

2010 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 managed by National Data System (NDS) at Austin Information Technology Center (AITC)
 - VistAWeb and CAPRI Data
 - VA Pharmacy Data
 - Patient Care Services Data (PCS)

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Audience Poll (Heidi please convert to poll)

- Have you ever requested access to VA data at AITC through NDS ?
 - Yes
 - No

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.

Common Terms & Acronyms

Term/ Acronym	Description
MedSAS	Medical SAS Data sets include the VHA Inpatient and Outpatient Databases
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

Austin Data

- **Medical SAS or Workload files**
- **DSS Data**
- **Vital Status Files**
- **VSSC and DSS Web Reports**
- **CDW**
- **VA BIRLS Death Data**

Level of Approval Depends on Identifier & Level of Data to be Accessed

Data Name	Identifier	Level of Data	Approval Required
MedSAS & DSS	SCR SSN	Local, VISN or National	Local
	Real SSN	Local	Local
	Real SSN	VISN or National	National
Vital Status & CDW	SCR SSN	Local, VISN or National	National
	Real SSN	Local, VISN or National	National

Local Approval - Austin Data

See your local CUPS POC for access to:

- **Real SSN data at local facility/station level:**

- MedSAS
- DSS

- **Scrambled SSN data at the local, VISN & national level for:**

- MedSAS
- DSS NDEs
- VSSC and DSS Web Reports



Local Approval - Procedures

1. Complete VA Form 9957 <see bonus slides at end for detailed instructions>
2. If appropriate, include DSS Non-disclosure Agreement form with your signature
3. Sign form(s), obtain approval signatures, and submit to CUPS POC who creates your TSO Account (your ID for accessing the Austin mainframe)
4. Receive your TSO login ID via email.



NDS Managed Approval - Austin Data

NDS manages authorization of requests for

■ Real SSN data at VISN or national level:

- MedSAS
- DSS Data and Web Reports
- VSSC Web Reports
- Vital Status Files
- CDW
- BIRLS

■ Scrambled SSN data at local, VISN or national level:

- Vital Status File
- CDW



Forms & Documents Submitted for Research Study, Site & Person

- **Specific documents are required for**
 - **The research study**
 - **Each site (for multi-site studies)**
 - **Individual study members**
 - Principal Investigator
 - Each study team member who will actually access Austin mainframe or CDW/VINCI to use the data

Documents Required Per Study & Site For MEDSAS, DSS, VSSC, VSF and CDW Data with REAL SSNs

Per Research Study	Per Site
<ul style="list-style-type: none">■ Research Protocol■ Sample Informed Consent and HIPAA Authorization, where applicable■ Data Use Agreement	<ul style="list-style-type: none">■ Research and Development (R&D) Committee Approval Letter■ Research Study Institutional Review Board (IRB) Approval Letter■ IRB Approval of Waiver of HIPAA-compliant Authorization

Required Documents Per Study & Site For Vital Status File – Scrambled SSNs

Per Research Study	Per Site
<ul style="list-style-type: none">■ Research Protocol■ Sample Informed Consent and HIPAA Authorization, where applicable	<ul style="list-style-type: none">■ Research and Development (R&D) Committee Approval Letter■ Research Study Institutional Review Board (IRB) Approval Letter■ IRB Approval of Waiver of HIPAA-compliant Authorization

Documents Required Per Person

Per Person Forms:

- VA Form 9957
- VHA Privacy Form
- DSS Non-Disclosure Agreement
- CDW-VINCI Rules of Behavior
- Vital Status Rules of Behavior

Links to these forms may be found at:

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



Documents Required Per Person For Real SSN Data at VISN or National Level

Data Source	Access	Extract (to be downloaded)
MedSAS Data	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement 	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement
BIRLS Death Data	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement 	N/A
VSSC Web Reports	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement 	N/A

Documents Required Per Person For Real SSN Data at VISN or National Level

Data Source	Access	Extract (to be downloaded)
DSS NDE Datasets	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ DSS Non-Disclosure Agreement 	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ DSS Non-Disclosure Agreement
DSS Web Reports	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ DSS Non-Disclosure Agreement 	N/A

Documents Required Per Person For Real SSN Data at VISN or National Level

Data Source	Access	Extract (to be downloaded)
Vital Status File Scrambled SSN	<ul style="list-style-type: none"> ■ VA Form 9957 ■ Vital Status Rules of Behavior 	N/A
Vital Status File Real SSN	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ Vital Status Rules of Behavior 	N/A

Documents Required Per Person For Real SSN Data at VISN or National Level

Data Source	Access	Extract (to be downloaded)
Corporate Data Warehouse Or VINCI Data	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ CDW-VINCI Rules of Behavior 	<ul style="list-style-type: none"> ■ VA Form 9957 ■ VA Privacy Statement ■ CDW-VINCI Rules of Behavior

Data Access Request to NDS for Real SSN Data

1. **Request a tracking number** for the research study from NDS
 - Include Name of PI and exact name of Protocol
 - Send all communications to VHA Real SSN Access Requests e-mailbox
 - Use the assigned Tracking # in subject line of all subsequent communications
2. **Send an email** describing the datasets needed, name, level and type of identifier.

Data Access Request to NDS for Real SSN Data – cont.

- 3. Establish a TSO account** (if you don't have one already) by applying for access to the desired national data with scrambled SSNs before access to real SSN data is approved.

Hint: Having an existing TSO account may reduce requestor waiting time, and can provide an opportunity to create and test programs while awaiting authorization for real SSN access.

- 4. Create electronic copies of the required documents** for the databases you are requesting, using the naming conventions outlined on the NDS real SSN data access web page.

Data Access Request to NDS for Real SSN Data – cont.

5. **Send the required documents** as attachments in a single email (where possible) to the real SSN mailbox
6. **NDS will coordinate all necessary reviews**
7. **NDS will notify the PI** when approvals are final

Details at: vaww.va.gov/nds



Contacts For Access to Austin Data

- **Local data access or scrambled SSN access:**
 - Your local CUPS POC (call the Austin Service Desk to identify your CUPS POC)
- **Tutorials about using the Austin mainframe are available at**
 - <http://vaww.virec.research.va.gov/Support/Training-NewUsersToolkit/UsingDataAAC.htm>
 - http://vaww.aac.va.gov/operations/austin_info.asp
- **Questions about using the mainframe – the Austin Service Desk:**
 - Austin ITC: 888-326-6780
 - <http://vaww.aac.va.gov/servicedesk>



Watch for Changes Coming Soon

- In late September, data access procedures for research access to data managed by NDS will change.
- A new on-line access point -- the “Data Access Request Tracker” (DART) will replace the VHA REAL SSN ACCESS e-mailbox.
- Announcements, Web site information and a VIREC special cyber seminar on how to use the DART to request data access will be forthcoming.



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- **Tips to researchers to facilitate the data request review process**

Audience Poll

(Heidi please convert to poll)

- **Have you ever requested access to local VistA (CPRS), VistAWeb or CAPRI?**
 - Yes
 - No

VistA

■ Local VistA Records

- Computerized Patient Records System (CPRS)
- Single facility access
- Contact your ADPAC (Automatic Data Processing Application Coordinator) who serves as your point of contact and grants access to your local VistA system
 - To identify your ADPAC see your facility's web site for a link to the ADPAC list, or
 - Ask your computer systems administrator



VistAWeb

■ National VistA Access

– VistAWeb

- Access to VistA for multiple VHA sites via web browser –
- VistA Imaging will be available in VistAWeb, planned release is the end of this year.



CAPRI

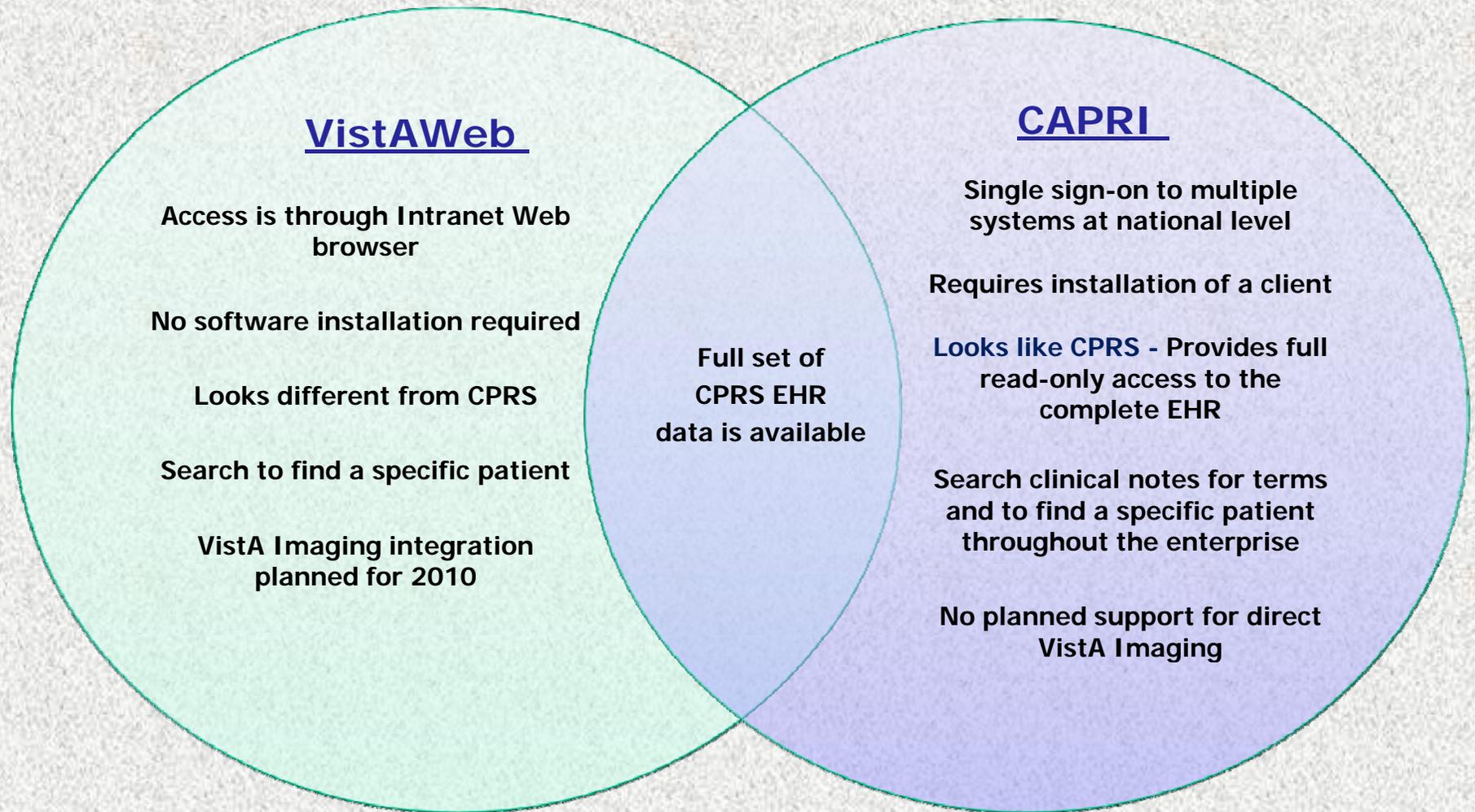
■ National VistA Access

– CAPRI

- Designed initially for Veterans' Benefits Administration,
- Each user's account can be linked to a patient restricted list, restricted site list, or national access,
- Complete access to current and past Automated Medical Information Exchange (AMIE) claims activity for determining eligibility for benefits,
- Full read-only access to EHR data & lab graphs
- CAPRI offers access to VISTAWEB (and indirectly VistA imaging)



Comparison



“Special User” Access

- “Special User” Access to VistAWeb and CAPRI is granted by HIA to those whose official duties require access to non-local medical records
- Request packets should be faxed to VHA Privacy Office - Health Information Access Program (HIA) and may 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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- **Tips to researchers to facilitate the data request review process**

VHA Pharmacy Data Sources

- **VistA:**
 - Local facility - ADPAC
 - VistAWeb/CAPRI - HIA
- **DSS – NDE – Pharmacy SAS® Datasets & Pharmacy Activity Cost Data**
 - NDS Data at Austin
- **Pharmacy Benefits Management (PBM)**

VHA Pharmacy Data Sources

- **VistA:**
 - Local facility - ADPAC
 - VistAWeb/CAPRI - HIA
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VHA Pharmacy Data Sources

- **VistA:**

- Local facility - ADPAC
- VistAWeb/CAPRI - HIA

- **DSS – NDE – Pharmacy SAS® Datasets & Pharmacy Activity Cost Data**

- NDS Data at Austin

- **Pharmacy Benefits Management (PBM)**

Audience Poll (Heidi please convert to poll)

- **Have you ever requested a data extract from PBM?**
 - Yes
 - No

Access to PBM Data

- Researchers cannot directly access the PBM database
- PBM Services creates a custom data extract in SAS, SQL, ACCESS, ACSII OR EXCEL for the researcher.
 - To request an extract from the PBM database submit to PBM:
 - a copy of IRB approval letter
 - a summary of the study protocol, and
 - a completed Research Data Request Form

Access to PBM Data

- The PBM Research Data Request Form and instructions for requesting an extract for research can be found on the PBM Intranet web site:

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

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 - VistAWeb and CAPRI Data
 - VA Pharmacy Data
 - **Patient Care Services Data (PCS)**
- **Tips to researchers to facilitate the data request review process**

Audience Poll (Heidi please convert to poll)

- **Have you ever requested access to PCS data?**
 - Yes
 - No

Types of PCS Data

Care Coordination	Dentistry	Diagnostic Services
Geriatrics & Extended Care	Medical - Surgical	Mental Health
Pharmacy Benefits Management	Prosthetics and Clinical Logistics	Primary Care
Rehabilitation Services	Care Management & Social Work Services	Spinal Cord Injury/Disorders

PCS Data

- PCS provides analytical datasets created from data that are within its stewardship
- A DTA is required
- DTA requirements vary for:
 - Research Studies
 - Quality Improvement Studies
 - Program Evaluation Studies

PCS Data Request Requirements

■ Common Requirements:

- Complete the appropriate DTA Request form
- Prepare a brief study description addressing items outlined in the PCS DTA policy
- Describe the data being requested
- Complete the PCS Data Security Checklist
- Provide FTE VA Appointment Verification Letters

PCS Data Request Requirements

- **Research specific requirements:**
 - Document mandatory research training for all participants
 - Provide copies of IRB and R&D approval documentation listing each study participant
- **Request instructions and contact information are available on the PCS Web page:**
vaww.ospm.wss.va.gov/default.aspx

VIReC Help

■ VIReC Webpage

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

- Information on VA data sources and how to access data
- Documentation on 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



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 for GETSSN are the same as access permissions for other NDS managed datasets**
 - Local approval for local cohorts
 - NDS-managed approval for VISN or national access
- **For more information visit the NDS Web site at:**
 - <http://vaww4.va.gov/nds/>
 - [Obtaining Real SSN Data Users Guide](#)

Completing VA Form 9957 & Other Per Person Forms

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://vaww.va.gov/NDS/DataAccess.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):

- For all scrambled SSN data, national real SSN data and all Vital Status Files:
 - For study staff: the PI
 - If you are 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



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	

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>	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER Your Facility Director and 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	



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	



Required Forms Depend on Type of Data Requested

- **VA Form 9957** – local signatures required
- **VHA Privacy Form** – requestor signature
- **DSS Non-Disclosure Agreement** – requestor signature
- **CDW-VINCI Rules of Behavior** – requestor & supervisor signatures
- **Vital Status Rules of Behavior** – requestor & supervisor signatures

Note: Links to forms at:

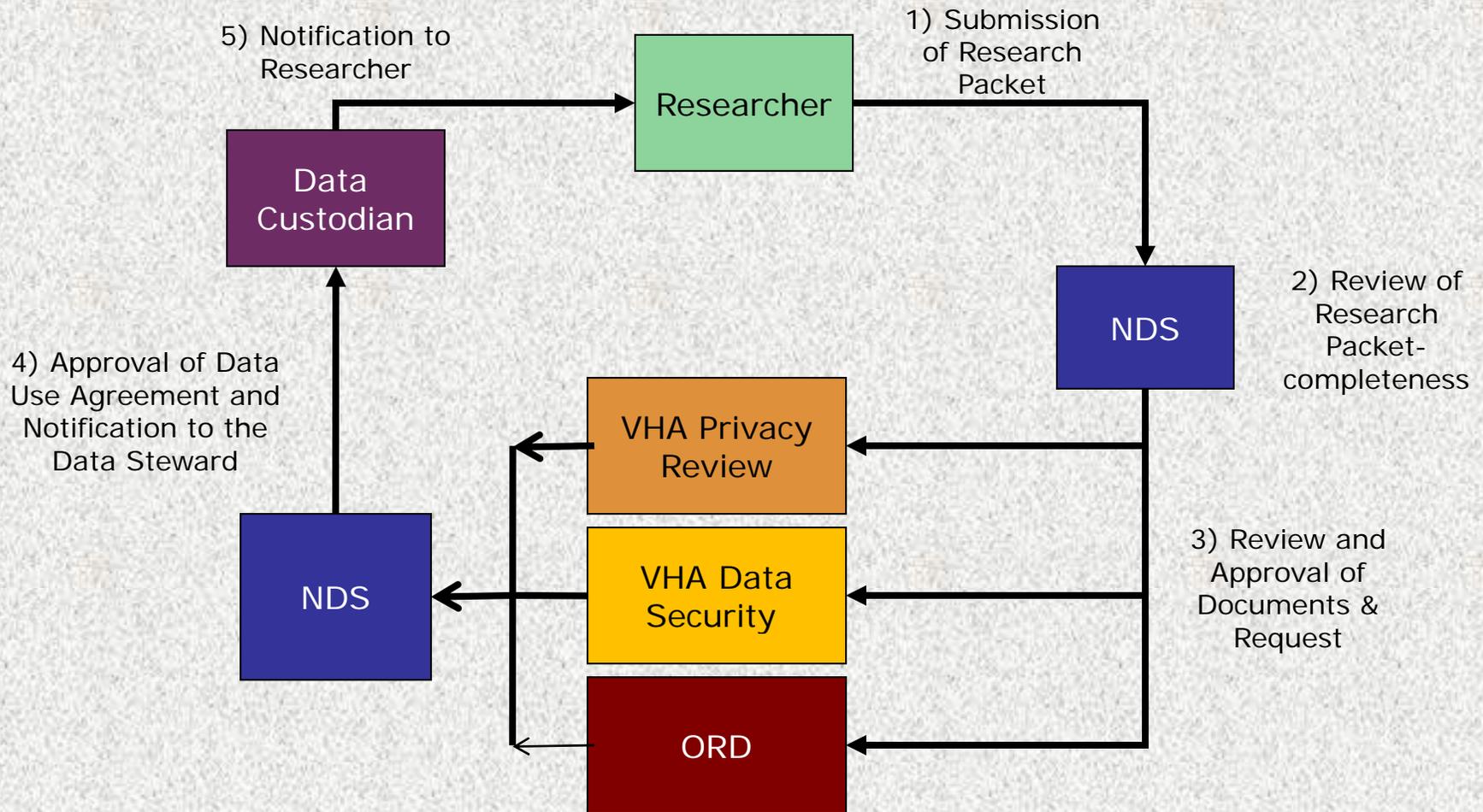
<http://vaww4.va.gov/NDS/DataAccess.asp>



National Approval Process

- Visit the NDS link for complete forms and instructions for obtaining national access approval:
<http://vaww.va.gov/NDS/DataAccess.asp>
- National-level real SSN data access requests are reviewed by privacy, security, ORD and the data steward
- VISN level data with real SSNs are reviewed by privacy & security and the data steward
- Vital Status File with scrambled SSNs are reviewed by NDS
- All are coordinated by NDS

Data Access Approval Process for Access to Real SSN Data at NDS



Facilitating the Real SSN Data Request Review Process



Facilitating the Real SSN Data Request Review Process

- To reduce processing and review time:
 - **Protocol:** Be sure your research design clearly supports a need for the identifiers, types & levels of data that will be requested
 - **IRB and R&D Committee Approvals:** Are they current and include:
 - HIPAA authorizations or waivers of authorization
 - Informed consent forms or waivers of informed consent
 - Where researchers at multiple sites will access the data, local IRB Approvals for each site or VA Central IRB approval for multi-site clinical trials

Facilitating the Data Request Review Process - continued

- **Data Security Plan** – Consult with your ISO to be sure your study's plan is appropriate
- **Approval signatures on forms (e.g., 9957)**: These should be accompanied by the person's name & title, **typed** for readability
- Create electronic copies of each type of study document (R&D and IRB approved protocol, original IRB & continuing reviews, waivers, etc.) and name and date them clearly.

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