

FY2012 VIReC Database and Methods Cyber Seminar Series



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Research Access to VA Data

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Session Objectives

- **Describe procedures for obtaining authorization to access:**
 - Data access approved by facility CUPS POC
 - Data access approved through DART
 - Pharmacy Benefits Management Data
 - Patient Care Services (PCS) Data
 - CAPRI and VistAWeb EHR Data
- **Identify approaches to facilitate the data request review process**



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Audience Poll

(Heidi please convert to poll)

- **Have you ever requested access for a national SAS dataset at Austin with scrambled SSNs?**
 - Yes
 - No
- **Have you ever requested access to a SAS dataset at Austin with real SSNs just for a cohort of patients entirely from your facility?**
 - Yes
 - No



Data Access Approvals Managed Locally

Data	Identifier	Type of Cohort	Approval Required
MedSAS Other SAS Workload Data DSS NDEs VSSC DSS Web Reports	SCR SSN	Station, VISN or National	Local Facility
	Real SSN	Station	Local Facility
	Real SSN	VISN or National	National Data Systems
	SCR SSN	Station, VISN or National	National Data Systems
Vital Status File CDW/VINCI	Real SSN	Station, VISN or National	National Data Systems



Data Access Approvals Managed Locally

■ Procedure

1. Complete & sign VA Form 9957 <see bonus slides at end for additional instructions>

- Functional Task Codes link:

<http://vaww4.va.gov/NDS/FTCGrid.asp>

- Obtain supervisor & local approval signatures

2. Submit to your facility CUPS POC

- Customer User Provisioning System Point Of Contact

- Often the facility Information Security Officer (ISO)

- Contact the Austin Service Desk to identify your CUPS POC

3. Receive e-mail with your login ID & temporary password.

■ **No need to submit a request through DART**



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Audience Poll

(Heidi please convert to poll)

- **Have you ever requested access to real SSN data for a national cohort of patients or for a cohort of patients entirely from your VISN?**
 - Yes
 - No
- **Have you ever requested access to CDW data or the VHA Vital Status Files?**
 - Yes
 - No



Data Access Approvals Managed Nationally

Data	Identifier	Type of Cohort	Approval Required
MedSAS Other SAS Workload Data DSS NDEs VSSC & DSS Web Reports	SCR SSN	Station, VISN or National	Local
	Real SSN	Station	Local
	Real SSN	VISN or National	National Data Systems
Vital Status File CDW	SCR SSN	Station, VISN or National	National Data Systems
	Real SSN	Station, VISN or National	National Data Systems ¹¹

Data Access Approvals Managed Nationally

■ **CDW & VINCI Workspace**

- CDW
- Vital Status File

■ **Other**

- BIRLS Death File
- Medical SAS datasets
- DSS NDEs
- Vital Status File
- OEF/OIF Roster File
- VSSC & DSS Web Reports



Where to Start DART Request Process

- **Begin on NDS web pages:**
 - Descriptions of required documents
 - Link to data access forms
 - Link to Functional Task Codes
 - Launch **DART** button
- **DART is a software application that automates data request submission, review and approvals**



The DART Request Process

- DART Procedure:
 - Enter project and PI information
 - Enter information about secondary research site, if needed
 - Enter information about study staff
 - Select data needed
 - Upload documents listed (verify)
 - Submit request



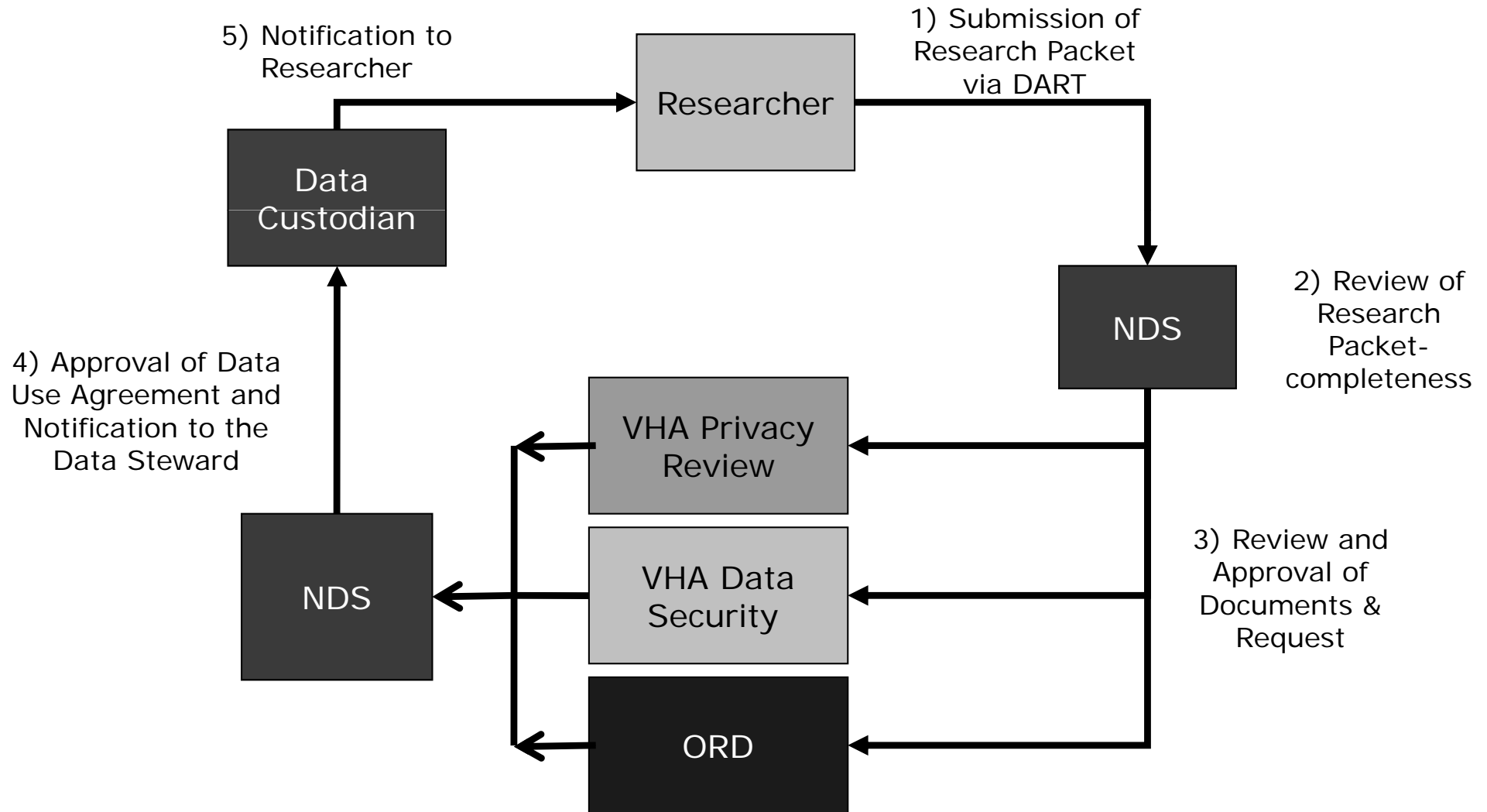
Required Documents

Per Research Study	Per Study Site	Per Person
<ul style="list-style-type: none"> ▪ Research Data Request Memo ▪ Research Protocol ▪ Data Use Agreement or VSSC Data Use Agreement ▪ Sample Informed Consent and HIPAA Authorization, where applicable 	<ul style="list-style-type: none"> ▪ Research and Development (R&D) Committee approval letter ▪ IRB approval letter ▪ Waiver of HIPAA authorization 	<ul style="list-style-type: none"> ▪ VA Form 9957 (PI & study staff with access to system) ▪ VA Privacy Data Access Agreement ▪ Vital Status Rules of Behavior, where applicable

Note: Not all documents are required for each data request.



Data Access Approval Process in DART



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Audience Poll

(Heidi please convert to poll)

- **Have you ever requested PBM data?**
 - Yes
 - No



Access to VHA Pharmacy Benefits Management (PBM) Data

- PBM Strategic Health Group (data steward)
- No direct researcher access
- PBM Services creates a custom data extract
 - SAS - SQL - ACCESS
 - ACSII - EXCEL
- Procedure:
 - Submit a copy of IRB approval letter
 - Submit a summary of the study protocol
 - Submit a completed research data request form



Access to PBM Data – cont.

- Available on PBM Intranet website:
 - Research data request form
 - Instructions for requesting a data extract

<http://vaww.apps.cmop.va.gov/PBMIntranetWEbSiteArchive/research-qualityimprovement/rdrf.asp>



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Audience Poll

(Heidi please convert to poll)

- **Have you ever requested access to Patient Care Services (PCS) data?**
 - Yes
 - No



Types of Data Available Through PCS

Care Coordination	Diagnostic Services
Dentistry (Moved to 10NC)	Specialty Care Services Cardiology Diabetes Eastern Pacemaker Foot Care (Podiatry) Infectious Disease MRSA Neurology Oncology (CRT) PADRECC Transplant Surgery (VASQIP) – Moved to 10NC
Geriatrics & Extended Care VA Form 9957 required for all RAI/MDS data use requests Functional Task Code: 1100RR08 VA Privacy Statement	
Mental Health Services	National Center for Health Promotion/Disease
Pharmacy Benefits Management	Primary Care
Prosthetics	Rehabilitation Service
Spinal Cord Injury	TeleHealth Services

Access to PCS Data

- PCS provides analytic datasets created from data within its stewardship
- Data Transfer Agreement (DTA) required
- DTA requirements vary for data requests for:
 - Research Studies
 - Quality Improvement Studies
 - Program Evaluation Studies



Access to PCS Data – cont.

■ Procedure for Research Use:

- Complete appropriate DTA Request form
- Prepare brief study description addressing items outlined in PCS DTA policy
 - Describe data requested
- Complete PCS Data Security Checklist
- Provide FTE VA Appointment Verification Letter
- Document mandatory research training for study staff
- Provide copies of IRB and R&D approvals



Access to PCS Data – cont.

- **Data request instructions and contact information are available on the PCS Web page:**

<http://vaww.infoshare.va.gov/sites/OSPM/default.aspx>



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Audience Poll

(Heidi please convert to poll)

- **Have you ever requested access to VistAWeb or CAPRI electronic health record (EHR) data?**
 - Yes
 - No



VistAWeb & CAPRI

VistAWeb

Access is through Intranet Web browser

No software installation required

Looks different from CPRS

VistA Imaging integration

CAPRI

Single sign-on for access to approved patient list, facilities or approval for all facilities

Requires installation of a client

Looks like CPRS

Search function, e.g., search clinical notes for terms about a specific patient

Access to VistAWeb

Direct VistA Imaging not available

Provides read-only access to the full set of CPRS EHR data, one patient at a time

Search to find a specific patient within a specific facility



Access to VistAWeb & CAPRI

- “Special User” access is required for VistAWeb and CAPRI.
- It is granted by VHA Privacy Office Health Information Access (HIA) program to those whose official duties require access to **non-local** medical records



“Special User” Access

■ Procedure:

- Fax or email (using PKI) request packets to HIA - include the following:
 - Special User Access Request Form
 - Rules of Behavior
 - Research Study Protocol
 - Informed Consent or Waiver of Consent
 - HIPAA Authorization or Waiver of Authorization
 - Research and Development (R&D) Committee Approval Letter
 - Research study Institutional Review Board (IRB) Approval Letter
 - DUA



“Special User” Access - Help

- **See HIA website for details of access requirements and faxing instructions:**

<http://vaww.va.gov/hia/>

- **Submit questions to HIA at:**

hia@va.gov



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Reduce Processing and Review Time

■ **IRB Protocol:**

- Verify that you have clearly justified
 - Identifiers requested (real vs scrambled SSNs)
 - Types of data
- Review data privacy & security plans with PO & ISO

■ **IRB and R&D Committee Approval Letters:**

- Provide original and current approvals
- Verify that your IRB approval includes
 - HIPAA authorization or waiver of authorization
 - Informed consent forms, where appropriate
- For multiple-site studies, provide
 - Local IRB approvals for each site or
 - VA Central IRB approval



Reduce Processing and Review Time– cont.

■ **Form 9957, when required:**

- Type all fields except the signatures
- Accompany approval signatures with person's name & title
- Electronic signatures are accepted

■ **General suggestions for DART:**

- Clearly name electronic documents
- Submit only .pdf or Word documents (e.g., .doc, .docx)
- Double check - before submitting the request
 - Are uploaded documents complete and
 - Verify that documents are uploaded to the correct requirement



EFFORTS ON BEHALF OF RESEARCHERS



Efforts to Improve Data Request Process

- **Solutions VIREC, VINCI, and OIA are pursuing include:**
 - Further simplify process
 - Educate researchers and operations staff
 - Increase staffing for request review
 - Expand & improve CDW data domains
- **DART to release new version soon**
 - More specific request status values
 - Adding VA/CMS data requests
 - Improving document submission process

* OIA = Office of Informatics and Analytics



CONTACTS & HELP



Austin Mainframe & DART Helpdesk Contact

- For questions regarding Austin Mainframe or DART
 - CDCO National Service Desk (NSD)
 - E-Mail: cdco-nsd@va.gov
 - Phone: 888-326-6780

- For a complete list of SAS Datasets on Austin Mainframe

<http://vaww4.va.gov/NDS/SAS/SASDataDictionaries/SASDataDictionaries.asp>



Data Access Help

- **NDS information about required documents**

<http://vaww4.va.gov/NDS/DataAccess/DataAccessRES.asp>

- **Latest version of data access forms for DART requests**

<http://vaww4.va.gov/NDS/DataAccess/DataAccessForms.asp>

- **VINCI Guide to required documents**

http://vaww.vinci.med.va.gov/vincicentral/Library/Data_Source_Required_Documentation_Guide.pdf

- **DART User Guide**

<http://vaww.vinci.med.va.gov/vincicentral/Library/DART%20User%20Guide.pdf>

- **DART Data Access presentation slides**

http://www.hsrp.research.va.gov/for_researchers/cyber_seminars/archives/vinci-092911.pdf

VIReC Help

■ VIReC website:

<http://www.virec.research.va.gov>

- Information on VA data sources and how to access data
- Documentation on select VA datasets used in research



VIReC Help (cont'd)

■ HSRData Listserv

- Join at the VIReC Web site
- Discussion among >500 data stewards, managers, and users
- Past messages in archive (on intranet)

■ VIReC Help Desk

- VIReC staff will answer your question and/or direct you to available resources on topics
- VIReC@va.gov
- (708) 202-2413



Questions?



BONUS SLIDES

- **Common Terms & Acronyms**
- **Completing VA Form 9957**
- **GETSSN Procedure**
- **Access to VA Data by Non-VA Researchers**



Common Terms & Acronyms



Common Terms & Acronyms

Term/ Acronym	Description
AITC	Austin Information Technology Center (AITC) is the VA's centralized computer processing center located in Austin, TX. Also referred to as: Corporate Data Center Operations, Austin Campus, Austin Automation Center, and Corporate Franchise Data Center.
CUPS POC	Customer User Provisioning System (CUPS) Point Of Contact (POC), formerly called the ACRS POC, provides local assistance in completing VA form 9957 and grants local access to AITC data. This role is frequently performed by the ISO. To identify your CUPS POC, contact the AITC Service Desk at (888) 326-6780 or send an email to cdco-nsd@va.gov
ISO	Information Security Officer at local facility/station - sits on IRB
PO	Privacy Officer at local facility - sits on facility IRB
Data Steward	The office responsible for maintenance and protection of a database, also known as Data Custodian or Information Custodian.
DUA/DTA	Data Use Agreement or Data Transfer Agreement
HIA	VHA Privacy Office, Health Information Access Program

Common Terms & Acronyms

Term/ Acronym	Description
NDS	National Data Systems is a division of VHA Office of Health Information (OHI), Health Data & Information (HDI) and is the data steward for some data at AITC, including the Medical SAS Datasets (MedSAS) and the VA Vital Status Files; and coordinates access to other data at AITC.
Real SSN Data	Data containing real Social Security Numbers
Scrambled SSN Data	Data containing coded or scrambled Social Security Numbers
TSO Account	Time Sharing Option account through which programs may be submitted to access data on the mainframe computers at AITC
VA Form 9957	Request form required as part of requests for authorization to access VA data at AITC. Links to this form maybe found on the NDS and VIREC intranet websites. Also called the CUPS form, formerly called the ACRS form.
FTC	Functional Task Code: Code associated with a type or group of datasets. Used on the 9957 form to identify data for which access is being requested.
MedSAS	Medical SAS Data sets include the VHA Inpatient, Outpatient and Fee-basis Databases

Common Terms & Acronyms

Term/ Acronym	Description
DSS	Decision Support System data includes National Data Extracts (NDE) for fact of lab and lab results and DSS Web Reports
BIRLS	Beneficiary Identification and Records Locator Subsystem Death File
PCS	Patient Care Services provides analytical datasets that are within its stewardship
CAPRI	Compensation and Pension Records Interchange.
VistAWeb	Read-only web interface to VistA at national level
VSSC	VISN System Support Center provides data cubes and web reports on many VHA data sources
PBM	Pharmacy Benefits Management provides extracts of VHA pharmacy data
CDW	Corporate Data Warehouse – a growing national repository of clinical and administrative data in a relational data warehouse architecture
VINCI	VA Informatics and Computing Infrastructure – a growing source of databases of interest to researchers

Completing VA Form 9957



VA Form 9957: Required for all data at Austin

1. Determine correct Functional Task Codes (FTC)

- See: *Functional Task Code Access Grid* on NDS intranet site:

<http://vaww4.va.gov/NDS/FTCGrid.asp>

- Or contact your local CUPS POC

2. Include Functional Task Codes in Form 9957, *Section 3. Access Requested*



VA Form 9957 cont.

3. Complete VA Form 9957, sign your name and obtain signatures of approving official(s) in Section 4:

- For all scrambled SSN data, VISN and national real SSN data and all Vital Status Files the approving officials are:
 - For study staff: the PI
 - For the PI: the ACOS-R or other supervisor,
- For local real SSN data
 - The signature above, plus local Facility Director
- For VISN real SSN data
 - The signature above, plus local HSR&D Director

**Note: Local policies may vary on additional required approvals
--- check with your CUPS POC**



VA Form 9957 cont.

3. Obtain the signature of the CUPS POC (or ISO) for your facility.

A. If VISN or national real SSN data are requested submit the Form 9957 with your DART request

B. Otherwise, for local access or national scrambled SSN access your CUPS POC will process the request.



Form 9957 - Signature Block

Any NDS Data with Scrambled SSNs

4. SIGNATURES	
A. REQUESTING OFFICIAL & TITLE Your Name and Title	B. DATE
C. APPROVING OFFICIAL & TITLE Your Supervisor and Title (PI or ACOS-R)	D. DATE
E. SECOND APPROVING OFFICIAL & TITLE <i>(if required)</i>	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER CUPS POC (ISO) & Title	

Form 9957 - Signature Block

Local Facility Data with Real SSNs

4. SIGNATURES	
A. REQUESTING OFFICIAL & TITLE Your Name and Title	B. DATE
C. APPROVING OFFICIAL & TITLE Your Supervisor and Title (PI or ACOS-R)	D. DATE
E. SECOND APPROVING OFFICIAL & TITLE <i>(If required)</i> Your Facility Director and Title	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER CUPS POC (ISO) & Title	

Form 9957 - Signature Block

VISN Data with Real SSNs

4. SIGNATURES	
A. REQUESTING OFFICIAL & TITLE Your Name and Title	B. DATE
C. APPROVING OFFICIAL & TITLE Your Supervisor and Title (PI or ACOS-R)	D. DATE
E. SECOND APPROVING OFFICIAL & TITLE <i>(If required)</i> Your ACOS-R or Local HSR&D Director Local requirements may vary.....	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER CUPS POC (ISO) & Title	

11 5011



Form 9957 - Signature Block

National Data with Real SSNs & All Vital Status Files

4. SIGNATURES	
A. REQUESTING OFFICIAL & TITLE Your Name and Title	B. DATE
C. APPROVING OFFICIAL & TITLE Your Supervisor and Title (PI or ACOS-R)	D. DATE
E. SECOND APPROVING OFFICIAL & TITLE <i>(If required)</i> Local requirements may vary.....	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER CUPS POC (ISO) & Title	

11 FORM



Using the GETSSN Procedure



Using the GETSSN Procedure

- The “GETSSN” procedure at Austin provides a tool to produce a cross-walk of scrambled to real SSNs or real to scrambled SSNs for your research cohort instead of access to entire real SSN dataset
- Used in SAS JCL on Austin mainframe
- Can be used for local, VISN or national level access to real SSNs
- Currently required for local station-only or VISN-only level access to real SSNs

Using GETSSN Procedure

- **Access permission requirements**
 - Same as for other NDS managed datasets
 - Local approval for local cohorts
 - NDS-managed approval for VISN or national access
- **GetSSN User Instructions:**

http://vaww.aac.va.gov/npcd/docfiles/GETSSN_User_Instructions.doc



Access to VA Data by Non-VA Researchers



Access to VA Data by Non-VA Researchers

- **The VA restricts release of data containing Protected Health Information (PHI) for research use to VA employees with approved VA research protocols**
- **Exceptions:**
 - Obtain written permission of the VA Under Secretary for Health
 - Obtain a signed HIPAA-compliant authorization from the patient or his/her personal representative for access to the individual's health records



Access to VA Data by Non-VA Researchers

- **Request data in the form of a de-identified dataset under the Freedom of Information Act (FOIA).**
 - To do this, contact the FOIA officer at your nearest VA medical center to submit a request (<http://www.foia.va.gov/>).
 - De-identified data may contain none of the 18 elements of Protected Health Information as defined by HIPAA, and may not contain other information that makes re-identification likely.



Access to VA Data by Non-VA Researchers

- **Researchers who are not VA employees and are interested in using VA data may consider becoming affiliated with the VA.**
 - Collaborate with a VA researcher and establish VA standing for oneself such as an Interagency Personnel Agreement or a VA-Without Compensation (WOC) affiliate to work under the supervision of a Principal Investigator who is a qualified VA employee.

