The COVID-19 & Cancer Consortium

Jeremy Warner MD, MS, FAMIA, FASCO

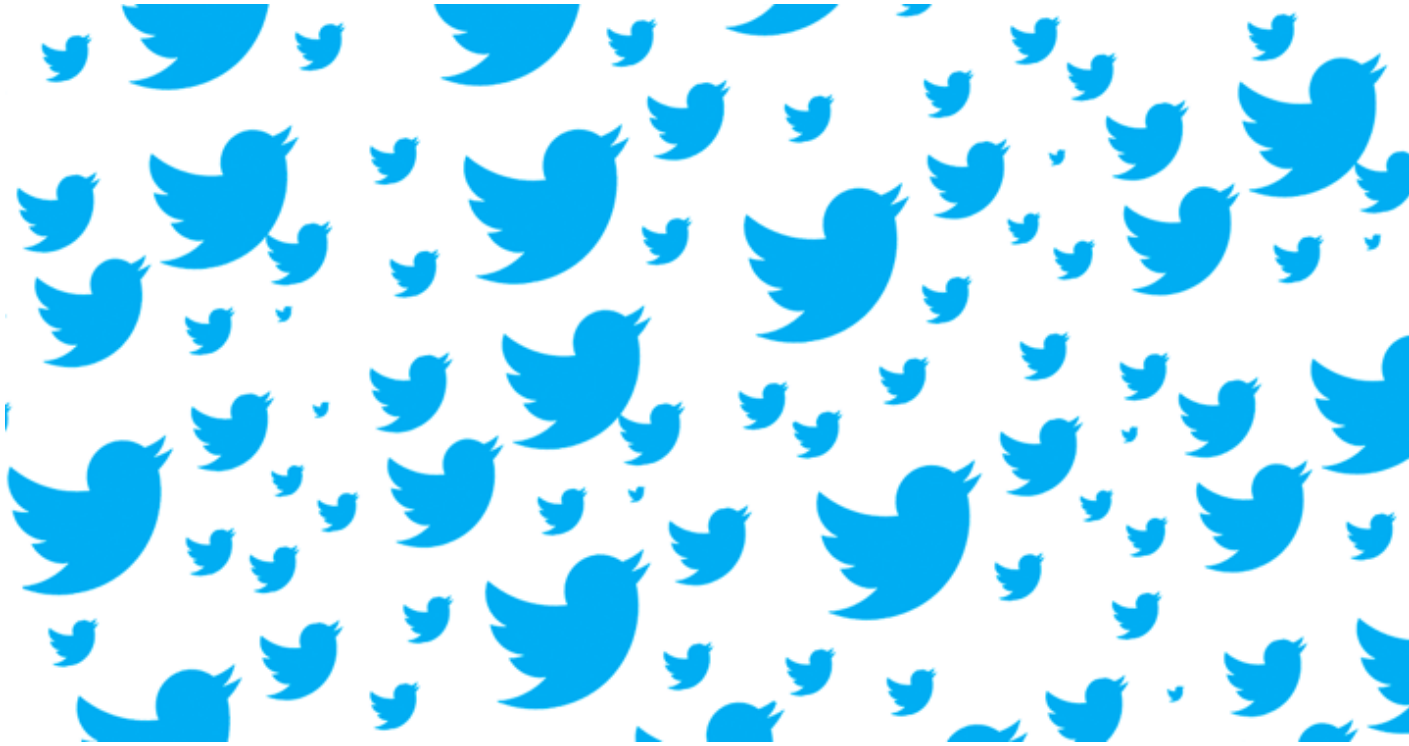
OHDSI Collaborator Meeting

April 7th, 2020

Origins

#covid19nCancer
~3/16

Aakash Desai



#CCC19
Symplur
@COVID19nCCC
>300 followers as of today

Climate Change & Consciousness Conference Livestream 20 – 26 April 2019

We are creating and offering our online spiritual resources to people around the world at this time, free of charge. However, until further notice we have also suspended our residential workshops and events, which we rely on for 80% of our income. We know that many people are facing challenging situations at the moment. If you feel passionate and are able to make a donation to help the Findhorn Foundation to support people around the world, it would be a real blessing. Thank you.

Freely Available to View Here

Climate Change & Consciousness Conference

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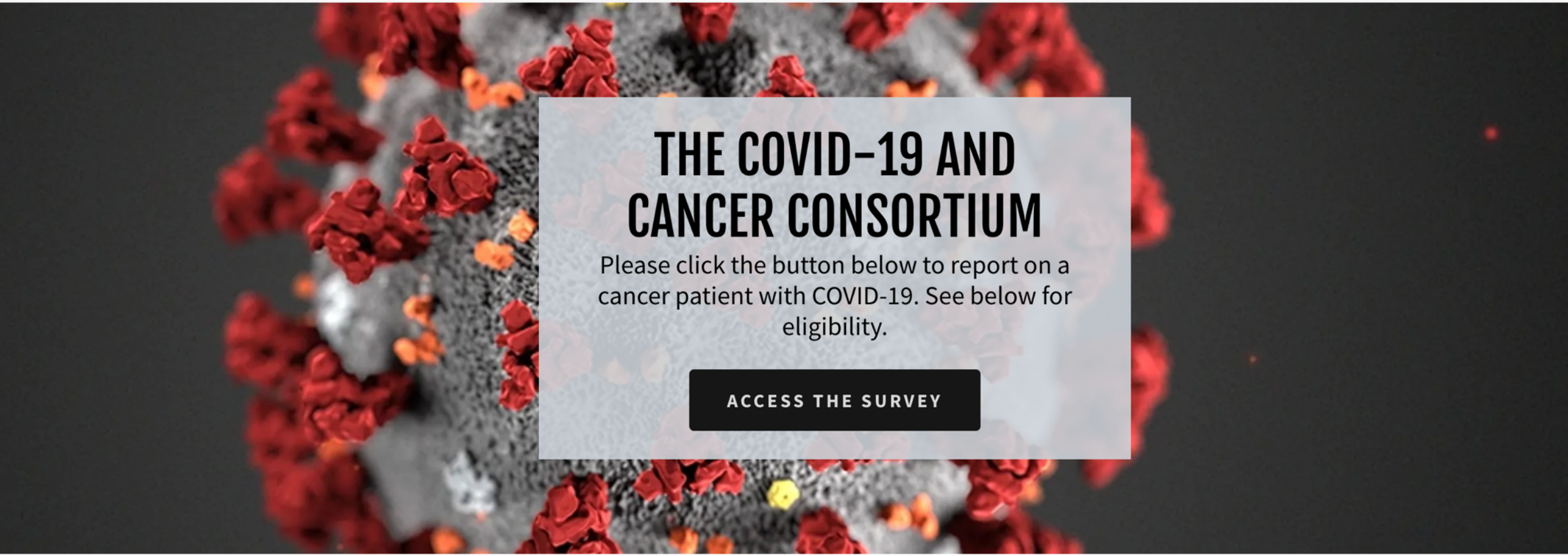
Please mention: the event you have booked and the specific tech issue you need help with

The COVID-19 & Cancer Consortium

HOME FAQS COLLABORATORS COVID19NCANCER PUBLICATIONS RESOURCES OTHER EFFORTS

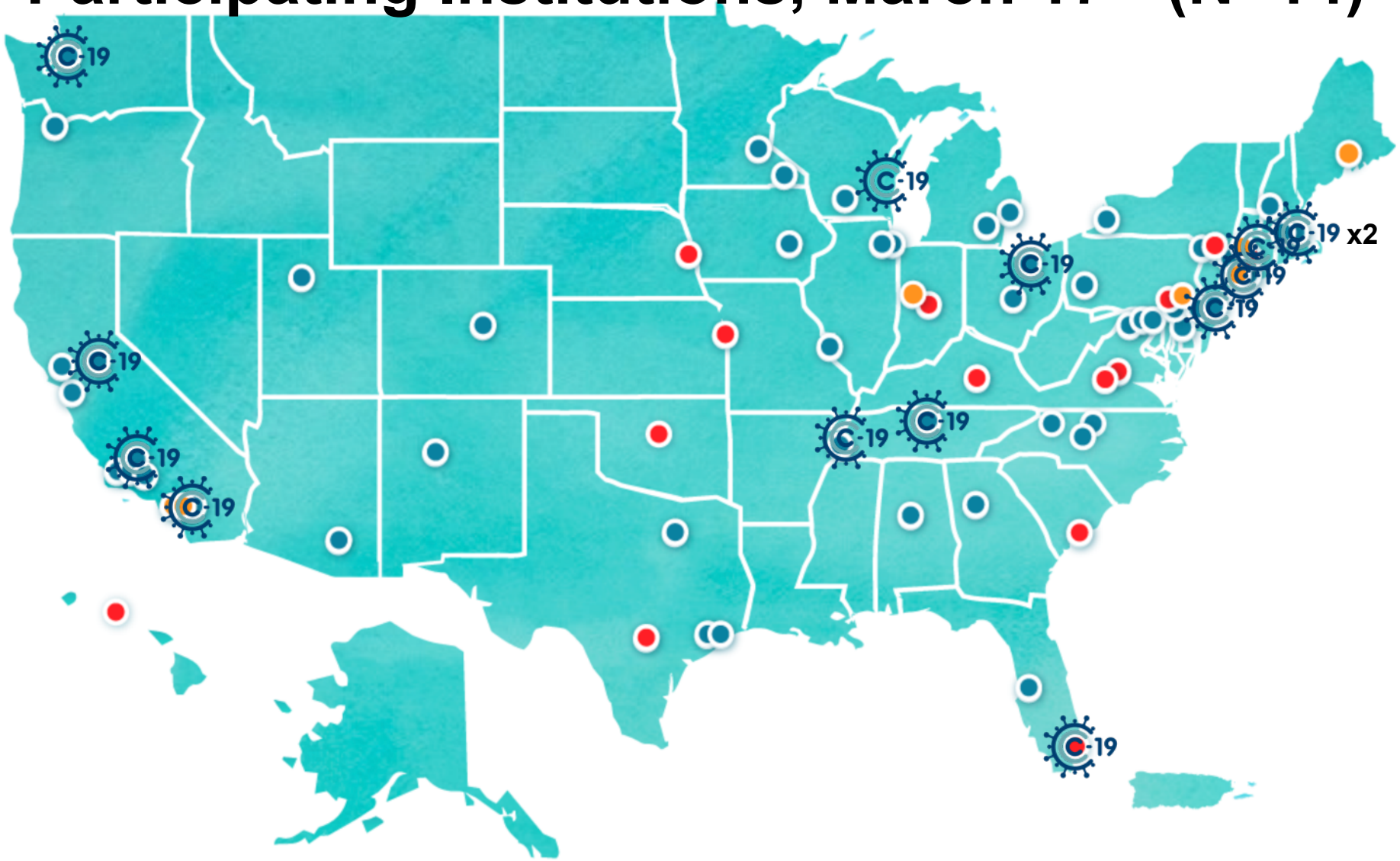


THE COVID-19 AND CANCER CONSORTIUM

Please click the button below to report on a cancer patient with COVID-19. See below for eligibility.

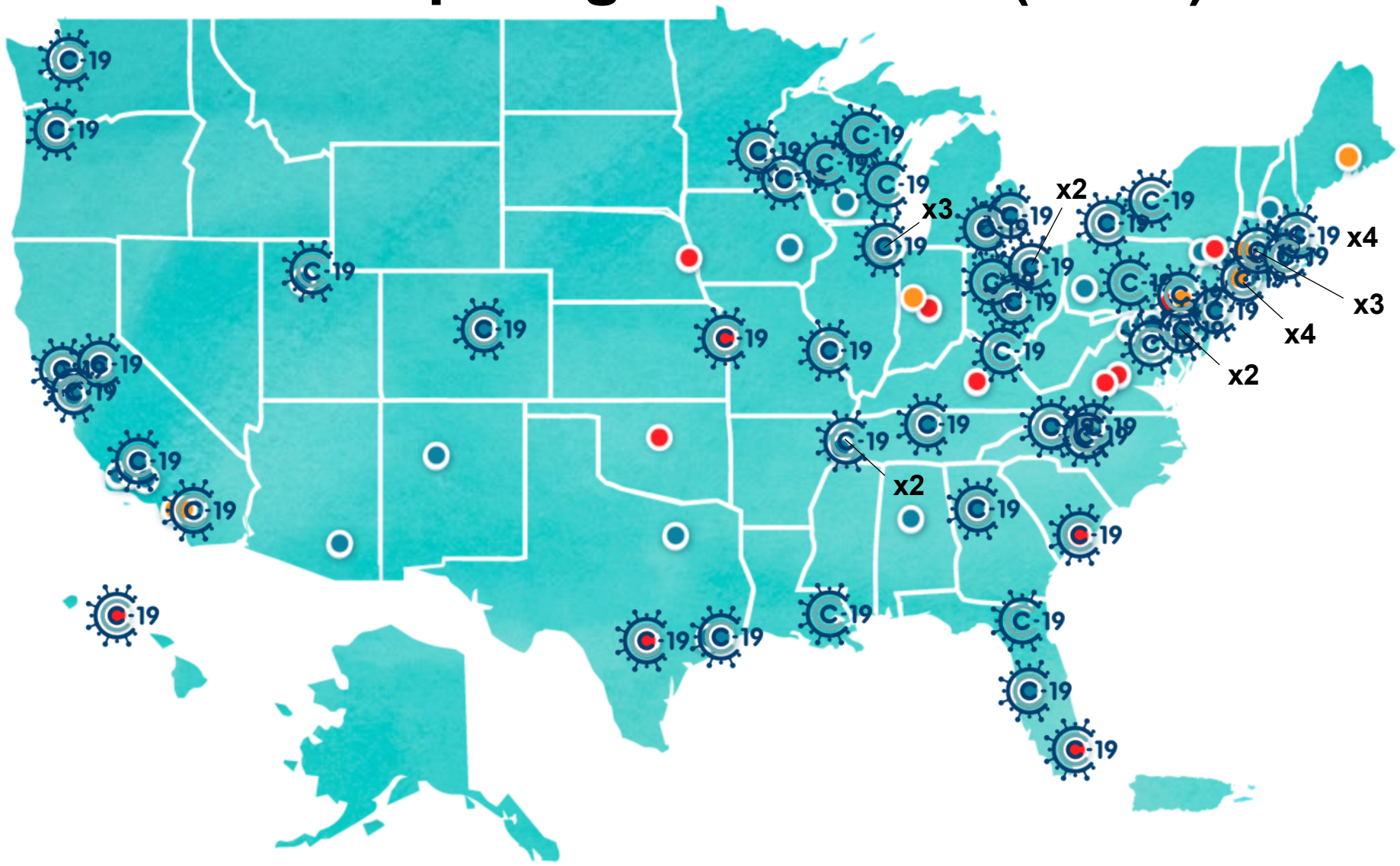
ACCESS THE SURVEY

Participating Institutions, March 17th (N=14)



Participating Institutions (N=62)

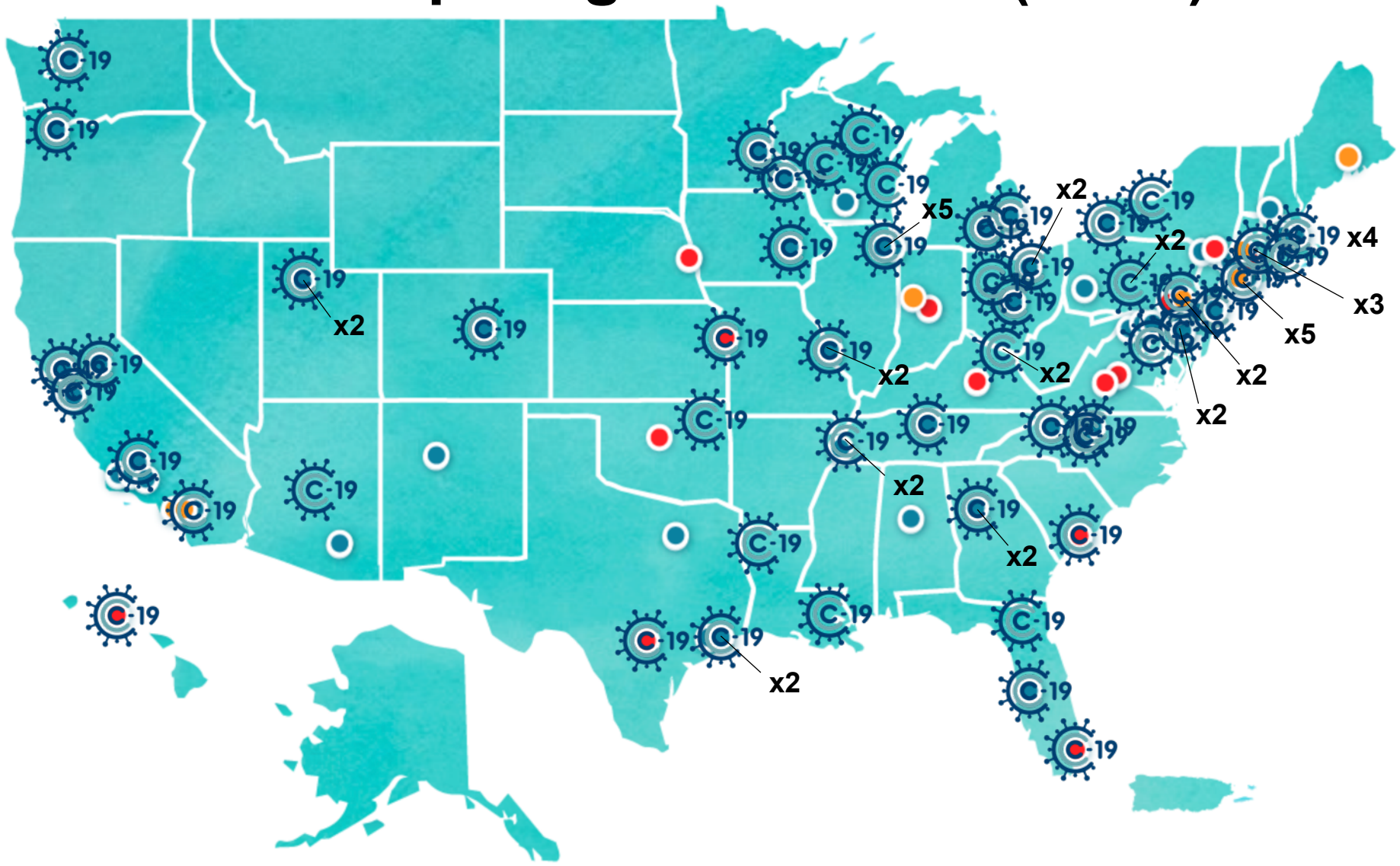
April 3rd



Adapted from NCI

Participating Institutions (N=72)

April 7th



Steering Committee

Jeremy L. Warner, MD, MS, FAMIA, FASCO

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Brian I. Rini, MD, FACP, FASCO

(Vanderbilt University Medical Center/Vanderbilt-Ingram Cancer Center)

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Corrie A. Painter, PhD

Count Me In

Nicole M. Kuderer, MD

(University of Washington/Seattle Cancer Care Alliance/Fred Hutch)

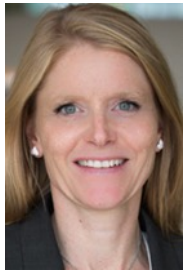
Petros Grivas, MD, PhD

(University of Washington/Seattle Cancer Care Alliance/Fred Hutch)

Mike Thompson, MD, PhD, FASCO

(Aurora Health Care)

Solange Peters, MD, PhD



Lausanne/ESMO

Gilberto de Lima Lopes Jr., MD, MBA, FAMS, FASCO

(University of Miami/Sylvester Comprehensive Cancer Center)

Toni Choueiri, MD

Harvard Medical School, Dana Farber Cancer Institute

Dimpy P. Shah, Ph.D

University of Texas Health San Antonio MD Anderson, Mays Cancer Center

Mission Statement

The driving goal of the consortium is to collect prospective, granular, uniformly organized information on cancer patients infected with COVID-19 at scale and as rapidly as possible.

We have a very large and active community of users for an electronic data capture system called

REDCap™
Research Electronic Data Capture

Courtesy of Paul Harris

Available at no cost to academic, government, non-profit partners

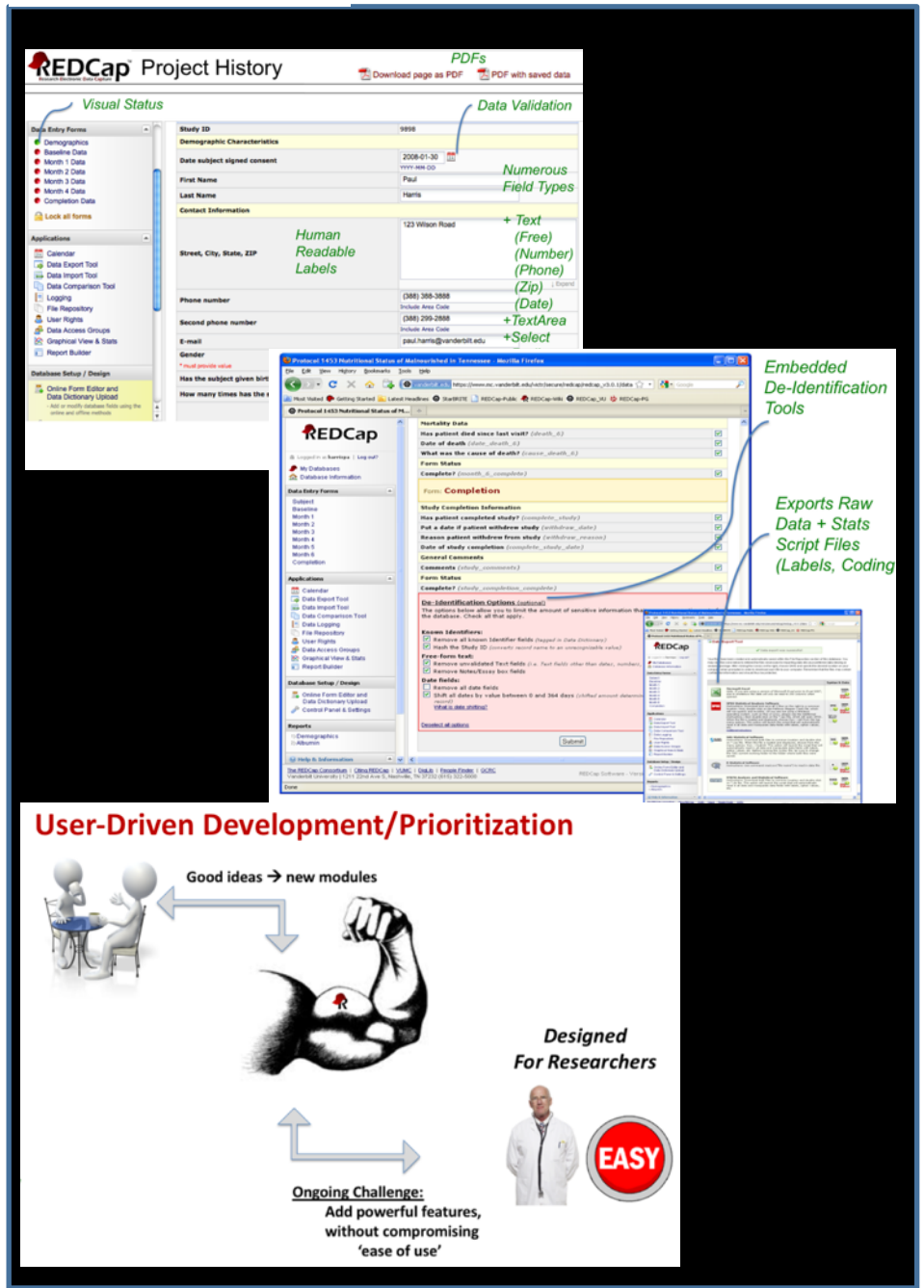
REDCap
Research Electronic Data Capture

Institutions	Countries	Projects	Users	Articles
4043	137	863k	1.2M	9569

Map of REDCap Consortium Partners

Courtesy of Paul Harris

REDCap™



Courtesy of Paul Harris

Summary:

- Data Planning ("easy way to do the right thing" with data capture, management, audits, security)
- Data Collection (researcher, provider, participant, patient)
- Data Export (all major statistical packages)
- Data Import (file or via API)
- Data Integration (API services)
- Consortium-wide REDCap library of shared instruments (e.g. validated scales, PROs)
- Consortium-wide repository of REDCap "plugins" to extend user interface and functionality
- Offline App Version (iOS, Android)
- Text/Audio/Video capabilities
- Multi-modal (web, SMS, phone)
- RCT features – randomization, data query workflow
- Document Repository
- E-consent (new)
- MyCap Integration (new)
- **EHR Interoperability - via FHIR (new)**

REDCap Survey – current status

COVID-19 and Cancer Consortium (CCC19) Registry v2

Project Home | Project Setup | Online Designer | Data Dictionary | Codebook

Create snapshot of instruments — VIDEO: How to use this page

Last snapshot: never

The Online Designer will allow you to make project modifications to fields and data collection instruments very easily using only your web browser. NOTE: While in development status, all field changes will take effect immediately in real time.

Data Collection Instruments

Survey options: Survey Queue | Survey Login | Survey Notifications | Upload or download Auto Invitations

Add new instrument:
- Create a new instrument from scratch
- Import a new instrument from the official REDCap Shared Library
- Upload instrument ZIP file from another project/user or external libraries

Instrument name	Fields	View PDF	Enabled as survey	Instrument actions	Survey-related options
Screening form	12			Choose action	Survey settings | + Automated Invitations
Patient Demographics	86			Choose action	Survey settings | + Automated Invitations
COVID-19 details	71			Choose action	Survey settings | + Automated Invitations
Cancer details	42			Choose action	Survey settings | + Automated Invitations
Respondent details	7			Choose action	Survey settings | + Automated Invitations
Follow-up	49			Choose action	Survey settings | + Automated Invitations

Steph Duda
TY!!!!!!!!!!!

Data Collection Schema

Patient Demographics and Predisposing Conditions

- Age, gender, race/ethnicity
- ECOG
- Smoking status
- Surgical and medical history
- Concomitant medications

COVID-19 Initial Course of Illness

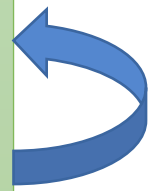
- Timing
- Presenting symptoms
- Presenting labs
- Diagnostic testing
- Initial severity of illness
- Co-infections
- Complications
- Treatments including trials
- Clinical status

Cancer Details

- Cancer type, stage, status
- Treatment details: recency, modality, context, irAEs
- Transplant & cellular therapy details
- History of cardiopulmonary toxic treatment

COVID-19 follow-up & Outcomes

- Interval severity of illness
- Co-infections
- Complications
- Treatments including trials
- Interval clinical status
- Final status
- Effects on anti-cancer treatment plans



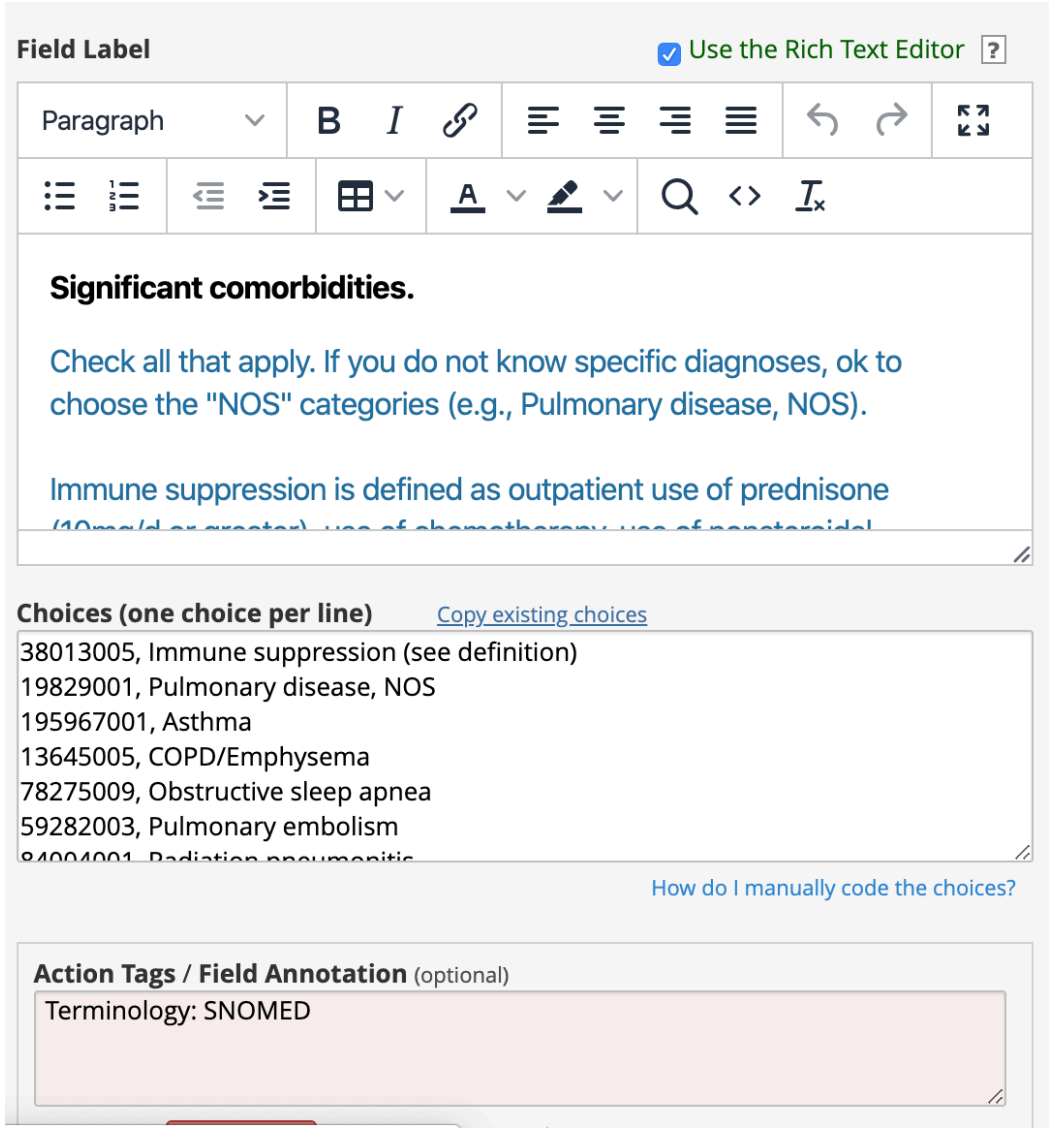
Repeating

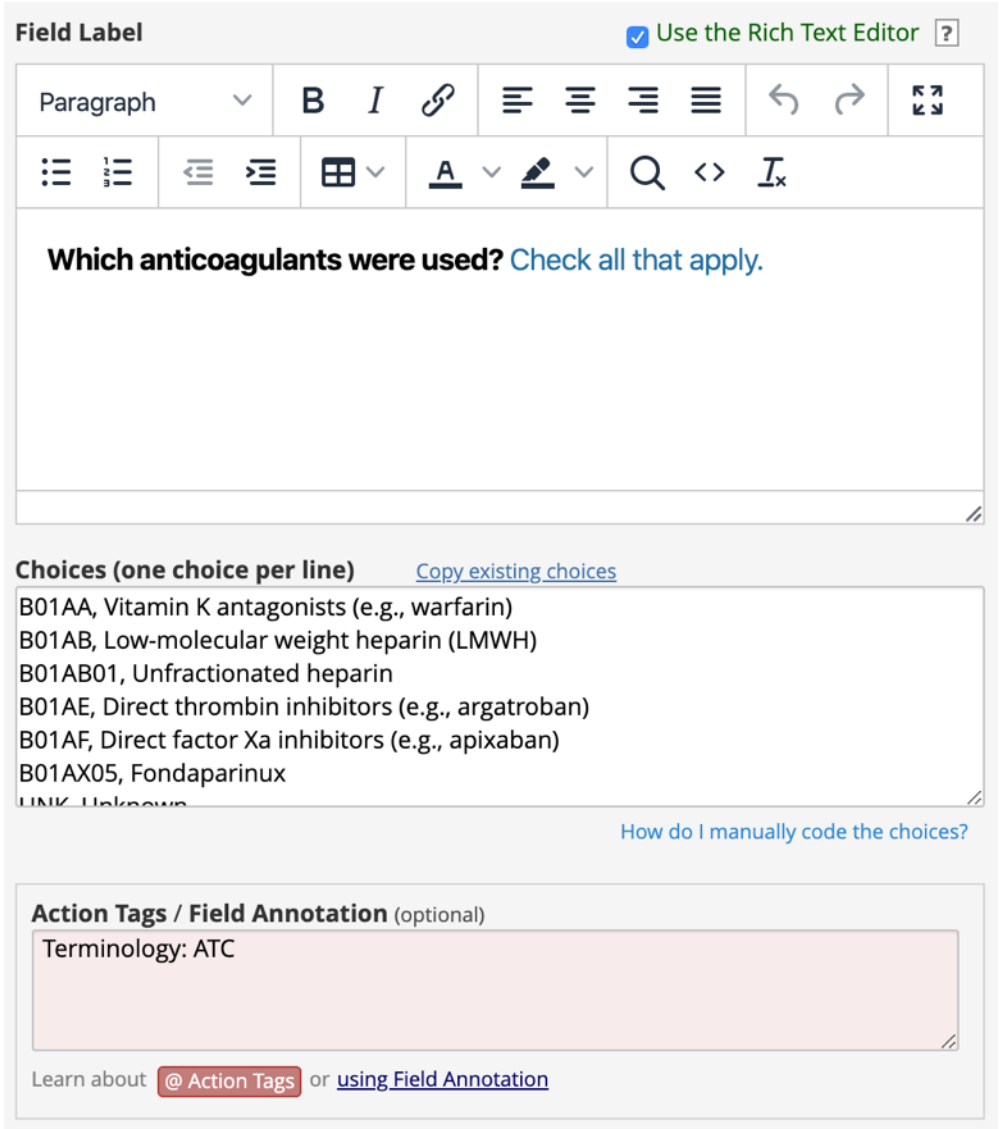
Mapping to standards from (almost) the get-go

Terminology bindings

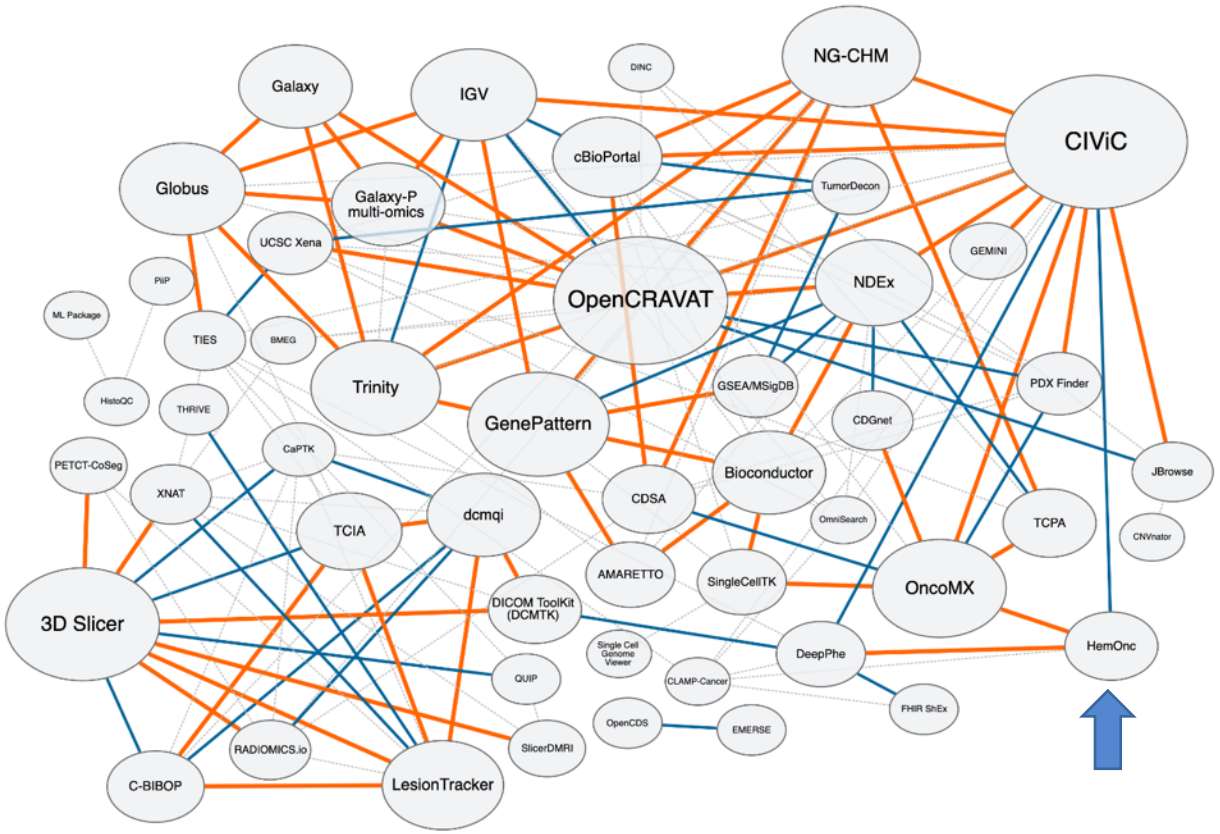
Encoding	Number of variables
ATC	12
HemOnc	8
NAACCR	1
NCIT	2
PHIN VADS	2
SNOMED	16
Y/N/UNK	30
Direct entry	41
Custom	57

Mapping to standards from (almost) the get-go





Shameless plug for HemOnc (U01 CA231840)



https://hemonc.org/wiki/Ontology

Field Label

Use the Rich Text Editor

Paragraph

Anti-cancer treatment modality. Check all that apply. For example, if a patient is receiving concurrent chemoradiation, check cytotoxic chemotherapy and radiotherapy.

Choices (one choice per line) Copy existing choices

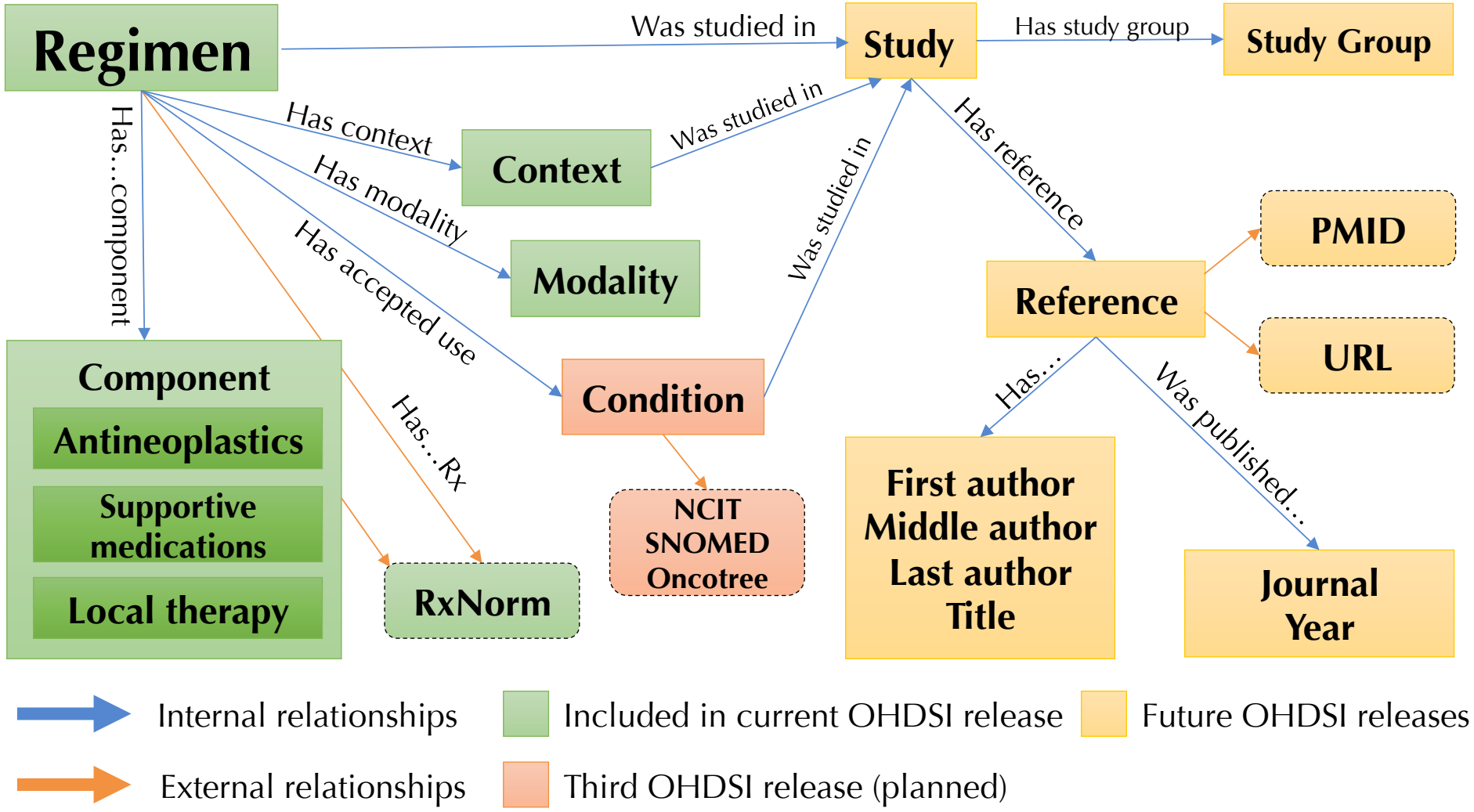
685, Cytotoxic chemotherapy
694, Immunotherapy
58229, Targeted therapy
691, Endocrine therapy
695, Radiotherapy
14051, Surgery
45186, Transplant/Cellular therapy

How do I manually code the choices?

Action Tags / Field Annotation (optional)

Terminology: HemOnc

Learn about @ Action Tags or using Field Annotation



HemOnc Regimen Model (simplified)

Episodes

- **Disease** and **treatment abstractions** are modeled as episodes
- **Disease abstractions include**: first occurrence, remissions, relapses, and end of life event.
- **Treatment abstractions include**: treatment course, treatment regimen, and treatment cycle.
- These **abstractions may be derived** algorithmically pre- or post-ETL or extracted from the source data directly.
  - In addition to the regular OMOP type concept ID, we propose to store **references to the derivation algorithms** in the vocabulary.

Courtesy of OHDSI Oncology Subgroup

Advantages of Using Episodes

- Supports levels of abstraction that are **clinically** and **analytically relevant**
- Supports **explicit connection between a disease/treatment abstraction** and **lower level events** (conditions, procedures, drugs) that are linked to this abstraction
- **Persists provenance of episode derivation** (e.g. directly from source data, algorithmically)
- Is **generalisable** to:
  - abstraction of **other chronic diseases**
  - Representation of **episode of care**

Courtesy of OHDSI Oncology Subgroup

EPISODE and EPISODE EVENT Tables

Field	Required	Type	Description
episode_id	yes	integer	A unique identifier for each Episode.
person_id	yes	integer	A foreign key identifier to the Person who is undergoing the Episode. The demographic details of that Person are stored in the PERSON table.
episode_concept_id	yes	integer	A foreign key that refers to a standard Episode Concept identifier in the Standardized Vocabularies. Examples of an Episode Concept can be: Treatment Regimen, Treatment Cycle, Disease First Occurrence, Remission, Relapse, Episode of Care
episode_start_datetime	yes	date	The date and time on which the Episode was started.
episode_end_datetime	yes	date	The date and time on which the Episode was ended.
episode_parent_id	no	integer	A foreign key that refers to a parent Episode entry representing an entire episode if the episode spans multiple cycles.
episode_number	no	integer	An ordinal count for an Episode that spans multiple times
episode_object_concept_id	yes	integer	A foreign key that refers to a concept identifier in the Standardized Vocabularies describing disease, treatment, or other abstraction that the episode describes. For example, 'Breast Carcinoma' or 'Chemotherapy'.
episode_type_concept_id	yes	integer	A foreign key that refers to a standard Episode Type Concept identifier in the Standardized Vocabularies reflecting the provenance of the episode derivation. It may reference a derivation algorithm, sources such as cancer registry, EMR, etc.
episode_source_value	no	varchar(50)	The source code for the Episode as it appears in the source data. This code is mapped to a standard episode Concept in the Standardized Vocabularies and the original code is, stored here for reference.
episode_source_concept_id	no	integer	A foreign key to a Episode Concept that refers to the code used in the source.

Field	Required	Type	Description
episode_id	yes	integer	A foreign key identifier to the Episode that the Episode Event belongs to.
event_id	Yes	integer	A foreign key identifier to the underlying event (condition, procedure, measurement, etc.) record in a respective table for which an episode is recorded.
event_table_concept_id	yes	integer	A foreign key identifier to the standardized concept corresponding to the table (condition_occurrence, procedure_occurrence, etc.) where the underlying event is stored.

Example of a Treatment Episode record

EPISODE

Field	Content
episode_id	**9900850**
person_id	**John Smith**
episode_concept_id	**Treatment Regimen**
episode_start_datetime	**August 1, 1996**
episode_end_datetime	**November 18, 1996**
episode_parent_id	
episode_number	
episode_object_concept_id	**Chemotherapy Treatment**
episode_type_concept_id	**Cancer Registry**
episode_source_value	**Chemotherapy**
episode_source_concept_id	**C25 (NAACCR ID)**

EPISODE

Field	Content
episode_id	**9900851**
person_id	**John Smith**
episode_concept_id	**Treatment Cycle**
episode_start_datetime	**August 1, 1996**
episode_end_datetime	**August 28, 1996**
episode_parent_id	**9900850**
episode_number	**1**
episode_object_concept_id	**Chemotherapy Treatment**
episode_type_concept_id	**EMR**
episode_source_value	**PACLITAXEL + CARBOPLATIN**
episode_source_concept_id	

EPISODE

Field	Content
episode_id	**9900852**
person_id	**John Smith**
episode_concept_id	**Treatment Cycle**
episode_start_datetime	**October 15, 1996**
episode_end_datetime	**November 18, 1996**
episode_parent_id	**9900850**
episode_number	**2**
episode_object_concept_id	**Chemotherapy Treatment**
episode_type_concept_id	**EMR**
episode_source_value	**PACLITAXEL + CARBOPLATIN**
episode_source_concept_id	

EPISODE_EVENT

Field	Content		
episode_id	**9900851**	**9900851**	**9900851**
event_id	**9900145**	**9900146**	**9900147**
event_domain_id	**drug_exposure**	**drug_exposure**	**drug_exposure**

DRUG_EXPOSURE

Field	Content
drug_exposure_id	**9900145**
person_id	**John Smith**
drug_concept_id	**Cyclophosphamide**
drug_exposure_start_datetime	**August 1, 1996**
drug_exposure_end_datetime	**August 1, 1996**
drug_exposure_type_concept_id	**EMR**
drug_exposure_source_value	**Cyclophosphamide 1000 MG Injection**

DRUG_EXPOSURE

Field	Content
drug_exposure_id	**9900146**
person_id	**John Smith**
drug_concept_id	**Doxorubicin hydrochloride**
drug_exposure_start_datetime	**August 4, 1996**
drug_exposure_end_datetime	**August 4, 1996**
drug_exposure_type_concept_id	**EMR**
drug_exposure_source_value	**Doxorubicin Hydrochloride 50 MG Injection**

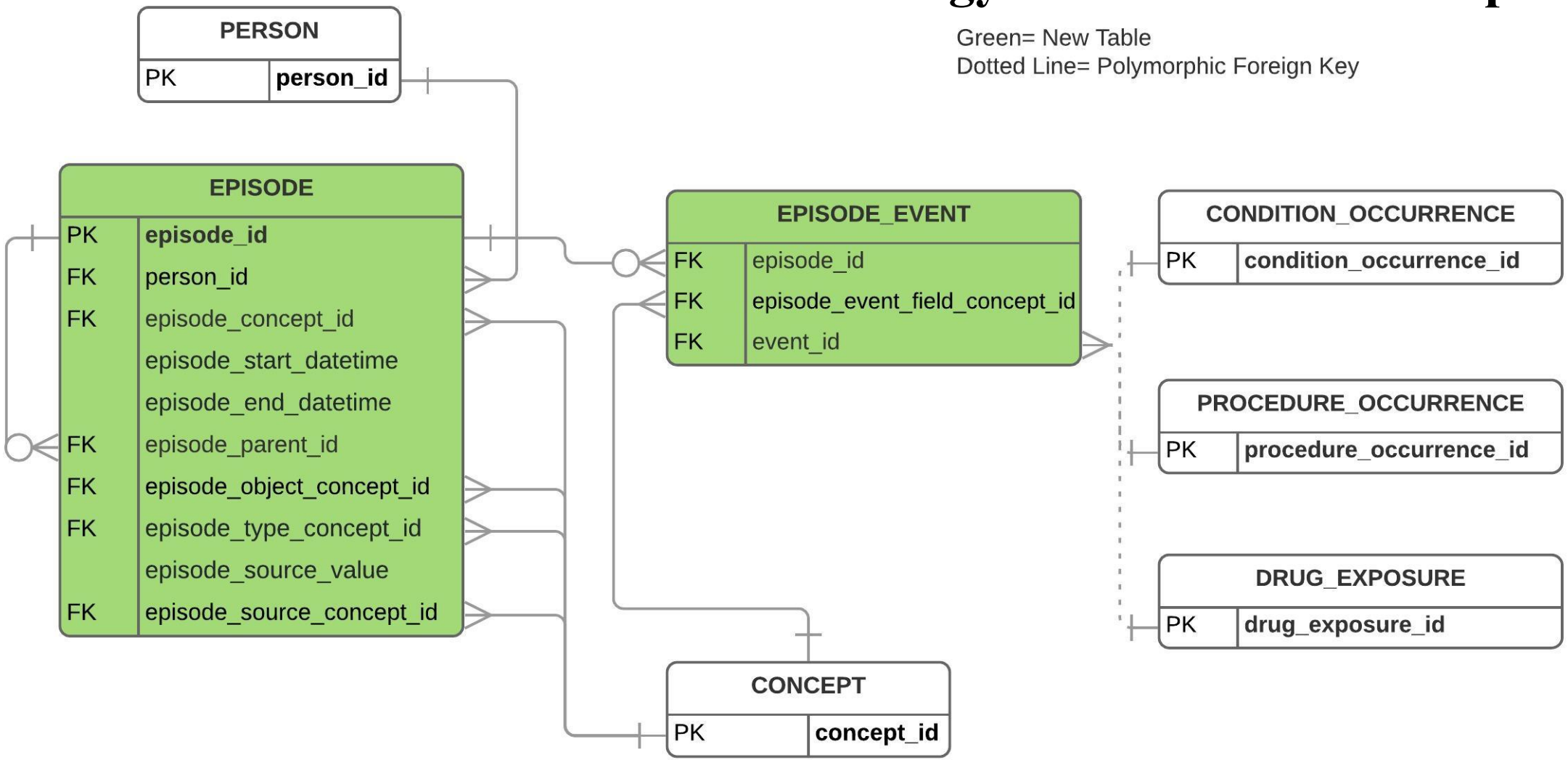
DRUG_EXPOSURE

Field	Content
drug_exposure_id	**9900147**
person_id	**John Smith**
drug_concept_id	**Dexamethasone acetate**
drug_exposure_start_datetime	**August 7, 1996**
drug_exposure_end_datetime	**August 7, 1996**
drug_exposure_type_concept_id	**EMR**
drug_exposure_source_value	**Dexamethasone acetate 8 MG/ML Injectable**

Courtesy of OHDSI Oncology Subgroup

Oncology CDM Extension Proposal

Green= New Table
Dotted Line= Polymorphic Foreign Key



https://doi.org/10.1016/j.jbi.2019.103239

CDP/CDIS

Surveys are good; EMR extracts are better!

Acknowledgments (130+ participants)

- Aurora Health Care
- Brown University
- City of Hope
- Cleveland Clinic
- Columbia University/New York Presbyterian
- Dana-Farber Cancer Institute
- Duke University
- Einstein Medical Center
- Emory University/Winship Cancer Institute
- Fred Hutchinson Cancer Research Center/ University of Washington/Seattle Cancer Care Alliance
- Gundersen Health System
- Hartford HealthCare Cancer Institute
- Houston Methodist Cancer Center
- Inova Schar Cancer Institute
- Intermountain Healthcare
- Johns Hopkins University
- Karmanos Cancer Institute
- Loyola University Medical Center
- LSU Health Sciences Center
- Massachusetts General Hospital
- Mayo Clinic, Rochester
- Mays Cancer Center at UT Health San Antonio
- MD Anderson Cancer Center
- Medical University of South Carolina/ Hollings Cancer Center
- Moffitt Cancer Center
- Mount Sinai/Tisch Cancer Institute
- Northwell Health
- Northwestern University/Lurie Cancer Center
- NYU Langone Health/Perlmutter Cancer Center
- Oregon Health & Sciences University/ Knight Cancer Institute
- Penn State Cancer Institute
- Roswell Park Comprehensive Cancer Center
- Rutgers Cancer Institute of New Jersey
- SSM Health Cancer Care
- Stanford University
- St. Elizabeth Healthcare
- The Ohio State University/The James
- University Hospitals, Cleveland
- University of California, Davis
- University of California, San Diego
- University of California, San Francisco
- University of Chicago
- University of Colorado Cancer Center
- University of Connecticut
- University of Kansas
- University of Maryland
- University of Miami/Sylvester Comprehensive Cancer Center
- University of Michigan/Rogel Cancer Center
- University of Minnesota/Masonic Cancer Center
- University of North Carolina/Lineberger Comprehensive Cancer Center
- University of Rochester Medical Center
- Vanderbilt University Medical Center/ Vanderbilt-Ingram Cancer Center
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