

**Ryan White HIV/AIDS Program  
Services Reporting System  
FY 2009 Data Collection Plan:  
Operations Details**

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**Introduction**

**Robert Mills, PhD  
HRSA HIV/AIDS Bureau  
Division of Science and Policy  
Epidemiology and Data Branch**

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**The Need for CLD Reporting**

- **Accuracy and Accountability**  
HAB can report accurate, unduplicated counts of clients
- **Service Delivery and Quality**
  - HAB and funded agencies can identify gaps between standards of care and the services clients actually receive
  - Providers can use CLD to identify service delivery needs

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## The Need for CLD (cont.)

- **Evaluation, Performance, and Funding**
  - **HAB can improve how we measure and report our program performance goals**
    - Government Performance and Results Act (GPRA) goals
    - Program Assessment Rating Tool (PART)
  - **Providers can evaluate their progress in meeting core clinical performance measures**
  - **Greater precision informs resource allocation decisions**

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## System Overview - Names

The data report - full title, short title, acronym

- Ryan White HIV/AIDS Program Services Report
- Ryan White Services Report (RSR)

RSR components

- Grantee Report ('Grantee Form')
- Provider Report ('Provider Form')
- Client Report ('Client-level data')

Data reporting system: full title, short title, acronym

- Ryan White HIV/AIDS Program Services Reporting System
- Ryan White Services Reporting System (RSRS)

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## Choosing a Unique Client Identifier for the Ryan White Services Report System



Margaret O'Brien-Strain, PhD  
Elizabeth Coombs, MPA




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**Today We Will Discuss**

- **Unique Client Identifier (UCI) process within the RSR System**
- **Choosing the UCI**
- **Implementing the UCI process**

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**Need for a UCI**

- **Ensures confidentiality of client personal and health information**
  - Encrypted within the RSR client record by providers/grantees
- **Facilitates estimates of client counts and health utilization patterns**
  - Links client data over time and across grantees and providers

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**UCI Process within the RSR System**

1. Client provides personal information to the grantee or provider during visit
2. The grantee's or provider's data management system creates the UCI from personal information
3. Program creates encrypted UCI (eUCI)
4. The eUCI is included as a field in the client record
5. The grantee or provider sends the client record to HAB
6. HAB links the client records with the same eUCIs from different grantees or providers

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### UCI Selection Criteria

- **Unique – Each Ryan White Program client has own UCI**
- **Permanent – The UCI remains constant over time and across grantees and providers**
- **Feasible – Does not require extensive system changes**

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### Unique Record Number (URN) Best Satisfies These Criteria

- **URN**
  - 1<sup>st</sup> and 3<sup>rd</sup> characters of first name
  - 1<sup>st</sup> and 3<sup>rd</sup> characters of last name
  - MM/DD/YY (Month/Day/Year)
  - Gender
- **Strikes a balance between uniqueness and permanence**
- **Used in a variety of grantee and provider systems**

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### Choosing the UCI: Inputs to the Selection Process

- **Literature review – Identified potential data elements**
- **Grantee feedback – Selected data elements for testing**
- **Empirical evaluation – Measured UCI performance based on permanence and uniqueness**

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### Constructing UCIs for Testing

- **Identified data elements based on grantee feedback**
  - **Already collected and used by providers**
  - **Easily recalled and reported by clients**
  - **Permanent over time**
- **Selected elements:** First name, Last name, Date of birth, Gender, Social Security Number (SSN)
- **Created 105 test UCIs from segments of selected data elements**

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### Evaluating Test UCIs: Measures of Performance

- **Permanence – Measured by false negative rate**
  - **One client given two or more UCIs**
  - **False negatives result in overestimates of client counts and incomplete pictures of service utilization**
- **Uniqueness – Measured by false positive rate**
  - **Two clients given the same UCI**
  - **False positives result in underestimates of client counts and inaccurate pictures of service utilization**

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### Evaluating Test UCIs: Method

- **False Negatives**
  - **Data source: Ryan White grantee data**
  - **Program run at grantee sites created test UCIs for each record**
  - **Grantees verified when two records, belonging to the same individual, received different UCIs**
- **False Positives**
  - **Data source: Marketing database of unique individuals**
  - **Created test UCIs for each individual in database**
  - **Any duplicate UCIs were deemed false positives**

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- Measuring UCI Performance in Different Contexts**
- Calculated grantee false positive and false negative rates
  - Simulated rates for the RSR database
    - False positive rates for a dataset of 500,000 unique people
    - False negative rates of the grantee data most similar to HAB
  - For each context, added false positive and false negative rates for total error rates

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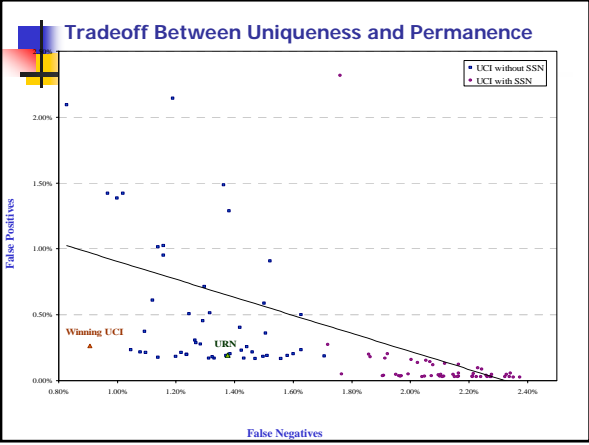
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**Grantee Error Rates Compared to Simulated Rates**

	UCI	Grantee	Simulated
URN	1 <sup>st</sup> and 3 <sup>rd</sup> FN, 1 <sup>st</sup> and 3 <sup>rd</sup> LN, DD/MM/YY, Gender	1.57%	8.77%
Top grantee UCI	1 <sup>st</sup> and 2 <sup>nd</sup> FN, 1 <sup>st</sup> and 2 <sup>nd</sup> LN, DD/MM/YY	1.17%	9.58%
Top simulation UCI	1 <sup>st</sup> and 2 <sup>nd</sup> FN, 1 <sup>st</sup> and 2 <sup>nd</sup> LN, DD/MM/YY, SSN	1.81%	5.60%

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**Findings Do Not Justify System Overhaul**

- Minimal differences in total error rates
- Grantees reluctant to collect new data elements
  - Costs of staff training and system modifications
- Grantees concerned with collecting SSN
  - Barrier to care
- Significant costs of implementing a new UCI

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**Implementing the UCI Process**

- Grantee and Provider Encryption of UCIs
- Standardize Data Recording
- Promote Data Cleaning for Report Linkage

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**UCI Encryption**

- Encryption protects clients' personal and health information
- Hashing (i.e., trap door) algorithm makes original UCI unrecoverable
  - SHA-1 algorithm satisfies federal security standards
- Encryption and UCI application will be installed on grantee and provider systems

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### Standardize Data Recording

- Grantee and provider recommendations
  - Train data entry staff to prevent common recording errors
  - Verify client information with documentation
- RSR System recommendations
  - Standardize protocol for recording data (e.g., multiple last names) and missing data across providers and grantees
  - Ensure UCI system can handle problematic data (e.g., different date conventions)

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### Promote Data Cleaning to Reduce UCI Error Rates

- Grantee and provider level
  - Internal data cleaning at provider and grantee sites can reduce false positives and false negatives
- HRSA HAB level
  - To reduce false positives, HRSA HAB can identify records with the same eUCI, from different geographic locations
  - Analysts can use additional data elements within the client record to verify client identity

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### Preview of the Ryan White Services Reporting System

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## Introduction

- Grantees will
  - Complete and submit one grantee form for each funding source (grant)
  - Review provider forms
  - Review a report containing aggregate data on the provider's client level upload
    - Grantee cannot view raw, record-level client data, only aggregate data (metadata) about the uploaded client data set as well as the validation report
  - Approve or return the provider report
    - If returned, changes can be requested to either the provider form, the CLD set, or both

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## Introduction

- Providers will
  - Complete the provider form
  - Create and upload client level records in compliant XML format
  - Validate and submit for grantee review
  - Process will be a combination of web system data entry and electronic file uploads

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## Introduction

- Responsibility to ensure CLD upload lies with grantee
- Security
  - The created data set uses the UCI
  - Data are transferred over an encrypted communication link (SSL)
  - All records are associated with the UCI (no client names, etc.)
- The web interface will follow current standards

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## Data Submission by Role

- **Grantee**
  - Completes Grantee Level Form Online (most pre-populated)
  - Grantee will verify/edit/add/delete providers within grantee form
- **Provider**
  - Provider-Level form
    - Online completion, or
    - XML submission
      - XML Submission is feasible if you use a vendor system that can generate this for you, and/or have previously done XML submission for RDR
      - Most providers will use the online option the first year
    - Some fields pre-populated
  - Client Level form
    - XML submission

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## Data Submission by Role *cont.*

- **Provider – CLD**
  - Provider Uses Major Vendor Systems: CAREWARE, LabTracker, Aries, AIRS/URS, CaseWatch Millennium
    - Vendors are working on export utility to export properly-formatted, upload-ready data set
    - This feature will be released as an upgrade to their systems, so if you use one of these systems, you will be able to export your data in the proper format
  - Provider Uses Custom System
    - Create program to export data from your system into the correct, HAB-provided XML schema format
  - Provider has No EMR System
    - “CAREWare Light,” a scaled-down implementation of CAREWare, will allow manual entry of data elements and provide the ability to export to compliant XML format

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## Responsibilities

- **Grantee responsible for monitoring status of provider submissions/uploads, both for provider forms and client-level data**
  - Ultimately responsible for submission from all their providers
- **Providers responsible for requesting assistance they need**
  - Contact their Project Officer if they require dedicated TA
  - Contact HAB’s Technical Contractor (SAIC), if they have questions while creating an XML export from a custom system
  - Contact the vendor of their EMR/software program if they require support in using the CLD XML Export feature of those systems

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## Security

- RSRs will conform to HIPAA standards data collection and handling
- HRSA never receives unencrypted personally identifiable information (PII), nor is such data transmitted via the Web unencrypted
- Major vendor systems will create XML upload-ready output
  - Each record will be identified using an encrypted UCI
- Providers who have custom systems and who must create their own export can use a utility provided by HAB
  - Utility for providers operating in a .NET environment to generate and encrypt the UCI
  - Uses standard encryption algorithms that are available in most other platforms
  - Data transmitted by encrypted communication link (SSL)

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## Timeline

- Fall 2008: RSRs "Pilot" to test system
  - Participants include vendors and grantee volunteers
- January 2009: RDR reports due March
- June 2009: RSRs opens for Grantees
- June 2009: RSRs opens for providers

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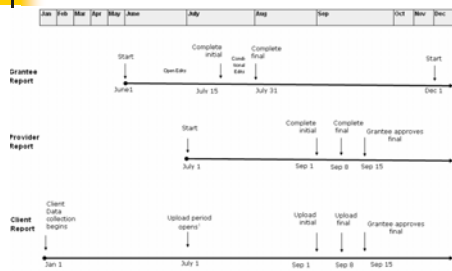
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## Timeline



Open Edit: No restrictions on modifying the report.  
 Conditional Edit: Creation of contact numbers requires a change request. All other modifications are allowed.  
 For the first two RDR reporting periods (January-June 2009 and January-December 2009), only service providers receiving Ryan White HIV/AIDS Program funds to provide individualized case management services (medical or non-medical) will be required to submit a Client Report.

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### Step-By-Step Preview: Grantee

- Communicate with your Providers Regarding CLD Requirements
  - What system do they use to enter/track client data?
    - CAREWARE, ARIES, AIRS, LabTracker, custom, none?
    - Refer them for TA as appropriate
    - Ensure that they have access to data forms and any instructional documents/websites that HAB makes available
    - Submit your Grantee report as early as possible to allow your Providers adequate time to work on their Provider reports

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### Step-By-Step Preview: Grantee

- Upon RSRS release, register or log in to the EHBs with appropriate permissions
- Access your grant portfolio and select the appropriate "Part" (A, B, C, or D)
- Complete and submit your Grantee forms (for each Part)
- Navigate to "Performance Reports" Menu




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### Step-By-Step Preview: Grantee

- Select Ryan White Services Report
- Complete and validate Grantee form
- Review and approve Provider submissions
  - Provider Forms
  - Client Data Upload
- Submit




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## Grantee Form

- Elements
  - Pre-populated
    - Grantee Address (pulled from EHB; not editable in RSRS)
    - DUNS # (pulled from EHB; not editable in RSRS)
    - Contact Information (pulled from RDR, you can edit)
    - Provider Names and Addresses (pulled from RDR, you can edit)
  - NOT Pre-populated (Data Entry)
    - Status of Clinical QM Program (select one)
    - Contract Information for Each Provider (Contract Reference, Start and End Dates, Amount)
    - Services Authorized Under Each Contract (Select All That Apply)
    - Fiscal Intermediaries

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## Grantee Form – A Look

Grantee Information

Providers Fetched by Your Grant

Reporting period: January 1, 2009 through June 30, 2009

(Pending Source - Grant Number)

1. Grantee of record address

a. Street 123 Stone Street, Suite 1000

b. City City

c. State State

d. ZIP Code 10000 1234

2. DUNS Number:

12 123 1234

3. Contact information of person completing this form:

a. Name Grantee Contact Name

b. Title Grantee Data Submitter

c. Phone (202) 555-1234 Extension 12345

d. Fax (202) 555-1232

e. Email person@grantee.com

4. Please select the status of your agency's clinical quality management program for assessing RFP health services (select only one):

Clinical quality management program introduced this reporting period

Previously established clinical quality management program

Previously established clinical quality management program with new quality standards added this reporting period

Not applicable

Next Save Cancel

- 1 form per grant
  - Items 1-3: display only (pulled from EHBs)
  - Item 4: Select one

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## Grantee Form – A Look

Grantee Information

Providers Fetched by Your Grant

Reporting period: January 1, 2009 through June 30, 2009

(Pending Source - Grant Number)

Review the list of your agency's service provider contracts. This list is pre-populated with information from the current Ryan White Data Report system. It should include all provider contracts that were active at any time during the January 1, 2009 through June 30, 2009 reporting period. Please add, edit, and remove provider contracts as appropriate.

Contract Year	Provider Name	Address	Contract Reference	Contract Start Date	Contract End Date	Services	Amount	Complete
09	Service Provider Name 1	123 East Street, Rockville, MD 20850	Contract 1	10/01/2008	10/31/2008	Services	\$1,000,000	<input type="checkbox"/>
09	Service Provider Name 2	456 Elm Street, Rockville, MD 20850	Contract 2	10/01/2008	09/30/2009	Services	\$2,000,000	<input type="checkbox"/>
09	Service Provider Name 3	789 Main Street, Rockville, MD 20850	Contract 3	10/01/2008	09/30/2009	Services	\$3,000,000	<input type="checkbox"/>

ADD PROVIDER CONTRACT

Previous Next Save Cancel

- Review/update provider contract list (for 1<sup>st</sup> cycle, pre-populated with your data from RDR; for subsequent cycles, pre-population with data from prior RSR)
  - Can add/remove provider contracts
  - Can edit provider address info, contract references, start and end dates and amounts
  - To select/edit services per contract, click services link to go to Services page
  - Indicate that contract data complete by checking "complete"

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### Step-by-Step Preview: Provider – Data Entry

- Providers (sub-grantees):
  - Register or log in to RSR system with appropriate permissions
  - Navigate to “Data Entry”
  - Complete Provider Form
  - Upload Client Data File
  - Validate
  - Submit

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    graph LR
      A[Register/Log in to CLD] --> B[Go To Data Entry]
      B --> C[Complete Provider Form]
      C --> D[Upload Client Data File]
      D --> E[Validate]
      E --> F[Submit]
  
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### Provider Options for CLD Submission

- Three models for providers to prepare data for submission
  1. Vendor clinical systems (e.g., CAREWare, ARIES, AIRS/URS, LabTracker, Provide Enterprise and others)
  2. Custom-built systems
  3. Manual data entry in CAREWare Light

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### Provider Form

- Elements
  - Pre-populated
    - Provider Address
    - Provider Contact Information
  - NOT Pre-populated (Data Entry and Upload)
    - Provider Type (select one)
    - Section 330 Funding Question (select one)
    - Ownership Status (select one)
    - Oral Health Care Expenditures (data entry)
    - MAI Funding Question (select one)
    - Agency Minority Representation Question (select all that apply)
    - FTEs (data entry)
    - Status of Clinical Quality Management Program (select one)
    - Counseling and Testing Statistics (six questions, data entry)
    - Services delivered under the contract (select all that apply)
    - CLD file upload

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## Provider Form - A Look

Provider Information	Provider Information (continued)	HIV Counseling & Testing	Imports
Provider Name: <b>Trinity</b>			Reporting Period: July 01, 2007 through December 31, 2007
	<input type="button" value="Import XML Provider File"/> Imported on June 20, 2008 4:19 PM <input type="button" value="Import XML Check File"/> Imported 121 checks on June 20, 2008 1:16 PM		
<input type="button" value="Previous"/> <input type="button" value="Save"/> <input type="button" value="Cancel"/>			

↑ **Upload Client Level Data**  
 (Also may submit Provider Level Data as XML if you choose to develop that XML export; format will be made available)

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## Provider Form - A Look

Administrative & Technical Services	Core Medical Services	Support Services	HIV Counseling & Testing
(Contract # of a-Contract Reference) Reporting period: January 1, 2009 through June 30, 2009 Please select the services delivered under the agreement during the given reporting period. (Check all that apply.)			
ID#	Included	Service	
1	<input type="checkbox"/>	Outpatient/ambulatory medical care	
2	<input type="checkbox"/>	Long-acting Pharmacological treatment (not ICD)	
3	<input type="checkbox"/>	Oral health care	
4	<input type="checkbox"/>	Early intervention services (Part A and B)	
5	<input type="checkbox"/>	Health Insurance Premium & Cost Sharing Assistance	
6	<input type="checkbox"/>	Home health care	
7	<input type="checkbox"/>	Home and community-based health services	← Select all that apply
8	<input type="checkbox"/>	Insurance services	
9	<input type="checkbox"/>	Nurse health services	
10	<input type="checkbox"/>	Medical nutrition therapy	
11	<input type="checkbox"/>	Medical case management (including treatment adherence)	
12	<input type="checkbox"/>	Substance abuse services (outpatient)	
<input type="button" value="Previous"/> <input type="button" value="Next"/> <input type="button" value="Save"/> <input type="button" value="Cancel"/>			

- Provider selects tabs for each category of services provided under this contract
  - Administrative and Technical Services
  - Core Medical Services
  - Support Services
  - HIV Counseling and Testing
- Checks all provided services

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## Next Steps For Grantees and Providers

Julia Hidalgo, ScD, MSW, MPH




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**Things to Do Before January 2009**

- Educate staff, subgrantees, Planning Councils and consortia, consumers, key policymakers
  - Explain the benefits to clients, your program, and HAB including the ability to count accurately the number of clients served, services they received, and other data critical for future federal funding
  - Dispel myths about CLD
  - Revise subgrantee contracts to require CLD collection and submission
    - Consider adding a contingency requirement to address subgrantee CLD submission when the times comes for them to do so

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**Things to Do Before January 2009**

- Assess your program's ability to collect CLD
  - If your program has a CLD system in place, determine the extent to which changes are needed in your forms and electronic data systems
  - Assess your intake and other CLD forms to reduce the number of other items collected and decrease client reporting burden
  - Consider the steps needed to collect accurate and reliable CLD over time to assess whether changes in your data collection cycle are needed
    - Work with front line staff to ensure services are accurately and completely documented in clients' records
    - Develop methods to identify clients receiving RWHAP-funded services ("eligible" clients)

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**Things to Do Before January 2009**

- Discuss with clinic chart staff the steps needed to routinely gather and collect CLD
  - While CLD submission will be twice annually, CLD should be entered into automated systems on a daily basis to ensure the data are up-to-date at the end of the reporting period
- Your IT consultant should identify challenges in transferring routinely encrypted CLD to HAB
- Identify subgrantees that do not collect CLD and assess their ability to do so
- Identify missing resources needed to collect and report CLD

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 **Implementation  
Technical Assistance**

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Division of Science and Policy  
Epidemiology and Data Branch

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 **TA Resources Available**

- **Special Projects of National Significance (SPNS)**  
Capacity building grants to develop standard electronic client information data systems
  - Eligibility: Part C and D grantees
  - Estimated total program funding: \$4,500,000
  - Expected number of awards: 50-100
  - Limited to acquisition and implementation of hardware and software components
  - Guidance at [Grants.gov](http://Grants.gov) (funding opportunity number: HRSA-09-135)

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 **TA Resources Available**

- **HAB Division of Training and Technical Assistance (DTTA)**
  - Cooperative agreement TA resources will be available to all grantees
  - DTTA is developing web-training modules
  - Contact your project officer with requests for DTTA TA

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### TA Resources Available

- CAREWare software
  - CAREWare will include all CLD elements required by HAB and an export format to generate a file that can be uploaded to the HRSA server
  - Listserve available to users
  - Help Desk TA available to users:
    - cwhelp@jprog.com
    - 1-877-294-3571

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### Web Site and Contact Information

- RSR (CLD) Web page
  - HAB home page, 'Manage your Ryan White Grant,' click on Client-Level Data
  - Or use the direct link:  
<http://hab.hrsa.gov/manage/CLD.htm>
- RSR System Help: Contact HRSA Call Center:
  - CallCenter@HRSA.gov
  - 1-877-464-4772

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### Questions and Answers

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