# Supporting Statement for the Ryan White HIV/AIDS Program Data Report Form

## A. Justification

#### 1. Circumstances of Information Collection

This is a revision request by the Health Resources and Services Administration (HRSA) for OMB approval to continue using the Ryan White HIV/AIDS Program Annual Data Report form (the Ryan White Data Report) for the collection of service and client data under OMB No. 0915-0253. The current expiration date is December 31, 2007. The Ryan White Data Report (RDR) (formerly called the CARE Act Data Report (CADR)) was initially created in 1999 by HRSA's HIV/AIDS Bureau (HAB). This submission reflects language changes to incorporate necessary legislative revisions that occurred when the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White HIV/AIDS Program) was reauthorized.

The purpose of the Ryan White HIV/AIDS Program is two fold: 1) to provide assistance to localities that are disproportionately affected by the HIV epidemic; and 2) to make financial assistance available for the development, organization, coordination, and operation of more effective and cost-efficient systems for the delivery of essential services to persons living with and affected by HIV and AIDS. HAB, a bureau within HRSA, administers funds for all Parts of the Ryan White HIV/AIDS Program. Each Part is authorized in the following sections: Part A in Section 2601, Part B in section 2612, Part C in Section 2651, and Part D in section 2671.

Part A of the Ryan White Program provides direct financial assistance to designated Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) that have been the most severely affected by the HIV/AIDS epidemic. The purpose of these funds is to deliver or enhance HIV-related core medical and support services to people living with HIV/AIDS and their affected partners and family members.

Part B of the Ryan White HIV/AIDS Program authorizes the distribution of Federal funds to States and Territories to improve the quality, availability, and delivery of core medical and support services for individuals living with HIV/AIDS, and their affected partners and family members. The Ryan White HIV/AIDS Program emphasizes that such care and support is part of a coordinated continuum of care designed to improve medical outcomes.

Part C of the Ryan White HIV/AIDS Program provides support for early intervention services, including preventive, diagnostic, and therapeutic services for people living with HIV/AIDS and their affected partners and family members. This support includes a comprehensive continuum of outpatient HIV primary care services including: HIV counseling, testing, and referral; medical evaluation and clinical care; other primary care services; and referrals to other health services.

Part D of the Ryan White HIV/AIDS Program supports coordinated family-centered outpatient care for women, infants, children, and youth with HIV/AIDS and their affected partners and family members. The Adolescent Initiative is a separate grant under the Part D program that is aimed at identifying adolescents who are HIV-positive and enrolling and retaining them in care.

All Ryan White HIV/AIDS Programs specify HRSA's responsibilities in the administration of grant funds, the allocation of funds, the evaluation of programs for the population served, and the improvement of the quantity and quality of care. Accurate records of the providers receiving Ryan White HIV/AIDS Program funding, the services provided, and the clients served continue to be critical to the implementation of the legislation and thus are necessary for HRSA to fulfill its responsibilities. Ryan White HIV/AIDS Program grantees are required to report aggregate data to HRSA annually. The RDR form is completed by grantees and their subcontracted service providers. The report has seven different sections that contain the following information: demographic information about the service providers and the clients served; information about the type of core and support services provided and the number of clients served; information about the services; clinical information about the clients served; demographic tables for Parts C and D; and, information about the Health Insurance Program. In addition, the RDR collects information on grantees' disbursal of funds and the cost of providing services.

HRSA is working on the development of a client level data system for Parts A-D of the Ryan White HIV/AIDS Program. When a client level system has been developed, tested and is ready

for implementation, HRSA will seek OMB review and approval and will discontinue this collection.

#### 2. Purpose and Use of Information

The primary purposes of the RDR are to: (1) characterize the organizations where clients receive services; (2) provide information on the number and characteristics of clients who receive Ryan White HIV/AIDS Program services; and (3) enable HAB to describe the type and number of services a client receives. This information supports the goal of accountability to the Congress, clients, advocacy groups, and the general public. The information collected on the RDR is critical for HRSA, State and local grantees, and individual providers to assess the status of existing HIV-related service delivery systems and the need for service expansion. The partnership among HRSA, grantees, providers, and clients provides a unique opportunity to ensure that all parties share in the benefits of accurate and timely information. These data help to support improved care for people living with HIV and AIDS, their affected partners and family members. The collective responsibility ensures that service dollars reach targeted populations, appropriate HIV services are provided, and adequate funding is available to meet future HIV-related service needs.

The descriptive elements in the RDR that address these issues include:

- 1. Aggregate counts of clients served by each service provider, in total and for different demographic groups;
- Utilization data about medical and support services and health insurance coverage that can be used to estimate the number of clients receiving each type of service and/or program; and
- 3. General provider and program characteristics that describe organizations providing services, such as agency type, ownership status, sources of revenue, expenditures, paid and volunteer staff, and eligibility criteria.

Annually, HRSA generates descriptive reports and conducts detailed analyses about the clients served and the range of core medical and support services provided. HRSA will continue to use

these data to demonstrate in annual Ryan White Data Reports, reports to Congress, and state profiles the progress being made by grantees in serving populations disproportionately affected by HIV/AIDS.

The new legislation required slight modifications in wording throughout the RDR, including the following overall changes: program name (formerly Title, now Part), the name of the annual report (formerly the CARE Act Data Report now the Ryan White HIV/AIDS Program Annual Data Report), and deletion of all references to the requirement that multiply-funded Part D (Title IV) Adolescent Initiative agencies file two reports. Elimination of this requirement reduces the burden on these particular grantees. These changes are minor. (See attachments for a copy of the updated Ryan White Data Report (RDR) instrument and for a copy of the instructions.)

There are also section-specific changes to the RDR, including the separation of core services from support services and changes to the services that are eligible for funding by the Ryan White HIV/AIDS Program. The names of some services have been slightly modified and the definitions of many services have been expanded for conformance to reauthorization language and for further clarity. Additionally, some service categories have been added or deleted: linguistic services is a new support service category, whereas buddy/companion services, child welfare services, client advocacy and referrals to clinical research are no longer eligible for funding under the Ryan White Program and therefore were deleted from the instrument. A crosswalk outlines changes made to all sections of the 2008 report; it fully documents the Item as it appeared in the 2005 form and the 2008 form and also describes the change that occurred. The crosswalk also documents changes made to the instruction text that appears on the instrument. (See attachments for a crosswalk that delineates the modifications.)

## 3. Use of Improved Information Technology

Data may be submitted by all agencies through direct data entry, RW CAREWare upload—a free software application designed specifically to assist agencies in collecting and reporting the required data—or through XML uploads. Grantees access their Ryan White Data Report deliverable and complete data entry and submission through HRSA's Electronic Handbooks (EHBs). They also access, review, and approve their providers' Ryan White Data Reports through the EHBs. Providers enter their data through a Web interface

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(<u>https://performance.hrsa.gov</u>) and if necessary, correct and resubmit Ryan White Data Reports at the request of their Grantee of record. This system has resulted in approximately 94 percent accuracy in initial data submissions (https://performance.hrsa.gov).

#### 4. Efforts to Identify Duplication

Data required to evaluate or monitor each of the Ryan White HIV/AIDS Programs are not available elsewhere. Research studies conducted on people living with HIV/AIDS and sample studies of people in defined demographic areas or risk groups cannot provide comprehensive, overall program information about grantees, providers, and beneficiaries of the Ryan White HIV/AIDS Program. No other federal agency collects these comprehensive data in one report.

#### 5. Involvement of Small Entities

This data collection effort does not significantly affect small businesses or other small entities.

#### 6. Consequences If Information Collected Less Frequently

Grantees routinely subcontract to service providers on an annual basis. Service providers are accountable to grantees and they, in turn, are responsible to HRSA for the quality and accuracy of the reported information. Without annual Ryan White Data Reports that document how grant funds are expended, HRSA would be unable to fulfill its responsibility to oversee compliance with the intent of the legislation and Congressional appropriations in a timely manner. In addition, annual reports documenting the characteristics of the program's beneficiaries confirm whether the administration of the funds is responsive to the changing epidemiology of HIV/AIDS.

### 7. Consistency With the Guidelines in 5 CFR 1320.5(d)(2)

The data will be collected in a manner consistent with the guidelines in 5 CFR 1320.6.

### 8. Consultation Outside the Agency

The notice required in 5 CFR 1320.8(d) was published in the *Federal Register* on August 15, 2007, (Volume 72, Number 157, Pages 45821-45822). No comments were received.

In addition to the publication of the *Federal Register* notice, all grantees (approximately 550) were informed about potential changes. The grantees reviewed drafts of the data instrument and instructions.

### 9. Remuneration of Respondents

Respondents will not be remunerated.

## **10.** Assurance of Confidentiality

The Ryan White Data Report does not require any information that could identify individual clients. It is an aggregate report; therefore, names and personal identifiers are not included. All reports and tabulated data that are released to the general public are summaries of information across providers, which protect individual providers from being identified.

Respondents are assured of the confidentiality of their identities and information to the maximum extent allowable by law. Data collection fully complies with all aspects of the Privacy Act. The grantee or provider maintains all client-identifying information. Respondents are assured that their participation in HRSA programs will not be affected by their responses to any of the questions.

For grantees that use CAREWare, several measures have been incorporated to fully protect the confidentiality of people receiving services. These precautions include an algorithm for the creation of unique, *encrypted* client numbers to protect client-level information stored in the local system and the submission of aggregate level data to HRSA by service providers and grantees.

## **11. Questions of a Sensitive Nature**

All the clients described in the RDR are either living with HIV/AIDS or are affected partners and family members. The purpose of the data collection is to describe the demographics of these clients, their health status, and the quality and provision of services being provided to them by Ryan White HIV/AIDS Program providers. However, the RDR does not contain patient- or client-level data. Data may be drawn from client-level databases and records collected by providers, but the data sent to HRSA do not include any client identifying information. All service providers are well aware of the sensitive nature of the data collected and the need to protect the privacy of their clients.

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#### 12. Estimates of Annualized Hour Burden

The estimated average annualized hour burden is shown in Table 1. The estimates for grantees and service providers are based on prior experience collecting, maintaining, and reporting data using the current report forms. Input was also obtained from selected grantees that reviewed the revised forms and based their estimates on past experiences with their service providers.

The estimated response burden for Ryan White HIV/AIDS Program grantees is based on the estimated time to collect, review, and prepare electronic files for submission to HRSA. The estimated number of hours for Part A and B grantees is a function of the number of service providers from whom they receive data (mean of 30 providers for Part A and 24 for Part B). Part C and D grantees are themselves direct service providers, although they may also subcontract to additional service providers. Part A and Part B grantees typically maintain data in a central location and require less time to assemble annual reports. The estimated response burden for a service provider is based on the estimated time required to submit its annual data.

Table 1: Annual Response Burden for Ryan White Grantees and Service Providers

Part under which	Number of	Responses	Hours to	Total	Hourly	Total hour
grantee is funded	grantee	per	coordinate	hour	wage	cost
	respondents	grantee	receipt of data	burden	rate	
Part A	56	1	40	2,240	\$24.00	53,760
Part B	59	1	40	2,360	24.00	56,640
Part C	361	1	20	7,220	24.00	173,280
Part D	90	1	20	1,800	24.00	43,200
Subtotal	566			13,620	24.00	\$326,880
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Source of	Number of	Responses	Hours per	Total	Hourly	Total hour
provider funding	service	per	response	hour	wage	cost
	provider	service		burden	rate	
	respondents	provider				
Part A only	792	1	26	20,592	\$18.00	370,656
Part B only	653	1	26	16,978	18.00	305,604
Part C only	108	1	44	4,752	18.00	85,536
Part D only	75	1	42	3,150	18.00	56,700
Multiply funded	703	1	50	35,150	18.00	632,700
Subtotal	2331			80,622		\$1,451,196
	Number of			Total		Total hour
	grantee/			hour		cost
	service			burden		
	provider					
	respondents					
Total	2,897			94,242		\$1,778,076

## 13. Estimates of Annualized Cost Burden to Respondents

Grantees are responsible for maintaining their own data system or using the RDR module of RW CAREWare. There are no direct costs to respondents other than their time in participating in the data collection.

## 14. Estimates of Annualized Cost to the Government

HRSA has maintained a contract to provide technical assistance, distribute OMB-approved Ryan White Data Report requirements to all Ryan White HIV/AIDS Program grantees and enter data from paper forms. A contract for data collection is currently in place through September 2009. The estimated annual contractor cost for the RDR is \$368,000. See the table below for information on federal staff time/cost to HAB.

## Table 2: HAB's Federal staff time/costs to analyze and report the data

800 hours by Health Statistician (GS-13) at \$43.26/hour	34,608.00
160 hours by Clerk Typist at (GS-3) at \$13.18 /hour	2,108.80
Analysis and Reporting of Data Subtotal	\$36,716.80
Maintenance of RW CAREWare to Conform with Ryan White Data Report: 160 hours by Supervisory Public Health Analyst at \$52.62/hour	8,419.20
Upload of Reports, Forms, Instructions and CAREWare: 40 hours by Program Analyst (GS-9) at \$25.09/hour)	1,003.60
Total	\$46,139.60

## 15. Changes in Burden

The total burden for this request is 94,242 hours, a decrease of 13% or 13,394 hours. This decrease in burden is due to a decrease in the number of providers funded by grantees. There were 2,331 Ryan White funded providers who were required to complete a Ryan White Data Report last year, whereas three years ago, there were 2,802 provider respondents, a decrease of 17%.

#### 16. Time Schedule, Publication and Analysis Plan

The following timetable shows the schedule of events for the RDR.

January – December	Ryan White grantees and service providers		
	provide services and collect data on services		
November - December	HAB and data contractor staff conduct Ryan White Data Report training for new grantee staff		
January – March 15	Agencies report data for prior calendar year		
April 1 – May 31	Data verification, if necessary		
Fall	Annual report published		

In addition to an annual report for the Secretary of the Department of Health and Human Services and Congress, HRSA uses the RDR to derive the information needed for many of its GPRA and PART measures. As needed, national summaries across programs and by each program as well as by states are produced by HAB analysts and disseminated to constituency and advocacy groups through the HAB Web site.

## 17. Exemption for Display of Expiration Date

The expiration date will be displayed on the form.

## 18. Exceptions to Certification for PRA Submissions

This information collection fully complies with the guidelines in 5 CFR 1320.9. The necessary certifications are included in the package.

## **Attachments**

Ryan White HIV/AIDS Program Data Report Form

Ryan White HIV/AIDS Program Data Report Instructions

Crosswalk