

# **Ryan White HIV/AIDS Program Modeling Study**

## **Paperwork Reduction Act Supporting Statement Part A**

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Department of Health and Human Services  
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## **SUPPORTING STATEMENT PART A FOR RYAN WHITE HIV/AIDS PROGRAM MODELING STUDY**

### **A. Justification**

#### **1. Circumstances Making the Collection of Information Necessary**

The Ryan White HIV/AIDS Program (RWHAP) is the largest federal funding program specifically dedicated to serving the health care needs of people living with HIV/AIDS (PLWHA) and their families. It is a discretionary spending program that serves more than 550,000 PLWHA annually and has been reauthorized since 1990 every three to five years. Originally enacted in 1990 as the Ryan White Comprehensive AIDS Relief Emergency (CARE) Act, Congress has made substantial changes to the program as the HIV/AIDS epidemic has evolved (Kaiser 2006). It remains to be seen whether new changes will be considered and enacted in the next reauthorization of the program, scheduled for 2013, in anticipation of the full implementation of the Patient Protection and Affordable Care Act of 2010 (Affordable Care Act) in 2014.

The Affordable Care Act promises to reduce significantly the number of uninsured U.S. residents, including PLWHA, through expansion of Medicaid in some states and new private health insurance coverage options. Expanded coverage through Medicaid and the new state health insurance exchanges could significantly reduce the number of people requiring RWHAP-funded core medical services.<sup>a</sup> To the extent that state Medicaid programs and health exchanges will also cover HIV support services, there might be a reduced demand for transportation assistance, nonmedical case management, and other support services currently covered under the RWHAP. Appendix A contains a copy of sections of the Affordable Care Act that are relevant to this study.<sup>b</sup>

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<sup>a</sup> Core medical services include outpatient and ambulatory medical services, medications, mental health and substance abuse services, oral health care, hospice care, early intervention services, health insurance premium and cost-sharing assistance, medical nutrition therapy, medical case management, home and community-based health services, and home health care (Ryan White HIV/AIDS Treatment Extension Act of 2009, Public Law 111-87).

<sup>b</sup> We have identified sections 1001 (Amendments to the Public Health Service Act), 1302 (Essential health benefits requirements), and 2001 (Medicaid coverage for the lowest income populations) as the sections of the Affordable Care Act most relevant to this study. These sections have been included in Appendix A of this document. While we believe these three sections to be most relevant to PLWHAs, sections 1401 (Refundable tax credit providing premium assistance for coverage under a qualified health plan), 1402 (Reduced cost-sharing for individuals enrolling in qualified health plans), 4104 (Removal of barriers to preventive services in Medicare), 4105 (Evidence-based coverage of preventive services in Medicare), 4106 (Improving access to preventive services for eligible adults with Medicaid), and 5601 (Spending for Federally Qualified Health Centers (FQHCs)) are also important to the PLWHA population.

However, gaps in HIV/AIDS care will continue, and even with full implementation of the Affordable Care Act, many U.S. residents will remain uninsured, particularly (1) people who are eligible for but not enrolled in Medicaid; (2) undocumented immigrants, who are barred from participation in Medicaid and state health insurance exchanges; (3) people who are exempt from the individual mandate (which requires individuals to purchase health insurance) because they do not have affordable insurance options; (4) individuals who are eligible for but are not enrolled in subsidized coverage available under the new state health insurance exchanges; and (5) uninsured adults who have an affordable insurance coverage option (Buettgens and Hall 2011). In addition, individuals who are currently insured and those who transition to Medicaid or private health insurance under the Affordable Care Act may have ongoing needs for wraparound medical and support services (services that are not covered under public and private insurance plans) and enhanced services (services that are not sufficiently covered under public and private insurance plans) provided by RWHAP. Recognizing these problems, the National HIV/AIDS Strategy (NHAS) published by the White House in 2010 states that “gaps in essential care and services for people living with HIV will continue to need to be addressed along with the unique biological, psychological, and social effects of living with HIV. ...Therefore, the RWHAP and other Federal and State HIV-focused programs will continue to be necessary after the [Affordable Care Act] is implemented” (Office of National AIDS Policy 2010).

The RWHAP modeling study sponsored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services (DHHS) is an important step in the federal government’s attempt to understand and plan for potential changes that may be needed as a result of shifts in demand for RWHAP-funded services under the Affordable Care Act.

## **2. Purpose and Use of Information Collection**

The overall goals of the study are to project the service needs of low-income and uninsured or underinsured people living with HIV/AIDS as the provisions of the Affordable Care Act are implemented in 2014 and to identify strategies for ensuring that available federal resources are directed to areas of greatest need for HIV/AIDS care under federal health reform.

The primary objectives of this study are to:

- 1.** Develop projections about the level of need for RWHAP-funded HIV medical care, wraparound support services, and HIV drug coverage after Affordable Care Act implementation
- 2.** Determine the implications of the Affordable Care Act implementation for the future allocation and distribution of RWHAP funds

- 3.** Identify eligible jurisdictions and populations that will depend on RWHAP-funded core and supportive services for their HIV care
- 4.** Project the types of HIV/AIDS service gaps that will remain, even after implementation of coverage expansions under the Affordable Care Act in 2014
- 5.** Identify options for improved monitoring of the cost of RWHAP-funded services, and developing alternative payment methods for reimbursing HIV care providers

The study will analyze a range of existing quantitative data sources, including RWHAP administrative data, RWHAP allocation and expenditure reports, Medicaid enrollment and claims data, and HIV surveillance data. These data will be used to estimate the current distribution of funding for different types of services to Ryan White clients with different types of health insurance coverage or without health insurance, as well as to calculate future gaps between the current level of RWHAP-funded services and the projected services needed after Affordable Care Act implementation. In addition to analyzing these secondary data, this project includes primary data collection. The source of these new data and the subject of this information collection request will be primary data collection in the form of 210 telephone semi-structured interviews<sup>c</sup> with RWHAP grant program managers and administrators and with administrators of medical provider organizations receiving RWHAP funding. These interviews will be used to collect information about (1) HIV service needs and use; (2) RWHAP funding prioritization and allocation processes; (3) funding sources to support the provision of HIV care; (4) coordination of client insurance eligibility determination, and enrollment; and (5) strategies to manage RWHAP expenditures. This information will help ASPE understand the potential impact of the implementation of the Affordable Care Act on RWHAP funding needs, funding allocations, and services from the perspectives of its grantees and providers.

### **3. Use of Improved Information Technology and Burden Reduction**

Data collection will rely on paper-and-pencil interview guides used by staff at our contracting organization, Mathematica Policy Research. Development and use of information technology for data collection, particularly programming an automated instrument, would not be cost-effective for 210 semi-structured interviews that contain open-ended questions. In addition, live telephone interviews allow an open dialogue between respondent and interviewer that can help elicit richer responses to open-ended questions. Furthermore, the technical complexity of the topics covered in the interviews requires skilled and experienced interviewers with substantive knowledge of the RWHAP to facilitate the discussions. Data from the telephone semi-structured interviews will be entered into a Microsoft

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<sup>c</sup> Semi-structured interviews will consist of structured questions with open-ended responses.

Word template, where the responses will be coded for later entry into Atlas.ti, a qualitative analysis application.

#### **4. Efforts to Identify Duplication and Use of Similar Information**

This information collection is associated with a new project for ASPE, does not duplicate any other effort, and will provide unique information unavailable from any other source. The Health Resources and Services Administration (HRSA) is responsible for developing a plan for transitioning RWHAP in light of the changes brought about by the Affordable Care Act (Senate Report 2010) and has completed a study to understand the potential impact of the Affordable Care Act on RWHAP grantees, providers, clients, and other low-income and uninsured or underinsured PLWHA. The HRSA study collected information from RWHAP and Medicaid administrators from only seven states and therefore did not provide information that could be generalized across all grantees. In addition, the HRSA study did not collect information from Ryan White Part A grantees or any RWHAP-funded provider organizations. Thus, the information collected through the grantee and provider semi-structured interviews in the RWHAP modeling study will provide a unique and important opportunity to understand the Ryan White clients' service use and service needs from the perspective of a representative sample of RWHAP grantees and providers, prior to implementation of Affordable Care Act coverage expansions.

#### **5. Impact on Small Businesses or Other Small Entities**

Small businesses will not be affected by this data collection effort. The RWHAP grantees and providers targeted by this study represent state, county, and municipal governments and medical providers, including hospitals, university-based outpatient clinics, federally qualified health centers, and other medical providers with 10 or more HIV patients.

#### **6. Consequences of Collecting the Information Less Frequently**

The semi-structured interviews will be administered a single time for each respondent, and participants will be contacted a second time only if clarification is needed on any of their responses.

#### **7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5**

There are no special circumstances related to the proposed data collection.

#### **8. Comments in Response to the Federal Register Notice/Outside Consultation**

A 60-day Federal Register Notice was published in the *Federal Register* on March 8, 2012, Volume 77, No. 46, p. 14016. (see Appendix B).



**Public comment and responses.** Two comments were received in response to the first Federal Register notice; the responses were from two of the external consultants that were notified of this work and are listed below in the consultation section. The two response letters are in Appendix C; both are supportive of the proposed work and provide specific suggestions to the proposed procedures and questions to the grantees and providers. Their comments and those of the other seven consultants are compiled into Appendix D, as described below.

**Consultation outside the agency.** On March 31, 2012, Mathematica Policy Research (the organization contracted by HRSA to conduct this study) sent emails to external organizations that had expressed interest in reviewing the study's guides to alert them of the publication of the study's 60-day notice and to provide them with copies of the draft interview guides. In response, HRSA received comments from nine individuals, listed below. Their comments and our responses are provided in Appendix D: Responses to Comments from External Reviewers. We used the comments to revise the interview guides, which were then pre-tested in telephone interviews with two Ryan White program grantees and two Ryan White program providers between May 11 and 15. The results of the pre-test interviews were used to make a subsequent round of revisions in the interview guides, particularly with respect to revised wording of probes and additional notes to interviewers to help in conducting the interview. The revised grantee and provider interview guides are provided in Appendices F and G, respectively.

- Lucy Bradley-Springer, Mountain Plains AIDS Education and Training Center
- Jenny Collier, Ryan White Medical Provider Coalition
- James Friedman, American Academy of HIV Medicine
- Ernest Hopkins, CAEAR Coalition
- Kali Lindsey, National Minority AIDS Council
- Britten Pund, National Alliance of State and Territorial AIDS Directors
- Julie Scofield, National Alliance of State and Territorial AIDS Directors
- Carl Schmid, The AIDS Institute
- Andrea Weddle, HIV Medicine Association

## **9. Explanation of Any Payment/Gift to Respondents**

No payments will be made to RWHAP grantees or providers for completion of the semi-structured telephone interview.

## **10. Assurance of Confidentiality Provided to Respondents**

Interviewers will take several steps to assure respondents that the information they provide will be kept private to the extent allowed by law and will be used for informational purposes only. Before each interview, the interviewer will read a confidentiality statement assuring the respondents that none of their comments will be attributable to them individually or to their organization, that their participation is voluntary, and that their decision to participate will have no impact on their organization's RWHAP funding. Respondents will also be assured that data collected during the interview will be analyzed and reported in aggregate and will not be identifiable at the individual level. We will also send respondents a letter requesting their participation in advance of the interview that contains the same set of assurances (see Appendix E), along with a copy of the relevant interview guide (see Appendices F and G).

After the interview, interviewers will type the open-ended responses into a Microsoft Word template, where the responses will be coded for entry into Atlas.ti. These files will be saved on a secure server. The contractor, Mathematica Policy Research, protects its LAN with several security mechanisms available through the network operating system. Access to private information stored on LAN directories is restricted to authorized project staff by means of IDs and passwords. In addition, network servers containing private information are kept in a locked area. All contractor staff sign a confidentiality pledge as a term of employment; the confidentiality pledge requires that staff maintain the confidentiality of all information collected.

## **11. Justification for Sensitive Questions**

The interview guide does not contain sensitive questions. Respondents will not be asked about their personal information; rather, they will be asked for information about the organization for which they work and about the population they serve. Topics that will be covered include (1) HIV service needs and use; (2) RWHAP funding prioritization and allocation; (3) sources of funding for HIV services; (4) coordination of client insurance eligibility determination and enrollment; and (5) strategies to manage RWHAP expenditures. See Appendices F and G for copies of the grantee and provider interview guides.

## **12. Estimates of Annualized Hour and Cost Burden**

Tables A and B present estimates of annualized respondent burden for completing semi-structured telephone interviews. They show the expected

number of respondents, the hours per response, and the annual hour and total cost burden for the data collected. A total of 210 telephone interviews with administrators of RWHAP Part A and Part B grants and with program managers and administrators of provider organizations receiving RWHAP Parts A, B, C, D, and/or Minority AIDS Initiative (MAI) funding will be conducted. For Part A and B grantees, the length of the interviews will average 65 minutes; for providers, the interviews will average 55 minutes. Each participant will be interviewed a single time.

**Table A.1. Estimated Annualized Burden Hours**

Type of Respondent	Number of Respondents	Number of Responses per Respondent	Average Burden Hours per Response	Total Burden Hours
Part A Grantee	26	1	1.08	28.16
Part B Grantee	51	1	1.08	55.25
Provider	133	1	55/60	122.00
<b>Total</b>	<b>210</b>			<b>205.41</b>

**Table A.2. Respondent Costs**

Type of Respondent	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Part A Grantee	28.16	36.89	1,038.82
Part B Grantee	55.25	36.89	2,038.17
Provider	122.00	47.49	5,793.78
<b>Total</b>	<b>-</b>	<b>-</b>	<b>8,870.78</b>

Note: The national hourly median wage, according to the Bureau of Labor Statistics' 2010 "National Compensation Survey," is \$36.89 for state and local government "administrative services manager" and is \$47.49 for "medical and health service manager" (BLS 2011).

### **13. Estimates of Other Total Annual Cost Burden to Respondents or Recordkeepers/Capital Costs**

The interviews are a one-time data collection effort. There are no direct costs to respondents other than their time to participate in the study.

### **14. Annualized Cost to Federal Government**

The total value for the RWHAP modeling study is \$565,124 over 32 months. The annualized cost to the government is \$211,921.50. These estimates are based on the contractor's costs for supporting data collection efforts, including labor and travel; other direct costs for computer, telephone, postage, reproduction, fax, and printing; and indirect costs for fringe benefits and general and administrative costs and fees.

In addition to the evaluation costs, there are personnel costs of several federal employees involved in the oversight and analysis of information collection that amount to an annualized cost of \$36,600 for federal labor.

The total annualized cost for the evaluation is therefore the sum of the annual contracted evaluation cost (\$211,921.50) and the annual federal labor cost (\$36,000), or a total of \$248,521.50.

### **15.Explanation for Program Changes or Adjustments**

This is a new data collection; therefore, there are no changes to burden.

### **16.Plans for Tabulation and Publication and Project Time Schedule**

The RWHAP modeling study’s primary data collection will begin upon receiving OMB clearance; the target date for conducting our data collection is between August and November of 2013. Data will be collected only once, and the field period is expected to be 12 weeks. These data will be entered into Atlas.ti, and analyzed using response codes developed and refined during the interview process. Findings from the qualitative interview data analysis, including an analysis of responses concerning program clients’ service use and service needs, will be summarized in a technical memorandum to be delivered to ASPE by the contractor by January 21, 2014.

The RWHAP modeling study also requires the contractor to deliver a final contract completion report in May 2013. The final report will provide key findings and explore the implications of the implementation of the Affordable Care Act provisions on timely access by PLWHA to quality HIV care, including supportive services and HIV medications. In addition, the final report will provide a set of policy options, including criteria for prioritizing areas and populations with the greatest needs for RWHAP-funded services, methods for improved data collection to monitor RWHAP costs, and policy options concerning reauthorization of the RWHAP. Table C provides a timeline for the major project milestones.

**Table A.3. Project Time Schedule**

Deliverables	Due Date
Semi-structured telephone interviews	08/15/2012-11/15/2013
Final summary of qualitative data findings	01/21/2014
Final synthesis report	05/30/2014

### **17.Reason(s) Display of OMB Expiration Date Is Inappropriate**

The OMB number and expiration date will be displayed on the letters that will be sent out to respondents in advance of the semi-structured telephone interviews.

### **18.Exceptions to Certification for Paperwork Reduction Act Submissions**

Data collection efforts for the interviews will conform to all provisions of the Paperwork Reduction Act.



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