SESSION 6

Improving Cancer Surveillance – Enhanced Registries and Beyond

Co-Moderators

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Speakers

Session 1: Lisa Richardson and Nadia Howlader
Session 2: Scarlett Lin Gomez and Larissa Nekhlyudov
Session 3: Lawrence Shulman and Peter Paul Yu
Session 4: Bryan Palis *(participating virtually)* and Lisa Richardson
Session 5: Robin Yabroff and Cathy Bradley

NATIONAL
CANCER POLICY
FORUM

SESSION 1

Overview of the Current State of Cancer Surveillance

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS AND POLICY OPPORTUNITIES TO ADVANCE PROGRESS

Issue 1:

- **Data Collection Challenges**: all presentations highlighted the difficulties in capturing comprehensive, real-world cancer data due to rapid advancements in treatments, variability in data sources, and limitations in current reporting systems.
- **Policy Opportunity 1: Encourage Comprehensive Disease Status Reporting Linked to Reimbursement**
- **Rationale:** Linking cancer reporting to reimbursement to incentivize healthcare providers to ensure complete and accurate data submission (all payers and/or institutions)
- Develop standardized reporting protocols to ensure consistency and accuracy across different healthcare facilities and encourage use of the standardized report.
- Provide training and resources to healthcare providers and others to facilitate compliance with the new reporting requirements.
- Consider the use population-based registry as a sampling frame to obtain detailed clinical information (e.g., recurrence, biomarkers, treatment) on a population-representative sample and use this information to make inference for the whole population.

SESSION 1

Overview of the Current State of Cancer Surveillance

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS AND POLICY OPPORTUNITIES TO ADVANCE PROGRESS

Issue 2:

- **Need for Improved Data Integration**: there was a shared emphasis on the need for better integration and interoperability of data sources to enhance cancer surveillance and reporting.
- **Policy Opportunity 2: Enhance Data Integration and Interoperability through National Standards**
- **Rationale:** Establishing national standards for data exchange can streamline the process and ensure effective integration of data from various sources.
- Develop and enforce national standards for cancer data exchange, such as the FHIR Implementation guide for cancer case reporting.
- Encourage collaboration between government agencies, healthcare providers, and technology vendors to ensure the widespread adoption of these standards and platforms.
- Provide funding and technical support to healthcare facilities, labs and others to upgrade their data systems and comply with the new standards.

SESSION 2

Lessons Learned from U.S. and International Cancer Surveillance Efforts

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS

- State/governmental regulatory policies play a major role (barrier/facilitator) in data access, linkage & sharing
- Level/flat/reduced funding challenging, especially to support innovations when having to maintain current procedures & lack of IT support
- Delays in data availability for reporting and research
- Insufficient funding for cancer surveillance
- Existing data gaps – recurrence & disease progression
- Challenges in linkages to other data and patient surveys leads to other important gaps (for example, survivorship outcomes including patient experience)
- Lack of denominator data → disparities in reporting for population groups & granular geographies
- Underutilization of patient advocacy for surveillance/tumor registry

SESSION 2

Lessons Learned from U.S. and International Cancer Surveillance Efforts

POLICY OPPORTUNITIES TO ADVANCE PROGRESS

Surveillance data need to be more rapidly available and complete with no gaps in key elements

- Multi-pronged approach (e.g., recurrence)
- Efficient, seamless linkages with other data sources
- Ability to use and link data with patient surveys
- Ensure efforts do not exacerbate disparities

Revise state policies to facilitate data access, linkages & sharing while protecting patient privacy

- Leverage Privacy Preserving Record Linkage (PPRL) methods & federated query model
- NAACCR's Virtual Pooled Registry as model
- Partner with patient advocates

Increase funding for cancer registries

- Registries remain costly (human review still essential) and need to be supported
- Need additional support for technological innovations
- Need more investment towards robust data integration infrastructure
- Need for more rapid data availability

Ensure health equity always when looking to advance innovations

SESSION 3

Data Collection Methodologies and Technological Advances in Cancer Surveillance

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS

- Data entered are not in a digitally readable format.
- Not all critical clinical and testing (path/radiology) data points entered at all.
- Registry data currently not as timely as needed
- We don’t have good data intra-operability and sharing standards.
- What data do we really need – do we need use cases that help to define what data we really need.
- What will be the balance between structured data capture, generative AI and human curation.
- Documentation burden on physicians and nurses is already at a critical point
- Current payment incentives do not support good data entry
- What is the business case for doing better with data entry and extraction and registry population.

SESSION 3

Data Collection Methodologies and Technological Advances in Cancer Surveillance

POLICY OPPORTUNITIES TO ADVANCE PROGRESS

- Increase incentives to document critical data points in structured data
    - Clinic notes
    - Pathology reports
    - Radiology reports
- Understand the right balance between entry of structured data, use of AI/MML, and manual abstraction for both cancer quality and surveillance registries
- We need to figure out how to get more granular data intro registries to help better understand treatment patterns and related outcomes, without increasing the clinical or registrar burden
- We need to populate registries in a more timely fashion using technology, etc
- Align federal agencies around data capture, EHRs, registries – CDC, ONC, CMS, NCI, FDA, mCODE/CODEX
- Move to a more coherent data standardization and sharing mechanisms/policies
- Foster public-private partnerships to solve some of these challenges
- Federal legislation to harmonize state legislation that inhibits data usage and sharing
- Re-structure privacy laws that continue to protect privacy but advance the common good.

SESSION 4

The Infrastructure and Workforce Supporting Cancer Surveillance

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS

- The cancer registry workforce is evolving as evidenced in the NCRA survey
- Use of CAP Protocols improve patient outcomes, quality, efficiency, and cost
- Workflow relative to pathology/EHR has the potential to transition workforce to concurrent abstraction
- Linkage of registry and electronic health records yield a comprehensive view of patient cancer experience
- Enhanced quality control may be achieved through education and use of machine-learning for data integration; there are clear benefits and challenges associated with linkages
- Structured data elements will shape EHR with value in using AI and ML to extract data from synoptic reports

SESSION 4

The Infrastructure and Workforce Supporting Cancer Surveillance

POLICY OPPORTUNITIES TO ADVANCE PROGRESS

- Continued education is necessary to navigate the ever-changing landscape of data capture
- We need to retain and recruit more registry staff highlighting the important work they do with data quality and quality improvement (market the benefits of the ODT profession)
- We need to ensure we count everyone, capturing everyone from rural patients from small hospitals to those treated in hospitals with fewer resources (keeping equity at the forefront)
- Use existing tools and develop new ones to assist registries with case finding could accelerate the reporting process (Epic example)
- Combined structured and unstructured electronic health record data could provide a more complete cancer patient journey, however with linkage challenges to overcome (ADT notifications as a solution)

SESSION 5

Policy Opportunities for Advancing Progress

KEY ISSUES IDENTIFIED BY SESSION SPEAKERS AND PANELISTS

- Lack of interoperability between systems
- Labor intensive with duplicative efforts
- Workforce needs for cancer data analytics
- Multiple data sources, data types, distinct processes
- Lack of real-time resources for patients and families, patient trust
- Lack of real-time, high quality registry data for quality improvement and evaluating care delivery and payment models.
- Challenges with data linkages
  - Restrictions on data use and sharing; de-identification
  - Funding for maintaining and updating linkages
- Sustainability of specimens and registries
- Data protections can limit data sharing without addressing patient privacy
- Ethical challenges and false dichotomies

SESSION 5

Panel Discussion on Policy Opportunities for Advancing Progress

POLICY OPPORTUNITIES TO ADVANCE PROGRESS

- Incentivize data integration and interoperability through qualified health information networks
- Mandated reporting electronic cancer pathology data to cancer registries
- Fund collaborations with EHR vendors and registry data
- Investment in Artificial Intelligence/Machine Learning and other novel methods for data capture and transformation
- Facilitate, fund, and maintain data linkages (e.g., Medicare, APCD, genomic data) for longitudinal surveillance of treatment, non-cancer care, and new primaries
- Multi-pronged approaches (e.g., recurrence: NED, progression, recurrence)
  - Synoptic reporting
  - Payor mandates
- Unified data governance
- Workforce education and training
- Model legislation for state data linkages and sharing; removing NIH barriers
- Communication and education
- NAACR as potential convener