Use of Electronic Health Records and Health Information Exchanges to Streamline Registry Processes

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Electronic Health Records (EHR) and Health Information Exchanges (HIE)

- Collaboration with HIEs and use of EHR data is
  - Highly variable across central cancer registries
  - Generally in early stages

- Most registries predominantly rely on manual processes to complete data abstraction

- Number of variables that registries are expected to collect is continually increasing while funding/resources are decreasing
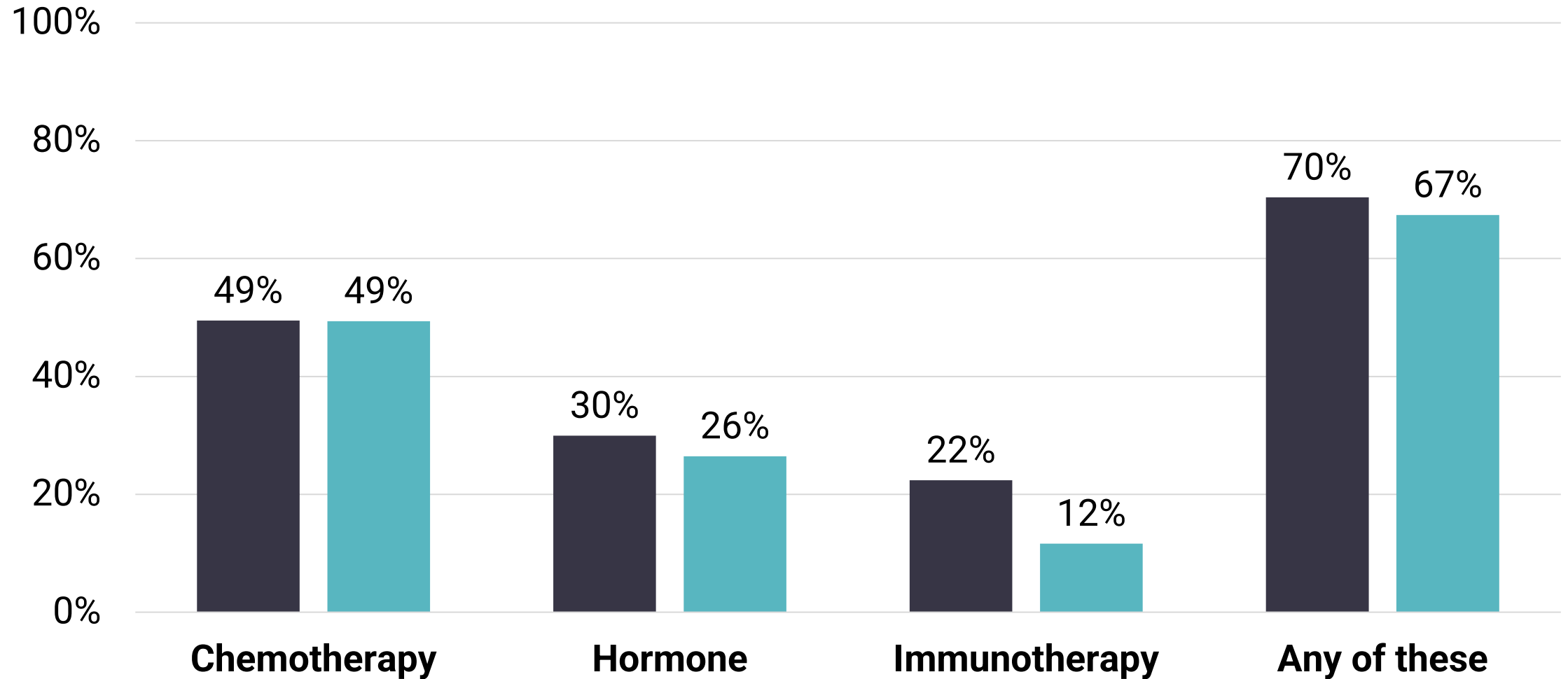
Iowa CANCER REGISTRY ICR
STATE HEALTH REGISTRY OF IOWA

Lessons Learned from EHR data

- Conducted a linkage between the Iowa Cancer Registry and EHR data within ASCO CancerLinQ to compare completeness

- Linkages with EHRs are messy without good variables on which to link!

  - Need SSN, full name (including at least a middle initial), DOB, gender for a good linkage, and additional variable such as race and address would be helpful

- Extremely difficult to link EHR data of patients with multiple cancers

  - No definitive diagnosis date, histology or consistent TNM stage in the EHR

- Linkage demonstrated opportunities to capture better treatment data from EHRs – especially hormone and immunotherapy

Iowa CANCER REGISTRY **ICR**
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Receipt of therapy within 12 months of diagnosis for patients diagnosed with first cancer, 2013-2017

■ CancerLinQ ■ Registry

	Chemotherapy	Hormone	Immunotherapy	Any of these
CancerLinQ	49%	30%	22%	70%
Registry	49%	26%	12%	67%

Receipt of therapies within 12 months of diagnosis for first <u>breast</u> cancers, 2013-2017

CancerLinQ ■ Registry ■

	Chemotherapy	Hormone	Immunotherapy	Any of these
CancerLinQ	30%	76%	18%	85%
Registry	30%	64%	9%	79%
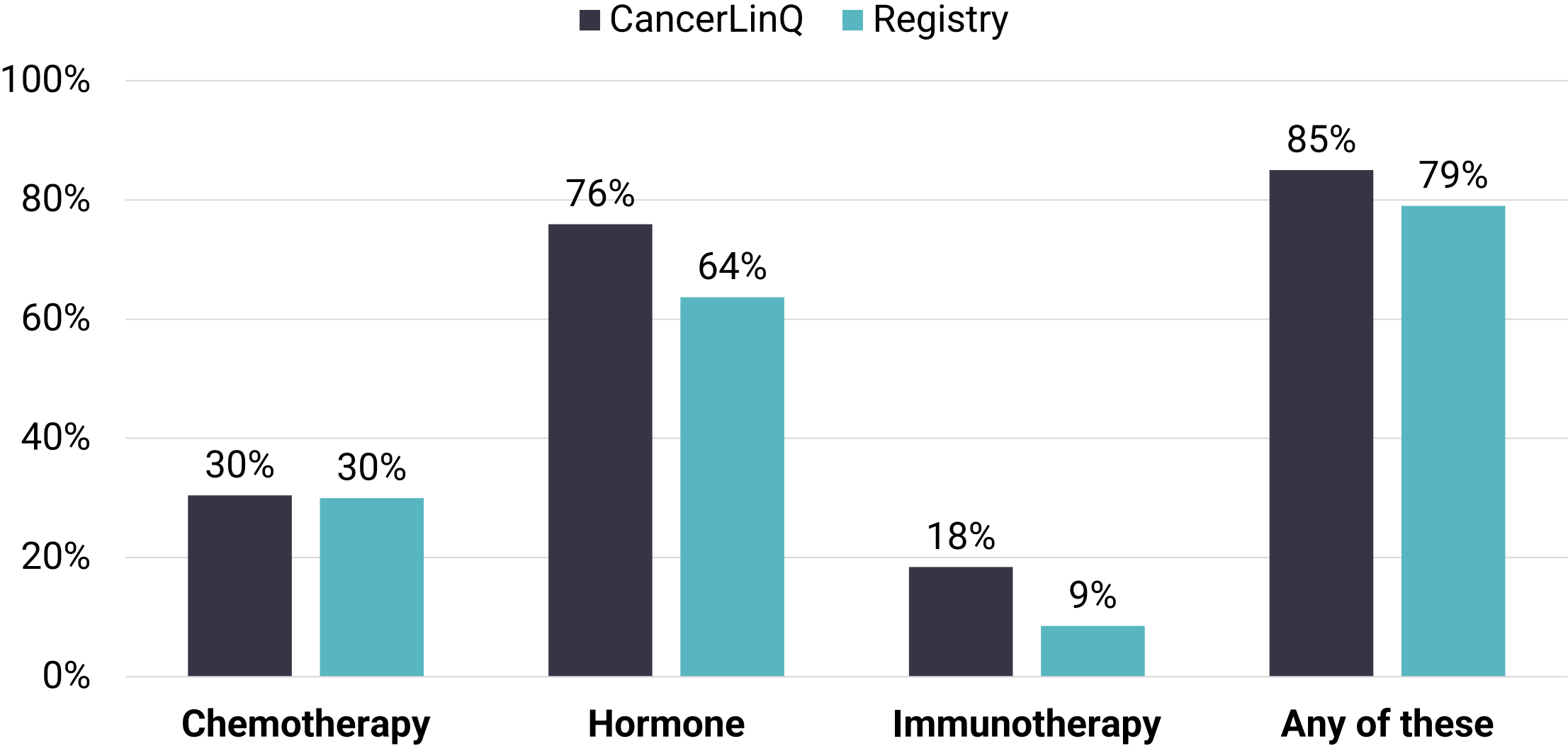
Example of Automated Extraction of EHR Data

ExtractEHR

- R software package

- Developed by the Children's Oncology Group to automate laboratory adverse event ascertainment and grading

References
- Miller TP, 2017, British Journal of Haematology
- Miller TP, 2022, Lancet Haematology
- Miller TP, 2023, JCO Clinical Cancer Informatics

Capability to automatically extract a variety of variables from the following:

- Visit information

- Clinic notes

- Lab results

- Genomics reports

- Medication orders and administration

- Procedures

- Radiology reports

Leveraging HIEs Beyond EHR Data

Casefinding can be a tedious and resource intensive process for hospitals, as well as for registries

- HL7 ADTs (Admission, Discharge, Transfer notifications) are a promising avenue for streamlining and centralizing the case-finding function

- Collaboration between registries and HIEs provide opportunities to leverage info in ADTs since they (theoretically) contain good linkage variables

- Can be used by registries as a case-finding audit tool to provide feedback to hospitals/reporting facilities to improve completeness of case ascertainment

Leveraging HIEs Beyond EHR Data

- CyncHealth is the HIE in Iowa

  – 108 out of Iowa's 118 hospitals are fully sharing data with CyncHealth with the others underway

- Already meeting ONC standards for V3 (target date 2026)

  – Working towards standards for V4 (target date 2028) which will allow for richer data to be exchanged for cancer cases

- CyncHealth and Iowa Cancer Registry are partnering to use ADTs for statewide cancer case finding

https://www.healthit.gov/sites/default/files/page/2023-07/Standards_Bulletin_2023-2.pdf

Leveraging HIEs Beyond EHR Data

- Death Certificate Only (DCO) cases are a significant problem for registries:

  - Require intensive efforts to find information

  - Cases are typically excluded from research due to insufficient data

- Maryland Cancer Registry/Myriddian partnered with their HIE (CRISP)

  - CRISP was able to provide information including:

    - Date of First Visit for a cancer diagnosis, Facility, Cancer Diagnosis, Diagnosis Description, Race, and Ethnicity

  - Enriched dataset allowed for efficient follow up with healthcare facilities to get needed information to decrease DCO cases

Thank you

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