MEDLIOR
HEALTH OUTCOMES RESEARCH

UNTAPPED: Innovative ways to use big data in healthcare

Tara Cowling
October 21, 2019

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Disclosures

Tara Cowling is the owner of Medlior Health Outcomes Research Ltd.,

where we engage in industry-funded research projects.

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HEALTH OUTCOMES RESEARCH

About Medlior

Canadian owned and operated since 2008, Medlior has a strong reputation for providing health economics and outcomes research services in Canada, the US and the UK.

Our multidisciplinary team offers substantial health system, academic, and industry experience which ensures every Medlior project provides meaningful insights.

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Objectives

1. Overview of Canadian RWD

2. Opportunities for prospective data collection in Ophthalmology

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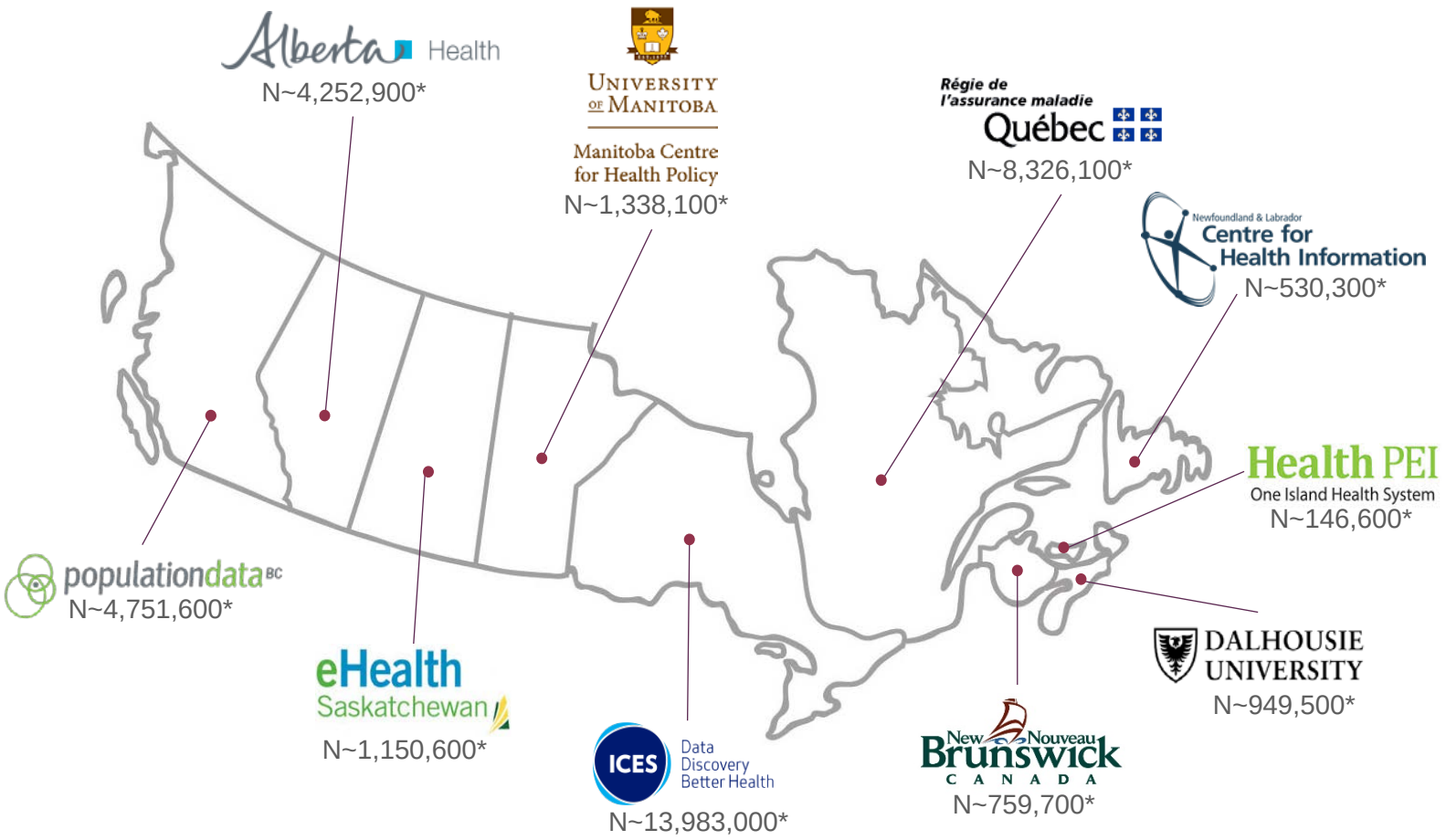
Canadian RWD Available



Canadian RWE typically includes the following data:

1. Health insurance plan registration
2. Vital statistics
3. Health service records
4. Pharmaceutical claims
5. Laboratory service tests
6. Diagnostic imaging
7. Cancer Registry

*Number of available admin records based on provincial population estimates (country population of 36,286,400 in 2016)

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Canadian Provincial RWD Overview

Province	Health Services			Pharmaceutical		Public Health Insurance	Vital Statistics	Long-term/ Home Care	Provincial Laboratory Data
	Inpatient Hospitalizations	Ambulatory Care	Physician Claims	Pharmacy-level	Public plan only				
British Columbia	✓	✓	-	✓	✓	✓	✓	✓	-
Alberta	✓	✓	✓	✓	✓	✓	✓	✓	✓
Saskatchewan	✓	✓	✓	✓	✓	-	✓	✓	-
Manitoba	✓	✓	✓	✓	-	✓	✓	✓	✓
Ontario	✓	✓	✓	-	✓	✓	✓	✓	✓ (80%)
Quebec	✓	✓	✓	-	✓	✓	✓	-	-
New Brunswick	✓	-	✓	Unclear	✓	-	✓	Forthcoming	-
Nova Scotia	✓	✓	✓	-	✓	✓	✓	-	-
Prince Edward Island	✓	✓	✓	✓	-	-	✓	✓	✓
Newfoundland & Labrador	Information not available								

Note: Data availability for research may vary across jurisdiction, data holdings and data custodians/owners.

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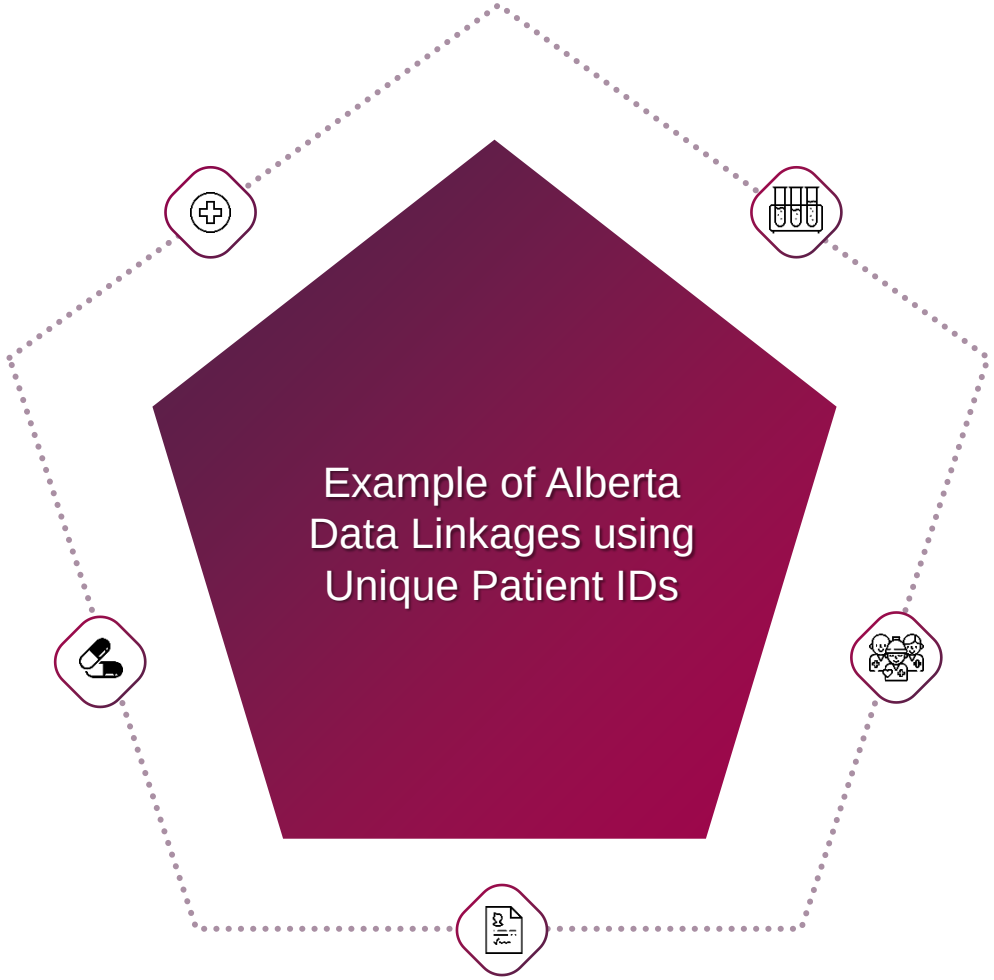
Alberta Data Linkages

Health Services Data

- Hospitalizations
- Ambulatory care visits
- Physician claims
- Diagnosis and procedure codes
- Length of stay



Lab Data

- Test name, date, results
- Abnormal diagnosis
- Reason for test
- IHC/cytopathology

Drug Data

- Private and public plan claims
- Drug names
- Medication Possession Ratio
- Proportion of Days Covered
- Gaps in treatment
- Treatment switching
- Concomitant medication use

Alberta Cancer Registry

- Patient demographics
- Tumour information
  - Site and stage at diagnosis
  - Topography and morphology
- Initial cancer treatment

Vital Statistics

- Births/Deaths
- Marriage
- Gender and geographic Information

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Ophthalmology Disease Surveillance and Burden of Illness in Alberta

Overview

- The economic burden of vision loss in Canada is estimated at **$15.8 billion CAD** (2007), with the highest direct healthcare cost ($8.6 billion) for any disease category in Canada.
- Age-related macular degeneration (AMD) is the leading cause of vision loss in those ≥50 years
- By 2032 nearly 1 in 4 Canadians will be ≥65 years

CPCSSN RCSSSP
Canadian Primary Care Sentinel Surveillance Network
Réseau canadien de surveillance sentinelle en soins primaires

Cumming School of Medicine
Centre for Health Informatics
UNIVERSITY OF CALGARY

Public Health Agency of Canada
Agence de la santé publique du Canada

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Ophthalmology Disease Surveillance and Burden of Illness in Alberta

Rationale

- The surveillance of chronic ophthalmological diseases, like AMD, has remained a persistent gap in public health knowledge, hindering policy development and intervention.
- Real-world evidence in ophthalmology in Canada is lacking

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Ophthalmology Disease Surveillance and Burden of Illness in Alberta

Purpose

- Request for funding from the Public Health Agency of Canada **Enhanced Surveillance for Chronic Disease Program**
- Objective to establish the foundation for a longitudinal, province-wide database and perform a burden of disease study
- Medlior will collaborate with the Southern Alberta Primary Care Research Network (SAPRCReN) and the University of Calgary, Centre for Health Informatics

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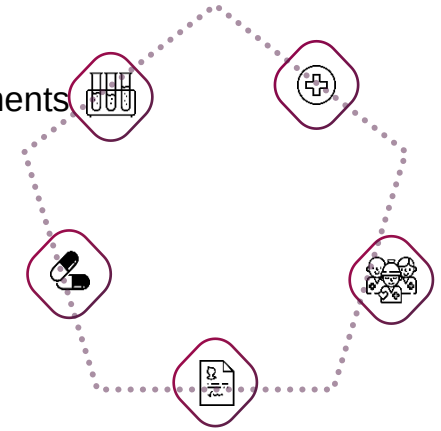
Ophthalmology Disease Surveillance and Burden of Illness in Alberta

Data Available in Alberta



RAPID Data
- Anti-VEGF retinal treatments
- Indication

Drug Data (PIN)
- Drug Names
- Date/dose of dispense

Health Services Data
- Inpatient & Outpatient visits
- Practitioner claims
- Diagnosis and Procedure Codes
- Comorbidities

Population Registry
- Demographics
- Out-of-province migration
- Geographic distribution

Vital Statistics
- Mortality

- ICD-10 CA codes do not differentiate causes of macular degeneration (age-related/senile cannot be distinguished from other types)
- ✓ In Alberta, anti-VEGF treatments are covered through the Retina Anti-Vascular Endothelial Growth Factor Program for Intraocular Disease (RAPID) Program (2015-present)
- No clinical ophthalmology outcomes are captured in administrative data

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Ophthalmology Disease Surveillance and Burden of Illness in Alberta

Objective 1: Case Definition and Validation

- A novel case definition/data algorithm will be developed and validated to identify patients with AMD in Canada using CPCSSN
- Data will be linked to administrative health data (including the RAPID) program.

Objective 2: Analysis and Prospective Data Collection

- Data will be analyzed to establish the burden of AMD and current management in Alberta (incidence, prevalence, healthcare utilization)
- A patient survey will be administered via Alberta Health Services to collect PROs prospectively

Objective 3: Simulation Model Development

- Using the data generated in Objectives 1 and 2, patient-level simulation model will be developed to project the health and economic impact of AMD in Canada over the next 30 years

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From Real-World Data to Real-World Patients: The O2 Program

Winson Y. Cheung, MD, MPH, FRCPC
Professor of Medicine, University of Calgary
Director, Real-World Evidence, Cancer Control Alberta
Lead, Oncology Outcomes (O2) Program
@WinsonCheung
@OncOutcomes

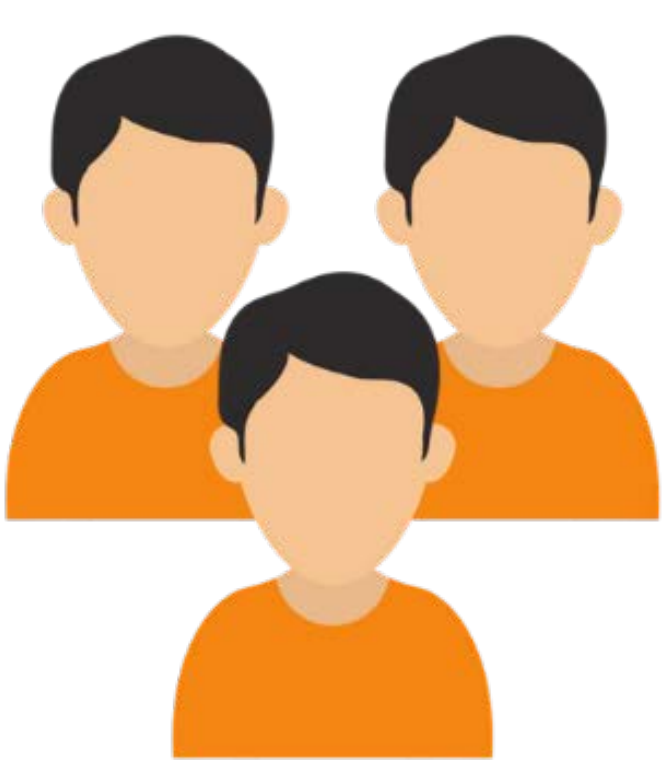
Objectives

- Introduce the Oncology Outcomes (O2) Program
- Describe real-world evidence (RWE) generation along the oncology product lifecycle: HTA, PHC
- Highlight examples of innovative data technologies and precision/predictive analytics for oncology: AI, ML, and NLP

ONCOLOGY OUTCOMES O2

Why RWE and why now?

Controlled Setting ≠ Real World



ONCOLOGY OUTCOMES

RCTs ≠ Real World

Clinical Trials	Real World Evidence
Internal validity	**External** validity
Young and **fitter** patients	**Older** and **frailer** patients
Finite follow-up	**Longitudinal** follow-up
Tumor-**specific**	Tumor-**agnostic**
Singular primary endpoints	**Multiple** potential endpoints
Limited cost and healthcare use information	**Comprehensive** cost and healthcare use information
Granular data on **selected** patients	**General** data on **unselected** patients
Resource **intensive**	Relatively **inexpensive**

ONCOLOGY OUTCOMES

Breadth of Data | Real-World Inspiration

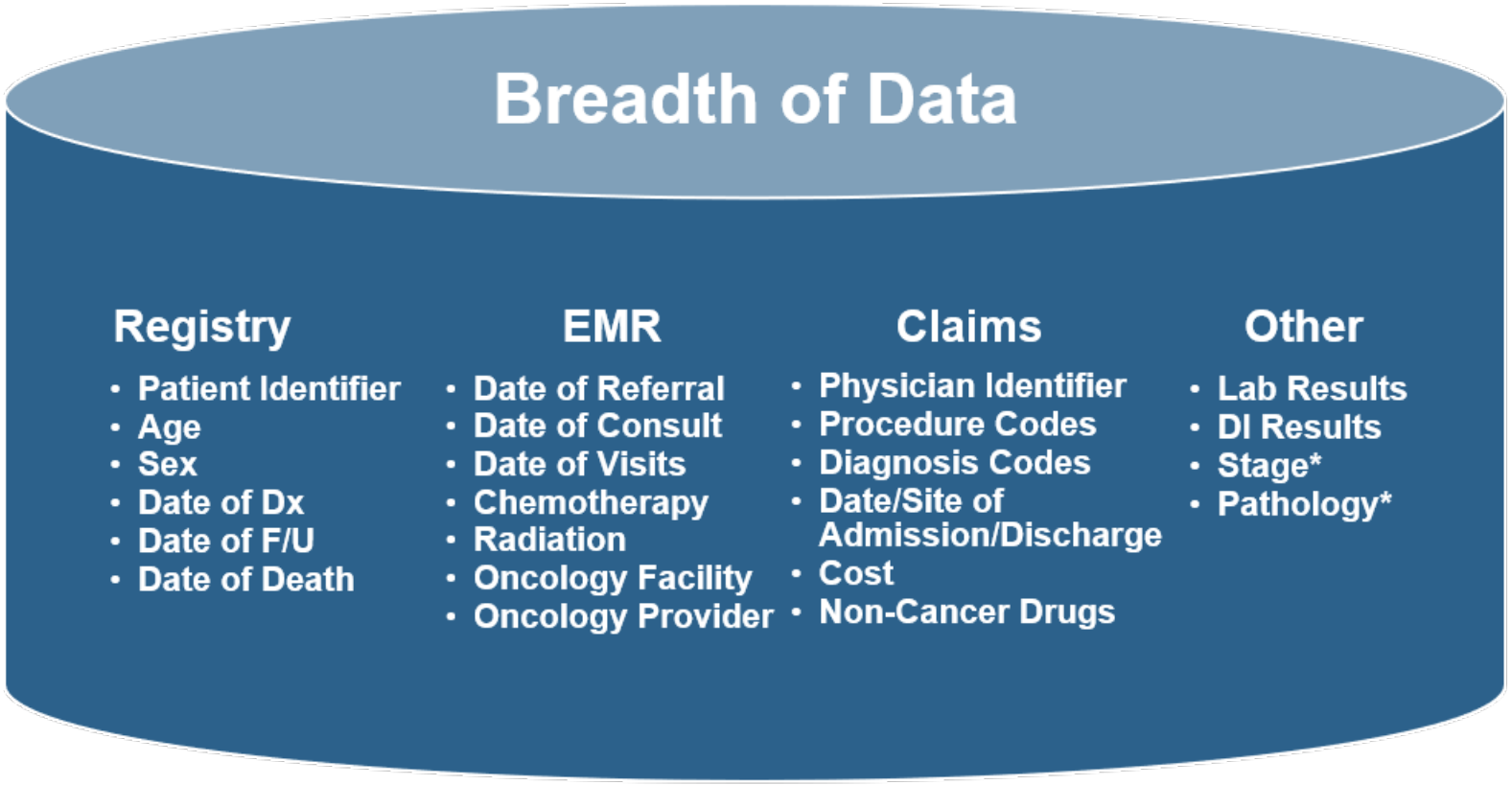
“To lead in **precision** oncology through a **forward-thinking real-world evidence** approach that incorporates **enriched data sources** and **advanced analytics**”

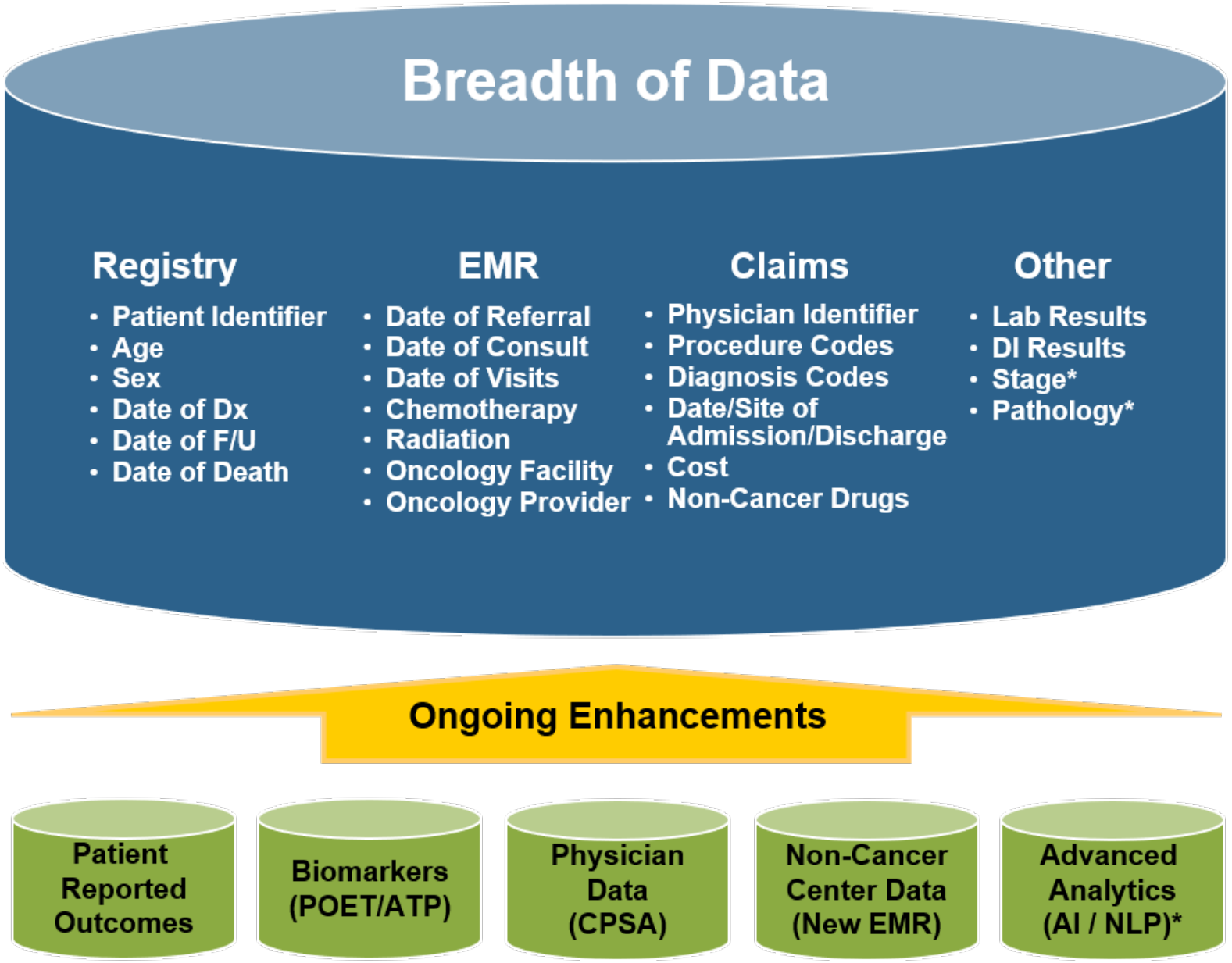
ONCOLOGY OUTCOMES

Breadth of Data | Real-World Inspiration

ONCOLOGY
OUTCOMES

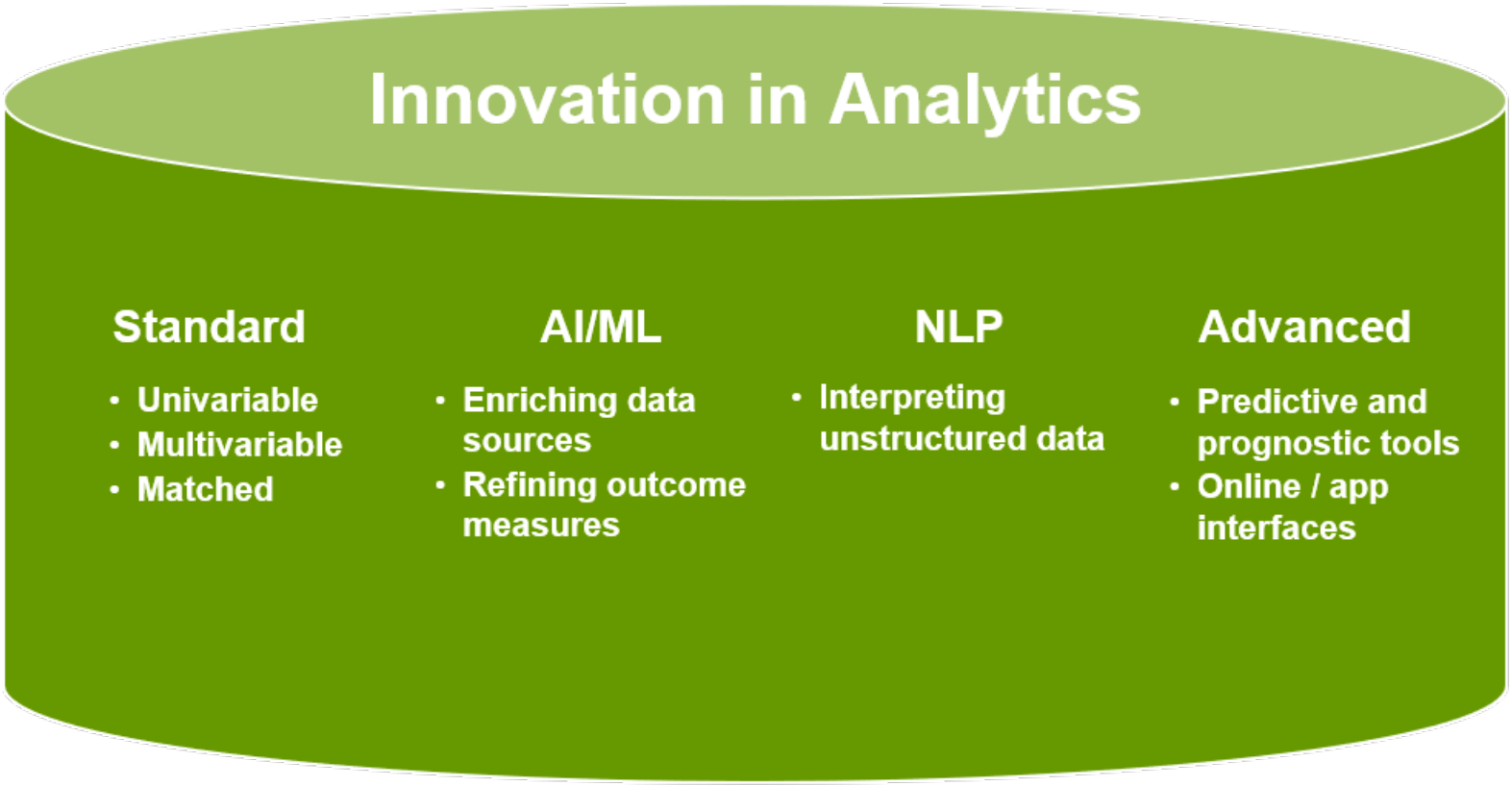
Breadth of Data | Real-World Inspiration


Breadth of Data
Registry
• Patient Identifier
• Age
• Sex
• Date of Dx
• Date of F/U
• Date of Death
EMR
• Date of Referral
• Date of Consult
• Date of Visits
• Chemotherapy
• Radiation
• Oncology Facility
• Oncology Provider
Claims
• Physician Identifier
• Procedure Codes
• Diagnosis Codes
• Date/Site of Admission/Discharge
• Cost
• Non-Cancer Drugs
Other
• Lab Results
• DI Results
• Stage*
• Pathology*



Population-based data

- 2 tertiary centres
- 4 regional centres
- 11 community centres


Innovation in Analytics
Standard
• Univariable
• Multivariable
• Matched
AI/ML
• Enriching data sources
• Refining outcome measures
NLP
• Interpreting unstructured data
Advanced
• Predictive and prognostic tools
• Online / app interfaces

Innovation in Analytics

Standard

- Univariable
- Multivariable
- Matched

AI/ML

- Enriching data sources
- Refining outcome measures

NLP

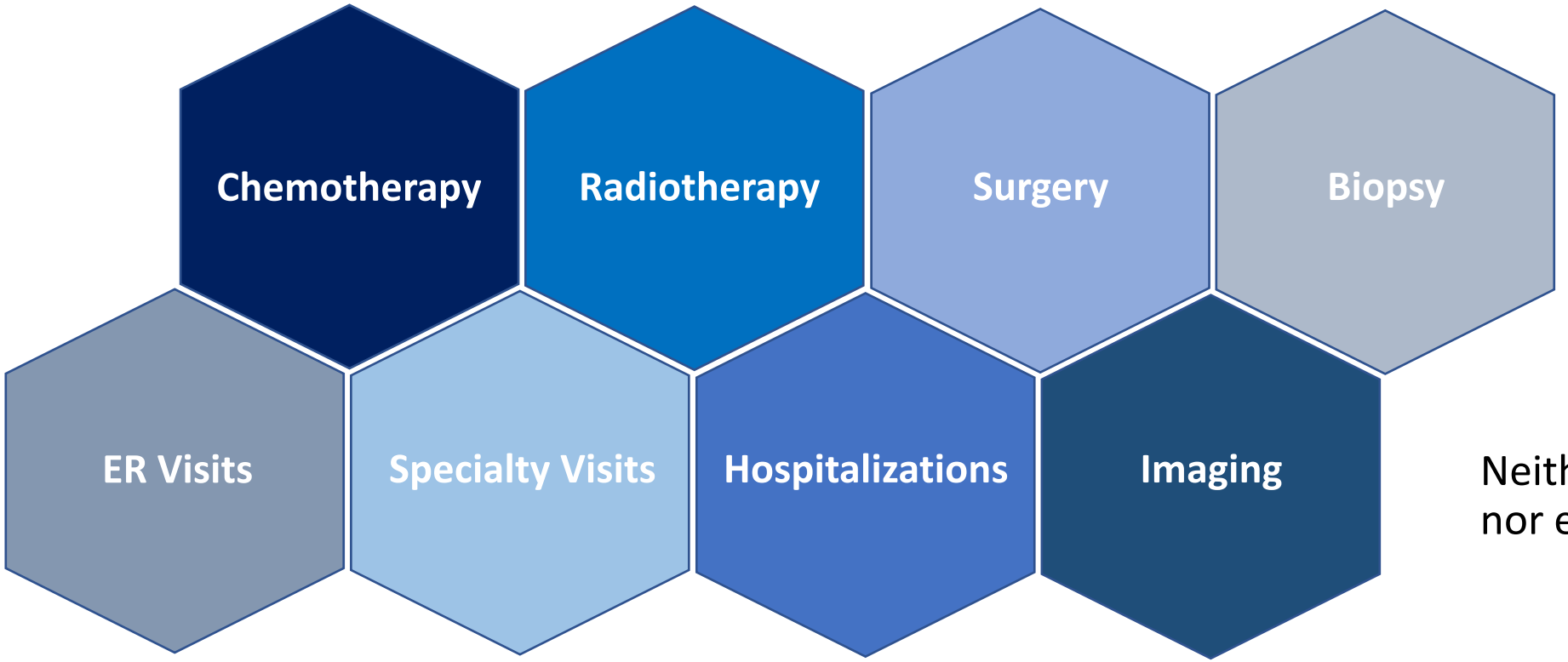
- Interpreting unstructured data

Advanced

- Predictive and prognostic tools
- Online / app interfaces

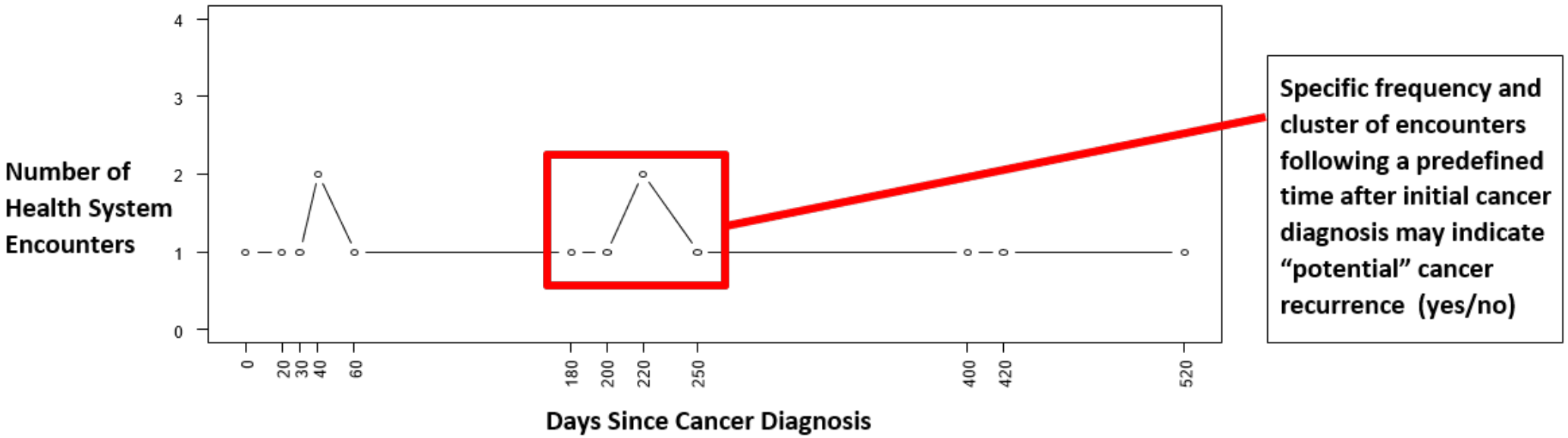
Important events such as cancer recurrence and/or progression are not routinely captured by real-world data sources

Cancer Recurrence Algorithms

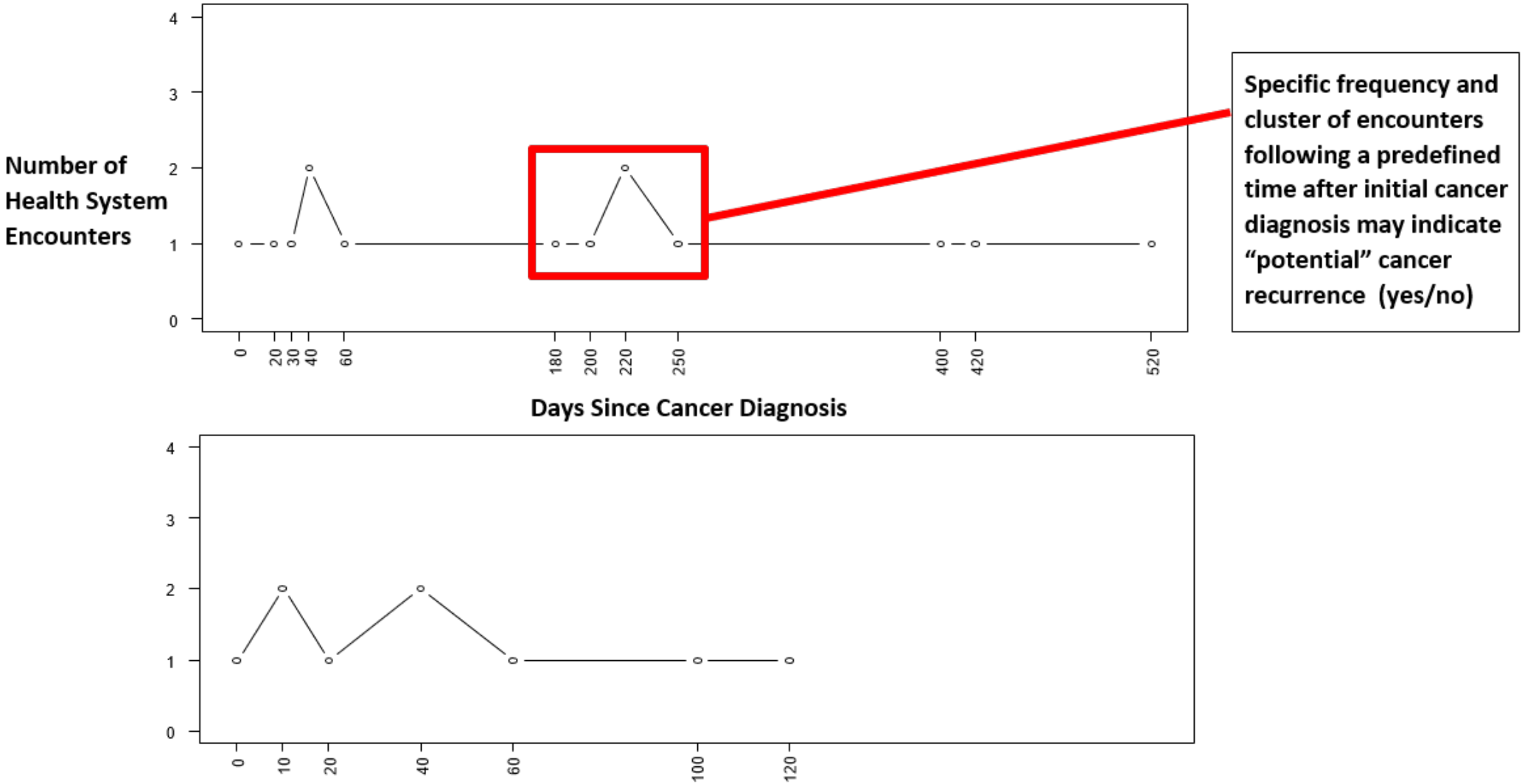


Neither exhaustive nor exclusive*

Cancer Recurrence Algorithms



Cancer Recurrence Algorithms



RESEARCH ARTICLE Open Access

Development and validation of case-finding algorithms for recurrence of breast cancer using routinely collected administrative data

Yuan Xu[1,2,3*], Shiying Kong[1,2,3], Winson Y. Cheung[2,3], Antoine Bouchard-Fortier[1,2,3], Joseph C. Dort[1,2,3,4], Hude Quan[2], Elizabeth M. Buie[1], Geoff McKinnon[1] and May Lynn Quan[1,2,3]

Abstract

Background: Recurrence is not explicitly documented in cancer registry data that are widely used for research. Patterns of events after initial treatment such as oncology visits, re-operation, and receipt of subsequent chemotherapy or radiation may indicate recurrence. This study aimed to develop and validate algorithms for identifying breast cancer recurrence using routinely collected administrative data.

Methods: The study cohort included all young (≤ 40 years) breast cancer patients (2007–2010), and all patients receiving neoadjuvant chemotherapy (2012–2014) in Alberta, Canada. Health events (including mastectomy, chemotherapy, radiation, biopsy and specialist visits) were obtained from provincial administrative data. The algorithms were developed using classification and regression tree (CART) models and validated against primary chart review.

Results: Among 598 patients, 121 (20.2%) had recurrence after a median follow-up of 4 years. The high sensitivity algorithm achieved 94.2% (95% CI: 90.1–98.4%) sensitivity, 93.7% (91.5–95.9%) specificity, 79.2% (72.5–85.8%) positive predictive value (PPV), and 98.5% (97.3–99.6%) negative predictive value (NPV). The high PPV algorithm had 75.2% (67.5–82.9%) sensitivity, 98.3% (97.2–99.5%) specificity, 91.9% (86.6–97.3%) PPV and 94% (91.9–96.1%) NPV. Combining high PPV and high sensitivity algorithms with additional (7.5%) chart review to resolve discordant cases resulted in 94.2% (90.1–98.4%) sensitivity, 98.3% (97.2–99.5%) specificity, 93.4% (89.1–97.8%) PPV, and 98.5% (97.4–99.6%) NPV.

94% sensitivity
92% PPV

Xu Y, Cheung WY, et al. BMC Cancer. 2019 Mar 8;19(1):210. doi: 10.1186/s12885-019-5432-8.

Cancer Care Pathways

- **Provincial RWE in pancreatic cancer**
  - What proportion of advanced pancreatic cancer patients are referred to an oncologist?
  - What proportion of referred patients are given systemic therapy?
  - What are the timeliness of:
    - Referral to consultation?
    - Consultation to treatment?

Cancer Care Pathways

- **Provincial RWE in pancreatic cancer**
  - What proportion of advanced pancreatic cancer patients are referred to an oncologist? **56/100**
  - What proportion of referred patients are given systemic therapy? **31/56**
  - What are the timeliness of:
    - Referral to consultation? **22/56 wait >2 weeks**
    - Consultation to treatment? **25/31 wait <2 weeks**

Pancreatic Cancer
Patient Flow Chart

URGENT symptoms suggesting **Pancreatic Cancer**

- New diagnosis of diabetes with normal BMI and no family risk factors
- Painless jaundice
- Abdominal pain
- Pale, oily and floating stool

OTHER symptoms possibly associated with **Pancreatic Cancer**

- Continued back pain
- Itchy skin
- Weight loss
- Nausea and vomiting
- Dark urine
- DVT's
- New diagnosis of depression (along with some urgent symptoms)
- Fatigue

Imaging and Lab Work

Ultrasound

(if Ultrasound is negative, please still refer for urgent CT as Ultrasound doesn't always detect masses in pancreas)

CT Scan

Chest, abdomen and pelvis for Pancreatic Cancer
Fax: 1 855-776-3818

1. Mass in pancreas
2. Suspicious lesions in liver or lung

Most Likely Metastatic

GASTROENTEROLOGY GROUP
EUS and Biopsy to confirm Diagnosis

1. Isolated mass found in pancreas
2. NO Suspicious lesions in lungs or liver

Most Likely Local Disease

PANCREATIC CANCER SURGEONS
(also referred to as Hepatobiliary Surgeons)

No mass found in pancreas

Needs Further Investigation

GASTROENTEROLOGY GROUP
Further investigation to rule out suspected Pancreatic Cancer

Pancreatic Cancer
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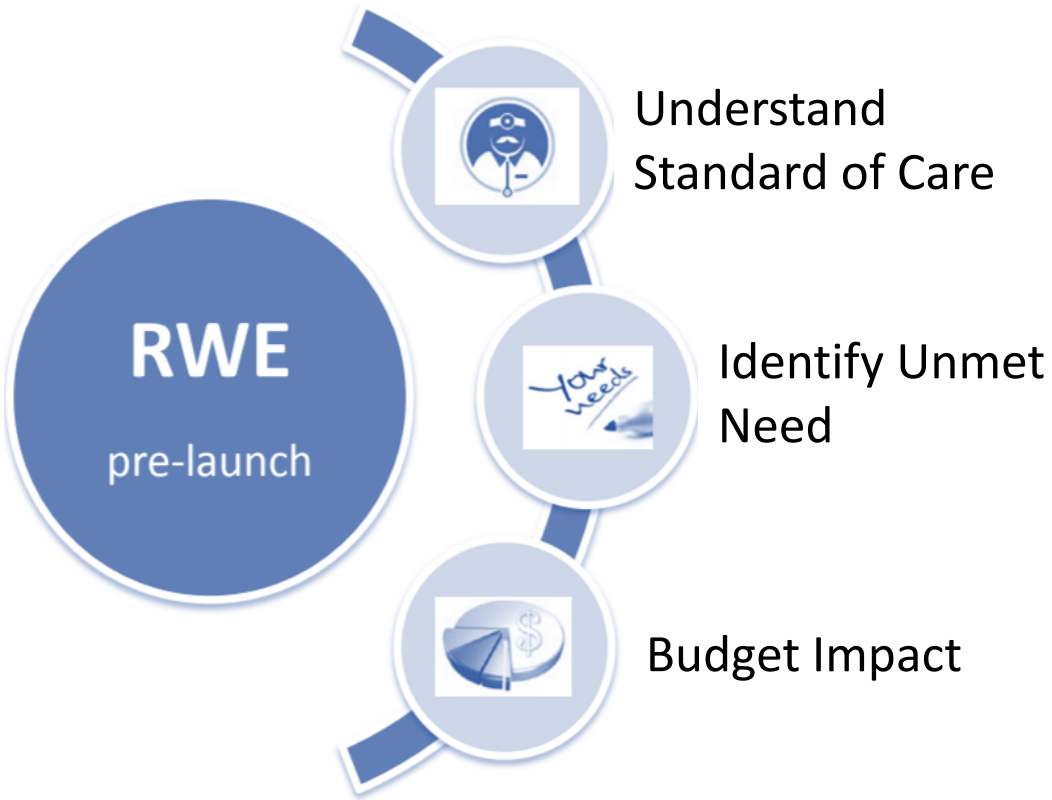
1. Mass in pancreas 2. Suspicious lesions in liver or lung	1. Isolated mass found in pancreas 2. NO Suspicious lesions in lungs or liver	No mass found in pancreas
Most Likely Metastatic	**Most Likely Local Disease**	**Needs Further Investigation**
GASTROENTEROLOGY GROUP EUS and Biopsy to confirm Diagnosis	**PANCREATIC CANCER SURGEONS** (also referred to as Hepatobiliary Surgeons)	**GASTROENTEROLOGY GROUP** Further investigation to rule out suspected Pancreatic Cancer

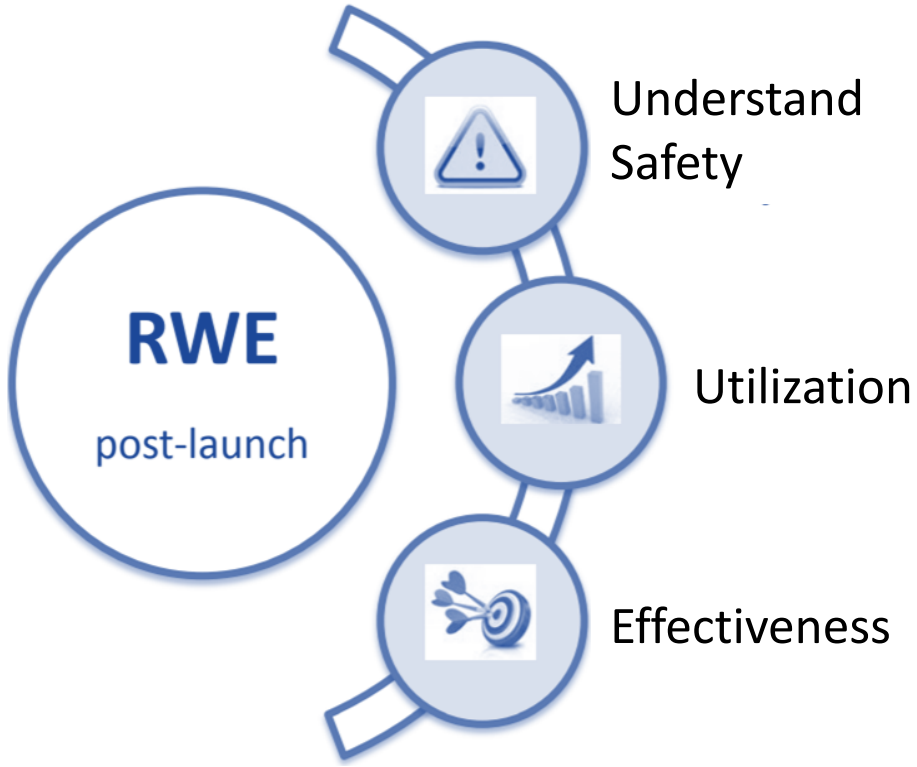
Referral: 56% → 65%
Treatment: 55% → 67%
Timeliness: 39% → 21%

Health Technology Assessments

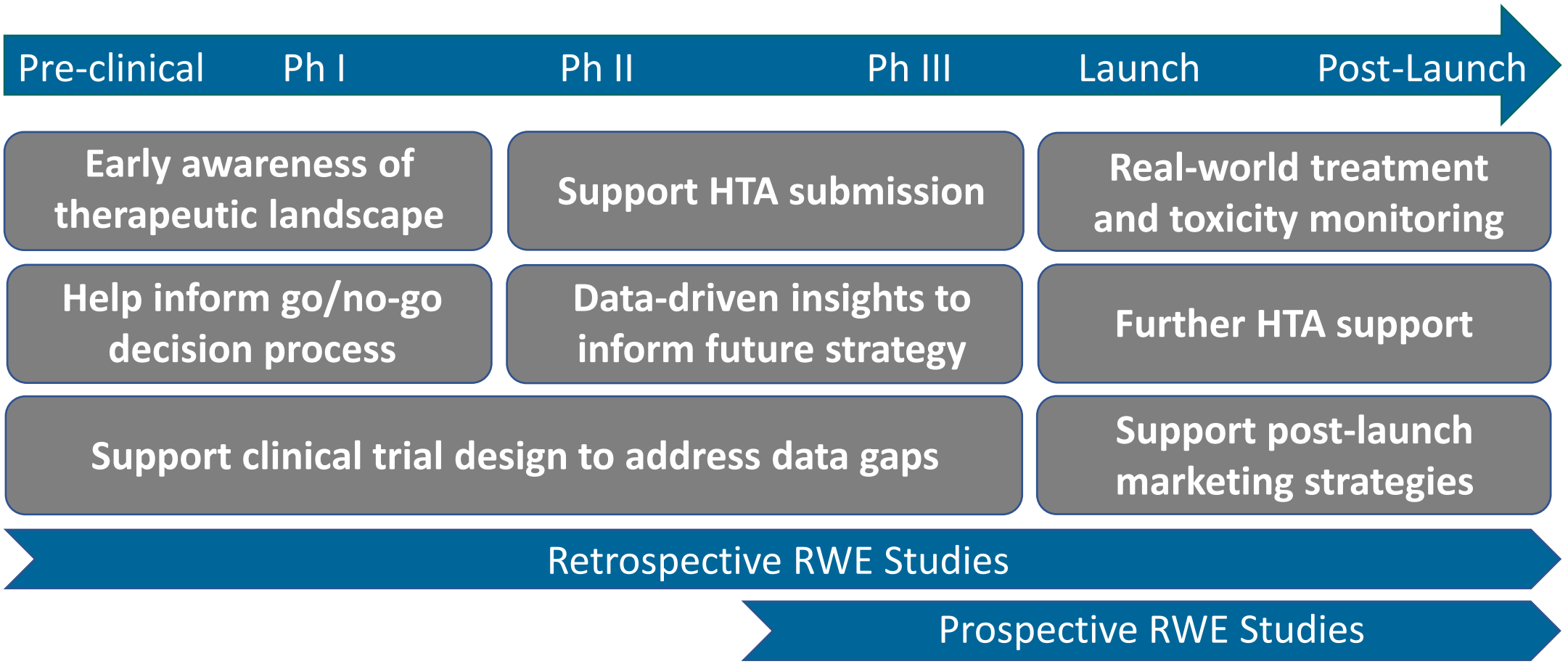
- **Role of RWE in HTA bodies**
  - Routinely collected data or RWE within health systems are increasingly being viewed as a means to increase payers' and HTA bodies' certainty about the true performance of the drugs or interventions that are funded
  - CADTH/pCODR (oncology)
    - RWE incorporated into 42% of HTA submissions
    - Increasing RWE integration over time

Health Technology Assessments

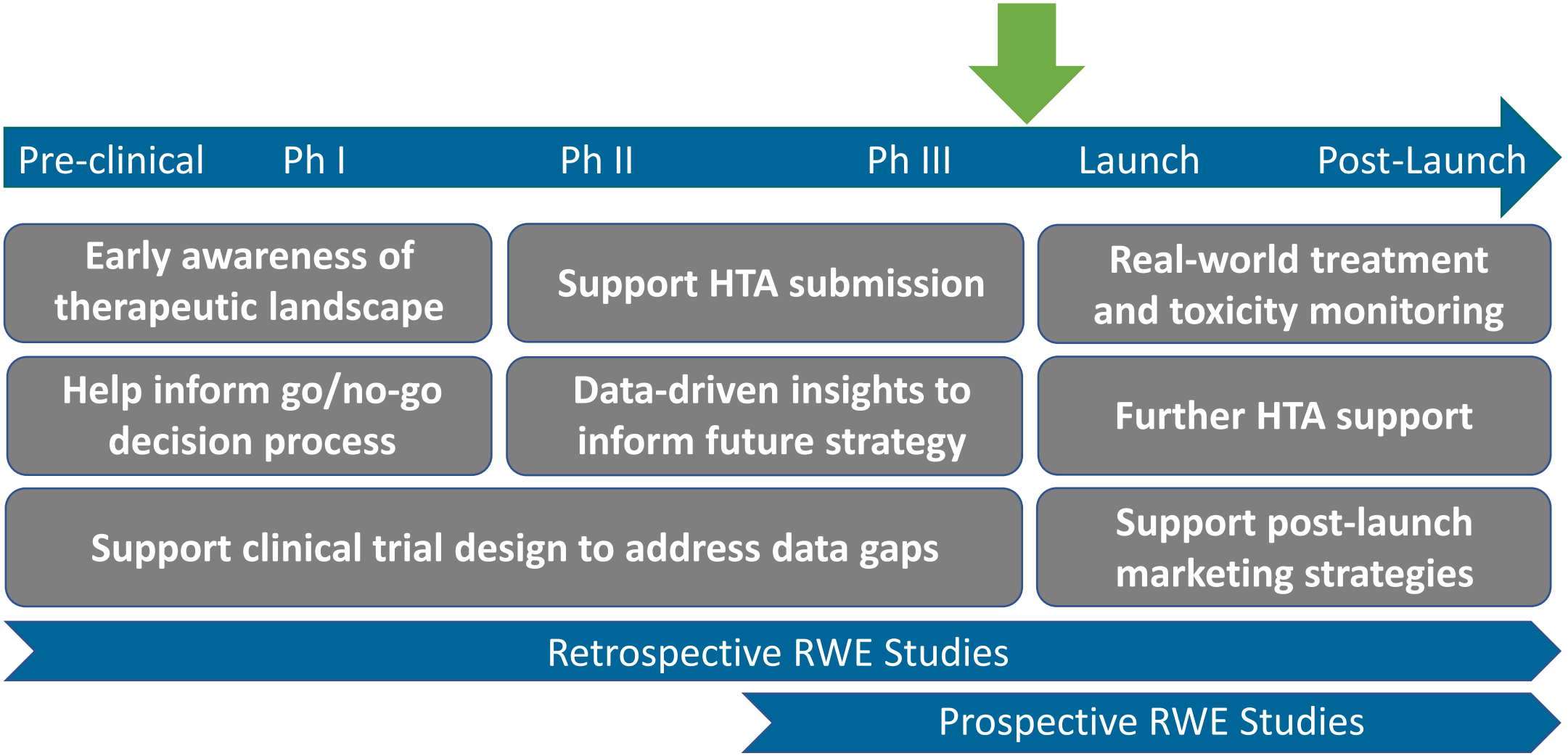




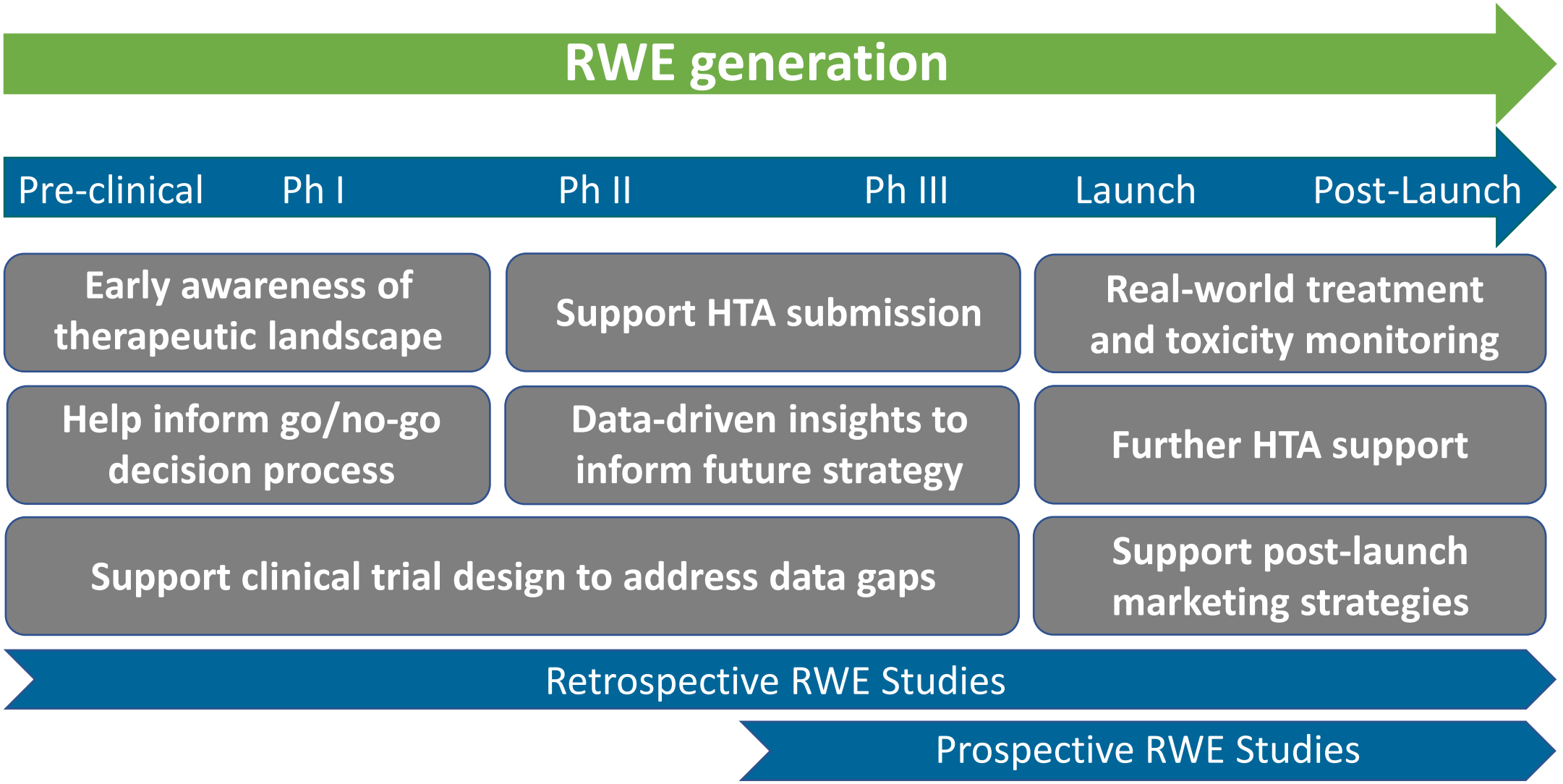
RWE Across Product Lifecycle



RWE Across Product Lifecycle



RWE Across Product Lifecycle



RWE Beyond Borders

- **Barriers**
  - Different interpretation and implementation of data privacy legislation
    - Agreements/contracts
  - Challenges associated with data harmonization
    - DD/MM/YY vs. MMM/DD/YYYY
  - Authorship governance
  - New EMR systems

RWE Beyond Borders

“To lead in **precision** oncology through a **forward-thinking real-world evidence** approach that incorporates **enriched data sources** and **advanced analytics**”

@WinsonCheung
@OncOutcomes

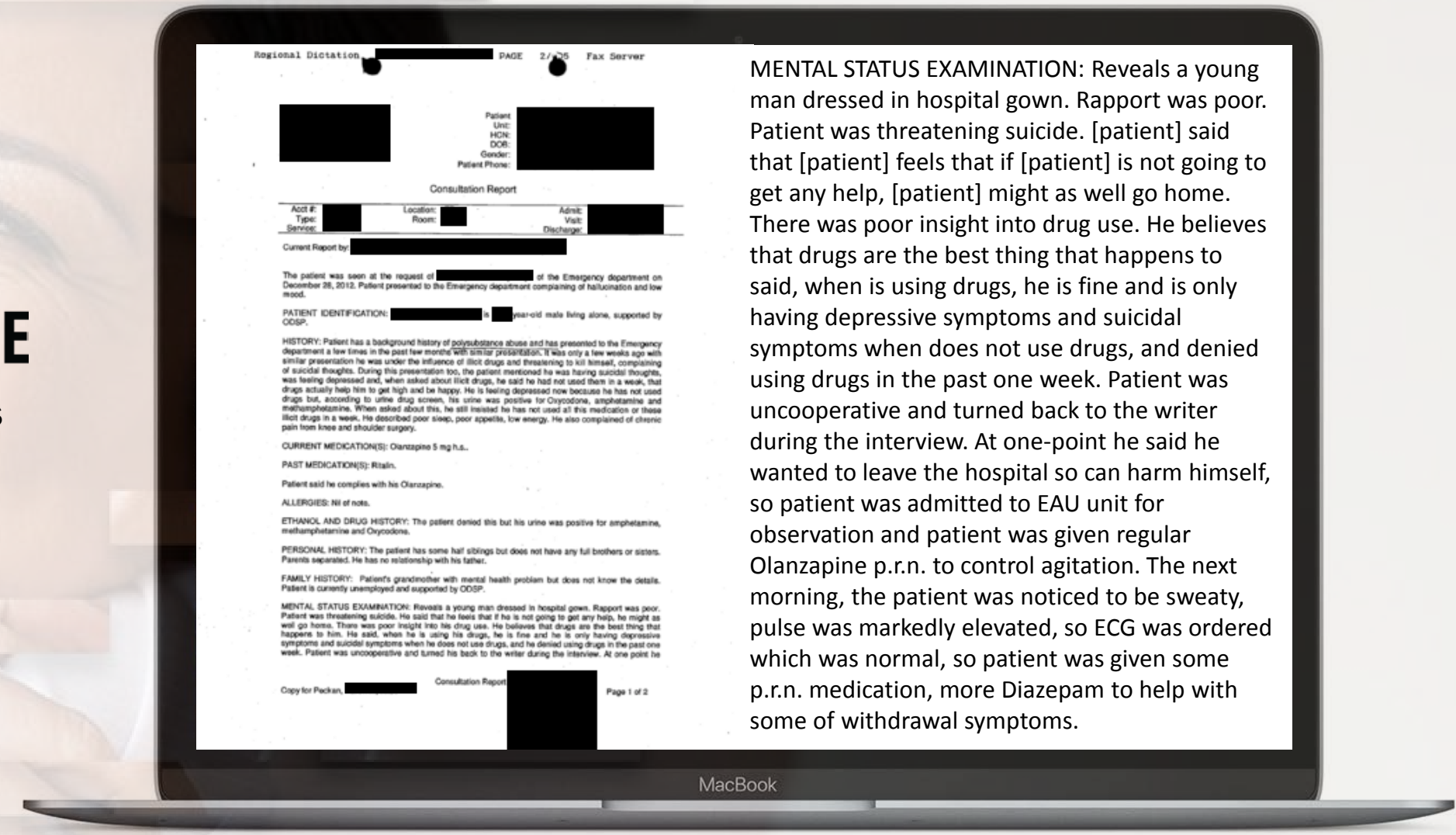
ONCOLOGY OUTCOMES
Breadth of Data | Real-World Inspiration

PENTAVERE


Back to Patients list
Preventative Care Dashboard
Daily
Weekly
Monthly
Rebecca Rowe
3rd F, Room 7, Bed 4
67
Years old
Female
Gender
176 cm
Height
63.4 kg
Weight
Allergies
Nuts
Penicilin
Conditions
Glaucoma
Add
Edit
Heart Rate
84 bpm
165
Average
188
Highest
83
Lowest
Temperature
36.8 °C
Oxygen Level
93%
Recent Activity
400
300
200
100
9AM
12PM
3PM - 4.30PM
5PM
Blood Pressure
130/80 mmHG
Blood Levels
Vitamine
HDL
LDL
Sodium
Glucose
55.2
43
73
51.6
69
Body Activity
ACTIVITY DETECTED
We have detected an abnormal activity and sent a notification to the doctor.
MacBook

PENTAVERE

In Healthcare, Good Data Saves Lives



MENTAL STATUS EXAMINATION: Reveals a young man dressed in hospital gown. Rapport was poor. Patient was threatening suicide. [patient] said that [patient] feels that if [patient] is not going to get any help, [patient] might as well go home. There was poor insight into drug use. He believes that drugs are the best thing that happens to said, when is using drugs, he is fine and is only having depressive symptoms and suicidal symptoms when does not use drugs, and denied using drugs in the past one week. Patient was uncooperative and turned back to the writer during the interview. At one-point he said he wanted to leave the hospital so can harm himself, so patient was admitted to EAU unit for observation and patient was given regular Olanzapine p.r.n. to control agitation. The next morning, the patient was noticed to be sweaty, pulse was markedly elevated, so ECG was ordered which was normal, so patient was given some p.r.n. medication, more Diazepam to help with some of withdrawal symptoms.

“80% of the health information we create is buried in unstructured clinical documentation”

Wang, Y, Kung, L, Byrd, T ; "Big data analytics: Understanding its capabilities and potential benefits for healthcare organizations" Technological Forecasting and Social Change.

“We have been working on a few big projects, and we’ve had to spend most of the time just cleaning the data sets before you can even run the algorithm. That’s taken us years just to clean the datasets. I think people underestimate how little clean data there is out there”

Vas Narasimhan, CEO of Novartis AG ; “Novartis CEO Who Wanted To Bring Tech Into Pharma Now Explains Why It's So Hard” Forbes Magazine Jan 2019

MANUAL CHART REVIEW

TIME PER RECORD
Number of Variables + Complexity of Variables

x

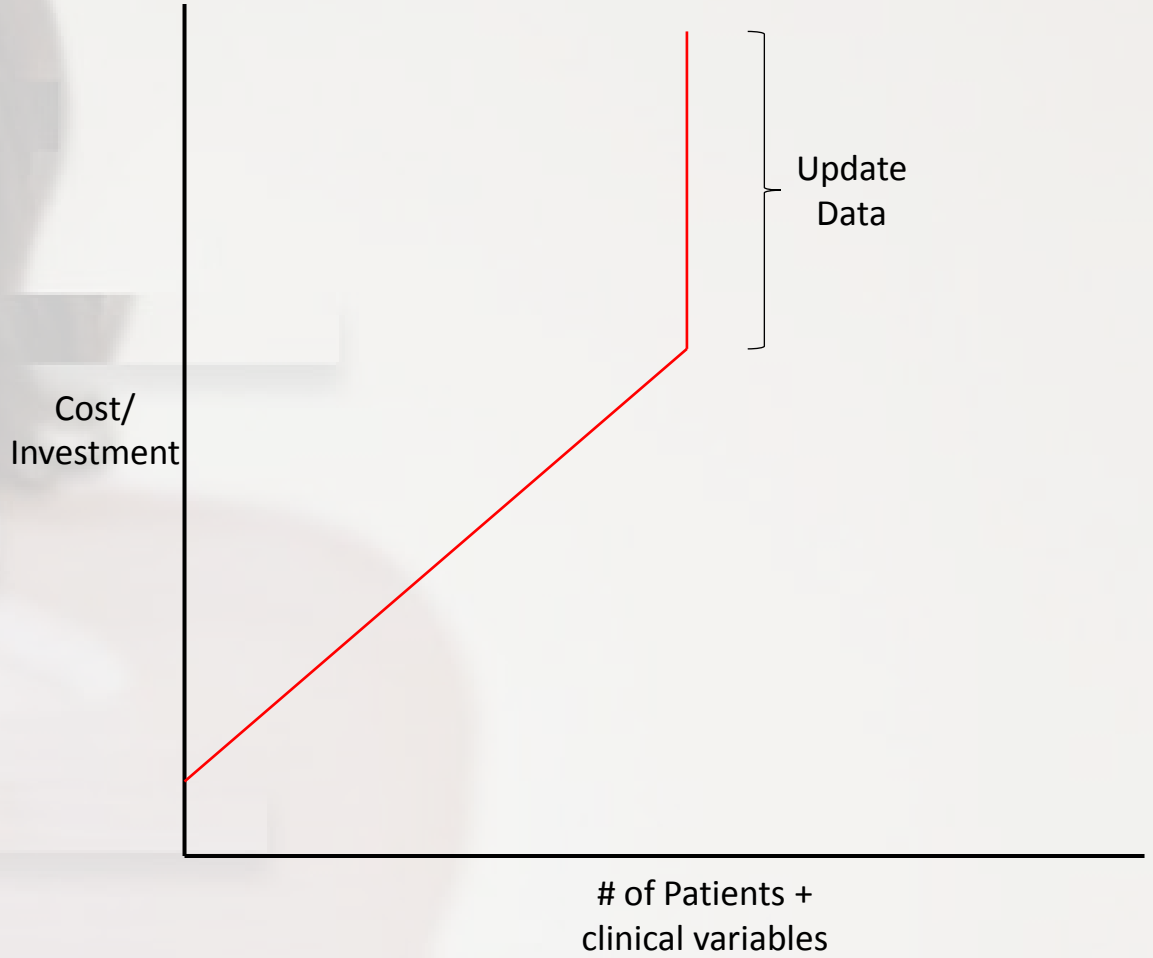
NUMBER OF PATIENTS

x

HOURLY RATE

=

COST



DARWEN™ TECHNOLOGY

ONE-TIME COST TO TUNE ALGORITHMS & BUILD MODELS

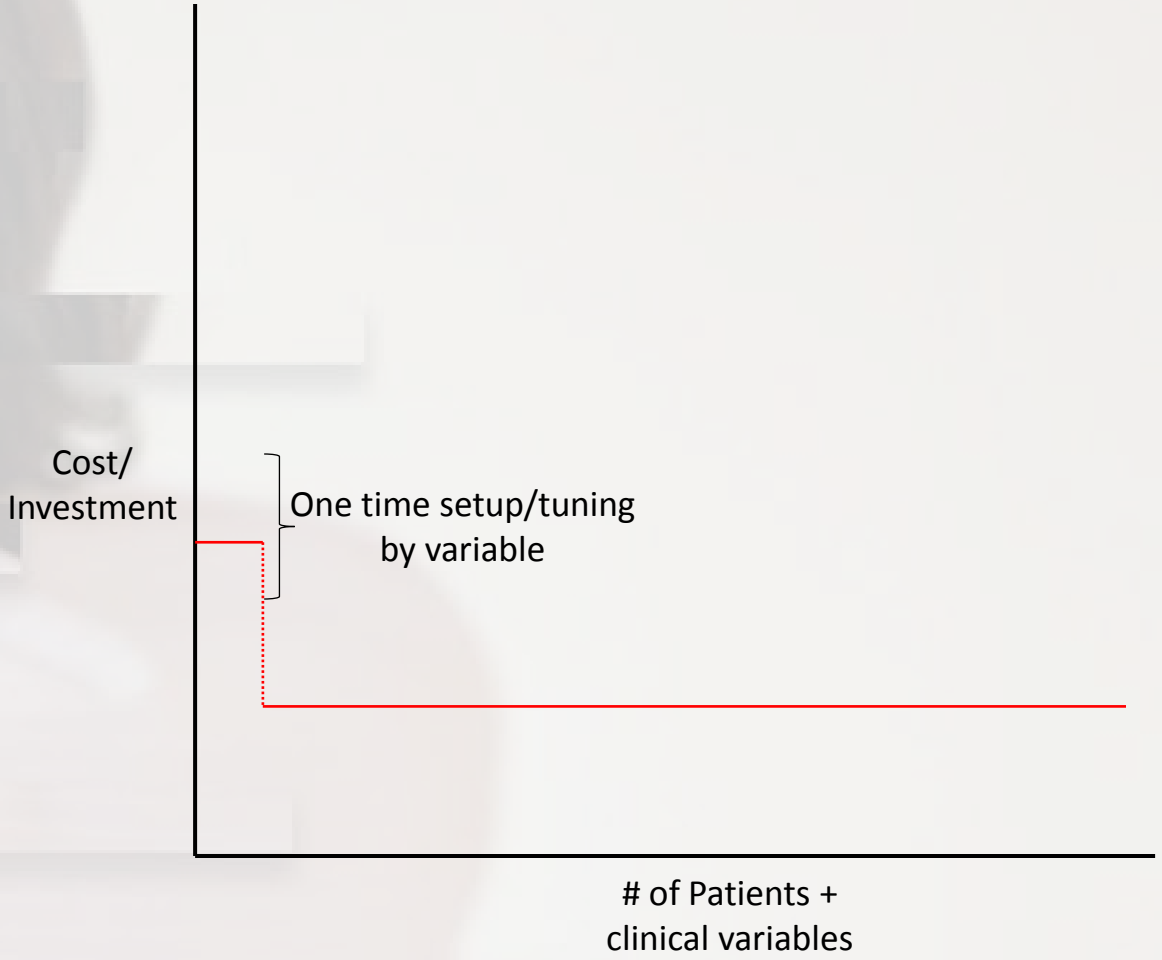
+

LICENSE TO PROCESS RECORDS ONGOING

No limit on # of patients

=

COST

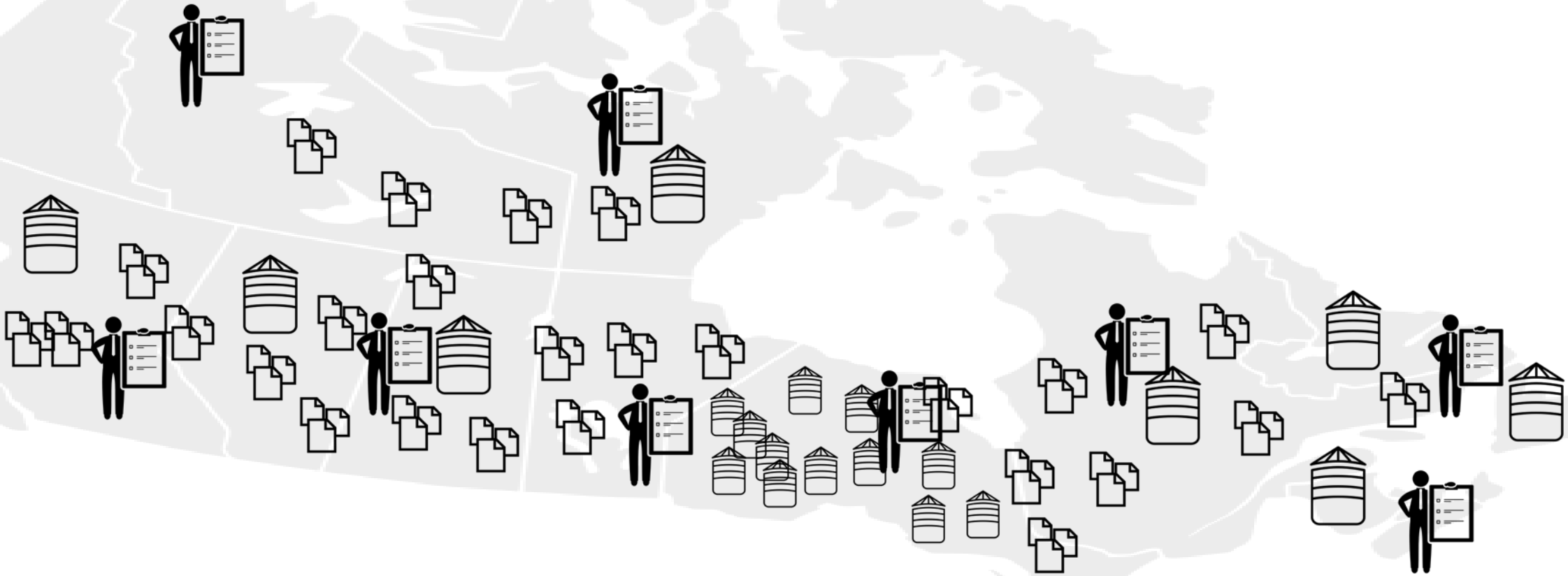


The State of Play of Health Data in Canada

SILOD

DIFFERENT FORMATS & STANDARDS

DIFFERENT RULES & REGULATIONS



Canadian Personalized Health Innovation Network

- The Canadian Personalized Healthcare Innovation Network (CPHIN) endeavours to address these challenges by **transforming the healthcare system through data**. This transformation will ensure **access to personalized healthcare and precision medicine** for patients from coast to coast to coast. It's about using and leveraging big data in health to **make a positive difference in the lives of patients**.

- CPHIN **convenes stakeholders and orchestrates initiatives that generate evidence** to accelerate system transformation for personalized healthcare. Through these programs, we will demonstrate **the value of data integration, harmonization, portability, and accessibility** with a focus on real world data for use by clinics, researchers, and innovators.

- The benefits will be **nationwide**: CPHIN will analyze data housed at institutions across Canada and make the insights available across Canada. **Transparency will lead to equitability in knowledge, insight, access, and most importantly, benefits for patients.**

CPHIN is a pan-Canadian non-profit backed by a unique group of public and private sector partners:

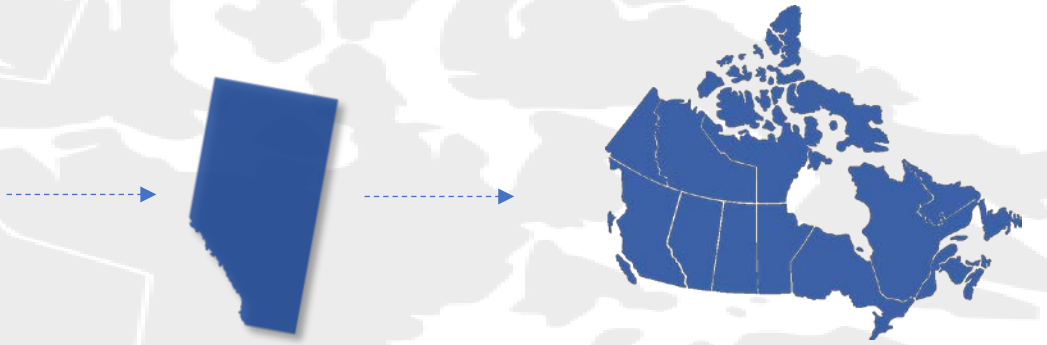
CPHIN

Canadian Personalized Healthcare Innovation Network

CPHIN Lung Kick Start Program

Goal of the Lung Kick Start Program

To determine, through real-world data, the sequencing of testing and treatment that produces the best health outcomes for specific lung cancer patients.

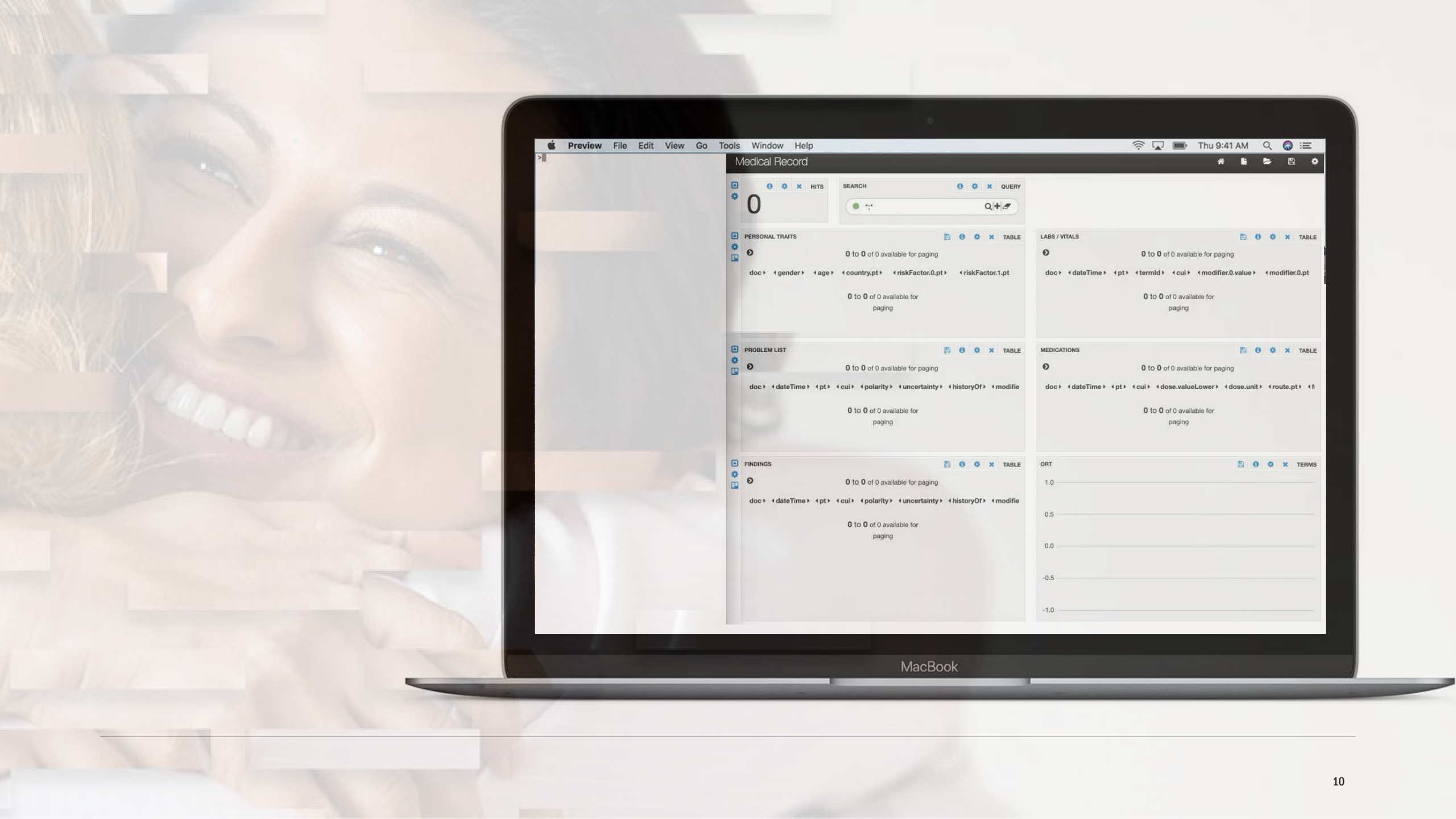


CPHIN will use data analyzed from TBCC as a "small data" dataset and compare to larger, "big data".

CPHIN will compare TBCC data to all of Alberta's lung cancer data to see how insights change when comparing institution data with provincial data, and to determine intra-provincial variations in care.

Finally, CPHIN will analyze data aggregated from Alberta plus other provinces. This will allow CPHIN to see how insights change when comparing provincial data to multi-provincial data and to determine if variations are securing better outcomes for patients.

Partners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PERSONAL TRAITS
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LABS / VITALS
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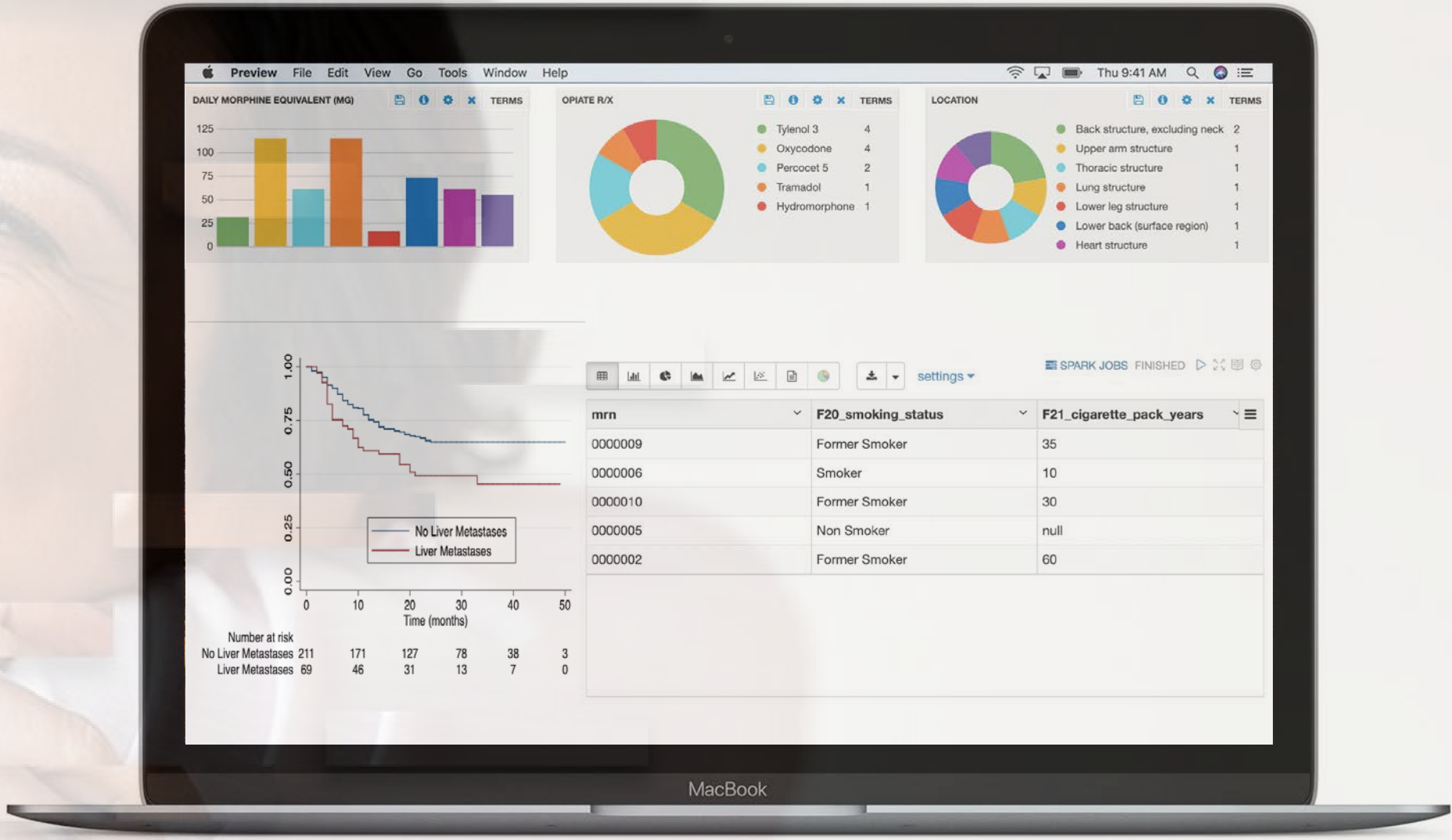
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DAILY MORPHINE EQUIVALENT (MG)
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125
100
75
50
25
0
OPIATE R/X
TERMS
Tylenol 3 4
Oxycodone 4
Percocet 5 2
Tramadol 1
Hydromorphone 1
LOCATION
TERMS
Back structure, excluding neck 2
Upper arm structure 1
Thoracic structure 1
Lung structure 1
Lower leg structure 1
Lower back (surface region) 1
Heart structure 1
1.00
0.75
0.50
0.25
0.00
No Liver Metastases
Liver Metastases
0 10 20 30 40 50
Time (months)
Number at risk
No Liver Metastases 211 171 127 78 38 3
Liver Metastases 69 46 31 13 7 0
settings
SPARK JOBS FINISHED
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F21_cigarette_pack_years
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THANK YOU