What kinds of UVA cancer patient clinical, genomics, and specimen data are available and how to get them (currently available)?

Systems	Cost for end-user	Access Type and Requirements	Patient Population and Update Frequency	Definition of Cancer Patient	Cohort	Data Source	Genomics Data	How to Request Access	Example of Project
Epic Cosmos	Free	Self-serve No CITI training or IRB required	**300M** Refreshed every two weeks Aggregate or row-level, de-identified	ICD-10 codes	1560 hospitals (can filter for just UVA)	CosmosDataDomain Encyclopedia	Available through the Variants Data Model (Epic Aura)	Request Access Epic Cosmos	Melanoma and IO/diabetes, meds/surg, hx/county of residence UVA vs. national data
ORIEN cBioPortal and Patient Timeline	Free	Self-serve No CITI training or IRB required	**33,774** Refreshed every quarter ~75 clinical data elements per patient, de-identified, row-level	ICD-O-3 codes for primary sites and histology	Total Cancer Care consented patients across 19 ORIEN sites	Manually curated by tumor registrars across 19 ORIEN sites EHRs, Cancer Registries, SSDI, etc.	WES_normal WES_tumor RNAseq_tumor	Email Elizabeth Mulcahy: qx3k@uvahealth.org	Colorectal BRAF or KRAS mutation Discovery tool and pt level gen and clin data Survival curves
TriNetX*	Free	Self-serve CITItraining No IRB required	**1.9M** Refreshed weekly Aggregate, de-identified RCTA can re-identify (IRB approval required)	ICD-10 codes ICD-O-3 codes	UVA MC UVA CH	UVA Epic (since 2010) UVA Cancer Registry (since 2018)	Few select genes per cancer as reported by Cancer Registry	Email: researchdata@uvahealth.org	Breast, stage and BMI distribution, monthly arrival rates Feasibility analysis
EMERSE	Free	Self-serve CITItraining IRB approval (for PHIs)	**1.9M** Refreshed weekly Row-level data with PHI (name, MRN, DOB)	Associated terms	UVA MC UVA CH	UVA Epic clinical notes (since 2011)	Cytogenetics NGS panels	Click on Link: EMERSE&OMOP AccessRequestForm (virginia.edu)	Lung and brain mets AML and TP53
Cancer Registry	Free	No public access; must work with registry	**~140,000+ "tumors"†** Partial data is refreshed daily Full abstractions have a 6+ months lag time	ICD-O-3 codes (Only patients diagnosed and/or treated at UVA are included)	UVA MC plus Culpepper & Augusta (RadOnc & HemOnc) 2011+	UVA Epic Curation based on national manuals Manually curated starting in 1960s ("reportable conditions" per national std)	Few select genes per cancer as defined in the national SSDI manual	Email Cancer Registry: cancerregistry@uvahealth.org	Stage Cancer Type Biopsy, surgery
Cancer Research DataMart (DM)	Hourly Charge (currently, $100/hour)	No public access; must work with RCTA and Elizabeth Mulcahy	**Variable** Refreshed weekly/monthly Example: Thoracic DM has ~3000	ICD-O-3 codes Medications Procedures Genomics	UVA MC	UVA Epic UVA Cancer Registry Virginia Department of Health (mortality data)	Variable Example: Thoracic DM gets Guardant and Foundation Med extracts	Email Elizabeth Mulcahy: qx3k@uvahealth.org	Display real-time reports (pie, bar graphs) dashboard

Includes cancer registry data for diagnosis year 2018 & later starting 7/31/2024

Highlights indicate the uniqueness of the system.

† includes reportable benign & borderline tumors

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What kinds of UVA cancer patient clinical, genomics, and specimen data are available and how to get them (<u>upcoming</u>)?

Systems	Cost for end-user	Access Type and Requirements	Patient Population and Update Frequency	Definition of Cancer Patient	Cohort	Data Source	Genomics Data	How to Request Access	Example of Project
Caris POA CODEai (currently available)	Free	Self-serve No CITI training or IRB required	**~450,000** Refreshed twice a year De-identified	Diagnosed by physician placing the order Typically stage 3 or 4 cancers	Data from hospitals that order Caris sequencing	Caris molecular sequencing data Claims data from several insurance claims providers	WES, RNAseq 592 gene panel data	Email Elizabeth Mulcahy: qx3k@uvahealth.org	POA publications
Manifold Stage II (upcoming)	Free	Self-serve Requirements TBD	**130,000** Row-level, de-identified	Diagnosed and/or received 1st line treatment at UVA	All patients in Cancer Registry ORIEN Avatar sequencing Biospecimens	UVA Cancer Registry UVA ORIEN Avatar sequencing Caisis (LIMS)	WES tumor and normal RNAseq tumor available for ~1200 pts	Email Elizabeth Mulcahy: qx3k@uvahealth.org	Prostate, stage ¾, with biospecimens available Consented patients available for additional questionnaires and surveys
Tempus Lens (upcoming)	Free	Self-serve No CITI training or IRB required Requires training with Tempus	**~8M** Refreshed nightly Subsets made available for end-user analysis as determined via Discover program	Curated primary cancer diagnosis	Variable	Clinical Tempus testing and data curation, public data sets and other private/3rd party sources	DNA, RNA, tumor cell staining data natively generated by Tempus as well as from 3rd party sources	Email Elizabeth Mulcahy: qx3k@uvahealth.org	https://www.tempus.com/publications/?post-search=&filter=oncology
ORIEN Galaxy Atlas (upcoming)	Free	Self-serve No CITI training or IRB requires	**~200,000-300,000** Refreshed once/month	Total Cancer Care consented patients across ORIEN sites	120 clinical data from EHRs 500 NAACCR elements	EHRs from ORIEN sites Cancer Registry from 19 ORIEN sites	None, but where available, patients are mapped to ORIEN cBioPortal	Email Elizabeth Mulcahy: qx3k@uvahealth.org	TBD

Additional information and resources beyond UVA health and beyond cancer patients –

For other national datasets, you can go here:
iTHRIV
Includes NIH All of Us Researcher Workbench, COVID data
Population Health & Cancer Outcomes Core (PHCOC) - UVA Comprehensive Cancer Center (virginia.edu)
Includes catchment area data, SEER-Medicare data, Virginia Behavioral Risk Factor Surveillance System (BRFSS), Virginia All Payer Claims

If you want to pay for others to look for you:
RCTA Research Data Request (virginia.edu) (rate is currently $100/hour)
PHCOC Request Form (can also use to request super-user access to Epic Cosmos' Data Science Virtual Machine; rate is currently $91/hour for non-members, $68.25/hour for members)

Highlights indicate the uniqueness of the system.

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