NEAR TIME DATA TO SUPPORT RESEARCH AND CANCER CONTROL PLANNING

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Disclosures

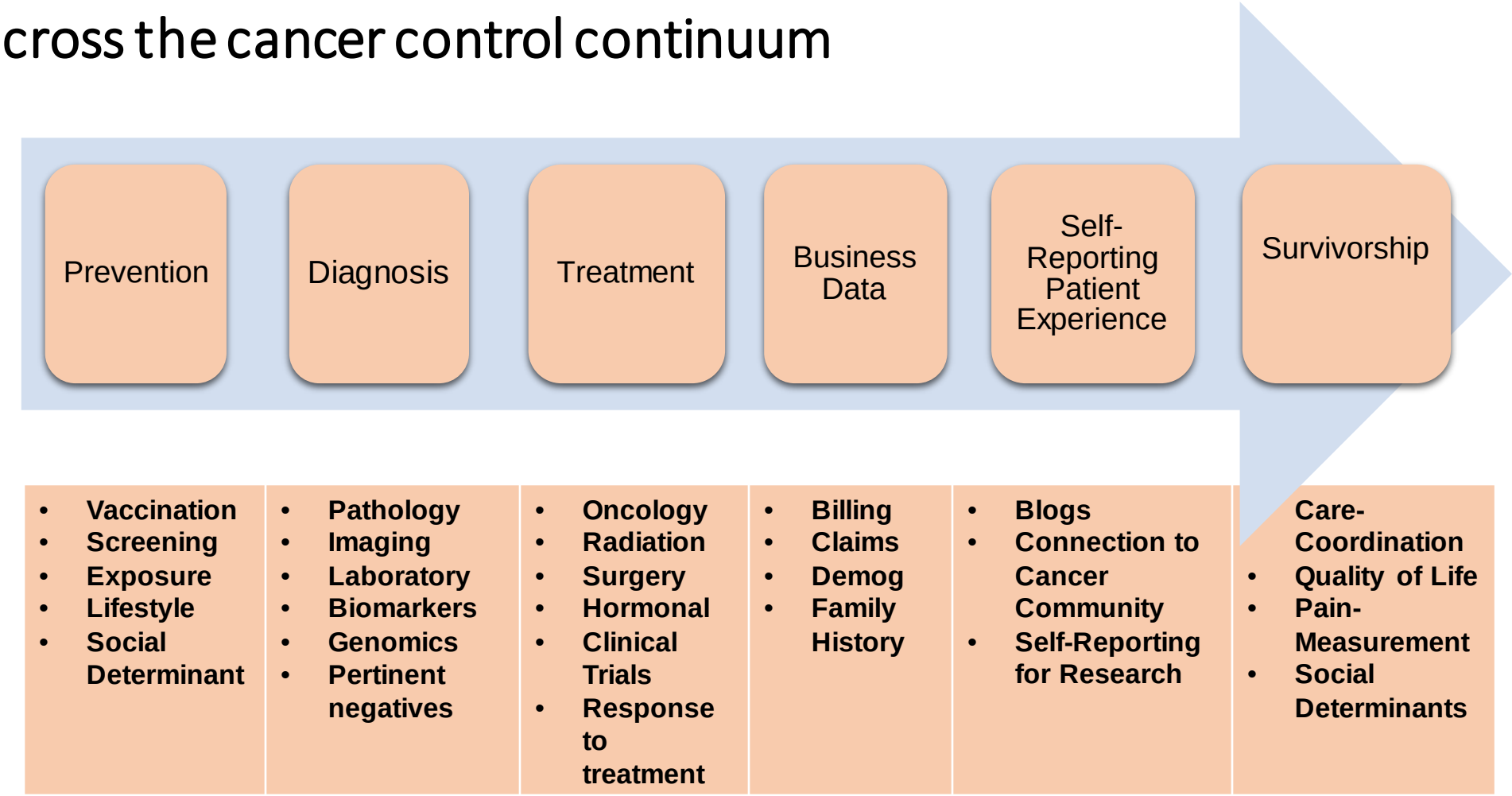
- No disclosures to report

Objectives: Briefly Review

- Legal Authority
- Current and future uses of Cancer Registry Data
- Key Success Factor: Near-real time data
- Achieving near-real time data
- Patient Considerations

Cancer pathway to the 21st Century

Fundamental Priorities: Near-time, standardized, structured data across the cancer control continuum



CDPH California Department of Public Health

Legal Authority

- Current Status
  - Cancer Reporting is typically governed by laws put in place before electronic interoperability of health records was possible
- Opportunity
  - Cancer registries can benefit greatly from laws that allow or require providers to report cases electronically
- Example:
  - In 2016, the California legislature passed Assembly Bill 2325, requiring electronic pathology reporting

Cancer Registry Data

- Registries are valuable for many reasons
  - They represent data on all cancer patients in a defined geographic area- not just from a cancer center or hospital system
    - Many real world data sources represent a nonrandom set of patients (from a single center) which may not reflect what is going on in the 85% of patients not treated at these centers
  - Consolidation of information across many sources, not just a single EMR
    - Typically more than one source of information is used by registries to complete each cancer abstract:
    - Average of 4 records/ case
      - hospital abstracts, physician reports, pathology reports and death certificates
      - Plus additional sources of real time data feeds from pharmacies and oncology practices

Uses of Registry Data- Current

- Active monitoring of patients from diagnosis until death
  - Most data are lacking in outcomes to provide context for a dataset (The Cancer Genome Atlas [TCGA], Clinical Trials, pharma studies etc.)
- Data are curated and adjudicated by trained and experienced personnel
  - While not perfect, the consolidation, manual review and centralization makes the data highly accurate and complete

Uses of Registry Data- Future

- Research and Treatment Support
  - Research Data: The importance of up to date information
  - It is estimated that up to 50% of clinical trials are not completed due to insufficient enrollment (Topaloglu et al, 2018)
    - To fulfill their potential, cancer registries should explore ways to enhance clinical trial matching
  - ***For both these objectives, the cycle time for cancer registry data must be reduced from ~2 years to less than 6 months***

Strategies to achieve near-real time reporting

- Electronic Reporting
- Automation

Electronic Reporting

- Electronic reporting makes possible the vision of near-real time data
- It has a number of advantages in addition to the speed of data acquisition

Electronic Medical Record Data Flow
Trigger/Send to Public Health

Electronic Health Record Data (EHR)

Health Level 7 (HL7) Standard Data can be triggered and sent

ADT – Demographics

ORU – Sending of the order results (R01)

State or Federal Disease Registry

Data Standards

- Data standards are critical for electronic data exchange
- Founded in 1987, Health Level Seven International (HL7) is a not-for-profit, ANSI-accredited standards developing organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services

Electronic Reporting: CDC Success

- Even with legislation in place, establishing electronic data connections is a challenging task for state cancer registries that operate with limited resources
- In response, the CDC has established data agreements with some of the largest national pathology labs (eg, Quest and LabCorp) to facilitate state access to electronic medical records
- States with statute supporting electronic reporting are able to receive electronic feeds due to the CDC agreements

Electronic Reporting: California Success

- As enabled by AB2325 (mentioned earlier), California began receiving electronic pathology reports on January 1, 2019
- Implementation was a major undertaking for the California registry, involving development of technical standards, a technical implementation guide, and extensive outreach to impacted groups
- Implementation Status (as of September, 2019)
  - 563 Reporting entities have registered
  - 404 Reporting entities have completed onboarding
  - Nearly 400,000 records received in CY 2019

Automation- Reducing human burden and increasing speed of cancer case acquisition/processing

- Goal in automation is to leverage deep learning (via natural language processing) to
  - to reduce manual burden
  - improve timeliness, completeness and consistency
- Initial focus is on path screening and automating data capture for 5 data items: Site, Histology, Behavior, Grade and Laterality
- Why is this important?
  - Useful in case identification and other registry operations
  - Potentially reduces effort at registries

Using automation to reduce manual burden in cancer surveillance – California experience

- Project completed by California in collaboration with Health Language Analytics- Global (HLAG)
  - Using 2016 California data
- Auto-coding achieved 90% accuracy on Site, Stage, Histology, Grade and Laterality
- Over 100,000 reports were auto-coded through the engine for 2016 data
  - roughly 40% of reporting pathology reports did not have to be touched by registry staff

Considering the Patient First

- Critical consideration for individual level utilization of near-real time data
- Receiving a cancer diagnosis is a life changing event and time is needed for adjustment
- Technological and other advances make it possible to make information available before the patient has made the necessary adjustments
- Protections must be in place to protect the patient
- California requires a waiting period of 6 weeks after diagnosis before any patient contact may be conducted

Thank You

Questions?

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