Ohio Cancer Incidence Surveillance System



Cancer Reporting from Federal Agencies

2019 NPCR Program Review Meeting Atlanta, Georgia April 25, 2019

Objectives

- Describe Ohio's experiences in getting data directly from:
 - ✓ Ohio's 5 Veterans Affairs (VA) hospitals
 - ✓ Ohio's 1 Department of Defense (DoD) hospital
- Describe Ohio's experience in getting data from the Veterans Affairs Central Cancer Registry
- Describe Ohio's experience in obtaining data from the Department of Defense



Background

- Ohio's VA and DoD hospitals have never reported directly to the Ohio cancer registry
- Historically, facilities have indicated:
 - prohibited from reporting
 - state reporting law and rules do not apply



Veterans Affairs Background

- August 17, 2007: VHA Directive 2007-023
- October 1, 2009: VHA Directive 2009-046
- July 23, 2014: VHA Directive 1072
- Directives:
 - Allow for reporting by VA facilities to state cancer registries
 - Require data use agreements and written request letter from State
 - ✓ De-identified data can be sent to CDC, NAACCR, SEER
 - Identified data can be sent to NDI and IHS for linkage
 - Identified data cannot be released to other states
 - Data can be used for research with appropriate approvals



Veterans Affairs Background

- Ohio started to develop individual data use agreements with all 5 Ohio VA facilities
- Learned that a single agreement with the VA Central Cancer Registry (in Washington, DC) was possible
- Pursued option for single agreement



VA Single Agreement

- Data Security
 - Data transmission
 - Server environment
 - ✓ Firewall technology
 - Encryption standard
- September 28, 2012: CDC informs states that VA indicates Web Plus is acceptable for uploading data



VA Single Agreement

- Lengthy process
- Agreement in effect for 3 years from 2012-2014
- VA provided data on all Ohio residents not just from the 5 Ohio facilities
- VA provided data back to our reference year
- New data provided annually
- Increased data completeness by 1.5%



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VA Single Agreement

- Started renewal process
- New requirements for data security
- Concerns re: Web Plus; decided to go with secure FTP
- Changes in VA personnel
- Person who previously provided data retired; position not backfilled
- VA approved new MOU but did not obtain all necessary signatures to execute
- No agreement in place; no VA data since 2014



Department of Defense Background

- Communication from 2010 indicated states needed to sign a Memorandum of Understanding to obtain data
- Ohio began this process in 2013
- Agreement is with the Department of Defense (DoD)
 Defense Manpower Data Center Automated Central Tumor
 Registry (ACTUR)



DoD Agreement

- Data Security
 - Data transmission
 - Certification and accreditation standards
- Worked with CDC re: Web Plus acceptability
- Worked with internal IT to obtain Certification and Accreditation documentation – Authority to Operate (ATO)



DoD Agreement

- Initially, took some time to set up
- Agreement in effect since 2014; remains in effect for 10 years
- DoD provided data back to our reference year
- Data for single DoD facility in Ohio
- New data provided annually
- Need to update Authority to Operate letter every 3 years



DoD Data

- Ohio receives 150-250 new cases each year
- DoD unable to send only new cases we must de-duplicate
- Due to size of files, no longer use Web Plus for file transfer
- Good working relationship with our DoD facility follow-up if we see issues with data quality
 - Need to specify that we only want 'complete' data



Conclusions

- Cancer reports from federal agencies are important to the completeness of central cancer registry data.
- Ohio's experience is that agreements must be in place to obtain these data.
- Need to coordinate with internal IT.
- We look forward to learning from other states' experiences.



Questions?

Contact Information

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