Addressing challenges in new data collection items: How can registries be nimble, flexible and relevant?

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Challenges to collection of emerging data elements by registries

- Data can be difficult to find in hospital medical records despite electronic medical records
- Cancer registrars are too overloaded in both volume and complexity of the data to add more manually collected data items
- Current process for evaluating potential new data elements is long and costly
- How can registries stay current?
Challenges to collection of emerging data elements by registries

- New data collection via large data capture linkages
- Take what we can get without first investing years assessing availability, quality, validity, utility, or how to add to NAACCR format
- Can be done by just one registry
  - minimize effort
  - exploit local expertise or other advantages
  - can share results with other registries
Three examples

1. Pharmacy Linkage
2. Genomic Health Linkage
3. Genetic Testing Linkages
Seer Pharmacy Linkage (IMS health)

- Chemotherapy is perhaps the most often missing variable in central cancer registries due to outpatient administration.

- Pilot to evaluate the completeness and representativeness of orally administered anti-neoplastic treatments for cancer cases in select SEER registries.

- IMS Health aggregates filled prescription data from large pharmacy chains, mail order and specialty pharmacies.

- Compare chemotherapy data from (1) IMS Health, (2) cancer registry, and (3) SEER-MEDICARE parts B and D and SEER Patterns of Care.

**Cancer sites included:** Colon, Breast, CML and Myeloma

**Geographical areas included:** Connecticut, Louisiana, California, and Seattle
Data Flow for Pharmaceutical Pilot

- **Step 1**: IRB approval at registries

- **Step 1**: Finder file

  - Registry 1
  - Registry 2
  - Registry 3

- **Step 1**: Link treatment data to SEER*STAT, SEER *Medicare, SEER POC

- **Step 2**: Send IMS Health Unique Identifiers for matched cases

- **Step 2**: Send information on cancer treatment statins and flag for any transaction by year on matched cases

- **Step 3**: Send de-identified data to NCI

- **Step 4**: Analysis for completeness
- Validation of treatment data using SEER + external data sources (Medicare B, Medicare D, Patterns of care)
- Assessment of bias in cases covered in IMS Health data
Pharmacy linkage analyses

- Match rates by registry
  - By site, year dx, age dx, sex, race, stage

- Agreement between IMS Health and Medicare
  - By disease
  - By treatment

- Expect results in early 2016
Genomic Health, Inc.

- Oncotype DX
- A genomic test that looks at groups of genes and how active they are. This activity can influence how a cancer is likely to grow and respond to treatment. Unlike a breast cancer genetic test, the Oncotype DX breast cancer test does not provide information about a person’s inherited genetic make-up. Instead, the Oncotype DX breast cancer test looks at genes in a patient’s breast tumor to understand how these genes interact and influence the tumor’s behavior.
Genomic Health, Inc.: tumor genomic expression profiling

Breast Cancer Test and Early Stage Breast Cancer
- help individualize breast cancer treatment planning to predict
  - likelihood of chemotherapy benefit
  - recurrence in early-stage breast cancer

DCIS (Ductal Carcinoma In Situ) and Pre-Invasive Breast Cancer
- provide an individualized prediction of the 10-year risk of local recurrence

Stage II and Stage III Colon Cancer
- determine the likelihood of recurrence following surgical resection

Early-Stage Prostate Cancer
- predict aggressive prostate cancer prior to treatment intervention
Planned analysis include:

1. Quality assessment of the manually collected Oncotype Dx (completeness and precision) and the added value
2. Factors associated with having the test and possible disparities in who gets the test
3. Compliance with guidelines
4. Treatment (hormonal and chemotherapy) according to Oncotype Dx RS risk categories in SEER Medicare
5. Evaluation of Oncotype Dx linkage
6. Expect results in early 2016
Genetic testing

- Creating a personalized cancer screening and treatment plan includes:
  - Determining the chances that a person will develop cancer and selecting screening strategies to lower the risk
  - Matching patients with treatments that are more likely to be effective and cause fewer side effects
  - Predicting the risk of recurrence
Genetic testing: BRCA and multi-gene sequencing or panel testing

- Breast and ovarian cancer cases 2013-15
- Four companies providing the test have expressed willingness for linkage
  - Myriad
  - Ambry
  - Invitae
  - Genomic Health
I. Linkage analyses
   • Frequency distribution of availability of linkage variables
     • GA vs. CA
     • For each industry partner*
   • Numbers (percents) of “exact matches by state and industry partner”*
     • Numbers of possible matches for manual review and number (percents) determined to be true matches
     • Tracking of staff time
   • Evaluation of 1-3 for each incidence year
   • Evaluation of “yield” or value of results

II. Genetic data analyses
   • Overall prevalence of genetic test data
   • Detailed breakdown of genetic test data by patient/disease characteristics
   • Patient-specific comparison of genetic test data with existing registry genetic test data
   • Evaluation of “yield” or value of results

Expect results in mid-2016
Future genetic testing registry research opportunities

- Answer essential questions for clinical practice and health policy, including:
  - What are the trends in test use (BRCA1/2 and MGS panels) across different patient subgroups?
  - What is the distribution of results among breast cancer patients in the community?
- If collect patient and provider surveys:
  - What do patients understand about their test results and cancer risks?
  - What are the clinician factors that influence test use? How do test results influence treatment decisions?
Other future registry data collection opportunities

- Varian Oncology Systems
  - Radiotherapy machines have information systems capturing
    - patient identifiers
    - dose delivered
    - treatment dates

- Largest US radiation therapy system provider

- Corporate office Palo Alto

- Also offer medical oncology data system which might serve as data aggregator for CCR
Issues regarding collection of genetic data for CCR consideration

If any of these pilots are “successful”
1. What data analyses/assessments does CCR wish to perform?
2. Should the providers be added to California cancer reporting facilities?
3. If so, what review/approvals are necessary? -IRB? -health department?
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