large patient populations but can have limitations in research given their design for administrative use and the potential for data quality concerns including inconsistent or incomplete data.

While there are standards for medical billing, accessing, extracting, preparing and analyzing medical claims and enrollment files can be time consuming and complicated. Data use agreements are often required from state authorities with competing demands.

## Insights from Use of Medicaid Claims and Enrollment Data to Monitor and Evaluate Health Reform

Relationships with source organizations are essential.

 Some SHARE researchers have involved organizations responsible for state claims and enrollment data early in project planning.
Engaging stakeholders such as state officials or agency staff at the research proposal stage can help facilitate mutual investment in research questions, address issues that may arise from data access and use, and facilitate needed interagency collaboration. If feasible and appropriate, consideration should be given to allocating funds to source agencies for their involvement in the research and the processing of data requests.

- One SHARE grantee suggested developing a Memorandum of Understanding between the grantee institution and data source organizations, rather than only obtaining a letter of support. Establishing a formal partnership with source organizations may prioritize project data requests and provide a platform for information sharing.
- State privacy concerns need to be addressed in order to fully execute data authorization and use agreements with source agencies. SHARE researchers recommended specifying and prioritizing data elements necessary for research and being flexible to adapt the analysis to address privacy issues. If possible and appropriate, building upon existing data use agreements with agencies may facilitate partnerships and help to clarify and address data sharing expectations and concerns. Identifying a central source for accessing data to simplify the data request, reduce the number of data use agreements required, and minimize state burden is advisable.
- Researchers suggested conducting periodic, pre-arranged check-ins with the source organizations or state stakeholders over the course of the project in order to answer questions, vet preliminary findings, and keep pace with state policy and program developments.

## *Research/evaluation project goals and timelines need to be clear but flexible.*

- Even with state backing of research and evaluation efforts, data requests can take longer than expected to process. State agencies are juggling multiple demands, competing priorities, and fluid political climates. Institutional Review Board reviews and other reviews are sometimes required even when working with de-identified data. SHARE researchers suggested preparing and submitting complete yet manageable data requests to source agencies as early as possible as well as developing flexible evaluation designs to accommodate delays.
- In addition, initial data extracts may not meet project information needs due to incomplete or inaccurate data. Building in time to accommodate the iterative process of requesting data from source agencies is important. Some SHARE grantees have been able to obtain new data files from the same source or similar data from a different source, while others have been forced to re-define the scope of analysis to accommodate data issues.

- A back-up plan may be necessary in the event that desired enrollment and/or claims data are not available or easily obtained. Some SHARE researchers have been able to identify and access alternative data sources or secure approval from funders to redefine the scope of the data collection and analysis.
- Enrollment and claims data sets tend to be large and complicated, and shortcomings often can only be identified when

working with data files. Adequate computing and staff resources and a flexible methodological approach and timeline are needed to manipulate, clean, and prepare these datasets for analysis. Be prepared to use alternative indicators, proxies, or datasets to address evaluation questions in the event of unexpected data characteristics.

#### TABLE 6. KEY CHARACTERISTICS OF MEDICAL CLAIMS AND ENROLLMENT DATA USED IN SHARE-FUNDED RESEARCH

Principal Investigator	Policies & Programs Studied	State & Population Studied	Data Source	Who Conducted Analysis	Data Use Agreement Obtained?	How Data Used					
Studies That Paired	Claims and Enrollment	Data									
E. Richard Brown UCLA	Medicaid/CHIP	CA; low-income children in CA	CA Medicaid claims and eligibility	Grantee institution	✓	Evaluated the effect of continuous eligibility on Medi-Cal enrollment and utilization among children					
<b>Deborah Chollet</b> Mathematica Policy Research	Employer Strategies	MA; low-income adults ineligible for Medicaid	MA non-Medicaid public programs claims, eligibility and enrollment (CommCare)	Subcontracted organization (file prep); Grantee institution (analysis)	$\checkmark^{\dagger}$	Evaluated risk selection in CommCare					
Thomas DeLeire University of Wisconsin - Madison	Medicaid/CHIP	WI: low-income childless adults	WI Medicaid claims, eligibility and enrollment (BadgerCare Plus Core Plan)	Grantee institution	$\checkmark^{\dagger}$	Examined effect of reform on access to care and service utilization					
<b>Stan Dorn</b> Urban Institute	Medicaid/CHIP	LA; uninsured low- income children	LA Medicaid claims and enrollment	Grantee institution	Not specified	Explored differences between Express Lane Eligibility (ELE) children and non-ELE children					
<b>Richard Hirth</b> University of	Benefit Design/ Service Delivery; Employer Strategies	Service Delivery;	Service Delivery;	Service Delivery;	Service Delivery;	Service Delivery;	CT; state employees and retirees	CT State employee claims and enrollment data (Milliman)	Database administrator (file prep); State officials (analysis)	Not specified	Evaluated effect of reform on utilization and cost
Michigan			CT State employee claims and enrollment data (Thomson Reuters)	Database administrator							
	Medicaid/CHIP; Benefit Design/ Service Delivery				KY Medicaid claims and enrollment	Subcontracted university		Fuch stard offerst of			
Genevieve Kenney Urban Institute		Benefit Design/ KY and ID; low- income adults	ID Medicaid claims and enrollment	Subcontracted university (file prep); Grantee institution (analysis)	√*	Evaluated effect of KY and ID reforms on access to care and program costs					
							MA Non-Medicaid public programs claims and eligibility data (CommCare); MA State employee claims data	Subcontracted			
<b>Elizabeth Kilbreth</b> University of Southern Maine	Premium Assistance	MA, ME, and VT; state employees and low-income working adults	ME State employee claims data; ME All Payer Claims Database (Maine Health Data Organization)	organization (file prep); Grantee institution	~	Evaluated program enrollment, access to care, and utilization					
			VT non-Medicaid public programs claims and eligibility data (Catamount Health, ESI Premium Assistance); VT State employee claims data	(analysis) t							



#### TABLE 6. KEY CHARACTERISTICS OF MEDICAL CLAIMS AND ENROLLMENT DATA USED IN SHARE-FUNDED RESEARCH (CONTINUED)

Principal Investigator	Policies & Programs Studied	Population & State Studied	Data Source	Who Conducted Analysis	Data Use Agreement Obtained?	How Data Used
Lindsey Leininger University of Illinois at Chicago	Medicaid/CHIP; Benefit Design/ Service Delivery	WI; low-income childless adults	WI Medicaid claims and enrollment (BadgerCare Plus Core Plan)	Grantee institution	$\checkmark^{\dagger}$	Assessed ability of health needs assessments to predict utilization and costs
Studies That Used C	laims Data Only					
Kate Baicker Harvard School of Public Health	Medicaid/CHIP; Benefit Design/ Service Delivery	OK; Medicaid enrollees withType Il diabetes	OK Medicaid claims	Grantee institution	Not specified	Evaluated effectiveness of financial incentives on prescription adherence
<b>Amanda Kowalski</b> Yale University	Comprehensive State Reform	MA; uninsured adults	MA All Payer Claims Database supplemented by hospital discharge data and regulatory filings	Grantee institution	$\checkmark$	Modeled risk preferences and risk types
<b>Karin Rhodes</b> University of Pennsylvania	Benefit Design/ Service Delivery	PA; low-income adults with at least one chronic condition and behavioral health issue	PA Medicaid claims data	Grantee institution	$\checkmark^\dagger$	Evaluated effect of reform on access, utilization and costs
<b>Jeanene Smith</b> Oregon Health Policy Research	Benefit Design/ Service Delivery	OR; low-income adults enrolled in CCOs	OR All Payer Claims Database	Grantee institution	$\checkmark^\dagger$	Evaluated CCO effect on quality, health, utilization, per-member costs, and per-user costs
Studies That Used E	nrollment Data Only					
Cynthia Boddie- Willis The Hilltop Institute	Medicaid/ CHIP; Benefit Design/ Service Delivery; Employer Strategies; Premium Assistance	NM; uninsured non-elderly adults below 200% FPL and small employer groups	NM Medicaid SCI enrollment data	Grantee institution	Not specified	Assessed the impact that changes to the program have had on the number of employers participating and enrollee composition
Michael Cousineau University of Southern California	Medicaid/CHIP	CA; uninsured low- income children	CA Medicaid enrollment data	Grantee institution	Not specified	Assessed whether outreach and enrollment strategies affected enrollment and retention
<b>Ronald Deprez</b> University of New England	Comprehensive State Reform	VT; uninsured non- elderly adults	VT non-Medicaid public programs enrollment data (Catamount Health)	Grantee institution	Not specified	Assessed the impact of reform on access to comprehensive affordable health insurance coverage
<b>David Idala</b> Maryland Department of Health & Mental Hygiene	Medicaid/CHIP	MD; uninsured low-income children	MD Medicaid enrollment data	Grantee institution	Not specified	Evaluated the impact of the Maryland Kids First Act on identification and enrollment of uninsured children eligible for Medicaid/CHIP
Edward Miller Brown University	Medicaid/CHIP; Benefit Design/ Service Delivery; Employer Strategies	RI; employees of small businesses	RI Non-Medicaid public programs enrollment data (HEALTHpact)	Grantee institution	Not specified	Estimated the number of enrollees in the HEALTHpact program
<b>Thomas Oliver</b> University of Wisconsin - Madison	Medicaid/CHIP; Employer Strategies	WI; children and their parents/adult caretakers	WI Medicaid eligibility and enrollment data (BadgerCare Plus Core Plan)	Subcontracted organization (file prep); Grantee institution (analysis)	$\checkmark^\dagger$	Compared enrollment, take-up and exit trends before and after the introduction of the BadgerCare Plus program

\* Data use agreement was obtained by subcontracted university.
+ Researchers used existing data-sharing agreements to obtain claims files.

## **Qualitative Data**

Qualitative data collection is the systematic collection of evidence often for the purpose of investigating complex situations and contexts. In health research, qualitative data collection is often inductive, where textual information is gathered through observation of or exploration with targeted respondents, reviewed for themes, coded, and interpreted. Advantages to qualitative data collection include the ability to: 1) ask open-ended questions, 2) probe for additional explanation, 3) assess the political, social, and historical context of health reform programs or policies, and 4) collect multiple stakeholder perspectives related to program processes, implementation issues, and outcomes.

To date, seventeen of the 33 SHARE researchers have relied on qualitative data collection methods, namely semi-structured interviews, focus groups, and site visits (which often consist of both individual and group interviews, as well as focus groups), to aid in answering health reform monitoring and evaluation questions. Twelve SHARE grantees have supplemented quantitative elements of their evaluation with qualitative data collection.

One disadvantage to qualitative methods is the time- and resourceintensive nature of qualitative data collection and analysis. These methods can require many hours to identify and invite targeted respondents, conduct interviews and focus groups, transcribe notes or recordings, and code and analyze data. Another disadvantage of qualitative designs is a lack of generalizability of findings. Qualitative and quantitative methods can be used in tandem, however, to address this limitation and to leverage the strengths of both types of methods and data. For example, findings from qualitative research can aid in the interpretation or validation of quantitative findings or surface new inquiries that can be addressed using quantitative methods. See Table 7 for more detailed information on how SHARE researchers collected and used qualitative data.

#### Insights from the Collection and Use of Qualitative Data to Monitor and Evaluate Health Reform

State contacts and collaborators facilitate respondent identification and participation.

- Stakeholders such as state officials, consumers, and payers can play an important role in informing the development of salient research questions, as well as serve as part of a knowledgeable test group to pilot questions and length of data collection guides.
- Existing contacts within states have facilitated the recruitment of respondents for SHARE qualitative data collection efforts. States can be helpful in recommending respondents who represent multiple perspectives on a policy or program topic or

key individuals who evaluators may have overlooked. According to SHARE investigators, state officials were more likely to participate in research efforts when referred by a colleague or aware that the project was backed by a state agency.

## Several factors may interfere with state and local level qualitative research, and researchers must anticipate and address barriers.

- SHARE researchers have found state staff/officials and other stakeholders usually very motivated and willing to participate in health reform research. Nonetheless, state officials may have difficulty finding time to participate due to other demands and the unpredictability of reform implementation on top of regular business. Project budgets and timelines should reflect respondent recruitment and scheduling challenges. Researchers should also budget extra time for monitoring emerging information (e.g., newly released rules and regulations) throughout the policy/ program implementation process.
- Similarly, conducting research during reform implementation may pose challenges. It is recommended that research teams interested in impact and/or outcome evaluations choose to study more fully implemented programs, as evaluation that occurs concurrently with implementation can limit the scope of the project. Researchers interested in conducting process evaluations may want to bear in mind these challenges, yet still choose to begin evaluation during implementation to ameliorate potential recall bias later on.
- Site visit scheduling should take into account the timing of state legislative sessions and monitor recent state developments in order to avoid conflicts and minimize respondent burden
- Evaluators should keep in mind that state government can have high turnover, especially after a change in administration, and new personnel may be unaware of the context of initial policy or program implementation.
- Visual aids, such as program or policy timelines, can be helpful to respondents and aid in the accuracy of data collection when respondents are asked to reflect on particular situations or programmatic changes.

#### TABLE 7. KEY CHARACTERISTICS OF QUALITATIVE DATA COLLECTED IN SHARE-FUNDED RESEARCH

Principal Investigator	Study Population	Study State(s)	Data Collection Methods	Study Respondents <sup>1</sup>	Examples of Topics Discussed	How Data Used
<b>Cynthia Boddie-Willis</b> The Hilltop Institute at University of Maryland Baltimore County	Uninsured non- elderly adults	NM	Site Visits	State program administrators, program staff, brokers, managed care organizations (n = 60)	Study design; survey instrument	Sought input on study design; assessed ongoing data collection strategies
<b>Joel Cantor</b> Rutgers University	19 – 29 year olds	All	Interviews	State regulatory officials, insurance groups, business groups, consumer groups (n = 23)	Nature of the policy debate leading to enactment of young adult dependent coverage law; implementation issues and concerns; extent of and strategies for promoting public awareness of the expanded dependent coverage; extent of young adult dependent enrollment; impressions of the intended and unintended impacts of the law; plans for changes in the law or associated regulations	Augmented findings from state policy review
<b>Andrew Coburn</b> University of Southern Maine	Rural residents	ME, NY, NC, FL, PA, WI, OR, MN	Interviews	Stakeholders, insurers, payers	CO-OP plans in rural areas; geographic rating in the individual and small group markets; access standards for Qualified Health Plans in rural health insurance exchanges	Gained variety of perspectives to understand the program's development and implementation
<b>Michael Cousineau</b> University of Southern California	Uninsured low- income children	CA	Interviews, Site Visits	County program administrators, program staff, contracted outreach agencies, school districts, other organizations	Outreach and enrollment and technology-based strategies employed; general timelines; number of full-time employees at respondent organizations; design, application, strengths and weaknesses of identified strategies; extent to which each strategy was utilized	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
<b>Ronald Deprez</b> University of New England	Uninsured non- elderly adults	VT	Interviews, Site Visits	Legislative representatives, executive staff, insurers, provider organizations, non-profits (n = 24)	Policy context for initial program design; program implementation experience to date, including success factors and modifications required; predictions and concerns regarding the future of health reform programs and viability of funding; plan affordability; reduction of uninsured; crowd out; offer rate; benefit design; deductibles; premium contribution	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
Stan Dorn	Uninsured low-	MA	Interviews, Site Visits	Program administrators, provider organizations, insurers, health care advocates, researchers, community-based organizations (n = 15)	Implementation of health care reform; reasons behind enrollment success	Gained variety of perspectives to understand the program's development and implementation
Stan Dorn Urban Institute	income children	LA	Interviews, Focus Groups, Site Visits	State program administrators, administrators of other state programs, local program staff, community- based organizations (n = $15$ )	Express Lane Eligibility's effects on coverage, access to care, enrollment and renewal outcomes, and administrative costs	Gained variety of perspectives to understand the program's development and implementation
<b>Lisa Dubay</b> Johns Hopkins University	Uninsured non- elderly adults	il, MD, NJ, NM, OK	Interviews, Site Visits	State program administrators, executive staff, legislative leadership, business groups, provider organizations, health care advocates $(n = 9)$	Political and economic context; factors that affect the sustainability of the initiative; estimate the impact of these incremental strategies	Gained variety of perspectives to understand the programs' development and implementation

#### TABLE 7. KEY CHARACTERISTICS OF QUALITATIVE DATA COLLECTED IN SHARE-FUNDED RESEARCH (CONTINUED)

Principal Investigator	Study Population	Study State(s)	Data Collection Methods	Study Respondents*	Examples of Topics Discussed	How Data Used
Jose Escarce UCLA	Uninsured children	IL, PA, WA	Interviews, Site Visits	State program administrators, executive staff, legislative representatives, advocacy groups ( $n = 31$ )	Process of establishing the expansion; the implementation of the program, including enrollment and outreach strategies; determination of affordability of premiums; extent of crowd-out and whether and how it was resolved; program sustainability	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
<b>Mark Hall</b> Wake Forest University	Employees	MA, IN, MO	Interviews, Site Visits	Agents/benefit advisors, insurers, government officials, third party administrators, employer groups, trade associations (n = 68)	Whether Section 125 Plans met goals; extent of employer and employee take-up; administrative or legal issues; identification of employers and employees that find these plans most and least attractive; whether section 125 plans for individual insurance are a good idea	Gained variety of perspectives to understand the program's success
<b>David Idala</b> MD Dept. of Health and Mental Hygiene	Uninsured low- income children	MD	Interviews	State program administrators, staff of other state agencies, county program administrators, legislators (n = 14)	Policy decisions and key considerations of leadership in designing and implementing the Maryland Kids First Act initiative; implementation processes	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
<b>Genevieve Kenney</b> Urban Institute	Low-income adults	ID, KY	Interviews, Site Visits	State program administrators, providers, provider organizations, managed care organizations, community- based organizations	Design and implementation of the Medicaid reform efforts	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
Elizabeth Kilbreth University of Southern Maine	Low-income working adults; state employees	MA, ME, VT	Interviews	Researchers, policymakers (n = 50)	Policy environment and decisions regarding program design and funding; stakeholder engagement; program implementation issues and mid-course corrections	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
Edward Miller	Employees of small businesses	RI	Interviews	State officials, insurers, brokers, employers, direct- pay customers (n = 25)	Passage, design, and implementation of HEALTHpact; other state- mandated plan designs; the role of government in the small-group health insurance market	Gained variety of perspectives to understand the program's development and implementation
Brown University	Low-income adults	RI	Interviews	Agency officials, legislative staff, providers, other knowledgeable observers (n = 30)	Design of the RI Global Consumer Choice Compact Waiver; waiver's approval by the federal government; eventual adoption in RI	Gained variety of perspectives to understand the program's development and implementation

#### TABLE 7. KEY CHARACTERISTICS OF QUALITATIVE DATA COLLECTED IN SHARE-FUNDED RESEARCH (CONTINUED)

Principal Investigator	Study Population	Study State(s)	Data Collection Methods	Study Respondents <sup>1</sup>	Examples of Topics Discussed	How Data Used
Len Nichols George Mason University	U.S. citizens and legal residents	All	Focus Groups	Federal officials, state officials, researchers, advocates	Coverage expansion; delivery system reform; workforce development; public health improvement	Gained variety of perspectives to understand opportunities for future work
<b>Mike O'Grady</b> NORC at the University of Chicago	None	None	Interviews	CMS staff, Census staff, MACPAC staff, Center for Consumer Information and Insurance Oversight staff, National Center for Health Statistics staff	The most useful set of data linkage projects to inform health reform; barriers to comprehensive access to these linked data sets; current limits on data access; possible coalitions of interest both inside and outside the federal government to sustain the project over time	Gained variety of perspectives to understand opportunities for future work
<b>Thomas Oliver</b> University of Wisconsin – Madison	Children and their parents/ adult caretakers	WI	Interviews	State program administrators, county program staff, health care associations, advocacy groups ( $n = 17$ )	Process of program design and implementation; intent of policy makers and program administrators	Gained variety of perspectives to understand the program's development and implementation; helped to interpret quantitative results
<b>Theresa Sachs</b> Health Management Associates	Low-income adults	DC, MD, MN, NY, OK, WA	Interviews	State program administrators, program staff, state officials	Implementation, policy and legal issues related to Medicaid expansion; benefits and challenges of coverage options under consideration; impact on current enrollees; state/ federal approval requirements; impact of Maintenance of Eligibility requirements and restriction of state- funded programs	Gained variety of perspectives to understand options for the future of state- funded programs
<b>Jeanene Smith</b> Oregon Health Policy Research	Low-income adults	OR	Interviews, Focus Groups	Coordinated Care Organization (CCO) leaders, providers, stakeholders, local community leaders	CCO governance, organization, finance, and operations	Tied CCO characteristics to survey and administrative performance data

\*SHARE researchers used non-probability sampling methods, typically purposive sampling, to identify potential respondents. Some researchers identified respondents through guidance from state contacts and from State Health Access Data Assistance Center (SHADAC) staff.

## **Summary and Conclusions**

Policy relevant data and ample state level information are needed to monitor and assess health reform at the state level and must come from a variety of sources; no one data source has it all. SHARE researchers have employed survey, claims, enrollment, and qualitative data, primarily, and have worked closely with state organizations to do so, which has facilitated both quantitative and qualitative data collection.

Relying on states for information requires strategic planning and execution due to the enormous pressure states are under to implement both national and state reforms and state sensitivities to data use. Insights from SHARE researchers confirm the importance of relationships at the state level to help ensure that project goals, timelines, and products are meaningful to not only the researchers and funders but also to the "on the ground" decision makers. In addition, it is critical that evaluation plans are clear and flexible to accommodate state concerns and changing priorities as well as to address inherent delays in accessing needed information and data limitations.

National health reform has triggered new data needs, such as more useful state-level data in federal surveys and upgraded state eligibility and enrollment systems for public programs, as well as the potential for new data sources, such as data from federal and state health care marketplaces. Efforts to aggregate claims (and administrative data) in APCDs are being considered in more states. SHADAC and the SHARE program will continue to monitor and assess the wealth of information available for needed health reform evaluation and research into the future.

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### REFERENCES

Planalp, C. Sonier, J., & Turner, J. 2014. "Using Recent Revisions to Federal Surveys for Measuring the Effects of the Affordable Care act." Issue Brief #41. Minneapolis, MN: State Health Access Data Assistance Center, University of Minnesota.

## Appendix A: SHARE Grants, 2008 - Present

For a full list of awarded grants, visit www.shadac.org/share/awarded-grants.

#### Round One Grants (2008)

#### Achieving Universal Coverage through Comprehensive

Health Reform: The Vermont Experience

Ronald D. Deprez Institution: University of New England RWJF Grant Number: 64212 Grant Period: 04/30/2008 – 06/30/2010

#### An Evaluation of the Impacts of State Health Reform

#### Initiatives in IL, MA, and NY

Sharon K. Long Institution: Urban Institute RWJF Grant Number: 64315 Grant Period: 05/01/2008 – 06/30/2011

#### Assessing the First Use of Auto-Enrollment for a State

#### **Coverage Expansion**

**Stan L. Dorn** Institution: University of Wisconsin-Madison RWJF Grant Number: 64275 Grant Period: 04/01/2008 – 04/30/2012

## Effects of Medicaid Reform on Access to Care, Program Sustainability, and Administrative Efficiency in Kentucky

#### and Idaho

**Genevieve Kenney** 

Institution: Urban Institute RWJF Grant Number: 64208 Grant Period: 04/01/2008 – 06/30/2010

#### **Evaluating Small Group Employer Participation in New**

#### Mexico's SCI Program

#### **Cynthia Boddie-Willis**

Institution: The Hilltop Institute at University of Maryland Baltimore County RWJF Grant Number: 64309 Grant Period: 05/01/2008 – 10/31/2010

#### **Evaluating the Impact of Outreach and Enrollment**

#### Strategies in California

Michael R. Cousineau

Institution: University of Southern California RWJF Grant Number: 64276 Grant Period: 04/01/2008 – 02/28/2010

#### Evaluating the Implementation of the Rhode Island HealthPact Plans and the Design and Implementation of Rhode Island's Medicaid Block Grant

## Edward Miller

Institution: Brown University (completed grant at University of Massachusetts - Boston) RWJF Grant Number: 64214

Grant Period: 04/01/2008 – 08/31/2010

#### Evaluating Wisconsin's BadgerCare Plus Reform

#### Package on Enrollment, Efficiency, and Churning Thomas Oliver

Institution: University of Wisconsin-Madison RWJF Grant Number: 64222 Grant Period: 04/01/2008 – 01/31/2010

#### Evaluation of 12-Month Continuous Eligibility in

Medicaid E. Richard Brown Institution: University of California, Los Angeles RWJF Grant Number: 64209 Grant Period: 04/01/2008 – 09/30/2010

## Evaluation of Extending Dependent Coverage to Young

Adults Joel C. Cantor Institution: Rutgers University RWJF Grant Number: 64320 Grant Period: 05/01/2008 – 10/31/2010

#### **Evaluation of Risk Selection in Market-Based State**

Programs

**Deborah Chollet** Institution: Mathematica Policy Research, Inc. RWJF Grant Number: 64215 Grant Period: 05/01/2008 – 12/31/2011

#### **Evaluation of Three States' Reforms to Cover All**

#### Children Jose J. Escarce

Institution: University of California, Los Angeles RWJF Grant Number: 64211 Grant Period: 04/01/2008 – 12/31/2010

#### How Affordable are State Coverage Plans?

#### Elizabeth Kilbreth

Institution: University of Southern Maine RWJF Grant Number: 64216 Grant Period: 04/01/2008 – 07/31/2011

#### Incremental Strategies to Cover Low-Income

#### **Uninsured Adults**

Lisa Dubay Institution: Johns Hopkins University RWJF Grant Number: 64219 Grant Period: 04/01/2008 – 09/30/2010

#### Maryland Kids First Act Outreach Evaluation

David Idala Institution: Maryland Department of Health and Mental Hygiene RWJF Grant Number: 64216 Grant Period: 12/01/2008 – 05/31/2012

#### Sheltering Employee Premium Contributions from Tax

#### Using "Section 125 Plans"

**Mark A. Hall** Institution: Wake Forest University RWJF Grant Number: 64207 Grant Period: 04/01/2008 – 03/31/2010

## Round Two Grants (2010)

#### Developing a Monitoring Strategy for Health Reform's

#### Progress and Effects Len Nichols

Institution: George Mason University RWJF Grant Number: 67971 Grant Period: 09/01/2010 – 12/31/2012

#### Eligibility Determination Using Modified Adjusted Gross Income: Implications for Enrollment under Health

#### Reform

John Czajka

Institution: Mathematica Policy Research, Inc. RWJF Grant Number: 68232 Grant Period: 10/15/2010 – 04/30/2012

#### **Evaluation of State & Federal Young Adult Dependent**

**Coverage Expansion Policies** Joel C. Cantor Institution: Rutgers University RWJF Grant Number: 68071 Grant Period: 11/01/2010 – 04/30/2013

#### Expanding Coverage and Ensuring Access: The

Challenges and Opportunities of Implementing Health

#### **Reform in Rural America**

Andrew Coburn Institution: University of Southern Maine RWJF Grant Number: 68077 Grant Period: 09/01/2010 – 02/29/2012

### Implications and Options for State-Funded Programs

under Health Reform Theresa Sachs Institution: Health Management Associates, Inc. RWJF Grant Number: 68076 Grant Period: 08/01/2010 – 06/30/2012

#### Income Dynamics and Characteristics of Health Reform

## Expansion Populations

Lara Shore-Sheppard Institution: Williams College RWJF Grant Number: 68069 Grant Period: 09/01/2010 – 08/31/2012

#### Strategies for Moving the SNACC Project to the

Next Level: Leveraging SNACC Data for Policy and Evaluation

**Mike O'Grady** Institution: NORC at the University of Chicago RWJF Grant Number: 68321 Grant Period: 10/15/2010 – 05/31/2011

#### Using Behavior Nudges to Improve Disease

Management: Cost-Effective Strategies for Improving

#### Care of Low-Income Diabetics Kate Baicker

Institution: Harvard University RWJF Grant Number: 68057 Grant Period: 09/01/2010 – 08/12/2012

### Round Three Grants (2012)

Medical Homes Measures in Household Survey Data: State-Level Estimates Using Alternative Methodological

#### **Approaches**

Lisa Clemans-Cope Institution: Urban Institute RWJF Grant Number: 70167 Grant Period: 07/01/2012 – 06/30/2013

#### **Rural Implementation and Impact of Medicaid**

#### Expansions Andrew Coburn

Institution: University of Southern Maine RWJF Grant Number: 70166 Grant Period: 07/01/2012 – 06/30/2013

## Planning for ACA Coverage Expansion: How Insurance

Coverage for Childless Adults Will Affect Utilization Thomas DeLeire

Institution: University of Wisconsin-Madison RWJF Grant Number: 70169 Grant Period: 07/01/2012 – 12/31/2013

## Small-Area Microsimulation to Study Geographic

## Variation in Coverage Expansions and Access Under

#### the Affordable Care Act

John Graves Institution: Vanderbilt University RWJF Grant Number: 70161 Grant Period: 07/01/2012 – 06/30/2013

#### Innovative Benefit Design for CT State Employees Richard Hirth

Institution: University of Michigan RWJF Grant Number: 70168 Grant Period: 07/01/2012 – 06/30/2014

#### **Understanding Health Insurance and Policy Using**

## Massachusetts Health Reform

Amanda Kowalski Institution: Yale University RWJF Grant Number: 70162 Grant Period: 07/01/2012 – 06/30/2014

## Informing Medicaid Program Design for Low-Income Childless Adults: The Promise of Self-Reported Health

## Measures

**Lindsey Leininger** Institution: University of Illinois at Chicago RWJF Grant Number: 70164 Grant Period: 09/01/2012 – 08/31/2013

## Behavioral Health and Care for Chronic Medical Conditions in Pennsylvania: The Role of the Medical

Home Karin Rhodes Institution: University of Pennsylvania RWJF Grant Number: 70165 Grant Period: 07/01/2012 – 06/30/2014

## Achieving the Triple Aim in Medicaid: Evaluating the Access, Quality, Health and Cost Impacts of

## Coordinated Care Organizations in Oregon

Jeanene Smith Institution: Office of Oregon Health Policy and Research RWJF Grant Number: 70163 Grant Period: 07/01/2012 – 06/30/2014

## Appendix B: Examples of SHADAC's Resources on Federal Survey and Administrative Data

Blewett, LA and Beebe, TJ (2003). "Estimating the Size of the Uninsured and Other Vulnerable Populations in a Local Area." In Weinick, R.M. and Billings, J. (eds), Monitoring the Health Care Safety Net – Book III: Tools for Monitoring the Health Care Safety Net, Rockville, MD: Agency for Healthcare Research and Quality. AHRQ Publication No. 03-0027. Available at: http://archive.ahrq.gov/data/safetynet/ blewett.htm

Relevant federal survey data resource: Behavioral Risk Factor Surveillance System (BRFSS)

Call, KT (2013). "Examining Errors in Medicaid Reporting Across Four National Surveys: ACS, CPS, MEPS, and NHIS," at the AAPOR 28th Annual Conference in Boston on May 17, 2013. Available at: http://www.shadac.org/publications/examining-errors-in-medicaidreporting-across-four-national-surveys-acs-cps-meps-and-nh

Relevant federal survey data resources: Medical Expenditure Panel Survey - Household Component (MEPS-HC), and the National Health Interview Survey (NHIS)

Casey, M, Call, KT, and Klingner, J (2001). "Are Rural Residents Less Likely to Obtain Recommended Preventive Healthcare Services?" American Journal of Preventive Medicine 21 (3):182-188. Available at: http://www.shadac.org/publications/are-rural-residents-less-likely-obtainrecommended-preventive-healthcare-services

Relevant federal survey data resource: BRFSS

Planalp, C, Sonier, J, and Turner, J (2014). "Using Recent Revisions to Federal Surveys for Measuring the Effects of the Affordable Care Act." Available at: http://www.shadac.org/files/shadac/publications/FINAL\_SHADAC%20Brief%2041.pdf

Relevant federal survey data sources: American Community Survey (ACS), Current Population Survey (CPS), NHIS, MEPS-HC, BRFSS, National Survey of Children's Health (NSCH), Survey of Income and Program Participation (SIPP)

SHADAC (2014). "SHADAC Data Center." Available at: http://datacenter.shadac.org

Relevant federal survey data resources: BRFSS and NHIS

SHADAC (2014). "Robert Wood Johnson Foundation (RWJF) DataHub: Health Statistics You Can Visualize, Customize, and Share." Available at: http://www.rwjf.org/en/research-publications/research-features/rwjf-datahub.html (analyses conducted and updated by SHDAC)

Relevant federal survey and administrative data resources: BRFSS and Healthcare Cost and Utilization Project (HCUP)

SHADAC (July 2013). "Review of Existing Data Sources to Assess the Impacts of the Affordable Care Act Medicaid Expansions: Working Paper." SHADAC: Minneapolis, MN. Available at: http://www.shadac.org/publications/review-existing-data-sources-assess-impacts-affordablecare-act-medicaid-expansions-wor

Relevant federal survey data resource: BRFSS

SHADAC (January 2013). "NHIS Questionnaire Changes Addressing the Patient Protection and Affordable Care Act." SHADAC: Minneapolis, MN. Available at: http://www.shadac.org/files/shadac/publications/NHIS\_ACA\_Brief34.pdf

Relevant federal survey data resource: NHIS

SHADAC (2012). "Considerable Variation Exists in Obesity Rates among States and by Race and Ethnicity." SHADAC: Minneapolis, MN. http://www.rwjf.org/en/research-publications/research-features/rwjf-datahub/data-stories/rates-of-obesity.html

Relevant federal survey data resource: BRFSS

SHADAC (2012). "These Hospitalizations Drive up Costs and are Tough on Patients." SHADAC: Minneapolis, MN. Available at: http://www.rwjf.org/en/research-publications/research-features/rwjf-datahub/data-stories/preventable-hospitalizations.html

Relevant federal administrative data resource: HCUP

SHADAC (2011). "Monitoring the Impacts of Health Reform at the State Level: Using Federal Survey Data." SHADAC: Minneapolis, MN. Available at: http://www.shadac.org/files/shadac/publications/SHADAC\_Brief24.pdf

Relevant federal survey data resources: BRFSS, MEPS-HC, and NHIS

SHADAC (2003). "A State Perspective on National Survey Data on the Uninsured." SHADAC: Minneapolis, MN. Available at http://www.shadac.org/publications/state-perspective-national-survey-data-uninsured

Relevant federal survey data resources: BRFSS, MEPS-HC, and NHIS



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