Fred Hutch Cancer Center

One success & one failure: the ups and downs of attempts to improve cancer registry value

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Disclosures

- Contract funding from the National Cancer Institute to lead the Fred Hutch Cancer Surveillance System (CSS), a SEER registry

- Grant funding from the National Cancer Institute to conduct epidemiologic research on cancer risk factors and on methodological research on use of NLP to extract information on recurrences from electronic medical records

A success: *Reducing Delays in Cancer Case Ascertainment*

Rationale for Reducing Delays in Cancer Case Ascertainment

Public Health Surveillance Mission

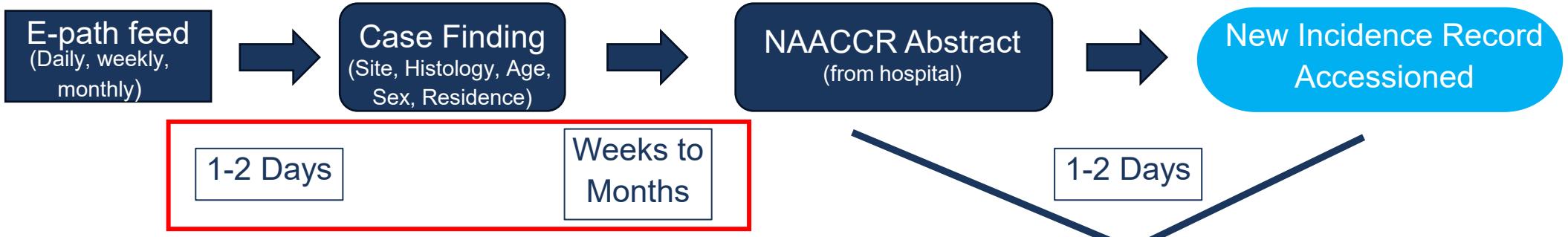
- Trend assessments reflect most recent data
- Address problematic trends more rapidly

Research Mission

- Case recruitment closer to diagnosis
- Higher likelihood of successful recruitment for cancers that are rapid fatal.
- Necessary for population-based studies of patient-physician dynamics in treatment decision process

Reducing Delays in Cancer Case Ascertainment

Single-Tier Reporting Strategy



Two-Tier Reporting Strategy

A Failure: *Accessing State Administrative Health Data*

Potential Value of State Administrative Health Data

Expansion of Cancer Registry Scope

- Data on diagnostic modalities
- More complete data on cancer treatments
- Monitor health of cancer survivors
- Estimate cost of cancer care

Examples of Data Sources

- Hospital discharge databases
- Insurance claims databases (e.g., All Payers Claims Databases)

"Large State databases that include medical claims, pharmacy claims, dental claims, and eligibility and provider files collected from private and public payers."

A Failure: *Accessing State Administrative Health Data*

Reality of Washington State All Payers Claim Database

Access Substantially Limited by State Regulation

- Only circumscribed research projects
- No approvals for on-going activities such as public health surveillance
- Data cannot be re-released (e.g., to NCI, CDC)

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Thank you