

**Enabling 21st Century Applications for Cancer
Surveillance through Enhanced Registries and Beyond
Session 5.**

**Key policy changes that could impact
cancer surveillance**

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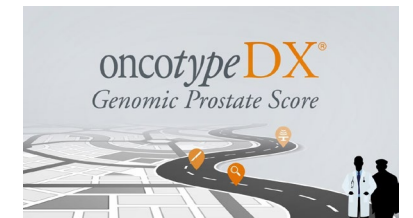
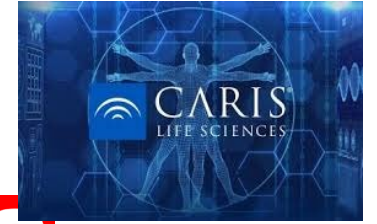
Data sources leveraged for cancer surveillance

While EHR data are important – Many more data sources (up to 35) are essential for creating a complete cancer case across SEER

- Hospital Abstracts
- Physician office reporting
- E path reports
- Pathology Images
- Radiology reports (case identification and recurrence/mets)
- Genomic testing data from labs/specialty labs
 - Exact Sciences
 - Decipher
 - Foundation
 - Castle Life Sciences
- Medical Claims based treatment information from physician practices initial and subsequent infusion treatments (oncology, radiation oncology)
 - United Health Group (All registries)
 - Unlimited Systems
 - State Medicaid
 - Humana
 - Anthem
 - Blue Cross
 - Varian
 - Dermatology Clinical reports
- Genetic testing data from labs (germline mutations for actionable mutations) Myriad, Invitae, Ambry
- Pharmacy data from CVS, Walgreens, RiteAid, UHC PBM (longitudinal prescriptions anti-neoplastics)
- Treatment information from inpatient-based claims (surgery, radiation, infusion-based codes)
- Clinical Trials/Research Studies (COG, National Breast & Cervical Cancer Early Detection Network, Multi-Ethnic Cohort)
- All Payer Claims data
- Vital Records
- NDI
- Motor Vehicle Data
- Voter Registration
- Interstate Data Exchange
- Veteran's Administration data exchange
- Lexis Nexis (res hx, measures of financial status)
- SSA
- CMS
- Indian Health Service Linkage for confirmation of Native American Status

Adaptations that would increase the ROI for cancer registries

- Reducing the gap in reporting time from 2 years leveraging e-path
- Incorporating key clinical variables (biomarkers, detailed longitudinal treatment and outcomes other than survival (e.g. recurrence))
 - Through novel linkages (claims, pharmacy, pathology labs, genomic and genetic testing labs)
- Increasing the research ROI for registries through
 - Out-linkages to other important systems to broaden the footprint of registries in the research community
 - Examples from SEER
 - VA
 - Myriad cloud application
 - N3C
 - All of Us
 - Genomic testing labs (Caris)

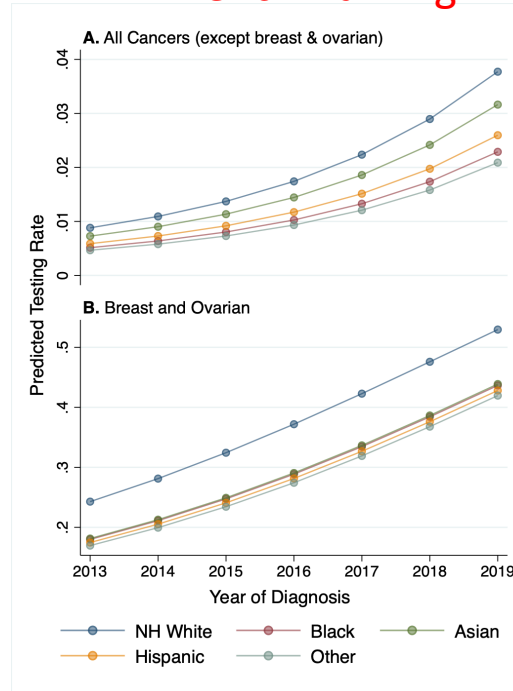


Adaptations that would increase the ROI for cancer registries

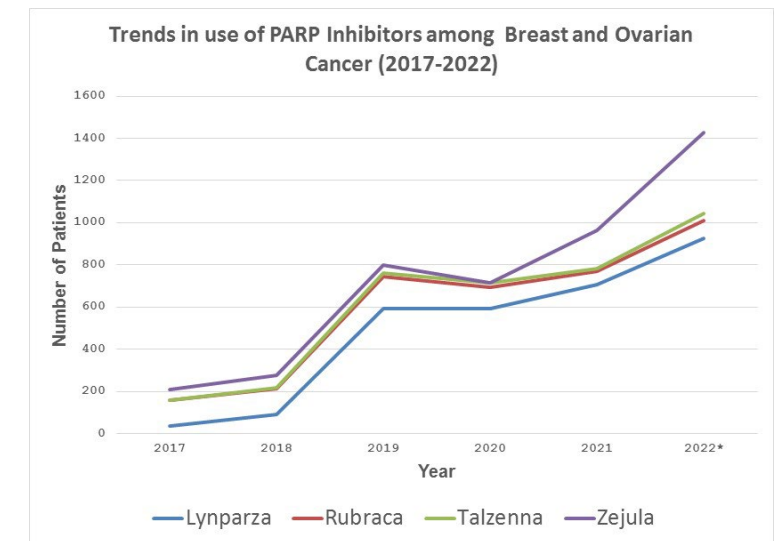
Supporting analyses on important quality indicators at the **population** level:

- Benchmarking quality of care markers at the population level (BRCA testing in ovarian CA patients)
- Monitoring trends in dissemination of new agents over time (leveraging pharmacy data)
- Providing population level data to identify high risk population subgroups for poor outcomes
- Providing real time access (via pathology) to rapidly identify patients eligible for:
 - Cohort studies
 - Clinical trials
 - Other studies

Benchmarking



Monitoring Dissemination



Real time access for study enrollment

Example registries for real time study accrual: RESPOND Study

C Haimin 10,000 AA prostate cancer study

- Population-based cohort from 6 SEER registries
- Using registry sampling frame enabled focus on racial subgroup and high-risk population
- Data on non-responders from the registries (understanding bias)
- Rich survey data matched with clinical SEER data
- Saliva and tissue data matched with clinical SEER data and pathology report data

Key policy changes likely to positively impact cancer surveillance*

- Mandated electronic pathology reporting in all states (currently CA, LA) enables:
 - Real time reporting
 - Eligibility assessment for enrollment in trials/studies
- Mandated authorization for registries to access All Payer claims supports:
 - Detailed longitudinal treatment and recurrence
 - Comorbid conditions
- CMS claims sharing for surveillance – to incorporate into the registry data
- Mandated reporting by CMS for information on recurrence (disease status) provides
 - Longitudinal capture of disease progression, recurrence across all potential sources

*Note: These represent the opinion of Lynne Penberthy NOT NCI