A New Approach: Using electronic health records to capture unreported cases and missing data

NAACCR 2012 – 7 June 2012

Jeannette Jackson-Thompson, MSPH, PhD
Missouri Cancer Registry and Research Center (MCR-ARC)
Department of Health Management & Informatics, School of Medicine
University of Missouri – Columbia
Acknowledgments

- Project funded as part of American Recovery and Reinvestment Act (ARRA) Comparative Effectiveness Research activities through the Centers for Disease Control and Prevention (CDC)
- MCR-ARC data collection activities are supported by a Cooperative Agreement between the Missouri Department of Health and Senior Services (DHSS) and the CDC and a Surveillance Contract between DHSS and the University of Missouri (#U58/DP00820-04/05)
Key Staff

- Suzanne Culter, RN, PhD (Project Coordinator)
- Alena Headd, MSIT (Software Support Analyst)
- Chester Schmaltz, PhD (Senior Statistician)
Presenting Objectives

- Describe how MCR-ARC is obtaining previously unreported cases and treatment information through use of EHRs
- Discuss issues & challenges
Laws/Statutes in every state
- Facilities must report new cancer cases to a central cancer registry (CCR)

In past, emphasis on hospital-based cases
- Abstracted by hospital CTR

Capturing non-registry cases & treatment is resource intensive
- Clinics/ physician offices (C/POs)
- Other non-hospital facilities
- Small hospitals without registries
Increasing number/type of cases being diagnosed/treated entirely outside a hospital setting

- Melanoma & prostate cancers
- Leukemias & lymphomas
- In situ & localized breast and colorectal cancers

Finding a cost-effective way to obtain such cases and more complete treatment information becomes increasingly important

- Accurate incidence rates/trends
- Avoid bias
Informatics/information technology and the adoption of electronic health records (EHRs) by C/POs offers an opportunity for CCRs to improve case completeness & data quality

- Spurred on my Meaningful Use requirements

- ARRA funding of two special projects by CDC/NPCR through contracts with ICF Macro
  - MCR-ARC
  - Kentucky Cancer Registry (KCR)
Improve annual case completeness and timeliness through innovative, yet practical, approaches that:

- Focus on importing data from primary care & targeted specialty physician office EHRs; and
- Can be replicated or adapted by other CCRs
Project Description

- **Project Period** – 34 months – 12.01.10 – 09.30.13

- **First Steps (pre-award): Identify**
  - Potential sites
    - Commitment from at least one physician
  - Potential partners/collaborators/resources
    - MO-HITECH
    - MO HIT Assistance Center (MO’s Regional Extension Center)
    - Missouri Cancer Consortium (MCC)
    - CDC/NPCR AERRO Physician Office/Clinic Work Group
Entered into subcontract with ICF (Macro)
Engaged in internal strategic planning
Made two strategic decisions:
  - Created MCR-ARC
  - Redesigned website ([http://mcr.umh.edu](http://mcr.umh.edu))
Worked with internal/external partners to identify potential implementation sites
Reviewed work plan

Assigned % of existing staff & hired new staff

Revised work plan
- Already had commitment from influential MD
- No need to ID primary care (PC) EHR vendors – obtain from MO HIT Assistance Center
- Need to obtain commitment from urologist(s) & medical oncologist(s)

Prioritized activities
Methods/Activities

- Regular meetings & conference calls
  - CDC/NPCR AERRO Workgroup
  - MO-HITECH
  - MO HIT Assistance Center
  - CDC/ICF Macro/Funded SPs
  - MCR-ARC SP #3 team

- Reports
  - Monthly/quarterly reports to ICF Macro/CDC
  - Quarterly ARRA reports
Obtained list of certified (Meaningful Use) PCP EHR vendors from MO HIT Assistance Center
- MO & KS RECs agreed on common list – 12 vendors
- Discussed with KCR Director

Met with vendor reps at 2011 & 2012 HIMSS annual meetings
- Discussed project – night & day difference 2011 to ‘12
- Demos of software
- Arranged for web-based demos (2011; dropped)
First Challenge (Feb 2011)

- EHR vendors can be certified for meaningful use without following OMB guidelines on race & ethnicity
  - No provision being made for multiple race fields
  - In some EHR systems it is even possible to choose Hispanic as race and African-American as ethnicity
- Cancer not in Stage 1 of MU
  - Vendors resistant to make changes (but not if in Stage 2)
Next Challenges (2011)

- Clinic withdrew
  - Volunteer participant
  - Reason: Cancer not in Stage 1 of MU

- Delays
  - Identifying PC practices
  - Developing/distributing brochures
  - Going live with revamped website
  - Obtaining list of med oncs/hematologists
Methods/Activities

- Identified/recruited C/POs & CAHs
- Made site visits/obtained commitments
  - Hannibal Clinic – Vitera (I) – sent test data
  - CAH #1 – McKesson (I)
  - C/PO #1 – eClinical Works (I)
  - CAH #2 – NextGen (PI)
  - C/PO #2 – Next Gen (S)
  - CAH #3 – Miditech (S)
  - C/PO #3 – Meditech (I)

Note: I = Implemented; PI = Partly implemented; S = Selected
Methods/Activities

- Made site visits/obtained commitments
  - C/PO #4 – Meditech (I) – test file & data file
  - C/PO #5 – All Scripts Pro (I) (Impact?)
  - C/PO #6 – GE Centricity (I)

Other

- Radiology Dept, MU Hospitals & Clinics
  - Pilot project – QuantumMark & AIM
- Specialty C/POs
  - Urologist – developed own EHR, create/send form
  - Med Oncs/Hematologists – work with L&LS
Results

- Bringing in previously unreported cases/obtaining additional information:
  - Directly from C/PO EHRs
  - Download from hospital Radiation Dept.
  - Test report from EHR developed by Urologist
  - Later in year, CAH that sends paper copies of med records will submit EHR file
  - Plan add one or more Med Oncs/Hematologists
Next Challenges

- When data from EHRs brought into MCR-ARC
  - Where store
  - How process
  - How integrate into QA activities
- Assess impact of
  - Cut in NPCR funding
  - End of ARRA funding
- Utilize strategic planning to offset impact:
  - Policies, procedures, workflow, etc.
  - ID funding opportunities, alternative funding
Conclusions

- Underreporting of cases is largely due to lack of human and financial resources.
- Funding to improve infrastructure and import data directly from EHRs can:
  - Improve data quality and completeness;
  - Provide data needed for public health surveillance; and
  - Facilitate comparative effectiveness and other research.
Anticipate positive outcome for MCR-ARC
- Improve data quality, completeness & timeliness
- Continue collaborations

Big picture
- Other NPCR-funded CCRs adopt or adapt
- Reducing # of missed cases & improving timeliness - implications for surveillance & CER
  - Describe/reduce disparities in population subgroups.

Challenges remain – approaches & resources
Contact info:

- Jeannette Jackson-Thompson, MSPH, PhD
  Director, Missouri Cancer Registry & Research Center
  Research Associate Professor, Health Management & Informatics, School of Medicine
  Core Faculty, MU Informatics Institute
  University of Missouri, Columbia, MO 65211
  jacksonthompsonj@health.missouri.edu
  (573) 882-7775

Website: [http://mcr.umh.edu](http://mcr.umh.edu)