The Road to VA Data:
Patience, Persistence & Penalties

Missouri Cancer Registry (MCR)

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Background

• 3 VA facilities in MO with registries.
• All had been reporting to MCR under agreements renewed every 3 years.
• No major problems with data collection until VA directive in 2007.
  – Federal facilities only unaudited hospitals.
• MCR had already received most 2005 cases from one facility & a few cases from a second facility.
Timeline: August 2007

• NPCR states notified by CDC:
  – Existing data release agreements between CCRs and VA facilities are no longer in effect.
  – New agreement and standing letter of request for data must be implemented by 27 Sept. 07.

• VA Directive:
  – DTA must be completed & signed using the VA’s DTA Template.
Timeline: Sept. – Oct. 2007

- MCR staff draft a DTA for 1st MO VA facility.
  - Tried to follow VA DTA template.
  - Realized we couldn’t comply.
  - Now what?
- MCR PM learned that the NCR had executed a DTA with their VA facility.

• MCR focused on NAACCR & NPCR Calls for Data, NPCR application/progress report, new protocol to obtain death records, etc.

• Obtained copy of DTA from NCR.

• Otherwise, little progress toward a DTA for MO facilities.
Timeline: April 2008

• Draft DTA prepared.
  – Web Plus (WP) for submission of VA data to MCR.
  – MCR flag all VA cases, no re-release of PHI.
• APM verified names/titles of VA directors.
• OD sent certified letter & DTA to each VA facility.
  – Requested response within 2 weeks of receipt.
Timeline: May 2008

• Regional VA attorney in St. Louis called OD.
  – Contacted by one MO VA facility.
    • Not been contacted by other two facilities.
  – Requested copy of MO cancer reporting statutes.
  – Main question: Any penalties? YES!

• 2\textsuperscript{nd} call from attorney.
  – ISOs question whether submission by WP140-2 compliant.
May 2008 (continued)

• APM checked MU’s FTP site.
  – Not FIPS 140-2 compliant.
  – No timeframe for updating to 140-2.

• At MCR’s request, WP development team sent WP info to VA attorney who forwarded info to ISOS.

• VA ISOs at 1st facility “not comfortable” & won’t agree WP meets FIPS 140-2 standards.
May 2008 (continued)

- 2nd MO VA facility – MCR’s DTA does not match VA template.
  - Registrar sends cover letter & DTA to national VA who responds that:
    - Cover letter & DTA text don’t match.
    - MCR needs to change cover letter to match DTA. *(MCR re-words cover letter).*
  - No comment about DTA not matching template.
Timeline: June 2008

• No response from 3rd MO VA facility.
• APM called facility director’s office.
  – Claimed certified letter never received.
  – Letter & DTA resent via certified email & fax to director (and clerical support person).
Timeline: July 2008

• VA attorney – ISOs say WP site must have trusted certificate provider (e.g., VeriSign, Verizon, Thawte, etc.)

• MU is its own authority.
  – Considered “untrusted” by VA.
  – VA won’t recognize.

• VA: “If the website can correct the certificate issue, all security issues/concerns will have been addressed.”
July 2008 (continued)

- Hospital IT contacted – FIPS 140-2 program?
  - Told few on campus aware of FIPS standards.
- Contacted Campus IT:
  - Told they have recently purchased new program, MoveIT.
  - MCR staff have discussions with IT.
- Contacted VA attorney.
  - She forwarded info on MoveIT to ISOs.
  - Informed MCR she now has all 3 DTAs to review.
Timeline: August 2008

• APM contacts VA attorney –
  – Says OD is asking what is delaying execution of DTAs.
  – Do we need to address other issues?
  – Do we need to work with facilities individually?
  – VA attorney says she’ll handle.
August (continued)

• APM contacts VA attorney again.
  – Status of DTAs?
  – Suggests may be best if we contact each one.

• Confirmation from all 3 VA facilities that MoveIT is okay.

• MCR changes DTAs
  – MoveIT, not WP, for data submission.
  – Minor changes made to cover letter.
Timeline: September 2008

• Revised cover letter/DTAs sent to VA attorney.
  – She’ll get signatures & return each to MCR.
• First signed DTA received.
• VA attorney calls:
  – Hold agreements.
  – DTAs are hot topic at national meeting.
  – Confirmation of law enforcement piece needed.
September 2007 (continued)

- VA attorney calls again.
  - Materials & DTAs have been reviewed.
  - MO is okay!
  - Says she thinks many CCRs will have a different result.

- If the CCR cannot qualify as a “law enforcement entity” VA cannot provide data.
  - That MO statutes give possible sanction of fines is what allows VA to provide data to MCR.
Timeline: Oct. – Nov. 2008

• All 3 signed DTAs are in MCR’s possession.
• MCR staff continue to work with:
  – MU IT to get MoveIT set up.
  – VA ISOs and registrars to get data files submitted to MCR.
• All MU IT staff sign MCR confidentiality agreements.
Nov. 2008 (continued)

• All 3 signed DTAs are in MCR’s possession.
• MCR staff continue to work with:
  – MU IT to get MoveIT set up.
  – VA ISOs and registrars to get data files submitted to MCR.
• All MU IT staff sign MCR confidentiality agreements.
• So, we’re ready? Right?
Wrong!

Processing issues:
  – To be continued – Security session on Friday.

• By early December 2008, MCR was receiving files.
  – Internal processing issues not resolved.
  – No cases in the NAACCR & NPCR 22-month calls for data.

• By January 2009, MCR was able to resolve some processing issues.
  – Some VA data included in NPCR 12-month call for data.
Summary

• Communication issues:
  – Registrars not in loop on facility side. MCR provided status reports.
  – Copies of the DTA not always provided to HIM director and registrars at a VA facility.

• Keys to success:
  – Patience, perseverance and penalties.
  – Without penalties (even though not enforced), we would not have succeeded.
  – Location at a university facilitated success.