

**2009-2010
VIReC
Database and Methods
Cyber Seminar Series**



Research Access to VA Data

Session 6
October 5, 2009

Presented by:
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Acknowledgements

- **John Quinn & Irma McCaffrey**, National Data Systems
- **Shawn Hardenbrook & Sam White**, Health Information Access
- **Drs. Seth Eisen & Brenda Cuccherini**, Office of Research & Development
- **Michael Wlezien**, Hines ISO and Hines CUPS POC

Session Objectives

- **Describe procedures for obtaining authorization to access:**
 - National Data System (NDS) data from Austin Information Technology Center (AITC)
 - VistAWeb and CAPRI Data
 - VA Pharmacy Data
 - Patient Care Services Data (PCS)
- **Tips to researchers to facilitate the data request review process**

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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 VA data at AITC/NDS?**
 - Yes
 - No

AITC

- **Data at Austin Information Technology Center (AITC) include:**
 - Medical SAS or Workload files
 - DSS National Data Extracts (NDEs)
 - Vital Status Files
 - VA BIRLS Death Data
 - Corporate Data Warehouse (CDW)
 - VHA Support Service Center or DSS Reports
 - Resident Assessment Instrument Minimum Data Set (RAI/MDS)

AITC

■ Our focus today will be:

- Medical SAS or Workload files
- DSS National Data Extracts (NDEs)
- Vital Status Files
- VA BIRLS Death Data
- Corporate Data Warehouse (CDW)
- VHA Support Service Center or DSS Reports
- Resident Assessment Instrument Minimum Data Set (RAI/MDS)

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

Data Name	Type of Data	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	SCR SSN	Local, VISN or National	National
	Real SSN	Local, VISN or National	National

VA Form 9957: Required for all data at AITC

1. Determine correct Functional Task Codes (FTC)

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

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

- Your local Customer User Provisioning System (CUPS) Point Of Contact (POC), formerly called the ACRS POC

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

VA Form 9957 cont.

3. Complete VA Form 9957, sign and obtain signatures:

- For all scrambled SSN data; national real SSN data and all Vital Status Files:
 - For project staff: the Principal Investigator (PI)
 - For the PI: the ACOS-R or other supervisor,
- For local real SSN data
 - The signatures above, plus local Facility Director
- For VISN real SSN data
 - The signatures above, plus local HSR&D Director
- **Local policies may vary on additional approvals required so check with your CUPS POC**



Form 9957 - Signature Block

All 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	

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	

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	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER	

National Data with Real SSNs and 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>	F. DATE
G. NAME AND TITLE OF FACILITY POINT OF CONTACT OR INFORMATION SECURITY OFFICER	

Local Approval

- 1. Complete VA Form 9957 as indicated above**
- 2. For access to DSS data print and sign the DSS Non-disclosure Agreement form**
- 3. Submit completed, signed form(s) to CUPS POC who creates the Time Sharing Option (TSO) Account (the access portal for creating, managing and running programs on the AITC mainframe)**
- 4. Receive TSO login ID via email.**

National Approval

- In this presentation we will discuss procedures for requesting NDS data access only (not data extracts)
- NDS link for complete forms and instructions for obtaining national 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 – coordinated by NDS
- VISN level data with real SSNs are not reviewed by ORD

Data Access Request to NDS for Real SSN Data

1. Request a tracking number for the research project from NDS

- Include Name of Principal Investigator and exact name of Protocol
- Use assigned Project Tracking# in all subsequent communications in subject line
- Send all communications via e-mail to VHA Real SSN Access Requests Mailbox

2. Using the assigned Tracking #, send email describing the datasets needed to the VHA Real SSN Access Requests Mailbox

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

- 3. If you are applying for real SSN access, NDS recommends that you establish a TSO account (if you don't have one already) by applying for scrambled SSN access to national NDS data before the real SSN access is approved.**

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

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

4. Create electronic files for the following documents using the assigned tracking # and naming conventions as outlined on the NDS real SSN data access web page:

For the research project:

- Research Study Protocol
- Research and Development (R&D) Committee Original and Current Approval Letter(s)
- Institutional Review Board (IRB) Original and Current Approval Letter(s)
- Informed Consent or Waiver of Informed Consent
- HIPAA Authorization or Waiver of Authorization
- Data Use Agreement (not PDF form) filled out, but not signed (The PI & Data Steward will sign it when authorization has been approved)

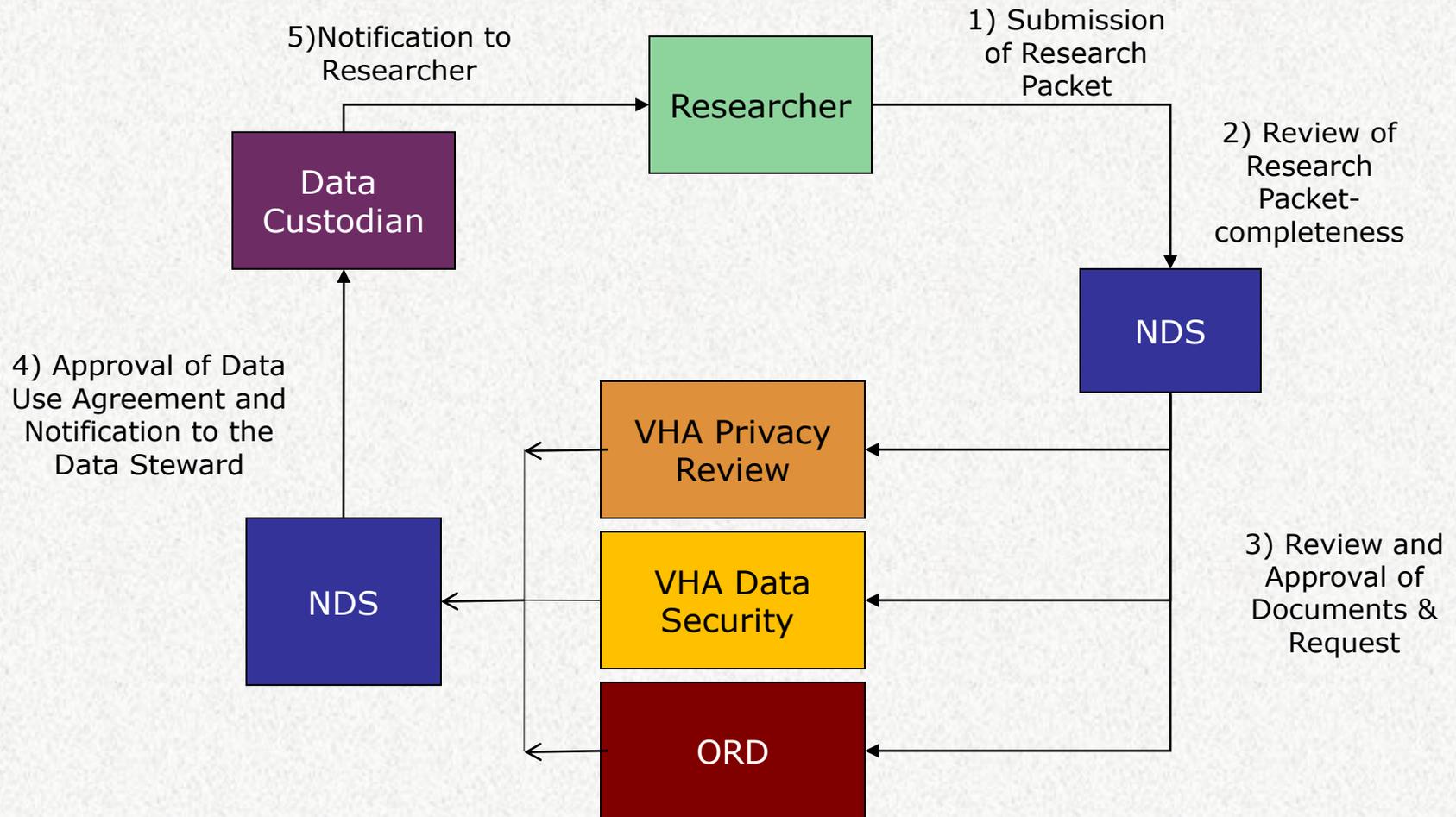
For each person accessing the data:

- Form 9957 with appropriate FTC and signatures
- Signed VA Privacy Statements
- DSS Non-Disclosure Statements (if applicable)
- Vital Status Rules of Behavior Forms (if applicable)

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

- 5. Send these documents as attachments in a single email to the real SSN mailbox**
- 6. NDS will coordinate ORD, VHA Privacy & Security reviews**
- 7. NDS will notify the PI when approvals are final**

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



Contacts

- **Local data access or scrambled SSN access:**
 - Your local CUPS Point of Contact (call the Austin Service Desk to identify your CUPS POC)
- **National real SSN data access:**
 - NDS Real SSN Mailbox
- **Tutorials about using the Austin mainframe**
 - <http://vaww.virec.research.va.gov/Support/Training-NewUsersToolkit/UsingDataAAC.htm>
 - http://vaww.aac.va.gov/operations/austin_info.asp
- **Questions about creating managing or running programs at AITC – the Austin Service Desk:**
 - Austin ITC: 888-326-6780
 - <http://vaww.aac.va.gov/servicedesk/>



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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 & CAPRI

■ National VistA Access

- VistAWeb
 - Access to VistA for multiple VHA sites via web browser
- CAPRI
 - Designed initially for Veterans' Benefits Administration,
 - Each user's account can be linked to a patient list
 - 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

Comparison

VistAWeb

Access is through Internet browser

No software installation required

Looks different from CPRS

Search to find a specific patient

No planned support for VistA Imaging

CAPRI

Single sign-on to multiple systems at national level

Requires installation of a client

Looks like CPRS - Provides full read-only access to the complete EHR

Search clinical notes for terms and to find a specific patient throughout the enterprise

VistA Imaging integration planned for FY '09

Full set of CPRS EHR data is available

“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)**
 - VA/VHA access request form.
 - 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

"Special User" Access

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

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

- **Submit questions to HIA at: hia@va.gov**

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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)**

VHA Pharmacy Data Sources

- **VistA:**
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- **Pharmacy Benefits Management (PBM)**

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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 Pharmacy Benefits Management?**
 - Yes
 - No

(UPDATED) 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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Audience Poll (Heidi please convert to poll)

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

Types of Patient Care Services 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 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

- **Request requirements common to all:**
 - Complete the appropriate DTA Request form
 - Prepare a brief study description addressing items outlined in the PCS DTA policy (no more than 5 pages)
 - 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
- **Database dictionaries and complete request instructions are available on the PCS SharePoint site: vaww.ospm.wss.va.gov/default.aspx**

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**
- **Researchers who are not VA employees and are interested in using VA data have the following options:**
 - Consider becoming affiliated with the VA.
 - Collaborate with a VA researcher, and establish VA standing for oneself such as an IPA or a WOC
 - 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 contain none of the 18 elements of Protected Health Information as defined by HIPAA.
 - Researchers frequently find de-identified data lack enough detail for meaningful analysis.

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Facilitating the Data Request Review Process

- To reduce processing and review time ensure:
 - **Protocol:** research design clearly supports a need for the types and levels of data that will be requested – particularly if real SSN data or the Vital Status file is needed
 - **IRB and R&D Committee approvals** are valid and 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

Facilitating the Data Request Review Process - continued

- **Data Security Plan (among other required elements) includes:**
 - Location where the data will be maintained and used, including building & room #, and
 - List of those who will have access to the data
- **Approval signatures on forms (e.g., 9957) should be accompanied by the person's name & title, either printed or typed for readability**

Questions?

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
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
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.
HIA	VHA Privacy Office, Health Information Access Program oversees data access policy, tracks Data Use Agreements in the VHA, and provides privacy review for research data access requests for VistAWeb, CAPRI, Corporate Data Warehouse, and national NDS data.
ISO	Information Security Officer at local facility - sits on IRB

Common Terms & Acronyms

Term/ Acronym	Description
NDS	National Data Systems is a division of VHA Office of Health Information (OHI), Health Data & Informatics (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.
PCS	Patient Care Services provides analytical datasets that are within its stewardship.
PO	Privacy Officer at local facility - sits on facility IRB
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. Formerly called the ACRS form.

■ 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



Next Seminar

■ **November 2, 2009**

- VA/CMS Data for Research
- Denise Hynes, PhD, MPH, RN &
- Linda Kok, MA